THE UNIVERSITY OF BRITISH COLUMBIA
Canadian Institute for Inclusion and Citizenship

Individualized Funding and Supports: A Scoping Review

Prepared for the British Columbia Ministry of Children and Family Development

January 31, 2024

About this report

This Review of Individualized Funding and Supports: A Scoping Review presents findings of a scoping review of peer-reviewed literature. This subset and data are part of a larger research endeavour providing an international understanding of individualized funding approaches. Funding for this report was provided by the BC Ministry of Children and Family Development.

Our larger research endeavour includes an extensive scoping review of the literature on individualized funding that includes a jurisdictional scan of individualized funding approaches in Canada.

Contributors:

Researchers:

- Dr. Rachelle Hole, Co-Director, Canadian Institute for Inclusion and Citizenship, University of British Columbia Okanagan
- Dr. Tim Stainton, Co-Director, Canadian Institute for Inclusion and Citizenship, University of British Columbia Vancouver

Graduate Research Assistants:

- Laura Mudde, PhD Candidate, Interdisciplinary Studies, University of British Columbia Okanagan
- Trevor Gray, PhD Student, University of British Columbia Vancouver
- Maddy Côté-Dear, MSW Student, School of Social Work, University of British Columbia Okanagan

Research Librarian:

- Arielle Lomness, Social Work Librarian, University of British Columbia Okanagan

Contact Information

For information about this report, please contact:
Canadian Institute for Inclusion and Citizenship
University of British Columbia
cic.ubc@ubc.ca
604-822-5872

To cite this report:
Hole, R., Stainton, T., Mudde, L., Lomness, A., Côté-Dear, M., & Gray, T. (2023). *Individualized Funding and Supports: A Scoping Review*. Canadian Institute for Inclusion and Citizenship, 262 pp.

Contents

List of Abbreviations

AAT: Administrative Appeals Tribunal
AFB: Autism Funding Branch
ASD: Autism Spectrum Disorder
ASD-IF: Autism Spectrum Disorder Individualized Funding
BC: British Columbia
Better Start: Better Start for Children with Disability
BHLP: Budget Holding Lead Professional
CALD: Culturally and Linguistically Diverse
CDS: Children’s disABILITY Services
CIIC: Canadian Institute for Inclusion and Citizenship
CILT: Centre for Independent Living Toronto
CLBC: Community Living British Columbia
CLSC: Mission Centre Local de Services Communautaire (Local Community Service Center)
CLSD: Community Living Service Delivery
CMS: Centers for Medicare and Medicaid Services
COSLA: Convention of Scottish Local Authorities
CP: Cerebral Palsy
CSIL: Choices for Supports in Independent Living
CTCES: Centre de Traitement du Chèque Emploi-Service (Service Employment Paycheque Processing Center)
CYSN: Children and Youth with Support Needs
DFSC: Direct Family Support for Children
DLA: Daily Living Activity
DLSA: Daily Living Support Activities
DP: Direct Payment
DPSA: Day Program Support Activities
DSO: Developmental Services Ontario
DSP: Disability Support Program
ECI: Early Childhood Intervention
EFSC: Enhanced Family Support for Children
EHCP: Education Health and Care Plan
FCAON: Family/Child Assessment of Needs
FSCD: Family Support for Children with Disabilities
GSA: Guide to Support Allocation
HCBS: Home and Community-Based Services
HCCSS: Home and Community Care Support Services
HCWA: Helping Children with Autism
IF: Individualized Funding
ILRC: Independent Living Resource Centre
CALD
MCCSS: Ministry of Children, Community, and Social Services
MCFD: Ministry of Children and Family Development
NDIA: National Disability Insurance Agency
NDIS: National Disability Insurance Scheme
NHS: National Health Service
OAP: Ontario Autism Program
ONILC: Ontario Network of Independent Living Centres
PAS: Personal Assistance Services
PB: Personal Budget
PCP: Person-centred Planning
PD: Participant-directed
PHB: Personal Health Budget
PMF: Person Managing Funds
RASP: Registry of Autism Service Providers
SCWA: Special Child Welfare Allowance
SDF: Self-directed Funding
SDS: Self-directed Support
SSAH: Special Services at Home
UK: United Kingdom
UNCRPD: United Nations Convention on the Rights of Persons with Disabilities
US: United States

Executive Summary

The current report presents findings of a scoping review of the peer-reviewed literature on individualized funding (IF) as it pertains to IF models for children and youth with disabilities/support needs and their families and carers. IF is defined as:

> Funding that is allocated directly to an individual or, in the case of a child, their parents or legal guardian, to provide the support necessary to meet disability related needs. IF has two fundamental characteristics: 1) the amount of funding is determined by direct reference to the individual and/or family's specific needs and aspirations; and 2) the individual and/or their family determine how funds are used to meet those needs eligible for funding. (Stainton, 2009)

This review identifies best practices, strengths, and challenges of IF in the various models described in the literature. Financial and budgetary implications and policy considerations as identified in the literature are also included. All included articles reported on IF as it pertains to children, youth, young adults with disabilities (ages 1-21 years) and were published between 2011 and 2023 in English.

Fifty-eight peer-reviewed primary research studies (6 quantitative, 43 qualitative, and 7 mixed-methods) and secondary journal articles (2 knowledge syntheses) are included in this literature review. Of the 58 articles, 36 were conducted in Australia, 4 in the United States, 14 in the United Kingdom, and 4 in other (Canada, Europe, New Zealand).

Benefits and Facilitators of IF

One overarching theme related to positive outcomes of IF was greater choice, control, and flexibility. IF models offer greater access to and choice of supports and therapy providers, and recipients report appreciating the flexibility IF provides. Key facilitators of positive outcomes are family status (e.g., socioeconomic status), social capital (e.g., supportive family and community relations), capacity, interagency collaboration, and geographic location e.g., being in/near centres to access providers and supports). In fact, families who are well-resourced, socio-economically advantaged, and knowledgeable about navigating IF tend to benefit the most from IF models. Of note, families who had relationships and capacities to build connections to early childhood interventions (ECI) through IF benefited as effective and collaborative ECIs can assist families early in learning how to navigate IF systems. When IF during ECI works well "[e]ffective decision making is thus co-constructed, with the ECI professional and family members co-contributing their specialist knowledge to inform decision making" (Brien et al., 2017, p 39). Finally, interagency collaboration facilitated positive outcomes for families accessing IF.

Barriers Associated with IF

Common barriers associated with IF include times of transition, challenges navigating supports, administrative burden, contextual barriers based on sociocultural factors, availability of appropriate human resources, rural and remote factors, and macro considerations. With respect to transitions, age-based transitions associated with IF and child and family needs can lead to negative outcomes; the initial periods of accessing IF, transitioning from high school to adult supports; transitioning from child and youth health services to adult health services are some examples of age-based transitions where complexity and navigation changes may impact families' experiences and outcomes of IF models.

A second barrier associated with IF are the challenges in navigation and seem to exist across IF models and jurisdictions. These include accessible information, strained communication about the IF application processes and provision, and financial and administrative burden. People navigating access to IF reported limited guidance on services, inequalities in planning, approval, and review processes, and consequences of unequal capacity to take on self-management.

While connected to navigation, a third barrier is administrative burden related to both logistic problems and a lack of capacity and access to self-management. This administrative burden led to feelings of stress and concern among family members and carers of disabled children and youth. A contributing barrier to administrative burden was poor communication (e.g., inaccessible materials, lack of transparent processes).

A fourth barrier across IF models and jurisdictions relate to socio-cultural factors: e.g., family resources and capacities, socio-economic status, disparate experiences of culturally and linguistically diverse individuals and of Indigenous communities, families, and individuals, rural and remote disparities. A lack of family resources and capacity presents various challenges for families; for example, a single parent family taking on the administrative burden of self-management. Lower social capital results in added difficulties in navigating IF.

Research identifies that IF operates within existing socio-cultural disparities, as such IF can lead to increases in these disparities leading to further alienation and complications for equity deserving groups and those with more complex disability related support needs. In particular, four studies explicitly recognized compounding marginalization of people with Indigenous and culturally and linguistically diverse backgrounds as a barrier to accessing IF. Key barriers to navigating health and social care systems included unfamiliarity, cultural and language differences, and a lack of access to interpreters (see Appendix 3 for further expansion).

A fifth barrier identified was a common concern with all types of disparity identified in accessing IF supports is the availability of professional and skilled staff to provide the support families want to purchase or employ with their IF.

A sixth barrier relates to factors associated to living in rural and remote geographic areas: in the context of rural and remote areas there is: a) lack of information and advice; b) limited local service options and capacity; b) higher costs and fewer services; and (c) complexity of self-managing packages (Dew et al., 2013). Many challenges are due to the difficulties service providers encounter providing therapy across large geographic areas. For families of children and youth, lack of age appropriate supports and providers may mean limited age appropriate choices and/or a lack of specialized supports for a particular child's support needs.

Finally, macro considerations were identified as a barrier for IF. For example, in Australia, part of the problem was the scale of transition from block funding to IF that caused complications and a lack of suitable personnel.

Block funding is a method of financial allocation in which the government provides funding to an agency who then provide services to individuals and families. This normally involves a contract which specifies the type and volume of service to be provided.

Moreover, in a market-driven system increased costs associated with therapies increased significantly over time. Researchers also described a tension between the imagined rights and the fair and sustainable administration of IF. Whereas eligible participants want their choices recognized based on perceived need, the government wants value for money and a sustainable system. In addition, shifting from block-funding to the IF model in Australia meant that agencies needed to adopt a different service delivery model. This required agencies and their staff to adopt a customer service selling-style in which funding limitations impacted previously block-funded service providers negatively leading to a lack of budgetary security. These market-based impacts were also noted in the UK.

Policy considerations

Policy considerations relate to the barriers and facilitators identified in the literature. Various authors identified the need for system integration and collaboration between health care, social care, and education systems. A context-dependent consideration identified is the need to account for the political and economic context in which IF models operate, such as thin markets, budget cuts, and lack of available services or skilled workers in rural and remote areas. Another important policy consideration relates to the role of facilitators/navigators to address the importance of clear and transparent communication and the administrative burden that families experience.

Historically, IF is anchored in a person-centred planning and self-directed/determined model. For children and youth with disabilities and their families/carers, researchers recommend policies to incorporate both person-centred and family-centred practices. Moreover, explicit commitments to culturally safety and equity considerations in IF policies and practices can help to address socio-cultural-economic inequities of equity deserving groups in the implementation of IF models.

Financial and Budgetary Considerations

Two financial and budgetary highlights in the report are as follows. First are the implications of the financial context in times of austerity. Apart from financial flexibility for IF scheme participants in spending their funding according to their own needs, the majority of peer-reviewed research addressed in this scoping review made some reference to financial and budgetary constraints. Second, several researchers highlighted the financial and budgetary considerations on the role of quasi-markets in the IF model (discussed below) and the strain these markets have on the workforce, including reductions in accessible and skilled workers that intersect with low wages for social workers and service providers.

Quasi-market system: An approach to structuring the provision of services that blends elements of market-driven and government-controlled mechanisms. Often implemented within public services, it aims to enhance efficiency, quality, and consumer choice, while still maintaining some level of government oversight and regulation.

Concluding Considerations

IF models are implemented across diverse jurisdictions and local contexts are unique requiring local frameworks for development and implementation. Some further policy considerations include: equitable access; attention to needs assessment and planning; transparent funding allocation; quality standards and accountability; education and support for families; provider certification and oversight; integration and collaboration with other services; addressing cultural competency and equity; a legal and ethical framework; ensuring prevention of exploitation and abuse; commitments to ongoing evaluation and improvement; public awareness and education; and collaboration across stakeholders.

All in all, the implementing an IF model requires a thoughtful and comprehensive approach to evolving needs and challenges. The implementation of IF depends on various factors, such as (not limited to) the specific care and support needs of individuals, the objective of the funding model, and the socioeconomic and political context. The common IF models documented in the literature are direct (cash) payments, individual budgets, agency-managed budgets or funding, and hybrid approaches.

Finally, Appendix 3 offers a further expansion on key points related to IF beyond the scope of the current review to provide an expanded understanding of key IF considerations. The commentary focuses on 1) the challenges with navigation impacting supports; 2) the concerns related to administrative burden; 3) the contextual barriers based on socio-cultural factors; 4) the availability of appropriate human resources; 5) the factors associated with implementation in rural and remote communities; and 6) final reflections and a discussion of Global Standards for Self-Directed Supports.

Introduction

The current report is a scoping review undertaken by researchers and assistants at the University of British Columbia Canadian Institute for Inclusion and Citizenship (CIIC). It addresses the international peer-reviewed literature on individualized funding (IF). IF is considered part of an international personalization agenda in social care. IF, also termed direct payments or direct funding and linked to other funding models, such as personal budgets or self-directed supports, provides people and their families and carers choice and control. Specifically, IF provides choice and control to disabled individuals and their families and carers by assessing individual need and allotting funding that then can be procured for the services and care they select.[1] IF, in this report, is defined as:

> Funding that is allocated directly to an individual or – in the case of a child – their parents or legal guardian, to provide the support necessary to meet disability related needs. IF has two fundamental characteristics; 1) the amount of funding is determined by direct reference to the individual and/or family's specific needs and aspirations; and 2) the individual and/or their family determine how funds are used to meet those needs eligible for funding.
> (Stainton, 2009)[2]

In other words, IF is a distinct model different from a fixed or standardized payment such as income support, which fails to meet the first criteria. It is also distinct from block funding or payments to agencies and services not individually chosen, which fails to meet the second criteria. While there is variation in the ways IF models are implemented internationally, these two characteristics should to some degree be present to qualify as IF.

This review specifically focuses on IF as it pertains to funding supports for children and youth with support needs and their families and carers. When it comes to children and youth with support needs, families and carers frequently shape the IF decisions, especially for younger children. This review identifies best practices, strengths, and challenges of IF in the

---

[1] This report presents information in both person-first language that emphasizes the person before the disability, and identity-first language that puts the disability first in the description.

[2] In BC, IF for families with children and youth with support needs is not needs-based.

various models described in the literature. This includes the capacities for disabled children and young adults, their families and carers, support and social workers, service provider organizations, and other professionals to navigate IF models. Financial and budgetary implications of funding models and policy considerations as identified in the literature are reported, including the impact of IF on both private and publicly funded programs and services. The review includes research from Canada, Europe, the United Kingdom, the United States, Australia, and New Zealand.

The questions guiding this review include three levels of analysis:

1) Definitions of IF and other funding models

What is IF?

- What is the difference between IF and other funding models?
- What do various IF and other funding models entail?

2) Barriers and facilitators to successful IF models

Which IF models are successful? What aspects of IF models are successful?

- What makes these models successful?
- What barriers might there be to using IF approaches?
- What are some of the ethical implications of using IF models?

3) IF implications and operational considerations

What are important considerations for the application of an IF model?

- What type of IF model is recommended in the context of different care and support needs?
- How do IF approaches compare in effectiveness?
- What are costing or budgetary implications for models that utilize an IF structure?
- What is the impact of IF on the publicly and privately funded programs and services' workforce?
    - How does IF reduce pressures on publicly funded programs and services?
    - How do private services impact publicly funded programs? (i.e., deterring professionals from entering the publicly funded sector)
    - What are the pros/cons of having both publicly funded and privately practicing professionals offering programs and services for children and youth with support needs?

1. Methods

Researchers at the CIIC conducted a scoping review of the international literature on IF to fulfill the requirements of the research within an agreed shorter time frame. This scoping review followed the PRISMA Scoping Review (PRISMA-ScR) and PRISMA for Searching (PRISMA-S) extensions which outline checklists for reporting the methods and analysis completed (Rethlefsen et al., 2021; Tricco et al., 2018). This report addresses a subset of the international literature and included citations for a scoping review focussed on disabled children and youth with support needs and their families and carers in October 2023. This method section conveys the overall approach to the larger international scoping review and provides applicable notations where this report's subset of the literature was separated.

1.1 Protocol and Registration

A search protocol was created in May 2023 by the research team members and the UBC Okanagan social work librarian. The search protocol was not registered or posted online due to time constraints which meant the research moved through to the search phase immediately. PROSPERO (The International Prospective Register of Systematic Reviews), the Campbell Collaboration, the Cochrane Collaboration, and Google Scholar were all searched for any registered studies that matched the criteria of this review to ensure there was no duplication in the field. While related reviews were found, they were not found to match the specific parameters set out for the larger research endeavour or the subset used for this scoping review and report.

1.2 Eligibility Criteria

The eligibility criteria for this research included various elements of disability and IF that translated into the search terms and limiters that were utilized in the searches. The review included peer-reviewed primary research studies (quantitative, qualitative, and mixed-methods) and secondary journal articles (knowledge syntheses) that had been published between 2011 and 2023 in English that looked at IF or directed support models and services for individuals with disabilities. Articles were included from all age groups and all geographic regions of the world to contextualize and compare similar funding models and services. The articles were only included when funding was going directly to the person requiring the funding, or a caregiver in lieu, while other forms of income support were excluded. Individuals receiving the funding had to meet definitions of intellectual, physical, or mental disabilities; old age dementia and visual and hearing impairments were excluded for the purposes of this review. Based on related reviews around IF, these criteria were outlined to cover a wider breadth of the literature, as many reviews were limited by age, type of disability, databases and search terms used, or were completed with literature prior to 2011.

In addition, the subset for the current review employed a narrower eligibility criterion based on age. To accurately capture literature engaging with children and young adults with intellectual, physical, or mental disabilities, age in this subset was limited to 0-21 years of age. Articles from the larger scoping review were excluded if they did not report specifically on IF and supports for families (rather, general support services) or if the article focused on individuals above the age of 21 years.

1.3 Information Sources

A total of five databases and two multi-database platforms of a further 7 databases or indexes were used in this scoping review: Scopus (Elsevier), APA PsycINFO (EBSCO), CINAHL (EBSCO), Medline (EBSCO), Embase (Ovid), Sociology Collection including Social Services Abstracts, Sociological Abstracts and ASSIA (ProQuest), and Web of Science including the SCI-EXPANDED, SSCI, A&HCI, and ESCI indexes (Clarivate). The databases were searched first on May 18, 2023 and an update to the search was run on September 28, 2023.

In addition, the research team conducted a reference list search of all eligible articles to capture potential sources not captured in the search protocol. The reference lists for most of the included articles were extracted from Scopus on October 14, 2023 and reviewed by the research team. This process included searching the Digital Object Indentifiers (DOIs) of all included 347 articles and adding them to a saved list. Using Scopus's reverse lookup for references, the librarian extracted 4,523 references for research team members to review.[3]

---

[3] Fourteen articles were unavailable in Scopus and no reference lists were pulled from those sources. The 4,523 reference results included many format types (e.g., books, book chapters, policy reports, grey literature) that were excluded from the scope of this review.

1.4 Search

All of the completed searches can be found in Appendix 1. Due to a lack of subject headings available around IF, a comprehensive set of synonyms was drafted by the social work librarian through the review of existing literature with input by research team members. Search methodologies from related previous reviews (e.g., Fleming et al., 2019; Pattyn et al., 2023) also informed the search terms. IF is not yet a standardized phrase in practice around the world, which prompted the robust list of synonyms and an awareness that this list may not be exhaustive of all terminology used in the field. As indicated in the introduction to this report, close-reading of the contents of articles was used to determine if the funding model in question matched the key characteristics of IF. Additionally, terminology describing individuals with disabilities was left open to keyword, abstract, and title fields (or more) when available. Subject headings were considered but ultimately not utilized as their scope notes did not adhere to definitions in the field of disability research. The terminology used was validated to ensure that anything that would have been found through subject heading searches was covered by the free-text search terms and phrases.

In general, search results were vetted based on broad definitions and policy approaches to IF and related supports. Researchers relied on the idea of personalization and self-direction as a common understanding and practise that all definitions and policy approaches to IF and related supports have in common. Personalization and self-direction refer to the use of funds by the eligible recipient of that funding, their family members and caregivers, or an appointed or employed proxy as decided by the eligible recipient of the support funding. Researchers also relied on broad definitions of disability, as the international literature on IF and related supports reflect engagements with various definitions of intellectual, developmental, physical, and mental disabilities that informed eligibility for IF and related supports.

1.5 Selection of Sources of Evidence

The social work research librarian ensured all of the results from the database and platform searches were imported into Covidence for de-duplication, title and abstract screening, and full-text screening. The updated search results were imported into a new Covidence review where de-duplication against the earlier results was run and the remaining additions were screened again through title and abstract and full-text review phases. One result was dropped during the updated import due to a technical error with the database. System duplicates were manually check by one researcher to ensure no results were wrongfully listed as duplicates. Manual duplicates were identified by the research team and excluded in Covidence as well.

To ensure a systematic and rigorous approach to the peer-reviewed literature, various members of the research team engaged with the database and platform search results and communicated concerns about in- or exclusion of source materials. Title and abstract screening of the original results were completed by two members of the research team, followed by the full-text review phase, also completed by those two members. Any conflicts for exclusion of results were resolved by a third research member. The title and abstract screening, as well as the full-text review, of the updated search results was completed by one team member and concerns communicated and resolved by a second team member. Most materials were screened out based on unmet eligibility criteria. Most commonly, excluded sources were not peer-reviewed, did not center IF approaches as defined by the research team, or did not include disabled individuals.

Furthermore, the references extracted from Scopus were imported into a third Covidence review to de-duplicate against both sets of earlier results from the original and updated searches. One member of the research team reviewed the references for additional sources that were missed in the original and updated search. Missed sources often did not explicitly state IF models or disabled participant groups in the title or abstract, whereas contents did effectively engage with the themes and questions specific to the research. Additional eligible articles were confirmed as relevant by a second member of the research team.

1.6 Data Charting Process

A data extraction template was designed and applied to all of the included articles within Covidence (see Appendix 1). The extraction template was drafted and validated through consultation and discussion among members of the research team. Two members of the research team utilized the template to perform the extraction under a single reviewer process. We recognize the two-step selection process for reviews or double-screening is more commonly recommended. However, this approach is resource intensive and not feasible in the shorter timeframe allotted for conducting this scoping review. Double-screening occurred when discussion about a source was needed. Researchers met and consulted with each other regarding articles that required double-screening. Based on the extraction template and single reviewer process, remaining conflicts about source inclusion not resolved during consultation were reviewed by a third member of the research team for in- or exclusion.

The data extraction template included data items to interrogate each source's contribution to our knowledge and reporting on IF and related supports. We extracted data on article characteristics, including general information gleaned from each individual article as well as the aims and methods, including methodology, study design, and policy parameters. The template addressed each source's research sample and the research participants (if relevant) followed by the research outcomes and findings. Common themes were identified in additional open fields during extraction and each source was identified as relevant or irrelevant to families, children, and youth with support needs.

1.7 Critical Appraisal of Individual Sources of Evidence

Critical appraisal/quality assessment of the individual sources was not completed for this scoping review, as PRISMA-ScR (Tricco et al., 2018) lists this step as being optional and the purpose of this review was to scope the entire landscape of literature. The quality of the individual sources was established through the eligibility criteria, meaning that articles eligible for the scoping review were deemed of adequate quality.

1.8 Synthesis of Results

The results synthesized in this report relate specifically to the research questions addressed in the introduction. The reported findings and discussion speak to three levels of engagement with the source materials. First, this report reviews the various definitions of IF and other funding models internationally identified in the personalization agenda. Second, this report addresses the various barriers and facilitators to IF models and approaches to self-direction in funding as identified in the literature. Third, this report reports the IF implications and operational considerations identified in the literature. Results are synthesized based on article recommendations of care and support needs, budgetary implications, and impact on IF programming and the work force.

The discussion section of the review findings considers the research findings and expands on IF implications and operational considerations identified in the literature. The discussion relies on information retrieved through a jurisdictional scan of IF models in Canada completed by two members of the research team. Limitations and considerations for IF approaches to supporting families with children and youth with support needs are discussed. Finally, the conclusions and considerations sections of this review summarizes the results and key takeaways and research on IF models/approaches.

1.9 Final Selection of Sources

A total of 4,056 citations were imported into Covidence from the first set of searches. After de-duplication, a total of 1,530 citations were reviewed through the title and abstract screening phase from the first search, with 970 citations being excluded at this phase. 560 citations had their full-text retrieved and assessed for eligibility, with one title being unavailable for review. Of these, 277 were excluded, which resulted in 283 included citations. The updated search yielded an additional 60 citations following de-duplication to be screened via title and abstract and then full-text retrieval. Of these, 43 were excluded, resulting in an additional 17 included citations. Finally, the 4,523 reference list citations were imported into Covidence, with 4,175 remaining after de-duplication. Of these, 4,123 were excluded, which resulted in additional 52 included citations. In total, 347 citations were included to move ahead with data extraction. A full breakdown of the totals is seen in the PRISMA flow diagram (Appendix 1).

For the purposes of this scoping review and report, a subset of 58 citations of the total 347 articles were extracted to be reviewed. This included 52 from the original search, one article from the updated search and five additional articles identified through the references review. Table 1 summarizes the basic information for the 58 articles addressed in this report. These sources were extracted based on their relevance to the research questions and based on age eligibility criterion: Disabled children and young adults aged 0-21 and their parents, carers, and proxies.

Table 1: Study Design and Jurisdiction of 58 Peer-reviewed Articles on IF

	Number of Sources
Study Design	
Qualitative	43
Quantitative	6
Mixed Methods	7
Knowledge Synthesis	2
Jurisdiction	
Australia	36
USA	4
UK	14
Other and Europe	4

2. Findings

A total of 58 peer-reviewed articles met the established inclusion criteria. These are summarized in Appendix 2, Tables A, B, and C. Table A lists the peer-reviewed published articles in alphabetical order by author and includes general source information; “study design”, “jurisdiction”, “policy title”, “participant sample (N=)”, “population (Dx)”, and “study participants” of each listed article. Table B presents these articles alphabetically and describes content specific to each source’s “research question”, “research aim”, “IF definitions”, and “general findings” as per our analysis. Table C presents a summary of each source’s identified “barriers and facilitators”, “policy considerations”, “financial considerations”, “important points” raised in the articles, as well as “themes and keywords”.

The peer reviewed articles were published between 2011 and 2023, with the majority of the articles published after 2016 and the highest number of publications in 2022. Articles reflected knowledge syntheses (*n* = 2), quantitative (*n* = 6), mixed methods (*n* = 7), and qualitative (*n* = 43) methods. The most commonly used methodology was qualitative and relied on semi-structured and individual interviews or policy analysis with disabled individuals, their families and carers, and policy officials and social workers (*n* = 43).

The range of participants can be divided in three groups. Of the 58 studies, nine directly involved children or young adults with disabilities (population Dx), 46 involved parents and carers of children as participants, and twelve involved care workers, experts in health and social care, and service providers and policy makers. In the parent and carer group, the majority was identified as White mothers, female relatives, or female carers. Ten studies did not involve explicit participant samples and instead were more policy focused.

With respect to the population (Dx) and participant samples, nine articles did not identify a specific population group or disability. A common reference to the study sample or population (Dx) referenced children or young adults with disabilities in general terms (*n* = 50), with some studies elaborating on different types of disability identified in their sample (*n* = 27). Seven studies referenced children with autism spectrum disorder (ASD), ten studies referenced children with complex health needs, and 18 studies referenced intellectual or development delay (also referred to as learning disabilities in the UK). Four studies referenced children or young adults with cerebral palsy (CP).

Ages of children and young adults included in this review ranged from 0 to 21. However, several studies included here contain empirical data for people older than 21. Articles were still included if the sample contained children under 21 in addition to individuals older than 21. This means some comparative studies engage with a population (Dx) ranging in age from 0 to 69 years old (e.g., Gallego et al., 2018). Relevance of these studies lies in their engagement with a segment of their participant sample specifically addressing the younger end of the age range and experiences of their families and carers. Some articles that were included addressed barriers and facilitators for disabled young adults transitioning out of child services and referenced individuals 18 to 25 years of age and their families and carers.

The studies reviewed focused on IF approaches and models internationally. Geographically, these studies represented higher income jurisdictions. The highest number of studies focusing on IF models and disabled children and their families and carers relate to Australia (*n* = 36) and their implementation of a national IF scheme. Fourteen sources were conducted in the United Kingdom, specifically England, Scotland, and Northern Ireland. Two studies were from European countries (Dudová, 2022; Nieboer et al., 2022), and one study (Simpson & Douglas, 2016) was comparative and international in scope. Priestley et al. (2022) focused on New Zealand and four studies (Harry et al., 2017; Leutz et al., 2015; Swenson & Lakin, 2014; Timberlake et al., 2014) focused on self-directed funding models in the USA (specifically programs in the states of New Jersey, Arkansas, Florida, and Massachusetts).

In the following sections, we present the findings from our scoping review. First, we address definitions of IF and other funding approaches and models as set out in the various jurisdictions included in the articles. Second, we address the barriers and facilitators identified in these approaches and funding models. Third, we report on the identified implications and considerations of these approaches and models as identified in the literature from the perspective of policy implementation. Finally, we address some of the financial and budgetary considerations presented in the literature.

2.1 Definitions

Policies for families with children and youth with special needs (e.g., disability and complex health and support needs) are diverse. Similarly, funding refers to a range of policy initiatives and approaches in various contexts and jurisdictions. To avoid confusion, individualized funding (IF) described in this report does not solely refer to the 'IF' scheme in Australia. When referring to the scheme in Australia, we will reference the National Disability Insurance Scheme (NDIS) IF in this report refers to the working definition set out in the introduction as; a) funding allocated directly to a child or individual or their parents or legal guardian, b) funding to meet disability related needs as determined by direct reference to the individual and family's specific needs, and c) funding aspirations in which the individual or their family determine how funds are used to meet those needs eligible for funding (Stainton, 2009).

In general, IF is defined as the latest funding model that emerged internationally in response to disability advocates and advocacy groups in the US and community living organizations in the US, Canada, and the UK. The push for a personalization of care that centers the rights of disabled people led to the United Nations Conventions on the Rights of Persons with Disabilities (CRPD) of 2006 (open to signature in 2007). The UNCRPD follows decades of work by disability advocates and advocacy groups to change attitudes and approaches regarding disabilities and disabled persons. Specifically, the advocacy work aimed at a personalization of care and a movement aimed at viewing disabled persons not as "objects" of charity, medical treatment, and social protection towards viewing disabled persons as "subjects" with rights, capable of claiming rights and making decisions for their lives, and being active members of society. Self-direction, personal budgets, and IF rely on the principles of choice and control, self-determination, and personalization; an approach in which signatories to the UNCRPD increasingly developed funding models where funding is directed to each individual based on their unique needs and strengths. Given the diversity in jurisdictional adaptation of these principles set out in the UNCRPD, the articles included for this report reflect the transition to IF and related policy implementation specific to each jurisdiction.

2.1.1 Australia

The **National Disability Insurance Scheme** (NDIS) is a scheme of the Australian Government operated through the National Disability Insurance Agency (NDIA) that funds costs associated with disability. Scheme participants have an annually approved plan in which they can choose how to manage their funds and what services to purchase. The scheme was legislated in 2013 and went into full operation in 2020.

In Australia, Laragy and Ottman (2011) and Dew et al. (2013) describe IF as a funding mechanism for disability supports to enable people to live more independently and promote community participation. Before the rollout of the National Disability Insurance Scheme (NDIS), authors refer to IF in different individual funding programs across Australia's six states and two territories. Although programs varied greatly, Laragy and Ottman (2011) assert that IF gave disabled people greater control over the use of their allocated funding and the option to purchase services and supports outside of the agency-based disability services system and block-funding (McDonald et al., 2016). According to Dew et al. (2013), IF in Australia is part of person-centred practices, enhancing disabled people's opportunities for self-determination and choice. Person-centred approaches may involve IF (also referred to as direct payments) for the purchase of required support to allow disabled people and their carers greater choice in access to therapy: IF participants have the "freedom to move away from rehabilitation and traditional disability service delivery if desired, and are encouraged to do so as appropriate" (Whitburn et al., 2017, p. 1066).

In 2011, there was governmental agreement that the disability sector needed reform (Boaden et al., 2021; Loadsman & Donelly, 2021; Venning et al., 2021). In March of 2013, the

NDIS Act 2013 passed and led to the rollout of various NDIS trial sites (Brien, 2018). National implementation occurred in 2016 with full operation in 2020. As Dew et al. (2014) summarise, the focus of the NDIS is to provide individualized funding services that give users choice and control so that their community participation and inclusion are enhanced. According to the NDIS Act and website, the scheme entitles people with a 'permanent and significant' disability (under the age of 65) to funding for 'reasonable and necessary' supports related to their disability. Howard et al. (2015) define IF as self-managed funding packages that reflect a policy shift towards greater choice and control as an individualized fee-for-service funding model. This means

> The NDIS is based on two key premises: recognition of the right of people with a disability to be at the centre of decision-making and planning for their life; and the implementation of a no-fault tiered insurance model as a cost-effective way to manage and organize funding and support for disabled people over their lifetime. (p. 1367)

Robinson et al. (2016) define the NDIS IF scheme as a model of self-directed support (Self-directed Support) representing a paradigmatic shift in how disabled people organize their required supports to meet their daily living needs and aspirations; "In the best case, it brings together personalized services and a more equal partnership between people in need of support and professionals, and emphasizes choice and control with a focus on outcomes" (p. 269). This publicly funded scheme is based on an individual's application and annually established need and funding through the NDIS authority, the National Disability Insurance Agency (NDIA). The individual and/or their guardian controls the funding allocated and chooses which providers supply the needed goods and services. This insurance funding is independent of the Disability Support Pension and Australia's universal health care insurance, Medicare. As such, NDIS legislation distinguishes health care from disability supports or social care.

In line with Robinson et al. (2016), Marchbank (2019) asserts that IF signals a shift away from historical views of disability with a reliance on medical definitions of impairment and limitation to one of capacity and empowerment. However, this shift away from medical definitions through the NDIS provision does not appear to apply to early childhood programs.

Specifically, early childhood interventions (ECI) and qualification for NDIS funding and services still relies on medical categories and a determination of developmental risk (p. 188). Previous to NDIS, IF packages for disability supports and services had been available to eligible Australian children under the Better Start for Children with Disability (Better Start) and Helping Children with Autism (HCWA) programs (Russo et al., 2021). IF as offered through the NDIS, specifically to young children and their parents or caregivers replaces these programs and reflects more managed aspects of IF for disabled children and the important role of professionals in ECI and support (Alexander et al., 2019; Marchbank, 2017).

IF under the NDIS is based on consumerism that re-orients funding to the participant, which effectively assumes that choices can be authentic and knowledgeable regarding what constitutes quality in service provision (Brien et al., 2017, p. 37). This hints at some tensions for participants, new to the scheme, particularly as it relates to early diagnosis and interventions for young children. Moreover, authentic and knowledgeable decision-making for new parents and caregivers relies heavily on professionals in health care and education settings to provide accurate information for service provision (Ranasinghe et al., 2017). In turn, the IF objective of establishing the disabled individual as a full and active social and economic agent (Tracey et al., 2018) has to effectively engage with parents and caregivers of disabled children first through family-centred practices. This family-centred planning at times might be at odds with the person-centred planning aims set out in the UNCRPD and the NDIS (Meltzer & Davy, 2019). Successful IF planning for children and their families and caregivers requires a network of relations and support provision not confined to social care, but integrating education experts, health experts, and community (Johnson et al., 2020; Russo et al., 2021). According to Small et al. (2020), the support accessed through IF requires attitudinal change for disabled children and young adults, carers, and service providers. In addition, the development of an IF plan for young children and their parents and carers should try and avoid the longer administrative process associated with more complex funding needs (Smethurst et al., 2021).

In general, IF funds supports and services to meet the disability-related needs of “Australians with a permanent and significant disability; or developmental delay if under the age of seven” (Thompson, 2022, p. 267). This personalized funding model presents “a shift from established block funding and service contracting model to one providing consumers with their own packages and capacity to purchase services directly” (Salvador-Carulla et al., 2022, p. 876). This reflects an economic model and vision as IF through the NDIS was "intended to transform the disability sector into a more competitive market, where individualized funding would attract new services in a market matching demand with appropriate, affordable supply" (Salvador-Carulla et al. 2022, p. 876). As Comito et al. (2023) specify, participant funding plans contain three funding categories: core, capacity building, and capital supports, which participants can self-manage, plan-manage, or agency-manage. Participants who self-manage independently arrange supports and invoices, whereas plan-managed participants receive funded assistance from an expert for financial reporting. Agency-managed support mean the NDIS is responsible for planning supports through services from registered NDIS providers (p. 2). Specific to disabled children and young adults, IF models reflect a more complex engagement requirement from families and carers.

2.1.2 United Kingdom

A **Personal Budget** is an agreed amount of money that is allocated to an individual by their local council or authority (and other funding streams) following an assessment of individual care and support needs. This support is participant-directed, as the individual chooses how to manage and spend their funds for their care and support. The personal budget was made mandatory according to the Care Act 2014, that came into force in 2015.

In the UK, personalization and individual budgets are part of a longer trajectory toward self-determination and choice and control for disabled persons. Williams and Dickinson (2015) discuss IF in connection to the UK's National Health Service (NHS) policy from the mid-1990s to 2015 (p. 151). Social care in the mid-1990s and later expanded across health, education, and other areas referred to a policy of *personalization*; a broad approach giving individuals more control to co-produce their care in an effort to better meet their needs. From 1997, social care introduced *direct payments*; a cash payment to individuals who choose their service delivery by allocating their resources. In 2008, the NHS introduced *personal budgets* (individual budgets) as an approach that identified how much money is to be allocated to individuals based on their needs to enhance personal choice and control over how allocated money is spent. In 2014 and after, the NHS introduced *personal health budgets*, which refer to an amount of money provided for health and wellbeing that is spent according to a personal plan between the individual and health professionals.

In England, Welch et al. (2012) define direct payments as an example of a growing body of cash-for-care initiatives internationally; where cash sums are paid “to people who have been assessed as being entitled to services to enable them to purchase these services for themselves” through local authorities (p. 901; see also Collins et al., 2014). In the context of young adults or children transitioning into adult care, Cowen et al. (2011) define individual budgets as a system that ensures young people’s entitlement to support, funding or access to particular services, and such “entitlements must be clear and transparent so that people can evaluate what is available, plan effectively and know how best use any resources they can control” (p. 32). Cowen et al. (2011) specifically refer to individual budgets and their use in school-based planning for young people transitioning from high school to post-high school life, termed personalized transition. Personalized transition requires a collaborative approach with individual budgets that considers the needs of disabled young adults and their families beyond the school system that mixes “health, social care and education according to individual needs” (p. 30). This is placed in a policy context of individual budgets as managed through local authority leadership receiving NHS funding to service the community. A model of personalized transition in the local authority of Sheffield identifies three periods of support for disabled children (up to 16; 16-19; and over 18/19) that require integration of child health, local education, social care, learning and skills council, and adult health and social care (Duffy & Murray, 2013, p. 309). In addition, Duffy and Murray underscore the importance of family and other community support systems. In the context of planning, self-directed support through personalized care shifts choice and control of supports to the recipient of care and their caregivers. In the context of IF, this means policy and action should

> ensure that young disabled people have the means to exercise their rights [which is] not just a matter of budgets ... [i]t is also about ensuring people have the independence, information, skills, experiences and relationships that enable the active exercise of those rights. (p. 313)

This conclusion about effective personalized care for transitioning youth offered by Duffy and Murray (2013) can be placed in the broader changes in personalization and social care in England (Needham, 2011).

According to Whitaker (2015), personal budgets are connected to children's services through personalization programmes providing universal access and responsive and tailored help for families (p. 278). In 2005, the personalization in social care for children and their families reflected a managed budget. A Budget Holding Lead Professional (BHLP) would be tasked with working with families holistically to meet children's support needs based on a defined budget (Whitaker, 2015). In 2007, a new policy surrounding personal budgets in children's services emerged "to trial individual budgets giving families and disabled young people real choice and control" to design needs-based flexible packages of services (p. 279). This would lead to *The Children and Families Act* 2014 which continued rights of families of disabled children to request a personal budget to create integrated support plans (p. 280). It is through this act that Hutton and King (2018) address the promotion of personalized budgets as the "person-centred alternative to generically provided services" where families can decide which services to buy for their child and how to arrange care, taking individual circumstances, preferences and needs into account (p. 254). Personalized budgets through local authorities do not intend to substitute all services, but provide flexibility to purchase personalized care as set out in an Education Health and Care Plan (EHCP).

Apart from personalized care and the personal health budgets (PHB) more clearly promoted after 2015, Bisp et al. (2023) explore the use of such Personal Health Budgets for young people, their families, and clinicians when transitioning from child and adolescent to adult services. Similar to Cowen et al. (2011) and Duffy and Murray (2013), Bisp et al. (2023) refer to the importance of integration and personalized care and support planning for youth and young adults transitioning into adult care that is particularly relevant for the appropriate use of money used to support a person's health and well-being. The transition to individualized support in the local community is recognized as important for the provision of a PHB that enables young people to access individualized support tailored to the person and their individual strengths and needs (Bisp et al., 2023, p. 30). This presents some tension between managed programs that better facilitated the integration of support services and the individualized and self-managed push promoted through government.

In the context of Scotland, Manthorpe et al. (2015) recognize that responsibilities for social care policy are devolved in the UK and are leading towards a divergent social care policy in Scotland. Direct Payments (DPs) have been available in Scotland to disabled people since 2001 and self-directed support (Self-directed Support) builds on Direct Payments legislation per the *Disability Discrimination Act (Scotland)* 2003. Self-directed Support is used instead of, or in addition to, support services provided by local authorities. The context of personalization in Scotland saw the publication of the ‘Self Directed Support - A National Strategy for Scotland’ in 2010, which defined Self-directed Support as “the support individuals and families have after making an informed choice on how their individual budget is used to meet the outcomes they have agreed [upon]” (Scottish Government, 2010, p. 229). This strategy became part of *The Social Care (Self-directed Support) (Scotland) Act* 2013, meaning that as of April 2014, all councils in Scotland must offer personalization to people with a wide range of support needs, including learning disabilities, physical disabilities, mental health issues, and other long-term health conditions. Similar to IF under NDIS in Australia and Personal Health Budgets in England, an individual’s needs are assessed and individuals are given a budget according to the established need to spend on care and support as the individual sees fit. According to Biziewska and Palattiyil (2022), the act states that Self-directed Support encompasses four options for managing and arranging support:

> Option 1 is called Direct Payments and allows service users to manage their social care budget and to employ personal assistants. Option 2 is called an Individual Service Fund and gives service users choice and control over how their support is managed without the responsibility of managing the financial aspects (which are handled by a third party). Option 3 refers to a traditional service provision whereby a local authority makes decisions about and manages service users’ care. Finally, Option 4 constitutes a combination of the three other options which gives even greater flexibility for people with disabilities regarding how they want to arrange their social care budget. (p. 1284)

All service options are intended to give users choice and control over their support funds (Pearson et al., 2014), centering ‘choice and control’ as the defining aspects of Self-directed

Support. As such, Self-directed Support was a policy initiative to promote personalized services and equal partnership between professionals and those in need of support.

Mitchell (2012; 2014; 2015) addresses the literature and background to self-directed support (Self-directed Support) as introduced by the Scottish Government. Mitchell (2012; 2014; 2015) centers the same period of transition for young people with disabilities and their carers and family members as addressed by Cowen et al. (2011), Duffy and Murray (2013), and Bisp et al. (2023) in the context of England. Informed choice is a central principle of Self-directed Support and the transition from youth to adult services requires the integration of services for the disabled individual and their community. Mitchell (2014) identified barriers and facilitators to informed choice for individuals in the process of transitioning into adult services. The study highlights opportunities for supportive and informative relationships between service providers, workers, and disabled young people that would support informed choice. This finding is unpacked further in Mitchell (2015), where "findings point to the need to involve young people with disability at an early stage in choice-making, and to foster self-advocacy skills and supportive social networks" (p. 190). According to Henderson et al. (2018), Self-directed Support is a "catch-all payment system which brings challenges to local authorities, service delivery organizations and the service users it is intended to empower" (p. 651). Similar to Mitchell (2012; 2014; 2015), Henderson et al. (2018) propose the need for hybridity in the provision of Self-directed Support by third-sector organizations and local authorities to more effectively meet the needs of disabled young adults and children and their families and carers.[4]

In response to Self-directed Support implementation after 2014, the Scottish government acknowledged some of the barriers identified by Henderson et al. (2018) in a 2019 implementation plan. In this plan, several strategies were set out for public and voluntary organizations to support authorities in building more flexible and responsive social care support, co-produced with communities and supported people. In June 2023, Scottish Government and The Convention of Scottish Local Authorities (COSLA) published a Self-directed Support Improvement Plan for 2023-2027 to further improve the delivery of Self-

---

[4] A side effect of personalised services in quasi-market systems and budget cuts means the choice and control for disabled individuals are limited as third-sector funding cuts limit services offered by third-sector organizations. Social implications of thin markets outside of previously block-funded contracts present new barriers to informed choice and control that will also be addressed later in this report.

directed Support involving local councils, third sector organizations, independent support organizations, and others.

Third-sector social and health care industries: Not-for-profit and community organizations that are neither government nor private for profit entities.

Two articles included in this report speaking to IF in the UK, specifically address children and young adults with disabilities and their families and carers in Northern Ireland. In Northern Ireland, health and social care trusts are the local authorities tasked with providing Direct Payment (DP). In 1996, the Personal Social Services (Direct Payments) (NI) Order, “gave statutory social services discretionary power” to disabled adults, which permitted the five local health and care trusts to provide DP (McNeill & Wilson, 2017, p. 1905). In 2002, another order “gave parents/carers of disabled children the right to have their needs as carers assessed and met by trusts either through a service directly provided by or commissioned by the trust or by providing a Direct Payment to employ someone to meet that assessed need” (p. 1905-1906).

According to McGuigan et al. (2016), although the National Health Service (NHS) Confederation places the responsibilities for promoting DP uptake with social care providers, the rate of implementation has been poor (p. 40). Outside of England, implementation of DP at a local level, with different policies and health care structures at work in Northern Ireland, encountered various barriers, among which concern about managing a DP, social assistance resistance to DP, and limited numbers of available carers outside of institutions (McGuigan et al., 2016, p. 49). According to McNeill and Wilson (2017), reporting on the experiences of parents and carers of children with disabilities in one of the five health and social care trusts in Northern Ireland, DP bring both opportunities and concerns (p. 1903). Although personalization and DP have become cornerstones of the UK government’s agenda aimed at improving user choice and facilitating self-directed support and individual control over services, practical challenges associated with financial and resource constraints have limited uptake in Northern Ireland.

2.1.3 United States

Self-direction is a model of long-term care service delivery for people of all ages, with all types of disabilities, that aims to maintain their independence at home. When a person self-directs, they decide how, when, and from whom their services and supports will be delivered. As a model, self-direction prioritizes participant choice, control, and flexibility. This is a state-based model organized through the Centers for Medicare and Medicaid Services.

Four articles address self-direction and individualized budgets in the context of the USA. According to Swenson and Lakin (2014), the US

> has made a national commitment to family life for persons with disabilities … [and] has greatly expanded assistance to families to maintain children and adult members with disabilities in the family through expanded personal care and other in-home services, cash payments, information, counseling, and respite care. (p. 186)

Nevertheless, this national commitment is fragmented and specific to each individual state and often relates to the state-specific availability and commitment to individualized budgets through Home and Community-Based Services (HCBS) offered through Centers for Medicare and Medicaid Services (CMS).

According to Harry et al. (2017), speaking to experiences in Arkansas, Florida, and New Jersey, individualized budgets through HCBS can be a self-determined support for young adults in transition toward adult services. As Harry et al. (2017) explain, such budgets are flexible, self-directed and typically utilized by eligible disabled people for purchasing personal care attendants, supports, and goods that enhance independence and community living; “Specifically, self-directed budgets allow individuals to adapt care services to meet their unique health and personal care needs, giving them control over the services they need to live at home in the community” (p. 493). A self-directed budget model is called Cash and Counseling, which refers to a “state-based HCBS option that grants Medicaid-eligible participants both budget and employer authority over an individualized monthly cash allowance of comparable value to agency-based services" (Harry et al. 2017, p. 493). Since Medicaid-eligibility for HCBS self-directed funding is determined per state, not all states have options for disabled individuals to access this type of self-direction, with some states only offering budget authority (individual authority to purchase services) and not employer authority (individual authority to hire and manage personal assistants). An individual budget in the end, is determined based person-centred planning (PCP) where the amount of funding is based on the necessary service and support needs of the disabled individual enrolled in HCBS. More recently,

> programs now permit relatives of a program participant to act as paid caregivers. Federal Medicaid regulations prohibit legally responsible relatives from serving as paid providers of personal care/personal assistance services (PAS) (42 CFR 440.167). The meaning of legal responsibility is defined in state law and therefore varies from state to state, but generally the term refers to the parents of a minor child. (National Council on Disability, 2023)

As parents and other relatives are often not considered legally liable to provide care under state law, they may receive Medicaid for personal care/assistance services. This means young participants transitioning from youth to adult care under Cash and Counseling have an option to designate family members to help manage their budget or hire family members as personal care assistant (Harry et al., 2017, p. 493).

For young children with disabilities, other state-based programs grant participant (parent)-directed models. An example of such a program specifically providing participant/parent-direction is addressed by Timberlake et al. (2014) and Leutz et al. (2015) in the state of Massachusetts. Both Timberlake et al. (2014) and Leutz et al. (2015) engage with this state's Autism Waiver Program that "used a participant (parent)-directed model to help families to choose and manage services, staff, and their own budget" (Leutz, 2015, p. 27). Leutz et al. (2015) described "how the Commonwealth of Massachusetts structured and operated a participant-directed (PD) program through a Medicaid waiver that provided expanded habilitation, education, and related support services for children under age 9 with a verified diagnosis of ASD (Autism Spectrum Disorder)" (p. 28). Timberlake et al. (2014)

investigated “families’ experience of choice within a participant-directed Medicaid waiver program for young children with autism” (p. 903). Both articles address the participant-directed program from the perspective of available adult programs to promote a wider availability of participant (parent)-directed programs for children with disabilities and their parents/carers. Both articles also highlighted the importance of accurate and readily available information and service supports for parents/carers and service providers to foster effective collaboration in support of the child and the family/care relations around the child’s needs.[5]

2.1.4 Europe and Other Jurisdictions

Varied systems of **self-directed support** (SDS) organize people’s social care needs by empowering them to be equal partners in decisions about their care and support. SDS allows people to choose how their support is provided and gives them as much control as they want of their personal budget based on their individual needs.

An international scoping review on IF, specified for children and young adults and their parents/caregivers (Simpson & Douglass, 2016) included research from New Zealand (Priestley et al., 2022), the Netherlands (Nieboer et al., 2011), and the Czech Republic (Dudová, 2022).

According to Simpson and Douglas (2016), IF or self-directed funding (SDF) refers to individuals being assigned responsibility for managing a personalized support package that provides greater choice and greater flexibility. Based on their review of 12 studies, Simpson and Douglas (2016) identify a lack of research on the impacts of self-direction on children and young people with disabilities. General findings from the limited available studies highlight the

---

[5] It needs to be noted that since 2015, the National Council on Disability reports all states now offer adults programs tailored to self-direction and either budget or both budget and employer authority. More and more states now also offer HBCS to children with intellectual and developmental disabilities (https://www.appliedselfdirection.com/self-direction-programs).

importance of 1) self-direction for families with disabled children in the provision of autonomy, flexibility, and control in selecting supports best suited to individual needs, 2) self-direction having a positive impact on the overall sense of well-being and the quality of life for either carers or the children themselves, 3) self-direction reporting increased social participation that improved family relationships. Other reported outcomes of self-direction highlighted barriers presented by the administrative burden and lack of information and choice adding to feelings of parental/caregiver stress.

In the context of the Netherlands, Nieboer et al. (2011) address personal budgets and IF as available to parents of children and young adults with intellectual disabilities. More specifically, they provide an experimental study into parental support and access to information to inform choice and satisfaction with care. Although personal budgets expand the decision-making opportunities and level of control over the supports obtained for children or young adults with intellectual disabilities, the type of support received to inform parents' choices did not enhance the satisfaction with care. Nieboer et al. (2011) show that parents and caregivers are better supported with an intensified personal approach than the reliance on online available information about care options for their children (p. 134).

In the context of the Czech Republic, Dudová (2022) evaluated direct payment to care receivers to determine the impact of such funding on informal care and close relationships. Dudová's (2022) study addresses both adult children providing care to their parents and mothers caring for a disabled child. Regarding the latter, Dudová (2022) asserts that gender norms determined how the money was used and that the discretionary use of this money for the child's disability did not improve the caregivers' situation (p. 329):

> The mothers caring for their disabled child – be that minor or adult – regarded the care allowance as their personal income, which was included in the budget of their entire household and considered it remuneration for their care work. The care allowance was their main and often only income and was very important for them. This interpretation of the care allowance was surely linked to the economic situation of these women: they were jobless and were either homemakers or unemployed; or they had some precarious form of employment – a temporary job, occasional work, or an insecure short-term contract, always for low wages. (p. 345)

Specific to the context of the Czech Republic, cash for care did not lead to a commodification or marketization of care, and informal carers remained in that informal position caring for their disabled child (p. 349).

Commodification/marketization of care: The process by which care services are treated like market commodities, which represents a shift from the view of care as a social good or responsibility to a service that can be commercialized. The term "commodification of care" was initially used to describe the practice of governments providing allowances or subsidies to individuals to enable them to purchase care services as one would purchase any other good or service.

In connection to parental wellbeing, Priestley et al. (2022) address mothers' wellbeing in IF policy in Aotearoa New Zealand. IF is meant "to promote autonomy for disabled people and their family to make decisions about services to meet their needs" (p. 116). Priestley et al. (2022) frame IF as a consumer or client-led approach "to enable disabled people to exercise their rights which have been previously neglected and marginalised" (p. 116). However, the study reveals that despite IF, mothers interviewed in this study report ongoing negative impacts on their overall wellbeing and the stress of caring for a child with autism. Some of these barriers and limitations of IF will be addressed in the next section as not unique to the context of Aotearoa New Zealand.

Consumer-directed approaches: Approaches to supports which allow the user to design and direct their supports and are designed to maximize the agency and citizenship of persons with disabilities by giving them greater choice and control over personal care, services, and providers.

2.2 Barriers and Facilitators

The introduction and maturation of various IF models presented in the academic literature reveal common themes as well as barriers and facilitators identified in relation to IF schemes. Generally, authors agree successful IF models are facilitated by clear lines of communication with participants and their families and carers. On the contrary, a lack of accessible and timely information about IF are identified as barriers to participation in funding schemes that have the potential to impact funding recipients' and their family and care givers' wellbeing. This section will address the barriers and facilitators to IF for children and young adults with disabilities and their families and caregivers thematically. First, we address the facilitators to IF and positive experiences as highlighted by the research. Second, we address the barriers that often inform policy and budgetary consideration and implications.

In general, the research reviewed emphasized barriers to positive transitions and experiences of IF. These findings are useful in their ability to influence future policy decisions to improve IF models. That said, general positive themes can be discerned in the international literature on IF models (Table 2). One overarching theme is greater choice, control and flexibility.

Table 2: Facilitators to IF and Positive Experiences

Common Facilitators	**Positive Experiences**
Self-managed support funds	Increased choice and control
Accessible and timely information	Increased informed choice
Interagency collaboration for Early Childhood Interventions (ECI) / child to adult service transitions	Increased informed choice and effective decision-making
Access to alternative therapy options outside of medical models	Increased self-determination about support needs
Informal and paid family support and management of funds / Respite care	Positive family and community relations / Trust
Social worker or service coordinator to support transition to funding scheme and administration	Helping disabled children and families and carers with managing funds

2.2.1 Benefits of IF

According to Dew et al. (2013), Fisher et al. (2023), Harry et al. (2017), Laragy and Ottman (2011), and Timberlake et al. (2014), greater access to and choice of supports and therapy providers are benefits of IF. Specifically, study participants who self-managed benefited from the additional choices IF facilitated and the flexibility in changing the degree to which they chose to self-manage over time (Fisher et al., 2023; Laragy & Ottman, 2011). According to Harry et al. (2017), findings support the effectiveness of the Cash and Counseling Model of self-directed budgets for young adults with long-term care disabilities, as they “had significantly greater likelihoods of being very satisfied with life and a wide array of areas affected by self-directed budgets and had significantly lower likelihoods of unmet needs for assistance” (p. 497). In the context of Northern Ireland, McNeill and Wilson (2017) reported that participants felt Direct Payments (DPs) provided a sense of control, choice, reliability, and flexibility. In addition, the use of self-directed budgets in Massachusetts, Arkansas, New Jersey, and Florida suggest that this use of budgets contributes to greater satisfaction for disabled young adults and familial caregivers (Harry et al., 2017; Timberlake et al., 2014). While the literature underscores these important benefits and positive experiences associated with IF, positive outcomes associated with self-directed funding models were dependent on contextual variables (Simpson & Douglas, 2016). The next section discusses these facilitators to IF.

2.2.1.1 Positive Outcomes

Key facilitators of positive outcomes resulting from participation in IF are family status, social capital (e.g., supportive family and community relations), capacity, interagency collaboration, and geographic location (Simpson & Douglas, 2016). According to research by Boaden et al. (2021), Fisher et al. (2023), McDonald et al. (2016), and Russo et al. (2021), higher social capital and family capacity to use resources and advocate for support resulted in more service allocation and increased choice and control. Specifically, “socio-economic advantage and previous experience assisted participants to successfully self-manage,” referring to participant capacity to locate and use systems and manage uncertainties (Fisher et al., 2023, p. 16). Parents that opt for contemporary therapeutic approaches and benefits, are those who are likely well resourced, socio-economically advantaged, and have participated in previous IF models (McDonald et al., 2016; Russo et al., 2021).

Nine studies highlighted the importance of secure and supportive family and community relations that facilitated positive experiences with IF models (Bisp et al., 2023; Boaden et al., 2021; Cowen et al., 2011; Dew et al., 2023; Fisher et al., 2023; Howard et al., 2015; Leatz et al., 2015; Mitchell, 2014; 2015). These relations were underscored for increasing participant capacity to make informed choices about their IF package (Boaden et al., 2021; Dew et al., 2023). Such relations invoked trust and could be further enhanced with the support from trusted service providers or support workers familiar with the family and child's needs (Bisp et al., 2023; Fisher et al., 2023; Howard et al., 2015; Small et al., 2020). According to Cowen et al. (2011) and Mitchell (2014; 2015), these relations and community supports facilitate collaboration that also enforce a person-centred approach amongst providers, invoking mutual respect, role-sharing, and centralization of young people and their families. According to Bisp et al. (2023), this also facilitates interagency collaboration which expands access of services and young people's advocacy (p. 31). The role of trusted service providers or support workers facilitated families' introduction, choice, service plan development, and overall experience with IF (Leutz et al., 2015).

Seven studies specifically address facilitators to IF models in relation to Early Childhood Intervention (ECI) (Boaden et al., 2021; Brien et al., 2017; Brien, 2018; Clark & Dissanayake, 2022; Comito et al., 2023; Gavidia-Payne, 2020; Tracey et al., 2018). According to Boaden et al. (2021), families coped better where service providers linked them to interim ECI supports, information, and community networks (p. 301). Similarly, Tracey et al. (2018) argue that "early childhood intervention services emerged as a key instrument in developing the capacity of families to make informed choices" (p. 25). Brien et al. (2017) center the role of expertise and information sharing for ECI; "Effective decision making is thus co-constructed, with the ECI professional and family members co-contributing their specialist knowledge to inform decision making" (p. 39).

Comito et al. (2023) also recognize the pivotal role of interagency collaboration and continuous funding support for families transitioning from clinical to home-based settings. This also means that a lack of support from professionals and trusted service providers can lead to difficulties in navigating multiple systems with IF (Clark & Dissanayake, 2022; Gavidia-Payne, 2020). In turn, interagency collaboration should acknowledge the child's initiatives through both experienced and impartial observation to consider and support the best interests and developing capacities of the child (Brien, 2018, p. 432).

2.2.2 Barriers associated with IF and Negative Experiences

The literature points to diverse experiences of families and children in navigating IF models. Likewise, the barriers experienced are diverse and varied. Common themes and barriers associated with IF include times of transition, challenges with navigating impacting supports, administrative burden, contextual barriers based on socio-cultural factors, availability of appropriate human resources, rural and remote factors, and macro considerations. See Appendix 3 for further expansion of some of these key issues related to IF beyond the scope of the current review. The next section describes barriers associated with IF and negative outcomes (Table 3).

Table 3: Barriers to IF and Negative Experiences

Common Barriers	Negative Experiences
Lack of accessible and timely information	Administrative burden / Long wait times
Lack of integration navigating education, health and social care	Support gaps in transitions to child and adult services
Lack of or strained communication about funding	Financial stress and burden / Support gaps
Lack of family resources and informal support relations	Reduced capacity to navigate funding schemes / Support gaps
Lack of culturally appropriate funding information and support / cultural and linguistic barriers	No access or limited access to funding based on individual needs
Lack of understanding and support from support workers and third sector	Marginalisation of vulnerable groups and traumatization through disablism
Lack of accessible supports due to socio-cultural and geographic barriers	No access or limited access to funding without properly skilled staff or services available

2.2.2.1 Times of transition

One barrier is the difficulty of navigating various age-based transitions associated with IF and child and family needs for support. Alexander et al. (2019), Gavidia-Payne (2020), Loadsman and Donelly (2021), and McDonald et al. (2016) identified ECI barriers due to the introduction of IF. According to Alexander et al. (2019), the initial design of the National Disability Insurance Scheme (NDIS) in Australia caused children and their families to experience unintended negative impacts through medical multidisciplinarity, in which multiple professionals engaging with the child caused unresponsive or contradictory advice leading to increased parental stress levels (p. 189). According to Gavidia-Payne (2020), some participants reported difficulties with IF under the NDIS, which undermined timely access to ECI practices and parental ability to support their children (p. 190; see also Loadsman & Donelly, 2021). Another negative consequence of a consumer-centred disability funding scheme is that such a model could undermine 'non-traditional' therapeutic approaches in ECI via deeply held cultural assumptions regarding healthcare delivery and traditional biomedical approaches, as "these cultural assumptions will most likely play a significant role in parents' decision-making regarding therapeutic treatments for their children as part of the NDIS" (McDonald et al., 2016, p. 281).

Another important period for disabled children and young adults and their families and carers is the transition from child to adult services. Six articles specifically address this transition out of education systems and studied parental and carer concern about transitions into adult services with IF (Cowen et al., 2011; Duffy & Murray, 2013; Mitchell, 2012; Nucifora et al., 2022; Whitburn et al., 2017; Yates et al., 2021). According to Nucifora et al. (2022), participants felt that leaving school was difficult, primarily as the education system "provides reassurance that the child is progressing and is following a curriculum aimed at increasing skills," where the end of school involves transition to dependency on the NDIS, a new service which lacks structure (p. 6). A significant barrier identified by Whitburn et al. (2017) and Yates et al. (2021) was the siloed approach to the NDIS and IF that separate the education system and health care system from the social care system. The most significant barrier to effective IF planning and child to adult care transitions related to the lack of communication between the NDIS and the education system. This led to added complexity and support gaps during the COVID-19 pandemic, when both social care and education systems were perceived as lacking in the support of disabled children and their families and carers (Yates et al., 2021).

In the UK, Cowen et al. (2011), Duffy and Murray (2013), and Mitchell (2012) also identify a lack of a framework for support for young people and their families after the education system. According to Duffy and Murray (2013), disabled young people and their families have to overcome the gap between children's services and adult services, as 1) entitlements change and new assessments might mean young people are no longer eligible for support; 2) family representatives no longer have involvement in key decisions; and 3) school, respite services, medical services, social workers are all changed (p. 307). According to Mitchell (2012), barriers to self-directed support for disabled youth transitioning to adult services reflect a lack of a wider integrated network involving service users and unpaid carers as partners in co-production. In Northern Ireland, McGuigan et al. (2016) reported users also have difficulty with the distinction between health and social care as the Direct Payment (DP) scheme does not allow for crossover between health and social care needs.

2.2.2.2 Challenges with navigation impacting supports

More general concerns and barriers identified are less age-specific and seem to exist across IF models and jurisdictions. These include a lack of accessible information, strained communication about IF application processes and provision, and financial and administrative burden. According to Alexander et al. (2019) and Boaden et al. (2021), the transition to the NDIS in Australia came with uncertainty and families reported a complex application process with long wait times. People navigating access to IF reported limited guidance on services, inequalities in planning, approval, and review processes, and consequences of unequal capacity to take on self-management (Alexander et al., 2019; Boaden et al., 2021; Fisher et al., 2023; Nucifora et al., 2022; Ranasinghe et al., 2017).

According to Nucifora et al. (2022), Ranasinghe et al. (2017), Small et al. (2020), and Smethurst et al. (2021), many parents communicated difficulty with the application forms and arranging a funding plan to suit their child’s needs. At times, this difficulty would result in parents perceiving lack of expertise and understanding of disability within the NDIS, placing limitations on children’s plans that reduced the family's ability to exercise choice and control (Smethurst et al., 2021, p. 210). In fact, according to Carney et al. (2019), Australian states and territories provided information to the National Disability Insurance Agency (NDIA) based on legacy clients that identified priority applicants for transitioning into the NDIS that together with an intake questionnaire informed individual metrics used to generate access decisions and preliminary plan profiles for NDIS participants (p. 787). This resulted in data deficiencies and broad-spectrum questionnaires or intake information that led to decision errors “at odds with the needs of participants” (p. 787).

Nine articles identified parental or carer difficulty communicating with the IF agency and inadequate online information resources (Boaden et al., 2021; Gavidia-Payne, 2020; Loadsman & Donelly, 2021; Leutz et al., 2015; McDonald et al., 2016; Nucifora et al., 2022; Prowse et al., 2022; Ranasinghe et al., 2017; Russo et al., 2021; Tracey et al., 2018).

According to McDonald et al. (2016), this absence of communication and information could lead parents to make decisions they may regret. Ranasinghe et al. (2017) and Tracey et al. (2018) reported parents expressed difficulty in understanding online information about the NDIS. In the Netherlands, Nieboer et al. (2011) similarly spoke about the limitations of IF information available through online resources. Strained NDIA communication was linked to delays in assessment, and the development and coordination of children's plan implementation (Boaden et al., 2021; Gavidia-Payne, 2020; Russo et al., 2021).

Strained communication led to increased frustration about barriers facing the families of children with more complex support needs (Russo et al., 2021). In addition, Loadsman and Donelly (2021) specify that parental frustration and failure to access social services was linked to parents' experience of personal wellbeing. Family members felt they were letting their child down in not being able to secure supports (p. 1463). According to Prowse et al. (2022), participants felt the NDIS created additional stress and confusion, hindering goal achievement of their disabled family member (p. 212). Available social support through a trusted service provider or coordinator, identified as a facilitator, is a barrier when absent or not available to parents and family members navigating the IF system (Nucifora et al., 2022).

2.2.2.3 Administrative burden

Administrative and financial burden experienced with IF models included both logistic problems and a lack of access to self-management, leading to feelings of stress and concern among family members and carers of disabled children. According to Leutz et al. (2015), logistic problems included cumbersome steps for purchasing goods or services where families either had to pay up front or were not allowed to pay up front, complicating access to goods and services (p. 35). Logistic problems could lead to services not being utilized as hoped or leading to service gaps and financial distress (Alexander et al., 2019; Boaden et al., 2021; Laragy & Ottman, 2011). According to Gavidia-Payne (2020), participants experienced concerns in their new transactions with the disability system and felt overwhelmed in dealing with uncertainty around terminology, systems, settings, and funding (p. 190). McGuigan et al. (2016) reported that responsibility levels of DP caused anxiety for some concerned about the paperwork for employing personal assistants and other concerns associated with bureaucracy, paperwork, and administration. Similarly in Northern Ireland, McNeill and Wilson's (2017) found that respondents identified recruitment, administration and monitoring, and financing and rates of payment stressful aspects of DP management. Laragy and Ottman (2011) add that family stress due to a lack of information about funding and inadequate funding, led self-managing families to have to invest funds in seeking information, leaving fewer funds for personal support needs.

A lack of clarity about funding allocation and IF spending created barriers to using funding for specific types of support. According to Nucifora et al. (2022), parents managing housing and the associated financial costs results in a reduction in the child's independence and their child's ability to self-manage their funds. Collins et al. (2014) discuss various barriers to accessing DPs for respite or short breaks that caused concerns among parents. According to Priestley et al. (2022), mothers raising an autistic child in Aotearoa New Zealand faced complex funding systems, in which respite breaks were important but difficult to arrange serving as one example of significant confusion around funding guidelines (p. 123).

2.2.2.4 Contextual barriers based on socio-cultural factors

Other barriers identified across IF models and jurisdictions pertain to family resources and capacities, socio-economic status, disparate experiences based on Culturally and Linguistically Diverse (CALD) or Indigenous backgrounds, availability of skilled workers, and geographic disparities for those living in rural and remote areas with significant distance to a metropolitan centre or support service locations. A lack of personal family resources and capacity presented various challenges for families with a disabled child (Boaden et al., 2021; Ellem et al., 2019; Laragy & Ottman, 2011). Whereas valuable family relations and community connections have been identified as facilitators to experiences with IF, lacking relationships and community support presents a barrier to IF experiences. In turn, Meltzer and Davy (2019) indicate that IF practices mean that the support disabled people may need or benefit from to participate in reciprocal, positive, and fulfilling relationships risk being overlooked in the individualized planning and funding process.

A lack of capacity on behalf of family members according to Ellem et al. (2019) and Laragy and Ottman (2011) means planning around disabled family members presents challenges for families, who might be resistant to change, and may have a different agenda for the disabled person. In addition, planning often does not involve disabled children or young people in planning (Laragy & Ottman, 2011; Mitchell, 2014). According to Brien (2018), this barrier involves the limited capacity and/or unwillingness for adults and professionals to adopt a child-centred attitude, at times assuming that children are not capable or competent (see also Mitchell, 2015). Ellem et al. (2019), Cowen et al. (2011), and Mitchell (2014) point at a lack of trust or low confidence in programs offering self-directed support among family members with lower socio-economic status and resources.

According to Boaden et al. (2021), lower social capital results in added difficulties navigating access to the NDIS and IF (p. 300). Other research similarly identifies that IF models operate within socio-cultural disparities and in some cases increase disparity due to a lack of social inclusion leading to further alienation of equity deserving groups and those with more complex disability support needs (Laragy & Ottman, 2011; Marks et al., 2022; McDonald et al., 2016; Small et al., 2020). Simpson and Douglas (2016) found that poorer families, minority groups, and rurally-based families achieve poorer support outcomes using self-directed funding models.

Four studies explicitly recognize compounding marginalization of people with Indigenous and CALD backgrounds as a barrier to accessing IF (Boaden et al., 2021; Dew et al., 2023; Laragy & Ottman, 2011; White et al., 2021). Key barriers to navigating health and social care systems included unfamiliarity, cultural and language differences, and a lack of access to interpreters. According to White et al. (2021), “the NDIS application process can be complex and often inaccessible for disabled Aboriginal and Torres Strait Islander people” (p. 2). Barriers include but are not limited to: a lack of culturally appropriate and accessible support and training for Aboriginal and Torres Strait Islander people as well as culturally safe support workers; a lack of understanding across language and cultural barriers about normalisation; fear of stigmatization; and, a history of culturally inappropriate services marked by colonisation (White et al., 2021). These barriers are further complicated by geographic constraints experienced by Aboriginal and Torres Strait Islander people living in Country. Dew et al. (2023) add that the NDIS presents several barriers for equity deserving groups, including disabled refugee children and their families: for example, the online application lacks culturally appropriate assessment tools for families with limited access to histories of diagnosis and service use. Furthermore, disparate understanding of disability, community stigma, and a lack of interpreters who understand disability-specific needs further complicate access to IF supports.

2.2.2.5 Availability of appropriate human resources

A common concern with all types of disparity identified in accessing IF supports is the availability of professional and skilled staff to provide the support families want to purchase or employ with their IF. According to McDonald et al. (2016), concerns about the NDIS include “shortages of appropriately skilled staff” (p. 279). Similarly, Ranasinghe et al. (2017) state that parents reported issues in finding suitable, available therapists to provide therapy in a timely manner (p. 30). Concerns about skilled staff were compounded by geographic constraints that limited the availability of affordable skilled support workers, even with approved IF plans.

2.2.2.6 Rural and remote factors

Eleven articles address barriers experienced by those families and disabled young individuals living in rural and remote areas (Boaden et al., 2021; Dew et al., 2013; Dew et al., 2014; Gallego et al., 2018; Howard et al., 2015; Johnson et al., 2020; Laragy & Ottman, 2011; McDonald et al., 2016; Simpson & Douglas, 2016; Prowse et al., 2022; Small et al., 2020). As Dew et al. (2013) summarise, in the context of rural and remote areas there is: a) lack of information and advice; b) limited local service options and capacity; b) higher costs and fewer services; and (c) complexity of self-managing packages. According to Skinner and Rosenberg (2006), who conducted an analysis of non-profit and for-profit services in long-term care services in rural Ontario, IF constraints are to be expected in the context of geographic, sociocultural, technological, and workforce barriers, especially in market-oriented model. This is evident in the research by Dew et al. (2014), who discuss the challenges faced by rural service users in Australia. Most challenges are due to the difficulties service providers encounter in providing therapy across large geographic areas to dispersed populations (p. 60). Services that used to be delivered based on block-funding offered by a mix of government providers, non-government organizations, and private practitioners using outreach services are now meant to be serviced in a quasi-market system with publicly funded IF packages (Gallego et al., 2018). “Dependent on proximity to a larger centre, rural service users travel long distances, wait a long time, and receive less frequent interventions than their metropolitan counterparts” leading to choices among service users to remain in their rural communities or move to larger centres (Dew et al., 2014, p. 60). In addition, according to Howard et al. (2015), families with a disabled child aged under five years, living in regional or rural locations experience the scheme as focused on disabled adults, making choice and control not age appropriate (p. 1366). Howard et al. (2015) report that a limited accessibility of services, including home visiting, was a major concern for research participants dealing with transport and logistical challenges (p. 1372).

Several articles specifically address the complications of the IF model in a publicly funded market system of supply and demand. According to Johnson et al. (2020) and Prowse et al. (2022), this context presents barriers to accessing disability supports in rural and remote areas based on workforce shortages, lack of specialist services, high staff turnover, and a lack of timeliness in intervention due to minimal availability of local or outreach services. Rurally available workers may not be familiar with practices in disability support and are sparsely distributed making accessing clinical supports difficult (Johnson et al., p. 2210). As Johnson et al. (2020) conclude, choice and control in rural or remote areas may mean choosing the only clinician or having no options to choose from (p. 2210). Similarly, Laragy and Ottman (2011) acknowledge that the primary objective of choice and control under IF for families in rural areas is limited (see also McDonald et al., 2016). According Simpson and Douglas (2016), even though self-directed funding "offered families greater flexibility in how to spend funding, there was a very limited number of service options to spend it on" (p. 60; see also Small et al. (2020).

2.2.2.7 Macro considerations

Research included in this report also provided more macro considerations of the implementation of IF models and associated barriers. According to Carney et al. (2019), reflecting on the rollout of the NDIS in Australia, part of the problem is the scale of transition from block funding to IF that caused complication and a lack of suitable personnel (p. 785). This meant that instead of ironing out initial planning issues, complications went unaddressed or were delayed relying on participants to challenge their NDIS plan and IF allocation (p. 786). Howard et al. (2015) agree that the scale and complexity of the policy shift to NDIS is part of the reason that brought forward many challenges that impacted participant engagement and experiences. In turn, according to McDonald et al. (2016), consumer-centred disability funding schemes could be seen as the state handing back responsibility to individuals. Venning et al. (2021) add that the NDIS's mission, vision, and values and the Administrative Appeals Tribunal (AAT) reveal a tension between the imagined rights and the fair and sustainable administration of IF. Whereas eligible participants want their choices recognized based on perceived need, the government wants value for money and a sustainable system (p. 98). This tension between participant needs and government objectives complicates decisions about support eligibility and what constitutes reasonable and necessary support for disabled children and their families and carers (Meltzer & Davy, 2019). Decisions about funded support are based on competing ideas of need, choice and control, best practice, aptness of other services, cost effectiveness, and sustainability (Venning et al., 2021).

According to Marchbank (2017), reporting on the impact of shifting from block-funding to the IF model on local services, “agencies needed to adopt a different service delivery consistent with a business model” (p. 48). This meant administrators had little time to change as this process of change to a competitive business model required “an immediate response to become financially viable commercial organisations” (p. 48). As Marchbank (2017) shows, this required service staff to adopt a customer service selling-style in which funding limitations to these agencies (a lack of budgetary security) impacted negatively on equitable service delivery to families (p. 51). Staff employment became contingent on the staff’s own ability to accrue and maintain family revenue based on IF choices made by those families. These market-based influences were also recognized in the context of the UK in England and Scotland (Cowen et al., 2011; Henderson et al., 2018): the expected creation of competitive service markets for families to choose from in the context of personal budgets was slow or limited. Social barriers were assumptions about the organizational transition from charity to social enterprise (Henderson et al., 2018).

Social enterprise: Businesses characterized by a mission focused on providing social welfare services specifically for individuals who are disadvantaged or otherwise excluded from mainstream resources. These businesses prioritize social objectives over profit, aiming to address societal issues and support those who face barriers in accessing essential services.

This organizational shift and new policy based on choice and control for participants and consumer-direction actually removed choice through a loss of services in the marketplace (p.

651). From the perspective of agencies and service providers, the reduction in financial resources puts the provision of services and supports under pressure.

Moreover, this funding approach created a dual role for social workers and individual workers. According to Robinson et al. (2016), IF models mean social support workers might have to balance the role of providing personal support and planning with the role of providing responsible administration and management of funds. This joint accountability to both service-users and to organizations can create dissonance “between the worker and the person they support and the outcome focus of programs, governments, and policy” (p. 270). Underlying “assumptions of increased efficiency through organizational scaling up and a greater diversity in range of service availability [through IF models] were not borne out” (Salvador-Carulla et al., p. 875). McGuigan et al. (2016) reported that in times of high employment, Direct Payment (DP) participants found it more difficult to recruit appropriate carers and people with very specific needs worried about the training and experience carers may have and the impact this could have on their care (p. 39). According to Marchbank (2019), IF through the NDIS rollout in Australia led to the loss of local specialist networks impacting Early Childhood Intervention (ECI) and hindering access to services.

Finally, specific to England and the use of Personal Health Budgets that intend to give parents and carers greater choice and control over decisions about health care for their child, Hutton and King (2018) found that few parents and carers opted to have a Personal Health Budget (PHB). In turn, availability of PHB for parents of disabled children with complex needs varies across the country (p. 254). In an earlier study, Welch et al. (2012) similarly concluded that the implementation of DPs had been relatively slow with variations in uptake between constituencies across local authorities. The use of DPs is socially patterned, with greater uptake by educated, younger adults, physically disabled, with professional backgrounds, and without mental ill health (Welch et al., p. 901). More specifically, the uptake of DPs was slow in families with disabled children and is inequitably distributed with higher levels of use by families in “less deprived neighborhoods”, carers with higher education, White British carers, female carers, and families with younger children (p. 902). According to Whitaker (2015), self-directed funding mechanisms meant families could realize control, but still had to account for their personal budgets in detail and on a regular basis with their local authority. This means parents had to become managers, accountants, auditors, and commissioners as they coordinated services around their child, with associated burdens to those tasks.

2.3 Policy Implications and Considerations

The findings of this scoping review identified various implications for IF policy specific to disabled children and young adults and their parents, carers, and support networks. Some important considerations for the implementation of IF connect to the identified barriers and facilitators identified in the previous section. On the level of policy, various authors (e.g., Duffy & Murray, 2013; Hutton & King, 2018; Comito et al., 2023) identified the need for system integration and collaboration between health care, social care, and education systems. Another important consideration pertains to the role of co-production presented by family and community relationships that can function as important facilitators to the positive experiences of young disabled people and their families and carers; a factor not always considered in IF policy. A context-dependent consideration identified is the need to account for the political and economic context in which IF models operate, such as thin markets, budget cuts, and lack of available services or skilled workers in rural and remote areas. As policies differ internationally, the next sections consider the research and their policy implications and considerations for Australia, the United Kingdom, the United States, and Europe, and other jurisdictions when available.

2.3.1 Australia

The majority of sources in this report address the policy shift in Australia in which the National Disability Insurance Scheme (NDIS) and IF represented a move away from block-funding that was characterized as inadequate with disability services delivering significantly varied supports across jurisdictions (https://www.pc.gov.au/inquiries/completed/disability-support/report). Following the analysis of several barriers and facilitators to disability supports for disabled children, young adults, and their families and carers, these articles present various considerations for policymakers and the IF model managed by the National Disability Insurance Agency (NDIA).

The acknowledgement by the Australian government about the need for disability reform in 2011 foreshadowed individualized funding options through the NDIS. According to Laragy and Ottman's (2011), early localized programs based on IF models were increasingly encouraged. Laragy and Ottman also indicated the need for government policy makers to acquire more knowledge regarding effective implementation strategies for IF for both disability agencies and governments (p. 18). Moreover, optimal use of IF requires close collaboration between participants, service providers, and policymakers to develop a coordinated approach to IF to ensure effective support worker recruitment and retention strategies (Dew et al., 2013). This is particularly important, if is to better address the inequitable provision of disability services as criticized under fragmented block-funding (Dew et al., 2014). Another policy consideration underscored by Dew et al. (2014) is the need to consider service users in rural and remote areas in the roll-out of the NDIS and accommodated in NDIS policies (see also Loadsman & Donelly, 2021).

Howard et al. (2015) argue policymakers and service providers can make important contributions to national and international disability policy by emphasizing family and community relations of disabled children and young adults through co-production; communicating information with particular attention to language, timing and methods; building in processes to support and facilitate choice, decision-making, integration, coordination, and managing associated stress (p. 1376; see also Boaden et al., 2021; Small et al., 2020). Similarly, Tracey et al. (2018) emphasize that understanding families' perspectives should be critical "as policy-makers and service providers shift practice to meet the rise of IF" (p. 25). This also means IF should be able to communicate different therapeutic approaches to parents of disabled children without overwhelming them to ensure that IF facilitates informed, meaningful choices (McDonald et al., 2016).

Another important policy consideration is the role of facilitators/case managers. Policy should include effective support and case management to address individual and family goals (Brien et al., 2017; Robinson et al., 2016). Further policy implications include managing power differentials, financial constraints, and the capacity and training of case managers, so that "even in the context of a very small funding allocation, a facilitative case management approach to flexibility and person-centeredness in planning, control over allocated funding, and capacity building can enhance the effectiveness of self-directed support" (Robinson et al., p. 276).

Person-centered/family centered practice :An approach that places individuals and families at the center of their disability support decisions. This approach prioritizes the individual needs, preferences, strengths, and values of service users and families, ensuring that they maintain control and choice in their care.

According to Meltzer and Davy (2019), “effective policy implementation requires stronger recognition of the importance of relationships to achieving positive policy outcomes, even in a system focused on individual choice and control” (p. 252). In the context of ECI, Alexander et al. (2019) assert the NDIA should consider introducing the Key Worker Model for a holistic approach to IF and child and family support.

There is a need for policy to consider both person-centred and family-centred practices (Thompson, 2022). To achieve this effectively, scheme participant experiences should inform and guide practitioners and policymakers’ decisions (p. 410). As Brien (2018) suggests, policy should be sensitive to the child’s voice in allocating IF plans for disabled children, young adults, their families and carers and wider community support systems. Family-centred practices in particular should inform care for children 0 to 6 years of age (Gavidia-Payne, 2020). According to Gavidia-Payne (2020), “gaining a greater understanding of families’ lived experiences of the NDIS, its impact on their young children … and more broadly on their everyday lives, can inform policy and practice improvements” (p. 185; see also Clark & Dissanayake, 2022; Russo et al., 2021). Moreover, person-centred planning should include strategies to help families anticipate barriers (Ellem et al., 2019). The NDIS should provide families training and support in self-directed funding without adding to bureaucracy or abdicating service system responsibilities (see also Small et al., 2020).

As discussed above, intersectoral collaboration between IF, social care, education, and health is imperative and policy is needed to advance this. For example, Whitburn et al. (2017) assert that it is crucial for policy to correspond more closely with scheme participants and education services “to ensure children and young people with disabilities are provided full access to the curriculum in a comprehensive, inclusive education system” (p. 1076). Whitburn et al. (2017) argue integration should be high on the policy agenda to streamline access to NDIS and “its capacity to affirmatively affect the lives of people with disabilities and the wider community” (p. 1076; see also Dew et al., 2023). Alexander et al. (2019) address the need for integration of ECI services access under the NDIS as well to significantly impact the scheme’s functional capacity (see also Boaden et al., 2021; Johnson et al., 2020; Smethurst et al., 2021).

Various authors acknowledge that financial constraints will limit the level of funding and accessibility of services initially promised to disabled children and their families (Marchbank, 2017; Ranasinghe et al., 2017; Salvador-Carulla et al., 2022; Venning et al., 2021). Implications of these constraints for policymakers include finding ways to make sure service delivery organizations can switch to cost effective services and ensure families have access to skilled staff, avoiding support gaps. As Gallego et al. (2018) contend, for the NDIS to meet its policy objectives, addressing workforce issues is critical. Moreover, the workforce should include specialist training for support workers and nurses needed to address more complex disability needs for disabled children, young adults, and their families (Marks et al., 2022; Nucifora et al., 2022).

Policy makers need to prioritize cultural safety. NDIS policy should be made culturally appropriate for Aboriginal and Torres Strait Islander people (White et al., 2021). White et al. (2021) identified Aboriginal-led approaches as “best placed to overcome the historical and systemic factors that contribute to low levels of engagement” by disabled Aboriginal people (p. 10). Relatedly, IF policy should expand NDIS delivery in rural and remote areas in collaboration with community-controlled organizations to increase place-based engagement. People living in rural and remote areas generally report that the NDIS has exacerbated inequalities to equity deserving groups (Prowse et al., 2022). According to Prowse et al. (2022), reports about the NDIS reveal that those “marginalised, of low-socioeconomic status, or who live in rural and remote areas might need the most support yet receive the least benefit from the NDIS” (p. 215) highlighting key policy considerations. IF policy should address inequalities among equity deserving groups to adequately serve disabled people and their families (Fisher et al., 2023).

2.3.2 United Kingdom

The innovation of self-direction in the U.K. highlights the importance of shifting control to citizens and families (Cowen et al., 2011). Self-direction can integrate competing services by applying personalization to education, health, and social care as a whole-of-life policy framework (p. 36). That said, Direct Payment (DP) processes could be improved by clearer provision of information, clarification of eligibility criteria, simplification of assessment processes, and streamlining of administration (Welch et al., p. 907). Duffy and Murray (2013) assert the National Health Service should consider system integration to enable self-direction beyond adult social care for services for children. According to Whitaker (2015), children's services and the personalization of disability support meant policy moved from managed to individual to personal budgets. This carries important implications for potential resource sharing by various professionals that lead to strategic integration of budgets at the organizational level. According to Whitaker (2015), “there are significant cultural and political struggles ahead for education, health and social care to come together to genuinely support disabled children within their families” (p. 284). Integration requires a culture shift among service professionals to support entitled needs for children and their families. Hutton and King (2018) add, that the roll out of Personal Health Budgets provides “a potential solution to provision of care for those with complex needs allowing parents and carers greater choice and control may also contribute to more efficient use of limited resources at a time of diminished budgets” (p. 266). In Scotland, Mitchell (2012) proposed policy integration (variously referred to as whole systems working, joint working, partnership working, networks, or integrated working) as a needed cornerstone to address devolved health and social care policy (p. 53). Self-directed support connects to a rising demand for health and social care integration to deal with increasingly scarce resources.

In an era of healthcare co-production, personalization, and recognizing carers as co-workers, there has been little attention paid to the roles and experiences of service users and informal carers (Bisp et al., 2023). Service users and informal carers should inform effective integration of care supported by social workers and professionals (Mitchell, 2014). This can support disabled young people and their families to engage with wider social networks to increase social capital and access information to build trusted relationships to support informed choice, including engagement with peer advocacy and carers’ organizations (p. 261). Integration might present significant challenges for local authorities, service provider agencies; that said, IF should aim to ensure that young disabled people and their families have access to adequate assistance to make informed choice a reality alongside supportive and innovative networks (Mitchell, 2015).

In line with these challenges, Henderson et al. (2018) recognize “challenges of hybridity amongst the third-sector” (p. 662). Hybridity refers to the “shift in the emphasis of the operational goals of the organization with an increase in the necessity for financial sustainability at the expense of the social mission” (p. 661-2). This is a challenge for the third sector, referring to charities, social enterprises and voluntary groups that deliver essential services. This challenge spans jurisdictions and has been recognized in the international research with potentially important implications that we will address in the financial and budgetary considerations section as well.

Other policy considerations include furthering service developments and expanding IF to a wider range of young people and families (Bisp et al., 2023, p. 32). Collins et al. (2014) propose clearer policy and broader policy interpretations among social workers regarding the use of DPs for respite or “short breaks” for parents and carers. In Northern Ireland, McGuigan et al. (2016) and McNeill and Wilson (2017) identify strategic challenges for local agencies in seeking to further develop DPs to meet the needs of disabled children and their families and carers against poor implementation rates.

2.3.3 United States

“Cash and Counseling” in Arkansas, Florida, and New Jersey function as the IF model designed for disabled young adults (Harry et al., 2017). This self-directed budget model offers an important option for young adults transitioning into adulthood, including addressing service gaps after pediatric services (Children's Medicaid, IDEA) have ended (p. 493). Program support brokers, who can assist young adults “in utilizing community resources and thinking creatively about budgeting for meeting personalized needs such as community involvement or needs for assistance” are a valuable policy consideration (p. 500). According to Swenson and Lakin (2014), segmentation study could be of specific use to policy consideration as a strategy to support planning for serving the diversity of family needs and to develop strategies for reaching families with the right support at the right time. Segmentation study refers to the use of “U.S. Census and other data including commercial data that describe decisions and behaviors to create categories that are meaningful to commercial, civic, and other interests”

(p. 188). Questions for setting up effective policy support might consider behavioural, demographic, geographic, and psychographic characteristics and needs based on segmentation studies.

Policy considerations in the context of Massachusetts include the availability of accessible information from programs and services, as well as the potential of including information and experiences of navigating programs and services from previous recipients. According to Timberlake et al. (2014) and Leutz et al. (2015), autism waiver services in Massachusetts should understand the value of accessible information materials to ensure families get accurate information. This should include more training for providers and the simplification of record keeping and budget information. Policy should explore the improvement of family participation and whether experienced parents are willing to support new parents. Program improvements should consider the diversity of experiences for low-income parents raising children with multiple challenges.

2.3.4 Europe and other Jurisdictions

Research in Europe and other jurisdictions demonstrates that IF through monetary transfer for care carries social implications for both the privatization and marketization of care (Dudová, 2022, p. 331). The general social welfare landscape in Europe makes service provision less a public responsibility and more a move toward consumer-directed approaches that provide care recipients power to organize their care (p. 332). However, this marketization of care also risks worsening quality of care, lowering compensation of care work, and growing gender inequalities. According to Dudová (2022), in the context of the Czech Republic, this has implications for policymakers as they will need to try to find a solution to care deficits that are foreshadowed with an ageing population and reduction of available informal and unpaid care provided by women (p. 351).

Regarding IF policy in New Zealand, practitioners and policymakers should support parents in more flexible and holistic ways (Priestley et al., 2022). In turn, as governments change disability systems, social workers and health practitioners should be educated in their ability to practise with knowledge of disability to support IF recipients.

2.4 Financial and Budgetary Considerations

Costing or budgetary implications for models that utilize an IF structure include the overall estimated national budgets for publicly funded social care. Apart from financial flexibility for IF scheme participants in spending their funding according to their own needs, the majority of peer-reviewed research addressed in this scoping review made some reference to financial and budgetary constraints. On a personal level, articles addressed financial and budgetary burden on families, carers, and service workers. Articles related to the NDIS in Australia acknowledged that the transition from block-funded agency programs to publicly funded IF models affected and continue to affect costing and budgetary practices for third-sector agencies and privately funded programs and services. Several articles comment on the role of quasi-markets in the IF model (discussed below) and the strain these markets have on the workforce, including reductions in accessible and skilled workers that intersect with low wages for social workers and service providers.

A common concern across different jurisdictions was economic austerity and budget cuts in social services (most commonly associated with economic climates in Australia and the UK). This concern also connected to the experiences of participants who experienced financial burden in periods of policy transition or insufficient funds allotted for the care of their disabled child or family member. Several studies (ex. Dew et al. 2014) mentioned the impact of additional informal care requirements leading to the inability to remain employed as well as care for a disabled child or family member. Common themes related to financial and budgetary considerations and implications were accountability and sustainability (Brien et al., 2017).

According to Carney et al. (2019), there were tensions in the administrative implementation and rollout of the NDIS that led to questions around financial viability of the NDIS and “the quality of individual lives of both those not covered (reliant on state/territory services) and NDIS participants (in retention of their supplementary general supports)” (p. 798). Similarly, the fiscal implications of the policy change were “influenced by service availability, modality and the quality of relationships and connections between the family and service providers” (Howard et al., 2015, p. 1368). The NDIS and IF in Australia rely on quasi-markets and an insurance logic that complicate personalization of funding and services. This IF model puts lesser weight on expert case planning and relies on participant or familial expressions of preferences of the person, leading “to the imposition of distinctions between disability-specific costs (fundable) and associated complex needs (not funded)” (Carney et al., 2019, p. 811).

In turn, the quasi-market system assumes third-sector social and health care industries are able to adopt a business model, where families and participants inform service demand that impacts service supply. According to Marchbank (2017), administrators had to adopt a commercial standpoint with a high degree of accountability for time management to remain financially viable (see also Prowse et al., 2022). According to Henderson et al. (2018), in the context of self-directed supports and commercialisation of the sector in Scotland, this presents various challenges in the third-sector (p. 662). In fact, Salvador-Carulla et al. (2022) assert, “tentative hypotheses that disability services will transition towards a market was flawed” (p. 881): the assumed responsiveness of service supply to demand was limited by structural external factors to IF. This raised questions about whether this type of market competition encourages stagnation rather than diversification of care as services struggled to remain viable.

Such quasi-markets also increased the thin market experience in rural and remote areas with services moving away from more sparsely populated regions, concentrating in more urban regions (Dew et al., 2013; Dew et al., 2014; Johnson, et al., 2020). In fact, according to Loadsman and Donelly (2021), the National Disability Insurance Agency (NDIA) stated it is not financially viable to put more supports in rural communities, placing the financial burden on families who are to absorb the costs and stressors linked to the IF business model (p. 1464). Social implications of thin markets outside of previously block-funded contracts thereby presented new barriers to informed choice and control for scheme participants.

The ‘quasi’ aspect of the IF model is visible in the NDIA supported services registered under the NDIS and used for NDIA managed support plans. NDIS funding recipients (similar to self-directed support in the UK) can: 1) self-manage funds with which participants pay any business, presenting invoices to the NDIA through to the NDIS Portal; 2) plan-manage by an intermediary agency who handle the funds and administrative work to pay chosen support providers; or 3) agency-manage through the NDIA with only NDIS-registered service providers (Fisher et al., 2023). In addition, participants can mix funding types to facilitate choice to purchase services from both NDIS-registered providers and non-registered providers (p. 4).

The Australian government, through the NDIA, controls part of the social care market by offering registered service to managed scheme participants and plays a price-setting role for services offered by non-governmental organizations or public service markets. According to Green et al. (2022),

> There has been contestation over who is responsible for stewardship of the scheme …. Official documentation indicates the NDIA is primarily responsible for market stewardship [through] 'monitoring, evaluation, oversight and, where necessary, intervention' (National Disability Insurance Agency , 2018). In practice there has been a reluctance by the NDIA to take up this role and stewardship activities have fallen to state governments and … local actors. (p. 1141)

This means non-government actors shape the NDIS market through social care stewardship (p. 1138). This is primarily by offering information and supports to participants (through advocacy), shaping markets to participant needs to improve access and for individuals to spend their funding packages (Carey et al., 2021). However, non-governmental organizations operate within yearly funding cycles, which is adding distress and uncertainty, limiting providers' ability to plan for future need (Salvador-Carulla et al., 2022).

However, according to Green et al. (2022), there are also pros to having both publicly funded supports given to participants and privately practicing professionals offering programs and services for children and youth with support needs. Effective market stewardship requires both central agencies and distributed stewardship with local-level actors to reach and service IF recipients. Agencies providing supports in more rural and remote regions, servicing Culturally and Linguistically Diverse and Aboriginal and Torres Strait Islander people in Australia underscore the importance of local actors providing culturally appropriate products and services.

Boaden et al. (2021) argue that the shift from block-funding programs presents subsequent uncertainty and assumes participant capacity and individual advocacy in the funding application process and yearly funding reviews. Carney et al. (2019) acknowledge that the UNCRPD promotes the inclusion of personal statements of goals, aspirations, and circumstances to reflect needs. However, capacity to communicate complicated needs and the burden to document social contextual data can limit access to the NDIS to the skill and capacity of applying for NDIS. This presents barriers for people accessing IF (Clark & Dissanayake, 2022; Ellem et al., 2019). According to Gavidia-Payne (2020), “parents reported that substantial knowledge was required to ‘work the system’ once deemed to be eligible to receive funding for services” (p. 188): the need to work the system raises doubts about the allocation of adequate and appropriate funding (Nucifora et al., 2002; see also Thompson, 2022). In addition, the system complicates accessing funds based on situational vulnerability for disabled individuals with changing needs (Small et al., 2020). When funds are not spent, the person with a disability may receive less funding next time, which may increase their long-term vulnerability.

In general, NDIS implementation ensued with both political and economic concerns about its sustainability (Venning et al., 2021; Whitburn et al., 2017). The higher average cost per participant than initially anticipated operating costs challenged the scheme’s person-centred framework. This means that in its core, self-directed support and IF are to provide services at less cost, creating tensions around the quality of care and continued availability of services. Similar challenges are reported in the context of the UK (Bisp et al., 2023; Collins et al., 2014; McGuigan et al., 2016; McNeill & Wilson, 2017; Whitaker, 2015). Even though Henderson et al. (2018), in the context of Scotland, assert that

> the personalization agenda has provided an opportunity to both satisfy the demands for more choice and control by the disabled community and cut state costs, both through reducing state-run services and through cutting the amount of money which might be spent on each individual case. (p. 652)

These opportunities are curtailed by continued budget cuts and service delivery cuts.

In the context of the US, Harry et al. (2017), Leutz et al. (2015), and Timberlake et al. (2014) assert that the IF program in various states led to higher reports of satisfaction among service users, although some respondents, expressed worry about managing budgets and finances. According to Leutz et al. (2015), few participants fit the economic model of the fully informed buyer. Even though self-direction might reduce the cost of care for the state, it is unclear if this reduction is due to the barriers experienced with managing one’s own budget.

Three studies found that the IF model relies on the unpaid and informal work done by predominantly women. According to Swenson and Lakin (2014), the unpaid caregiving by family members accounts for the sustainability of the system of long-term services and supports in the US. Studies suggest that the direct value of uncompensated caregiving is in the range of 3 to 4 times the total state and federal Medicaid expenditures for long-term services and supports. According to Dudová (2022), financial benefits or self-directed funding through family appointment are presented as compensation for caregiving, but do not reduce gender-related inequalities of care. Often caregiving and management of funds does not adequately address the caregivers' need for support for their own wellbeing. In Aotearoa New Zealand, Priestley et al. (2022) found that adjustable funding for counselling care would be used if available. Finally, as Simpson and Douglas (2016) acknowledge that socio-economic status disparities continue to intersect with minority status and geographic access to services under IF models.

3. Discussion

This scoping review addressed 58 peer-reviewed articles that engaged with IF to inform an understanding of the efficiency and implications of such funding models on people, services, and policy. Different from previous block-funding models, IF assesses the individual's needs to inform a funding allotment that participants can then use to purchase directly the services and supports they require. This is in line with the UNCRPD and its recognition of disabled people's rights, opportunities for choice and control, and self-determination that align with the personalization of care agenda.

In general, the research agrees and affirms the importance of this personalization agenda and the push toward self-direction in care as made available through IF. The majority of studies included in this report acknowledge the positive responses about IF among disabled individuals and their families and carers in providing increased choice and control and a level of flexibility in spending allotted funding on services that best support their needs. What makes IF models successful are some common facilitators that were identified as conducive to positive experiences:

- Self-managed support funds led to increased choice and control;
- Accessible and timely information about funds led to increased informed choice;

- Interagency collaboration for Early Childhood Intervention (ECI) and transitions from child to adult service increased informed choice and effective decision-making;
- Access to alternative therapy options outside of medical models of care informed self-determination about support needs;
- Informal and paid family support and management of funds including respite care for carers were associated with positive family and community relations marked by trust;
- The availability of social workers or service coordinators to support the transition to the funding scheme
- Supports to assist in the administrations of funds helped disabled children and their families and carers effectively utilize their funds.

However, as addressed in this report, some IF components have been identified as unsuccessful or at odds with what personalization and self-direction seek to establish and accomplish for disabled individuals and their families and carers. Common barriers identified in the literature are tied to: 1) times of transition, 2) challenges with navigating impacting supports, 3) administrative burden, 4) contextual barriers based on socio-cultural factors, 5) availability of appropriate human resources, 6) rural and remote factors, and 7) macro considerations. These 7 themes were connected to:

- ❖ Gaps in policy implementation and a lack of effective transitions between care systems.
- ❖ A lack in personal access to services leading to a lack of funding.
- ❖ Familial and carer stress in managing the support system including financial and administrative burden
- ❖ Relational barriers to funding such as cultural and linguistic barriers, lack of culturally appropriate information, low socioeconomic status and social capital, and geographic constraints.
- ❖ A lack of access to skilled service and support workers reducing informed choice regarding service providers or alternative therapy options.

The specific focus of this report on IF models and the experiences of disabled children, young adults, and their families and carers revealed that age-specific needs intersect with disability-related support and family and carer needs. Two transition periods, children under six and youth over 18, were identified in the research as requiring more support and service integration than regularly available through IF. Both respective groups are identified as requiring integrated support across systems, including health care, social care, and education. IF models in most jurisdictions employ strict policies between what IF supports and what supports and services is in the realm of health care and education. For disabled children under six years of age, the separation between health and social care in IF models presented complications during ECI as more complex ECI relies on clinical assessment from health professionals and less complex ECI relies on teachers and professionals in education settings. For disabled youth and young adults in the eighteen years and older category, various researchers reported a similar lack of integration between child and adult services and transitions between education systems to other systems

The research also shows some of the ethical implications of using IF models and the tensions that exist between definitions of IF in theory and the rollout of IF for disabled children, young adults and their families and carers in practice. First, the common definition of IF and policy set-up has been criticized as focused on disabled adults when it comes to ‘choice and control’ and ‘self-determination in care’. Initial policy gaps often identified that IF models did not have children in mind. The characteristics and needs of younger populations present some tensions in how funding is allotted and used, specifically practices do not always keep both the individual’s (child) and carers’ needs in mind. Several researchers (e.g., Brien et al., 2017; Johnson et al., 2020; Small et al., 2020) address the tension between a family-centred practice and a person-centred practice when the focus is on the *individualization* of care funding and not the relations surrounding the child.

Individualization (of care): A personalized approach to providing support and services that is tailored to the unique needs, preferences, and context of the individual eligible for services. This approach aims to reflect the holistic person, thereby empowering the individual, promoting agency and enhancing quality of life.

Second, some gender and ethic of care issues were identified. Common assumptions about informal and unpaid care are informed by gender norms in which IF used for respite care or breaks is not equitably accessible (e.g., McNeill & Wilson, 2017). For example, Clark and Dissanayake (2022) identified respite was not considered an appropriate use of IF. According to Collins et al. (2014), local authorities were ill-informed about the use of Direct Payment (DP) for respite among families caring for disabled children. In addition, Dudová (2022), Tracey et al. (2018), and Whitburn et al. (2017) considered how previous gendered carer norms and inequalities appear to be increased through IF models and their itinerant rules on the use of a child's funding allocations.

In addition, pre-existing social disparities and inequalities in care were at times exacerbated by IF models. From an intersectional standpoint, some experiences with IF models increased a lack of access to appropriate funding and support among equity deserving groups, with specific attention to the compounding marginalization of care for disabled children and their families and carers living in rural and remote areas. This was identified as especially problematic in research engaging with access to IF among Indigenous populations (Boaden et al., 2021; Tracey et al., 2018; White et al., 2021). Those participants that reported positive experiences with IF models were predominantly White people living in more urban areas with greater socioeconomic status and income capital (e.g., Welch et al., 2012). In contrast, compound marginalization experienced by Indigenous individuals with disabilities and their carers, more often living in remote and rural areas, means more vulnerable individuals are less likely to be able to access culturally appropriate funding and supports through quasi-market funding models (Boaden et al., 2021; Tracey et al., 2018; White et al., 2021).

These disparities were in part exacerbated by the commercialization of social care and the lack of third sector support and block funding for supports previously available in underserviced areas. The quasi-market system or insurance-based model of care provided through publicly funded care moved supply and demand to more urban areas and decreased the availability of skilled workers, especially for disabled children and their families and carers with more complex health needs. Lower wages due to competitive price setting and a lack of budgetary support also meant a decrease in available and skilled care workers.

3.1 Jurisdictional Information Canada

In the current report, none of the included research (n = 58) focused on Canada or provincial and territorial jurisdictions in Canada. This points at a more general lack of research and information about IF in Canada. This finding is underscored when looking at the IF literature that focuses on IF and individuals with disabilities and support needs across the life span (n = 347). This gap in research increases when limiting the included articles to research focused on children and youth and their families and carers. The following section will discuss preliminary findings of a jurisdictional scan of IF programs and models in Canada.

As of 2022, there are no specific federal programs in Canada with a standardized IF component, as seen in Australia with the National Disability Insurance Agency. Canadian health and social services related to disabled individuals are primarily within the jurisdiction of the individual provinces and territories. Therefore, funding and programs related to individualized supports are administered at the provincial or territorial level. A jurisdictional scan of available IF programs per province or territory can be summarized as a patchwork, with some specific programs tailoring to disabled children under 21 and their families and carers.

3.1.1 BC

IF approaches currently available in the province of British Columbia (BC), specifically, are addressed in Table 4.

Table 4: Programs and Supports with IF Components Available in BC[6]

<table>
<tr><th>Program</th><th>Jurisdiction: People Serviced</th><th>Public/private</th><th>Funding Scheme</th><th>IF components</th></tr>
<tr>
<td>Individualized Funding
Community Living BC</td>
<td>Province wide – this program is accessed through Community Living BC (CLBC) offices. This program serves residents of British Columbia who are 19 years of age or older who have DD, significant limitations in adaptive functioning, or a diagnosis of FASD or Autism Spectrum Disorder (Community Living British Columbia, 2023a).</td>
<td>Public – This program is administered and funded through CLBC, a Crown agency under the Ministry of Social Development and Poverty Reduction. The program is governed under The Community Living Authority Act and Community Living Authority Regulation (Community Living British Columbia, 2022).</td>
<td>Individualized Funding provides self-directed payment to individuals as an alternative to or in addition to contracted services. There are two funding payment options:
1. Direct Funding: Individuals or their designated agent receives money directly from CLBC to purchase individualized supports and services agreed to by the individual, agent, and CLBC (Community Living British Columbia, 2023b).
2. Host Agency Funding: Individuals or their agents use a CLBC approved Host Agency to administer funds allocated to the individual. The Host Agency arranges for the delivery of individualized services and supports as agreed upon by the individual, agent, and CLBC (Community Living British Columbia, 2023c).</td>
<td>Direct funding – funds are sent directly to the individual/assigned agent.
→ Individualized funding amount is based on the individual's need.
→ Person centred planning – the plan is designed around the individual's specific needs and goals.
→ Monitoring and review – adjustments can be made to the plan as necessary.
→ Supports to implement plan – CLBC facilitator is available to individual/family for support.
→ Flexibility in how funds are used – the individual is able to select from a range of service options and providers that best fit their needs.
→ Self-directed support – the individual or family direct and manage services and supports.</td>
</tr>
<tr>
<td colspan="5">Applying: Individuals apply at their local CLBC office to determine program eligibility and funding amount; determined based on the Guide to Support Allocation (GSA) assessment instrument.
Planning: Eligible individuals and their families/support networks create a Personal Summary containing information about their support requirements supported by CLBC (Community Living British Columbia, 2021).
Scope: Funds can be used to support individuals in their home, community, and to support the general well-being of the individual and their family. Funds may also be used for support workers to join in activities and for costs associated with employment related expenses. A non-immediate family member may be paid to provide service for an individual where there is a need for CLBC funded supports (Community Living British Columbia, 2023d).
Responsibilities: The individual or agent is responsible for the coordination and management of funded services. They also assume the legal responsibilities of an employer in British Columbia; Host Agency: The Host Agency is responsible for managing and coordinating funded supports. The Host Agency assumes the legal responsibilities of an employer in British Columbia (Community Living British Columbia, 2023a).</td>
</tr>
</table>

---

[6] Does not include one-time grants available through a myriad of channels.

Program	Jurisdiction: People Serviced	Public/private	Funding Scheme	IF components
Choices for Supports in Independent Living (CSIL) Home and Community Care	**Province wide** – this program is available province wide and is accessed through Home and Community Care in the Regional Health Authorities; This program serves residents of British Columbia who are 19 years of age or older with significant physical care needs and a physical disability (British Columbia Ministry of Health, 2018).	**Public** – This program is funded by the Ministry of Health and administered by the Regional Health Authorities.	CSIL provides direct funding to individuals with physical disabilities and individuals with both developmental and physical disabilities. The program has two "phases": **Phase One**: For individuals who are mentally capable of self-managing their care. Individuals receive funds directly from CSIL and are responsible for the hiring and training of personal attendants. **Phase Two**: For individuals who are not capable of managing their own care. Individuals must form a support group (i.e., microboard) to receive funds on behalf of the individual and to manage their care. The individual may also have a CSIL representative manage their care.	**Direct funding** – funds are sent directly to the individual/support group. → Individualized funding amount – based on the individual's need. → Person centred planning – the plan is designed around the individual's specific home care needs. → Monitoring and review – the plan is monitored and reviewed by the CSIL case manager. → Supports to implement plan – CSIL case manager available to provide information and support the individual and/or support group. → Self-directed support – the individual and/or support group manages home care services.
Applying: Individual must be assessed by their regional health authority Home Support Services. A financial assessment is completed to assess whether a client rate is applicable. **Planning**: CSIL case manager orients the individual to roles and responsibilities of an employer. A CSIL agreement outlining the assessment of needs, hours, approved expenditures and monthly funding amount is created and signed. **Scope**: Funding is for a care provider only and cannot be used to purchase equipment or supplies. An immediate family member cannot be paid to provide care for a client unless an exception is approved by the health authority. **Responsibilities**: The employer (i.e., the individual or support group is responsible for the coordination and management of the funded services, and legal responsibilities of an employer in British Columbia. The employer is also required to submit monthly financial reports and receipts (Government of British Columbia, 2018).				

<table>
<tr><th>Program</th><th>Jurisdiction: People Serviced</th><th>Public/private</th><th>Funding Scheme</th><th>IF components</th></tr>
<tr><td>Direct Autism Funding
MCFD</td><td>Province wide – this program is available province wide and is accessed through local Children and Youth with Support Needs (CYSN) Ministry of Children and Family Development (MCFD) offices. This program provides funding to families with children 12 years or older with a diagnosis of ASD; If a family has more than one child with ASD, they are also eligible to receive direct funding for younger siblings (between 6-12).</td><td>Public – This program is funded by the Ministry of Children and Family Development (MCFD) and administered through the Autism Funding Branch (AFB).</td><td>Funding is provided directly to the parent/legal guardian. The parent chooses eligible autism intervention services that best suit their child’s needs. The parent is responsible for paying service providers for those services.</td><td>Direct funding – funds are sent directly to the child’s parent.
→ Supports available – CYSN worker is available to support the individual and family.
→ Self-directed support – the family chooses, hires, and manages services and supports listed on the Registry of Autism Service Providers (RASP).</td></tr>
<tr><td colspan="5">Applying: Family meets with a Children and Youth with Support Needs (CYSN) worker at local CYSN MCFD office. The child’s family must provide diagnosis or confirmation of diagnosis form, proof of child’s age, BC Card, and completed application form. Eligibility is confirmed by The Autism Funding Branch (AFB).
Planning: Once approved by the AFB, up to $22,000 per annum for children under six and $6,000 for children 6-18 is paid to the parent at the start of the first funding period.
Scope: Funding may be used services for a wide array of services and supports, including therapeutic services (e.g., counsellors, occupational therapists, and physical therapists), life skills and social skills programs, out-of-school learning support, specialized therapeutic activities. Professionals must be listed on the Registry of Autism Service Providers (RASP). A small portion of funds may also be used for administrative costs.
Responsibilities: A separate bank account must be created for direct autism funding. Parents are responsible for the coordination and management of funded services and meeting all necessary employer obligations. Funding must be accounted for at the end of each funding period. Unspent funds are counted as part of the new funding period’s total amount (Government of British Columbia, 2021).</td></tr>
</table>

Program	Jurisdiction: People Serviced	Public/private	Funding Scheme	IF components
At Home Program MCFD	**Province wide** – this program is available province wide and is accessed through At Home Program regional offices; This program supports residents of British Columbia who are 17 years old or younger (for medical benefits) or 18 years old or younger (for respite benefits) with a disability. Children must be living at home assessed as dependent in at least three of four functional activities of daily living (eating, dressing, toileting and washing).	**Public** – This program is funded by the Ministry of Children and Family Development (MCFD) and administered through regional At Home Program offices.	This program provides funding for respite services and medical items and services. A child may be eligible for both benefits or one benefit.	**Direct funding** – funds are sent directly to the family for respite services. However, the medical benefit only provides direct funding for incontinence supplies. → Flexibility in how funds are used – the family determines the type of respite service that fits their child's needs (e.g., household supports, caregiving supports, programs or program support). → Self-directed support – the family directs and manages respite services.

Applying: At Home Program application to be completed by the child's family and doctor. The application is sent to local At Home Program regional office.
Planning: At Home Program staff conduct in-home functional assessment of the child's activities of daily living. Information from other health care providers may also be included in assessment. The assessment and application are reviewed by regional committee who determine eligibility. Children who are dependent in all four functional activities of daily living are eligible for both Respite Benefits and Medical Benefits. Children who are dependent in three out of four functional activities of daily living are eligible for a choice of Respite Benefits or Medical Benefits.
Scope: Respite: funding is $4,135.56 per year. Families may choose the type of respite services that best suit their needs – either in their home or at another location. The program does not cover services that are provided by a parent of the child or any other MCFD program.
Medical Benefits: A range of medical items, equipment and services are provided by The At Home Program. Most benefits require pre-approval and are available from or paid for directly by the program. Direct funding is available for the purchase of incontinence supplies.
Responsibilities: Families are responsible for arranging respite, paying service providers, and managing their respite budget (Government of British Columbia, 2023).

<table>
<tr><th>Program</th><th>Jurisdiction: People Serviced</th><th>Public/private</th><th>Funding Scheme</th><th>IF components</th></tr>
<tr><td>Individual Funding - CKNW Kids' Fund</td><td>Province wide – this program is available province wide and accessed through the charitable organization CKNW Kids' Fund (online). This program provides grant funding to families with children under the age of 19 and living in British Columbia. There are no disability specific eligibility requirements.
Qualifications:
1. Children whose needs have been assessed and supported by a health/social/ educational professional;
2. Children who do not qualify for existing services provided by government funding, or are on an extensive waiting list, have exhausted other sources of financial assistance, or who do not meet all of the government criteria;
3. Children who are financially at risk.</td><td>Private – Individual grants are administered through the registered charity, CKNW Kids' Fund. The program is funded by charitable donations made by organizations and individuals.</td><td>Individual Funding through CKNW Kids' Fund provides grants for a wide array of services, supports, and equipment.</td><td>Individualized funding amount – based on the individual's need. However, there are grant maximums.
→ Person centred planning – funding grants meet the individual's specific needs and goals.
→ Flexibility in how funds are used – wide scope of funded supports, services, and equipment.</td></tr>
<tr><td colspan="5">Applying: The grant application to be completed by the parent/guardian of the child. In addition to the completed application, the family must send a letter of introduction from a parent regarding the family situation and need for funding assistance, letter of support from a professional, indicating the need for the specific request, most recent Notice of Assessment from Revenue Canada, and a current record of monthly income and expenses.
Planning: Families are advised upon approval. Services/purchases of equipment paid by the family are reimbursed by the program upon receiving an invoice or proof of purchase.
Scope: Therapies (maximum $2,500), Tutoring (maximum $1,800), Bursaries (Maximum $1,500) – requests are accepted three consecutive years with an updated application each year. Funding is also available for equipment (maximum $5,000).
Responsibilities: When the family no longer requires equipment purchased with funding, it is requested that the item(s) be made available to others with similar needs (CKNW Kids' Fund, 2023).</td></tr>
</table>

In addition to Table 4 specifying some programs and services with IF components available in British Columbia (BC), the next sections address some of the most prominent programs and supports that contain an IF concept, available in Canada, outside of BC.

3.1.2 Alberta

Family Support for Children with Disabilities (FSCD) Program

Established in 2004, Alberta's Family Support for Children with Disabilities (FSCD) Program provides financial reimbursement to qualifying families with children with disabilities. The reimbursement is determined based on the assessed needs of each child and family. FSCD is funded and overseen by the Ministry of Community and Social Services and administered through local FSCD offices. Families with a child under the age of 18, residing in Alberta, and meeting the criteria for disability as defined by the FSCD Act are eligible for the program. Families are required to provide documentation confirming that the child has a disability or is awaiting a diagnosis (Government of Alberta, 2022).

Families meeting the eligibility criteria for the FSCD qualify for Family Support Services, including respite, counselling, medical appointment-related costs (i.e., parking, mileage, accommodation, sibling care), and an annual allocation of up to $400 for clothing and footwear. To qualify for Child Focused Services, an additional needs assessment is required, indicating that the child is significantly limited in activities of daily living. Beyond the services offered under Family Support Services, Child Focused Services may include funding for respite services, child care supports, aide supports, health-related supports, specialized supports, and out-of-home living arrangements (Government of Alberta, 2022).

The FSCD worker collaborates with the family to identify the child and family's needs using the Family/Child Assessment of Needs (FSCD). An Individualized Family Support Plan is then created by the FSCD worker and the family, outlining the child and family's needs and goals. The services provided are documented in an FSCD Agreement, which is signed by the family. While the FSCD Agreement term may be up to three-years, staff meet with the family at least annually for the reassessment of needs and support planning. The program prohibits parents from receiving funding for the provision of respite. However, if appropriate, another adult family member can provide services. The family is required to spend funds per the terms of the FSCD agreement, adhere to relevant employment standards, and submit documentation of costs incurred when requested (Government of Alberta, 2022).

3.1.3 Manitoba

Children’s disABILITY Services (CDS) – Self-Managed Services

Administered by the Department of Families, Manitoba’s Children’s disABILITY Services (CDS) program provides supports to families for caring for disabled children at home in their communities. To be eligible, a child must be under 18 years of age, residing in Manitoba with their birth, adoptive, or extended family, and have a diagnosis of intellectual disability, developmental delay, autism spectrum disorder, lifelong physical disability, or a high probability of developmental delay due to a pre-existing condition (Government of Manitoba, 2021). Among the services offered, CDS provides funding for respite for families to have a break from the additional disability related demands of parenting a disabled child not met by available formal and informal supports (Government of Manitoba, 2019).

The amount of respite offered is based on the individual assessed disability-related needs of the child and family. CDS provides direct funding to the family based on their assessed needs and approved respite plans. An assessment is conducted by a community services worker who determines the families’ respite needs. Funding is exclusively allocated to compensate the respite worker for their services. A plan is developed in partnership with families, department staff, and respite providers to meet the needs of the family. In addition to the options of department-managed respite and the use of agencies, families may choose to self-manage respite services. With this option, families are responsible for recruiting respite providers, establishing a service schedule, and managing funds. Families are required to submit invoices, a respite care time sheet, and all supporting documentation to CDS to demonstrate that respite service were received. Respite providers must not reside in the home of the family receiving respite services (Government of Manitoba, 2019).

3.1.4 New Brunswick

Family Support for Children with Disabilities (FSCD)

The Family Supports for Children with Disabilities (FSCD) program in New Brunswick provides families with social work support and financial resources. This assistance is designed to help families meet the unique developmental needs of their disabled children, providing the necessary care and support. The program is funded by the Department of Social Development and administered through the regional Social Development offices. To qualify for FSCD, families must have identified unmet needs as a result of raising a disabled child. Eligibility criteria include having a child under the age of 19 who is a resident of New Brunswick, possesses a New Brunswick Medicare card, and has a severe disability (Government of New Brunswick, n.d.). The program defines disability as a lifelong physical, sensory, cognitive, or neurological condition or impairment which, in interaction with various barriers, significantly limits a child's ability to function in daily living (Government of New Brunswick, 2021). Eligibility for the FSCD program is not based on family income or the child having a specific diagnosis. However, families must submit a letter of support from a professional indicating the child's limited ability to function in normal daily living, and the family must participate in a financial assessment to determine the applicability of a family financial contribution towards services (Government of New Brunswick, 2021).

Families apply at their regional Social Development office. Families who meet the pre-assessment criteria meet with a social worker to complete the application process. This includes providing information about the child, the family's strengths, unmet needs, and the names of professionals and organizations providing services to the child and family culminating in a Family Support Plan. Some examples of eligible supports are relief care, child care services, therapeutically based recreational programs, family counselling, medical equipment, and special dietary foods. Families must access any other relevant supports available to them before FSCD will fund a similar service. This includes insurance coverage, health benefits plan and other government or community programs. FSCD has a two-pronged service delivery model allowing families to self-manage or request social worker support. Families who opt for the self-managed model are responsible for coordinating, managing, and directing the supports identified in their Family Support Plan (Government of New Brunswick, n.d.). FSCD funding is individualized to meet the family's specific needs; however, funding for services is not provided directly to the family but reimbursed.

3.1.5 Newfoundland & Labrador

Special Child Welfare Allowance (SCWA)

Newfoundland and Labrador's Special Child Welfare Allowance (SCWA) offers financial assistance to families with a child under the age of 18 who has a physical or developmental disability and resides at home. The program is funded by the Department of Health and Community Services and is administered through the regional health authorities. SCWA is intended to be accessed as a last resort after generic programs have been explored (Government of Newfoundland and Labrador, 2008).

In addition to meeting eligibility requirements, the program relies on a financial needs assessment. Alongside the completion of the financial assessment, families must provide documentation from a qualified professional verifying the child's disability and needs. After the initial application review, a social worker conducts a home visit to determine the family's needs. This information is reviewed by the regional health authority to determine the funding amount. Funding amounts are reviewed annually (Government of Newfoundland and Labrador, 2008).

Funds are disbursed directly to families as recurring monthly payments. A social worker collaborates with the child's family to create an Individual Support Service plan and determine the scope of eligible supports, services, and equipment. Funding may include coverage for medications not covered by a Drug Prescription Program, transportation to disability-related medical appointments or recreational activities, essential equipment or supplies, and disposable diapers. Funding can also be used for home support (supplemental to supervision provided by family), childcare, escorts to appointments and activities, one-on-one support in licensed child care, and residential short-term respite. However, a clear need must be established to utilize funds in these areas. Families are required to provide receipts to indicate that funds were used in accordance with approved supports (Government of Newfoundland and Labrador, 2008).

3.1.6 Nova Scotia

Direct Family Support for Children (DFSC)

Nova Scotia's Direct Family Support for Children (DFSC) is administered by regional Disability Support Program (DSP) offices, funded by the Department of Community Services. The program aims to facilitate and enhance the care of disabled children within their familial environments. DFSC offers direct funding to families with a child under the age of 19 residing at home and diagnosed with a mild or moderate intellectual developmental disability (with significant behavioural challenge documented within the last two years), a severe intellectual developmental disability or significant physical disability (with functional limitations severely limiting the ability to perform activities of daily living). Eligibility is further determined by a financial assessment that considers the family's size and annual net income. Families are deemed ineligible for DFSC when the child is under the care of the Minister, the family is currently receiving services through the Subsidized Adoption Program, the child and family qualify for funding through Indigenous and Northern Affairs Canada or when the child's needs align with the admission criteria for the category of Department of Health and Wellness licensed nursing home (Nova Scotia Department of Community Services, 2023).

DFSC provides funding for respite and special needs related to the child's disability (e.g., personal care supplies, transportation, medical equipment, medication, and child care). Family members living with the child may not be compensated for respite services; however, a family member may be paid to provide temporary respite services in exceptional circumstances. The funding amount is determined through a financial and functional assessment conducted by the DSP Care Coordinator. Funding amounts are tailored to individual circumstances, capped at $2,400 a month. For families with a child whose needs surpass DFSC support, there is an Enhanced Family Support for Children (EFSC) option, offering additional funding up to a maximum of $4,000 per month. This funding can be utilized for hiring additional specialized support workers. For both programs, families are required to make a monthly contribution, which is determined on a sliding scale based on their net income. Families receiving funding greater than $500 per month are required to provide receipts. Families with funding surpassing $500 per month can save a portion of their monthly funding for later use (Nova Scotia Department of Community Services, 2023).

3.1.7 Quebec

L'allocation Directe – Chèque Emploi-Service

Quebec's self-directed funding program, L'allocation Directe – Chèque Emploi-Service (Direct allowance/employment-service check) provides service users increased choice in employing and managing their home support service providers. Individuals of all ages may be eligible, if they meet the following criteria: a stable state of health, require long-term services, and are capable of undertaking the responsibilities associated with the management of service providers, alone or with the help of a friend or family member (MSSS, 2009).

The program is funded by the Ministère de la Santé et des Services sociaux (Ministry of Health and Social Services) and is administered through the Mission Centre Local de Services Communautaires (the Local Community Service Center, CLSC) along with Le Centre de Traitement du Chèque Emploi-Service (the Service Employment Paycheque

Processing Center, CTCES). The CLSC assumes a central role in program delivery. Specifically, this branch oversees the application and assessment procedures, establishes intervention plans and allocates funding, educates service users on their responsibilities, and conducts annual reviews and adjusts service users' plans as required (MSSS, 2009). The CTCES is responsible for the financial management of the program. Funding is not handled by the service user but flows from the CTCES to the service provider. The CTCES is responsible for tracking payroll, depositing Chèque Emploi-Service (an employment-service check) to service providers, and preparing government documentation (Government of Quebec, 2022; MSSS, 2009). Service users are responsible for hiring a service provider, managing administrative tasks (e.g., scheduling service providers and submitting bi-weekly timesheets to the CTCES), and directing their care (MSSS, 2009).

Applicants apply for this program through the CLSC. In order to create an intervention and funding plan, the CLSC conducts a needs-based assessment. In addition to the results of the needs-based assessment, the intervention plan and the associated funding amount also reflect the service user's care preferences, their ability to manage their care, along with other external resources (e.g., support from their family and community) (MSSS, 2009). As of 2020, the average monthly funding was reported to be $503 (Kelly et al., 2020). Eligible supports include personal assistance and housekeeping services. Service users have the option to hire a friend, neighbour, or a home care agency to provide services. Family members may also serve as service providers with approval from the CLSC (Eugeria, 2019; MSSS, 2009). In the case that service users are unable to secure a service provider, the CLSC provides a temporary service provider (MSSS, 2009). Once a service provider is secured, the CLSC registers the service user and their provider with the CTCES and initiates fund disbursement. The intervention plan is reviewed at least once a year. During this review, adjustments to the plan may be implemented in order better suit the service user's needs (MSSS, 2009).

3.1.8 Saskatchewan

Autism Spectrum Disorder Individualized Funding

Autism Spectrum Disorder Individualized Funding (ASD-IF) supports children with a diagnosis of Autism Spectrum Disorder and their families and is funded and administered by the Ministry of Health and the Ministry of Social Services. Representatives of the service user (i.e., a parent, guardian, and persons of sufficient interest) are to select and purchase services and supports that best meet their child's needs and goals. Eligibility criteria require the child is a resident of Saskatchewan, has a valid Saskatchewan Health Services Number, is under twelve years old, has been diagnosed with ASD, and is not ordinarily a resident on a reserve (Ministry of Social Services, 2022a). To access this program, the child's representative must submit an application and provide specific support documentation verifying eligibility criteria without a needs-based assessment (Ministry of Social Services, 2022a).

If approved, funding will be allocated based on the child's age; children under 6 years old may receive up to $8,000 annually and children 6 to 11 years old may receive up to $6,000 (Ministry of Social Services, n.d.-a). Eligible services include but are not limited to, regulated therapeutic services (e.g., occupational therapists and speech language pathologists), therapeutic programs and early learning services, respite services, sports/recreational fees or equipment, electronic equipment, safety-related purchases, family and caregiver ASD-specific training and education materials, and travel costs to access services.[7] In order to obtain the maximum funding each renewal year, all funds must be spent from the previous year; accordingly, unspent funds, as well as ineligible expenses, will be subtracted from the subsequent renewal payment (Ministry of Social Services, 2022a). To maintain ASD-IF, representatives must uphold the rules as well as the administration and financial responsibilities related to the funding contract. Representatives must purchase services from the Registry of Autism Service Providers, track and submit proof of expenses, report changes in the child's circumstance, and submit an annual review application to renew funding payments (Ministry of Social Services, 2022a).

Individualized Funding for Home Care

Funded by the Ministry of Health and administered and delivered by the Health Authority, Saskatchewan's Home Care program supports individuals with short and long-term illness or disability and support needs to live at home independently. This program offers an IF option to increase service users' choice and control over their home support services. The applicant must be eligible for home care support services; require long-term supportive care; be willing and capable of managing IF; have not obtained a third party to supplement the cost of services; and be accepted for employer coverage under *The Worker's Compensation Act*

---

[7] Eligible services for ASD-IF

(Ministry of Health, 2023). Children may access this program if their representative (i.e., parent/guardian) assumes the responsibilities and meets specific criteria associated with IF management. A needs-based assessment is completed by the service user, their representative (if applicable), and a Health Authority staff member. An individualized plan establishes the funding level with a monthly administrative allowance. The maximum monthly funding for 2023-2024 was reported as $8,269, with an administration allowance of $55.60 (Ministry of Health, 2023). This funding is dispersed through direct deposit, and recipients are responsible for opening a bank account specifically for IF. If a group of service users who live together wish to utilize IF as a collective group, they may pursue Collective Funding.[8]

Service users and their representatives may purchase personal care and home management services from private agencies or hire an individual contracting private service outlined by the individualized plan (Ministry of Health, 2023; Ministry of Health, n.d.). However, family members (related directly or by marriage or common law), health authority employees, and professional health services (e.g., registered nurses or therapies) cannot be hired (Ministry of Health, 2023; Ministry of Health, n.d.). Additional purchasing limitations include: paying for residential care associated with where the service user lives (e.g., group home); paying for costs acquired through hospital or long-term care services; and, purchasing products or services not included in the individualized plan or not associated with the home care program (Ministry of Health, 2023).

In selecting IF, service users and their representatives assume responsibility for the management of administrative tasks, including hiring, negotiating contracts, training, scheduling, and firing staff. They also maintain financial bookkeeping and submit monthly payroll, including Income Tax and Canada Pension, submitting a quarterly financial report, and upholding legal duties (e.g., applying for coverage under *The Workers' Compensation Act* and abiding by *The Saskatchewan Employment Act*). Users pay for home care fees that exceed funding level and an alternative care plan that is not dependent on the home care program (Ministry of Health, 2023). An annual needs review is required to renew funding.

---

[8] Collective Funding Policy in the Home Care Policy Manual

Community Living Service Delivery: Self-Directed Funding

Operating as a branch within the Ministry of Social Services, the Community Living Service Delivery (CLSD) offers a self-directed funding (SDF) option to assist individuals with intellectual disabilities in choosing and accessing community-based services to support independent living. While primarily designed for adults, the program is accessible at 18 years old. The eligibility criteria also require service users to be a resident of Saskatchewan, meet the general CLSD program requirement of having a diagnosis of an intellectual disability with an onset before age 18, and obtain a representative(s) (family, friend, etc.) to assist in executing the SDF plan (Ministry of Social Services, 2022b).

Once accepted into the CLSD program, the service user is assigned a CLSCMSD case manager with whom they can discuss their SDF. During an orientation meeting between the applicant, their chosen representative(s), the CLSD case manager, and a staff member of Inclusion Saskatchewan, all parties discuss the SDF plan along with the responsibilities and potential additional support for SDF management (Ministry of Social Services, 2022b). This meeting determines whether SDF is an optimal fit for the applicant. Applicants are required to submit an Expression of Interest document, build an SDF plan, and create a budget, which specify the reasons, the type, and the amount of care required (Ministry of Social Services, 2022b). Applicants may also employ a circle of support or personal support board.[9]

To determine necessary supports and the funding, the CLSD conducts two needs-based assessments which involve assessing the applicant's daily living support activities (DLSA) and day program support activities (DPSA). Once a contract detailing the SDF arrangement is satisfied and signed, funding is provided to the recipient through direct deposit. In 2017, the average monthly funding was reported as $6,250 per service user (Kelly et al., 2020). Service users may use SDF funding to access residential support, community inclusion supports and day programming, or a combination of both.[10] A portion of the SDF budget can be allocated to pay for professional services that assist with administrative responsibilities, such as an accountant or a community-based organization.

In case of unspent funds, the SDF recipient must notify the CLSD case manager. If they wish to utilize the unspent funds during the following funding year, the recipient must submit a plan detailing how the unspent funds will be allocated for approval by the CLSD

---

[9] Circle of support and personal support board in Self-Directed Funding Guidebook

[10] Eligible services and supports

(Ministry of Social Services, 2022b). The service user and their representative must uphold the SDF contract, and manage financial bookkeeping and reporting requirements, as well as operate as an employer, abiding by Canada Revenue Agency rules) (Ministry of Social Services, 2022b). The SDF is reviewed and signed annually.

3.1.9 Prince Edward Island

AccessAbility Supports

Prince Edward Island’s AccessAbility Supports, formerly the Disability Support Program, is an all-encompassing program that provides personalized support for all types of disability. Delivered by the Department of Social Development and Seniors, the overarching goal of this program is to facilitate access to resources that empower individuals to become active citizens within their community. In addition, this program is available to all applicants under 65 years old. Other eligibility requirements include documentation verifying that the applicant is a person with a disability diagnosed by a medical practitioner, holds permanent Canadian residency status along with residency status of Prince Edward Island, and has a provincial health number (Department of Social Development and Seniors, 2021). A Support Coordinator assesses eligibility and administers a needs-based assessment in order to identify the applicant’s unmet needs and the level of impact on their daily living activities.[11] The support program is means-tested to identify whether an applicant is required to pay contribution.[12] [13] Program eligibility along with the type of supports and the level of funding allocated to the applicant are determined by the results of these tests.

The Supports Coordinator and the service user (and representative if applicable) collaboratively construct a support plan that outlines critical funding and support details.[14] Funding is typically received on a monthly basis, and the amount ranges according to the level of assessed need (Legislative Counsel Office, 2021). Service users are provided the option to self-direct funds or manage funds through a representative (e.g., family member, spouse, etc.). Alternatively, the service user may utilize a third-party brokerage model to manage their funding and supports. The scope of funded supports falls under 8 categories:

---

[11] Capability assessment

[12] Supports needs assessment

[13] Applicant contribution

[14] Collaborative support plan

personal supports, housing supports, community supports, caregiver supports, employment and vocational supports, technical aids and assistive devices, home modifications, and vehicle modifications.[15] Similar to other IF programs, the service user or their representative is responsible for administrative and financial duties and partaking in annual reviews that seek to assess eligibility and the support plan (Legislative Counsel Office, 2021).

3.1.10 Yukon

Children's Disability Services

Yukon's Children's Disability Services, operating under the Department of Health and Social Services, facilitates access to supports and services that enhance the inclusion of disabled children within their community. This program is available to children under 19 years old, that are a Yukon resident, and have a disability of any category that results in significant restrictions to their daily living activities (DLAs) (Department of Health and Social Services, n.d.). This program is distinct in that a formal diagnosis is not a program requirement.

Family members may directly apply to the program or through referral with the family's permission. The application process requires the submission of basic information (e.g., full name, D.O.B, type of disability, caregiver names, and any relevant reports) (Department of Health and Social Services, n.d.). Subsequent steps include a meeting with a social worker who collects information about the child's needs and provides information about potential supports and services. Additionally, a report or assessment, like a needs-based test, outlining how the child's disability restricts their DLAs is required. If eligible, children and their families may access services such as an inclusion worker, respite care for families, a behaviour consultant and applied behaviour analysis therapy, occupational therapy and physical therapy, and speech-language pathology (Department of Health and Social Services, n.d.).

3.1.11 Ontario

Special Services at Home Funding

The Special Services at Home (SSAH) Funding is funded and delivered by the Ministry of Children, Community, and Social Services (MCCSS) and assists families in purchasing services to support children with developmental and physical disabilities. To qualify for

---

[15] Support plan policies and funded supports

support, applicants need to provide proof of their developmental and/or physical disability, reside in Ontario, be under 18 years of age, and either live at home requiring support beyond the capacity of the family or do not live at home without receiving support from residential services (MCCSS, 2023e).

Applicants and their representatives are required to complete an application form that describes the child's strengths, needs, current services, goals, and requests (MCCSS, 2021b). SSAH decision-making personnel apply a needs-based assessment to determine eligibility, funding level, and necessary supports and services. Factors influencing eligibility determination include the supports needs, the family's coping needs, the complexity of supports required, existing available community supports and services, and funding availability (MCCSS, 2021c). Funding is dispersed through a reimbursement model and recipients can opt for self-administered or agency administered funding (MCCSS, 2023e).

Funding may be used to purchase a wide variety of support and services that aid the development of the child and assist with primary caregiver relief. Eligible support and services range from a support worker, travel costs related to the child's disability, sport and recreational equipment and membership fees, respite care and home-making services, basic education supplies, and service delivery fees for essential items.[16] Workers may be contracted individually, through an agency. Non-primary caregiver family members, neighbours, and friends may be hired as well (MCCSS, 2023e). Additionally, recipients have the option to combine their funds with other families for joint service purchases (MCCSS, 2023e). If the recipient selects the self-administered funding option, they must assume responsibilities associated with IF management, which include administrative tasks, financial bookkeeping and reporting requirements, and upholding legal duties (e.g. maintaining liability coverage and human resource obligations) (MCCSS, 2021a).

Ontario Autism Program

The Ontario Autism Program (OAP) is funded through the Ministry of Children, Community, and Social Services. The program's administration and delivery are supported by AccessOAP. OAP supports children diagnosed with Autism Spectrum Disorder (ASD) and their families by facilitating the purchase of services and supports most fitting the child and family needs. OAP applicants must be under 18 years old, live in Ontario, and able to provide

---

[16] Eligible supports and services

professional documentation verifying their ASD diagnosis (MCCSS, 2023d). There are different funding pathways. For children who were registered with OAP prior to April 2021, the Childhood Budget and interim one-time funding may be available. The Childhood Budget allocates $20,000 for children under 6 and $5,000 for those aged 6 and older (MCCSS, 2023c). Service users and their representatives may purchase eligible services and supports, such as a behavioural assessment or evidence-based behavioural services.[17] Representatives may also apply to transition from a childhood budget to interim one-time funding.[18]

Service users registered after April 2021 may pursue the Direct Funding Option. This involves the representative of the service user (i.e., parent/guardian) choosing an eligible direct funding provider. Subsequently, an OAP behaviour plan, outlining the child's and family's needs, and a funding budget is developed jointly by the chosen service provider, the representative, and the OAP Family Team.[19] The final pathway, which seems the most representative of an IF scheme, is the Core Clinical Services Funding. This pathway requires care coordinators to employ a comprehensive determination of needs process that seeks to assesses 10 domains[20] in order to allocate a funding level. Funding allocation depends on the intensity of needs and age.[21] Service users receiving funding less than $25,000 annually will receive a single payment whereas service users receiving more than $25,000 annually will be given funding via installments (maximum $25,000 per installment) (MCCSS, 2023f). Once funding is established, the service user and their representative may select services (e.g., applied behaviour analysis, speech-language pathology, mental health services, and more[22]) and create a treatment plan with the service providers. Other eligible supports include travel expenses or professionally recommended materials and equipment. Care coordinators are available to assist families through the service selection process, and they, along with the representative, and the service user (if applicable), meet at least once a year to review and adjust the intervention plan as needed. For all funding pathways, the responsibilities primarily revolve around administration tasks (such as, selecting and hiring providers) and financial tasks (such as, submitting expense forms and additional documentation if requested).

---

[17] Eligible supports and services for childhood budgets
[18] Interim one-time funding
[19] Direct funding option
[20] Core clinical services determination of needs
[21] Funding levels for core clinical services
[22] Eligible services and supports

Family-Managed Home Care/Self-Directed Care

The self-directed option of Ontario's family-managed home care provides service users and their families a higher degree of choice and flexibility when selecting and managing home care services. This program is funded by the Ministry of Health and administered through Home and Community Care Support Services (HCCSS) organizations. It is intended for children with complex medical needs, home-schooled children with qualifying health care needs, and individuals in extraordinary circumstances.[23]

For service users falling under these classifications, their representative (i.e., parent/guardian) can connect with their regional HCCSS organization who will assign a care coordinator. To access the self-directed care option, the care coordinator conducts a needs-based assessment to determine the service user's program eligibility and needs. A care coordinator generates a plan of service, outlining the services and hours that may satisfy unmet needs. Care coordinators are authorized to allocate up to 21 hours per week; however, if necessary, additional hours beyond this limit may be approved by higher management within HCCSS (Guardian Home Care Toronto, n.d.). Eligible services include health care professionals (e.g., nurses, occupational therapists, etc.) as well as personal support services and homemaking services to meet 5s (e.g., washing, dressing, cleaning, caring for children) (Ministry of Health, 2023a). Expenses deemed eligible by the HCCSS may be covered by funding (Home and Community Care Support Services, 2022). Funding cannot be used to hire immediate family or individuals living in the same household (LIHN, n.d.).

While this program is typically self-directed, where service users and their representatives are given funds to purchase services, there may be instances where the HCCSS provide a combination of the Family Managed Home Care program and traditional home care (LIHN, n.d.). Similar to other self-directed care models, the responsibilities of the service user and their representative are related to administrative tasks, financial bookkeeping and reporting, legal duties, and reassessment procedures (Home and Community Care Support Services, 2022).

---

[23] Eligibility categories and extraordinary circumstances criteria

Self-Managed Attendant Services in Ontario Direct Funding Program

The Self-Managed Attendant Services in Ontario's Direct Funding (DF) Program is one of the longest standing IF programs in Ontario. Funded by Ontario's Ministry of Health and Long-Term Care through the Toronto Central Local Health Integration Network, this program is administered by the Centre for Independent Living Toronto (CILT) alongside the Ontario Network of Independent Living Centres (ONILC). This program promotes service users with physical disabilities to direct their care and manage their employees.

To be eligible, applicants must be 16 years old, Ontario residents, have a physical disability that creates a need for services, capable of completing a written application in their own words, and capable of proceeding with the application process and managing the responsibilities associated with IF (CILT, n.d.-b). After the applicant has submitted the written application detailing their needs and goals, they will partake in an in-person interview with a selection panel. CILT (n.d.-a) states that the waitlist for a selection panel interview is approximately two years. The selection panel consists of a representative from the local Independent Living Resource Centre (ILRC), a representative from the CILT, and a consumer of attendant services from the applicant's region. This interview intends for all parties to review the application, determine eligibility approval, and establish a budget according to the allocated funding amount. Funding is negotiated on an individual basis; however, the maximum of funded service hours is currently 7 hours per day (CILT, n.d.-a). Funds are dispersed monthly to service users so that they may purchase attendant services (i.e., assistance for daily living activities, such as transferring, washing, dressing etc.). A portion of the funding may be allocated to insurance and services that assist with the management of funds, such as payroll and bookkeeping (CILT, n.d.-a). However, attendant and other services may not be provided by family members (CILT, n.d.-a). The responsibilities of service users are of similar nature as other programs.[24] A distinctive feature of this program is that service users must possess the ability to self-direct and self-manage.

Passport Funding

Ontario's Passport Funding program enhances community integration for individuals with developmental disabilities and provides families and caregivers opportunities for reprieve.

---

[24] Responsibilities of DF service user

This program is funded by the Ministry of Children, Community, and Social Services and administered by the Developmental Services Ontario (DSO).

To be eligible, applicants must be 18 years old and have been approved to receive DSO services (i.e., applicants provided documentation verifying their diagnosis of a developmental disability and their Ontario residency) (MCCSS, 2023a). Service users may be referred to a local passport agency to apply for the program. Service users receive a fixed rate of $5,500 annually, without a needs-based test (MCCSS, 2023a). However, should service users require more funding, they may submit a pre-approval request for extenuating circumstance. This additional application includes the completion of a needs-based assessment. Eligibility approval is based on the level of need (i.e., those with higher support needs and higher risk factors are prioritized) in addition to the available government resources and existing external supports of the service user (MCCSS, 2023a).

The needs-based assessment scores are matched according to a funding chart; if approved, service users may receive up to $44,275 annually (MCCSS, 2023a; MCCSS, 2023b). Once funding allocation is confirmed, the next steps for the service user include selecting a Person Managing Funds (PMF) (this may be the service user or a family/friend), deciding between the Self Administer Service Option, the Transfer Payment Recipient Service Option, or the Broker Service Option;[25] and finalize the Passport Service Agreement. Funds are directly deposited or mailed when reimbursement claims are submitted; the party who submits claims and receives funding differs depending on the chosen service option.

Service users may choose from a wide variety of support and services, ranging from community participation supports, caregiver respite, employment supports, technology and educational opportunities, transportation, fitness classes, summer camps and ticketed, live events, and much more.[26] A portion of the funding (10%) may also be utilized for administrative management services and employer costs. Eligible services include professional service providers as well as non-professional providers (i.e., family members who do not reside with the service provider, friends and neighbours) (MCCSS, 2023a). Service users must uphold administrative, financial, and legal duties associated with IF schemes, although responsibilities may vary depending on the service option.[27]

---

[25] Passport service options

[26] Eligible supports and services

[27] Financial, administrative, legal, and service option specific responsibilities

3.2 Indigenous Programs and Services

A search of available IF programs among First Nations and Indigenous communities did not result in tangible results. However, an important consideration for IF models is consultation and collaboration with various Indigenous programs and services in British Columbia and Canada. Indigenous programs and services often operate within a framework that emphasizes cultural sensitivity and community involvement. This also means that while specific programs may not be labeled as IF in the same way, there should be consultation about available initiatives and approaches that align with principles of individualized and community-driven support within Indigenous communities that should respect the unique needs, values, and cultures of Indigenous individuals and communities. A culturally aware and appropriate IF model in any jurisdiction should recognize the diversity among Indigenous communities, and approaches may vary based on cultural practices, self-governance, and the specific needs of each community.

3.3 Policy Considerations

This scoping review found that the implementation of IF models necessitates careful consideration of various policy aspects to ensure its effectiveness, fairness, and sustainability. Considerations briefly addressed here include, but are not limited to, the following 13 points:

→ Equitable access: for example, promoting equitable access to services for children and youth with diverse needs and their families and carers, regardless of income, geography, or the nature of support requirements.

→ Needs assessment and planning: for example, developing clear policies for comprehensive needs assessment and balancing both family-centred and person-centered planning to determine the level of funding, while fostering collaboration between individuals, families, and professionals.

→Transparent funding allocation: for example, developing strategies which may include having transparent policies for determining and allocating funding amounts, ensuring explicit criteria and factors considered in determining the funding level for each individual, and ensuring that this information is accessible and understandable.

→ Quality standards and accountability: for example, implementing robust quality standards for services and supports funded through IF that include ongoing monitoring, evaluation, and accountability. This can ensure that services meet specified standards and use of public funds.

→ Participant training and support: for example, developing policies and strategies to provide training and support in managing IF can improve effectiveness. Areas to consider may include financial management, navigating services, self-determination for disabled young adults and their family, and strategies for advocating for their needs.

→ Provider certification and oversight: for example, developing a system for certifying and overseeing private providers to ensure quality standards, involving licensing, inspections, and mechanisms to address complaints or concerns.

→ Integration with other services: for example, developing policies that encourage collaboration and integration between IF-funded services and other funded programs. This may involve information sharing and coordination of care that avoids duplication.

→ Cultural competency and diversity: for example, ensuring cultural competence and addressing the unique needs and requirements of Indigenous communities and culturally and linguistically diverse individuals and families.

→ Legal and ethical framework: for example, establishing a legal and ethical framework that addresses consent, privacy, and the rights of children and families with support needs, and that defines the roles and responsibilities of all stakeholders involved.

→ Preventing exploitation and abuse: for example, implementing policies to prevent the potential exploitation or abuse of vulnerable individuals, including background checks for service providers, reporting mechanisms for suspected abuse, and establishing protective measures.

→ Evaluation and improvement: for example, developing and implementing a framework for ongoing evaluation and continuous improvement of the model that addresses the effectiveness of policies, assesses outcomes, and makes adjustments based on participant and stakeholder feedback.

- → Public awareness and education: for example, developing public awareness about IF, its benefits, and how people can access and navigate the system; and including the provision of educational resources may enhance informed choice and control.

- → Collaboration with stakeholders: for example, fostering stakeholder collaboration that includes disabled children and self-advocates, their families, the wider community, advocacy groups, service providers, and government agencies across the development, implementation, and evaluation of IF policies.

All in all, the implementing an IF model requires a thoughtful and comprehensive approach to evolving needs and challenges. As seen in the context of the UK and Australia, the choice of an IF model depends on various factors, such as the specific care and support needs of individuals, the objective of the funding model, and the socioeconomic and political context. The research documents the common types of IF models: direct (cash) payments, individual budgets, and agency-managed budgets or funding.

Direct (cash) payments, also referred to as **self-managed**, **consumer-directed** or **employer-authority**, describes a model in which disabled children, young adults, or their families receive direct cash payments from government or a funding agency. Recipients have the flexibility to use these funds to purchase needed services and supports, including hiring personal support workers, personal assistants, and accessing community resources. Some advantages highlighted with these direct payments include a high level of choice and control and flexibility to tailor services to unique needs. However, common barriers or disadvantages to this type of IF model include the more complex reality of managing funds for disabled children and young adults that often requires responsible financial management by family members or carers – the administrative burden. The increased choice and control inform independence that might also lead to variations in the quality and reliability of services chosen that are especially significant for more complex disability needs and Early Childhood Interventions (ECI). Some research raised concern from service providers about assumed misuse of funds due to lack of monitoring or oversight of the cash payments.

Individualized budgets or **plan managed IF models** allocate individuals and their families with a specific budget based on assessed needs. The budget is predetermined and individuals or their families and carers work with a support planner or case manager to plan and allocate funds. The planner or case manager is meant to assist in navigating service options and to ensure that the specific budget aligns with the disabled individual's goals. Some advantages to these types of IF models include the balance of both individual choice and budget constraints to ensure policy sustainability that provides support and guidance for people in planning and decision-making. However, these models also present some considerations, including the requirement that budgets are allotted based on the fair and accurate needs assessment. This type of planning involves ongoing communication and collaboration between individuals and support planners with transparency and mutual understanding of individual and family needs and budget allocation. At times, this IF model has led to tensions between families and support workers in determining what services are accessed through funding (respite care).

The **agency-managed IF models** available in several jurisdictions reflect a model in which funding is received by the disabled individual or their family and carers, but managed by a designated agency (such as the National Disability Insurance Agency in Australia). The agency plans, coordinates, and manages services based on the established needs and goals of the disabled individual, in which individuals have a say in the selection of services and providers. Advantages identified in the research include a sense of support and coordination for families with disabled children that invites collaboration between experienced agencies and service providers. Some considerations include the selection and oversight of managing agencies and the level of choice and control provided to the disabled individual and their families and carers in having meaningful input in decision-making.

In the UK and Australia, research points to options for **hybrid IF models** in which part of the funding is agency managed and part is self-managed. However, the research did not directly engage with the experiences of disabled children, young adults, and their families and carers in each of the categories or the hybrid option in comparative ways. What does become evident from the research is that the availability of choice between these models requires the availability of information and guidance to match the best model to the individual and family needs. This depends on factors such as the level of autonomy desired, the complexity of support needs, and foremost, the availability of different support structures. Hybrid models and customized approaches can address specific circumstances and preferences but make generalization harder to explore in the space of this report. In the end, the main characteristics of IF as set out in the introduction mean any IF model should align with a person or family-centered mindset that promotes choice and independence while keeping the best possible outcomes for individuals with diverse care and support needs in mind.

3.4 Financial Considerations

One of the most important considerations brought forward in the research on IF is the economic and political context or climate in which the IF model takes shape. This presented various costing or budgetary implications. IF models and budgetary structures vary based on the specific design of the model, the population served, and the scope of services covered.

IF models provide a high degree of flexibility in funding, especially in the direct (cash) payment and self-managed funding structure. Such a policy may have more unpredictable budgetary implications. The research showed some jurisdictions experienced lower costs based on this funding structure, due to a reduction in cost for services not needed. However, this individual amount of allocated funding might fluctuate based on assessed needs, goals, and impacts available resources. Some consideration should be made regarding the assessment process that ensures budgets are allocated fairly and reflective of support requirements. The accuracy and thoroughness of needs assessments not only affect the recipient and their families' experience with IF, but also have a direct impact on budgetary considerations. This requires agencies and policy makers to explore the potential use of robust needs assessment tools and include the in-depth training of assessors to understand diverse disability-related and care and health related support needs that effectively communicate with funding recipients and their families.

As some research indicated, IF models invited worry about the inappropriate use of funds and the level of capacity of individuals or families to 'work the system'. An equitable IF model addresses individual need and follows the objectives as set out in the UNCRPD while also employing effective monitoring and oversight mechanisms to prevent misuse of funds. This budgetary consideration also ensures the sustainability of the IF model and should help with maintaining the quality of services. An IF model should allocate internal resources or contract out audit and accountability measures to safeguard against fraud, abuse, or inefficiencies. It is important however that these be as light a touch as possible and do not add to the families' administrative burden.

Training and support in all facets of IF are required on the assessment and policy implementation level as well as on the personal and service provider or worker level. These training resources also have budgetary implications and adequate resources should be allocated to educational initiatives. Another important aspect is administration and case management as IF models involve administrative costs related to case management, support planning, and coordination of services. In particular, administrative support and effective case management were identified by families of disabled children as improving their level of satisfaction with IF. This requires administrative efficiency that is personalized and contributes to both positive outcomes and cost-effectiveness.

Costing and budgetary planning should also ensure the ethical and responsible use of funds. As mentioned in one of the 13 policy consideration points, this may mean conducting background checks for service providers, developing accessible complaint resolution mechanisms, and providing protection against financial exploitation. In part, this can be connected to budgetary resources made available for evaluative research. Such research can help assess the impact, effectiveness, and efficiency of IF models.

Whichever IF models are used or promoted, each requires resources for accessible information to increase public awareness and education about what IF is and how to access IF. Public awareness campaigns and educational initiatives should address various avenues of information distribution keeping the diverse needs of the disabled individual and their families, carers, and community in mind. These investments in public resources are important for informing the community about IF to promote understanding and garner public trust.

All in all, any costing or budgetary considerations should also include the international context of austerity referenced in the research and budget cuts among various social care policies in the twenty-first century. Political shifts mean budgetary implications are significant and multifaceted. A responsive and transparent system is paramount. Finally, it should be noted that as with any system an underfunded IF system is not likely to succeed and may in fact increase the burden on families rather than alleviate them.

3.5 Public and Private Supports and Support Workers

As previous sections in this report have addressed, IF models impact the available public and private supports and support workers engaging as mediators between funding recipients and service providers or agencies.

First, IF as an approach can potentially reduce pressures on publicly funded programs and services. Specifically, IF relies on tailored services which allows individuals and their families to customize their support services. This more tailored and personalized reliance on programs and services can lead to the more efficient and effective use of resources previously not available in public sector's one-size-fits-all programs. In addition, IF models have the potential to reduce administrative costs as individuals and their families might choose to self-manage. This reduces the bureaucracy and administrative overhead associated with traditional publicly funded programs. As individuals and families directly manage funds, there may be less administrative burden for programs that can lead to cost savings. It needs to be noted, however, that in more hybrid IF models or agency-managed funding, participants might rely on a case management worker or agency direction to help with the administrative aspects of their IF.

Second, IF models have the potential to clean out unnecessary supports traditionally offered. This is visible in increased efficiency as funding recipients control their funding and decide how and when to use their allocated resources. According to some articles addressed in previous sections, this autonomy can lead to more efficient utilization of funds in a timely manner. The flexibility provided by IF also invites innovation and creativity in service delivery, where disabled children, young adults, and their families and carers explore alternative and cost-effective therapy solutions, potentially reducing reliance on more expensive traditional services. This might help with the prevention of unnecessary services which reduces strain on programs.

Third, IF models can support increased family and community involvement. Especially IF models that are responsive to the local environment can create greater involvement of families and local communities in the care and support of individuals. This specific community-based approach acts as a supplement to publicly funded programs and can foster shared responsibility, reducing the burden on centralized services. When this potential is combined with culturally sensitive developments of information materials and support services, IF can also encourage of social inclusion. Local community or in-home supports can promote a more active participation, potentially reducing the need for specialized services that provide intensive, segregated services.

It needs to be noted that these three impacts of IF on public services and funded programs depends on planning, support, and coordination that do not come without challenges. As established before, the effective and positive outcomes rely on the assurance of the quality of services that prevent the risk of exploitation while addressing access to resource disparities.

The impact of IF on the workforce is a concern. This is especially in light of the quasi-market systems and the drain of skilled workers from more rural and remote areas and the availability of appropriate services and programs for support workers working with Indigenous peoples and people from Culturally and Linguistically Diverse backgrounds. Similar to other policy and budgetary considerations, IF impacts on the workforce within publicly and privately funded programs and services can vary, depending on the context and IF implementation.

In terms of flexibility and autonomy, IF can empower workers by providing more flexibility and autonomy in their service delivery as direct support workers have the opportunity to tailor their services to meet the specific needs and preferences of the individuals they are supporting. At the same time, this increased flexibility may also pose challenges for workers who need to shift their service delivery and might be accustomed to more structured and standardized approaches managed by an agency or service provider. This shift may require social workers and direct support worker to adapt their skills and practices. As has been noted, this flexibility can impact funding recipient negatively as skilled worker might move away to increase their client base.

In terms of job satisfaction and morale, some research briefly highlighted that the lack of clarity in transitioning to IF models impacted job satisfaction and morale in local authorities in the UK. If the IF implementation is not well-supported and if workers perceive increased stress due to changes in job expectations and duties coupled with uncertainty about funding, this could negatively affect morale. On the other hand, IF may enhance job satisfaction for workers who value the more direct connection with funding recipients they have been employed by and the ability to make a meaningful impact on the lives of the individuals and families they support. IF might present workers with the opportunity to engage in more personalized and creative care.

When we look at training and skill development, some literature addressed the overall lack of training among support workers that tailored to the specific needs of disabled children, young adults, and their families and carers. This reduced trust in direct support workers among families caring for children with complex needs. However, a shift towards individualized services may prompt workers to complete additional training and skill development in their adaptation to the new model and inspire workers to attain skills that make them more versatile and employable in a quasi-market system. This provides opportunities for both professional growth and specialization.

One of the more discussed components of the impact of IF on the workforce revolved around the availability of workforce stability. According to policy makers and the development of IF models in Australia, IF has the potential to create a more stable and committed workforce. However, various research about the effect of IF on workforce stability indicate that without intervention, instability may occur based on uncertainties in funding, inadequate support structures, or challenges in adapting to the new model. This could lead to higher turnover rates. In addition, support workers affected by price-setting in the quasi-market system might be forced to work in more urban locations due to low wages and high transportation costs in rural and remote areas that were previously safeguarded.

IF models and the impact they have on the available workforce are influenced by the level of collaboration and coordination available among workers, service providers, and other professionals. Similar to overall policy considerations for integration between support systems, as evidently important in providing supports for disabled children and young adults, enhanced communication can lead to more cohesive and integrated services. On the contrary, if there is a lack of coordination and communication between workers and support systems, including education, health care and social care, or between publicly funded and privately funded entities, this could result in confusion, service duplication, and inefficient service delivery.

In addition, the impact of private services on publicly funded programs through the use of IF can be complex. While private services offer additional choices and flexibility, they may impact the publicly funded sector and professionals in ways that potentially deter professionals from entering the publicly funded sector:

- Competition: Private services may compete with publicly funded programs for qualified professionals. It could be that private providers offer higher salaries and better benefits to attract skilled professionals. This can result in skilled work shortages within the publicly funded sector, making it harder to attract and retain experienced professionals.
- Resources: Private services can divert resources, including skilled professionals, away from publicly funded programs. Some individuals can access private services, leaving the publicly funded sector with individuals with greater support needs. This imbalance

could strain publicly funded programs and limit their capacity to provide high-quality services to individuals that cannot afford private alternatives.

- Inequality: Linked to resources, the availability of private services may lead to disparities in access to quality care. Individuals with more financial resources can opt for private services, while publicly funded programs with fewer resources have to tailor to greater support needs. This inequality in access can result in a two-tiered system, exacerbating socioeconomic disparities.
- Perception: Private services may be perceived as superior to publicly funded programs. This perception could influence individual choice for services toward seeking private services where publicly funded options are available. In turn, this can potentially lead to decreased public support and funding for publicly funded programs.
- Fragmentation: The coexistence of private and public services may lead to fragmentation and lack of coordination, resulting in disjointed care instead of integration.
- Erosion: The availability of private services may reduce funding and support for publicly funded programs. This can lead to insufficient funding and support for the publicly funded sector, exacerbating challenges in attracting professionals and providing quality services.

The integration of both publicly funded and privately practicing professionals in offering programs and services for disabled children and youth with support needs and their families and carers can have various advantages and disadvantages. We have summarised some general pros and cons in Table 6.

Table 5: The Pros and Cons of Private and Publicly Funded Service Integration

Pros	Cons
Having public and private providers increases the range and diversity of available services. Private practitioners offer specialized programs that complement the standardized services of the public sector.	Privately provided services often mean higher costs, creating inequality in access. Families with greater financial resources may have better access to services, leaving those with lower incomes at a disadvantage.
Competition between public and private providers can drive innovation and improvement in service quality in order to attract clients and funding.	The service quality in the private sector may vary, with less stringent oversight compared to publicly funded programs. This challenges quality control and adherence to standards.
Private practitioners have flexibility to tailor their services to individual needs, providing a more personalized approach. This can be particularly beneficial for disabled children.	Lack of coordination between providers may result in fragmented services, a lack of communication gaps, and a lack of integration that deter holistic support approaches.
Private practitioners may offer quicker access to services, reducing wait times for children and youth who require timely intervention.	Private practitioners are driven by profit, which might prioritize services that are financially lucrative. This can compromise the well-being of children and youth.
Private practitioners may operate more efficiently, offering cost-effective solutions. This can be appealing to families and seeking value for money.	The profit motive may result in the exploitation of vulnerable populations. Focus on financial gain could overshadow ethical responsibilities for quality care and support.

A well-designed and regulated system that leverages the strengths of both public and private sectors while addressing their weaknesses is essential for ensuring comprehensive and equitable support for disabled children and youth and their families and carers. Collaboration, oversight, and a commitment to the best interests of the children and youth are key factors in creating a balanced and effective system that incorporates an IF model.

3.6 Limitations

This report sought to inform our understanding of IF models internationally. It is important to acknowledge some limitations of this research and the resulting report. The peer-reviewed articles included here acknowledge some common limitations to the current state of the research and policy related to IF, specifically as it relates to young children under 21 years of age and their families and carers.

One common limitation in the literature is the lack of generalizability of the research results. Most qualitative articles that contained a participant sample indicated their sample was small and not representative of the population. In part, this limitation also speaks to the socioeconomic and cultural background of respondents, with a higher representation of White participants in urban areas that have the capacity to complete questionnaires or participate in interviews (Ranasinghe et al., 2017; Robinson et al., 2016). This also means children with more complex disabilities and their parents, families, and caregivers are underrepresented in the participant samples.

More specific limitations identified in the 58 articles reflect on future research need and considerations. In terms of IF policy and financial considerations, Alexander et al. (2019) identify that more research is needed to assess the impact of the financial strain on Early Childhood Intervention (ECI) service providers in the context of the quasi-market system of the National Disability Insurance Scheme (NDIS). According to Alexander et al. (2019), “many service provider organisations have broadened the age range of their client base to remain financially viable, thus reducing the expertise of the services available to families" (p. 191). Connected to this, Bisp et al. (2023) recommend more robust research “to examine the relationship between the various components of the service and respondents’ self-reported experiences and outcomes" (p. 31; see also Salvador-Carulla et al., 2022). In turn, according to Carney et al. (2019), research is needed into the bigger picture and some of the "conceptual and substantive questions going to the heart of contemporary understandings of disability and state responsibilities to vulnerable citizens with limited ability to self-advocate" (p. 812; see also Venning et al., 2021). These limitations of current research thereby also refer to needed future research endeavours that can inform policy and practice.

The literature often highlighted the importance of documenting the experiences of families of disabled young children and disabled young adults and their carer relations and community to guide policy and service development. Several articles also addressed the importance of engaging with service delivery from the perspective of social workers and expressed concern about the skill level of the workforce (e.g., Henderson et al., 2018) in providing supports and worker shortages (e.g., Dew et al., 2013), identifying a need for social work education adjustments (e.g., Gallego et al., 2018). However, the research objectives that guided this report did not specifically include articles that addressed worker experiences and this is an important area of research for the effective engagement with IF from a holistic systems perspective.

Limitations of this review can be found in the scope and generalization of the available research in peer-reviewed articles. This report did not directly engage with Canadian experiences in IF models or the available grey literature and opinions about IF from the general public. This review focuses primarily on academic research and research was predominantly available for Australia. Consequently, its findings and considerations may not be readily applicable to all sectors or regions. This presents limitations that could impact the precision of the analysis for a Canadian context and subsequent policy recommendations.

This report was written with some assumptions regarding IF definitions that underlie the review's analysis of the included literature. These assumptions and characteristics of IF may be subject to change or may not accurately reflect evolving conditions. In addition, this review needs to underscore the importance of the political and cultural contexts that play a crucial role in policy implementation as seen in barriers and policy and financial constraints also identified in jurisdictions outside of Canada.

The development of this specific report was somewhat constrained by limitations in time. As a result, certain areas of the policy landscape may not have been explored in as much depth as possible. In part, this is due to a more limited engagement with disabled children and young adults under 21 years of age. Another aspect to consider is the more recent rollout of IF models that have not been assessed at this date and time. Another constraint to keep in mind are the external variables, such as economic conditions and the unforeseen impact of the COVID-19 pandemic that has had a significant impact on the health care, education, and social care policies. The report recognizes such uncertainties may not be addressed in depth in the currently available literature and research on IF models and their impact on people, services, and policy.

While the research included here made efforts to incorporate diverse stakeholder perspectives, through for instance purposive sampling and presenting a focus on the experiences of Indigenous peoples, refugees, and people from Culturally and Linguistically Diverse backgrounds in rural and remote areas, the report may not fully capture the views of all relevant stakeholders. A context-specific and community-engaged research endeavour in BC, Canada should consider a more comprehensive engagement with diverse communities in various geographic areas to consider the needs and wants of the people IF is meant to support. As with all policy, the needs of people are dynamic in nature and policy considerations should keep this in mind. This means ongoing developments or emerging trends in IF as visible in the international literature could include some recommendations that are now outdated or insufficient. However, these previous trends can also inform best practices and prevent certain implementation challenges of IF models.

References

Alexander, S. L., Frederico, M., & Long, M. (2019). Attachment security, early childhood intervention and the NDIS: A risk and rights analysis. *Children Australia, 44*(4), 187-193. https://doi.org/10.1017/cha.2019.39

Bisp, S., Robertson, W., & Attree, S. (2023). Supporting young people who are leaving child and adolescent mental health services. *Mental Health Practice*, *26*(1), 28-33. https://doi.org/10.7748/mhp.2022.e1628

Biziewska, D., & Palattiyil, G. (2023). Promoting human rights or increasing expectations? effects of self-directed support on the realisation of human rights in Scotland. *Disability & Society, 38*(8), 1283-1303. https://doi.org/10.1080/09687599.2021.1994370

Boaden, N., Purcal, C., Fisher, K., & Meltzer, A. (2021). Transition experience of families with young children in the Australian NDIS (NDIS). *Australian Social Work, 74*(3), 294-306. https://doi.org/10.1080/0312407X.2020.1832549

Brien, J. (2018). How can the right of young children with disability to be heard be enacted within the policy constructs of participant choice and control? *The International Journal of Children's Rights, 26*(3), 423-445. https://doi.org/10.1163/15718182-02603001

Brien, J., Page, J., & Berman, J. (2017). Enabling the exercise of choice and control: How early childhood intervention professionals may support families and young children with a disability to exercise choice and control in the context of the National Disability Insurance Scheme. *Australasian Journal of Early Childhood, 42*(2), 37-44. https://doi.org/10.23965/AJEC.42.2.05

Carey, G., Malbon, E., & Blackwell, J. (2021). Administering inequality? The National Disability Insurance Scheme and administrative burdens on individuals. *Australian Journal of Public Administration, 80*(4), 854-872. https://doi.org/10.1111/1467-8500.12508

Carney, T., Then, S., Bigby, C., Wiesel, I., & Douglas, J. (2019). National Disability Insurance Scheme plan decision-making: Or when tailor-made case planning met Taylorism and the algorithms? *Melbourne University Law Review, 42*(3), 780-812.

Central Local Health Integration Network (LIHN). (n.d.). *Family-managed home care*. https://yssn.ca/wp-content/uploads/2021/11/Central-LHIN-FMHC-fact-Sheet.pdf

Centre for Independent Living in Toronto (CILT). (n.d.-a). General information. https://www.dfontario.ca/info/general-information.html

Centre for Independent Living in Toronto (CILT). (n.d.-b). *Self-managed attendant services in Ontario*. https://www.dfontario.ca/

CKNW Kids' Fund (2023). *Grant Application Guidelines.* Retrieved from https://www.cknwkidsfund.com/apply-for-a-grant

Clark, M., & Dissanayake, C. (2022). Characteristics of children attending an autism specific early learning and care setting prior to and following introduction of the National Disability Insurance Scheme. *Journal of Intellectual & Developmental Disability,* (ahead-of-print), 1-10. https://doi.org/10.3109/13668250.2022.2112509

Collins, M., Langer, S., Welch, V., Wells, E., Hatton, C., Robertson, J., & Emerson, E. (2014). A break from caring for a disabled child: Parent perceptions of the uses and benefits of short break provision in England. *The British Journal of Social Work, 44*(5), 1180-1196. https://doi.org/10.1093/bjsw/bcs209

Comito, M. A., Coster, K. M., & Gilbertson, H. R. (2023). Establishing a disability-specific home enteral nutrition service in a paediatric tertiary hospital: Experience and outcomes. *Nutrition & Dietetics,* https://doi.org/10.1111/1747-0080.12833

Community Living British Columbia. (2023a). *Individualized Funding Policy*.

Community Living British Columbia. (2023b). *Direct Funding Policy*.

Community Living British Columbia. (2023c). *Host Agency Funding Policy*.

Community Living British Columbia. (2023d). *Supports Funded by Community Living BC.*

Community Living British Columbia. (2022). *Policy Framework Policy*.

Community Living British Columbia. (2021). *Support and Planning Policy*.

Cowen, A., Murray, P., & Duffy, S. (2011). Personalized transition: A collaborative approach to funding individual budgets for young disabled people with complex needs leaving school. *Journal of Integrated Care (Brighton, England), 19*(2), 30-36. https://doi.org/10.5042/jic.2011.0158

Department of Health and Social Services. (n.d.). *Find supports for your child with a disability*. Government of Yukon. https://yukon.ca/en/health-and-wellness/babies-and-childrens-health/find-supports-your-child-disability

Department of Social Development and Seniors. (2021). *AccessAbility Supports: Eligibility (Policy no. 1.1)*. Government of Prince Edward Island. https://www.princeedwardisland.ca/sites/default/files/publications/1.1_eligibility.pdf

Dew, A., Bulkeley, K., Veitch, C., Bundy, A., Lincoln, M., Brentnall, J., Gallego, G., & Griffiths, S. (2013). Carer and service providers' experiences of individual funding models for children with a disability in rural and remote areas. *Health & Social Care in the Community, 21*(4), 432-441. https://doi.org/10.1111/hsc.12032

Dew, A., Happ, V., Bulkeley, K., Bundy, A., Lincoln, M., Gallego, G., Brentnall, J., & Veitch, C. (2014). Rural carers of people with disabilities: Making choices to move or to stay. *Research and Practice in Intellectual and Developmental Disabilities, 1*(1), 60-70. https://doi.org/10.1080/23297018.2014.908481

Dew, A., Lenette, C., Wells, R., Higgins, M., McMahon, T., Coello, M., Momartin, S., Raman, S., Bibby, H., Smith, L., & Boydell, K. (2023). ‘In the beginning it was difficult but things got easier’: Service use experiences of family members of people with disability from Iraqi and Syrian refugee backgrounds. *Journal of Policy and Practice in Intellectual Disabilities, 20*(1), 33-44. https://doi.org/10.1111/jppi.12424

Dudová, R. (2022). Cash for care as special money: The meaning and uses of the care allowance in close relationships in the Czech Republic. *Feminist Economics, 28*(2), 329-355. https://doi.org/10.1080/13545701.2021.1988126

Duffy, S., & Murray, P. (2013). Transition and integration – changing our starting point. *Journal of Integrated Care, 21*(6), 306-314. https://doi.org/10.1108/JICA-10-2013-0040

Ellem, K., Chenoweth, L., & Edwards, R. (2019). Choosing the harder road: Naming the challenges for families in person-centred planning. *Journal of Intellectual Disabilities, 23*(3), 397-412. https://doi.org/10.1177/1744629518784154

Eugeria. (2019, July 25). *Direct allocation program with service employment paycheque: How to see clearly*. https://info.eugeria.ca/en/direct-allocation-program-with-service-employment-paycheque-how-to-see-clearly/

Fisher, K. R., Purcal, C., Blaxland, M., Robinson, S., Quan Farrant, F., Kayess, R., & Edwards, Y. (2023). Factors that help people with disability to self-manage their support. *Disability & Society,* (ahead-of-print), 1-19. https://doi.org/10.1080/09687599.2022.2164707

Fleming, P., McGilloway, S., Hernon, M., Furlong, M., O'Doherty, S., Keogh, F., & Stainton, T. (2019). Individualized funding interventions to improve health and social care outcomes for people with a disability: A mixed-methods systematic review. *Campbell Systematic Reviews*, *15*(1-2), Article e1008. https://doi.org/10.4073/csr.2019.3

Gallego, G., Dew, A., Lincoln, M., Bundy, A., Bulkeley, K., Brentnall, J., & Veitch, C. (2018). Carers' preferences for the delivery of therapy services for people with disability in rural Australia: Evidence from a discrete choice experiment. Journal of Intellectual Disability Research, 62(5), 371-381. https://doi.org/10.1111/jir.12469

Gavidia-Payne, S. (2020). Implementation of Australia's NDIS: Experiences of families of young children with disabilities. Infants and Young Children, 33(3), 184-194. https://doi.org/10.1097/IYC.0000000000000169

Government of Alberta (2022). *Family Support for Children with Disabilities - Policy and Procedures Manual*.

Government of British Columbia. (2023). *At Home Program Guide: For Health Care Professionals and Families.* Ministry of Children and Family Development.

Government of British Columbia. (2021). *A Parent's Handbook: Your Guide to Autism Programs.* Ministry of Children and Family Development.

Government of British Columbia. (2018). *Home and Community Care Policy Manual.* Ministry of Health.

Government of Nova Scotia. (2023). *Direct Family Support for Children Program Policy.* Department of Community Services. Retrieved from https://novascotia.ca/coms/disabilities/documents/direct-and-enhancedfamily-support.pdf

Government of Newfoundland and Labrador. (2008). *Provincial Special Child Welfare AllowanceProgram Operational Standards.* Department of Health and Community Services. Retrieved from https://www.gov.nl.ca/hcs/files/publications-operational-standardsscwa.pdf

Government of New Brunswick. (2021). *Family Supports for Children with Disabilities* [Brochure]. https://www2.gnb.ca/content/dam/gnb/Departments/sd ds/pdf/Disabilities/FamilySupportsForChildrenWithDisabilities.pdf

Government of New Brunswick. (n.d.). *Family supports for children with disabilities.* https://www2.gnb.ca/content/gnb/en/services/services_renderer.10195.Family_Support_for_Children_with_Disabilities_.html

Government of Manitoba (2021). *Children's disABILITY Services Eligibility Policy*. Department of Families. Retrieved from *https://www.manitoba.ca/fs/cds/pubs/eligibility.pdf*

Government of Manitoba (2019). *Children's disABILITY Services Respite Policy.* Department of Families. Retrieved from https://www.gov.mb.ca/fs/cds/pubs/respite.pdf

Government of Quebec. (2022, May 26). *Employment-service check to facilitate access to home support services*. https://www.quebec.ca/famille-et-soutien-aux-personnes/inaptitude-perte-autonomie/services-soutien-domicile

Green, C., Carey, G., & Malbon, E. (2022). Market shaping: Understanding the role of non-government actors in social care quasi-market stewardship. *Social Policy & Administration, 56*(7), 1138-1155. https://doi.org/10.1111/spol.12845

Guardian Home Care Toronto. (n.d.). *Family-managed home care program from the HCCSS*. https://guardianhomecaretoronto.com/family-managed-home-care/

Harry, M. L., Mahoney, K. J., Mahoney, E. K., & Shen, C. (2017). The cash and counseling model of self-directed long-term care: Effectiveness with young adults with disabilities. *Disability and Health Journal, 10*(4), 492-501. https://doi.org/10.1016/j.dhjo.2017.03.001

Henderson, F., Reilly, C., Moyes, D., & Whittam, G. (2018). From charity to social enterprise: The marketization of social care. *International Journal of Entrepreneurial Behaviour & Research, 24*(3), 651-666. https://doi.org/10.1108/IJEBR-10-2016-0344

Home and Community Care Support Services. (2022, November). *Family-managed home care client and family fact sheet*. Government of Ontario. https://healthcareathome.ca/wp-content/uploads/2022/11/WW-Family-Managed-HC_Client-and-Family-Fact-Sheet_ENG.pdf

Howard, A., Blakemore, T., Johnston, L., Taylor, D., & Dibley, R. (2015). 'I'm not really sure but I hope it's better': Early thoughts of parents and carers in a regional trial site for the Australian NDIS. *Disability & Society, 30*(9), 1365- 1381. https://doi.org/10.1080/09687599.2015.1093462

Hutton, E., & King, A. (2018). Parent/carer views on personal health budgets for disabled children who use rehabilitation therapy services. *Disability & Society, 33*(2), 254-271. https://doi.org/10.1080/09687599.2017.1398636

Johnson, E., Lincoln, M., & Cumming, S. (2020). Principles of disability support in rural and remote Australia: Lessons from parents and carers. *Health & Social Care in the Community, 28*(6), 2208-2217. https://doi.org/10.1111/hsc.13033

Kelly, C., Dansereau, L., Balkaran, K., Tingey, E., Aubrecht, K., Hande, M.J., & Williams, A. (2020). *Directly-Funded Care Programs in Canada*. Centre on Aging, University of Manitoba, Winnipeg, Manitoba. https://doi.org/10.34991/847b-5q61

Laragy, C., & Ottmann, G. (2011). Towards a framework for implementing individual funding based on an Australian case study. *Journal of Policy and Practice in Intellectual Disabilities, 8*(1), 18-27. https://doi.org/10.1111/j.1741-1130.2011.00283.x

Legislative Counsel Office. (2021, September 4). *Supports for persons with disabilities act general regulations*. Government of Prince Edward Island. https://www.princeedwardisland.ca/sites/default/files/legislation/s09-2-supports_for_persons_with_disabilities_act_general_regulations.pdf

Leutz, W., Warfield, M. E., Timberlake, M., & Chiri, G. (2015). Infrastructure of participant direction for Medicaid-funded in-home autism services for children in Massachusetts. *Journal of Policy and Practice in Intellectual Disabilities, 12*(1), 27-36. https://doi.org/10.1111/jppi.12103

Loadsman, J. J., & Donelly, M. (2021). Exploring the wellbeing of Australian families engaging with the NDIS in rural and regional areas. *Disability & Society, 36*(9), 1449-1468. https://doi.org/10.1080/09687599.2020.1804327

Manthorpe, J., Martineau, S., Ridley, J., Cornes, M., Rosengard, A., & Hunter, S. (2015). Embarking on self-directed support in Scotland: A focused scoping review of the literature. *European Journal of Social Work, 18*(1), 36-50. https://doi.org/10.1080/13691457.2014.885883

Marchbank, A. M. (2017). The NDIS: Administrators' perspectives of agency transition to 'user pay' for early intervention service delivery. Australasian Journal of Early Childhood, 42(3), 46-53. https://doi.org/10.23965/AJEC.42.3.06

Marchbank, A. M. (2019). Repositioning: New storylines for preschool teachers and children with developmental delays. *Journal of Early Intervention, 41*(3), 187-201. https://doi.org/10.1177/1053815119830064

Marks, A. L., Mahoney, N., Chen, Y., Cordier, R., Buchanan, A., & Wilson, N. J. (2022). Health promotion challenges for young adults living with intellectual disability and type 1 diabetes. *Journal of Intellectual Disabilities, 26*(4), 853-868. https://doi.org/10.1177/17446295211032767

McDonald, M., Davis, K., & Mahar, N. (2016). When funding meets practice: The fate of contemporary therapeutic approaches and self-determination in a consumer-centred disability funding scheme. *Journal of Policy and Practice in Intellectual Disabilities, 13*(4), 277-286. https://doi.org/10.1111/jppi.12195

McGuigan, K., McDermott, L., Magowan, C., McCorkell, G., Witherow, A., & Coates, V. (2016). The impact of direct payments on service users requiring care and support at home. *Practice, 28*(1), 37-54. https://doi.org/10.1080/09503153.2015.1039973

McNeill, S., & Wilson, G. (2017). Use of direct payments in providing care and support to children with disabilities: Opportunities and concerns. *The British Journal of Social Work, 47*(7), 1903-1922. https://doi.org/10.1093/bjsw/bcw159

Meltzer, A., & Davy, L. (2019). Opportunities to enhance relational wellbeing through the NDIS: Implications from research on relationships and a content analysis of NDIS documentation. *Australian Journal of Public Administration, 78*(2), 250-264. https://doi.org/10.1111/1467-8500.12373

Ministère de la Santé et des Services sociaux (MSSS). (2009). *If you are receiving assistance: home care services and the service employment paycheque*. Government of Quebec. https://publications.msss.gouv.qc.ca/msss/fichiers/2008/08-513-02A.pdf

Ministry of Children, Community and Social Services (MCCSS). (2021a, April 22). *Administration of funding*. Government of Ontario. https://www.ontario.ca/document/special-services-home-program-guidelines/administration-funding

Ministry of Children, Community and Social Services (MCCSS). (2021b, April 22). *Application process*. Government of Ontario. https://www.ontario.ca/document/special-services-home-program-guidelines/application-process

Ministry of Children, Community and Social Services (MCCSS). (2021c, April 22). *Eligible and ineligible supports*. Government of Ontario. https://www.ontario.ca/document/special-services-home-program-guidelines/eligible-and-ineligible-supports

Ministry of Children, Community and Social Services (MCCSS). (2023a, April 1). *Passport program guidelines for adults with a developmental disability and their caregivers*. Government of Ontario. https://files.ontario.ca/mccss-passport-guidelines-april-2023-en-2023-03-06.pdf

Ministry of Children, Community and Social Services (MCCSS). (2023b, April 25). *Passport program for adults with a developmental disability*. Government of Ontario. https://www.ontario.ca/page/passport-program-adults-developmental-disability

Ministry of Children, Community and Social Services (MCCSS). (2023c, June 8). *Ontario autism program: Childhood budgets*. Government of Ontario. https://www.ontario.ca/page/ontario-autism-program-childhood-budgets

Ministry of Children, Community and Social Services (MCCSS). (2023d, August 17). *Ontario autism program*. Government of Ontario. https://www.ontario.ca/page/ontario-autism-program

Ministry of Children, Community and Social Services (MCCSS). (2023e, November 6). *Special services at home*. Government of Ontario. https://www.ontario.ca/page/special-services-home#section-0

Ministry of Children, Community and Social Services (MCCSS). (2023f, November 22). *Ontario autism program: Core clinical services*. Government of Ontario. https://www.ontario.ca/page/ontario-autism-program-core-clinical-services

Ministry of Health. (2023a, October 5). *Home and community care*. Government of Ontario. https://www.ontario.ca/page/home-community-care#section-0

Ministry of Health. (2023b). *Home Care Policy Manual*. Government of Saskatchewan. https://www.saskatchewan.ca/residents/health/accessing-health-care-services/care-at-home-and-outside-the-hospital/individualized-funding-for-home-care

Ministry of Health. (n.d.). *Individualized Funding for Home Care*. Government of Saskatchewan. https://www.saskatchewan.ca/residents/health/accessing-health-care-services/care-at-home-and-outside-the-hospital/individualized-funding-for-home-care

Ministry of Social Services. (n.d.-a). *Autism services*. Government of Saskatchewan. https://www.saskatchewan.ca/residents/health/accessing-health-care-services/health-services-for-people-with-disabilities/autism-services

Ministry of Social Services. (n.d.-b). *Housing and support for people with intellectual disabilities*. Government of Saskatchewan. https://www.saskatchewan.ca/residents/family-and-social-support/people-with-disabilities/housing-and-support-for-people-with-intellectual-disabilities

Ministry of Social Services. (2022a). *Autism Spectrum Disorder - Individualized Funding (ASD-IF): Policy Manual*. Government of Saskatchewan. https://www.saskatchewan.ca/residents/health/accessing-health-care-services/health-services-for-people-with-disabilities/autism-services

Ministry of Social Services. (2022b). *Self-Directed Funding Guidebook*. Government of Saskatchewan. https://publications.saskatchewan.ca/#/products/113591

Ministry of Social Services. (2023a). *Autism Spectrum Disorder Individualized Funding (ASD-IF): List of Eligible Services and Expenses*. Government of Saskatchewan. https://www.saskatchewan.ca/residents/health/accessing-health-care-services/health-services-for-people-with-disabilities/autism-services#individualized-funding

Ministry of Social Services. (2023b). *Autism Spectrum Disorder-Individualized Funding: Frequently Asked Questions*. Government of Saskatchewan. https://www.saskatchewan.ca/residents/health/accessing-health-care-services/health-services-for-people-with-disabilities/autism-services#individualized-funding

Mitchell, F. (2012). Self-directed support and disabled young people in transition (part 1). *Journal of Integrated Care, 20*(1), 51-61. https://doi.org/10.1108/14769011211202292

Mitchell, F. (2014). Informed choice for disabled young people in transition: A secondary analysis of qualitative data. *Practice, 26*(4), 259-270. https://doi.org/10.1080/09503153.2014.934800

Mitchell, F. (2015). Facilitators and barriers to informed choice in self-directed support for young people with disability in transition. *Health & Social Care in the Community, 23*(2), 190-199. https://doi.org/10.1111/hsc.12137

Needham, C. (2011). *Personalising public services: Understanding the personalisation narrative*. Policy Press. https://doi.org/10.46692/9781847427618

Nieboer, A. P., Cramm, J. M., Meij, B. v. d., & Huijsman, R. (2011). Choice processes and satisfaction with care according to parents of children and young adults with intellectual disability in the Netherlands. *Journal of Intellectual & Developmental Disability, 36*(2), 127-136. https://doi.org/10.1080/13668250.2011.573471

Nucifora, A., Walker, S., & Eivers, A. (2022). Parents perception and experience of transitioning to adulthood for their child diagnosed with an intellectual disability. *International Journal of Developmental Disabilities,* (ahead-of-print), 1-11. https://doi.org/10.1080/20473869.2022.2141877

Pattyn, E., Gemmel, P., Vandepitte, S., & Trybou, J. (2023). Do case-for-care schemes increase care users' experience of empowerment? A systematic review. The Patient – Patient-Centered Outcomes Research, 16, 317-341. https://doi.org/10.1007/s40271-023-00624-z

Pearson, C., J. Ridley, & S. Hunter. (2014). *Self-Directed Support: Personalisation, Choice and Control*. Edinburgh: Dunedin

Priestley, R., Yeung, P. H. Y., & Cooper, L. (2022). The impact of individualized funding on the wellbeing of mothers raising an autistic child in Aotearoa New Zealand. *Aotearoa New Zealand Social Work, 34*(3), 116-129.

Prowse, A., Wolfgang, R., Little, A., Wakely, K., & Wakely, L. (2022). Lived experience of parents and carers of people receiving services in rural areas under the National Disability Insurance Scheme. *The Australian Journal of Rural Health, 30*(2), 208-217. https://doi.org/10.1111/ajr.12837

Ranasinghe, T., Jeyaseelan, D., White, D., & Russo, R. (2017). Parents' experiences in registering with and accessing funding under the NDIS for early intervention services for children with developmental disabilities. *Journal of Paediatrics and Child Health, 53*(1), 26-32. https://doi.org/10.1111/jpc.13312

Rethlefsen, M. L., Kirtley, S., Waffenschmidt, S., Ayala, A. P., Moher, D., Page, M. J., Koffel, J. B., & PRISMA-S Group. (2021). PRISMA-S: An extension to the PRISMA Statement for Reporting Literature Searches in Systematic Reviews. *Systematic Reviews*, *10*, Article 39. https://doi.org/10.1186/s13643-020-01542-z

Robinson, S., Fisher, K. R., & Gendera, S. (2016). Can case management contribute to effective use of small self-directed support packages for people with disabilities? *Asian Social Work and Policy Review, 10*(3), 268-279. https://doi.org/10.1111/aswp.12095

Russo, F., Brownlow, C., & Machin, T. (2021). Parental experiences of engaging with the NDIS for their children: A systematic literature review. *Journal of Disability Policy Studies 32*(2), 67-75. https://doi.org/10.1177/1044207320943607

Salvador-Carulla, L., Furst, M. A., Gillespie, J., Rosenberg, S., Aryani, A., Anthes, L., Ferdousi, S., & Salinas-Perez, J. A. (2023). Regional evolution of psychosocial services in Australia before and after the implementation of the National Disability Insurance Scheme. *Australian and New Zealand Journal of Psychiatry, 57*(6), 875-883. https://doi.org/10.1177/00048674221130981

Scottish Government. (2010). *Self-directed support: A national strategy for Scotland: Consultation*. Edinburgh

Simpson, A., & Douglas, J. (2016). An examination of the impact of self-directed funding models on children with disabilities. Journal of Clinical Practice in Speech-Language Pathology 18(2), 55-61.

Small, F., Mehmet, M., & Kleinschafer, J. (2020). The circle of vulnerability and the myth of choice. *Journal of Social Marketing, 10*(4), 489-506. https://doi.org/10.1108/JSOCM-09-2019-0149

Smethurst, G., Bourke-Taylor, H. M., Cotter, C., & Beauchamp, F. (2021). Controlled choice, not choice and control: Families' reflections after one year using the National Disability Insurance Scheme. *Australian Occupational Therapy Journal, 68*(3), 205-216. https://doi.org/10.1111/1440-1630.12715

Stainton, T. (2009) Individualized Funding: An International Review of Approaches, Outcomes and Challenges. In Bigby, C & Fyffe, C. *Achieving their own lives: the implementation of individualized funding for people with intellectual disability, Proceedings of the third annual roundtable on intellectual disability policy.* Melbourne. School of Social Work and Social Policy La Trobe University.

Swenson, S., & Lakin, C. (2014). A wicked problem: Can governments be fair to families living with disabilities? *Family Relations, 63*(1), 185-191. https://doi.org/10.1111/fare.12056

Thompson, R. (2022). The NDIS review process: Weaknesses and opportunities to enhance the CRPD. *Australian Journal of Human Rights, 28*(2-3), 266-285. https://doi.org/10.1080/1323238X.2022.2139882

Timberlake, M. T., Leutz, W. N., Warfield, M. E., & Chiri, G. (2014). “In the Driver’s seat”: Parent perceptions of choice in a participant-directed Medicaid waiver program for young children with autism. *Journal of Autism and Developmental Disorders, 44*(4), 903-914. https://doi.org/10.1007/s10803-013-1942-4

Tracey, D., Johnston, C., Papps, F. A., & Mahmic, S. (2018). How do parents acquire information to support their child with a disability and navigate individualized funding schemes? *Journal of Research in Special Educational Needs, 18*(1), 25-35. https://doi.org/10.1111/1471-3802.12390

Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garritty, C., … Straus, S. E. (2018). PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine*, *169*(7), 467-473. https://doi.org/10.7326/M18-0850

Venning, A., Hummell, E., Foster, M., Burns, K., & Harris Rimmer, S. (2021). Adjudicating reasonable and necessary funded supports in the National Disability Insurance Scheme: A critical review of the values and priorities indicated in the decisions of the Administrative Appeals Tribunal. *Australian Journal of Public Administration, 80*(1), 97-113. https://doi.org/10.1111/1467-8500.12438

Welch, V., Hatton, C., Emerson, E., Collins, M., Robertson, J., Langer, S., & Wells, E. (2012). Using direct payments to fund short breaks for families with a disabled child. *Child: Care, Health & Development, 38*(6), 900-909. https://doi.org/10.1111/j.1365-2214.2011.01339.x

Whitaker, E. M. (2015). Personalisation in children's social work: From family support to "the child's budget". *Journal of Integrated Care, 23*(5), 277-286. https://doi.org/10.1108/JICA-07-2015-0031

Whitburn, B., Moss, J., & O'Mara, J. (2017). The NDIS and access to education: Progressive or coercive policy discourse? *International Journal of Inclusive Education, 21*(10), 1065-1079. https://doi.org/10.1080/13603116.2017.1348549

White, C. S., Spry, E., Griffiths, E., & Carlin, E. (2021). Equity in access: A mixed methods exploration of the NDIS access program for the Kimberley region, Western Australia. *International Journal of Environmental Research and Public Health, 18*(17), 8907. https://doi.org/10.3390/ijerph18178907

Williams, I., & Dickinson, H. (2016). Going it alone or playing to the crowd? A critique of individual budgets and the personalisation of health care in the English National Health

Service. *Australian Journal of Public Administration, 75*(2), 149-158. https://doi.org/10.1111/1467-8500.12155

Yates, S., Dickinson, H., Smith, C., & Tani, M. (2021). Flexibility in individual funding schemes: How well did Australia's NDIS support remote learning for students with disability during COVID-19? *Social Policy & Administration, 55*(5), 906-920. https://doi.org/10.1111/spol.12670

Appendix 1: Search Strategy and PRISMA Flowchart

The following tables reflect all of the original searches completed on May 18, 2023, as well as the updates completed in each database on September 28, 2023 (with notes where variations in the search were required for the update).

Scopus (Clarivate)			
Date	Search #	Search Terms, Fields, and Limiters	# of Results
18-May-23	S1	(TITLE-ABS-KEY ("individualized fund*" OR "individualised fund*" OR "individual fund*" OR "individualized grant*" OR "individualised grant*" OR "individual grant*" OR "individualized payment*" OR "individualised payment*" OR "individual payment*" OR "individualized budget*" OR "individualised budget*" OR "individual budget*" OR "individualized disability support*" OR "individualized disability fund*" OR "individualized disability grant*" OR "individualized disability payment*" OR "individualized disability scheme*" OR "individualized disability plan*" OR "individualized disability budget*" OR "individualised disability support*" OR "individualised disability fund*" OR "individualised disability grant*" OR "individualised disability payment*" OR "individualised disability scheme*" OR "individualised disability plan*" OR "individualised disability budget*" OR "individual disability support*" OR "individual disability fund*" OR "individual disability grant*" OR "individual disability payment*" OR "individual disability scheme*" OR "individual disability plan*" OR "individual disability budget*" OR "funded support" OR "self-directed support*" OR "self-directed disability support*" OR "self-directed grant*" OR "self-directed fund*" OR "self-directed payment*" OR "self-directed scheme*" OR "self-directed plan*" OR "self-directed budget*" OR "self-directed care" OR "direct fund*" OR "directly fund*" OR "disability support fund*" OR "direct payment*" OR "personal budget*" OR "personal health budget*" OR "personalized health budget*" OR "personalised health budget*" OR "personalized budget*" OR "personalised budget*" OR "self-managed attendant service*" OR microboard* OR "canadian assistance plan" OR "canada assistance plan" OR "ndis" OR "NDIS" OR "national health insurance scheme" OR "cash for care" OR "cash-for-care" OR "short term case management" OR "fee waiver*" OR "direct financing" OR "personal care budget" OR "individual health budget" OR "individual care budget" OR "personal healthcare budget" OR "individual healthcare budget" OR "personal assistance budget" OR "individual assistance budget" OR "cash and counseling" OR "cash and counselling" OR "cash for counseling" OR "cash for counselling" OR "cash-and-counseling" OR "cash-and-counselling" OR "cash-for-counseling" OR "cash-for-counselling" OR "personalised fund*" OR "personalized fund*" OR "individual service fund" OR "personal service fund" OR "cash payment" OR "assistance allowance" OR "monetary transfer" OR "cash program" OR "cash programme" OR "cash benefit" OR "cash transfer" OR "attendance allowance" OR "care allowance" OR "consumer funding" OR "funding package" OR "individualised package" OR "individualized package" OR "managed budget" OR "budget holder" OR "self-managed budget" OR "individual support budget" OR "personal support budget" OR "flexible funding" OR "healthcare voucher" OR "health voucher" OR "care voucher" OR "attendance voucher" OR "assistance voucher"	1,045

Scopus (Clarivate)			
Date	Search #	Search Terms, Fields, and Limiters	# of Results
		OR "consumer-directed voucher" OR "self-directed voucher" OR "self-managed voucher" OR "voucher holder" OR "individualized voucher" OR "individualised voucher" OR "personalized voucher" OR "personalised voucher" OR "personal voucher" OR "individual voucher" OR "persoonsgebonden budget" OR "social care support*" OR "care dependency grant")) AND (TITLE-ABS-KEY (disab* OR handicap* OR "developmental delay" OR "developmentally delay*" OR "idd" OR "intellectual limit*" OR "intellectually limit*" OR "complex needs" OR "complex support needs" OR "complex health needs" OR "special needs" OR "extra support needs" OR neurodiver* OR "learning difficult*" OR "learning disorder*" OR "mental health" OR "mental ill*" OR "mentally ill" OR "mental disorder*" OR "psychiatric illness*" OR autis* OR "diverse abilit*" OR ableism OR ableist OR "chronic illness*" OR "chronic disease*" OR "chronic condition*" OR "chronic disorder*") AND PUBYEAR > 2010 AND PUBYEAR < 2024 AND PUBYEAR > 2010 AND PUBYEAR < 2024) AND (LIMIT-TO (DOCTYPE , "ar") OR LIMIT-TO (DOCTYPE , "re") OR LIMIT-TO (DOCTYPE , "er") OR LIMIT-TO (DOCTYPE , "undefined"))	
28-Sep-23	UPDATE	Re-ran the above search. Note: there was no undefined document type to select when it was re-ran.	1,099

APA PsycInfo (EBSCO)				
Date	Search #	Search Terms	Fields and Limiters	# of Results
18-May-23	S1	"individualized fund*" OR “individualised fund*” OR “individual fund*” OR “individualized grant*” OR “individualised grant*” OR “individual grant*” OR “individualized payment*” OR “individualised payment*” OR “individual payment*” OR “individualized budget*” OR “individualised budget*” OR “individual budget*” OR “individualized disability support*” OR “individualized disability fund*” OR “individualized disability grant*” OR “individualized disability payment*” OR “individualized disability scheme*” OR “individualized disability plan*” OR "individualized disability budget*" OR “individualised disability support*” OR “individualised disability fund*” OR “individualised disability grant*” OR “individualised disability payment*” OR “individualised disability scheme*” OR “individualised disability plan*” OR "individualised disability budget*" OR “individual disability support*” OR “individual disability fund*” OR “individual disability grant*” OR “individual disability payment*” OR “individual disability scheme*” OR “individual disability plan*” OR "individual disability budget*" OR “funded support” OR “self-directed support*” OR “self-directed disability support*” OR “self-	Field: Select a Field (Optional) Limiters - Scholarly (Peer Reviewed) Journals; Published Date: 20110101-20231231 Search modes - Boolean/Phrase	801

APA PsycInfo (EBSCO)				
Date	Search #	Search Terms	Fields and Limiters	# of Results
		directed grant*” OR “self-directed fund*” OR “self-directed payment*” OR “self-directed scheme*” OR “self-directed plan*” OR “self-directed budget*” OR "self-directed care" OR “direct fund*” OR “directly fund*” OR “disability support fund*” OR “direct payment*” OR “personal budget*” OR “personal health budget*” OR “personalized health budget*” OR “personalised health budget*” OR “personalized budget*” OR “personalised budget*” OR “self-managed attendant service*” OR microboard* OR “Canadian assistance plan” OR “Canada assistance plan” OR “NDIS” OR “NDIS” OR "national health insurance scheme" OR “cash for care” OR "cash-for-care" OR “short term case management” OR "fee waiver*" OR "direct financing" OR "personal care budget" OR "individual health budget" OR "individual care budget" OR "personal healthcare budget" OR "individual healthcare budget" OR "personal assistance budget" OR "individual assistance budget" OR "cash and counseling" OR "cash and counselling" OR "cash for counseling" OR "cash for counselling" OR "cash-and-counseling" OR "cash-and-counselling" OR "cash-for-counseling" OR "cash-for-counselling" OR "personalised fund*" OR "personalized fund*" OR "individual service fund" OR "personal service fund" OR "cash payment" OR "assistance allowance" OR "monetary transfer" OR "cash program" OR "cash programme" OR "cash benefit" OR "cash transfer" OR "attendance allowance" OR "care allowance" OR "consumer funding" OR "funding package" OR "individualised package" OR "individualized package" OR "managed budget" OR "budget holder" OR "self-managed budget" OR "individual support budget" OR "personal support budget" OR "flexible funding" OR "healthcare voucher" OR "health voucher" OR "care voucher" OR "attendance voucher" OR "assistance voucher" OR "consumer-directed voucher" OR "self-directed voucher" OR "self-managed voucher" OR "voucher holder" OR "individualized voucher" OR "individualised voucher" OR "personalized voucher" OR "personalised voucher" OR "personal voucher" OR "individual voucher" OR "persoonsgebonden budget" OR "social care support*" OR "care dependency grant"		
18-May-23	S2	disab* OR handicap* OR “developmental delay” OR “developmentally delay*” OR “IDD” OR “intellectual limit*” OR “intellectually limit*” OR “complex needs” OR “complex support needs” OR “complex health needs” OR “special needs”	Field: Select a Field (Optional) Limiters: Scholarly (Peer Reviewed)	427,102

APA PsycInfo (EBSCO)				
Date	Search #	Search Terms	Fields and Limiters	# of Results
		OR “extra support needs” OR neurodiver* OR “learning difficult*” OR “learning disorder*” OR "mental health" OR "mental ill*" OR "mentally ill" OR "mental disorder*" OR "psychiatric illness*" OR autis* OR “diverse abilit*” OR ableism OR ableist OR "chronic illness*" OR "chronic disease*" OR "chronic condition*" OR "chronic disorder*"	Journals; Published Date: 20110101-20231231 Search modes: Boolean/Phrase	
18-May-23	S3	S1 AND S2		488
28-Sep-23	UPDATE	Re-ran the above search exactly.		504

CINAHL (EBSCO)				
Date	Search #	Search Terms	Fields and Limiters	# of Results
18-May-23	S1	"individualized fund*" OR “individualised fund*” OR “individual fund*” OR “individualized grant*” OR “individualised grant*” OR “individual grant*” OR “individualized payment*” OR “individualised payment*” OR “individual payment*” OR “individualized budget*” OR “individualised budget*” OR “individual budget*” OR “individualized disability support*” OR “individualized disability fund*” OR “individualized disability grant*” OR “individualized disability payment*” OR “individualized disability scheme*” OR “individualized disability plan*” OR "individualized disability budget*" OR “individualised disability support*” OR “individualised disability fund*” OR “individualised disability grant*” OR “individualised disability payment*” OR “individualised disability scheme*” OR “individualised disability plan*” OR "individualised disability budget*" OR “individual disability support*” OR “individual disability fund*” OR “individual disability grant*” OR “individual disability payment*” OR “individual disability scheme*” OR “individual disability plan*” OR "individual disability budget*" OR “funded support” OR “self-directed support*” OR “self-directed disability support*” OR “self-directed grant*” OR “self-directed fund*” OR “self-directed payment*” OR “self-directed scheme*” OR “self-directed plan*” OR “self-directed budget*” OR "self-directed care" OR “direct fund*” OR “directly fund*” OR “disability support fund*” OR “direct payment*” OR “personal budget*” OR “personal health budget*” OR “personalized health budget*” OR “personalised health budget*” OR “personalized	Field: Select a Field (Optional) Limiters - Published Date: 20110101-20231231; Peer Reviewed Search modes - Boolean/Phrase	1,531

CINAHL (EBSCO)				
Date	Search #	Search Terms	Fields and Limiters	# of Results
		budget*" OR "personalised budget*" OR "self-managed attendant service*" OR microboard* OR "Canadian assistance plan" OR "Canada assistance plan" OR "NDIS" OR "NDIS" OR "national health insurance scheme" OR "cash for care" OR "cash-for-care" OR "short term case management" OR "fee waiver*" OR "direct financing" OR "personal care budget" OR "individual health budget" OR "individual care budget" OR "personal healthcare budget" OR "individual healthcare budget" OR "personal assistance budget" OR "individual assistance budget" OR "cash and counseling" OR "cash and counselling" OR "cash for counseling" OR "cash for counselling" OR "cash-and-counseling" OR "cash-and-counselling" OR "cash-for-counseling" OR "cash-for-counselling" OR "personalised fund*" OR "personalized fund*" OR "individual service fund" OR "personal service fund" OR "cash payment" OR "assistance allowance" OR "monetary transfer" OR "cash program" OR "cash programme" OR "cash benefit" OR "cash transfer" OR "attendance allowance" OR "care allowance" OR "consumer funding" OR "funding package" OR "individualised package" OR "individualized package" OR "managed budget" OR "budget holder" OR "self-managed budget" OR "individual support budget" OR "personal support budget" OR "flexible funding" OR "healthcare voucher" OR "health voucher" OR "care voucher" OR "attendance voucher" OR "assistance voucher" OR "consumer-directed voucher" OR "self-directed voucher" OR "self-managed voucher" OR "voucher holder" OR "individualized voucher" OR "individualised voucher" OR "personalized voucher" OR "personalised voucher" OR "personal voucher" OR "individual voucher" OR "persoonsgebonden budget" OR "social care support*" OR "care dependency grant"		
18-May-23	S2	disab* OR handicap* OR "developmental delay" OR "developmentally delay*" OR "IDD" OR "intellectual limit*" OR "intellectually limit*" OR "complex needs" OR "complex support needs" OR "complex health needs" OR "special needs" OR "extra support needs" OR neurodiver* OR "learning difficult*" OR "learning disorder*" OR "mental health" OR "mental ill*" OR "mentally ill" OR "mental disorder*" OR "psychiatric illness*" OR autis* OR "diverse abilit*" OR ableism OR ableist OR "chronic illness*" OR "chronic disease*" OR "chronic condition*" OR "chronic disorder*"	Field: Select a Field (Optional) Limiters - Published Date: 20110101-20231231; Peer Reviewed Search modes - Boolean/Phrase	314,754

CINAHL (EBSCO)				
Date	Search #	Search Terms	Fields and Limiters	# of Results
18-May-23	S3	S1 AND S2		488
28-Sep-23	UPDATE	Re-ran the above search exactly.		501

Medline (EBSCO)				
Date	Search #	Search Terms	Fields and Limiters	# of Results
18-May-23	S1	"individualized fund*" OR "individualised fund*" OR "individual fund*" OR "individualized grant*" OR "individualised grant*" OR "individual grant*" OR "individualized payment*" OR "individualised payment*" OR "individual payment*" OR "individualized budget*" OR "individualised budget*" OR "individual budget*" OR "individualized disability support*" OR "individualized disability fund*" OR "individualized disability grant*" OR "individualized disability payment*" OR "individualized disability scheme*" OR "individualized disability plan*" OR "individualized disability budget*" OR "individualised disability support*" OR "individualised disability fund*" OR "individualised disability grant*" OR "individualised disability payment*" OR "individualised disability scheme*" OR "individualised disability plan*" OR "individualised disability budget*" OR "individual disability support*" OR "individual disability fund*" OR "individual disability grant*" OR "individual disability payment*" OR "individual disability scheme*" OR "individual disability plan*" OR "individual disability budget*" OR "funded support" OR "self-directed support*" OR "self-directed disability support*" OR "self-directed grant*" OR "self-directed fund*" OR "self-directed payment*" OR "self-directed scheme*" OR "self-directed plan*" OR "self-directed budget*" OR "self-directed care" OR "direct fund*" OR "directly fund*" OR "disability support fund*" OR "direct payment*" OR "personal budget*" OR "personal health budget*" OR "personalized health budget*" OR "personalised health budget*" OR "personalized budget*" OR "personalised budget*" OR "self-managed attendant service*" OR "microboard*" OR "Canadian assistance plan" OR "Canada assistance plan" OR "NDIS" OR "NDIS" OR "national health insurance scheme" OR "cash for care" OR "cash-for-care" OR "short term case management" OR "fee waiver*" OR "direct financing" OR "personal care budget" OR	Field: Select a Field (Optional) Limiters - Date of Publication: 20110101-20231231; Scholarly (Peer Reviewed) Journals Search modes - Boolean/Phrase	2,602

Medline (EBSCO)				
Date	Search #	Search Terms	Fields and Limiters	# of Results
		"individual health budget" OR "individual care budget" OR "personal healthcare budget" OR "individual healthcare budget" OR "personal assistance budget" OR "individual assistance budget" OR "cash and counseling" OR "cash and counselling" OR "cash for counseling" OR "cash for counselling" OR "cash-and-counseling" OR "cash-and-counselling" OR "cash-for-counseling" OR "cash-for-counselling" OR "personalised fund*" OR "personalized fund*" OR "individual service fund" OR "personal service fund" OR "cash payment" OR "assistance allowance" OR "monetary transfer" OR "cash program" OR "cash programme" OR "cash benefit" OR "cash transfer" OR "attendance allowance" OR "care allowance" OR "consumer funding" OR "funding package" OR "individualised package" OR "individualized package" OR "managed budget" OR "budget holder" OR "self-managed budget" OR "individual support budget" OR "personal support budget" OR "flexible funding" OR "healthcare voucher" OR "health voucher" OR "care voucher" OR "attendance voucher" OR "assistance voucher" OR "consumer-directed voucher" OR "self-directed voucher" OR "self-managed voucher" OR "voucher holder" OR "individualized voucher" OR "individualised voucher" OR "personalized voucher" OR "personalised voucher" OR "personal voucher" OR "individual voucher" OR "persoonsgebonden budget" OR "social care support*" OR "care dependency grant"		
18-May-23	S2	"disab*" OR "handicap*" OR "developmental delay" OR "developmentally delay*" OR "IDD" OR "intellectual limit*" OR "intellectually limit*" OR "complex needs" OR "complex support needs" OR "complex health needs" OR "special needs" OR "extra support needs" OR "neurodiver*" OR "learning difficult*" OR "learning disorder*" OR "mental health" OR "mental ill*" OR "mentally ill" OR "mental disorder*" OR "psychiatric illness*" OR "autis*" OR "diverse abilit*" OR "ableism" OR "ableist" OR "chronic illness*" OR "chronic disease*" OR "chronic condition*" OR "chronic disorder*"	Field: Select a Field (Optional) Limiters - Date of Publication: 20110101-20231231; Scholarly (Peer Reviewed) Journals Search modes - Boolean/Phrase	718,992
18-May-23	S3	S1 AND S2		534
28-Sep-23	UPDATE	Re-ran the above search exactly.		555

Embase (Ovid)				
Date	Search #	Search Terms	Fields and Limiters	# of Results
18-May-23	S1	("individualized fund*" or "individualised fund*" or "individual fund*" or "individualized grant*" or "individualised grant*" or "individual grant*" or "individualized payment*" or "individualised payment*" or "individual payment*" or "individualized budget*" or "individualised budget*" or "individual budget*" or "individualized disability support*" or "individualized disability fund*" or "individualized disability grant*" or "individualized disability payment*" or "individualized disability scheme*" or "individualized disability plan*" or "individualized disability budget*" or "individualised disability support*" or "individualised disability fund*" or "individualised disability grant*" or "individualised disability payment*" or "individualised disability scheme*" or "individualised disability plan*" or "individualised disability budget*" or "individual disability support*" or "individual disability fund*" or "individual disability grant*" or "individual disability payment*" or "individual disability scheme*" or "individual disability plan*" or "individual disability budget*" or "funded support" or "self-directed support*" or "self-directed disability support*" or "self-directed grant*" or "self-directed fund*" or "self-directed payment*" or "self-directed scheme*" or "self-directed plan*" or "self-directed budget*" or "self-directed care" or "direct fund*" or "directly fund*" or "disability support fund*" or "direct payment*" or "personal budget*" or "personal health budget*" or "personalized health budget*" or "personalised health budget*" or "personalized budget*" or "personalised budget*" or "self-managed attendant service*" or "microboard*" or "Canadian assistance plan" or "Canada assistance plan" or "NDIS" or "NDIS" or "national health insurance scheme" or "cash for care" or "cash-for-care" or "short term case management" or "fee waiver*" or "direct financing" or "personal care budget" or "individual health budget" or "individual care budget" or "personal healthcare budget" or "individual healthcare budget" or "personal assistance budget" or "individual assistance budget" or "cash and counseling" or "cash and counselling" or "cash for counseling" or "cash for counselling" or "cash-and-counseling" or "cash-and-counselling" or "cash-for-counseling" or "cash-for-counselling" or "personalised fund*" or "personalized fund*" or "individual service fund" or "personal service fund" or "cash payment" or "assistance allowance" or "monetary transfer" or "cash program" or "cash	Run in Advanced Search - keyword selected limit 1 to (yr="2011 - 2023" and (article or article in press or "review"))	2,355

Embase (Ovid)				
Date	Search #	Search Terms	Fields and Limiters	# of Results
		programme" or "cash benefit" or "cash transfer" or "attendance allowance" or "care allowance" or "consumer funding" or "funding package" or "individualised package" or "individualized package" or "managed budget" or "budget holder" or "self-managed budget" or "individual support budget" or "personal support budget" or "flexible funding" or "healthcare voucher" or "health voucher" or "care voucher" or "attendance voucher" or "assistance voucher" or "consumer-directed voucher" or "self-directed voucher" or "self-managed voucher" or "voucher holder" or "individualized voucher" or "individualised voucher" or "personalized voucher" or "personalised voucher" or "personal voucher" or "individual voucher" or "persoonsgebonden budget" or "social care support*" or "care dependency grant").mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]		
18-May-23	S2	("disab*" or "handicap*" or "developmental delay" or "developmentally delay*" or "IDD" or "intellectual limit*" or "intellectually limit*" or "complex needs" or "complex support needs" or "complex health needs" or "special needs" or "extra support needs" or "neurodiver*" or "learning difficult*" or "learning disorder*" or "mental health" or "mental ill*" or "mentally ill" or "mental disorder*" or "psychiatric illness*" or "autis*" or "diverse abilit*" or "ableism" or "ableist" or "chronic illness*" or "chronic disease*" or "chronic condition*" or "chronic disorder*").mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword heading word, floating subheading word, candidate term word]	Run in Advanced Search - keyword selected limit 2 to (yr="2011 - 2023" and (article or article in press or "review"))	629,935
18-May-23	S3	S1 AND S2	limit 3 to (embase only)	256
28-Sep-23	UPDATE	Re-ran the above search exactly.		272

Sociology Collection (ProQuest)				
Date	Search #	Search Terms and Fields	Limiters	# of Results
18-May-23	S1	noft("individualized fund*" OR "individualised fund*" OR "individual fund*" OR "individualized grant*" OR "individualised grant*" OR "individual grant*" OR "individualized payment*" OR "individualised payment*" OR "individual payment*" OR "individualized budget*" OR "individualised budget*" OR "individual budget*" OR "individualized disability support*" OR "individualized disability fund*" OR "individualized disability grant*" OR "individualized disability payment*" OR "individualized disability scheme*" OR "individualized disability plan*" OR "individualized disability budget*" OR "individualised disability support*" OR "individualised disability fund*" OR "individualised disability grant*" OR "individualised disability payment*" OR "individualised disability scheme*" OR "individualised disability plan*" OR "individualised disability budget*" OR "individual disability support*" OR "individual disability fund*" OR "individual disability grant*" OR "individual disability payment*" OR "individual disability scheme*" OR "individual disability plan*" OR "individual disability budget*" OR "funded support" OR "self-directed support*" OR "self-directed disability support*" OR "self-directed grant*" OR "self-directed fund*" OR "self-directed payment*" OR "self-directed scheme*" OR "self-directed plan*" OR "self-directed budget*" OR "self-directed care" OR "direct fund*" OR "directly fund*" OR "disability support fund*" OR "direct payment*" OR "personal budget*" OR "personal health budget*" OR "personalized health budget*" OR "personalised health budget*" OR "personalized budget*" OR "personalised budget*" OR "self-managed attendant service*" OR "microboard*" OR "Canadian assistance plan" OR "Canada assistance plan" OR "NDIS" OR "NDIS" OR "national health insurance scheme" OR "cash for care" OR "cash-for-care" OR "short term case management" OR "fee waiver*" OR "direct financing" OR "personal care budget" OR "individual health budget" OR "individual care budget" OR "personal healthcare budget" OR "individual healthcare budget" OR "personal assistance budget" OR "individual assistance budget" OR "cash and counseling" OR "cash and counselling" OR "cash for counseling" OR "cash for counselling" OR "cash-and-counseling" OR "cash-and-counselling" OR "cash-for-counseling" OR "cash-for-counselling" OR "personalised fund*" OR "personalized	Databases: Sociology Collection Limited by: Peer reviewed Date: From January 01 2011 to December 31 2023	1,574

Sociology Collection (ProQuest)				
Date	Search #	Search Terms and Fields	Limiters	# of Results
		fund*" OR "individual service fund" OR "personal service fund" OR "cash payment" OR "assistance allowance" OR "monetary transfer" OR "cash program" OR "cash programme" OR "cash benefit" OR "cash transfer" OR "attendance allowance" OR "care allowance" OR "consumer funding" OR "funding package" OR "individualised package" OR "individualized package" OR "managed budget" OR "budget holder" OR "self-managed budget" OR "individual support budget" OR "personal support budget" OR "flexible funding" OR "healthcare voucher" OR "health voucher" OR "care voucher" OR "attendance voucher" OR "assistance voucher" OR "consumer-directed voucher" OR "self-directed voucher" OR "self-managed voucher" OR "voucher holder" OR "individualized voucher" OR "individualised voucher" OR "personalized voucher" OR "personalised voucher" OR "personal voucher" OR "individual voucher" OR "persoonsgebonden budget" OR "social care support*" OR "care dependency grant")		
18-May-23	S2	noft("disab*" OR "handicap*" OR "developmental delay" OR "developmentally delay*" OR "IDD" OR "intellectual limit*" OR "intellectually limit*" OR "complex needs" OR "complex support needs" OR "complex health needs" OR "special needs" OR "extra support needs" OR "neurodiver*" OR "learning difficult*" OR "learning disorder*" OR "mental health" OR "mental ill*" OR "mentally ill" OR "mental disorder*" OR "psychiatric illness*" OR "autis*" OR "diverse abilit*" OR "ableism" OR "ableist" OR "chronic illness*" OR "chronic disease*" OR "chronic condition*" OR "chronic disorder*")	Databases: Sociology Collection Limited by: Peer reviewed Date: From January 01 2011 to December 31 2023	152,912
18-May-23	S3	S1 AND S2		471
28-Sep-23	UPDATE	Re-ran the above search exactly.		483

Web if Science (Clarivate)

- **Science Citation Index Expanded (SCI-EXPANDED),**
- **Social Sciences Citation Index (SSCI),**
- **Arts & Humanities Citation Index (A&HCI),**
- **Emerging Sources Citation Index (ESCI)**

Date	Search #	Search Terms, Fields and Limiters	# of Results
18-May-23	S1	"individualized fund*" OR "individualised fund*" OR "individual fund*" OR "individualized grant*" OR "individualised grant*" OR "individual grant*" OR "individualized payment*" OR "individualised payment*" OR "individual payment*" OR "individualized budget*" OR "individualised budget*" OR "individual budget*" OR "individualized disability support*" OR "individualized disability fund*" OR "individualized disability grant*" OR "individualized disability payment*" OR "individualized disability scheme*" OR "individualized disability plan*" OR "individualized disability budget*" OR "individualised disability support*" OR "individualised disability fund*" OR "individualised disability grant*" OR "individualised disability payment*" OR "individualised disability scheme*" OR "individualised disability plan*" OR "individualised disability budget*" OR "individual disability support*" OR "individual disability fund*" OR "individual disability grant*" OR "individual disability payment*" OR "individual disability scheme*" OR "individual disability plan*" OR "individual disability budget*" OR "funded support" OR "self-directed support*" OR "self-directed disability support*" OR "self-directed grant*" OR "self-directed fund*" OR "self-directed payment*" OR "self-directed scheme*" OR "self-directed plan*" OR "self-directed budget*" OR "self-directed care" OR "direct fund*" OR "directly fund*" OR "disability support fund*" OR "direct payment*" OR "personal budget*" OR "personal health budget*" OR "personalized health budget*" OR "personalised health budget*" OR "personalized budget*" OR "personalised budget*" OR "self-managed attendant service*" OR "microboard*" OR "Canadian assistance plan" OR "Canada assistance plan" OR "NDIS" OR "NDIS" OR "national health insurance scheme" OR "cash for care" OR "cash-for-care" OR "short term case management" OR "fee waiver*" OR "direct financing" OR "personal care budget" OR "individual health budget" OR "individual care budget" OR "personal healthcare budget" OR "individual healthcare budget" OR "personal assistance budget" OR "individual assistance budget" OR "cash and counseling" OR "cash and counselling" OR "cash for counseling" OR "cash for counselling" OR "cash-and-counseling" OR "cash-and-counselling" OR "cash-for-counseling" OR "cash-for-counselling" OR "personalised fund*" OR "personalized fund*" OR "individual service fund" OR "personal service fund" OR "cash payment" OR "assistance allowance" OR "monetary transfer" OR "cash program" OR "cash programme" OR "cash benefit" OR "cash transfer" OR "attendance allowance" OR "care allowance" OR "consumer funding" OR "funding package" OR "individualised package" OR "individualized package" OR "managed budget" OR "budget holder" OR "self-managed budget" OR "individual support budget" OR "personal support budget" OR "flexible funding" OR "healthcare voucher" OR "health voucher" OR "care voucher" OR "attendance voucher" OR "assistance voucher" OR "consumer-directed voucher" OR "self-directed voucher" OR "self-managed voucher" OR "voucher holder" OR "individualized voucher" OR "individualised voucher" OR "personalized voucher" OR "personalised voucher" OR "personal voucher" OR "individual voucher" OR "persoonsgebonden budget" OR "social care support*" OR "care dependency grant" (Topic) and Article or Review Article or Early Access	4,801

Web if Science (Clarivate)

- **Science Citation Index Expanded (SCI-EXPANDED),**
- **Social Sciences Citation Index (SSCI),**
- **Arts & Humanities Citation Index (A&HCI),**
- **Emerging Sources Citation Index (ESCI)**

Date	Search #	Search Terms, Fields and Limiters	# of Results
		(Document Types) Timespan: 2011-01-31 to 2023-12-31 (Publication Date)	
18-May-23	S2	"disab*" OR "handicap*" OR "developmental delay" OR "developmentally delay*" OR "IDD" OR "intellectual limit*" OR "intellectually limit*" OR "complex needs" OR "complex support needs" OR "complex health needs" OR "special needs" OR "extra support needs" OR "neurodiver*" OR "learning difficult*" OR "learning disorder*" OR "mental health" OR "mental ill*" OR "mentally ill" OR "mental disorder*" OR "psychiatric illness*" OR "autis*" OR "diverse abilit*" OR "ableism" OR "ableist" OR "chronic illness*" OR "chronic disease*" OR "chronic condition*" OR "chronic disorder*" (Topic) and Article or Review Article or Early Access (Document Types) and Article or Review Article or Early Access (Document Types) Timespan: 2011-01-31 to 2023-12-31 (Publication Date)	603,496
18-May-23	S3	S1 AND S2	774
28-Sep-23	UPDATE	Re-ran the above search exactly.	816

Data Extraction Items

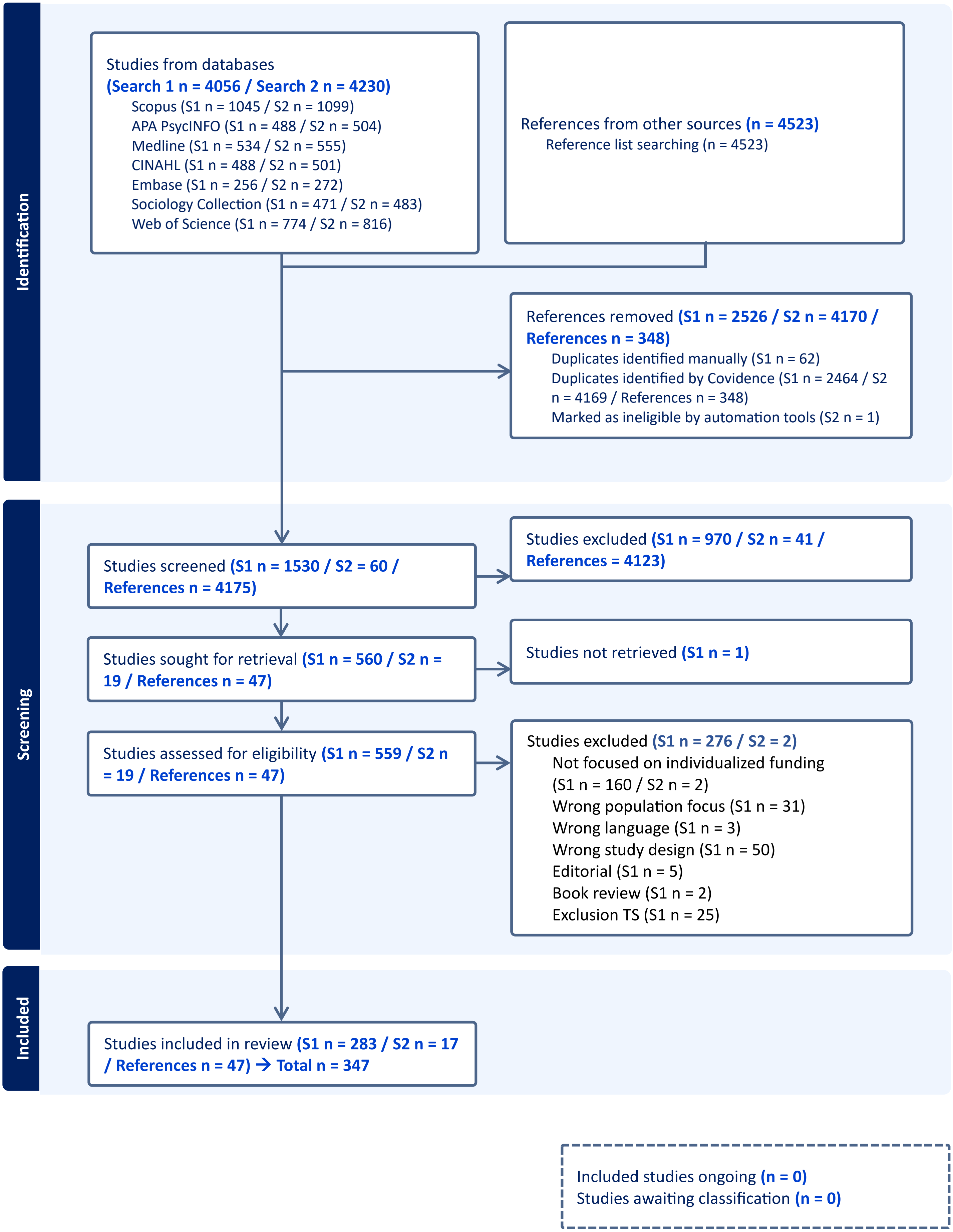
We extracted data on article characteristics. Data variables included:

- General information:
    - Title: Title of article that data are extracted from.
    - Authors: Last name followed by initials for each of the listed authors (e.g., Smith, A., Smith, B., & Smith, C. according to APA style guide).
    - Year: Publication year.
    - Journal/Publication: Name of journal and publication.
    - Country/Region: Publication location of the journal.
    - Notes: miscellaneous information (e.g., international/open access journal without publication location).
- Aims and Methods: Methodology:
    - Aim of Study: Scope and type of analysis (objective of the article as often listed in the abstract).
    - Research question/Hypothesis.
    - Funding definitions: Direct definitions related to IF.
    - Related definitions: Affiliated definitions or scope-based nuances used in the article. Examples include definitions of personalization, self-direction, and choice-and-control that speak to IF approaches.
    - Study design: Qualitative, Quantitative, Knowledge syntheses, or Mixed methods.
    - Study method: Examples include randomized trial, cross-sectional study, longitudinal study, case-control study, observational study, diagnostic test study, prognostic factor study, family-based or population-based study.
    - Time period: Scope of article (e.g., the article looks at policy and experiences between 2015 - 2022).
    - Jurisdictional funding level: National, regional, local, or comparative.

    - Policy title (e.g., PBs, NDIS, Self-directed Support or other policy names specific to IF/self-directed support, personal budgets).
    - Policy agency/funder (e.g., NHS, National Disability Insurance Agency or Centers for Medicare & Medicaid Services).
- Sample/Participants:
    - N= (number of participants or research subjects).
    - Population (Dx): Inclusion and exclusion criteria for the sample (e.g., types of disability or complex health/support needs).
    - Participants (e.g., population (Dx), parents, care-givers, professionals, administrators, informers, service providers, key informants, decision supports, and support workers).
    - Age: age for population (Dx) and/or other participants if listed.
    - Gender: for population (Dx) and/or other participants if listed.
    - Ethnicity: for population (Dx) and/or other participants if listed.
    - SES status of sample: Socio-economic status addressed in the article for population (Dx) and/or other participants if listed.
    - Notes: Other demographic details pertaining to the sample (e.g., education level, geographic constraints, rural barriers, SDOH)/Recruitment issues or limitations mentioned in the article specific to the funding experience.
- Outcomes and Discussion:
    - General findings: How funding is used and discussions about the funding model/use of funding in answers to the article's aim/research questions.
    - Barriers/facilitators: What facilitators/barriers to IF models are identified at the policy level/individual level/health professional level (if applicable).
    - Limitations identified: What the article or study does not address/directions for further research.
    - Experiential details: Population (Dx) and participant quotes from the sample that speak to experiences with IF.
    - Policy/administrative considerations (e.g., implications for future IF models and planning at the policy level).
    - Financial considerations: References to financial burden on the system/policy, notions of austerity, or the potential lack of available funding.
    - Notes: Other important points identified in the article's results or findings.
- Objectives (Yes/No checkboxes): does this article speak to:
    - Objective 1: Global IF Scoping Review: "How is the recent global literature discussing individualized funding (IF) and self-directed supports? What are the major thematic areas and how might these inform IF policy and practice?"
    - Objective 2: Ministry of Children and Family Development (MCFD) IF Scoping Review: “Can this article inform MCFD consultations on the new Children and Youth with Support Needs Framework?"
- Thematic Notes: Notes for inductive thematic analysis:
    - Themes identified in the article through listed keywords and other dominant themes that we recognize across the literature.
    - Significant quotes.

If a variable could not be distinguished, researcher would note ‘N/A’ for that variable. All direct quotes and references to the article were cited using APA references to page numbers.

PRISMA Flowchart



Appendix 2: Summary Tables of Literature

Table A: Source Information and Study Participants

Source	Study design	Jurisdiction	Policy title	N=	Population (Dx)	Participants
Alexander et al. (2019)	Qualitative *Policy analysis*	Australia	NDIS	N/A	Children with disabilities.	Population Dx and their parents.
Bisp et al. (2022)	Quantitative *Survey study*	UK: England: Southend Essex Thurrock	PBs	N=18	Young people who are approaching the point of discharge from SET CAMHS and have ongoing mental health needs, but do not qualify for support from adult mental health services	Population Dx
Boaden et al. (2021)	Mixed methods *Longitudinal study*	Australia: New South Wales	NDIS	N=344 (Surveys)* N=38 (Interviews)**	Children with developmental delay/disability	Family members and service providers to Population Dx *28/153 family members and 34/191 service providers completed both survey rounds. 282 distinct respondents ** 5/16 family members and 5/22 service providers completed both rounds of interviews. 28 distinct respondents
Brien (2018)	Qualitative *Policy analysis*	Australia	NDIS	N/A	Children with disabilities	N/A
Brien et al. (2017)	Qualitative *Policy analysis*	Australia	NDIS	N/A	Children with disabilities	N/A
Carney et al. (2019)	Qualitative *Policy analysis*	Australia	NDIS	N/A	N/A	N/A
Clark & Dissanayake (2022)	Quantitative *Comparative survey study*	Australia: Victoria	NDIS	N=202	Children with autism spectrum disorder covered under DSS (n=58)/NDIS (n=58)	Parents of Population Dx in DDS (n=55)/NDIS (n=31)

Source	Study design	Jurisdiction	Policy title	N=	Population (Dx)	Participants
Collins et al. (2014)	Qualitative *Population-based study*	UK: England: three regions	Direct Payments (DP)	N=25	Children with disabilities/disabled children	Parents and carers of Population Dx
Comito et al. (2023)	Quantitative *Retrospective observational study*	Australia: Victoria	NDIS (HEN)	N=333	Paediatric patients with disability eligible for HEN support	Population Dx
Cowen et al. (2011)	Qualitative *Case study*	UK: England: Sheffield	N/A	N/A	Young disabled people with complex needs leaving school	Parents and professionals connected to Population Dx
Dew et al. (2013)	Qualitative *Policy analysis*	Australia: New South Wales	IF packages Local Area Coordination (LAC)	N=70	Children with disabilities	Government (n=21); non-government service providers (n=39); Parents Population Dx (n=10)
Dew et al. (2014)	Qualitative *Population-based study*	Australia: New South Wales	NDIS	N=78	Children with disabilities	Parents and carers of Population Dx
Dew et al. (2023)	Qualitative *Exploratory study*	Australia: New South Wales	NDIS Medicare for Refugees	N=16	Persons with a range of disabilities including intellectual or developmental, physical and sensory disabilities	Family members of Population Dx (n=9) Practitioners working in refugee specific services (n=7)
Dudová (2022)	Qualitative *Policy analysis*	Czech Republic	Cash-for-care benefit	N=48	Disabled children and disabled elders	Women and men caring for a disabled elder (n=35) Parents caring for a disabled child (n=13)
Duffy & Murray (2013)	Qualitative *Policy analysis*	UK: England: Sheffield	Personalisation	N/A	N/A	N/A
Ellem et al. (2019)	Qualitative *Reflective participatory study*	Australia: New South Wales	Person-Centred Planning (PCP)	N=26	People with an intellectual disability	Family members of Population Dx

Source	Study design	Jurisdiction	Policy title	N=	Population (Dx)	Participants
Fisher et al. (2023)	Qualitative *Policy analysis*	Australia	NDIS	N=9	Self-managed disabled NDIS recipients and family members who managed on behalf of a disabled person	Self-managed or were nominees of their family member (n=7) Plan-managed (n=2)
Gallego et al. (2018)	Quantitative *Discrete choice study*	Australia: New South Wales	NDIS	N=133	People in rural Australia eligible under the NDIS	Carers of Population Dx
Gavidia-Payne (2020)	Qualitative *Population-based study*	Australia: Victoria	NDIS	N=17 (Online survey) *	Children with disabilities autism spectrum disorder (ASD) (n=12); Global Developmental Delay (n=4); Cerebral Palsy (n=1); Language delay (n=7); Rare genetic disorders (n=3)	Parents of Population Dx *In addition, 11/17 completed focus groups (n=11) and 6/17 completed interviews (n=6)
Harry et al. (2017)	Quantitative *Secondary analysis of randomized control trial*	USA: Arkansas Florida New Jersey	Cash and Counseling Programs	N=456	Young adults 18 to 30 with disabilities **Florida** n=300; Treatment n=139; Control n=161 **New Jersey** n=93; Treatment n=41; Control n=52 **Arkansas** n=63; Treatment n=27; Control n=36	Population Dx or their proxy
Henderson et al. (2018)	Qualitative *Case study*	UK: Scotland	Self-Directed Support (Self-directed Support)	N=9	Children with physical and learning disabilities	Parents of Population Dx (n=4); Service managers (n=3); Director (n=1); Chief Executive (n=1)
Howard et al. (2015)	Mixed methods *Population-based study*	Australia: New South Wales	NDIS	N=75 (Surveys) N=34 (Interviews)	Disabled children under five	Parents and carers of Population Dx

Source	Study design	Jurisdiction	Policy title	N=	Population (Dx)	Participants
Hutton & King (2018)	Qualitative *Population-based study*	UK: England	Personalised budget	N=9	Disabled children under 18	Parents/carers of Population Dx who accessed at least 2 rehabilitation therapy services
Johnson et al. (2020)	Qualitative *Population-based study*	Australia	NDIS	N=13	Children with an intellectual disability aged 6-16	Parents or carers of Population Dx
Laragy & Ottmann (2011)	Qualitative *Exploratory Participant-observation study*	Australia	NDIS	N=12	Disabled young people: Developmental disability (n=1); Intellectual and mental health (n=2); Intellectual and physical (n=3); Intellectual disability (n=1); Intellectual disability and CP (n=1); Physical (n=1); Physical and communication (n=1); Intellectual and Asperger's syndrome (n=1); Severe intellectual and physical (n=1); Autism (n=2)	Families of Population Dx
Leutz et al. (2015)	Qualitative *Policy analysis*	USA: Massachusetts	Autism Waiver Program	N=8 (Focus group) N=27 (Interviews)	N/A	**Focus group:** State DDS program administrators (n=2); DDS clinical managers (n=2); Autism Support Centers Brokers (n=2); Staff fiscal intermediary (n=2) **Interviews:** DDS clinical managers (n=2); DDS waiver administrator (n=1); Core FI staff (n=3); Brokers (n=8); Broker-supervisors Autism Support Centers (n=3); Senior therapists (n=5); Direct support providers (n=5)

Source	Study design	Jurisdiction	Policy title	N=	Population (Dx)	Participants
Loadsman & Donelly (2021)	Qualitative *Interpretative analysis*	Australia	NDIS	N=8	Child or young person with a disability and a complex medical condition	Primary caregivers for Population Dx
Marchbank (2017)	Qualitative *Phenomenology*	Australia	NDIS	N=6	Young children diagnosed with a variety of disabilities	Administrators of ECEI community services to parents of Population Dx
Marchbank (2019)	Qualitative *Population-based study*	Australia	NDIS	N=14 (Online survey) N=4 (Interviews)	Children with disabilities/ developmental delays	Preschool teachers
Marks et al. (2022)	Qualitative *Population-based study*	Australia	NDIS	N=5 (Youth adult) N=7 (Parents)	Young adults with intellectual disability, aged 17-26 years	Population Dx and parents
McDonald et al. (2016)	Qualitative *Policy analysis*	Australia	NDIS	N/A	N/A	N/A
McGuigan et al. (2016)	Qualitative *Cross-sectional study*	UK: Northern Ireland	Direct Payments (DP)	N=30	People receiving DP	Respondents in direct receipt of DP (n=2); Informal carers who implement the budget on behalf of DP service user (n=28)
McNeill & Wilson (2017)	Mixed methods *Population-based study*	UK: Northern Ireland	Direct Payments (DP)	N=25	Children with disabilities	Parents and carers of Population Dx
Meltzer & Davy (2019)	Qualitative *Document-based content analysis*	Australia	NDIS	N/A	N/A	N/A
Mitchell (2012)	Qualitative *Policy analysis*	UK: Scotland	Self-Directed Support (Self-directed Support)	N/A	N/A	N/A

Source	Study design	Jurisdiction	Policy title	N=	Population (Dx)	Participants
Mitchell (2014)	Qualitative *Secondary analysis/ Thematic network approach*	UK: Scotland	Self-Directed Support (Self-directed Support)	N=6	Disabled young people with cognitive and communication difficulties	Disabled young people with cognitive and communication difficulties and their carers/parents
Mitchell (2015)	Qualitative *Two-phase exploratory study*	UK: Scotland	Self-Directed Support (Self-directed Support)	N=9	Young people with disabilities transition into adult care and their parents/caregivers	Young people with disability and their parents
Nieboer et al. (2011)	Quantitative *Experimental study*	Netherlands: Rotterdam Utrecht Enschede Amsterdam	Personal Budget (PB)	N=147 (at T0) N=108 (at T1)	Children aged 0-24 years with intellectual disability	Parents of population Dx
Nucifora et al. (2022)	Qualitative *Exploratory Population-based study*	Australia	NDIS	N=8	Person with an intellectual disability: Autism Spectrum Disorder (ASD) (n=1); Psychosis (n=1); Genetic disorder (n=1); Prader-Willi Syndrome (PWS) (n=1); Down Syndrome (n=4)	Parents of Population (Dx)
Priestley et al. (2022)	Qualitative *Population-based study*	New Zealand	IF	N=7	Autistic children/disabled children under 21	7 Mothers of Population (Dx)
Prowse et al. (2022)	Qualitative *Phenomenology*	Australia	NDIS	N=6	NDIS participants under 18 (n=4); NDIS participants over 18 (n=2)	6 parents and carers of Population (Dx)

Source	Study design	Jurisdiction	Policy title	N=	Population (Dx)	Participants
Ranasinghe et al. (2017)	Qualitative *Evaluative research study*	Australia	NDIS	N=42	Children with complex developmental and behavioural difficulties autism spectrum disorder (ASD) (n=31); Genetic/ syndrome (n=3); Global Developmental Delay (GDD) (n=2); Language impairment (n=2); Cerebral Palsy (CP) (n=1)	Parents of Population (Dx)
Robinson et al. (2016)	Qualitative *Longitudinal case study*	Australia: Queensland	NDIS - Self-Directed Support (Self-directed Support) pilot program 2010-2012	N=50	Adult participants with acquired brain injury (n=15); Young children with disabilities (n=15)	Adult participants with acquired brain injury (N=15); their family/ supporters (N=7); family members with young children with disabilities (N=15); service providers/managers (N=13).
Russo et al. (2021)	Knowledge syntheses *Systematic review*	Australia	NDIS	N=7	Children with disabilities	Parental experiences with NDIS services
Salvador-Carulla et al. (2023)	Mixed methods *Cross-sectional Policy analysis*	Australia: Western Sydney Australian Capital Territory	NDIS	N/A	N/A	N/A
Simpson & Douglas (2016)	Knowledge syntheses *Systematic review*	International	Self-directed funding	N=12	Children with disabilities	Main carers and families of Population (Dx)
Small et al. (2020)	Qualitative *Family-based study*	Australia	NDIS	N=18 (Initial phase) N=14 (Post phase)	Young people eligible under NDIS and transitioning into NDIS	Stakeholders in the NDIS program and carers

Source	Study design	Jurisdiction	Policy title	N=	Population (Dx)	Participants
Smethurst et al. (2021)	Qualitative *Exploratory Study*	Australia	NDIS	N=8	Children with Cerebral Palsy	Parents of Population Dx
Swenson & Lakin (2014)	Qualitative *Policy analysis*	USA	Medicaid (Direct payments)	N/A	N/A	N/A
Thompson (2022)	Qualitative *Policy analysis*	Australia	NDIS	N/A	N/A	N/A
Timberlake et al. (2014)	Qualitative *Policy analysis*	USA: Massachusetts	Home and Community Based Services (HCBS)	N=14 (Interviews) N=74 (Waiver study)	Children eligible for an autism waiver in the state of Massachusetts	Families of Population Dx
Tracey et al. (2018)	Mixed methods *Community-engaged research*	Australia	NDIS	N=291 (Quantitative) N=56 (Qualitative)	Children with a disability aged 14 years or younger	Main carers and families of Population (Dx)
Venning et al. (2021)	Qualitative *Policy analysis*	Australia	NDIS	N=36	Physical disability (34%); Intellectual disability (31%); Head injury, stroke, or acquired brain injury (14%)	People appealing NDIS/National Disability Insurance Agency funds to the Administrative Appeals Tribunal
Welch et al. (2012)	Mixed methods *Community-engaged research*	UK: England	Direct Payments (DPs)	N=348 (Quantitative) N=43 (Qualitative)	Children and young people with disabilities; 47% (n=164) autistic spectrum disorder; 23% (n=79) complex health difficulty; 66.5% (n=228) behavioural difficulty; 92% (n=318) learning disability with 59% (n=186) being severe.	Main carers and families of Population (Dx)
Whitaker (2015)	Qualitative *Ethnographic study*	UK: England: “Anyshire”	Self-Directed Support	N=7	Disabled children or children with additional and complex needs	7 families and their support teams of Population (Dx)

Source	Study design	Jurisdiction	Policy title	N=	Population (Dx)	Participants
			(Self-directed Support)			
Whitburn et al. (2017)	Qualitative *Policy analysis*	Australia	NDIS	N=7	Children with sensory or intellectual disabilities	7 parents or caregivers of Population (Dx)
White et al. (2021)	Mixed methods *Exploratory study*	Australia: Kimberley Region	NDIS	N=373 (Quantitative) N=14 (Qualitative)	NDIS participants	11 Access Program staff; 3 Program managers/executives
Yates et al. (2021)	Qualitative *Population-based study*	Australia	NDIS	N= 719;	Children and young people with disability	Population Dx (5%) and Family members of Population Dx (95%)

Table B: Source Research Question, Aim, Definitions, and General Findings

	Research question	Research Aim	IF Definitions	General Findings
Alexander et al. (2019)	Article identifies that NDIS design and implementation may be counterproductive to fostering early attachment security in children.	Highlights the NDIS design implications for children with a disability and their families and identifies improvements in design and social policy.	The NDIS funds reasonable and necessary supports to disabled people 0-65 years old. Funding is individualized, meaning services and supports are available for purchase from government, non-government, not-for-profit, and for-profit providers.	Design improvements for NDIS: Need for investment in Early Childhood Intervention (ECI) to save money across the lifespan of individuals; ECEI could be separated from the NDIS and made accessible as a community service to young families concerned about their child's development between ages 0-7; Implement a Key Worker Model to work with vulnerable families in financially viable ways that ensure staff are skilled.
Bisp et al. (2022)	The Positive Pathways service that aims to provide support on discharge using personalised care planning (person-centred-care), social prescribing and access to a personal health budget provides more positive participant experiences for young people discharged from a CAMHS transitioning into empowered care planning.	The aim is to show the importance of a service, called Positive Pathways, to provide collaborative personalised care planning with a dedicated youth facilitator, in some cases providing a personal health budget, to enable young people to access individualized support in their local community.	Personal health budgets (Personal Health Budgets) refer to an amount of money used to support a person's health and well-being that is planned and agreed between the person, their representative and their local CCG, personalising care based on what is important to the person and their individual strengths and needs.	Personal Health Budgets improved psychological functioning and mental well-being of young participants; Personal Health Budgets supported personalisation/choice and control/ person-centred care through allowing access to services; Personalised care and support planning models were effective in supporting young people from complex backgrounds with multiple disadvantages, reporting young people felt understood with budgets providing choice and control; Clinicians reported Personal Health Budgets allowed for flexibility in clinical systems tailored to individual needs increasing confidence in available support upon discharge from CAMHS.

	Research question	Research Aim	IF Definitions	General Findings
Boaden et al. (2021)	Article examines families' experiences of the transition of ECI to the NDIS to examine risk of unequal access, focusing on the experiences of families to identify factors associated with positive experiences of the transition. (1) What are the family, ECI service provider, and mainstream provider experiences of the current transition to the NDIS in NSW? (2) How can ECI service types be delivered to best achieve a) good practice services for children and families; b) innovation and sustainability of ECI service types; and c) an effective interface with other service types?	This research applied a social ecological model to understand families' experiences in the transition from ECI to NDIS that has important implications for children with developmental delay or disability and their families, as personalisation schemes can often extend existing social inequalities.	Individualized funding refers to a personalised approach. NDIS offers individualized packages to provide greater choice, control, and opportunity of supports to people with disability. This funding approach intends to ensure that disabled people are at the centre of decision-making processes that affect them and their goals for a better quality of life, with supports tailored to individual needs.	Experiences among families differed from positive to negative and related to personal characteristics (e.g., education level, culture/language backgrounds), connections within community (e.g., professional or relational assistance with navigating the NDIS process), and system level influences (e.g., NDIS response times and service); The longitudinal measures showed modest change as many disadvantaged families continued to experience delays and communication issues in transitioning to the NDIS; Positive experiences were associated with the capacity to navigate the NDIS within the family, community, or service provider. Findings suggest that interactions between different social ecological levels are important in families' transitions to the NDIS; Some families gained greater system navigation capacity by having a professional in the community to provide emotional support face-to-face. Families experienced a better transition when they were referred on to mental health support, sibling support, and peer-support groups in the wider community.

	Research question	Research Aim	IF Definitions	General Findings
Brien (2018)	How can the rights of young children with disability be heard and enacted within the policy constructs of participant choice and control?	A comprehensive literature review that provides a critical examination of the concepts inherent in Australia's NDIS, participant choice and control. These concepts are explored in relation to enacting the child's right to be heard, as outlined in the UNCRC and the UNCRPD.	Individualized funding and self-directed supports and service as stipulated in the NDIS Act of 2013 legislated by the Australian Government have the intention of enabling participants with disability to receive the self-directed supports and services needed to live an ordinary life in the community.	Australian legislation, NDIS policies, and international conventions promote the rights of children's voices to be heard. These frameworks and ethics are meant to ensure the rights of young children with disabilities, aligning with participant choice and control inherent in the NDIS. This rights-based perspective obligates early childhood professionals and families to enable children experiencing disability to express their views. The NDIS aligns with this perspective by ensuring participants' choice and control over service provision; Supporting the rights of children requires a balancing act amongst the collective family unit, as the parents have the ability to enable or obstruct the child's voice. Adult participatory practices model skills necessary to for choice and control; Challenges for adults in supporting these rights for children relate to both the role which adults undertake in the exercise of rights by children, and how infant and children's voices are heard; Evolving capacities of disabled young children should be taken into account by parents and early childhood professionals, mediating on behalf of the child while considering the child's expressed view.

	Research question	Research Aim	IF Definitions	General Findings
Brien et al. (2017)	The article explores existing research to delineate effective evidence-based practices that enable ECI professionals to support families and children to exercise choice and control. This article argues that to effectively support families and children to experience choice and control, ECI professionals must build and share specialist knowledge and expertise to support informed decision making, engage in positive relationship-building practices, and develop a shared approach to accountability.	The NDIS promotes choice and control over decisions about service provision for disabled people. The article aims to review research that investigates the notion of choice and control for service provision, what this means for families and disabled children with a disability, and how early childhood intervention (ECI) professionals can effectively support this decision making.	Individualized funding under the NDIS is based on a model of consumerism that re-orients funding to the participant rather than the provider which effectively assumes that choices can be authentic and knowledgeable regarding what constitutes quality in service provision.	Findings highlight the need for collaboration to strengthen support and choice and control for families and disabled children. Choices made by families regarding service provision go hand-in-hand with ECI professionals requiring well-developed skills in working with parents and mainstream early childhood educators. The policy context for choice and control requires foundational specialist expertise and knowledge be made available to families to support their decision-making; Although choice is a key principle inherent to the NDIS, this does not necessarily guarantee the availability of authentic choice; Families reported they do not always experience choice and control over ECI service provision and indicate they want better access to reliable information and supportive conversations with ECI professionals to assist in clarification of choices and expectations; Professional ECI practice development and communication of specialist knowledge and expertise can inform decision making while engaging in positive relationship building and shared accountability practices to assist families and disabled children with building capacity to exercise choice and control.

	Research question	Research Aim	IF Definitions	General Findings
Carney et al. (2019)	The article addresses recent public hearings that indicate the National Disability Insurance Agency does not place the participant, and their support, at the centre of the Scheme; 1) How does the actual process square with legislative and other obligations? 2) How adequate and effective are the avenues of review? 3) Does the planning process adequately meet standards of good administration? 4) Is it equitable that more articulate, better supported, or more experienced individuals and families are more likely to achieve an optimal level of plan resourcing? 5) Are the Administrative Appeals Tribunal (AAT) review rights broad enough and accessible?	This paper analyses the legal architecture, policy assumptions and NDIS administration to establish whether its guiding philosophy lies in a) professional person-centred planning, b) an insurance logic, or c) principles of equity and efficiency of decision-making; and assesses the contribution of legal remedies in ensuring fidelity of purpose to policy goals.	Individualized funding refers to a personalised resource packages tailored to the needs of each participant.	Despite criticism about NDIS administrative standardisation and data-driven planning, it is not an error of law and not responsive to merits review avenues. Nevertheless, undue weighting of equity and efficiency over the needs of participants is ethically problematic as it elevates an ethics of justice over an ethics of care, which arguably is what the NDIS was designed to promote; This reflects a tension between an ethics of justice (that seeks impartial and abstract planning applied consistently to all participants) and an ethics of care (that views each participant as unique, seeking a more relational approach to planning); NDIS reflects issues of lack of transparency of process, inadequate communication with planners, and being surprised by plans with little relationship with individual needs. Questions arise about 'conformity' to the intent of the NDIS; judicial challenge; and remediation through merits review of decisions in the AAT.

	Research question	Research Aim	IF Definitions	General Findings
Clark & Dissanayake (2022)	This study examined whether the profiles of autistic children and their families accessing an early intervention (EI) setting have changed following NDIS introduction; It was hypothesised that; a) children attending EI funded under the NDIS will present with more severe characteristics (lower verbal and non-verbal cognition, more severe autism behaviours and lower adaptive functioning) relative to the cohort of children accessing the centre when it was funded by the DSS; and b) parents accessing NDIS will report higher levels of stress and lower QoL than parents of children accessing the centre under former DSS funding.	The study focussed on children and their families' transition to the NDIS to determine whether children funded under the former individualized block funding model and the new individualized NDIS funding model, present with similar or different baseline characteristics to determine if the allocation of individualized NDIS funding is prioritising children with more severe presentation; A secondary aim was to examine the wellbeing of parents of children accessing earlier and current funding schemes.	The overarching goal of the NDIS is to provide financial assistance to individuals living with a disability and their families, to facilitate access to appropriate supports, thus, increasing their independence, participation, and integration into the community. It does so by providing individual funding packages.	Findings suggest that the transition to the NDIS may not have achieved its intended purpose of streamlining access to funding to improve the lives of autistic children and their families. There were no differences in the baseline behaviours or cognition of children in either funding scheme, meaning increased mental health difficulties of families and parents cannot be attributed to that baseline; The findings accord with one leading criticism of the NDIS: the sole focus on the autistic individual, without considering those most closely involved in their care, their parents.

	Research question	Research Aim	IF Definitions	General Findings
Collins et al. (2014)	This study addressed experiences of short breaks among families of disabled children.	This study explored the perceptions of twenty-five parents whose children accessed short breaks.	Direct payments from local authorities that can be used to pay for respite/short breaks.	Parents reported that their needs for short breaks had not been met and this appeared to arise from contested interpretations of what 'breaks from caring' mean; Evidence indicates that parents continue to report that some of their needs for short breaks are going unmet. Unmet needs for short breaks were framed by parents in our study as a matter of contested conceptualisations of the purpose of short breaks rather than (or perhaps as well as) a resource-driven lack of provision.
Comito et al. (2023)	Study directs attention to the NDIS HEN [home enteral nutrition] service and degree of impact on patients accessing this stream following funding changes. This study aims to evaluate the implementation of a new service model within a paediatric tertiary hospital setting.	HEN provision is a well-established support for patients that has had to deal with significant inconsistencies in funding result in financial burden for some healthcare services; Recent government-initiated funding changes prompted the development of a new HEN service for eligible disabled patients moving from a universal to more individualized approach to care that this article examines.	Individualized government-funded supports for disabled people are meant to assist with meeting goals, enhance community involvement and improve quality of life; Participant funding plans contain 3 funding categories: Core, Capacity Building, and Capital supports; Participants can self, plan, or agency-manage their allocated funds; Those who self-manage must independently arrange supports and invoices. Plan-managed participants receive funded assistance. The NDIS is responsible for planning agency-managed participants, through services from registered NDIS providers.	Initial NDIS funding changes meant pre-existing HEN funding was no longer applicable for NDIS participants who required nutrition-related supports as a direct result of their disability. To ensure ongoing service accessibility at no additional cost to the patient, tertiary hospital services were left to bridge the financial shortfall whilst NDIS funding processes and applications were explored. The NDIS funding changes presented a unique opportunity to meet the pre-existing resourcing deficits impacting employees, patients and their families; Funding changes presented a unique opportunity to meet pre-existing resource deficits and enabled individualized access to HEN supports for disabled paediatric patients; Findings reflect an increase in paediatric patients accessing HEN support, likely caused by advancements in medical treatment, increased life expectancy and patient complexity; NDIS funding changes may have also influenced this trend, with the notion of choice and control resulting in additional participants joining the program.

	Research question	Research Aim	IF Definitions	General Findings
Cowen et al. (2011)	Personalised demonstrates that a collaborative approach to funding individual budgets for disabled school leavers with complex needs leads to more positive, individualized outcomes for young people and their families.	The article provides information about and promote the model of personalised transition using individualized budgets.	Individual budgets ensure young people are entitled to support, funding or access to particular services, and such entitlements must be clear and transparent so that people can evaluate what is available, plan effectively and know how best use resources.	Individual budgets and personalisation of support outcomes made a significant difference to the lives of young people and their families, including employment and community involvement; Personalisation of care provides dignity, increased well-being, efficiency, and better quality of care.
Dew et al. (2013)	Study addresses a gap in the literature by reporting on the benefits and barriers of using IF to access therapy services from the perspectives of carers of disabled people and service providers in rural and remote areas of NSW, Australia.	This study describes some benefits and barriers to using IF to access therapy services in rural areas.	Individual funding is part of person-centred practices with opportunities for self-determination and choice; Person-centred approaches may involve IF for the purchase of required support to allow people with a disability and their carers greater choice in therapy access that is also referred to as direct payments.	Main findings highlight issues related to accessing IF in rural and remote areas; The article suggests strategies for enhancing the IF experience for service users and providers in rural and remote areas; Carers indicated a need for: accessible information; a local contact person for support and guidance; adequate financial compensation to offset additional travel expenses and coordinated eligibility and accountability systems; Service providers required: coordinated cross-sector approaches; local workforce planning to address therapist shortages; certainty around service viability and growth; clear policies and procedures around implementation of IF.

	Research question	Research Aim	IF Definitions	General Findings
Dew et al. (2014)	This paper explores the factors rural carers weigh up in making the decision to move or to stay in rural and remote areas caring for a disabled child or family member requiring access to services.	The aim of this paper is to explore the factors rural carers weigh up in making the decision to move or to stay. Understanding these factors will inform the successful implementation of the NDIS in rural areas.	The focus of the NDIS is to provide individualized funding services that give users choice and control so that their community participation and inclusion are enhanced.	Findings suggest participants made decisions about whether to move to a larger centre according to three interlinked factors: personal factors related to other family caring responsibilities; social factors including informal support networks of family, friends, and community; and economic factors including employment and the time and cost of travelling to access services; With the NDIS, the ability to offer families more flexible, localised, and person-centred supports may assist rural families to have a choice about where they live. This will only become a reality with reasonable access to a range of local support options and funded capacity to travel to access support when needed.

	Research question	Research Aim	IF Definitions	General Findings
Dew et al. (2023)	Paper reports on a small-scale, exploratory study on service use experiences from the perspectives of family members of disabled people with from refugee backgrounds, and service providers; Questions included: How did you find out about these services in Australia? How helpful do you find these services? How culturally appropriate are the supports and services they provide? Are there supports and services that you need, that are you not currently getting?	The aim of this article is to provide evidence on service disparities for resettled disabled refugees and their families; The aim was to explore, from multiple stakeholder perspectives, the experiences of disabled people with refugee backgrounds resettled in Australia, with a view to informing future services and supports.	The NDIS provides IF to those deemed eligible due to permanent and significant disability following an assessment. To receive funding, eligible participants complete an annual individualized plan outlining the supports they require to achieve their goals; Funding is allocated according to this plan alongside determining what is reasonable and necessary support to improve participation and inclusion in the community; NDIS participants use their funding package to purchase services; Disabled refugees are eligible for NDIS funding.	Findings address two themes: (1) Getting the basics right: Refugee specific services played a crucial role during early settlement in ensuring access to medical, health and social care including diagnosis, medication, equipment, housing and financial support; (2) Ongoing access to disability supports: Refugee specific services assisted families with longer-term supports once immediate needs were met, including accessing services through the NDIS. Participants described benefits such as access to interpreters and Arabic-speaking staff, cultural sensitivity and safety, and problems included wait times, bureaucratic processes and housing. Findings highlight the importance of refugee-specific services in providing short and longer-term coordinated, holistic supports to increase the likelihood of positive settlement outcomes and reduce access disparities. Results identified that refugee-specific services responded by establishing mechanisms and teams to help people navigate and access disability supports and services.

	Research question	Research Aim	IF Definitions	General Findings
Dudová (2022)	This article describes and analyzes the ways caregivers assign meaning to the cash-for-care monies in close family relationships. What happens when money in the form of a cash-for-care public measure is introduced into relationships between family members? How is the meaning assigned to the cash-for-care monies in close family relationships?	This research aims to provide a direct investigation into what happens when money in the form of a cash-for-care benefit enters family relationships, in the context of long-term family care in the Czech Republic where a care allowance was introduced in 2007.	Cash for care is an unconditional, direct payment to the care receivers to support and valuate care.	Findings assess different practices of earmarking special monies affirmed and maintained gendered normative expectations; The introduction of the benefit did not lead to differentiated gender outcomes; Women and men from different socioeconomic backgrounds did not differ in their understanding of the allowance money; Mothers caring for a disabled child tended to be in a worse economic situation, mainly because they were either not working or doing occasional work; The economic situation of the respondents was a consequence of the situation of having to provide care; The norms of care are gendered: personal care in the family was expected more intensively from daughters than from sons and from mothers than from fathers; The cash for care money was not used to buy formal domiciliary care services, did not lead to an increase in formal care, and did not give rise to a varied market of domiciliary care services; The study provides insight into the cultural factors that lead to the unintended interpretations of the cash for care monies in close relationships by the caregivers and how the gendered norms of care act as barriers to the process of commodification and marketization of care.

	Research question	Research Aim	IF Definitions	General Findings
Duffy & Murray (2013)	This paper draws on the experience of the authors in developing, testing and sustaining a radical model of integrated self-directed support, called personalised transition. They argue that many initiatives to improve the transition process to self-directed support models are fundamentally flawed as they fail to respect the basic rights of young people and families.	This paper offers a hypothesis about the core elements of an effective transition process in a system of self-directed support and to suggest that the approach to integration in public services may need to radically change.	Self-directed support through personalised care transitions choice and control of supports to the recipient of care and their caregivers.	Findings address that typical solutions to the problem of transition focus on system change instead of ensuring that power and control shifts to families and young people; At the heart of personalised transition should be the will of the individual and support of family and friends; The real focus for professional action and the locus of their responsibility, is to ensure that young disabled people have the means to exercise their rights. This is not just a matter of budgets, it is also about ensuring people have the independence, information, skills, experiences and relationships that enable the active exercise of those rights; This is the paradox: the best approach for raising the expectations of disabled people is for professionals to have higher expectations of themselves and the systems they administer. System integration and team integration may not be essential requirements and may distract us from personalised transition.

	Research question	Research Aim	IF Definitions	General Findings
Ellem et al. (2019)	This study evaluates the extent to which Helping Families built the knowledge, skills and confidence of families of disabled people to imagine a better life, to exercise more choice and control over supports and their lives and to strengthen their networks and community. It explored changes in families' intentions and actions in building a better life for their disabled loved one as well as perceived changes for the disabled persons.	This article presents findings from an evaluation of a family resourcing and capacity building project in New South Wales, Australia that explored capacity building initiatives undertaken with families of disabled persons in urban, regional and rural areas including a series of workshops and online resources to help families engage in person-centred planning.	Personalised supports refer to different ways of self-managing, including direct payments and employing staff; Also referred to as the Direct Payment Self-Managed System.	Family accounts show merits of building knowledge, skills, and confidence, but these family efforts can be undermined by apathy and discrimination to disability from extended family, community and service providers. Asking families to be the primary support in person-centred planning initiatives may ignore the impacts of structural and psycho-emotional disablism on all family members. For families to support people with intellectual disability in person-centred planning there is a need to acknowledge and respond to the material, cultural and personal challenges for all family members in planning processes.

	Research question	Research Aim	IF Definitions	General Findings
Fisher et al. (2023)	The study used Katzman and Kinsella's typology of self-management work to analyse the current conditions that facilitate or hinder self-management. What is the profile of people with disability who self-manage their NDIS plan? What is their experience of self-managing and what helps them to self-manage successfully?	This project explored the conditions and resources conducive to self-management in the interests of the disabled person.	There has been a shift from supporting disabled people through institutions, charity and welfare towards disabled people having choice and control over their support. The shift includes disabled people controlling their support funds. IF approaches to promote control by disabled people over their support include individual budgets, personal budgets, direct payments and cash for care. Related practices include person-centred care and consumer-directed care.	Findings have implications for change at the personal level through to the policy and international conceptual levels. Self-management capacities inform personal choices about control of disability support, practice changes in service organizations, and policy changes about how people can be supported to make choices about and set up sustainable self-management processes; Data demonstrated the unequal take-up of self-management; Children, through their parent nominees, were more likely to use self-management; Disabled people who self-managed NDIS plans skewed towards parents of young children with autism, who entered NDIS as their first point of contact with disability support. Only 1 in 10 participants with cognitive disability self-managed their plan, and even fewer were people with intellectual disability. The three-part framework of administrative, supplemental and uncertainty work helped understand the degree to which socio-economic capacity affects people's confidence to self-manage, and for understanding the types of resources they need to redress any imbalance.
Gallego et al. (2018)	Study determined the relative importance that carers of disabled people living in rural Australia place on different therapy service characteristics using a discrete choice experiment.	Study aimed to determine quantitatively the relative importance that carers of disabled people in rural Australia place on different therapy service delivery characteristics and the factors that influence carers' decisions about choosing and using such services.	Individualized funding models are expected to allow people with a disability greater service access, flexibility and choice.	133 carers completed the discrete choice experiment of which the majority cared for a disabled child (84%) with an average age of 17 years (SD 14.25); Findings show strong preferences for short waiting times; services delivered by a therapist without out-of-pocket costs; travelling up to 4 h to receive a therapy session.

	Research question	Research Aim	IF Definitions	General Findings
Gavidia-Payne (2020)	Study examines the scheme's introduction with young children with DD, grounded in families' experiences of the ECEI implementation in the State of Victoria. Of specific interest was to explore families' journeys through this new service system path and understand the impact on their children, families, and themselves.	For young children with DD, NDIS services fall under the early childhood early intervention (ECEI) approach, the impact of which is yet to be documented. Considering the critical role of families in supporting their disabled children, the aim of the present study was to examine their experiences of the ECEI approach.	Individualized funding within the NDIS means participants receive direct funding and are encouraged to purchase their own services, thus, consumers must understand, navigate, and source the markets of private and non-for-profit providers.	Findings clustered around five themes: (1) accessing the NDIS and ECEI; (2) plan development and implementation; (3) choice and control; (4) family and community life; and (5) parental distress; Prior to accessing the NDIS, participants understood the importance gained supports as early as possible; Participants referred to the NDIS, with a minimal mention of the ECEI approach when discussing services for their child with DD; Participants reported long and confusing waiting times for ECEI planning; Parents conveyed limited choice and control in their interactions with the NDIS due to a lack of information; Participants perceived the NDIS' child focus was at the expense of the family system; Participants characterized the ECEI as stressful, from contact to planning process to securing funding; Parents expressed uncertainty about making the best decisions and that limited knowledge could be a barrier to service provision especially where they had just learned about their child's developmental delay.

	Research question	Research Aim	IF Definitions	General Findings
Harry et al. (2017)	This study examined the effectiveness of the Cash and Counseling self-directed budget authority model for young adults with long-term care disabilities; Authors hypothesized that treatment and control group members would differ significantly in four areas: community involvement; satisfaction ratings; unmet needs for assistance; and health status rating compared to their peers.	The study's aim was to evaluate the effectiveness of the Cash and Counseling model of self-directed budgets for young adults with long-term care disabilities by analyzing secondary data from the Cash and Counseling Demonstration and Evaluation randomized control trial.	Individualized budgets for purchasing home and community-based services (HCBS) are a self-determined support for young adults in transition. Flexible, self-directed (also referred to as participant-directed or consumer-directed) budgets are typically utilized by eligible disabled people for purchasing HCBS, such as personal care attendants, supports, and goods that enhance independence and community living. Specifically, self-directed budgets allow individuals to adapt care services to meet their unique health and personal care needs, giving them control over the services they need to live at home in the community. A seminal model of self-directed budgets is Cash and Counseling.	Multivariate logistic regression models showed that compared to controls at nine-month follow-up, treatment group members had significantly greater odds of being very satisfied with life, when care was received, the care arrangement, transportation, help around the house and community, personal care, and getting along with paid attendants, and significantly lower odds of unmet needs with medication and routine health care at home and with transportation; Cash and Counseling performed better than or comparable with agency-based care for young adults with long-term care disabilities, suggesting its viability as a service option for this population.

	Research question	Research Aim	IF Definitions	General Findings
Henderson et al. (2018)	This paper captures the experiences and views of managers, staff and parents advocating for their children through interviews with a purposive sample from each group.	The purpose is to provide evidence of the challenges faced by one charity as it engages in a process of hybridity to accommodate changes in its funding due to the introduction of Self-Directed Supports.	Self-Directed Support (Self-directed Support) is a catch-all payment system which brings challenges to local authorities, service delivery organizations and the service users it is intended to empower; In Scotland the introduction of the Social Care (Self-directed Support) (Scotland) Act 2013 promotes four options for Self-directed Support, and since April 2014 requires new cases applying for adult or child social care to be offered opportunities for personalising of their care.	Findings identify issues arisen because of the proposed changes in strategic direction of the organization due to the introduction of Self-directed Support and are all related to hybridity. Themes emerged in interviews related to the practical delivery of care; tensions between care and quality, the care workforce, and the parent perspective; Findings address the beginning of a transition towards greater hybridity in one national charity in Scotland, and uncovers considerable reluctance to forced marketization of social care delivery to children with complex needs; Parents expressed concern that Self-directed Support is a way for local authorities to save money; Parents attributed Self-directed Support policy to local authorities instead of the government suggesting that a neoliberalist government's approach to devolving power to local authorities can enable the responsibility and accountability to be placed at local level, leaving the national policymakers disassociated from blame and/or failure; Parents reported concerns: the potential threat of the quality of service; the potential threat to the existence of the charity organization; the risks inherent within selecting and organizing their child's care.

	Research question	Research Aim	IF Definitions	General Findings
Howard et al. (2015)	The purpose of the research and its central question, is what can we learn from the experiences and narratives of parents and carers with a disabled child under five in regional areas to improve the NDIS and similar schemes?	This article presents findings from a mixed-method pilot study examining perspectives of parents and carers of disabled children in one NDIS trial site.	Individualized funding refers to funding packages that are self-managed by the disabled person or in collaboration with a nominated carer. This policy shift towards greater choice and control is supported by disabled individuals, advocacy groups and the broader community as an individualized fee-for-service funding model; The NDIS is based on two key premises: recognition of the right of people with a disability to be at the centre of decision-making and planning for their life; and the implementation of a no-fault tiered insurance model as a cost-effective way to manage and organize funding and support for disabled people over their lifetime.	Findings highlight a number of policy assumptions potentially impacting on NDIS take up for young disabled children and their families in regional contexts based on the challenges and strengths of regional and rural supports and services in meeting the needs of families caring for a disabled child, and what the experience of policy shift outside a major metropolis might mean for engagement, uptake and effectiveness. 63% (n = 22) reported using local early intervention services with their child for up to two years. The remainder had used these services between three and seven years. Interview participants also reported use of other services in the local area; Findings reveal that parents of young disabled children were hopeful about the NDIS but had low-level knowledge about the Scheme and changes, despite living in a trial site. Research participants described confusing communication around the launch of the NDIS especially for those new to disability support and in the early stages of their child's support needs.

	Research question	Research Aim	IF Definitions	General Findings
Hutton & King (2018)	This article examines the responses of parents interviewed about the prospect of using a personalised health budget for their children regarding therapeutic rehabilitation services.	Focus group/interviews explored views [carers/ parents] on the proposed introduction of personalised budgets.	Personalised budgets are promoted as the person-centred alternative to generically provided services where families can decide which services to buy for their child and how to arrange care, taking individual circumstances, preferences and needs into account. The intention is not to substitute all services, but to provide flexibility to purchase elements of personalised care; The personal health budget is defined in the Children and Families Act (2014) as an amount of money identified by the local authority to deliver all or some of the provision set out in an Education Health and Care Plan (EHCP).	Parents and carers viewed a Personal Health Budget (PHB) with caution and benefits were tempered by experiences of current provision (DP); Concerns were raised about entitlement and how a personal budget would work; Personal budgets were not a simplistic choice of having one or not; Parents were aware of the advantages of personal budgets and could see how it might benefit their children by providing more personalised and timely health provision. However, they were also aware of pitfalls of under-provision due to the costs of services and the managerial burden of decision-making associated with administering a budget; The study provides insights into parents and carers' ideas about PHB, when personalisation more generally is seen as providing a solution to poor coordination and integration of services; There is evidence that the introduction of DPs, a precursor to PHB, for carers of disabled children is a welcome initiative enabling parents and carers to take control and reducing the need for contact with different service providers regarded as one of the most stressful aspects of caring for a disabled child.

	Research question	Research Aim	IF Definitions	General Findings
Johnson et al. (2020)	This study describes the understanding, experiences and expectations of families living in rural and remote Australia regarding core concepts relating to disability service provision, including person-centred practice, family-centred practice (FCP), transdisciplinary practice (TDP), choice, control, inclusion, and equity.	This study aims to describe the understanding, experiences and expectations of families living in rural and remote Australia regarding core concepts relating to disability service provision, including person-centred practice, family-centred practice (FCP), transdisciplinary practice (TDP), choice, control, inclusion and equity, with a view to presenting a more coherent set of solutions and preferences for achieving choice and control.	Individualized funding focuses on the person as agent and expert in their own life, with the team as peripheral expert in their relationship or discipline, but not necessarily expert in the life of the individual. The person chooses how they want to be supported, and controls the nature of the support and its provision.	Participants reported that their understanding of many of the disability principles (PCP, FCP, choice, control, inclusion, and equity) was different from providers, and many providers struggled to understand families, and therefore they did not share meaning of the principles of best practice disability supports. Families did not identify transdisciplinary practice as a core tenet of effective service delivery; Families also reported experiences of missing out on services, feeling a sense of isolation in their communities, struggling to access skilled therapists, and difficulty finding supports and goals that were relevant to their child. The quality of supports that these families accessed was often below the standard that they expected. They did not expect that support standards will change in rural and remote Australia, so many have very low expectations of the NDIS; Four themes emerged that families are struggling to find service providers who can relate to them, missing out on choice and control in many cases, and feeling excluded from community participation because of the limited flexibility of support provision.

	Research question	Research Aim	IF Definitions	General Findings
Laragy & Ottmann (2011)	This paper proposes a framework for the successful introduction and implementation of individual funding programs based on the analysis of data collected in a qualitative case study conducted in an Australian not-for-profit disability agency over a 4-year period from 2003 to 2007	The aim is to present the case study and analyze the findings using a four-system level analysis to identify what factors were effective in the program's implementation.	Individualized funding is a funding mechanism for disability supports to enable people to live more independently and participate in the community; Although the goals and procedures in individual funding programs vary greatly, they give people with disability greater control over the use of their allocated funding and the option to purchase services and supports outside of the disability services system.	The following factors were found to be important for successful implementation: the meaningful involvement of the person with disability in decision-making; adequate resources; access to information and appropriate supports; suitable activities being available; knowledge of policies and procedures; policies ensuring oversight and responsible accountability; employment conditions for workers being safeguarded; and support for staff and managers to adjust to their new roles.
Leutz et al. (2015)	Article addresses how Massachusetts operated a Participant-directed (PD) program through a Medicaid waiver that provided expanded habilitation, education, and related support services for children under age 9 with a verified diagnosis of Autism Spectrum Disorder (ASD); How is the Massachusetts Autism Waiver Program structured and operated? What have been the facilitators and barriers to operations, effectiveness, and efficiency? What does the program cost?	Program was designed to help low-income children with autism under 9 from diverse cultural backgrounds to gain access to therapeutic supports. The program used a participant (parent)-directed model to help families choose and manage services, staff, and budget. The study evaluates the costs and factors contributing to successful operations.	Massachusetts uses a participant direction (PD) model for Medicaid-funded community supports for young children with ASD; This PD program presents individuals with the option to control and direct Medicaid funds identified in an individual budget, based on research from adult programs.	Factors contributing to successful operations included educated/trained families, skilled in-home therapists, clear communication with families and among staff, good information systems, and participation of families in carryover of interventions. Families varied in their capacities and time to choose and manage services, but staff adjusted their levels of assistance to compensate. Of the total program budget, individual budgets comprised 82% and administrative costs comprised 18% of the expenses; Program staff were generally satisfied with the structure and operation of the program.

	Research question	Research Aim	IF Definitions	General Findings
Loadsman & Donelly (2021)	This article looks at the lived experiences of families navigating supports provided under the NDIS and other primary service systems in rural regions across Eastern Australia; The purpose is to examine the lived experiences of carer families, residing in regional, rural or remote regions providing primary care to a child or young person under the age of 18 years with both a disability and chronic health condition; This paper investigates how families access NDIS services and provisions and the impact on their perceived level of subjective wellbeing.	The aim of this study was to explore the experiences of families living outside urban areas engaging within the scheme.	Individualized funding is based on the NDIS user's listed goals for social and economic participation; people will experience greater choice and control over the frequency and delivery of their supports including the selection of service providers.	Findings provide insights into the contextual factors that influence the subjective wellbeing of all family members and the manner in which the market-based NDIS may produce inequities in wellbeing outcomes; Individuals and carer families who are already facing geographical disadvantage felt they had little or no choice or control over disability supports and little access to the NDIS-funded services and supports; Families were required to negotiate often long and extensive delays in accessing therapists and supports in regional, rural and remote communities; Accessing essential consumables and complex care products in regional and rural communities was also challenged by lack of services and product deliveries in these areas, despite participants being allocated funding; Participants indicated the system was difficult to understand and navigate; A lack of support within these regions exacerbated existing inequities prior to the NDIS.
Marchbank (2017)	This study conducted in a NDIS pilot rollout site in 2013 and 2014 explored administrators' first-person views regarding the impact on agencies and implication for practice moving away from block-funding.	This funded study was conducted in one pilot rollout site with administrators from two agencies delivering such services. Analysis of the data identified factors that challenged professional practice and personal philosophy.	Individualized funding is a user pay system that offers participants the opportunity to select their own services according to individual choice.	Findings suggest that the NDIS puts long-term financial viability of community agencies is at risk. A crucial dilemma emerged concerning parent choice: to what extent does a user pay system impose limitations to services being delivered in a family centred way? Statewide services had a capacity to cover funding shortfalls during transition whereas the local community-based agencies did not. Three themes central to understanding the transition process emerged to illuminate the impact on the agencies' organization and management of service delivery: (1) the business model, (2) the funding stream, (3) staffing capacity.

	Research question	Research Aim	IF Definitions	General Findings
Marchbank (2019)	This study examines 2 research questions (Survey-based): As a preschool teacher, what is important to your practice when working with children with DD and their families? (Interview-based): With the rollout of the NDIS, what are the key change experiences for working with parents and children with DD to enable them to access EI services provided through the NDIS?	This article reports a formative study conducted with qualified preschool teachers in one site in a context of change during NDIS rollout.	Individualized funding under NDIS signals a substantial shift away from historical views of disability with a reliance on medical definitions of impairment and limitation to one of capacity and empowerment. As a user pay or self-directed funding scheme, people who are accepted into the scheme are entitled to purchase the services of their choice according to an allocated funding package. The scheme also includes the provision of early childhood EI programs. For children, qualification for the NDIS funding for services still relies on medical categories and a determination of developmental risk.	Findings suggest that teachers detecting DDs in 4-year-old children needed to reposition themselves to develop collaborative relationships with parents for early detection, medical confirmation, and the benefits of EI; A user pay model for EI services to children with DDs detected later than 4 years would poorly serve families; With NDIS parents refer themselves into the system, rather than professionals; A discourse of delay, to talk about developmental progress, must compete with the profiles of disabling conditions for eligibility in NDIS; Surveys centred the importance of attention to detail, respect, focus, and being good communicators; 70% rated a family centred approach and knowledge as important. More than half rated experience, training, and professional networks as important; Conversations with parents include concerns about development, parenting skills, and child behaviour; All respondents agreed it is important to spot a child DD early; 60% agreed they preferred to get to know a family before raising a developmental concern. More than half preferred to have a recommendation before talking to a parent.

	Research question	Research Aim	IF Definitions	General Findings
Marks et al. (2022)	Exploratory research about the self-management of diabetes for young adults with intellectual disability is extremely limited, in particular in the Australian context where models of support and care differ from international contexts. This research gap is disconcerting given the high health and economic burden of poor self-management of diabetes. This research talks directly to people with intellectual disability and their families in order to identify the barriers and facilitators to optimal T1DM self-management for young adults with intellectual disability.	The study aim was to identify barriers and facilitators to T1DM self-management for young adults with intellectual disability and the implications for health promotion.	Individualized funding requires eligible individuals to submit an application form with supporting evidence from their health care professional(s). The NDIS is a new model where the Australian Government funds the individual who decides how the money is expended, rather than the disability service.	Parents are critical for the support of people with intellectual disability and T1DM in the absence of disability staff with appropriate skills; Diabetes self-management is complex (carbohydrate counting, BGL monitoring, insulin therapy); 2) support for diabetes care (reliance on parents and carers, the NDIS, mainstream diabetes service support); None of the participants was able to count carbohydrates independently or had difficulty with insulin administration and BGL monitoring limiting diabetes self-management; Parents reported a lack of access to insulin pump therapy and CGM, leading to reliance on parents and carers outside the home due to the complexity of accessing direct NDIS health support, lacking intellectual disability-specific diabetes supports; Parental support for diabetes care, written guidelines, continuous glucose monitoring, insulin pump therapy, funding for carers outside the home and diabetes training are facilitators of self-management.

	Research question	Research Aim	IF Definitions	General Findings
McDonald et al. (2016)	Article describes how a funding model designed to support and encourage self-determination (i.e., the NDIS) could undermine therapeutic practices that are founded upon the very same thing (i.e., contemporary therapeutic approaches in Early Childhood Intervention [ECI]).	This article highlights the potential for a consumer-centred model of funding (NDIS), to undermine therapeutic approaches in Early Childhood Intervention (ECI) that facilitate self-determination amongst young disabled children with developmental delay and their families.	Individualized funding enables disabled people to purchase their own services (consumer-centred disability funding schemes or CCDF schemes), rather than funding government and nongovernment organizations for that purpose (commonly referred to as block funding).	Self-determination for young children is unrealistic/inappropriate, as young children cannot be solely responsible for determining their fate; Behavioral characteristics associated with self-determination are not a natural, inevitable outcome of childhood; Children need to have opportunities to be self-determining, and adults can support young children to build the foundations of self-determination by developing the capacity of parents/ family members to provide children with learning opportunities in everyday environments; Contemporary therapeutic approaches appear to be effectively developing the foundational skills of self-determination over traditional approaches which do not emphasise parent/family involvement; Self-determination relies on collaborative relationships between families and professionals facilitating self-determination in the child by coordinating efforts to embed complementary activities into existing routines at home, at school, and in the community; Contemporary approaches situate parents as active participants and collaborators in treatment and experts on their individual child.

	Research question	Research Aim	IF Definitions	General Findings
McGuigan et al. (2016)	Research aimed to discover the impact of DP on service users; Participants were asked about their experiences of the DP programme and its impact.	To examine the impact of DP on service users in a large Health and Social Care Trust, in Northern Ireland receiving care or support at home and highlight potential barriers to uptake of DP.	Direct Payments (DP) is a service user-implemented scheme in which the individuals assessed as needing personal, social or health-related care services are given cash payments, allowing them to buy in services they require. Previous research indicates DP offer the user greater control and flexibility over their care.	Findings show service users are generally satisfied with most aspects of DP; Difficulties exist around provision of information, support, user responsibilities and public awareness; For the majority, DP offers a flexible care option controlled by the user, to deliver a user-specified, tailored programme of care that could not be facilitated under any other current care provision offered by the Trust; A lack of standardisation of information, support and advice offered appears to create a difference of opinion about user experience.

	Research question	Research Aim	IF Definitions	General Findings
McNeill & Wilson (2017)	Study identifies the demographic characteristics of Direct Payment recipients, the nature of care and support provided, and trends in take-up rates to evaluate recipients' perceptions of what features of Direct Payments are working well and what aspects could be further developed; Study examines the implications of the findings for parents/carers and the strategic challenges for agencies seeking to further develop Direct Payments as a method of meeting health and social care needs.	This study, which focused on the experiences of parents/carers of disabled children in one of the five health and social care trusts in Northern Ireland, highlights both opportunities and concerns about using Direct Payments; The main aim of this research project was to investigate parent/carer experiences of using Direct Payments in providing care and support services to disabled children in the Northern Health and Social Care Trust (NHSCT) in Northern Ireland.	Direct Payments (DP) have become a cornerstone of the government's personalisation agenda aimed at improving user choice and facilitating self-directed support and individual control over services.	Findings highlight problems with inadequate information, administrative support, funding arrangements, and safeguarding vulnerable children; Some respondents had more than one service, but short breaks/respite care both away from the home environment and in the families' home was the most commonly provided service; 52% felt verbal information was good; 40% felt written information was good; 28% felt both written and verbal information was poor; Some commented on the lack of information when they first took up DP and others were critical of the lack of clarity and succinctness in the written information provided by the trust; Respondents reported using a range of methods to recruit employees/carers for their children; 56 % recruited on the basis of word of mouth and/or recommendation. 36 % had recruited individuals who previously knew their child through school. 20% advertised in newspapers and local bulletins; 72% employed a family member; Flexibility, choice, control and the opportunity to provide targeted support to suit their child's needs were among the most important advantages of using DPs; Findings suggest safe-guarding might be a particular concern for parents of disabled children using DPs.

	Research question	Research Aim	IF Definitions	General Findings
Meltzer & Davy (2019)	This paper reports on a content analysis of the NDIS Act, NDIS Rules, Operational Guidelines, and Price Guide to examine the extent to which the scheme's conceptual foundations and funded supports in individual plans enable it to support relationships.	This paper focuses on the opportunities presented by the NDIS to positively impact on the social connections and relationships of disabled people.	With personalized planning and individualized funding, the NDIS aims to enhance choice and control and broaden the opportunities and supports available to foster the participation of disabled people in social, economic, and community life; Individual budgets enable participants to purchase the services they need. A person-centered planning process aims to identify the individual's goals and the supports they require to achieve those goals and determine the amount of individual funding they will receive. Personal agency is understood to be central to the planning process, reflecting key principles within the UNCRPD such the right of disabled people to exercise self-determination and make decisions about their own lives.	Findings highlight the benefits of direct payment and individual funding schemes: enhanced choice and control over services; increased satisfaction with services; and increased participation in broader social and economic activities; The presence of supportive interpersonal relationships is critically important to ensuring that people can access these benefits; Positive relationships with family members, friends, support staff, and advocates can be a determining factor toward people's ability to exercise choice and control, negotiate the service and funding system, and participate in community life; Disabled people without supportive interpersonal relationships may face barriers within these service/funding arrangements, particularly those with high and complex needs; Content analysis of main NDIS documents show little conceptualization of the interpersonal relationships as sources of connection, reciprocity, and identity; Relationships are conceptualized as a source of practical support and care that mitigates the cost of formal services provided through NDIS funding.

	Research question	Research Aim	IF Definitions	General Findings
Mitchell (2012)	This paper aims to summarise the literature on self-directed support (Self-directed Support) in transitions for disabled children and young people moving from children to adult services.	The aim is to summarise the literature on self-directed support (Self-directed Support).	Self-directed support (Self-directed Support) is a major policy initiative being introduced by the Scottish Government to promote personalised services and to encourage a more equal partnership between professionals and those in need of support; Direct Payments (DPs) have been available in Scotland to disabled people of age groups since 2001; Self-directed Support builds on the platform provided by Direct Payments legislation and the rights enshrined in the Disability Discrimination Act (Scotland) 2003. It is used instead of, or in addition to, support services that the local authority might otherwise have provided. Self-directed Support is at the centre of the Scottish agenda to promote personalised services.	Findings asserts that Self-directed Support has the potential to encourage creativity at an individual and organizational level that can result in integrated service improvement; Transitions for disabled children and young people are recognised as being problematic; Effective multi-agency working is seen as being essential to achieving good outcomes, but collaborative working in transitions is challenging due to the boundary issues between child and adult services, the diverse range of agencies involved, and the challenges for young people and their parents due to issues of maturation; Self-directed Support in Scotland, while promising greater choice and control for service users, presents potential pitfalls and benefits for disabled young people and their families, and the organizations involved; Self-directed Support has both the potential to fragment services if agencies compete to protect budgets and power, and the capacity to improve integration if a person-centred approach is fostered.

	Research question	Research Aim	IF Definitions	General Findings
Mitchell (2014)	Article explores the phenomenon of informed choice for young disabled people around significant life events.	This paper explores informed choice (a key component of self-directed support and personalised services) for disabled young people in transition by means of secondary analysis of archived qualitative interview data using a thematic network approach.	Self-directed support (Self-directed Support) includes informed choice for personalised services.	Findings provided insights into the roles of parents, professionals and how information is used in informing choice for disabled young people. The findings identified facilitators and barriers to informed choice for disabled young people in transition. Choice-making was seen to involve both rational and emotional components in which experiential knowledge was highly valued. The role of professionals was perceived as absent or unhelpful; The opportunity for supportive and informative relationships between workers and disabled young people was possible in situations where longer term and consistent contact was evident; The study reported that the process of making significant choices was shared between the young people and parents, but this may be biased in favour of parental involvement in supporting choices. Only one of the six young people in this secondary study commented on the role of wider social networks such as extended family or friends in choice-making activity.

	Research question	Research Aim	IF Definitions	General Findings
Mitchell (2015)	The purpose of this study was to explore the concept of informed choice in the context of Self-directed Support for young people with disability in transition to inform emerging policy and practice.	The objective of this qualitative study was to explore the concept of informed choice in the context of self-directed support (Self-directed Support) for young people with disability in transition from child to adult services.	Self-directed support (Self-directed Support) is a major policy initiative introduced by the Scottish government to promote personalised services by redefining the relationship between the citizen and the state regarding social care supports. Informed choice is one of the underpinning principles of the Social Care (Self-directed Support) (Scotland) Act 2013.	Findings include hypotheses concerning the facilitators and barriers to informed choice for disabled young people with disability. Factors facilitating informed choice included supportive family and professional networks, advocacy, accessible information and experiential knowledge; Informed choice requires accessible information and individuals being able to express opinions within supportive social networks of parents and professionals. The mechanisms that get in the way of informed choice include low expectations of parents and professionals in relation to young people's abilities, a bias towards the status quo of supports and services, organizations that are characterised by bureaucracy and a lack of collaboration, especially between child and adult services. The study found that feelings and rational thoughts were involved in choice making; This suggests that social capital may have a significant impact on informed choice; Strong family networks in rural areas were seen as a solution to the lack of service providers, but there are dangers that bonding social capital in family networks that are deficit-focused and risk-averse could restrict informed choice for young people with disability.

	Research question	Research Aim	IF Definitions	General Findings
Nieboer et al. (2011)	Study established the effects of providing decision-support information only (services/ quality indicators) and providing a combination of information and personal decision-making support (counselling/peer meetings) on the choice process and satisfaction with care.	Due to a lack research on the decision-making processes and on how these processes are influenced, this study employs real-life decision choices to young people and their parents/carers.	Personal budgets are not explicitly defined.	Forms of support affected the choice process, but did not affect satisfaction with care. Decision-support information combined with personal decision-making support led to less frequent switching of care providers and more satisfaction with choice information; Parents make limited use of online decision-support information, but did use decision counselling; Findings showed that forms of support positively affected the choice process. Fewer parents than control group parents switched to another care provider and more parents were satisfied with the availability of information; Parents who received counselling sought an appropriate disability service provider purposefully; Parents who were given only online decision-support information sought information from fewer disability service providers, but were satisfied with the availability of choice information than parents in the control group; The majority of all parents were satisfied with the usefulness and availability of information; Parents were generally satisfied with the care provided and these forms of support did not affect satisfaction with care received from the disability service provider they chose.

	Research question	Research Aim	IF Definitions	General Findings
Nucifora et al. (2022)	Article examines parents' perceptions of adulthood for their child with an ID, as well as their experience of the child's transition to adulthood. Reflections on the impacts of the NDIS were also invited to provide information about parents' perception and experience of the transition to adulthood by their child with an ID.	This paper aims to report on parents' perception and experience of adulthood for their son or daughter with an Intellectual Disability (ID).	The NDIS provides financial support for personalised plans that allocate funding according to different categories of need (i.e., transport, core supports, capacity-building). This is a more flexible funding model than the previous State-based but Federally-funded arrangement whereby services (i.e., therapies) were only accessible to people with intellectual disability through specific organizations.	Findings show that perceptions of adulthood encompassed independence and normality categorised under government services, responsibility and social supports; Parents reported that their child's capacity to make decisions was linked to their child's level of independence, and whether they viewed them as an adult. Parents reported their experiences with government services impacted their wellbeing; Education Services (ES) had been experienced as both beneficial and disadvantageous; Participants whose child had attended special school reported this experience as favourable. Parent commentary centred the transition to the NDIS. All reported accessing or having applied to access NDIS funding. Parents perceived the transition to the NDIS as a positive change, with a few describing a lack of support; Parents suggested that the NDIS had provided more funding flexibility, reducing parent-carer responsibility. The flexibility of service selection meant more power to assert their view of adulthood, and the goals they and their child had, in contrast to government-delegated service; There were suggestions that the NDIS is more complicated once a child transitions to adulthood.

	Research question	Research Aim	IF Definitions	General Findings
Priestley et al. (2022)	Article discuss parent/carer experiences of raising an autistic children and how individualized funding has impacted them.	The purpose of this research was to explore how individualized funding has impacted on mothers raising autistic children and their wellbeing.	Individualized funding is meant to promote autonomy for disabled people and their family to make decisions about services to meet their needs and is a consumer or client-led approach to enable disabled people to exercise their rights which have been previously neglected and marginalised.	Key findings indicate that caring for an autistic child has an ongoing negative impact on mothers' overall wellbeing and the individualized funding did not seem to ease the stresses of caring; Two major themes have been identified as: 1) the overall impact of caring for an autistic child, and 2) the disability system does not support mothers' wellbeing adequately; Cultural norms and societal motherhood beliefs have been strongly linked to the expectation of the good mother discourse, which was woven throughout the discussions of the participants' interviews.

	Research question	Research Aim	IF Definitions	General Findings
Prowse et al. (2022)	What is the lived experience of parenting or caring for a person receiving services under the NDIS in rural Australia?	The purpose of this study was to investigate the lived experience of parenting or caring for a disabled person receiving services under the NDIS in rural Australia.	Individualized funding is not directly defined in the article but seen as a NDIS policy.	More than a disability described the absence of understanding of family and carer challenges when NDIS plans were designed and implemented; Fighting for funding and services described that while the NDIS increased funding support, parents/ carers experienced limited support navigating the NDIS; Cold as Ice encompassed parents' and carers' descriptions of their relationship with NDIS staff; Challenges were impacted by limited choice and available health service providers in rural areas; Participants shared positive experiences regarding access to funding, but encounters with the NDIS were negative; Funding was characterised by absent of understanding/inclusion of parents/ carer needs; The NDIS presents challenges regarding equity of access in rural areas; Despite increased funding, participants and parents/carers experienced difficulty accessing support; Participants reported limited choice in service providers, long waiting times, and lacking specialist experience and skills. Self-management of funding can reduce the incidence of unmet demands but participants usually lacked time, knowledge and skills to self-manage the NDIS plans.

	Research question	Research Aim	IF Definitions	General Findings
Ranasinghe et al. (2017)	This study is an evaluation of parents' feedback regarding their experience in registering their child with the NDIS, accessing the NDIS funding and their ability to communicate with the National Disability Insurance Agency (NDIA).	To evaluate parents' feedback regarding their experience in registering and accessing funding with the NDIS and communicating with the NDIA.	Individualized funding and early intervention focus on funding early intervention support for children with disabilities, in a family friendly and customised funding arrangement to meet the individual needs.	85.7% parents reported having no difficulty with the NDIS registration process; 64.3% reported having no difficulty accessing funding; 61.9% reported that it was easy to communicate with the National Disability Insurance Agency ; 61.9% were satisfied with the NDIS and National Disability Insurance Agency ; The majority of the children referred to the NDIS from the Child Development Unit were diagnosed with ASD; Parents were satisfied with the processes required to register, access funding and their ability to communicate with the National Disability Insurance Agency ; Families want more state-specific information regarding service providers on the NDIS website and more personalised interaction with the National Disability Insurance Agency ; 90.5% parents provided information about the time between registration with the NDIS and first contact by the National Disability Insurance Agency ; 81.6% were contacted within 3 months of registration, ranging from 2 days to 13 months. The time period between the registration and the approval of funding ranged from 1 week to 1 year. Of the 35 children who received funding approval, the majority (78.8%) received their funding approval within 10 weeks.

	Research question	Research Aim	IF Definitions	General Findings
Robinson et al. (2016)	This article focuses on the experience of children and young people with disabilities and their families in which they had a case manager and some discretionary funding. It analyses the impact on their choice and control over self-directed support when these mechanisms are combined, in both facilitative and constraining ways. It focussed on examining the caseworker impact on facilitating support when the funding package is small allowing a limited range of choices; Can case management contribute to effective use of small self-directed support packages for people with disabilities?	While self-directed support for people with disabilities and their families represents a welcome shift toward self-determination and increasing control, the risk of managing with insufficient funds remains; This article examines whether different types of case management can mitigate that risk by providing support when people have only a small direct funding package.	Self-directed support (Self-directed Support) represents a paradigmatic shift in the way people with disabilities organize the assistance they may require to meet their daily living needs and aspirations. In the best case, it brings together personalized services and a more equal partnership between people in need of support and professionals, and emphasizes choice and control with a focus on outcomes; A range of permutations of self-directed support operates internationally, variously known as personalization, individualized funding, and personal budgets.	Themes emerged related to people's choices/aspirations; the empowerment of service users; self-direction of budgets/funding; the role of families and informal supporters; community inclusion; social and economic participation; organizational approach and capacity; planning and case management; the challenges of the pilot to families; the challenges of the pilot to young adults; The quality of the relationship with the case manager was clear; families and young adults spoke at length about how the interpersonal and relational qualities of the case manager relationship made a difference to both their feelings about the program and their outcomes; Participants were motivated by case managers who demonstrated respect and a rights-based approach to support, and took a proactive approach to developing plans for self-direction; Case managers were guided by participants, offering new opportunities that participants were not aware of, while at the same time confirming and endorsing the decisions and choices made.

	Research question	Research Aim	IF Definitions	General Findings
Russo et al. (2021)	How do parents of children with complex health needs experience their engagement with the Australian NDIS?	This systematic review of literature presents research describing the experiences of parents of children with disabilities in accessing and participating in the NDIS and makes recommendations to National Disability Insurance Agency in better supporting new participant families.	An individualized funding scheme delivered within an insurance model; Its central tenet is choice and control for persons with disabilities; Under NDIS, a person with disabilities (or their agent) may request any support or equipment that meets the reasonable and necessary test; Individualized funding packages for disability supports and services have been available to eligible Australian children under the Better Start for Children with Disability (Better Start) and Helping Children with Autism (HCWA) programs; The NDIS will progressively replace these programs as children join the Scheme. Traditionally block-funded supports for children with disability will also be replaced as the NDIS rolls out.	7 articles retained were broad in focus; Four areas of focus: a) access to information/services; b) system complexity; c) family self-advocacy; d) effective support systems; Dew et al. (2013): Positive findings in greater access to choice of therapy; negative findings in limitations of therapies available, complexity of self-managing packages, and higher costs; Howard et al. (2015): Identification of policy assumptions about parents/carers impacting on NDIS in regional towns; Johnston et al. (2013): Challenge of reliable information online; importance of skilled case manager; challenge of jargon and clarity of information; Ranasinghe et al. (2017): Mixed experiences in accessing funding, communicating with the National Disability Insurance Agency , and satisfaction; Sheppard et al. (2013): Focused discussions concerning relevance, relationship building and choice; Simpson et al. (2016): Perceived transfer of responsibility onto families; importance of preparation in making a case for resources; difficulties in working with professionals; information overload; Tracey et al. (2018): Importance of experiential knowledge of parents; challenge of sourcing reliable online information; importance of early intervention.

	Research question	Research Aim	IF Definitions	General Findings
Salvador-Carulla et al. (2023)	This paper compares the evolution of psychosocial care provided by the NGO sector in two health jurisdictions in Australia over 4 years, pre and post NDIS; What is the availability of psychosocial care in the ACT and Western Sydney (WS) before and after the implementation of the NDIS? What are the differences and similarities in subsystem evolution of psychosocial care between the two regions? Do these longitudinal and cross-sectional data support the transformation of the disability sector in an increase of offer and scaling up of service availability?	This paper compares the evolution of the psychosocial sector in two Australian regions pre and post introduction of the NDIS to see the extent to which the NDIS has reduced unmet needs requires a comparison of the prior delivery system and the changes incurred over time.	Personalised funding model presents a shift from established block funding and service contracting model to one providing consumers with their own packages and capacity to purchase services directly; Individualized funding is intended to transform the disability sector into a more competitive market, where individualized funding would attract new services in a market matching demand with appropriate, affordable supply.	Authors identified different evolutionary pathways in the two regions. Service availability increased in Western Sydney but decreased in the Australian Capital Territory. The diversity of services available did not increase in either Primary Health Network 4 years after the reform. Many services were experiencing ongoing funding uncertainty; Overall service availability in the NGO sector declined in ACT during the period of study, but increased in WS; This trend in service availability was not uniform across age groups: services for older adults decreasing in WS, while in ACT those for children and adolescents increased modestly; Overall number of service providers in ACT decreased from 28 in 2016 to 21 in 2020. In WS, 22 service providers were identified in both periods; The decrease in availability of psychosocial care in ACT was reflected in a decline in its diversity; The increase in available services in WS did not correspond with a significant increase in diversity; A high number of services experienced organizational vulnerability 4 years after the implementation of NDIS, indicating distress due to a lack of capacity to set up a sustainable business plan.

	Research question	Research Aim	IF Definitions	General Findings
Simpson & Douglas (2016)	What is the impact of Self - directed funding (SDF) support models on families with children with disabilities? What is the research-based evidence that underpins SDF support models for families with children with disabilities?	This study systematically reviews the existing academic literature to examine self-directed funding (SDF) models specifically in the context of families with children with disabilities.	Self-directed funding (SDF) refers to individuals being assigned responsibility for managing a personalised support package that provide greater choice and greater flexibility and is also referred to as Cash for Care and Individual budgets.	Families reportedly experienced benefits of greater involvement in decision-making for their child in 8 of the 12 studies; 7 of the 12 studies reported an improvement to the well-being and quality of life either for carers or the children themselves; 8 of the 12 studies reported that families using SDF models had some positive outcomes in their social lives; 6 of the 12 studies identified that the administrative process of managing SDF was a source of stress for families; 6 of the 12 studies reported that while SDF offered families greater flexibility in how to spend funding, there was a very limited number of service options to spend it on; 4 of the 12 studies discussed how the positive outcomes associated with SDF were dependent on contextual variables, including socioeconomic status, minority group status and geographical location, with poorer families, minority groups and families based rurally achieving poorer outcomes using SDF models.

	Research question	Research Aim	IF Definitions	General Findings
Small et al. (2020)	This paper explores the expectations and experiences of carers in regional areas of New South Wales (NSW) during the first year of transition into the NDIS; It examines the transition adding to the complexity of the regional and rural context, as living in a regional area may impact the capabilities of PWD and carers that increases the vulnerability of these groups.	This paper aims to explore the implementation of new social and financial policy reforms aimed at transforming the disability sector. Authors explore the experience of carers and evaluate how this sector may have become more exposed and vulnerable as a consequence of the NDIS using the capabilities and vulnerabilities frameworks.	Individualized funding is part of the NDIS and refers to a funding model for PWD, giving them choice and control over their support services; IF is centered on participants getting access to money rather that setting capacity-building goals and personal challenges that are drivers of a fulfilling life; As a capacity-building model with choice for services and activities resting in the hands of the end-user this new process and mindset requires behavioral change for PWD, carers and service providers.	Findings show that there are many ways PWD and carers are experiencing increased levels of vulnerability because of their capabilities; There is increased vulnerability in the intersections between PWD/carers' inherent nature, the disruption to vital social relationships and conflicting values and interests of stakeholders and the complexity of situational policy changes; The inherent traits for PWD that increased their vulnerability were social, intellectual and physical; Many respondents reported their PWD did not know that they were disabled or that they needed extra support; PWD being transitioned into relationships with new carers were more vulnerable because new carers could misinterpret the PWD's attempts to communicate leading to a lack of responsiveness to needs and accidents; Many carers reported their PWD to be very social and trusting; this inherent positive characteristic led to reports of potential abuse from carers as the PWD did not have the capability to assess risks in the relationships.

	Research question	Research Aim	IF Definitions	General Findings
Smethurst et al. (2021)	What are the experiences of parents of children who have been NDIS participants over the past 12 months? How do parents reflect upon previous funding systems since utilising the NDIS? Based on parents' experiences, what are some recommendations that they believe the NDIS should incorporate to improve service delivery?	The aim of this research was to explore the experiences of families with a child with cerebral palsy (CP), who have been in receipt of the NDIS for 12 months, comparisons to previous funding systems, and recommendations for the NDIS going forward.	Personalised funding is to provide disabled people with more choice and control over decision-making that impacts on the services they utilise, therefore increasing opportunities for economic and social participation; Scheme participants (children and adults) meet with a NDIS planner, and an individualized plan is developed to meet the participant's goals. Plans may be approved by the National Disability Insurance Agency , and some participants receive access to funds quickly. A longer administrative process is required for more extensive plans; Once approved, scheme participants then have choice within an open market of suppliers including allied health and equipment providers.	Families reported challenges navigating the NDIS including administrative challenges and extensive wait times for assistive technology, as well as gratefulness for increased opportunities for support; Three overarching themes were derived from the data: Equipment impacts on all areas of life; Frustration navigating the NDIS; Gratitude, hope and suggestions; Outcomes suggest allied health practitioners might consider how their role in service provision may change in accordance with the implementation of the NDIS; There is a clear role for occupational therapists in supporting families through the navigation of the NDIS, so that families and their children experience greater choice and control; Findings suggest occupational therapists must continue to provide services to children and their families using a family focused framework as participation for the child and family are interconnected, reliant on assistive technology and appropriate supports for the family; It should be a priority to assist families with temporary assistive devices to prevent injury from ill-fitting and outdated equipment, as well as exclusion from every day activities.

	Research question	Research Aim	IF Definitions	General Findings
Swenson & Lakin (2014)	How do we create fair, effective, and cost-beneficial approaches to supporting families given the variety of disabilities and of families, and given the need to appreciate and leverage the efforts families make to fulfill societal promises of family lives for children and non-institutional lives for all citizens (Olmstead et al. v. L.C. et al., 1999)?	This article offers a modest commentary on how in the midst of such complexities our society can develop fair, effective, and cost-beneficial approaches to supporting families and their individual members.	No definition explicitly provided.	Findings would be useful to social scientists or human services professionals involved in promoting healthy behaviors or desired outcomes among all families, not just families with a disabled member; Key segments may have characteristics that are especially important for a particular service; Implementers of the Affordable Care Act found that the people without bank accounts will be limited in their ability to pay for health insurance through exchanges that only accept checks; Implementers identified key segment to target for enrollment in the health care exchanges; Segmentation is useful beyond the design of promotional strategies to be used to design products and services responsive to the needs/wants of particular groups of consumers, enabling manufacturers/ marketers to manage product and service development to maximize profit; Assistive communications and management technologies are often thought of as the keys to a better future for disabled people and their families; Technological innovations are not available equally to all segments of the population, so knowledge of segments and prediction of behaviors might be a necessary precursor to government investment in technology.

	Research question	Research Aim	IF Definitions	General Findings
Thompson (2022)	This article examines the shortcomings of the review process that disabled persons may encounter when they disagree with a decision made by the National Disability Insurance Agency , the body administering the NDIS, relating to their funding; This article explores the significant rise in NDIS reviews, the factors contributing to this, and concludes that the weaknesses of the NDIS review process negatively impact disabled persons and interferes with realising certain rights in the UNCRPD.	To provide a deeper knowledge of the human rights weaknesses of the NDIS review process and how this impacts disabled persons.	Individualized funding refers to funding the NDIS provides to support meeting disability-related needs of Australians with a permanent and significant disability; or developmental delay if under the age of seven. Key objects of the NDIS Act include: placing persons with disability at the centre of decision-making; recognising right to choice and control; providing reasonable and necessary support to maximise independence, social and economic participation, and inclusion in the community. When a person meets the access criteria for the NDIS, they are referred to as a participant and they receive a plan which specifies the funding provided for reasonable and necessary support.	Findings highlight inconsistencies with the CRPD article 13 Access to justice, article 12 Equal recognition before the law and article 9 Accessibility; The article identifies shortcomings of the NDIS review process and lack of transparency; cumbersome process and reduction of choice and control as stipulated under the NDIS; Advocacy groups highlight that due to the complexities, frustration and stress many participants give up and do not request a review to the AAT; lack of support to pursue the AAT process for disabled people.

	Research question	Research Aim	IF Definitions	General Findings
Timberlake et al. (2014)	The research questions of interest here were: What characterizes parents' descriptions of choice? How do how parent perceptions of choice vary within the participant directed model? What do parent perceptions of choice reveal about the participant-direction requirement of the children's waiver program?	This study investigated families' experience of choice within a participant-directed Medicaid waiver program for young children with autism; The aim was to understand how parents experienced participant-direction, particularly the responsibilities of choice, under the Massachusetts Children's Autism Waiver program. As family-centered approaches are now considered the ideal for medical and educational services and supports, the participants in our research provide important lessons for clinicians, supervisors and researchers about how choice, respect and partnership is experienced by a sample of families.	Participant-directed service model refers to participant-direction in program design where individuals and/or family members determining the selection and distribution of their services and providers; Participant-direction in long-term care and disability supports for adults has included finding, interviewing and hiring in-home or personal care staff, managing a budget, and working with a team of therapists, a fiscal intermediary, and a support broker or case manager; Participant-direction has become widespread in long-term care supports for adults; Less is known about participant-directed program models for children.	Key findings included families' preference to hire providers with whom they have a prior relationship, parent empowerment and differences of opinion about parents as teachers; Professionals implementing participant directed service models could benefit from understanding the strong value parents' placed on the personalities and interpersonal skills of providers; Parents' descriptions of directing rather than accepting autism services revealed increased confidence in ability to choose and manage the multiple components of their children's HCBS autism waiver program; Findings revealed families overwhelmingly reported positive perceptions and an appreciation of choice, but exercised their choice-making authority in different ways with different levels of confidence and assertiveness; Five themes emerged related to families' experience of choice: choosing what you know; the importance of interpersonal characteristics; varying degrees of readiness and ability to participate; parent advocacy and empowerment; parent as teacher.

	Research question	Research Aim	IF Definitions	General Findings
Tracey et al. (2018)	What sources do parents use to access information about their child's disability? What sources do parents use to access information about how to use individualized funding schemes? What perceptions are held about the utility and value of these sources?	The research used a two stage, mixed method sequential approach (with 291 parents surveyed and 56 parents participating in focus groups) to determine how parents acquire information to enhance their understanding of their child's disability and determine how to use an individualized funding scheme to benefit their child and family.	Individualized funding schemes or packages allocate funds to individuals to spend on disability support needs and is a portable package of funds allocated for a particular person who is supported to choose how to spend it on their disability support needs; One of the fundamental goals of individualized funding is to establish the individual, and parents of children with disabilities, as a full and active social and economic agent.	Parents attested to the importance of person-to-person communication and valued information that originated from other parents of a disabled child and from professionals who knew their child; Quantitative findings from phase 1 support parents' preferred channels of information when it comes to obtaining information about their child and IF; In phase 2 3 themes were identified: the importance of person-to-person communication, the value of early childhood intervention services and a role for the internet; Parents reported accessing information in diverse formats; Parents wished for information to be personalised and targeted for their purposes; Parents made subtle references to wanting accurate, consistent and timely information; Parents voiced desires to obtain information from individuals who had earned credibility and trust; The principle of independent source was less important than trusted sources; ESL and Aboriginal parents attested to the need for culturally appropriate information; Parents highlighted the shortcoming of the internet.

	Research question	Research Aim	IF Definitions	General Findings
Venning et al. (2021)	This paper synthesises and critiques 35 appeals to the AAT and one Federal Court Appeal to make explicit the decisional ambiguities and contestations in the scheme and the values and priorities that are currently dominant in the allocation of reasonable and necessary support. This in turn is used as a basis for a discussion about the operation of rights in the scheme and what counts as legitimate support.	The aim of this study is to review administrative appeals tribunal (AAT) appeals.	Individualized funding refers to funded support packages, a core platform of the NDIS, that entitles all Australians who acquire a disability before 65 years of age to non-means-tested services; The rights-based universal approach of the scheme is an obvious contrast to the historical state-based targeted systems, which had perpetuated gross neglect and inequities.	The position in this paper is that this test of reasonable and necessary when determining funded supports, raises value dilemmas for government and citizens; Two prominent storylines pertained to the ambiguities and contestations about reasonable and necessary support, and the associated ideas inherent in the justifications for decisions; There was a prominence of conflicts about the responsibilities for provision of support; 7 appeals reveal dominant expectations about the amount of care and type of care that a family should provide and what the National Disability Insurance Agency should provide; Appeals demonstrate that the responsibility of the family to provide support is maintaining the sustainability of the scheme; There continues to be tension around the boundaries of the fundamental responsibilities of the funding systems and the presumed responsibilities of families; There was an emphasis on the legitimacy and credibility of evidence provided from applicant and respondent; Appeals indicate that expert and experiential evidence may be weighted differently; National Disability Insurance Agency rebuttals were: requested supports were beyond ordinary life requirements; were not linked to disability.

	Research question	Research Aim	IF Definitions	General Findings
Welch et al. (2012)	This research examines the characteristics, circumstances and experiences of families who use DPs to fund short breaks with those who use short breaks funded in other ways.	This paper is concerned with exploring whether the characteristics of families using DPs to fund their short breaks differ from those using directly delivered services. Authors examined families' motivations for and experiences of using DPs.	Direct payments in the UK are an example of a growing body of cash for care initiatives in a number of countries; DPs are cash sums paid to people who have been assessed as being entitled to services to enable them to purchase these services for themselves.	Direct payments can bring a number of important benefits for families with disabled children; Use of DPs can present busy families with further tasks, responsibilities and concerns. Families with disabled children using short breaks, mean DPs are not distributed equitably. Systems for using DPs need to be simple, explicit and flexible and families need appropriate support; reducing inequitable take-up will require provision of support which is individualized or at least tailored to the needs of different groups of families. Such measures will be resource-intensive and may necessitate a trade-off between equity, efficiency and effectiveness; DPs cannot yet be relied upon to produce either a pool of suitable care workers or a marketplace of short break provision and it seems likely that statutory agencies will need to retain some strategic responsibilities for ensuring availability, sufficiency and quality of short breaks however they are funded.

	Research question	Research Aim	IF Definitions	General Findings
Whitaker (2015)	The paper explores the discursive change from early help to intervention as a shifting conceptualisation of parents and the turn away from family support towards a focus upon individualized commissioning to meet needs.	The purpose of this paper is to explore the changing meaning of personalisation from the New Labour era of bespoke, integrated family support to the more recent implementation of personal budgets for disabled children to deliver choice and control.	Personal budgets are connected to children's services through personalisation programmes providing universal access and responsive and tailored help for families; This 2005 focus reflected a managed budget; The Budget Holding Lead Professional (BHLP) would be tasked with working with families holistically; The lead professional had access to a defined budget for the family; Pilots were set up to see if managed budgets enabled swifter access and better coordination of support; A new policy surrounding personal budgets in children's services emerged in 2007 to trial individual budgets giving families and disabled young people real choice and control to design flexible packages of services; The Children and Families Act 2014 continued rights of families of disabled children to request a personal budget to produce integrated support plans.	Findings from children's disability social workers reveal the frontline and familial challenges of delivering choice and control in a climate of austerity and child-centrism. Salient points for integration around families and between organizations as personalisation narrows in scope are considered; DPs offered scope to families to employ someone of their own choosing who would be available when they needed and was someone the child and family could maintain a continuous relationship with; Personal budgets were referred to as belonging to the child. In place of a family programme of support, there tended to be a singular focus upon meeting the child's needs whereby the parent was situated as a responsible partner for delivering upon identified outcomes for the child; Self-directed support reveals itself to be individualized public funding: funding that belongs to the state, but is spent with the consent of the individual. Social workers constructing the family as unreliable consumers re-validates gatekeeping roles, even more so at a time of austerity.

	Research question	Research Aim	IF Definitions	General Findings
Whitburn et al. (2017)	This paper explores the experiences of a small group of families in Australia in relation to recent reform to disability policy by way of the NDIS.	The paper focuses on the extent to which the NDIS articulates inclusive opportunities for children and young people with disabilities, particularly in relation to facilitating access to education; It analyses discursive constructions of disability and education in and through the NDIS and explores how policy shapes disabled subjects through education policy. Authors' focus is to explore the possibilities, limits, enunciations and silences of the policy as it is enacted in the lives of young people and their families who both access the scheme and attend compulsory schooling.	Individualized funding under the NDIS means people with disabilities with individual plans can purportedly exercise full choice and control over individualized funded support packages; They have the freedom to move away from rehabilitation and traditional disability service delivery if desired, and are encouraged to do so as appropriate.	Interview data illustrated families' expectations of the scheme and latter-day experiences, coercions and negotiations highlight the tensions that exist for scheme participants who draw on its provision to support their education; As the impetus for the new NDIS policy is to support the independence and social and economic participation of disabled people findings are connecting to the enunciations and silences that accompany the policy (its engendered practices and effects) on the emergent disability assemblage; Once entering the initial planning phase, families realised that provisions may not match expectations; Planning was a confronting activity; Despite increased control, most participants of expressed ambivalence about the detachment of the NDIS and education; Guidelines exist that determine the NDIS's responsibility in combination with other service systems, but a disconnect is apparent confounding participants. Provision of in-school support remains the responsibility of the education jurisdiction which misses the opportunity for the NDIS to develop a coordinated program that would incorporate all of a child's needs.

	Research question	Research Aim	IF Definitions	General Findings
White et al. (2021)	Study used a mixed methods approach to explore the process and early outcomes of the NDIS Access Program for Kimberley Aboriginal people and organizations. A qualitative descriptive approach was used to engage Access Program staff respondents around the following four topics: engagement with potential NDIS participants; facilitating next steps with potential NDIS participants; experience of the program's outcomes; and barriers to and enablers of the program. A quantitative component descriptively analysed participant engagement data collected prospectively by Access Program staff during the early implementation phase of the project.	This study explored the process and early outcomes of work undertaken by a program to increase Aboriginal people's awareness of, and access to, the NDIS; This aims to explore the work being undertaken by Kimberley Access Program staff who are tasked with identifying and connecting eligible Aboriginal community members to the NDIS. Authors aim to contribute to an understanding of the challenges, successes and future directions of ensuring equitable access to the NDIS for Aboriginal people in the Kimberley.	Launched in 2013 and progressively rolled out since 2016, the NDIS was developed to provide a better funding model for all Australians with permanent and significant disabilities. The NDIS is a national system for allocating funding for disability support services to individuals based on their needs; The NDIS restructures funding from services to individuals promoting greater choice and control.	Theme 1: Perceptions of disability: disability is often not recognised by the individual or by the individual's family group. High levels of resiliency and normalisation of the disability were raised as contributing factors; Some have fear and stigma associated with disability; disability often had a different meaning within Aboriginal communities and not seen as central to a person's identity; Theme 2: Engagement for NDIS access; the Kimberley region experienced a lack of disability support services. This complicated people's engagement as trust had been broken; Staff discussed positive impacts of Aboriginal Community Controlled Organizations delivering the Access Program as trusted, culturally appropriate, and holding pre-existing relationships with clients; Theme 3: The Importance of getting it right: powerful advocacy for the region as EACPs discussed being an important source of contact for the National Disability Insurance Agency to clarify issues in applications to facilitate meeting access and avoid lengthy decision-making delays; Access Program staff still reported the NDIS access pathway was challenging due to bureaucratic inflexibility; National Disability Insurance Agency resources were not culturally appropriate for Aboriginal people in the Kimberley.

	Research question	Research Aim	IF Definitions	General Findings
Yates et al. (2021)	How well did Australia's NDIS support remote learning for students with disability during COVID-19?	This study shows that individual funding schemes are not necessarily more flexible than traditional systems in an emergency situation useful flexibility depends on many factors, such as clarity of information giving, all actors having a shared message, proactive support of flexibility initiatives, and participants' ability to quickly navigate a complicated system. This research also highlights problems with the interface between the NDIS and mainstream services such as education.	Individualized funding schemes offer people with disability greater choice and control over the services they receive; This is intended to expand choice and control of services so they are more flexible to individual needs, which in turn should help to integrate individuals into society, restoring people's rights as citizens.	The article reports the results of an online survey with over 700 responses from children and young people and their families regarding the types of educational supports they received during COVID-19 and the impact this had on their lives; Results suggest significantly changed needs for NDIS funding during the pandemic, primarily due to responsibility for children's education shifting from teachers to parents and carers; About half of respondents reported that students with disability needed changes to their NDIS plans and supports, but only a fraction had been able to. Many respondents described not being able to access supports; Barriers to flexibility included confusion and inconsistent information about whether the NDIS could fund educational supports; previous negative experiences with the NDIS; administrative burden; inability to move funding between different support budgets; Some people received proactive and flexible service but the NDIS principle of choice and control was not realized for all; Emerging evidence suggests that individualized disability funding schemes may have significant equity implications, with some able to achieve better outcomes than others.

Table C: Thematic Source Information and Considerations

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Alexander et al. (2019)	The NDIS design causes children and their families to experience unintended negative impacts regarding attachment security in clinical settings. A medical multidisciplinary ECI approach with multiple professionals engaging with the child may cause disadvantages such as unresponsive or contradictory advice leading to parental stress levels. Complex process to access IF (long wait times, multiple professionals, limited guidance on services). Financial struggles.	ECI services access under the NDIS significantly impacts their functional capacity. National Disability Insurance Agency should ensure skilled workers. Attachment should be the central focus of ECI under the NDIS and failing to take a proactive stance in ECI clinical settings goes against NDIS goals and the rights of access for disabled people. Consider introducing the Key Worker Model for a holistic approach to ECI.	ECEI Partners introduced since 2017 by the National Disability Insurance Agency function as the entry point to services funded under the NDIS. ECEI Partners have a gatekeeping role of in which only half of the disabled children meeting the eligibility criteria enter as participants. Financial burden on parents.	Early childhood intervention; Parental/NDIS interactions; Eligibility gate keeping; Administrative burden. **Keywords**: attachment; children; disability; early intervention; social policy
Bisp et al. (2022)	A facilitator is the introduction of dedicated youth facilitators to guide Personal Health Budgets processes that work collaboratively with young participants and clinical interdisciplinary teams. Youth facilitators provide a bridge to CAMHS sharing information about available supports in the local community to clinicians, enabling proactive planning for young people's discharge. Interagency collaboration expands access of services and young people's advocacy.	This Personal Health Budgets approach to mental health service delivery demonstrates the benefits of personalised care increasing young people's empowerment and meaningful involvement in care planning that can inform further service developments, expanding of Personal Health Budgets to a wider range of young people and families.	Personal Health Budgets and interagency collaboration with CAMHS may save costs, reducing the need for Personal Health Budgets long-term.	Benefits of Personal Health Budgets for adolescents; benefits of Personal Health Budgets for mental health conditions; benefits of Personal Health Budgets in clinical settings. **Keywords**: adolescents, care planning, child health, child and adolescent mental health, families, mental health, patients, personalisation, person-centred care, professional

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Boaden et al. (2021)	Personal family resources, social inequities, and lower social capital result in difficulties navigating access to the NDIS; Low SES, intergenerational poverty, Aboriginal or Culturally and Linguistically Diverse backgrounds, and living in geographically remote areas limited capacity to seek information and access supports; Higher social capital and family capacity to use resources and advocate for support resulted in more service allocation; Family and communal support increased capacity to make informed choices; Families coped better where service providers linked them to interim ECI supports, information, and community networks; Transition to the NDIS came with uncertainty about the application process, strained National Disability Insurance Agency communication, service gaps, wait times, and inequalities in planning, approval, and review processes.	Families accessing the NDIS need support on all social ecological levels to increase the likelihood of a positive experience. Policy should incorporate attention to the role of social work in providing a holistic approach that links families' experiences and needs to community resources, local specialist service providers, and wider systems that facilitate family capacity-building in culturally informed and accessible ways. Need for more collaborative practice between the National Disability Insurance Agency and ECI through Linkages and Capacity Building (ILC) grants.	Families varied in socio-economic status. Some families had capacity to self-fund all or part of their services while waiting on NDIS access whereas others could not. Families with capacity to self-fund took funds out of their mortgage payments while others took out a second mortgage to cover expenses, which influences the financial sustainability of supports and financial security of families; Shift from block funding and subsequent uncertainty related to the funding application process and yearly funding reviews, long wait times and funding gaps were a common concern.	Individual, communal, and systematic factors that facilitate or obstruct families' positive experiences with the NDIS; social inequity and social capital disparities among NDIS users; administrative downfalls of NDIS **Keywords**: Early Childhood Intervention; NDIS; Disability; Social Work

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Brien (2018)	Facilitator in rights-based approach to NDIS and supports is a child-centred attitude which aims to consult and collaborate. It builds on the child's strengths and development, and assumes capacity of the child as an enabler of participatory practices, promoting children's choices; Barrier can be the limited capacity for adults and professionals to adopt a child-centred attitude, including the perspective that children are not capable or competent. Families and early childhood professionals should acknowledge the child's initiatives through both experienced and impartial observation to consider and support the best interests and developing capacities of the child; Dangers inherent in not supporting disabled children to exercise their right to be heard risks their capacities to develop participatory practices.	For disabled young children to realise the right to be heard within the policy constructs of choice and control requires the balancing of the needs-based right to protection with the right to be heard. Policy should be sensitive to the child's voice. There is a notable opportunity to consult with, and support young children to articulate and advocate for what they need.	N/A	Ethical considerations for participant choice and control for disabled children and their families and professionals. **Keywords**: children's rights; early childhood; disability; policy

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Brien et al. (2017)	A facilitator to ECI and NDIS supports for families and disabled children is the sharing of specialist expertise and knowledge to support informed decision-making; Effective decision making is thus co-constructed, with the ECI professional and family members co-contributing their specialist knowledge to inform decision making; An important skill for ECI professionals in this changing policy environment will be the ability to articulate the approaches and benefits of their service provision in a way that families understand and approve of; The construct of choice and control as set out in the NDIS are reliant on the sharing of power and responsibility between families and education and health care professionals.	Family-centred practice is undertaken within the context of government policy; Expectations underpinning policy have the potential to impact on the effectiveness of professional practice and partnerships; The new NDIS policy reflects a policy shift to a consumerism model, involving a re-orientation of funding to the participant (similar to changes in mainstream early childhood education and care), assuming that authentic choices can be made about quality in service provision.	The constructs of choice and control as central tenets of the NDIS must be considered alongside notions of accountability—to children, families, professional evidence-based knowledge and government policy. Effective practices that support families to exercise choice and control acknowledge the accountability required by both ECI professionals and families of young children with disabilities to government policies and funding.	Collaboration and communication across families and services to promote choice and control for disabled children and their families. **Keywords**: early childhood intervention; family-centred practice; decision making; choice and control; NDIS; collaboration; expertise knowledge.

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Carney et al. (2019)	States and territories provided information provided to the National Disability Insurance Agency based on legacy clients that identified priority applicants for transitioning into the NDIS and together with an intake questionnaire became individual metrics used to generate access decisions and preliminary plan profiles for NDIS participants; Legacy data deficiencies, broad spectrum questionnaires, or other intake information resulted in decision errors at odds with the needs of participants; The scale of transition from block funding to the NDIS caused complication and a lack of suitable personnel, which meant that instead of ironing out initial planning issues, complications went unaddressed or were delayed relying on participants to challenge their NDIS plan.	Tension in the NDIS policy design between past excesses of professional planning and the promotion of UNCRPD-compliant, person-centred planning is yet to be fully realised or understood as it places undue reliance on participants and their families often with limited ability to do so; Contrary to perceptions that the NDIS values personalisation, NDIS has objectives of equity and efficiency. The scale, speed and complexity of the roll-out led the National Disability Insurance Agency to adopt administrative practices inimical personalised planning which threatens both individual justice to participants and public confidence in its administration.	Tensions in the administrative implementation and rollout of the NDIS with the intend of the NDIS led to questions around financial viability of the NDIS and the quality of individual lives of both those not covered (reliant on state/territory services) and NDIS participants (in retention of their supplementary general supports); The insurance logic enshrined in the NDIS Act has crafted a contestable form of personalisation, with lesser weight on expert case planning and more reliance on participant or familial expressions of preferences of the person which led to the imposition of distinctions between disability-specific costs (fundable) and associated complex needs (not funded).	Taylorism or the administrative routinization and automation of the NDIS is not an error of law but leads to experiences of barriers and inaccessibility. **Keywords**: legislative framework; planning framework; personalisation and statement of needs; Administrative Appeals Tribunal; resource allocation boundaries; collaborative planning; merits review; reasonable and necessary supports; equity and advocacy; Human services delivery models; participant qualification.

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Clark & Dissanayake (2022)	Barriers and facilitators to NDIS funding for autistic children in EI and their families hinge on the mental health needs of those family members not properly addressed under the NDIS funding model.	A relevant consideration for the NDIS moving forward is to include carer respite into the package. This financial investment may reduce the ongoing economic impact of long-term carer burnout and mental health difficulties, by virtue, promoting positive mental health and wellbeing and subsequently increasing the QoL of parents experiencing elevated stressors; It is important that parents themselves are included as end-users of the NDIS, to allow the full breadth of experiences, both positive and negative, to shape and enhance NDIS processes.	"Social disadvantage and financial hardship have been identified as the largest barriers impacting access to the NDIS [..]. Thirty-two parents were interviewed about their experiences accessing funding, with 30% of families characterising the NDIS as "hard to reach". Families with low socio-economic status explained how their everyday needs including access to food, water and safe housing took precedence over the NDIS, which was "beyond the scope" of their day-to-day considerations (Cortese et al., 2020)" (p. 2).	**Keywords**: early intervention; DDS; NDIS; autism spectrum disorder; parent mental health; wellbeing; quality of life

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Collins et al. (2014)	Barriers to accessing DPs for respite or short breaks caused concerns among parents in this study. In one case, funding for a care worker to support a child attending a specialist sports club was withdrawn because it was felt that the club did not meet a health need; In the current context of budgetary constraint and restructuring of social care, access to and eligibility for short break provision will most likely become increasingly restricted.	Parents interviewed lived in different regions with a range of experiences regarding short break provision. Similarly, Direct Payments were used differently; Findings suggest assessments should identify the need of a break from caring and should include an understanding of how parents make sense of their need for a break; Decisions taken by social workers about eligibility for short break provision in must be taken with regard to the relevant legislation; Social workers must be sensitive to the different ways parents want to be enabled and should avoid overly narrow policy interpretations.	Direct Payments to pay for provision of short breaks are limited as local authorities take a very narrow view of what paying to get laundry done means in the context of family support. Families articulate a causal chain whereby paying to get the laundry done means that respite time can be used appropriately and not just in trying to catch up with everyday tasks. Withdrawal of the Direct Payment in order to help with the laundry has a knock-on effect in reducing the positive impact of short break provision; Implications for social work practice including those relating to social work assessments and to the provision of short breaks in a wider context of budgetary constraint.	Use of Direct Payments for respite is not equally understood as a legitimate use of funds in Local Authorities. **Keywords**: break from caring, contested interpretations, parent perceptions, short breaks, social work assessments, thematic analysis

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Comito et al. (2023)	Facilitators to HEN funding was provided by dietitians. They supported patients in obtaining appropriate funding via NDIS; Costs were forecasted following clinical assessment of requirements, predicted changes to nutrition-related supports, and equipment instructions; Supports were itemised in accordance with commercial prices; ensuring funding was not a barrier to participant's accessing their service of choice moving forward; Funding was approved prior to billing to ensure no additional financial expenses or disadvantage existed for the patient/carer; Supports continued via pre-existing DH HEN funding streams.	Historically inadequate funding for HEN patients was addressed during the 2019 NDIS funding as funding changes presented an opportunity to meet these resourcing deficits through the development of a self-sufficient comprehensive HEN service; Recommendations from hospital dietitians reinforce the idea that state-based funding is inadequate; NDIS HEN funding allocations are individualized and aimed to facilitate equitable access to HEN services and supports without additional costs to the patient.	Participants chose to receive care through the new HEN service, resulting in 330% higher than previous fixed price allocations, highlighting the true cost associated with HEN care, attributed to the diversity and complexity of patients; Additional fees required for some HEN services highlight the inadequate and inequitable funding across Australia; Patient complexity reinforces the importance of individualized HEN care and funding allocations through NDIS.	Article reflects the potential of integration of health and social care systems with HEN services transitioning from hospital to home care funded by the NDIS. **Keywords**: dietitian, health services for persons with disabilities, home enteral nutrition, NDIS, service development
Cowen et al. (2011)	Personalised and individualized funding facilitates collaboration and person-centred approaches amongst providers, invoking mutual respect, role-sharing, and centralisation of young people and their families; Barriers to individual budgets and supports include low confidence regarding self-directed support, slow or limited market development; lack of a framework for peer support for young people and their families after school.	The innovation of self-direction highlights the importance of such a reform in: shifting control to citizens and families which can resolve the ongoing difficulty of integrating competing services; applying reform for education, health, and social care can create personalised care as a whole-of-life policy framework.	Financially, improvements have been cost-neutral; Better use of professional staff and a reduction in the use of residential or segregated services signals potential further economic benefits; It is not possible to make strong claims about the economic impact of personalised transition.	Benefits of self-directed support/IF schemes; facilitators to ease transition into self-directed support/IF schemes **Keywords**: personal budgets; self-directed support; disabled school leavers; transition; personalisation; collaborative care

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Dew et al. (2013)	Greater access to and choice of therapy providers are benefits of IF; however in the context of rural and remote areas there is (i) lack of information and advice; (ii) limited local service options and capacity; (iii) higher costs and fewer services and (iv) complexity of self-managing packages; Individuals who live in rural and remote areas have less choice and access to services than their metropolitan counterparts; Skinner and Rosenberg (2006) attribute constraints to the geographic, sociocultural, technological and workforce barriers in rural communities, including rural limits of a market-oriented model.	To optimise IF therapy packages, participants need: (1) Access to up-to-date information in a variety of formats; (2) Personal contact to build rapport, face-to-face, telephone, or online; (3) Financial compensation to cover travelling costs; (4) Flexible support options to build inclusive support networks. Service providers need: (1) Engagement with policy-makers to develop a coordinated approach to IF; (2) Collaborative workforce planning, recruitment and retention strategies to address shortages; (3) Certainty around service viability and growth; (4) Policies and procedures using IF packages.	Limited local service options are combined with higher costs associated with accessing services resulting in a lack of choice; Participants could not spend their IF or spent it on things not a priority to their care; Participants reported increased costs due to the need to travel long distances to access services. Service providers were fearful of the impact of IF on workforce planning due to uncertainties about the demand for their existing service model by service users with discretionary funds.	Important elements of participant-centred personalisation schemes such as IF are not available to services and participants in rural and remote areas. **Keywords**: disability, Individual funding, person centred, rural and remote

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Dew et al. (2014)	Service users in rural Australia face challenges in accessing support services; These challenges are due to the difficulties service providers encountered in providing therapy across large geographic areas to dispersed populations commonly delivered by a mix of government providers, non-government organizations, and private practitioners using outreach services to those living in smaller and more remote areas; Dependent on proximity to a larger centre, rural service users travel long distances, wait a long time, and receive less frequent interventions than their metropolitan counterparts leading to choices among service users to remain in their rural communities or move to larger centres.	The focus of the NDIS is to provide service users with choice and control to enhance their community participation and inclusion; This is not equally available to service users in rural and remote areas that need to be considered in the roll-out of the NDIS; Social and financial costs to living with a disability in rural areas should be accommodated within the NDIS; A rural and remote person-centred approach can be harnessed to meet service users' needs using IF allocated through the NDIS; Increasing uptake of online technologies may reduce travel for carers and therapists.	Economic factors identified by service users indicate the significant additional costs faced by rural carers; Distance, travel times, and transport are unique financial limits combined with difficulties carers face in maintaining employment; Within the NDIS model, rural carers need to be financially compensated for travel to larger centres and cities to access specialist supports. Lessons about financial compensation for rural service user travel can be learnt from existing individual funding schemes.	Considerations of barriers to NDIS IF models for service users in rural and remote areas. **Keywords**: carers; rural; disability

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Dew et al. (2023)	Key barriers to navigation of the health system included unfamiliarity, cultural and language differences, and access to interpreters. Facilitators are information sharing, support from family and friends, and interpreters; The NDIS presents several barriers for diverse individuals: the online application; lack of culturally appropriate assessment tools; limited access to histories of diagnosis and service use; community stigma; lack of interpreters who understand disability-specific needs; and limited knowledge of entitlements; To access the NDIS services, disabled refugees need support from someone to navigate complex systems; Refugee-specific services took responsibility for providing holistic support while disability services were largely absent.	Australia has extensive networks of health, refugee-specific and disability services, but they are not well integrated; Refugee specific services, disability services and health services should collaboratively develop and implement strategies to tackle the intersectional nature of issues resettled disabled refugees and their families encounter informed by the experiences of disabled people and family members from refugee backgrounds and privilege holistic practices that avoid reliance on one sector alone to address the complex needs.	NDIS funding access and funding packages to purchase supports and services for disabled family members led to a range of issues, such as the requirement of proof of permanent and significant disability and management of funds; Under the Australian government means-tested income support system, adults with disability who are not in paid employment are eligible to apply for a Disability Support Pension, and full-time carers can apply for a Carers Support payment. A key support that settlement services provided was to facilitate applications to access relevant payments.	**Keywords**: family members, intellectual disability, practice, refugees with disability, service access

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Dudová (2022)	The Czech Republic has a historical practice of institutionalizing disabled children and adults, but currently about 80 percent of care is provided in the family through the care allowance; The allowance could be regarded as partial recognition of the economic value of care or as an opportunity to obtain some formal care; However, this study of providing long-term care for a family member shows that other factors determine how money is used, most importantly the norm that family members should not pay each other for care and that care should be provided personally and by women; The assumption that the care allowance will provide people with freedom of choice in providing care is misguided and does not match real-world experiences.	Monetary transfers for care carry social implications for the privatization and marketization of care; The social welfare landscape in Europe makes service provision less a public responsibility and moves toward a consumer-directed approach giving care recipients power to organize their care; The marketization of care risks worsening quality of care, low compensation of care, and growing gender inequalities; This has implications for policymakers trying to find a solution to care deficits; Future migrant employment for private in-home care provision might address risks and shift family norms.	Family relationships are complex and attached monetary transfers have consequences in definitions of personal relations; Transfers are gendered with caregiving continually associated with women that do not shift financial resources to the caregiver; Financial rewards for providing informal family care may strengthen commitment and obligations, but are not necessarily beneficial to caregivers who may find it more difficult to refuse care than they would in the absence of payment; Policies increase the pressure on women to leave the labor market to care for family; Financial benefits are presented as compensation for caregiving, but do not reduce gender-related inequalities.	Cash-for-care benefit schemes in the Czech Republic do not result in the hiring of formal care outside gendered familial structures. **Keywords**: Caregiving, welfare measures, unpaid work, family, gendered and normative expectations in caring

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Duffy & Murray (2013)	Disabled young people and their families have to overcome the gap between children's services and adult services in a paternalistic system; This gap is legal, normative and practical: 1) Entitlements change and new assessments might mean young people are no longer eligible for support; 2) Family representatives no longer have involvement in key decisions; 3) School, respite services, medical services, social workers are all changed; Families will often blame adult services for acting too slowly, providing inadequate care and for not listening to their wishes; Adult services often blame families, schools and children's services for low expectations and resistance to the norms and services promoted by adult services; The transition period is associated with complaint, conflict, anger and poor decision-making.	Personalised transition provides a case study of the kind of positive changes that can flow from the application of self-directed beyond adult social care and into services for children, the NHS and education; The authors offer four lessons from developing and supporting the implementation of personalised transition: (1) change begins within; much of what we need is around us; (2) we need inspiration to change; and (3) progress is not inevitable.	Financial outcomes of personalised integration in the case study of the Sheffield area were positive; This system seemed to end the pressure to send young people away from the city to residential colleges outside Sheffield.	Professional integration for the sake of system integration risks true person-centred empowerment and personalised care. **Keywords**: Integration, Integrated health and social care, Community empowerment, Care and support, Holistic approaches to care, Personal budgets

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Ellem et al. (2019)	Involvement in planning around a disabled loved one presents challenges for families, who are resistant to change, and may have a different agenda to the disabled person; Some families have been reticent in seeking outside supports or fail to trust others to provide appropriate care; Families can either facilitate or impede choice-making by a person with an intellectual disability; Barriers include family experiences of social isolation, competing responsibilities in day-to-day life, and a lack of cooperation from professionals involved in the family's life; These physical, emotional and social forms of disablism have on families affect person-centred planning processes.	Person-centred planning should include strategies to help families anticipate barriers; Capacity building requires adequate understanding of the cultural nuances and complexities; Support must be feasible and consider existing relationship networks and the community; NDIS needs to provide training and support in self-directed funding; Accountability needs to be streamlined without adding to bureaucracy; Person-centred planning should not be an abdication of responsibilities of service systems; Participants should inform practitioners and policymakers.	Self-directed supports are indicated as burdensome and presenting a lot of financial administrative burden. Some family members opted for a financial intermediary. Other parents relate the complexity of navigating care and employment.	Person-centred planning and IF models come with several considerations for policy to enhance families' experiences of the upcoming transition to NDIS services. **Keywords**: disability services, family support, NDIS, person-centred planning, self-direction

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Fisher et al. (2023)	Study participants who self-managed benefited from additional choices it facilitated; Many participants changed the degree to which they self-managed over time; This reflected changes in their needs, experience and expertise; The participants' experience revealed unequal capacity to take on self-management; Socio-economic advantage and previous experience assisted participants to successfully self-manage; Participants with capacities located and used systems to manage the work having confidence and connections to manage uncertainties; Participants without socio-economic advantages sometimes had access to other resources to ease the work of self-management; Participants emphasised the need for additional support, particularly for person without a management background.	Implications are that resources such as advocates, peers, organizations or support coordination can help fill the gap between people with and without personal and social advantages; Attempts to improve the take-up and success of self-management might be targeted towards addressing inequalities among people who are considering the choice to self-manage all or some of their disability support, particularly people with cognitive disability who are generally excluded at present.	NDIS funding recipients can: 1. self-manage funds; they can choose and pay any business while being accountable to the National Disability Insurance Agency collecting invoices in to the NDIS Portal; 2. plan-manage by an intermediary agency who hand the funds to pay the support providers directly and do administrative work; 3. agency-managed by the National Disability Insurance Agency with only NDIS-registered service providers. The participant can check their NDIS electronic portal. Another option is to mix funding types to facilitate choice to purchase services from both NDIS-registered providers and non-registered providers, leaving the work and responsibility for managing part of their plan with the National Disability Insurance Agency .	Experiences and barriers to the self-managed and agency managed NDIS IF options **Keywords**: self-management; disability support; choice and control; NDIS; direct payments; individual budgets

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Gallego et al. (2018)	People living in rural and remote areas experience disadvantages because of their location; Access to therapy services poses challenges including long travel distances, limited service providers, and a lack of specialist services, resulting in long waiting times; Waiting time and cost of therapy services are important characteristics; carers in this sample may be willing to trade benefits of the other attributes (i.e. travel longer distances and/or pay more in order for their care recipient to receive timely therapy service); Long waiting times are a result of the difficulties in attracting and keeping therapists in rural areas; A key consideration with carers is a strong preference for therapists over assistants or support workers.	Reducing waiting and travel times may mean services are provided by staff other than therapists and services may need to be provided in new ways; Tele-therapy services reduce travel time, out-of-pocket expenses, and waiting time; Therapy assistants could conduct a prescribed service in areas without a resident therapist; Need to investigate social supports that families require within a broader context of support; For the NDIS to meet its policy objectives addressing workforce issues is critical; Carers did not exhibit strong preferences as to service providers.	The study showed a statistically significant preference for low out-of-pocket costs.	Discrete-choice experiment to address preferences for support. **Keywords:** Australia, carers, person with disability, preferences, rural, therapy

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Gavidia-Payne (2020)	Participants reported difficulties, undermining timely access to ECI practices and parental support; Participants experienced concerns in their new transactions with the disability system and felt overwhelmed in dealing with uncertainty around terminology, systems, settings, and funding. This limited their opportunities to exercise choice and control at various critical points of the ECEI service path, hindering participation; Parents faced delays in assessment, development and coordination of plan implementation; Experiences are inconsistent with effective ECI practice and indicate systemic and structural barriers; Parents reported difficulties in navigating systems without a support coordinator which limited access to resources;	For the NDIS to fulfil its promise substantive revisions will be required to be relevant and sensitive to the needs of young children with DD and their families; For children aged 0-6 years, NDIS' promise is yet to be fulfilled; Families experienced challenges in a system designed for disabled adults and lacked qualities that make an effective and efficient ECI support system; Gaining a greater understanding of families' lived experiences of the NDIS, its impact on their young children with DD, and more broadly on their everyday lives, can inform policy and practice improvements.	Parents reported that substantial knowledge was required to work the system once deemed eligible for funding and services; Parents who chose key workers felt conflicted as there was not enough funding to cover all services; Participants saw the ECEI as stressful, from the initial contact with the National Disability Insurance Agency , before, during, and after the planning process through securing funding; Securing NDIS funding and retaining it, was often reported as a cause of distress with the need to be consistently monitoring and justifying their funding; Parents reported unpredictability of the funding at the approval stage, depending on the local coordinator, the planner, or the wording in the plan.	Choice and control among parents and carers of young children with DD under ECEI and NDIS. **Keywords**: challenges and future directions, NDIS, parent perspectives

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Harry et al. (2017)	Findings support the effectiveness of the Cash and Counseling model of self-directed budgets for young adults with long-term care disabilities. Compared to those eligible for agency-based care, young adults assigned to the Cash and Counseling treatment groups had significantly greater likelihoods of being very satisfied with life and a wide array of areas affected by self-directed budgets and had significantly lower likelihoods of unmet needs for assistance; Qualitative findings suggest that targeted use of the budget towards young adults' community involvement goals may enhance outcomes in this area; The positive findings on Cash and Counseling reported here continue the pattern that the choice and control aspects of self-directed budgets may contribute to greater satisfaction for disabled young adults and familial caregivers.	Cash and Counseling functioned as designed for disabled young adults. The self-directed budget model offers an important option for young adults transitioning into adulthood, including addressing service gaps after pediatric services (Children's Medicaid, IDEA) have ended. Findings may motivate states and programs to offer self-directed budget options to young adults. Program support brokers could assist young adults, and program representatives, in utilizing community resources and thinking creatively about budgeting for meeting personalized needs such as community involvement or needs for assistance.	Few bivariate differences were seen in outcomes between young adult treatment group participants who did and did not receive a monthly cash benefit by nine-month follow-up. Treatment group members who received a cash benefit had 51% lower odds of working for pay at a preferred level at follow-up compared to those who had not received their benefit yet. Those who had received their cash benefit also had higher odds of being very satisfied with their care arrangement and transportation, and lower odds of unmet needs with transportation.	The effectiveness of the Cash and Counseling model of self-directed budgets for young adults with long-term care disabilities **Keywords**: Disability; Home and community-based services; Long-term care Self-directed budget; Young adult

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Henderson et al. (2018)	Article presents barriers to organizational transition from charity to social enterprise; A policy based on choice and control for the consumer risks removing choice through a loss of services in the marketplace, leaving vulnerable populations at risk; The reduction in financial resources puts affected institutions and organizations under pressure, and effects of this were seen by both parents and staff in the organization; Five reasons for resistance to Self-directed Support: (1) protecting the current service and the staff's jobs within it; (2) concerns over the quality of care of their child; (3) disagreement with local authority funding cuts; (4) responsibility on the parents to selecting a safe, quality service for their children themselves; and (5) the loss of a collective voice reducing care givers real power over the service provider.	Self-directed Support policy has had unexpected impacts and reactions whilst rolling out across regions in Scotland; Policymakers and people in the care sector face challenges in gathering evidence from vulnerable populations and from organizations under pressure from austerity-led cuts; Future enterprization of social care will result in challenges of hybridity amongst the third-sector; More evidence of attitudes towards and experiences of Self-directed Support should be collected from all users of personal budgets, including from the parents of children with complex conditions, social workers, and other frontline staff.	Scotland has some control over policy decisions through devolution, but is still dependent on Westminster for its budget, facing a budget reduction of 12.5 per cent by 2020; In social care, the personalisation agenda has provided an opportunity to both satisfy the demands for more choice and control by the disabled community and cut state costs, both through reducing state-run services and through cutting the amount of money which might be spent on each individual case. The reality of this policy is competition to provide a broader range of services for less cost, creating tensions around the quality of care and concern about Self-directed Support impact on continuing to offer services while adapting to the new model of funding.	Barriers and concerns about the increased hybridity of a Scottish charity organization as it moved from charity status to social enterprise under Self-directed Support. **Keywords**: Austerity, Neoliberalism, Personalisation, Self-directed support, Social Policy, Third-sector hybrids

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Howard et al. (2015)	The scale and complexity of the policy shift to NDIS is associated with challenges; Families with a disabled child aged under five years, living in regional or rural locations experience the scheme as focused on disabled adults, making choice and control not age appropriate; Shift to NDIS highlights the potential confluence of contexts of heightened stress, change and new information on likely engagement of participants in new initiatives; Many parents and carers of young disabled children in a regional setting see benefits in having access to a key worker and balancing choice/flexibility with integration/ coordination; Accessibility of services, including home visiting, was reported as a priority for research participants caring for a young disabled child often dealing with transport and logistical challenges.	Policy assumptions potentially exclude disabled children and their families from accessing the NDIS; Findings highlight considerations for policy-makers and service providers which can contribute to national and international disability policy; Emphasis should be on: building service user and community knowledge; communicating information with particular attention to language, timing and methods; building in processes to support and facilitate choice, decision-making, integration, coordination and managing associated stress.	Fiscal implications of the policy change are likely to be influenced by service availability, modality and the quality of relationships and connections between the family and service providers; More funding from the government would be good; not so much more money in the parents' pocket, but more so that the kids can get more services and everything your child needs.	Participant observations of NDIS trial site. **Keywords**: early intervention; regional; disability; policy change; families; children; NDIS

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Hutton & King (2018)	Personal Health Budgets (PHB) intended to give parents and carers greater choice and control over decisions about health care for their child; Few parents and carers opted to have a PHB and availability of PHB for parents of disabled children with complex needs vary across the country; Parents and carers interviewed saw both the benefits and drawbacks of a PHB; Purchase of items such as additional therapy or special equipment that parents perceived as potentially beneficial may not be possible under current eligibility criteria; As pressure on public services takes effect, tighter restrictions on what can and cannot by purchased with a PHB are likely.	From the perspective of NHS England, the roll out of PHB provides a potential solution to provision of care for those with complex needs allowing parents and carers greater choice and control that may contribute to more efficient use of limited resources at a time of diminished budgets; Parents and carers view the PHB with caution; Some families may not want the additional responsibility or pressure associated with managing a budget; Questions about entitlement and what can be purchased with a PHB are likely to be tested, as exemptions and limits curtail the original vision of a bespoke package of care.	Families may have one or both parents out of work and experience financial hardship, they are more at risk of family break up, while siblings are at risk of emotional and behavioural problems.	Discussion of the PHB rolled out through the NHS and parent/carer perceptions. **Keywords**: Personal health budget; disabled children; rehabilitation therapy; parent; carer

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Johnson et al. (2020)	Barriers to accessing disability supports in rural and remote areas: workforce shortages, lack of specialist services, and large distances; Barriers to the delivery of disability supports include a lack of services in close proximity, large distances between communities and services, lack of continuity in services due to high staff turnover, and a lack of timeliness in intervention due to minimal availability of local or outreach services; These barriers also mean that best practice and the principles of the NDIS may be more difficult to implement in rural areas; the workforce may not be familiar with best practice in disability, and he workforce is sparsely distributed so accessing clinical supports can be difficult; Choice in rural or remote areas may mean choosing the only clinician or having no options.	Parents and carers report a lack of alignment between best practice, NDIS principles, and parent/carer experiences; Differences between parent and provider conceptualisations of best practice and core disability principles underpinning the NDIS are described; This study teaches clinicians that parents and carers in rural and remote Australia are struggling to find service providers who have the skills to work in a way that fits with their goals and values. Notions of PCP were different for service providers, and families see this as a key factor that leads to poor outcomes.	Rollout of the Scheme has been the subject of criticism from participants, clinicians, and disability support providers. Some of the issues that have been raised are thin or absent markets in rural and remote Australia, an under-allocation of funds for individuals and for the Scheme, and over-bureaucratisation resulting in a lack of control over the nature and timeliness of supports; There is a lack of adequate funding for travel, and limited choice in clinical services in a given region.	Disconnect between NDIS terminology and family and carer experiences of services. **Keywords**: access, NDIS, person-centred practice, remote, rural, transdisciplinary practice

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Laragy & Ottmann (2011)	Inadequate funding; Limited personal opportunities due to lack of social inclusion; Agencies did not support accounting procedures; Greater choice and flexibility resulted in better outcomes for families who self-managed; Families want to select from a range of options but Australia's service options are limited; No procedures to involve disabled people in planning; Families stress due to funding; No information due to inadequate funding; Self-managing families had to invest a lot in seeking information; Less resourceful people are forced to use funds for help leaving fewer funds for personal support; Programs require diverse cultural and linguistic resources; Issues identified were accountability and protection of the vulnerable in terms of the well-being of the disabled person.	Bronfenbrenner's (1995) ecological systems theory highlights the interconnectedness of all levels of service design and delivery. A mix of encouraging and restrictive macro-system factors impacted upon personal experiences at the micro level; Government policies encouraged individual funding and resulted in better outcomes for those who self-managed; Knowledge of effective implementation strategies is important for disability agencies and for governments promoting individual funding because this radically different funding arrangement requires new implementation strategies.	The IF program resulted in increased access to a range of supports and services. Although financial resources were limited, there was improvement in the range of activities undertaken and outcomes achieved; The macro-system analysis showed that insufficient financial resources restricted the individual funding program's implementation in accord with its stated principles and policies; Families spoke of resources being insufficient; The successful coordinator model could not be sustained financially; Findings suggest that administrative services managing the accounts providing monthly financial statements needs to be distinguished from personal support.	Policy analysis for the implementation of individualized funding (prior to NDIS). **Keywords**: Australia, individual funding, intellectual disabilities, organizational change, program implementation

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Leutz et al. (2015)	Families went through five steps: induction, choosing approaches/ providers, service plan development /implementation, service monitoring, and budget management; Timing and complexity was related to family preference for service approach and existing connections; Families were advised about program limits, could choose and replace care coordinators, and received variable levels of guided choice; Facilitators: educated and trained families, staff skills, and communications; Barriers: hours of therapy and make-up hours; setting boundaries around provider jobs; whether family therapy participation and carrying over therapy was expected; Logistic problems: cumbersome steps for purchasing goods as families could not pay up front; services that could not be utilized as hoped.	Program improvement includes simplifying record keeping, online payments, and strengthening carryover approaches; Provide more training for providers, rules and procedures for dealing with make-up hours, and boundary setting with families; Improve the flow of budget information; Adjust services to align with family preferences; Explore clearer rules and training for family participation in therapy sessions. These program improvements relate to larger questions about the goals of the program - to improve the child's skills or also to train families to independently work with their child and find the supports their child needs.	There waiver program limits on how much can be spent, what can be purchased, availability and quality of covered services and supports, and scope of what is controlled by the participant; Few participant-directed (PD) participants fit the economic model of the fully informed buyer; Evaluations of the cash and counseling program model found that less than half of eligible beneficiaries who were offered the option were interested; PD programs reduced physical and financial strain; Of the $3 million spent on the program, 82% was spent on goods and services and 18% on administration; Administrative costs to get a PD program of this complexity through start-up to full capacity are significant and worth noting.	PD or parent directed program for funding supplied through Medicaid Waiver for young children with Autism, Spectrum Disorder (ASD). **Keywords**: autism, intellectual disabilities, long-term supportive services, Medicaid waiver, participant direction

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Loadsman & Donelly (2021)	Families experienced delays, feeling isolated and fearful their family member was missing out on essential supports and services, despite having approved funding packages under the NDIS; Frustration was not for their children but for the failure of the NDIS to demonstrate these values; Families were linked to employment, socio-economic status, housing and sub-optimal conditions for child development; Carer experiences of access to social services were linked to their personal wellbeing; Relationships were affected by the time and effort involved and the lack of supports; The safety and dignity of disabled family members and other family members was compromised; Family members felt they were letting their child down in not being able to secure the supports.	Extensive travel to meet services away from the primary residence consumed time that challenged employment tenure and family income; Time-consuming and challenging to negotiate and co-ordinate supports allocated; Participants were required to reduce working hours and/or struggled to get back into paid employment; This diminished the value and meaningfulness of the scheme for families; The needs of people in remote and rural communities had not been considered in the design of the NDIS; Feelings of accomplishment having their child approved for funding under the NDIS were overturned.	The National Disability Insurance Agency has stated that it is not financially viable to put more supports on the ground in rural communities; This places the financial burden on families who are to absorb the costs and stressors linked to the current business model.	Ideas about family wellbeing and access to NDIS support in geographically remote areas. **Keywords**: Family; wellbeing; NDIS; regional; rural; Australia

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Marchbank (2017)	Agencies needed to adopt a different service delivery consistent with a business model presented as an opportunity for growth; Administrators had little time to prepare for change; The process needed an immediate response to become a financially viable commercial organization; Required a cultural shift by staff to adopt a focus that reflected a market and customer service selling-style; Funding limitations impacted negatively on equitable service delivery to families without budgetary safety; Interruptions to services and travel costs interfered with a delicate financial balance crucial to the viability of the agencies; Administrators had to shift professional practice to staff accountability for family revenue to ensure employment.	For parents, NDIS funding plans would cover services to the full extent, this was a promise of direct service to families; For agencies, this understated the degree to which service delivery organizations needed to change to be cost effective; Before the NDIS, agencies planned for a number of families based on projections from past enrolments; Expected user pay systems to increase staff and decrease waiting lists/times did not materialise; Agencies were unable to generate an income stream to cover available staff; NDIS service provision reveals a rift between the medical and social models of disability.	Administrators had to adopt a commercial standpoint with a high degree of accountability for time management to remain financially viable in the transition period; To maintain income streams, manage professional staff and present with business-as-usual appearance with existing families were significant challenges; Developing a common understanding of income streams and cover/ costs and overhead expenditure was complex; The new system was not integrated smoothly with previous funded services; Leftover income from earlier systems needed to be completely disbursed before further monies could be expected from the NDIS.	NDIS early intervention to family with infants and young children with disabilities and in particular the rollout in 1 test site and the impact on administrators and services these families normally rely on. **Keywords**: ECI, family-centred approach; block-funding; choice and control; staff retention; budgetary limits for agencies; consumer-directed model.

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Marchbank (2019)	NDIS rollout led to the loss of a local specialist network; Teachers noticed changes in how parents engaged with their preschool program; Parent involvement was sliding and in 2 years, there was a marked lack of parent involvement in the children's learning; Various family arrangements (joint custody, two homes, partnering) limited engagement and communication; Teachers said the NDIS represented a change in workloads, referring to timing nightmares; The rise in numbers of unidentified children and urban growth, had doubled workloads; Little difference helping parents understand DD, huge difference in reaching access to EI services; NDIS process was complex and parents needed help accessing services.	Change was central to narrative accounts and talked about practice before and after NDIS; Before the NDIS, children recognized as delayed in preschool meant that the PSFOs undertook conversations about development with families, with completed developmental health checking providing a positive starting point; PSFOs reported changes to their practice as building capacity with teachers, rather than directly with families; Enabling parents' understanding of child development became important in the new context of referral, service provision, and self-directed funding.	N/A	Transition of NDIS proved difficult for the inner workings of ECI among 4-year old's – Research centers the perspectives of teachers and administrators in the shift to NDIS and barriers experienced in signaling early DDs to parents under new policies of 'disability' and the loss of previous care networks that facilitated ECI. **Keywords**: positioning theory, early childhood, developmental delay, NDIS, preschool teachers

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Marks et al. (2022)	1) Diabetes self-management is complex (carbohydrate counting, blood glucose level monitoring, insulin therapy); 2) Variable support for diabetes care (reliance on parents and carers, the NDIS, mainstream diabetes service support); Funding of direct health care and support under NDIS remains unclear and changing, representing a barrier to supported self-management of chronic illnesses for people with intellectual disability; The need diabetes care supervision and reluctance of others to accept responsibility limits access to employment, social activities and residential accommodation; Parents noted the amount of assistance their child required for diabetes care, causing parents to cease or adapt their employment to be available to facilitate diabetes care.	The NDIS enabled access to carers outside the home, but parents expressed their frustration with the new system; Disability services should consider employing staff, such as specialist nurses, who have the skills to care for and attend to any type and degree of chronicity; The NDIS should fund nurses to provide support to the person with T1DM and unlicensed disability support workers, as well as providing direct care and intervention; Specialist nurses would fulfil a vital role in health promotion for this vulnerable population.	The high cost of continuous glucose monitoring (CGM) prevented access to this technology; CGM assists with the identification and prevention of hypo- and hyperglycaemia to improve blood glucose control; Disability services charge parents the maximum.	Intellectual disability and self-management of T1DM is limited and requires a more holistic approach and understanding of care facilitated by the NDIS to support parents in those caregiving roles for young adults transitioning into adulthood. **Keywords**: parenting, inclusion, nursing, young adults, type 1 diabetes mellitus

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
McDonald et al. (2016)	CCDF schemes could be seen as the state handing back responsibility to individuals; Concerns about the NDIS include shortages of appropriately skilled staff, alienation of marginalised groups, a lack of choice for families in rural and regional Australia, and market-based influences; CCDF models could undermine approaches in ECI via deeply held cultural assumptions regarding healthcare delivery and the alignment between methods of evaluation and traditional biomedical approaches through consumer decision-making; In absence of information, parents make decisions they may regret highlighting the importance of informed choice; Parents might find out about contemporary therapeutic approaches and benefits, but those who do are likely well resourced (high literacy levels, access to technology) and socio-economically advantaged.	A funding model founded on the principle of self-determination should be able to communicate the complexity of the evidence regarding effectiveness of different therapeutic approaches to parents of disabled children without overwhelming them to ensure that CCDF facilitates informed, meaningful choices; CCDF risk reinforcing the simplistic assumption that some types of therapy are more legitimate.	Within the context of the Australian ECI sector where there are insufficient resources leading to rationing and extensive waiting lists, it would be wise to support therapeutic treatments that enable caregivers to support children's learning and development, rather than relying upon therapeutic approaches that discourage caregiver involvement and limit opportunities for caregiver capacity-building. Initial data indicates that the NDIS is going to cost more than expected, in which case cost-savings would appear to be especially important.	Considers if and how consumer-centred models of funding could impact self-determination and ECI negatively **Keywords**: funding, early childhood intervention, self-determination, quality

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
McGuigan et al. (2016)	Users reported that in times of high employment, they found it more difficult to recruit appropriate carers as advert response rates were low, with few candidates; Users recognised lower levels of pay on offer compared to those on offer for similar work with agencies and social services; Users with very specific needs worried about the training and experience carers may have and the impact this could have on their care; Users have difficulty with the distinction between health and social care made by some authorities; Direct Payment (DP) scheme does not allow for crossover between health and social care needs; Responsibility levels of DP caused anxiety for some concerned about the paperwork for employing personal assistants; Difficulties reported are those associated with bureaucracy, paperwork and administration.	DP schemes have many levels of checks; The NHS Confederation points to the responsibilities of social care providers to introduce the option of DP to those who are eligible; however, the rate of implementation has been poor, despite government eagerness to increase the number of DP users, with the issue high on the health and social care agenda; Policy barriers to DP uptake: 1) Concern about managing DP; 2) Social services staff resistance to DP; 3) Number of people available to take the role of carer; Respondents suggested improvements in the paperwork and accessible information templates.	DP were found to be cost-effective for providers with the research indicating user-controlled money was used more efficiently; Users reported difficulties with prompt payment under DP system, indicating they experienced late payments that had a knock on effect as they had to borrow money to pay the wages of their personal assistant; Resource cutbacks in local authorities in the current economic climate may make it difficult for providers to offer reasonable rates of payments to those requiring assistance, therefore this may prevent them from offering DP at all.	Impact and experiences of DP in Northern Ireland. **Keywords**: Direct Payments; social care; user experience

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
McNeill & Wilson (2017)	Recipients had varied experiences of using DPs and hold positive and negative views about the value and effectiveness of schemes in addressing their needs; Strengths and benefits from DPs: sense of control, choice, reliability, and flexibility; For many, being able to have short breaks with support provided by a person whom they had chosen, at a time that suited and in a manner they felt appropriate was of overwhelming importance; 76 % commented that the trust would not be able to provide them with a comparable level of service to that which they were currently receiving via DPs; Respondents identified a number of issues from their experience with DPs, including problems with recruitment, administration and monitoring, financing and rates of payment.	Policy considerations were identified in the strategic challenges for agencies seeking to further develop DPs as a method of meeting the needs of disabled children.	The merits of uptake of DPs against a background of prolonged financial and resource constraint have been the subject of intense critical debate; DPs has focused on anxieties about the adequacy of financial resourcing in the current climate of austerity and concerns that existing collective services will be undermined, leading ultimately to poorer choice and less effective provision; The NHSCT increased its overall spending on DPs by 11%; The increased spending by the trust suggested an increase in the cost of individual care packages; Respondents expressed concern about the adequacy of pay levels in DPs linked to difficulties in recruiting and retaining skilled employees with the skills.	The effectiveness of DPs as experienced by family members and carers of disabled children in Northern Ireland. **Keywords**: Children, disability, Direct Payments, personalisation

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Meltzer & Davy (2019)	Findings suggest the NDIS views relationships as a one-way source of practical support and care to complement reduce the cost of services formally provided through the scheme; This conceptualization of relationships as unidirectional sources of informal support risks perpetuating negative stereotypes of disabled people as dependent and lacking in reciprocity, and fails to recognize the complex, dynamic set of relationships that may exist; This means that the support disabled people may need or benefit from to participate in reciprocal, positive, and fulfilling relationships risks being overlooked in the individualized planning and funding process; No funding or allocation of resources in individualized funding packages actively support interpersonal relationships.	The NDIS' approach to relationships can be improved: by conceptualizing relationships rather than sources of informal support; through provisions to actively support relationships; by considering the relational support provided by family, carers, and friends; Effective policy implementation requires stronger recognition of the importance of relationships to achieving positive policy outcomes, even in a system focused on individual choice and control.	Documents made no reference to providing supports to family and carers through individualized funding packages, despite the reality that many of their needs may be interconnected with those of people with disability; The only place in the NDIS documents analyzed where there was direct reflection on the impact of funding on relationships was in a justification for not funding certain supports.	Document content analysis of key scheme documents reveals the main objectives, mission, vision, and values of IF for disabled people. **Keywords**: individual funding, NDIS, people with disability, policy implementation, relationships

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Mitchell (2012)	Barriers and facilitators to Self-directed Support for transitioning youth to adult services; The potential for a wider integrated network involving service users and unpaid carers as key partners in co-production is perhaps the greatest potential from Self-directed Support; The future of integration within a context of personalisation is unclear and may paradoxically be characterised by a fragmented market-place of service providers being drawn together in local networks by individual service users via the mechanism of Self-directed Support. Self-directed Support has the potential to encourage creativity at an individual/ organizational level leading to greater empowerment and more positive outcomes for disabled young people and their families in transition to adulthood.	Requires policy integration that has been acknowledged as a cornerstone of devolved policy on health and social care (variously referred to as whole systems working, joint working, partnership working, networks, or integrated working); Self-directed Support connects to a rising demand for health and social care integration to deal with increasingly scarce resources; In an era of healthcare co-production, personalisation, and recognising carers as co-workers, there has been little attention paid to the role of service users and informal carers in integration care networks.	Barriers to effective integrated working include structural, procedural, financial, professional, and status issues.	The introduction of Self-directed Support and the multi-agency collaboration requirements for disabled young people in transition to adult services and their families. **Keywords**: Self-directed support, Individual budgets, Personalization, Transitions, Disabled people, Children (ages 16-19 years), Realistic evaluation, Social care

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Mitchell (2014)	Facilitators to disabled young people having informed choice were found to be related to the following factors: Emotional support from mothers; Trusted professionals available for information when required; Information that was accessible and accurate; Experiential knowledge; Barriers to informed choice were seen to be related to: Parents making choices on behalf of their child; Lack of trust in professionals; Inaccurate or inaccessible information; Information overload.	The archived interview transcripts provided evidence of the diversity of experience for disabled young people in how choices are informed and made, and the role of others in supporting these choices; Social workers and professionals can play a valuable role in supporting disabled young people and their families to engage with wider social networks to increase social capital and access information to build trusted relationships to support informed choice, including encouraging engagement with peer advocacy and carers' organizations.	The article addresses financial constraint.	Secondary analysis of Self-directed Support experiences among disabled young adults transitioning out of youth health and social care services. **Keywords**: informed choice; self-directed support; personalisation; transitions; social capital; secondary analysis

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Mitchell (2015)	Facilitators to young disabled people having informed choice: Supportive networks of family and professionals; Advocacy; Information that was accessible and accurate; Experiential knowledge; Barriers to informed choice: Parents and professionals having low expectations for young people with disability; Capacity of the individual to make decisions and their communication skills; Lack of integration/collaboration between child and adult services; Organizational bureaucracy and risk-averse culture.	Self-directed Support is in the implementation phase of the policy cycle in Scotland; This study informs policy, practice, and research as the findings point to the need to involve disabled young people in choice-making to foster self-advocacy skills and supportive social networks. Informed choice needs to involve both information and emotions; Significant challenges for local authorities, service provider agencies and others are in ensuring that young disabled people and their families have access to adequate assistance to make informed choice a reality alongside supportive and innovative networks.	N/A	Self-directed Support and young adults transitioning from youth to adult services in Scotland. **Keywords**: disability, informed choice, personalisation, self-directed support, transitions

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Nieboer et al. (2011)	Availability of information from different channels to inform decision making in support for child with ID can be both a barrier and a facilitator to choices made regarding disability provider.	There is little proof that available information motivates people with ID to search for high-quality care; Results demonstrate that parents make limited use of online information; A mismatch between provided and needed information could be the reason why many parents did not utilise the online information; Given the reality of Choice processes and satisfaction with care limited resources of children with ID in maintaining their well-being levels due to additional life challenges imposed by their disability, one way of approaching this vexed issue is to concentrate on a global measure of outcome such as quality of life or wellbeing.	N/A	Decision-making processes and parent counseling in choosing disability support for their child with ID. **Keywords**: patient choice, decision-making support, decision-support information, intellectual disability, experimental design

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Nucifora et al. (2022)	Parents' experience of the transition period was influenced by interactions with government services, ongoing responsibility, and by the availability or lack of social supports; Participants felt that leaving school was difficult, primarily due to the cessation of ES's involvement; ES provides reassurance that the child is progressing and is following a curriculum aimed at increasing skills; The end of school involves transition to dependency on the NDIS, a new service which lacks structure; The application process appeared arduous with many citing difficulty navigating systems; Many mentioned that government services were still not flexible enough; Individuals have limited choice on where to reside depending on how long it takes to organize and socio-economic status; The financial costs of managing housing is a reduction in the child's independence.	Questions whether the NDIS will be able to uphold individual rights to control and choice when disability is complex and remains constant or progresses that does not present a reduced need for supports; Needs to assist parents to balance management of risk with encouragement of independence to reduce the ongoing burden parents experience; Child and adult services are poorly aligned; There is a gap for people with ID between end of schooling and entry into adult-oriented services, which includes moving to full reliance on the NDIS for funding support; Bridging this gap in close collaboration with parents is essential.	Doubts about the allocation of adequate and appropriate funding was raised as a concern.	Ideas about adulthood among parents/carers of young adults transitioning from ES into NDIS funding supports. **Keywords**: Intellectual disability; adulthood; transition to adulthood; parenting; NDIS; developmental psychology

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Priestley et al. (2022)	Mothers raising an autistic child in Aotearoa New Zealand face complex funding systems, which are difficult to navigate; Individualisation of disability funding frameworks continues to create barriers and negatively impact their wellbeing; The complexity of relationships for mothers raising an autistic child results in missed opportunities to develop relationships; Respite breaks were important but difficult to arrange; Participants wanted more respite support, and wanted more flexible support for the whole family; The needs assessment process was the first introduction to disability funding systems and described as oppressive, disjointed and complicated; There was still significant confusion around the funding guidelines.	Results urge practitioners and policymakers to support parents of an autistic child in more flexible/ holistic ways; Feedback indicated IF has not considered the needs of mothers; There is a lack of understanding from professionals; Social work is not supporting autistic people and their families; Social work education and training shapes professional practice and there appears to be a gap between curriculum and practice; As governments change disability systems, social workers and health practitioners should be able to practise with knowledge of disability.	Every mother commented that if there was some small provision of flexible funding to provide additional support to look after their wellbeing, they would use it. Most of the mothers felt they would benefit from some form of regular counselling; however, all of them remarked that the funding would need to be adjustable.	Experiences of motherhood and burden being unsupported in social care systems marked by IF. **Keywords**: Autism; individualized funding; mothers; wellbeing; disability

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Prowse et al. (2022)	Participants felt NDIS created additional stress and confusion, hindering goal achievement of their disabled family member; A history of inequity in access to services for disabled people in rural areas raised concerns about capacity of services to meet demands of NDIS funding; The shortage of services and thin markets complicate access to services; People must travel long distances to access care and support; Costs of travelling might increase financial strain and hinder the ability to maintain paid employment; Therapy sessions might be scheduled less frequently, compromising their effectiveness; People eligible for NDIS funding might be at risk of not being able to access services, have little choice or control over the services they request, and might be at risk of having unused funding withdrawn.	Rural parents/carers' need to be considered and supported in NDIS planning; The NDIS has resulted in few changes to the exacerbating inequalities, subsequently increasing the burden on parents/ carers; The successful use of NDIS funding for disabled people is reliant on parents' and carers' advocacy over their support; Those marginalised, of low-socioeconomic status, or in remote areas need the most support yet receive the least; It is crucial that providers have a thorough grasp of the needs of disabled people living in rural and remote areas.	Financial limitations and funding limitations associated with the NDIS as well as geographic distance as staff were more financially focused than client-centred.	Disparities and experiences of underservice and lack of support in rural areas **Keywords**: disability, phenomenology, qualitative research, rural health services

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Ranasinghe et al. (2017)	Aspects of the registration and funding process can be challenging for parents; the complexity of the application form, communicating with the National Disability Insurance Agency , and arranging a funding plan to suit their child's needs; Interaction with National Disability Insurance Agency planners was reported as the main reason for difficulty in accessing funding. Other reasons included not having up to date reports from health professionals or not meeting the eligibility criteria. Parents reported issues in finding suitable, available therapists to provide therapy in a timely manner; Parents provided feedback about the NDIS website, expressing difficulty in understanding the contents; The inability to locate service providers state by state on the website was a major concern.	The NDIS is continuously evolving, with further refinement to processes and eligibility criteria expected. It is possible that budgetary constraints will impact the progress of the roll out and funding allocation to individual children. A further study conducted anonymously and with a larger study sample size, particularly once the NDIS has been rolled for a longer period and to children of all ages, will provide more information about the success of the scheme in delivering early intervention services to all children with developmental disabilities.	N/A	Experiences of parents with accessing National Disability Insurance Agency /NDIS for their disabled child. **Keywords**: children; disability insurance; disabled children; early intervention; NDIS. Feedback from parents about their access to the National Disability Insurance Agency and NDIS in the early intervention rollout for their children with a disability under 7.

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Robinson et al. (2016)	Study presents tension between neo-liberal discourse and disability rights as the relationship between case management and the size of self-directed support packages; Vesting two roles of personal support/planning/ responsibility for administration, and the management of individual funds in the same person, invites conflict; Joint accountability for workers to both service-users and to organizations can be incompatible; A dissonance can arise in the relationship between the worker and the person they support and the outcome focus of programs, governments, and policy-makers; Some participants were sensitive to the power balance: those who questioned why support decisions and use of their funding packages required approval; those whose goals were not supported or rejected by their case manager.	Case management add effectiveness; Lessons from this project are that relationships, facilitative support, and control matter; Case management contributes to making effective use of the limited budgets and addressing people's goals when it promoted choice and control, built relationships, and enabled flexible fund use; A facilitative case management approach to flexibility and person-centeredness in planning, control over allocated funding, and capacity building can enhance the effectiveness of Self-directed Support. Implications include managing power differentials, financial constraints, the capacity/training of case managers.	Article draws conclusions about the benefits of case management approach, while raising questions about limitations to how much the most creative case management can mitigate the effects of inadequate funding; The implication is that the financial constraints on the young adults and case managers was considerable. Managing the financial complexities within the bureaucratic requirements was frustrating; Case managers purchased on behalf of young adults, who expressed a preference to act more independently with their money, some finding this stigmatizing and patronizing. It delayed purchases and meant that disabled people had a clear perception that they were not the decision-makers about their funding.	Self-directed support pilot project in Queensland Australia with young people and their families and the small funding case management opportunities **Keywords**: case management; disability support; disabled people; individual budgets; personalization

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Russo et al. (2021)	Frustration about systemic barriers facing the families of children with complex support needs was common; Sources identified advocacy engagement as a drain on parental resources, including emotional, financial, and sociocultural; Challenges for families identified in the current review; Parents whose children have participated in previous individualized funding packages are more likely to have existing relationships with early intervention services than those who have received no funded supports prior to the NDIS.	The NDIS commenced in 2013 with four trial sites including South Australia, the first to include young child participants' which tested policies, systems, regulations, and processes in anticipation of the full Scheme roll-out; It is plausible that parents in these studies experienced slightly different eligibility and planning processes as trials progressed; The central themes of their experiences carried through the various iterations and can provide valuable guidance for policymakers as the full Scheme is implemented across the country.	There is some reference to financial support as Dew et al. (2013) identified financial resources are necessary in the short term to enable people with disabilities and their families to overcome geographical barriers to service seeking.	Review of the literature on NDIS and its impact on children with disabilities and their families. **Keywords**: NDIS, parental experience, service provision, disability, individualized funding scheme

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Salvador-Carulla et al. (2023)	Assumptions of increased efficiency through organizational scaling up, and a greater diversity in range of service availability were not borne out; The two urban health regions' evolution of services was not consistent with the NDIS goal of creating a more diverse and responsive demand-driven system; This comparison of services before and after the NDIS has found a failure to achieve two main goals in service supply for persons with psychosocial disabilities: neither: (1) scaling up with fewer organizations providing more services nor (2) providing a higher diversity of services to meet the demands and aspirations of consumers. This study has identified that even where services have increased, service diversity has not.	A need for NDIS evaluation on the provision of psycho-social care. 4 years after NDIS rollout key objectives have not been met; It demonstrates the importance of standardised service mapping to monitor the effects of major reforms on mental health care and the need for focus at the local level; Whole system approaches are gaining attention as a key driver of health systems and should be adopted to the planning and evaluation of psychosocial services; The system should be transparent and accountable. Better measures of demand and experiences should be combined with a standard assessment of the supply.	Tentative hypotheses that disability services will transition towards a market was flawed; The responsiveness of service supply to demand is limited by structural external factors to the NDIS; Some structural factors are the weakness of the sector, minimal funding, and its peripheral place in the mental health sector; This raises questions about whether this type of market competition has encouraged stagnation rather than diversification in psychosocial care; Services struggle to remain viable by limiting the type of supports they provide. NGOs are operating within 12-month funding cycles, adding distress and uncertainty to providers, limiting their ability to plan for future need and add complexity/ instability to the system.	Pre and post analysis of service provision in WS and ACT related to NDIS rollout. **Keywords**: Mental health, service mapping, service planning, mental health ecosystems, NDIS

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Simpson & Douglas (2016)	6 of the 12 studies identified that the administrative process of managing Self-directed funding (SDF) was a source of stress for families; 6 of the 12 studies reported that while SDF offered families greater flexibility in how to spend funding, there was a very limited number of service options to spend it on; 4 of the 12 studies discussed how the positive outcomes associated with SDF were dependent on contextual variables. These variables include socioeconomic status, minority group status and geographical location, with poorer families, minority groups and families based rurally achieving poorer outcomes using SDF models.	The research-based evidence supporting the outcomes of SDF on families of children with disabilities is relatively poor; Further rigorous research is needed, particularly looking at comparing SDF against more traditional forms of service usage; Knowledge and information will be an ongoing challenge as SDF models progress; Families will be under more pressure to obtain information on what is available for their child as opposed to relying on referrals and advice; how will individuals navigate through the information available and which source will they choose to trust and act upon.	SES disparity is acknowledged as well as the intersections of SES, minority status, and geographic access to services.	Systematic review of research on SDF for children with disabilities and their families. **Keywords**: Cash-for-care; disability; Individual budgets; personalisation; self-directed funding

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Small et al. (2020)	Barriers include a lack of trusted information; Respondents reported that networks of personal contacts and relationships with service providers were their trusted sources; Messages from the government were viewed as propaganda increasing cynicism and doubts; The process of change was not well supported; Carers and PWD with lower levels of capability and internal resources could easily fall into the gap as information is missing, inaccessible, or too time consuming to comprehend; Respondents commented on the access to services in regional areas and the impact this had on the funding process, related to staffing concerns; Even respondents that had money for services, they could not enact choice and control; Some respondents saw services as babysitting rather than capacity building toward their goals.	Practical implications include identifying ways the government can improve social marketing and communication that considers the importance of building social support networks and capacity to address vulnerability; Agency staff were unable to support carers and PWD in decision-making processes often not providing timely information; Examine predictive models which forecast potential outcomes of the NDIS policy change on the well-being of individuals and their capacity to transition into services and testing mechanism designed to provide feedback of these outcomes to future policymakers.	In 2015, 1 in 5 Australians were identified as people living with a disability (PWD), of which 45% were living in poverty with higher unemployment rates; The median gross income for a disabled person aged 15-64 years was $465 per week against $950 per week for persons without disability; Financial constraints (situational vulnerability) were commonly reported issues; This reduces freedom and capability to make meaningful choices and retain control over their goals; When funds are not spent the PWD may receive less funding next time, further diminishing their ability to build capacity and creating a downward spiral that may increase their long-term vulnerability.	A three-factor vulnerability framework conceptualizes the nature of vulnerability, and examines and evaluates the intersections of these factors in relation to the capabilities approach; inherent vulnerability; situational vulnerability; pathogenic vulnerability **Keywords**: Capabilities, Social marketing, Disability, Vulnerability, NDIS, Well-being

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Smethurst et al. (2021)	Participants expressed similar frustrations: issues with equipment, placing limitations on children that reduced the family's ability to exercise the choice and control through what the NDIS is supposed to provide; Three sub-themes arose; crucial to family participation; wait times are unacceptable; and impact of not having equipment; Participants re-stated that it was frustrating to navigate; These feelings were linked to participants having the sense that they were being caught in a system where they were promised the idea of choice, but when they tried to exercise this, they were limited by the challenging systems in place under the NDIS. Three sub-themes emerged: depersonalisation through the system; administrative challenges; and lack of expertise in disability.	Occupational therapists and allied health professionals can assist by: being proactive in-service delivery and advocating for the needs of individual families and children; and finding ways to increase the preparedness of the NDIS to better understand the needs of children with CP and their families.	There were also financial burdens that were placed on the family as a result of equipment not materialising and the potential risk to children: Carers have ended up paying out of pocket with hiring fees; Carers acknowledged the stress experienced providing care managing the financial and participation issues related to their child.	choice and control limitations; participation targets; Family-centred practice (FCP) involves collaborative partnerships with families; children with multiple and complex needs; administrative burden **Keywords**: NDIS, NDIS, families, consumers, cerebral palsy, assistive technology, service provision

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Swenson & Lakin (2014)	Equity, efficiency, effectiveness, and elegance are at risk as new expectations and social and cultural challenges have been layered on top of systems of supports that have been constructed in a piecemeal fashion across decades by succeeding Congresses and defined interest groups, and managed by multiple layers of agencies with many different missions, used well or badly by many different kinds of families in many different circumstances with many different challenges and goals; It is unlikely that any part of the current delivery system is cost effective; Where would we get the courage to build a new system that responds, over time and distance, to meet the various and changing needs of all of the families who use it, as well as all who should be able to use it?	Segmentation studies offer a potential strategy to support planning for serving the diversity of family needs and to develop strategies for reaching families with the right support at the right time; Main segmentation strategies: Behavioral: What benefits do caregiving families seek from supports? Demographic: How do the ages, races, and ethnic backgrounds of caregiving families affect what they need and ask for? Geographic: Where are caregiving families located, and how can we reach them? Psychographic: How do education, income, urbanicity, cultural beliefs, and the age of caregivers or disabled family affect needs for family support?	Caregiving by family members of disabled individuals is the most important element to the sustainability of the system of long-term services and supports in the US. Without family members, the costs and demand for personal assistance providers would increase dramatically and well beyond what is currently considered affordable; Had those services been provided by paid support the costs were estimated at $450 billion dollars; Studies suggest that the direct value of uncompensated caregiving for adults with disabilities is in the range of 3 to 4 times the total state and federal Medicaid expenditures for compensated long-term services and supports.	Policy-based analysis of segmentation and technological innovation that can support disabled people and their families. **Keywords**: Family, support, disability, policy, respite, segmentation.

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Thompson (2022)	The current review process appears unsustainable and disproportionately limits the enjoyment of the rights to accessibility, equal recognition before the law, and access to justice under the CRPD.	Article demonstrates a pathway forward for the National Disability Insurance Agency and newly elected federal Labor government. This requires co-design with disabled persons, to define the problems and shape solutions; An Appeals Guiding Principles document should be established; An independent review for redesigning the review process should investigate options to promote a rights-based approach; Access to support must be increased; Transparency must be improved.	Plan funding reviews constitute the majority of review requests. This is because plans are individual and generally revised every one to two years; The review process consists of an internal review, which may be followed by an external appeal to the Administrative Appeals Tribunal. The AAT facilitates alternative dispute resolution methods between the applicant and the National Disability Insurance Agency , such as case conferencing and conciliation; Article reports widespread inconsistency in funding distribution.	AAT as a flawed process that exacerbates inequalities for disabled people contesting National Disability Insurance Agency funding decisions. **Keywords**: NDIS; disability; convention on the rights of persons with disabilities; access to justice; accessibility; equal recognition before the law

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Timberlake et al. (2014)	The analysis of parent perceptions of participant-direction was informed by three key findings about the concept of choice. Choice is unavoidable when parents have a child diagnosed with Autism Spectrum Disorder; Choice can be empowering; Informed choice can be costly and difficult to define, as families' desire for, and comprehension of information varied widely.	Personnel for autism waiver services should understand the value parents placed on interpersonal skills; Providing new waiver families with materials to ensure families get accurate information; Waiver staff might investigate whether experienced parents are willing to mentor/ support new parents; Further research: implications of parent choice about level of participation in carrying out the autism interventions; implications of expecting parents to interact with their child as a therapist/teacher; diversity of viewpoints concerning the level of active parent involvement expected in therapy for low-income parents raising children with multiple challenges.	Findings focused on relational and administrative elements of participant direction such as managing the personnel and the financial paperwork; Understanding the money was hard at first for some respondents, expressing worry about managing the budget and finances.	Perceptions of carers and families of participant direction in the Autism Waiver Program in Massachusetts. **Keywords**: Participant direction; Choice; Medicaid home and community-based services; Autism waiver

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Tracey et al. (2018)	Parents spoke about the limitations of the internet; Early childhood intervention services emerged as a key instrument in developing the capacity of families to make informed choices; It is of concern that despite the centrality of parental participation and empowerment to family-centred practice, the most commonly reported unmet need for parents of children with disabilities is that of access to information; This reported lack of information has been conveyed by parents from a range of different countries.	Understanding families' perspectives is critical as policy-makers and service providers shift practice to meet the rise of individualized funding; To support informed choices, policy-makers and providers must communicate information in helpful and accessible ways; 8 principles; information should be: a) accessible and diverse in format, mode, source and location; b) personal and targeted, appropriate for purpose and audience; b) accurate, consistent and timely; c) from a trusted source; d) from an independent source; e) culturally appropriate; f) proactive for hard to reach groups; g) gender appropriate.	N/A	Accessible, meaningful, and accurate information dissemination for parents of children with disabilities about IF schemes from professionals, early-childhood intervention that is family-centred and from other parents with children with similar diagnoses/ needs. **Keywords**: Children with disabilities, participation, individualized funding, information seeking, family-centred

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Venning et al. (2021)	AAT and NDIS relate to the imagined rights vs. fair and sustainable administration; Eligible participants want their choices recognised based on perceived need; Government wants value for money and sustainability; Entitlement involves decisions about eligibility and reasonable and necessary support; Decisions about funded support are based on competing ideas of best practice, aptness of other services, cost effectiveness, and sustainability; Choice and control raises the possibility of normative judgements about what support looks like as concerns about sustainability grow; Some individuals are able to derive greater benefit compared to others; The struggle between health-specific or disability-specific supports indicate sustainability concerns.	Scheme transparency and fairness should inform broader debate about core principles and values to inform decisions about scarce resources in society; Public debate about the principles and values that are important for the allocation of scarce resources and what this means for administrative justice in disability support provision; Tune (2019) provided 29 key recommendations to reduce the complexities in the NDIS; A vital recommendation was for the National Disability Insurance Agency to make more explicit how reasonable and necessary support decisions are made.	As implementation of the NDIS has proceeded, political and economic concerns about its sustainability have ensued as the average cost per participant and initial operating costs have far exceeded what was predicted highlighting the financial risks; This led to advocating for cost control through an ethos of reasonable and necessary support; The requested support should allow the participant to pursue goals and objectives; will facilitate economic and social participation; meets current good practice; is most appropriately provided by the NDIS; and cannot be reasonably expected from families, carers, informal networks, and community.	**Keywords**: Administrative Appeals Tribunal (AAT); NDIS; choice and control; cost-effectiveness; reasonable and necessary; Federal Court Appeal; ambiguities in NDIS assignments; legitimate supports; transparency and fairness; scarce resources; scheme sustainability; friction between what is deemed family responsibility versus NDIS responsibility.

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Welch et al. (2012)	Direct Payments (DP) implementation has been relatively slow with variations in uptake between constituencies of users and across local authorities; The use of DPs is socially patterned, with greater uptake by educated, younger adults, physically disabled, with professional backgrounds and without mental ill health; Uptake of DPs is slow in families with a disabled child; The use of DPs among families with disabled children is inequitably distributed with higher levels of use by families in less deprived areas, carers with higher education, White British carers, female carers and families with younger children; Families report benefits using DPs: a greater sense of control and increased service flexibility; Families report problems accessing DPs linked to the processes through which they are delivered.	Future research should evaluate services providing DP support to families from different ethnic backgrounds and in areas of higher deprivation, investigations of the experiences of male and female carers and the attitudes of practitioners to DP use by different groups; Direct payment processes could be improved by provision of clear information, eligibility criteria, simplification of assessment processes and streamlining of administration; Inequities could be reduced by tailored support for families considering and using DPs; sufficiently resourced to enable individualized responses family needs.	There was no significant difference in the reported financial concerns of families using DPs and other families. It seems likely that if DPs are to be distributed more equitably, both promotion of DPs and support for their use will need to be proportionately greater in relatively deprived areas.	Gender disparity in carers obtaining DPs for short breaks; SES disparity in carers obtaining DPs for their children for short breaks; administrative burden **Keywords**: Children, Direct payments, Disability, personalization.

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Whitaker (2015)	Despite recent developments there remains a lack of research on the frontline of personalisation, exploring how social workers and families experience, understand and manage it; Families could realise control by undertaking the role of coordinator and orchestrator by managing direct payments, enabling them to choose how and when their child was supported. Despite breaking away from local authority provision by becoming an employer, families still had to account for the spending on their personal budgets in detail and on a very regular basis. Parents become managers, accountants, auditors and commissioners as they coordinate services around their child.	Children's services and personalisation of disability support moved from managed to individual to personal budgets; Questions must be asked about professionals sharing resources across boundaries; There are real challenges ahead for the strategic integration of budgets at the organizational level. The idea of integrated support around family contends with ideas of greed, abject parents; There are significant cultural and political struggles ahead for education, health and social care to come together to genuinely support disabled children within their families.	Demands to manage risk and demonstrate fiscal responsibility seem to trump ideals of user empowerment and self-direction; Families had to open new bank accounts for direct payments to be deposited into; they had to report on their spending quarterly which required fastidious collecting of receipts and invoices. If families failed to adequately audit themselves, their direct payments could be stopped. If they did not spend their budget by the end of the year, the authority could claw it back. If a family stated they would use a service and then did not, the authority could restrict access the following year; The concern with the budget belonging to the child could lead to suspicion being raised about parental spending.	Personal budgets; self-directed supports; austerity; family roles; personal assistants. **Keywords**: Personalization, Integrated health and social care, Disability, Social care, Policy implementation, Children's social work

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Whitburn et al. (2017)	Educational access is highlighted as a strategic goal of the scheme's development, though how this takes affect for children and young people and their families is yet to be seen; The extent to which the new policy will articulate opportunities for increased inclusion of young people with disabilities in schooling is unclear; The move towards opportunity and social justice appear to be limited by these continued restraints [categorical and reductive positioning]; Participants anticipated the NDIS would incorporate their child's education that would support inclusion in schools; All participants experienced coercion as part of their experiences with the NDIS, and only one participant felt empowered which suggests that choice and control are notions that may seem inviting, though can be perplexing when considered in relation to articulated goals.	The paper concludes how NDIS might be reframed for better outcomes; It is imperative of the policy to correspond more closely with scheme participants and education services; The disconnect between the NDIS and education diminishes its capacity to affirmatively affect the lives of people with disabilities and the wider community, which will likely perpetuate if not addressed as the scheme matures.	Policy and financial pressures challenge the scheme's person-centred framework.	Lack of integration school jurisdiction/support, health services, and NDIS for people and children with disabilities and their support networks. **Keywords**: NDIS; critical disability studies; policy enactment; inclusive education; NDIS

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
White et al. (2021)	The NDIS restructured funding promoting greater choice and control; For remote communities there is concern that demand may be insufficient to secure the local supply of services needed. The NDIS application process can be complex and often inaccessible for disabled Aboriginal and Torres Strait Islander people; Advocates have raised the need for accessible support and training for people to self-manage their NDIS plans once access to the scheme is granted, especially for those who may experience language or cultural barriers; For some Aboriginal people access to a client advocate to support in navigating complex systems is necessary; Normalisation, fear of stigmatization, and a history of culturally inappropriate services further complicate Aboriginal people's self-identification with, and perceptions of, disability.	Awareness needed about differing perceptions of disability; Disability should not be seen as a deficit; Conversations need to be strength and resiliency focused; Engagement should be at the individual and community level; National Disability Insurance Agency resources should be made culturally appropriate for Aboriginal people in the Kimberley and delivered by community controlled organizations guided by place-based engagement; Aboriginal-led approaches were identified as best placed to overcome the historical and systemic factors that contribute to low levels of engagement by disabled Aboriginal people.	The program was frequently described as successful by staff. Despite this, there was a strong sense that the work had just begun with staff voicing fears that the project would not be funded after the current contract ends in the middle of 2021.	Aboriginal community networks and disability barriers; support programs for access to NDIS in remote and culturally diverse location. **Keywords**: NDIS; Aboriginal; disability; remote community connector; Aboriginal Community Controlled Health Service

	Barriers and Facilitators	Policy Considerations	Financial Considerations	Themes and Keywords
Yates et al. (2021)	Children and young people with disability and their families experienced significant disruption to their lives during the early stages of the pandemic, and for many this had detrimental impacts on their wellbeing; The implementation of the NDIS was patchy, with inequalities in participant outcomes and problems with accountability, flexibility for participants, and the market-based delivery model; Respondents experienced barriers to accessing NDIS supports to assist in the education of students with disability. One significant barrier related to the interface between the NDIS and the education system; NDIS was hard to interact with, involving administrative burden (e.g., ridiculous complexity and red tape) and frequent rule changes and delay.	NDIS has been criticized for being inflexible in accommodating changes to plans; Advocacy is important to ensure that the scheme operates in an equitable way, and yet these services have seen considerable cuts recently; NDIS funding to support education during the first COVID-19 lockdown period has shown that individual funding schemes are not more flexible than traditional systems in an emergency situation; Useful flexibility depends on clarity of information, proactive support and participants' ability to quickly navigate a complicated system; It is recommended to reinstate advocacy funding to better people in IF schemes.	Pandemic-related school closures meant that many supports previously provided by the education system ceased, meaning parents and carers became responsible for the day-to-day educational management of students. This led to changed needs for NDIS supports as parents struggled to balance work, caring and education. Of the students with disability who received NDIS funding represented in this survey, the needs of 45% had changed with respect to accessing education.	Barriers to services due to COVID-19 lockdown; educational burden shifted to family members and parents; administrative barriers and lack of flexibility; **Keywords**: care, personal budgets, purchaser provider relations, children and young people, coronavirus, disability, education, early years and schooling, individualized funding schemes.

Appendix 3: Commentary

In this commentary, we offer further expansion on key points related to IF beyond the scope of the literature review in the main body of this report to provide an expanded understanding of key IF considerations. The current literature review was based on facilitators and barriers as presented in the peer-reviewed sources specific to IF and children, youth, and young adults with disabilities/support needs as defined by the research methodology set out on pages 8-13 of the report. As such, the report delineates the synthesized findings based on 58 peer-reviewed articles meeting these inclusion criteria. A more in-depth understanding of socio-cultural factors, geographic location, accessibility of information, administrative burden goes beyond the included 58 articles for the current review.

The commentary offered here draws directly upon content included in the main report (citations in blue) and incorporates additional information from sources (citations in red) not specific to disabled youth and young adults and their families or carers (see references). These additional sources are peer-reviewed articles included in a larger scoping review of 347 sources that the UBC Canadian Institute for Inclusion and Citizenship is preparing for CLBC.[28] This commentary focuses on: 1) the challenges with navigation impacting supports; 2) the concerns related to administrative burden; 3) the contextual barriers based on socio-cultural factors; 4) the availability of appropriate human resources; 5) the factors associated with implementation in rural and remote communities; and 6) final reflections and a discussion of Global Standards for Self-Directed Supports.

2.2.2.2 Challenges with navigation impacting supports

While issues related to challenges with navigation impacting support exist in the children and youth with disabilities literature, more general concerns and barriers identified are less age-specific and seem to exist across IF models internationally. There are a number of aspects to communication that are potential barriers to effective use of IF. As noted, many of these will generalize across other service delivery approaches but can be exacerbated in an IF system where the family may be required to independently apply for funding, arrange services, and follow reporting and administrative guidelines. All these processes require a

---

[28] The original 58 articles are reflected in-text in blue. Outside sources from the larger 347-article review are red in-text and listed in the references in this document.

family or caregiver to have the ability to easily understand what can be complex material. This can create a significant disadvantage for non-native English speakers, persons with lower levels of literacy or digital literacy, people from cultures which do not emphasize written communication, or simply people unfamiliar with this type of activity. While this can be mitigated to some degree by ensuring broadly accessible information and communication, as well as access to support, it does create structural disadvantages for some individuals and communities, particularly individuals from equity deserving communities.

In a practical sense, communication barriers include a lack of accessible and understandable information, a lack of timely communication about IF application processes and provision, and financial and administrative burdens. In the context of Australia, Alexander et al. (2019) and Boaden et al. (2021) discuss how the transition to IF came with uncertainties. Families reported a complex application process with long wait times, at times leading to gaps in services and supports. Parents or carers expressed difficulty communicating with support workers, the NDIA, and struggled with inadequate online information resources (Boaden et al., 2021; Gavidia-Payne, 2020; Loadsman & Donelly, 2021; Leutz et al., 2015; McDonald et al., 2016; Nucifora et al., 2022; Prowse et al., 2022; Ranasinghe et al., 2017; Russo et al., 2021; Tracey et al., 2018).

People navigating access to IF reported limited guidance on services, inequalities in planning, approval, and review processes, and consequences of unequal capacity to take on self-management (Alexander et al., 2019; Boaden et al., 2021; Fisher et al., 2023; Nucifora et al., 2022; Ranasinghe et al., 2017). NDIS applicants expressed difficulties with the online portal (Mason et al., 2018; Stewart et al., 2020). According to Mason et al. (2018), "basic functions of the online portal [are] being reported as challenging and too complex by participants" (p. 143). Similarly, Stewart et al. (2020) assert that "the NDIS is highly reliant on people … to use the NDIS 'myplace' online portal to access and manage their funding package [which] impacts particularly on those who experience difficulties with digital access and digital literacy" (p. 36). The online system and virtual assistant 'Nadia' (Stewart et al., 2020), rely on information from Australian states and territories about 'legacy clients' identified as priority applicants by the NDIA that together with intake questionnaires inform metrics, access decisions, and preliminary plan profiles for NDIS participants (Carney et al., 2019, p. 787). This resulted in data deficiencies and broad-spectrum questionnaires or intake information that led to decision errors "at odds with the needs of participants" (p. 787). These communication barriers were linked to delays in assessment, and the delayed development and coordination of children's plan implementation (Boaden et al., 2021; Gavidia-Payne, 2020; Russo et al., 2021).

According to Nucifora et al. (2022), Ranasinghe et al. (2017), Small et al. (2020), and Smethurst et al. (2021), many parents communicated difficulty with arranging a funding plan to suit their child's needs. At times, this difficulty would result in parents perceiving lack of expertise and understanding of disability within the NDIA, placing limitations on children's plans that reduced the family's ability to exercise choice and control (Smethurst et al., 2021, p. 210). This strain was exacerbated by NDIS participants and their families being unable to meet support workers in person or having to communicate with different support workers each time their plan had to be adjusted or renewed (Fisher et al. 2019; Lloyd et al. 2021).

Strained communication led to increased frustration about barriers facing the families of children with more complex support needs (Russo et al., 2021). In addition, Loadsman and Donelly (2021) specify that parental frustration and failure to access social services was linked to parents' experience of personal wellbeing. Family members felt they were letting their child down in not being able to secure supports (p. 1463). According to Prowse et al. (2022), participants felt the NDIS created additional stress and confusion, hindering goal achievement of their disabled family member (p. 212). Some researchers address that the IF schemes rely on informal support systems, increasing the burden on family members (Arnold et al., 2015; Broady 2014; Cresswell 2017). Available social support through a trusted service provider or coordinator, identified as a facilitator, is a barrier when absent or not available to parents and family members navigating the IF system (Nucifora et al., 2022).

2.2.2.3 Administrative burden

Administrative and financial burden experienced with IF models included both logistic problems and a lack of access to self-management supports, leading to feelings of stress and concern among family members and carers of disabled children. According to Leutz et al. (2015), logistic problems included cumbersome steps for purchasing goods or services where families either had to pay up front or were not allowed to pay up front, complicating access to goods and services (p. 35). Logistic problems could lead to services not being utilized as hoped for or leading to service gaps and financial distress (Alexander et al., 2019; Boaden et al., 2021; Laragy & Ottman, 2011). According to Gavidia-Payne (2020), participants experienced concerns in their new transactions with the disability system and felt overwhelmed in dealing with uncertainty around terminology, systems, settings, and funding (p. 190). McGuigan et al. (2016) reported that responsibility levels of DP caused anxiety for some concerned about the paperwork for employing personal assistants and other concerns associated with bureaucracy, paperwork, and administration. Similarly in Northern Ireland, McNeill and Wilson's (2017) found that respondents identified recruitment, administration and monitoring, and financing and rates of payment stressful aspects of DP management. Laragy and Ottman (2011) add that family stress due to a lack of information about funding and inadequate funding, led self-managing families to have to invest funds in seeking information, leaving fewer funds for personal support needs.

A lack of clarity about funding allocation and IF spending created barriers to using funding for specific types of support. According to Nucifora et al. (2022), parents managing housing and the associated financial costs results in a reduction in the child's independence and their child's ability to self-manage their funds. Collins et al. (2014) discuss various barriers to accessing DPs for respite or short breaks that caused concerns among parents. According to Priestley et al. (2022), mothers raising an autistic child in Aotearoa New Zealand faced complex funding systems, in which respite breaks were important but difficult to arrange serving as one example of significant confusion around funding guidelines (p. 123).

More specific examples of administrative burden and the impact on service provision and experiences for people with disabilities include the impact of new NDIS policies for non-profit service providers that have to pivot their business model (Carey et al., 2018; Carey et al., 2020). As Carey et al. (2020) argue, these administrative barriers relate to burdens emerging from a marketized system, including new requirements in a variety of forms, new processes and requirements of government, new registration and compliance models, and the training of staff (p. 1368). This administrative burden goes hand-in-hand with financial burden as compliance with NDIS standards results in overhead costs for organizations. This impacts people with disabilities and their carers and families as the changing policy landscape makes it difficult to provide a consistent service. Funding has decreased and costs to deal with administrative tasks and implementation of the scheme led to out-of-pocket costs (p. 1369). These barriers for service providers resulted in waiting lists for participants. Some service providers are exiting from the market, causing a loss in services and thin markets.

2.2.2.4 Contextual barriers based on socio-cultural factors

IF can be an effective means of promoting respectful and culturally competent supports by devolving the power and control over how and by whom supports and services are provided. For example, an IF approach to respite allows families to employ those who are part of their own cultural community and whose values and traditions align with those of the broader community. Generic agencies not directly connected to the community can be met with distrust and unintentionally convey an invasive or colonial attitude. Many indigenous communities and individuals have a well-earned distrust of colonial social service systems and may avoid engagement with them based on this distrust, and culturally unsafe spaces and practice. In IF systems, individuals and broader communities, through the pooling of IF funds, can exercise a greater degree of control and ensure a greater degree cultural competency through a self directed/ IF model. That said, it does not address the broader issues discussed above regarding effective and culturally competent communication, availability of specialized supports, and the need for effective planning and facilitation supports. Frequently the absence of these creates challenges for effective IF based supports.

The identified barriers based on socio-cultural factors as specified on page 38 reflect those articles that specifically address the compounding marginalization of Indigenous people, Aboriginal and Torres Strait Islander people, and people from culturally and linguistically diverse backgrounds in IF schemes (Boaden et al., 2021; Dew et al., 2023; Laragy & Ottman, 2011; White et al., 2021). According to White et al. (2021), “[T]he NDIS application process can be complex and often inaccessible for disabled Aboriginal and Torres Strait Islander people” (p. 2). Barriers include but are not limited to: a lack of culturally appropriate and accessible support and training for Aboriginal and Torres Strait Islander people as well as culturally safe support workers; a lack of understanding across language and cultural barriers about disability; fear of stigmatization; and, a history of culturally inappropriate services marked by colonisation leading to distrust of disability services (White et al., 2021). Ferdinand et al. (2021) express that Indigenous people are neglected in disability research and literature. There is limited understanding and consideration of how Indigenous people experience disability that hinder the development of accessible services and the creation of disability policy that is appropriately responsive to the needs and realities of Indigenous people with disabilities (p. 1).

In Australia, researchers assert that supporting Aboriginal and Torres Strait Islander people with disabilities requires more disability support workers that listen to and respond to the specific needs of this population with an understanding of culture and community-based supports (Dew et al., 2020). This is complemented by what Phuong et al. (2017) identify as differences in conceptualizing ideas of disability between Australian mainstream services and Indigenous communities whose languages might not include an integrated notion of disability. Furthermore, impacts of colonization and mistrust of the government's disability services continue to challenge the lives of Indigenous people with disabilities and their trust in governmental systems (p. 51-52). These barriers are further complicated by geographic constraints of the IF scheme in Australia which have been identified as underserviced in rural and remote areas, where the quasi-market system has led to thin markets and a reduction in available services for Aboriginal and Torres Strait Islander people living in those regions (see section 2.2.2.6).

Specific to people from culturally and linguistically diverse backgrounds, identified barriers to navigating health and social care systems included unfamiliarity, cultural and language differences, and a lack of access to interpreters. Dew et al. (2023) address that for refugees from Iraqi and Syrian backgrounds the NDIS presents access barriers. Participants in the study indicated that the online application for IF was hard to navigate. In part this was because online systems lack culturally appropriate assessment tools for refugee families who report having only limited access to medical diagnoses in the absence of prior service use in their country of origin (Dew et al., 2023, p. 3). This lack of culturally appropriate assessment tools does not only speak to the experience of refugees but is also present for people with disabilities from culturally and linguistically diverse backgrounds and Indigenous people. Cultural diversity impacts some people eligible for IF under the NDIS as they and their communities might have disparate understandings of disability that connect to stigma, exacerbated by a lack of culturally appropriate documents and language interpreters (Ferdinand et al. 2021; Mellifont et al., 2022; White et al., 2021).

Other barriers identified across IF models and jurisdictions pertain to family resources and capacities, socio-economic status, disparate experiences of people from culturally and linguistically diverse backgrounds, availability of skilled workers, and geographic disparities for those living in rural and remote areas with significant distance to a metropolitan centre or support service locations. A lack of personal family resources and capacity present various challenges for families with a disabled child (Boaden et al., 2021; Ellem et al., 2019; Laragy & Ottman, 2011). Whereas valuable family relations and community connections have been identified as facilitators to experiences with IF, lacking relationships and community support presents a barrier to IF experiences. In turn, Meltzer and Davy (2019) indicate that IF practices mean that the support disabled people may need or benefit from to participate in reciprocal, positive, and fulfilling relationships risk being overlooked in the individualized planning and funding process.

A lack of capacity on behalf of family members according to Ellem et al. (2019) and Laragy and Ottman (2011) means planning around disabled family members presents challenges for families, who might be resistant to change, and may have a different agenda for the disabled person. In addition, planning often does not involve disabled children or young people in planning (Laragy & Ottman, 2011; Mitchell, 2014). According to Brien (2018), this barrier involves the limited capacity and/or unwillingness for caregivers and professionals to adopt a child-centred attitude, at times assuming that children are not capable or competent (see also Mitchell, 2015). Ellem et al. (2019), Cowen et al. (2011), and Mitchell (2014) point at a lack of trust or low confidence in programs offering self-directed support among family members with lower socio-economic status and resources.

According to Boaden et al. (2021), lower social capital results in added difficulties navigating access to the NDIS and IF (p. 300). Other research similarly identifies that IF models operate within socio-cultural disparities and in some cases increase disparity due to a lack of social inclusion leading to further alienation of equity deserving groups and those with more complex disability support needs (Laragy & Ottman, 2011; Marks et al., 2022; McDonald et al., 2016; Small et al., 2020). Simpson and Douglas (2016) found that poorer families, minority groups, and rurally-based families achieve poorer support outcomes using self-directed funding models.

There is no question that IF requires a higher degree of engagement from families and users than traditional block or agency-based supports. This can create significant challenges for families who are already struggling with poverty, single parenthood, lower educational outcomes, literacy or financial literacy. There is no simply answer to this, though effective communication and planning and facilitation supports can help. One solution may be to provide a ‘host agency’ type option where families can maintain decision making control but are not additionally burdened with the administrative and financial management. Various IF schemes in the United States and Europe provide financial management support options to reduce administrative and financial strain on families (Croft et al. 2018; Gross et al. 2012; Simon-Rusinowitz et al., 2014). Other sources point at the importance of market stewardship in mitigating barriers experienced by people with disabilities, most notably in the NDIA in Australia (Bracci 2014; David & West 2017; Dickinson et al., 2022).

2.2.2.5 Availability of appropriate human resources

A common concern with all types of disparity identified in accessing IF supports is the availability of professional and skilled staff to provide the support families want to purchase or employ with their IF. According to McDonald et al. (2016), concerns about the NDIS include "shortages of appropriately skilled staff" (p. 279). Similarly, Ranasinghe et al. (2017) state that parents reported issues in finding suitable, available therapists to provide therapy in a timely manner (p. 30). Concerns about skilled staff were compounded by geographic constraints that limited the availability of affordable skilled support workers, even with approved IF plans.

Geographic constraints mean people living in rural and remote areas experience skilled worker shortages and thin markets as an effect of the NDIS roll-out (Bracci 2014; David & West 2017; Dickinson et al., 2022). According to David and West (2017), the conflation of marketization and self-direction change the nature of relationships between citizens, the state and the market, with consequences for participant choice and control in potentially thin markets or even market failure (p. 339). A lack of services being offered in a particular area, or the lack of specialized services, according to Dickinson et al. (2022), "highlight the need for market stewardship, which refers to the government intervention necessary to ensure that public service markets are operating effectively" (p. 15). In addition, these thin markets or lack of access to services requires NDIS participants or workers to incur additional costs due to travelling expenses not covered by the NDIA (Fisher et al., 2023).

2.2.2.6 Rural and remote factors

In theory, IF has been seen as an alternative to block funded services not readily available in more remote communities. The ability to hire from one's own network or from the surrounding community mitigates against the absence of formal service providers. This, however, is more complex in relation to children's supports and services. In the adult population, the most extensive supports generally involve personal support, attendant care type services, and community engagement and employment supports. Evidence on the adult side shows many people prefer to hire and train their own support workers rather than rely on credentialed or agency-based workers. This flexibility means that even in remote communities there are potential workers available despite the absence of formal services or agencies. On the children's side, however, services and supports tend to be more specialized therapeutic or developmental supports, which require more professional and trained workers which are not available in many rural or remote communities. Hence, while IF can enhance respite type supports which do not require the same degree of specialized training, it does not resolve the challenge of obtaining more specialized supports in rural and remote communities. That said, this is also the case with block or agency-based services and IF can provide an advantage due to its flexibility and eliminating the need for a full agency. These issues are not insurmountable if systems are put in place to address them. Itinerant providers, funded through individuals' IF is a possible solution but would require some coordination and planning to implement and ensure broad coverage. Effective planning and facilitation supports are also required to makes this work effectively.

Eleven articles specific to children with disabilities and their carers address barriers experienced by those families and disabled young individuals living in rural and remote areas (Boaden et al., 2021; Dew et al., 2013; Dew et al., 2014; Gallego et al., 2018; Howard et al., 2015; Johnson et al., 2020; Laragy & Ottman, 2011; McDonald et al., 2016; Simpson & Douglas, 2016; Prowse et al., 2022; Small et al., 2020). As Dew et al. (2013) summarize, in the context of rural and remote areas there is: a) lack of information and advice; b) limited local service options and capacity; b) higher costs and fewer services; and c) complexity of self-managing packages. According to Skinner and Rosenberg (2006), who conducted an analysis of non-profit and for-profit services in long-term care services in rural Ontario, IF constraints are to be expected in the context of geographic, sociocultural, technological, and workforce barriers, especially in market-oriented model. This is evident in the research by Dew et al. (2014), who discuss the challenges faced by rural service users in Australia. Most challenges are due to the difficulties service providers encounter in providing therapy across large geographic areas to dispersed populations. Services that used to be delivered based on block-funding offered by a mix of government providers, non-government organizations, and private practitioners using outreach services are now meant to be serviced in a quasi-market system with publicly funded IF packages. "Dependent on proximity to a larger centre, rural service users travel long distances, wait a long time, and receive less frequent interventions than their metropolitan counterparts” leading to choices among service users to remain in their rural communities or move to larger centres (Dew et al., 2014, p. 60). In addition, according to Howard et al. (2015), families with a disabled child aged under five years, living in regional or rural locations experience the scheme as focused on disabled adults, making choice and control not age appropriate (p. 1366). Howard et al. (2015) report that a limited accessibility of services, including home visiting, was a major concern for research participants dealing with transport and logistical challenges (p. 1372).

Several articles specifically address the complications of the IF model in a publicly funded market system of supply and demand. This context presents barriers to accessing disability supports in rural and remote areas based on workforce shortages, lack of specialist services, high staff turnover, and a lack of timeliness in intervention due to minimal availability of local or outreach services (e.g., Johnson et al., 2020; Prowse et al., 2022). Rurally available workers may not be familiar with practices in disability support and are sparsely distributed making accessing clinical supports difficult. As choice and control in rural or remote areas may mean choosing the only clinician or having no options to choose from (Johnson et al., p. 2210). Similarly, Laragy and Ottman (2011) acknowledge that the primary objective of choice and control under IF for families in rural areas is limited (see also McDonald et al., 2016). According Simpson and Douglas (2016), even though self-directed funding “offered families greater flexibility in how to spend funding, there was a very limited number of service options to spend it on” (p. 60; see also Small et al., 2020).

Final Reflections

- How do we know when an IF system is effective? How is an effective IF system defined? Is it improved developmental outcomes in children?/ improved quality of life for young adults and adults?
    - There is no single answer to this as this will vary between jurisdictions and the goals they set for each program. In general measures such as developmental outcomes would be common. Quality of life (QoL) can be measured, though it is more subjective, good tools exist such as Brown and Brown’s Family QofL scales and Schalock’s QoL tools. Tools only measuring developmental outcomes but missing broader family wellbeing, risk not

capturing the ‘costs’ the developmental outcomes has on the family. In other words, you may likely want to measure both individual developmental outcomes in addition to family outcomes. In addition to these traditional measures, IF systems frequently also measure things like ‘felt degree of control’, choice etc. as measured by scales such as the National Core Indicators in the US.

- What does a ‘well-designed and regulated system’ (p 88) look like?

Again, this will vary between jurisdictions and the nature and goals of any given system. From an IF/Self-direction perspective common elements may include:

  - Funding that reflects differing levels of need (rather than a diagnosis-based fixed amount for example)
  - Clear and transparent assessment and allocation systems
  - Clear and accessible communication
  - Sufficient support systems for planning, facilitation and administration
  - A high degree of decision-making control
  - A high degree of flexibility in use
  - Portability within jurisdictions
  - A ‘least intrusive’ approach to monitoring and regulation

Recently, a group of experts came together through the International Initiative for Disability Leadership (now GLE) and the Self Direction Network to develop a set of standards for self directed supports. These are primarily adult focussed but would generally apply to children and family supports as well.

Global Standards for Self-Directed Supports

We all have the right to live a life of freedom and full community inclusion. These fundamental rights were articulated in the Universal Declaration of Human Rights in 1948. The 2006 Convention on the Rights of Persons with Disabilities underscored that human rights apply to all people regardless of disability or chronic illness. To ensure human rights for all, we must organize systems that maximize autonomy of the person to make choices and exercise control over their supports. The following are essential elements of a self-directed support system:

- A dedicated budget, individualized and controlled by the person with any support they choose, used flexibly and creatively to promote the person's best life
- Access to legally recognized supported decision-making that minimizes substitute decision-making and the loss of legal agency
- Outreach and education on self-directed supports, beginning in early childhood
- Clear and simple information on self-directed supports, widely available in the mainstream, tailored for cultural responsiveness and relevance, and fully accessible
- Practical administrative processes that minimize participant burden

References

Arnold, S. R., Riches, V. C., & Stancliffe, R. J. (2015). Does a Measure of Support Needs Predict Funding Need Better Than a Measure of Adaptive and Maladaptive Behavior? American Journal on Intellectual and Developmental Disabilities, 120(5), 375–394. https://doi.org/10.1352/1944-7558-120.5.375

Bracci, E. (2014). Accountability and governance in social care: The impact of personalisation. Qualitative Research in Accounting and Management, 11(2), 111–128. https://doi.org/10.1108/QRAM-04-2014-0033

Broady, T. (2014). What is a person-centred approach? Familiarity and understanding of individualised funding amongst carers in New South Wales: Australian Journal of Social Issues, 49(3), 285– 307. https://doi.org/10.1002/j.1839-4655.2014.tb00314.x

Carey, G., Malbon, E. R., Weier, M., Dickinson, H., & Duff, G. (2018). Making markets work for disability services: The question of price setting. Health and Social Care in the Community, 27(5), e716–e723. https://doi.org/10.1111/hsc.12780

Carey, G., Dickinson, H., Malbon, E., Weier, M., & Duff, G. (2020). Burdensome Administration and Its Risks: Competing Logics in Policy Implementation. Administration and Society, 52(9), 1362– 1381. https://doi.org/10.1177/0095399720908666

Cresswell, A. (2017). Collateral damage: Australian carers' services caught between aged care and disability care reforms. International Journal of Care and Caring, 1(2), 275–279. https://doi.org/10.1332/239788217X14951899318122

Croft, B., Simon-Rusinowitz, L., Loughlin, D. M., & Mahoney, K. J. (2018). Mental health leadership perspectives on self-direction. Social Work in Mental Health, 16(4), 381–399. https://doi.org/10.1080/15332985.2017.1395783

David, C., & West, R. (2017). NDIS Self-Management Approaches: Opportunities for choice and control or an Uber-style wild west? Australian Journal of Social Issues, 52(4), 331–346. https://doi.org/10.1002/ajs4.23

Dew, A., Barton, R., Gilroy, J., Ryall, L., Lincoln, M., Jensen, H., Flood, V., Taylor, K., & McCrae, K. (2020). Importance of Land, family and culture for a good life: Remote Aboriginal people with disability and carers. Australian Journal of Social Issues, 55(4), 418–438. https://doi.org/10.1002/ajs4.96

Dickinson, H., Yates, S., Dodd, S., Buick, F., & Doyle, C. (2022). "Most people don't like a client group that tell you to get fucked": Choice and control in Australia's National Disability Insurance Scheme for formerly incarcerated people. Public Policy and Administration. https://doi.org/10.1177/09520767221134320

Ferdinand, A., Massey, L., Cullen, J., Temple, J., Meiselbach, K., Paradies, Y., Baynam, G., Savarirayan, R., & Kelaher, M. (2021). Culturally competent communication in Indigenous disability assessment: A qualitative study. International Journal for Equity in Health, 20(1). https://doi.org/10.1186/s12939-021-01402-9

Fisher, K. R., Gendera, S., Graham, A., Robinson, S., Johnson, K., & Neale, K. (2019). Disability and support relationships: What role does policy play? Australian Journal of Public Administration, 78(1), 37–55. https://doi.org/10.1111/1467-8500.12351

Fisher, K. R., Gendera, S., & Kayess, R. (2023). Reaching people who are marginalized in major disability policy reform. Global Social Policy, 23(1), 109–126. https://doi.org/10.1177/14680181221075558

Gross, J. M. S., Wallace, L., Blue-Banning, M., Summers, J. A., & Turnbull, A. (2013). Examining the Experiences and Decisions of Parents/Guardians: Participant Directing the Supports and Services of Adults with Significant Intellectual and Developmental Disabilities. Journal of Disability Policy Studies, 24(2), 88–101. https://doi.org/10.1177/1044207312439102

Lloyd, J., Moni, K., Cuskelly, M., & Jobling, A. (2021). Exploring the complexity of implementing National Disability Insurance Scheme plans for adults with intellectual disability: Parents' perspectives. Journal of Intellectual and Developmental Disability. https://doi.org/10.3109/13668250.2020.1843764

Mason, J., Crowson, K., Katsikitis, M., & Moodie, M. (2018). Australia's National Disability Insurance Scheme: A collaboration opportunity for academia and industry. Tizard Learning Disability Review, 23(3), 139–146. https://doi.org/10.1108/TLDR-04-2017-0021Mellifont et al., 2022

Phuong, D. L. (2017). How well does the Australian National Disability Insurance Scheme respond to the issues challenging indigenous people with disability? Aotearoa New Zealand Social Work, 29(4), 49–60.

Simon-Rusinowitz, L., Schwartz, A. J., Loughlin, D., Sciegaj, M., Mahoney, K. J., & Donkoh, Y. (2014). Where are they now? Cash and counseling successes and challenges over time. Care Management Journals, 15(3), 104–110. https://doi.org/10.1891/1521-0987.15.3.104

Stewart, V., Visser, K., & Slattery, M. (2020). Supporting choice, recovery, and participation: Clear and easy to understand information is the key to NDIS access for those with psychosocial disability. Journal of Social Inclusion, 11(2), 33–46. https://www.scopus.com/inward/record.uri?eid=2-s2.0-85092442699&partnerID=40&md5=8cc2d18710cd95c4c69373eef499b2c9

Appendix 4: Infographic

See next page.

“Individualized Funding” (IF)...

... is funding given to an individual, or their parents/guardians, to support **disability-related needs.**

- the **amount** of funding is determined by the individual and/or family’s specific needs and wants
- the individual and/or their family determine **how** funds are used to meet those needs

Stainton, 2009

We conducted a **scoping review** of 58 articles on IF, from international literature.
In our review, we found...

Benefits

Person-centred and fosters **self-determination**

Control, choice, reliability, flexibility

Facilitators

Clear lines of **communication**

Family **status, social capital, capacity,** and geographic **location**

Interagency **collaboration**

Trusted **service providers**

Barriers

Administrative burden

Lack of **access to information**

Existing **inequities**

Rural and remote constraints

Availability of **professional and skilled staff**

Siloed systems
(e.g., health care, social care)

Age-based **transition periods**
(e.g., youth to adult services)

What does this all mean?

- IF can be used in a **broad range of ways** to support children and families
- To work well, IF requires support for: **planning;** recruitment and hiring of **professionals and support workers;** funding and employee **administration**
- IF will not replace all agency services
- IF presents unique challenges & opportunities for **rural and remote communities**
- IF presents unique challenges & opportunities for **Indigenous and other cultural communities**
- When done well, IF is **cost effective** and can support **positive outcomes** for children and families.

THE UNIVERSITY OF BRITISH COLUMBIA
Canadian Institute for Inclusion and Citizenship

BRITISH COLUMBIA
Ministry of Children and Family Development

Full report available at www.ciic.ubc.ca