McMaster University | HEALTH FORUM

Rapid Synthesis Appendices

Features and Impacts of Individualized Funding Models for Children and Youth with Support Needs and Their Families

27 September 2023

[MHF product code: RS 110]

Appendix 1: Methods

Background to the rapid synthesis

This rapid synthesis mobilizes both global and local research evidence about a question submitted to the McMaster Health Forum's Rapid Response program. Whenever possible, the rapid synthesis summarizes evidence drawn from existing evidence syntheses and from single research studies in areas not covered by existing evidence syntheses and/or if existing evidence syntheses are old or the science is moving fast. A systematic review is a summary of studies addressing a clearly formulated question that uses systematic and explicit methods to identify, select and appraise research studies, and to synthesize data from the included studies. The rapid synthesis does not contain recommendations, which would have required the authors to make judgments based on their personal values and preferences.

The Forum produces timely and demand-driven contextualized evidence syntheses that address pressing health and social system issues faced by decision-makers (see our website for more details and examples). This includes evidence syntheses produced within:

- days (e.g., rapid evidence profiles or living evidence profiles)
- weeks (e.g., rapid syntheses that at a minimum include a policy analysis of the best-available evidence, which can be requested in a 10-, 30-, 60- or 90-business-day timeframe)
- months (e.g., full evidence syntheses or living evidence syntheses with updates and enhancements over time).

This rapid synthesis was prepared over a 30-business-day timeframe and involved five steps:

1) submission of a question from a policymaker or stakeholder (in this case, British Columbia Ministry of Health)
2) identifying, selecting, appraising and synthesizing relevant research evidence about the question
3) conducting and synthesizing a jurisdictional scan of experiences about the question from other countries and Canadian provinces and territories
4) drafting the rapid synthesis in such a way as to present concisely and in accessible language the research evidence
5) finalizing the rapid synthesis based on the input of at least two merit reviewers.

Identification, selection, quality appraisal and synthesis of evidence

For this rapid synthesis, we searched PubMed, Health Systems Evidence, CINAHL, Medline and PsychInfo for:

1) guidelines (defined as providing recommendations or other normative statements derived from an explicit process for evidence synthesis)
2) evidence syntheses
3) protocols for evidence syntheses that are underway
4) single studies (when no guidelines or evidence syntheses are identified or when they are older).

We searched all of the databases mentioned above for evidence syntheses and primary studies between 21 and 29 August 2023 using the following search strings:

- PubMed:

  - Search 1: (child* OR youth) AND (individualized funding) AND (model OR approach) AND (special needs OR disability OR disable*)
  - Search 2: personal health budgets
- Health Systems Evidence: special needs
- CINAHL, Medline, and PsychInfo: (child* OR youth) AND (individualized funding OR personal health budget) AND (model OR approach) AND (special needs OR disability OR disable*).

Additionally, we hand searched reviews on funding models for any relevant studies focused on individualized funding models for children with support needs.

Each source for these documents is assigned to one team member who conducts hand searches (when a source contains a smaller number of documents) or keyword searches to identify potentially relevant documents. A final inclusion assessment is performed both by the person who did the initial screening and the lead author of the rapid synthesis, with disagreements resolved by consensus or with the input of a third reviewer on the team. The team uses a dedicated virtual channel to discuss and iteratively refine inclusion/exclusion criteria throughout the process, which provides a running list of considerations that all members can consult during the first stages of assessment.

For any included guidelines, two reviewers assess each guideline using three domains in the AGREE II tool (stakeholder involvement, rigour of development and editorial independence). Guidelines are classified as high quality if they were scored as 60% or higher across each of these domains.

For each evidence synthesis we included, we documented the dimension of the organizing framework (see Appendix 2) with which it aligns, key findings, living status, methodological quality (using AMSTAR), last year the literature was searched (as an indicator of how recently it was conducted), availability of GRADE profile, and equity considerations using PROGRESS PLUS.

For AMSTAR, two reviewers independently appraise the methodological quality of evidence syntheses that are deemed to be highly relevant. Disagreements are resolved by consensus with a third reviewer if needed. AMSTAR rates overall methodological quality on a scale of 0 to 11, where 11/11 represents a review of the highest quality. High-quality evidence syntheses are those with scores of eight or higher out of a possible 11, medium-quality evidence syntheses are those with scores between four and seven, and low-quality evidence syntheses are those with scores less than four. It is important to note that the AMSTAR tool was developed to assess evidence syntheses focused on clinical interventions, so not all criteria apply to those pertaining to health-system arrangements or to economic and social responses. Where the denominator is not 11, an aspect of the tool was considered not relevant by the raters. In comparing ratings, it is therefore important to keep both parts of the score (i.e., the numerator and denominator) in mind. For example, an evidence synthesis that scores 8/8 is generally of comparable quality to another scoring 11/11; both ratings are considered 'high scores.' A high score signals that readers of the evidence synthesis can have a high level of confidence in its findings. A low score, on the other hand, does not mean that the evidence synthesis should be discarded, merely that less confidence can be placed in its findings and that it needs to be examined closely to identify its limitations. (Lewin S, Oxman AD, Lavis JN, Fretheim A. SUPPORT Tools for evidence-informed health policymaking (STP): 8. Deciding how much confidence to place in a systematic review. *Health Research Policy and Systems* 2009; 7 (Suppl1):S8.)

For primary research (if included), we documented the dimension of the organizing framework with which it aligns, publication date, jurisdiction studied, methods used, a description of the sample and intervention, declarative title and key findings, and equity considerations using PROGRESS PLUS. We then used this extracted information to develop a synthesis of the key findings from the included syntheses and primary studies.

During this process we include published, pre-print and grey literature. We do not exclude documents based on the language of a document. However, we are not able to extract key findings from documents that are written in languages other than Chinese, English, French, Portuguese or Spanish. We provide any documents that do not have content available in these languages in an appendix containing documents excluded at the final stages of reviewing.

We excluded documents that did not directly address the research questions and the relevant organizing framework. All of the information provided in the appendix tables was taken into account by the authors in describing the findings in the rapid synthesis.

Identifying experiences from other countries and from Canadian provinces and territories

For each rapid synthesis, we collectively decide on what countries to examine based on the question posed. For other countries we searched relevant government and stakeholder websites. In Canada, we search websites from relevant national and provincial governments, ministries and agencies (e.g., Public Health Agency of Canada). While we do not exclude countries based on language, where information is not available in English, Chinese, French or Spanish we attempt to use site-specific translation functions or Google translate.

Appendix 2: Framework to organize what we looked for

We used the framework below to categorize each of the evidence documents included in the rapid synthesis and to structure the presentation of findings in the rapid synthesis and appendices 3 and 4.

- Age
    - Infants (<1)
    - Preschool-aged children (1–4)
    - Grade-school-aged children (5–12)
    - Adolescents (13–19)
- Support needs
    - Acquired brain injuries
    - Chronic and/or long-term medical conditions
    - Communication delays and disorders
    - Neurodevelopmental or other cognitive conditions
    - Other physical conditions
    - Specific diagnoses
        - Autism spectrum disorder
        - Cerebral palsy
        - Down syndrome
        - Fetal alcohol spectrum disorder
        - Spina bifida
- Features of individualized funding model
    - Eligibility criteria to access funding
        - Time-limited eligibility
        - Continuous eligibility after approval
        - Eligibility reassessment requirements
    - Wait-list management
        - First come, first served
        - Needs based
    - Amount of funding provided and how it is determined
        - Fixed amount
        - Income adjusted
        - Needs-based funding
    - How funds can be spent
        - Types of providers
        - Types of services
        - Types of products
        - Other (e.g., administrative costs)
    - Reporting requirements for how funds are spent

- Impacts of individualized funding models
    - Children and youth
    - Families
    - System

Appendix 3: Key findings from highly relevant evidence documents on individualized funding models for children and youth with support needs and their families

Table 1: Evidence of individualized funding models for children and youth with support needs and their families

Individualized funding models or approaches	Features of individualized funding model or approach	Impact of individualized funding model or approach
National Disability Insurance Scheme (NDIS) *Jurisdiction:* Australia	*Age* • Children under seven years of age with a development disability *Amount of funding provided and how it is determined* • NDIS allows eligible Australians to develop a service plan to support their needs alongside NDIS staff (1) • Workers from the NDIS were assigned to specific cases to facilitate budget planning • Participants of this NDIS study were allotted funding ranging from AUD $1,000 to $25,000, depending on their need (2) *How funds can be spent* • Eligible services include consumables, transport, assistance with self-care, assistance with social and community participation, counselling and mental health, employment services, and assistive technology and home modifications (1)	• A primary study found that the NDIS rollout in rural Australia has posed challenges for allied health providers, including limited funding input, inconsistent NDIS practices, increased service demand, and changes in case mix, highlighting the necessity of supporting the rural workforce (3) • During the early stages of the NDIS trials in Australia, parents and carers at one of the trial sites in this primary study identified limited access to services, including home visiting, and a lack of knowledge about the NDIS as key concerns (1) ○ Some parents also reported high levels of stress and indecision as a result of the responsibility of managing the funding • Another primary study reported that Australia's NDIS provides need-based funding to youth with neurodevelopmental conditions to relieve families' financial strain, but reporting procedures (e.g. difficulties in coordinating with the insurance workers, and difficulty identifying and accessing appropriate services) may strain parents (2)
Self-directed support program *Jurisdiction*: England	*Age* • Grade-school-aged children *Support needs* • Children with a disability or complex condition *Amount of funding provided and how it is determined* • Participants involved in the self-direct funding support program were allotted a personalized budget that could be spent on any type of product or service required for the child's condition or family's general well-being	• Flexible self-directed supports for families of youth with a disability or complex condition can improve overall family well-being and access to healthcare supports, but logistic constraints may act as a barrier to its implementation (4) • Families noted difficulty with reporting how funds were allocated, and social workers also described budget planning to distract from their other professional duties

Individualized funding models or approaches	Features of individualized funding model or approach	Impact of individualized funding model or approach
	- A social worker was assigned to each family to facilitate budget planning and management *How funds can be spent* - Families involved in this study spent their budgets on widespread services and products to benefit the family and child including assistants to help with daily tasks, preventative measures (e.g., parental mental health supports), youth extracurriculars, health-related services and more	
Personalization toolkit *Jurisdiction*: United Kingdom	*Age* - Disabled young people with mild or moderate learning disability with non-critical support needs *Amount of funding provided and how it is determined* - The toolkit of personalization during the initial stage of implementation included: self-assessment questionnaires, indicative budgets, person-centred plans (PCP), volunteer brokers (who supported young people and families with planning support, budget management and writing PCPs), personal budgets and direct payment - Professionals identified the lack of a robust process to allocate, agree and review funding and packages under personalized services as a challenge	- The personalization toolkit produced different results for different users, and it did not appear to empower everyone but rather has transferred not only choice and control, but also increased responsibilities, on users of care services (5)
Personal health budgets (for children) *Jurisdiction*: United Kingdom	*Age* - Disabled children (aged 18 years or younger) from one region in the south of England *Support needs* - Children accessed at least two pediatric rehabilitation therapy services locally (physiotherapy, occupational therapy, and speech and language therapy) - A personalized health budget was implemented for children in the context of therapeutic rehabilitation services currently provided by the U.K.'s National Health Service	- Parents and carers expressed confusion regarding the purpose and eligibility of personal health budgets, pointing out gaps in specialized therapy services, equipment accessibility and potential disparities in service delivery (6)
Personalized budgets	*Age* - In this systematic review, included articles focused on the U.S., U.K. and Italy, and populations included	- This high-quality systematic review found that children with disabilities and their caregivers generally experience improved satisfaction and well-being through

Individualized funding models or approaches	Features of individualized funding model or approach	Impact of individualized funding model or approach
Jurisdictions: United States, United Kingdom, Italy	children and adolescents but mostly adults and the elderly *Support needs* • People with physical disabilities and mental health conditions *How funds can be spent* • Unmet service needs, such as daily living tasks, household responsibilities, transportation, and routine healthcare, may be addressed using personalized budgets	personalized budgets, but the impact on costs varies depending on the specific budgeting model employed (7)
Personal health budgets (for adults) *Jurisdiction*: United Kingdom	*Age* • Adults with substance misuse and mental health service users *How funds can be spent* • Personal Health Budgets (PHBs) allow individuals to have more control over their healthcare funding, enabling them to choose and manage their own care services (8) • This primary study's main focus was on PHBs, a program where participants were encouraged to create customized care plans (9)	• Personal health budgets were found to be cost-effective and contributed to enhanced care-related quality of life and psychological well-being, endorsing their ongoing implementation post-2014 (9) • Organizational representatives believe that PHBs for substance misuse can be improved through flexible timing for post-detox, additional support and guidance, and improving patient-focused services and innovation in care (8) • One primary study reported that having active, informed family carers greatly improves the potential to effectively use personal budgets for people with some of the greatest support needs, but tensions frequently exist between carers and practitioners in determining the extent of carer involvement in social care (10) • Engaging nurses in the early development of personal health budgets is crucial for their success in chronic condition care, offering opportunities for a patient-centred role that aligns with nursing's holistic approach (11) • Personal health budgets positively improved well-being and family relationships across different health conditions, though challenges included delays, budget transparency and service variations (12)
Illinois Home Based Support Service *Jurisdiction*: United States	*Age*	• The Illinois Home Based Support Services consumer-direct program provided flexible allocation of funds to

Individualized funding models or approaches	**Features of individualized funding model or approach**	**Impact of individualized funding model or approach**
	• Adults with disabilities ranged from 19 to 47 years of age, with their relatives ranging from 44 to 80 years of age *Amount of funding provided and how it is determined* • The Illinois Home Based Support Services consumer-directed program was an initiative that provided a fixed budget of US$1,656 per month to families with an adult member who had an intellectual or cognitive disability • Funds to support this program were raised in joint efforts by all members of the program and their community members *How funds can be spent* • Funds were spent on healthcare services, transportation to clinics, assistive technology, respite and caregiving relief, and home modifications to improve accessibility	support accessibility of care and the well-being of families with adults who had an intellectual disability • However, families reported challenges with fundraising, auditing procedures and navigating the power dynamics of service providers who restricted fund allocation (13)

Appendix 4: Key findings from highly relevant jurisdictional experiences on individualized funding models for children and youth with support needs and their families

Table 1: Experiences in other countries of individualized funding models for children and youth with support needs and their families

Jurisdiction	Summary of findings
Australia	• Australian National Disability Insurance Scheme (NDIS) is an individualized funding scheme administered at the federal level • The NDIS is available for children and adults with disabilities and is administered to approximately 460,000 individuals, of which 56% are children and youth people under 25 • To be eligible, individuals must be: o between the ages of nine and 65 o an Australian citizen, permanent resident or hold a protected special category visa o currently living in Australia o have a disability that is ▪ permanent ▪ caused by an impairment (intellectual, cognitive, neurological, sensory or physical) that substantially reduces functional capacity to undertake one of more of moving around, communicating, socializing, learning or undertaking self-care or self-management tasks ▪ caused by an impairment that affects the ability to work, study or take part in social life • If these criteria are met, parents (on behalf of their children) can make either a written or verbal application which will include providing evidence related to age, citizenship, residence and of the disability o Evidence on the disability includes ▪ a diagnosis from a treating doctor or specialist ▪ evidence of the impact of the child's condition on their life from a child specialist, allied health professional or educational professional ▪ PEDI-CAT assessment, which examines functional capacity • Eligibility, if over nine, is provided within 21 days, if approved children and youth (with their parents) create a plan with the Local Area Coordinator from a NDIS partner organization that include personal goals o Once created the plan will provide a list of possible services and supports that are funded and delivered by community or other government services that may help to meet the individual goals o The plan includes funding amounts allocated to each relevant 'support category' and what this funding is for – it is possible that not all support categories are funded in every plan and depends on the individual's need • Funded budget categories (and sub-categories) include: o Core support budgets which help with everyday activities and current disability needs – these are the most flexible and can generally be used to support assistance with daily activities, consumables, assistance with social and community participation and transportation o Capacity building supports budget, which help to build independence and skills to pursue goals, but unlike core support budgets these cannot be moved from one support category to another; these include support coordination, improved living arrangements, increased social and community participation, finding and keeping a job, improved relationships, improved health and well-being, improved learning, improved life choices and improved daily living

Jurisdiction	Summary of findings
	o Capital supports, which focus on higher-cost pieces of assistive technology equipment and home or vehicle modifications, and funding for one-off purchases and may require advanced quotes prior to be provided with the funds • A separate program called NDIS early childhood approach is available for children younger than six with a developmental delay or children younger than nine with disability o Children younger than six do not need a diagnosis to get support through the early childhood approach where there are concerns about their development o Individualized budgets are not currently provided for spending for children under nine, but changes to the program are in the process of being made
New Zealand	• The Ministry of Disabled People in New Zealand (Whaikaha) provides an individualized funding model for those living with disabilities; this model provides funding to disabled individuals and their families directly in an effort to promote a more self-directed approach to their care needs o An estimated 35% of those accessing disability services received individualized funding support; of those under the age of 18 years, 64% were male and 36% were female o 81% of children accessing the individualized funding model were living with Autism Spectrum Disorder and/or other intellectual disorders o Auckland, Wellington and Waikato possess the highest percentage of individuals accessing individualized funding support o While purchasing guidelines and rules apply for the individualized funding model, funds are generally used for household management and personal care costs for a support worker, and broader disability services that improves quality of life o A nominated person can serve as the funding agent on behalf on the individual living with a disability (e.g., in the case of children under the age of 18 years, the legal parent/guardian will serve as their agent) o Every recipient of individualized funding model will receive support from one of nine ‘host’ organizations (e.g., Manawanui), who can be contacted to assist in monitoring budgets, providing coaches, and access to self-service platforms, scheduling services and legal advice • Individualized funding is one of three ‘all-in’ funding models offered by the Ministry for Children (Oranga Tamariki), and focuses on providing separate funding rates for individuals receiving care o This funding model should only be used if a child or adolescent requires a high level of support, which cannot be provided through other means • The New Zealand Government offers a variety of individualized funding options for children and youth with learning support needs; this can include: o Early intervention services for those with neurodevelopmental and communication delays who are under the age of six years o Special equipment (e.g., braille machine paper, pens, computers, seats, tables, hearing devices) or additional aide support funding for school-aged children through the School High Health Needs Fund • Variety Children's Charity offers a one-time individual grant for children and youth under the age of 19 years; grants can range from $200 to $2,000 o The individual grant can help cover the costs of everyday essential (e.g., beds or beddings, car seats, clothes, shoes), extra-curricular activities (e.g., sport lessons), technology (e.g., up to $800 for digital devices if the child is eight years or older), school costs (e.g., uniforms, camps, trips), and medical fees (e.g., glasses, prescriptions, mobility costs) o Applications are processed quarterly, with funds distributed in February, May, August and November

Jurisdiction	**Summary of findings**
	• The Cerebral Palsy Society of New Zealand offers an individual grant to support the independence and quality of life of a child and their parents/family
United Kingdom (U.K.)	• NHS England's personal health budgets for children, young people and families connects partners in education and social care to support children and youth with complex health needs eligible for NHS continuing healthcare and the National Framework for Children and Young People's Continuing Care outlines requirements for eligibility, assessment and decision-making around personal health budgets for children and young people's continuing care ○ Clinical Commissioning Groups (CCG) assess the child or young person, taking into account the preferences of the child and their family, holistic assessment of need, reports from a multidisciplinary team, and the Decision Support Tool for children and young people ○ After assessment, the multi-agency forum considers recommendations and decides whether the child or young person has a continuing care need ○ The child or young person and their family can request a personal health budget, which can consist of a direct payment to the young person or their family, a notional budget to be spent by the CCG following discussions with the child/young person and their family, or a transfer of a real budget to a person or organization who applies the money toward supporting the child or young person and their family based on a way agreed upon between these parties and the CCG • The special education needs and disability (SEND) code of practice: 0 to 25 years describes responsibilities of local authorities, health bodies, schools and colleges, including the responsibilities of integrated care boards (ICBs) to: ○ Commission services jointly for children and youth up to 25 years, including those with Education Health and Care (EHC) plans ○ Work with the local authority to develop the 'local offer' of services available ○ Establish mechanisms to ensure clinicians and practitioners can support the integrated EHC needs assessment process ○ Agree on personal budgets for those with EHC plans • The Transforming Care Programme, NHS England is working with the Local Government Association (LGA) ○ Personal health budgets and Integrated Personal Commissioning (IPC) are available to children and young people in this cohort to promote person-centred support and care
United States (U.S.)	• Supplemental Security Income (SSI) provides monthly payments to children and adults with disabilities who have little or no income or resources ○ The amount of the monthly payment depends on the person's living situation, income and other factors • In most states, a child who receives SSI is automatically qualified for Medicaid, which covers healthcare as well as durable medical equipment and, in some states, in-home support and other community-based services • Veteran's Aid and Attendance is a monthly cash payment provided by U.S. Department of Veterans Affairs (VA) for Veterans with disabilities who receive a VA pension, which increases if the veteran has a dependent child

Table 2: Experiences across Canadian provinces and territories of individualized funding models for children and youth with support needs and their families

Jurisdiction	Summary of findings
Pan-Canadian	• The Canada Child Benefit is available for all parents who live with a child under the age of 18 and who is primarily responsible for the care and upbringing of the child and is intended to help families with the cost of raising children ○ The Child Disability Benefit is added onto this and is a tax-free monthly payment made to families who care for a child under the age of 18 with a severe and prolonged impairment in physical or mental functions, which must be certified by a medical practitioner ○ Up to $264.41 per month is available for each child that is eligible, this is based on adjusted family net income
British Columbia	• Families in British Columbia are eligible for individualized funding for children and youth with an autism diagnosis ○ Funding for autism support is available to assist with the costs associated with services and skill development for children with autism ○ Children under the age of six can receive funding of up to $22,000 per year for each child ▪ Funding is available for professionals listed on the Registry of Autism Service Providers, supervised behaviour interventionists, administrative costs associated with managing service providers (up to $100 monthly), expenses related to employing service providers, and family counselling/therapy ○ Children aged six to 18 are eligible for funding of up to $6,000 per year for each child ▪ Funding covers a wide range of services including behaviour consultants, speech-language pathologists, occupational or physical therapists, supervised behaviour interventionists, life and social skills programs, out-of-school learning support, dietary counselling, family therapy, specialized camps, interventions recommended by eligible professionals, and associated administrative and employment costs • Parents have the flexibility to use up to 20% of the funding to pay for other supports such as purchasing equipment or supplies to aid in their child's development
Alberta	• Alberta Child and Youth Support is a government run funding initiative to support caregivers in providing care, including medical coverage, to youth whose parents are unable or unwilling to care for them ○ The program is available for youth under the age of 18 who do not have an income higher than financial guidelines, are attending school or employed full-time, and reside with the caregiver for seven days a week ○ The program also requires a letter of consent from the parents of the child or from the caregiver to demonstrate private guardianship of the child ○ Youth with extensive medical coverage due to chronic and/or long-term medical conditions may be eligible ○ Persons can reapply for funding annually if the child is attending school and their parent is unable or unwilling to provide care ○ The amount of funding is a fixed amount (ages zero to 11: maximum $105/month; ages 12 to 17: maximum $148/month), with a $200 supplementary benefit for medical coverage ○ The amount of funding is determined on a needs basis, depending on the youth's income ○ This individualized funding model impacts youth and their families • Alberta Child Health Benefit is a government run funding initiative to help low-income families access health products and services ○ The program is available for youth under the age of 18 ○ Youth with chronic and/or long-term medical conditions, including diabetes, are eligible to apply ○ Families may be eligible to reapply for funding every September ○ The amount of funding is determined on a needs basis

Jurisdiction	Summary of findings
	o Funding may be spent on over-the-counter medication, diabetes supplies, dental care, prescription drugs, eyeglasses and emergency ambulatory services o This individualized funding model impacts youth and their families • The Children's Ability fund is an organization based in Alberta that provides individualized funding for youth with chronic and/or long-term medical conditions o The program is available for youth under the age of 21 o Youth with chronic and/or long-term medical conditions are eligible to apply o Persons can reapply to the program yearly o Amount of funding is determined on a needs-basis; persons are eligible for up to a maximum amount of $10,000, depending on their income and type of request o All allocated funds may be spent on home care improvements, assistive devices, and medical travel o This individualized funding model impacts youth and their families • Cerebral Palsy Alberta is an independent organization providing funding initiatives for youth with cerebral palsy o Youth under the age of 18 with cerebral palsy are eligible to apply o Youth may reapply yearly o The amount of funding is determined on a needs basis, based on type of request o All allocated funds may be spent on products to improve mobility needs or electronic access o Persons must report receipts demonstrated how funds were spent o This individualized funding model impacts youth and their families
Saskatchewan	• Saskatchewan Autism Services is a government run funding program aimed to support children with autism spectrum disorder o This funding is available for grade school children ages six to 11 with autism spectrum disorder o The amount of funding is determined on a needs basis o All allocated funds can be spent on any required service or product that may benefit the child o This individualized funding model impacts children and their families • Individualized Funding for Home Care is a government run funding initiative to improve accessibility in home settings for persons with chronic and/or long-term medical conditions o This funding initiative is available to persons of all ages o Persons with all types of support needs who require modifications to their home settings are eligible to apply o Persons are eligible to reapply yearly; reassessment requirements mandate that a documentation of taxes and purchase receipts are reported the Saskatchewan Health Authority o The amount of funding is determined on a needs-basis o Allocated funds may be spent on any type of product to improve accessibility in home settings o This individualized funding model impacts youth and their families • Cerebral Palsy Saskatchewan is an independent organization helps individuals affected by cerebral palsy and other disabilities o Funding is available for individuals of all ages with cerebral palsy or other cognitive disabilities o The amount of funding is determined on a needs-basis; persons are eligible to a maximum of $500 in funding per year
Manitoba	• None identified
Ontario	• In Ontario, a range of individualized funding approaches exist for children living with disabilities, which include:

Jurisdiction	Summary of findings
	○ Special Services at Home (SSAH) funding ○ Enhanced Respite Funding ○ Assistance for Children with Severe Disabilities ○ Ontario Autism Program • The Special Services at Home (SSAH) funding is available for families who are caring for a child living with a developmental disability ○ Funds can be used to cover caregiver costs, and expenses related to personal growth activities, such as camps and sport classes ○ Funding can vary based on a range of factors, including 1) the type and cost of services a child may need, 2) support the family is already receiving, and 3) additional help available in the community • The Enhanced Respite Funding is a grant available for families caring for a child who is 'medically fragile' and/or requires a technological device (e.g., mechanical ventilator, apnea monitor, renal dialysis, colostomy bags) ○ Families may receive up to $3,500 per year for each eligible child • The Assistance for Children with Severe Disabilities is available for low- and middle-income families (household income of $74,760 or lower), who possess substantial costs associated with caring for a child living with a severe disability ○ In July 2023, the maximum monthly assistance increased to $618 per month for each eligible child (funding range is now from $25 to $618) ○ Funding can vary depending on the size of the family, the severity of the disability and the costs associated with caring for the child ○ Funds can be used towards covering travel costs, shoes, clothes and parental relief expenses • The Ontario Autism Program is for children and youth diagnosed with autism spectrum disorder (ASD); eligible children can receive support up until the age of 18 years, with the family receiving direct funds to purchase supports their child(ren) need(s) ○ Families of children with ASD can receive $20,000 per child (if the child is under the age of six), and $5,000 if the child is six years or older • Individualized funding is also available through the Family-Managed Home Care/Self-Directed Care services for children with complex medical needs, acquired brain injury, and home-schooled children that have qualifying needs
Quebec	• Families in Quebec eligible for the Family Allowance can apply for the Supplement for Handicapped Children, which covers a wide range of health-related and functional impairments as well as mental function disabilities (covers all support needs in this rapid synthesis framework) ○ Parents must provide, along with their application, supporting documentation relevant to the condition such as a detailed list of all medications that have been prescribed by a physician (including renewals) that were filled at a pharmacy, initial assessments of the condition by a provider along with any recent follow-ups, documents related to emergency room visits or hospitalization summary sheets, or school achievement reports to be filled out by school or daycare officials ○ The supplement provided is $218 a month, regardless of type of handicap or family income
New Brunswick	• The Individualized Support model of New Brunswick's Inclusion Support Program (ISP) provides support to children with the most intensive needs, such as those with chronic and complex medical conditions, by funding the wages of an Inclusion Support Worker working in licensed childcare facilities to provide individualized care ○ The Inclusion Support Worker provides an individualized care plan that addresses the child's ongoing needs in order for the child to remain actively engaged in programs and routines of the licensed early learning and childcare facilities of the ISP ○ Preschool- and school-aged children are eligible for ISP if their parent or guardian works or attends school/training and the child is enrolled or registered in a licensed early learning and childcare facility when applying

Jurisdiction	Summary of findings
	○ A referral from an external service provider is required for new applicants to be considered for funding ○ Children must be under 12 years of age and a New Brunswick resident ○ For preschool-aged children, facilities receive wage funding for 35 hours per week maximum, and for school-aged children, facilities receive funding for a maximum of 20 hours per week during school weeks and 35 hours per week in the summer
Nova Scotia	• Direct financial support is provided for families of children with disabilities at home through the Family Support for Children (DFSC) and Enhanced Family Support for Children (EFSC) ○ To be eligible for direct financial support, the child must have been diagnosed with a disability by an approved clinician and must be living in the home with a family member/guardian ○ Funding is provided for respite services to assist with scheduled breaks for caregivers, and the maximum funding rate for DFSC and exceptional circumstances is up to $2,400 per month ○ For families in need of enhanced respite funding for children with extremely challenging care needs, EFSC funding can be provided up to a maximum of $4,000 per month
Prince Edward Island	• AccessAbility Supports is a government-run funding initiative for persons with chronic and/or long-term medical conditions ○ This funding initiative is available to persons of all ages ○ Persons with chronic and/or long-term medical conditions are eligible to apply ○ Persons are eligible to reapply yearly ○ The amount of funding is determined on a needs basis ○ Allocated funds may be spent on services to improve quality of life and meaningful engagement (e.g., occupational therapy) and products to improve mobility (e.g., wheelchairs) ○ This individualized funding model impacts youth and their families
Newfoundland and Labrador	• The Provincial Special Child Welfare Allowance (SCWA) Program provides assistance with the cost of services/supports incurred to families with a child (under 18) who has a developmental/intellectual or physical disabilities living at home; families are required to seek out other program support (e.g., from the Drug Prescription Plan) prior to seeking funding from the SCWA Program ○ Eligibility criteria to access funding requires an eligibility reassessment and allowance amount review every 12 months by the Regional Health Authority Staff ○ Waitlist management is needs-based; the eligibility of child and family will be assessed based on child's long-term disability at home and financial need criteria determined by the provincial government ○ The amount of monthly allowance is determined based on the total cost of the child's special needs as determined by an evaluation through social worker's home visit. ○ The funds are spent on needs that are covered that include: medications (not covered by existing provincial drug prescription program), transportation to medical appointments or social/recreational activities, special equipment, apparatus and supplies, disposable diapers, and other supportive services such as babysitting or childcare to enable employment for children under 12, residential short-term respite care, and an escort for special transportation to medical appointments for parents needing physical assistant in managing their child ○ Social work support including counselling, advocacy, referrals and service planning is provided to families ○ There is no document found regarding the evaluation of the program's implementation in terms of its impact, but there are few news reports that many families still do not qualify for coverage for costly special equipment and respite care

Jurisdiction	Summary of findings
Yukon	• The Yukon Family Supports for Children with Disabilities Program provides support for children (up to 19 years old) with chronic developmental, physical, sensory, cognitive, mental health or neurological impairment that significantly limits a child's ability to function in normal daily living (without the need for formal diagnosis, or even while in the process of getting diagnosis). ○ Without a cap on family income as a financial eligibility criterion, it may provide funding for respite, family counselling, sibling care, a family coach, inclusion supports, specialized interventions, homemaker services for the family and in-home child care
Northwest Territories	• None identified
Nunavut	• None identified

Appendix 5: Detailed data extractions from evidence syntheses about individualized funding models for children and youth with support needs and their families

Table 1: Detailed findings from systematic reviews about individualized funding models for children and youth with support needs and their families

Dimension of organizing framework	Declarative title and key findings	Relevance	Living status	Quality (AMSTAR)	Last year literature searched	Availability of GRADE profile	Equity considerations

(personal health budget*) AND (child OR youth)
Total syntheses: 1
• Features of individualized funding model
  o Amount of funding provided and how it is determined
    ▪ Needs-based funding
  o How funds can be spent
    ▪ Types of providers
• Impacts of individualized funding models
  o Children and youth
  o Families
  o System
	Children with disabilities and their caregivers generally experience improved satisfaction and well-being through personalized budgets, but the impact on costs varies depending on the specific budgeting model employed.
	
	Unmet service needs, such as daily living tasks, household responsibilities, transportation and routine healthcare, may be addressed using personalized budgets. In this study, included articles focused on the U.S., U.K. and Italy, and populations included children and adolescents but mostly adults and the elderly.
		Medium	No	8/9	November 2022	Not available	None

Table 2: Summary of findings from primary studies about individualized funding models for children and youth with support needs and their families

Dimension of organizing framework	Study characteristics	Relevance	Sample and interventions description	Key findings
• Age o Grade-school aged children (5–12) • Support needs o Chronic and/or long-term medical conditions o Neurodevelopmental or other cognitive conditions • Features of individualized funding model o How funds can be spent ▪ Types of services ▪ Types of products ▪ Other o Reporting requirements for how funds are spent • Impacts of individualized funding models o Children and youth o Families o System	*Focus of study:* To explore a program providing individualized supports for families with children with disabilities *Publication date:* 2015 *Jurisdiction studied:* England, U.K. *Methods used:* Ethnographic case study	High	A total of seven families with children with a disability or complex condition were included in this study. An unspecified number of children's disability social workers were also interviewed.	Flexible self-directed supports for families of youth with a disability or complex condition can improve overall family well-being and access to healthcare supports, but logistic constraints may act as a barrier to its implementation. Participants involved in the self-directed funding support program were allotted a personalized budget that could be spent on any type of product or service required for the child's condition or family's general well-being. A social worker was assigned to each family to facilitate budget planning and management. Families involved in this study spent their budgets on widespread services and products to benefit the family and child including assistants to help with daily tasks, preventative measures (e.g., parental mental health supports), youth extracurriculars, health-related services, and more. Noted benefits of the self-directed support programs included increased flexibility and accessibility, as well as overall improvements to the quality of life of families and youth. Barriers to the implementation of the self-directed support program related to the logistics of the program for both families and social workers. Families

Dimension of organizing framework	**Study characteristics**	**Relevance**	**Sample and interventions description**	**Key findings**
				noted difficulty with reporting how funds were allocated. Social workers also described budget planning to distract from their other professional duties. However, some social workers remarked that rigorous audits were required to ensure that families did not abuse the system.
• Features of individualized funding model ○ How funds can be spent ▪ Types of providers	*Focus of study:* To explore in depth the experiences of providing clinical services under the Australia's National Disability Insurance Scheme (NDIS) in a rural area *Publication date:* 2019 *Jurisdiction studied:* New South Wales, Australia *Methods used:* Semi-structured interviews	Medium	NDIS service providers working in rural or remote areas in New South Wales. NDIS allows eligible Australians to develop a service plan to support their needs alongside NDIS staff. Eligible services include consumables, transport, assistance with self-care, assistance with social and community participation, counselling and mental health, employment services and assistive technology and home modifications.	The NDIS rollout in rural Australia has posed challenges for allied health providers, including limited funding input, inconsistent NDIS practices, increased service demand and changes in case mix, highlighting the necessity of supporting the rural workforce. Eight service providers working in rural and remote areas representing occupational therapy, nutrition and dietetics, physiotherapy and speech pathology reported difficulties in carrying out their practice with the implementation of NDIS. Providers reported increasing demand for services, changes to their case mix, and little control over funding for their clients.
• Impacts of individualized funding models ○ Children and youth ○ Families	*Focus of study:* To describe the narratives, ideas and experiences of parents and carers of disabled children under five years in regional and rural areas *Publication date:* 2015 *Jurisdiction studied:* Australia	Medium	The study sample included 171 families (parents and carers) receiving early-intervention services in the Hunter Region of New South Wales, one of the NDIS trial sites. The NDIS is an individualized funding scheme based on two key premises: 1) recognition of people with disabilities' right to be at the centre of decision-making and life planning, and 2) the application of a tiered insurance model to existing	During the early stages of the NDIS trials in Australia, parents and carers at one of the trial sites identified limited access to services, including home visiting, and a lack of knowledge about the NDIS as key concerns. Access to support is deemed more important than self-management of funding. Some parents reported high levels of stress and indecision as a result of the responsibility of managing the

Dimension of organizing framework	Study characteristics	Relevance	Sample and interventions description	Key findings
	Methods used: Mixed-method study, composed of online or mail survey and semi-structured interviews by telephone or in person		mainstream supports and services such as housing, health and education, with the severity of impairment used to determine eligibility for individualised support packages. The scheme includes disabled adults and disabled children.	funding, the fear that their child would be without support if the package ran out, and a lack of knowledge about how to best spend the funding. Caregivers were unable to attend services with their children or participate in information sessions about the scheme and its associated changes due to transportation and logistical issues. Coordination through the use of a key worker and the balancing of choice and flexibility is recommended as an essential inclusion in the NDIS.
• Age ○ Infants (<1) ○ Preschool-aged children (1–4) ○ Grade-school-aged children (5–12) • Support needs ○ Neurodevelopmental or cognitive conditions • Features of individualized funding model ○ Amount of funding provided and how it is determined ▪ Needs-based funding ○ Reporting requirements of how funds are spent • Impacts of individualized funding models ○ Children and youth ○ Families	*Focus of study:* This study explored parents' experiences utilizing an individualized insurance plan for children under seven years of age with a development disability *Publication date:* 2016 *Jurisdiction studied:* Australia *Methods used:* Qualitative survey response	Medium	A total of 42 parents from Australia completed a qualitative survey inquiring of their experiences with Australia's NDIS.	Australia's NDIS provides need-based funding to youth with neurodevelopmental conditions to relieve families' financial strain, but reporting procedures may strain parents. Participants were allotted funding ranging from AUD $1,000 to $25,000, depending on their need. Workers from the insurance company were assigned to specific cases to facilitate budget planning. The majority of participants (61.9%) were satisfied with the funding plan and communication with the program. Some participants noted challenges with the program, including difficulty with 1) reporting how funding was spent and 2) difficulty accessing services. First, parents described that a lack of information from both the insurance company and healthcare professionals, as well as difficulties in coordinating with the insurance workers,

Dimension of organizing framework	Study characteristics	Relevance	Sample and interventions description	Key findings
				acted as a barrier to reporting. Next, despite having available funding, participants reported difficulty identifying and accessing appropriate services.

- Impacts of individualized funding models
  ○ Children and youth
  ○ Families
	Focus of study: To explore experiences of professionals working in the field and users of services regarding how the vision of personalization translates into practice in social care services for disabled young people
	
	Publication date: 2018
	
	Jurisdiction studied: England, U.K.
	
	Methods used: Qualitative case study by means of participant observations and in-depth semi-structured interviews
		Medium	The study sample included five professionals (head of services and team managers/coordinators), four family members (mothers) and four disabled young people with mild or moderate learning disability with non-critical support needs in an urban local authority in England.
			
			Personalization as vision and toolkit is promoted by the U.K. government for social care and disability services. The toolkit of personalization during the initial stage of implementation included: self-assessment questionnaires, indicative budgets, person-centred plans (PCP), volunteer-brokers (who supported young people and families with planning support, budget management and writing PCPs), personal budgets and direct payment.
				The personalization toolkit produced different results for different users, and it did not appear to empower everyone. Its implementation has rather transferred not only choice and control, but also increased responsibilities on users of care services.
				
				Two main groups of challenges were identified: 1) infrastructural weaknesses, including the uneven quality of services and unsteady, ambiguous and sometimes contradictory implementation processes, and 2) behavioural failures, such as information asymmetries among users and the risk of unequal outcomes.
				
				Not all parents demonstrated a thorough understanding of the personalization toolkit, and their enthusiasm may be due to their interpretation of personalization rather than personalization as promoted by government policies or implemented by local authorities. The parents were generally unaware of the implications of personal budgeting regarding a new way of allocating resources and new roles and responsibilities in terms of planning. Findings from interviews with young people show that they have a minimal understanding of processes.
				
				Professionals identified the lack of a robust process to allocate, agree and

Dimension of organizing framework	Study characteristics	Relevance	Sample and interventions description	Key findings
				review funding and packages under personalized services as a challenge.
• Age o Infants (<1) o Preschool-aged children (1–4) o Grade-school-aged children (5-12) • Features of individualized funding model o Eligibility criteria to access funding o How funds can be spent ▪ Types of services ▪ Types of products ▪ Other	*Focus of study:* To describe views of parents and primary carers of disabled children (18 years old or younger) on personal health budgets *Publication date:* 2017 *Jurisdiction studied:* England, U.K. *Methods used:* Qualitative approach using focus group discussions, individual interviews or telephone interviews	Medium	The study sample included nine parents and primary carers of disabled children (aged 18 years or younger) from one region in the south of England who accessed at least two pediatric rehabilitation therapy services locally (physiotherapy, occupational therapy, and speech and language therapy). The intervention being examined is the use of a personalized health budget for children in the context of therapeutic rehabilitation services currently provided by the United Kingdom's National Health Service.	Parents and carers expressed confusion regarding the purpose and eligibility of personal health budgets, pointing out gaps in specialized therapy services, equipment accessibility and potential disparities in service delivery. Parents' and carers' concerns included: • lack of clarity about what a personal health budget might be used for and who is eligible to receive • having access to equipment more easily and quickly when needed, with the exception of parents with very young children • a 'wish list' that reflected gaps in the current NHS and statutory services, particularly a lack of access to highly specialized therapy services (this includes non-traditional, alternative, or complementary therapies that are not routinely available in NHS services, such as hydrotherapy, which is only available in very specific circumstances) • uneven service provision, wherein high demand for some services can lead to shortages in the provision and a reduction in 'less popular' services.
• Age o Adults • Features of individualized funding model	*Focus of study:* To evaluate the effectiveness and cost-effectiveness of personal health budgets *Publication date:* 2013	Low	The study's sample initially included 2,700 individuals (primarily adults) with a final active sample of 2,235, comprising 1,171 personal health budget recipients and 1,064 control group participants, encompassing various health conditions.	Personal health budgets were cost-effective and contributed to enhanced care-related quality of life and psychological well-being, endorsing their ongoing implementation post-2014.

Dimension of organizing framework	Study characteristics	Relevance	Sample and interventions description	Key findings
○ Amount of funding provided and how it is determined ▪ Needs-based funding ○ How funds can be spent ▪ Types of providers • Impacts of individualized funding models ○ System	*Jurisdiction studied:* U.K. *Methods used:* The study utilized a controlled trial with a pragmatic design, recruiting participants through different methods		The study's main focus was on personal health budgets, a program where participants were encouraged to create customized care plans.	The quality of care, social engagement and overall happiness in individuals were found to be significantly improved using personalized health budgets.
• Features of individualized funding model ○ Amount of funding provided and how it is determined ▪ Needs-based funding ○ How funds can be spent ▪ Types of services • Impacts of individualized funding models ○ System	*Focus of study:* To understand the perceptions of organizational representatives about the implementation of Personal Health Budgets (PHBs) *Publication date:* 2017 *Jurisdiction studied:* U.K. *Methods used:* Interviews	Low	Representatives or organizations providing substance misuse services through PHBs. PHBs allow individuals to have more control over their healthcare funding, enabling them to choose and manage their own care services. This study focused on the application of PHBs in the context of substance misuse.	Organizational representatives believe that Personal Health Budgets for substance misuse can be improved through flexible timing for post-detox, additional support and guidance, and improving patient-focused services and innovation in care. Interviewees, regardless of timing or profession, shared similar views about PHBs' potential and challenges, with frustrations mainly tied to introducing new initiatives, not PHBs themselves. They reported that implementing PHBs in substance misuse services can offer benefits like increased self-confidence, better engagement with clients, and a more holistic approach to care. Still, PHBs require strong leadership, appropriate timing of offering PHBs, guidance on their use, and flexibility in implementation in order to achieve success.
• Age ○ Adults	*Focus of study:* To explore experiences of family involvement in accessing	Low	The study's sample included 18 family carers and 52 adult mental health service users (who had used or were seeking personal budgets	Having active, informed family carers greatly improves the potential to effectively use personal budgets for

Dimension of organizing framework	Study characteristics	Relevance	Sample and interventions description	Key findings
• Features of individualized funding model ○ How funds can be spent ▪ Other • Impacts of individualized funding models ○ Families	and managing personal budgets for persons with mental health-related social care needs *Publication date:* 2015 *Jurisdiction studied:* England, U.K. *Methods used:* Qualitative approach using in-depth semi-structured interviews over telephone or face-to-face		for support in relation to a mental health problem) from three sites across England and from voluntary sector networks. Personal budgets are a key mechanism to meet the costs of a personally constructed support plan, although the take-up for personal budgets has been relatively limited for persons with mental health related social care needs.	people with some of the greatest support needs. Carers of people with mental health problems may influence the ability to access and manage personal budgets. Tensions frequently exist between carers and practitioners in determining the extent of carer involvement in social care.
• Features of individualized funding model ○ Amount of funding provided and how it is determined ▪ Needs-based funding ○ How funds can be spent ▪ Types of providers • Impacts of individualized funding models ○ System	*Focus of study:* To describe personal health budgets and the role of nursing, and to present early findings from pilots *Publication date:* 2011 *Jurisdiction studied:* U.K., U.S. *Methods used:* Commentary	Low	No information about the study sample provided PHBs allow individuals to have more control over their healthcare funding, enabling them to choose and manage their own care services.	Engaging nurses in the early development of personal health budgets is crucial for their success in chronic condition care, offering opportunities for a patient-centred role that aligns with nursing's holistic approach. Emerging findings indicate that self-directed care through personal health budgets allows individuals to access a broader range of goods and services beyond traditional healthcare, leading to increased satisfaction and positive experiences. Studies show potential benefits in terms of community engagement, quality of life improvements and cost savings, but more research is needed, especially regarding health outcomes and efficiency enhancements.
• Age ○ Adults • Support needs	*Focus of study:* This study explored the experiences of families participating in Illinois's consumer-	Low	Nine families with an adult who had an intellectual or cognitive disability, participating in the Illinois Home Based Support Service, were interviewed in this	The Illinois Home Based Support Services consumer-direct program provided flexible allocation of funds to support accessibility of care and the well-

Dimension of organizing framework	Study characteristics	Relevance	Sample and interventions description	Key findings
○ Neurodevelopmental or other cognitive conditions • Features of individualized funding model ○ Amount of funding provided and how it is determined ○ Fixed amount ○ How funds can be spent ▪ Types of providers ▪ Types of services ▪ Types of products ▪ Other ○ Reporting requirements for how funds are spent • Impacts of individualized funding models ○ Families ○ Systems	directed support program for adults with intellectual disabilities *Publication date:* October 2007 *Jurisdiction studied:* Illinois, U.S. *Methods used:* Qualitative study		study. The majority of families identified as White (66%), followed by African American (22%), and Hispanic (11%). Adults with disabilities ranged from 19 to 47 years of age, with their relatives ranging from 44 to 80 years of age.	being of families with adults who had an intellectual disability. However, families reported challenges with fundraising, auditing procedures, and navigating the power dynamics of service providers who restricted fund allocation. The Illinois Home Based Support Services consumer-directed program was an initiative that provided a fixed budget of US$1,656 per month to families with an adult member who had an intellectual or cognitive disability. Funds to support this program were raised in joint efforts by all members of the program and their community members. Service providers working for the organization supported participants in directing their budget and spending plans. Funds were spent on healthcare services, transportation to clinics, assistive technology, respite and caregiving relief, and home modifications to improve accessibility. Families who participated in the program noted beneficial impacts including financial relief, improved caregiver well-being and increased family connectedness. Families discussed challenges with the consumer-directed program. The task of fundraising was described as strenuous and time consuming. Some participants also described difficulties with navigating power dynamics of service providers who restricted the allocation of their funds. Additionally, some participants stated

Dimension of organizing framework	Study characteristics	Relevance	Sample and interventions description	Key findings
				that the auditing procedures were unclear and sometimes led to participants having to repay the agency.

- Age
  - Adults
- Features of individualized funding model
  - Amount of funding provided and how it is determined
    - Needs-based funding
  - How funds can be spent
    - Types of providers
- Impacts of individualized funding models
  - System
	Focus of study: To understand how people used personal health budgets and what they thought about them
	Publication date: 2013
	Jurisdiction studied: U.K.
	Methods used: Mixed-method approach involving controlled trials and qualitative interviews
		Low	The study included over 2,000 patients (primarily adults) from diverse backgrounds and health conditions, along with a sub-sample of 58 individuals for qualitative interviews.
			The intervention being studied was the implementation and use of personal health budgets.
				Personal health budgets positively improved well-being and family relationships across different health conditions, though challenges included delays, budget transparency and service variations.
				Though individuals found their overall well-being improved, including better mental health and stronger family bonds, they also encountered challenges due to inconsistent service options and limited budget information.

Appendix 6: Documents excluded at the final stage of reviewing

Document type	Hyperlinked title
Evidence syntheses	Accelerating progress on early childhood development for children under 5 years with disabilities by 2030
	Enabling risk and ensuring safety: self-directed support and personal budgets
	Being a personal health budget holder: becoming a 'professional parent'
	Children with complex health needs and personal health budgets
	Experiences of families with relatives with intellectual and developmental disabilities in a consumer-directed support program
	Life-long individual planning in children with developmental disability: the active role of parents in the Italian experience

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The rapid-response program through which this synthesis was prepared is funded by the British Columbia Ministry of Health. The McMaster Health Forum receives both financial and in-kind support from McMaster University. The views expressed in the rapid synthesis are the views of the authors and should not be taken to represent the views of the British Columbia Ministry of Health or McMaster University. The authors wish to thank Angela Wang and Sarah Saleh for the assistance with the AMSTAR appraisals and Ariana Jaspal for the assistance with referencing.

ISSN 2292-7999 (online)

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