McMaster University HEALTH FORUM

Rapid Synthesis

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

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Context

- Since the beginning of the child survival revolution in the 1980s, there has been a major focus globally on developing and improving health interventions for children.(1)
- Available data shows that globally, although a child is 10 times more likely to develop a disability than pass away before their fifth birthday, disability funding has progressively declined over the last decade.(2)
- Given this, there is a need to enhance funding options available to children with disabilities and their caregivers so that they can access the care, services and resources they need.
- Individualized funding, in particular, has been used as a tool in several jurisdictions to provide flexible and responsive financial support directly to disabled children and their families; however, the available body of synthesized evidence on the features and impacts of individualized funding models for children and youth with support needs is limited.(3)
- This rapid synthesis explores the features and impacts of individualized funding models for children and youth with support needs and their families.

Question

- What are the features and impacts of individualized funding models for children and youth with support needs and their families, in comparison to other models of funding allocation?

High-level summary of key findings

Research evidence

- We identified one high-quality evidence synthesis and 12 primary studies that described the features and impacts of individualized funding models for children and youth with support needs in a few countries.
- In Australia, the National Disability Insurance Scheme provides needs-based funding to disabled children, youth and adults and their families that can be used to pay for eligible services such as consumables, transport, counselling and mental health, and assistive technology and home modifications.
- The United Kingdom also has a few individualized funding programs for children and youth with disabilities that have reportedly improved access to care and support services for children and their families.
- Funding allocations for children and families participating in the individualized funding models we identified are typically dependent on the care needs of the child.
- While families were found to have benefited from the flexibility of individualized funding programs, some of the evidence sources highlighted barriers and challenges for families such as limited access to services, logistic constraints, stress and indecision related to managing the funding, and tensions that frequently exist when navigating the power dynamics of service providers who restricted fund allocation.

Jurisdictional scan

- We found that all individualized funding models we identified from our jurisdictional scan aimed to provide holistic supports to improve medical access and quality of life for youth with support needs.
- We identified individualized funding programs in all international jurisdictions and most Canadian provinces.
- Eligibility age range varies across programs and most individualized funding models are available for people with a broad range of chronic and/or long-term medical conditions.
- The amount of funding available to children and their families vary based on each program's purpose and unique characteristics, and many programs allow flexibility in spending to access services and social supports with the support of local coordinators.
- Finally, we found that some individualized funding programs require advanced quotes prior to spending, while others allow participants to be reimbursed for services they access after submitting receipts and tax forms.

Framework to organize what we looked for

We organized our findings from the research evidence and jurisdictional scan using the framework below that we also provide in Appendix 2.

- 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

Box 1: Approach and supporting materials

We identified evidence addressing the question by searching PubMed, Health Systems Evidence, CINAHL, Medline and PsychInfo to identify evidence syntheses, and primary studies. All searches were conducted between 21 and 29 August 2023. The search strategies used are included in Appendix 1. We identified jurisdictional experiences by hand searching government and stakeholder websites for information relevant to the question from four countries (Australia, New Zealand, United Kingdom, United States) and all Canadian provinces and territories.

In contrast to our rapid evidence profiles, which provide an overview and insights from relevant documents, this rapid synthesis provides an in-depth understanding of the evidence.

We appraised the methodological quality of evidence syntheses that were deemed to be highly relevant using AMSTAR. Note that quality appraisal scores for evidence syntheses such as rapid syntheses/reviews are often lower because of the methodological shortcuts that need to be taken to accommodate compressed timeframes. AMSTAR rates overall quality on a scale of 0 to 11, where 11/11 represents an evidence synthesis of the highest quality. 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 evidence syntheses pertaining to delivery, financial or governance arrangements within health systems or to broader social systems.

This rapid synthesis was prepared in a 30-business-day timeline.

A separate appendix document includes:

1) methodological details (Appendix 1)
2) a framework to organize what we looked for (Appendix 2)
3) a summary table of evidence organized by individualized funding model or approach (Appendix 3)
4) a summary table of experiences from other countries and select Canadian provinces and territories (Appendix 4)
5) findings from each evidence document, organized by document type and sorted by relevance to the question (Appendix 5)
6) documents excluded at the final stages of reviewing (Appendix 6)

    - 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

What we found

We identified 13 evidence documents relevant to the question, of which we deemed one to be highly relevant, six of medium relevance, and six of low relevance.

We outline in narrative form below our key findings related to the question from highly relevant evidence documents and based on experiences from the jurisdictional scan of four countries (Australia, New Zealand, United Kingdom, United States) and all Canadian provinces and territories (see Box 1 for more details).

A summary of the evidence organized by individualized funding model or approach is provided in Appendix 2, while a summary of the experiences from other countries and from Canadian provinces and territories is provided in Appendix 3. Detailed data extractions from each of the included evidence documents is provided in Appendix 4, and hyperlinks for documents excluded at the final stage of reviewing in Appendix 5.

Key findings from relevant evidence sources

We identified one high-quality evidence synthesis and 12 primary studies that provided insight into how individualized funding models or programs are implemented in different jurisdictions and how they have impacted the ability of families to meet the support needs of their loved ones.

We found evidence that described the features and impacts of individualized funding models for children and youth with support needs in a few countries, namely the National Disability Insurance Scheme (NDIS) in Australia and a few individualized funding programs in the U.K., including personal health budgets, a personalization toolkit and a self-directed support program. We provide insights from the evidence documents about these models in turn below.

Australia's NDIS (4) provides needs-based funding to disabled children, youth and adults to relieve families' financial strain. NDIS allows eligible Australians to develop a service plan and facilitate budget planning to support their needs with the help of NDIS staff.(5) Eligible services may include consumables, transport, assistance with social and community participation, counselling and mental health, assistive technology and home modifications. One study surveying 42 parents of children with neurodevelopmental conditions who received funding through NDIS found that families were allotted funding ranging from AUD $1,000 to $25,000, depending on the needs of the child.(4) The evidence we identified highlighted that parents and carers of children who received NDIS benefits reported several challenges with the program, including limited access to services, a lack of knowledge about the NDIS, stress and indecision as a result of the responsibility of managing the funding, and constraints with reporting procedures.(4; 5) Additional challenges were identified in one study by allied health providers who worked in rural and remote areas, including limited funding input, inconsistent NDIS practices, increased service demand, and changes in case mix.(6)

In the U.K., under the National Health Service (NHS), personal health budgets are available for children 18 years and younger with physical disabilities and their caregivers, as well as for adults and the elderly. The high-quality evidence synthesis we found highlighted that funding from personal health budgets can be spent on service needs, such as daily living tasks, household responsibilities, transportation and routine healthcare.(7) Although the evidence synthesis found that caregivers of disabled children experienced improved satisfaction and well-being through personal health budgets, one primary study reported that caregivers expressed confusion regarding the purpose and eligibility of personal health budgets, pointing out gaps in specialized therapy services and equipment accessibility, and potential disparities in service delivery.(7; 8)

We also identified evidence that described a self-directed support program in England for grade-school-aged children with a disability or complex condition.(9) 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, including child assistants to help with daily tasks, preventative measures (e.g., parental mental health supports), youth extracurriculars, and health-related services. It was reported that 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. These barriers were echoed in a primary study describing a personalized toolkit promoted by the U.K. government that provided direct funding for packages of personalized services for disabled young people with mild or moderate learning disability.(10) Its implementation transferred not only choice and control, but also increased responsibilities, on users of care services.

Additionally, we identified evidence on individualized funding models for adults with complex conditions that we included despite not being focused on children and youth because it provides more insight into the impact of this funding type on recipients and care providers. Personal health budgets for adults in the U.K. were found to be cost-effective and led to enhanced care-related quality of life and psychological well-being, as well as improved access to a broader range of goods and services beyond what is available through traditional healthcare packages of services.(11; 12) However, some individuals reportedly encountered challenges due to inconsistent service options, limited budget information, and tensions that frequently exist between carers and practitioners in determining the extent of carer involvement in social care.(13; 14) Lastly, families who participated in the Illinois Home Based Support Services consumer-direct initiative were provided a fixed budget of US$1,656 per month to support adults who had an intellectual disability. Although the participating families benefited from the flexibility of the program's funding, they reported challenges with fundraising amongst their community members, auditing procedures, and navigating the power dynamics of service providers who restricted fund allocation.(15)

Key findings from jurisdictional scans

We identified jurisdictional experiences of individualized funding models for children and youth with support needs and their families from four countries (Australia, New Zealand, United Kingdom, United States) and all Canadian provinces and territories. In all jurisdictions, funding models aimed to provide holistic supports to improve medical access and quality of life for youth with support needs.

Age and support needs

In terms of age range, we found that all individualized funding programs we identified from New Zealand and the U.S., as well as Canada's national program, are strictly available for youth under 18 years of age. Some programs also explicitly focus on targeting school-aged children, such as Australia's National Disability Insurance Scheme early childhood approach, Saskatchewan's Autism Services, and New Brunswick's Inclusion Support Program. Other programs have a wider focus and include young adults. For example, the U.K.'s special educational needs and disability (SEND) program is available for persons ages zero to 25 years old and Alberta's Children's Ability Fund provides services for persons under 21 years of age. Across jurisdictions, programs available for persons of all ages include England's personal health budgets for children, young people and families, Australia's National Disability Insurance Scheme, the U.S.'s Supplemental Security Income, Prince Edward Island's AccessAbility Supports and Saskatchewan's Individualized Funding for Home Care program.

Regarding support needs, most individualized funding models were available for people with a broad range of chronic and/or long-term medical conditions. However, some were focused on providing support to those with a specific diagnosis. For example, New Zealand's individual funding model is designed to support people with communication delays and disorders. Within Canada, Alberta has a funding program for people with cerebral palsy, B.C. and Ontario have programs for children with autism spectrum disorder, and Ontario and Newfoundland and Labrador have programs for children with any form of neurodevelopmental conditions causing physical and/or intellectual impairments (e.g., Down syndrome).

Funding model eligibility criteria

Most identified models require evidence of a diagnosis to confirm program eligibility. Australia's National Disability Insurance Scheme requires a Pedi-CAT assessment to confirm functional capacity, however, this requirement is waived for children younger than six years old. In the U.S., only children of Veterans who receive supports from the U.S. Department of Veteran Affairs are eligible for funding.

The most common barrier reported across jurisdictions was providing the required documentation (e.g., signed form from healthcare professional or receipts) and navigating the submission process of individual organizations. Within Canada, a formal diagnosis or signed form by a healthcare professional is needed to receive funding through the Canada Child Benefit, Nova Scotia's Direct Family Support for Children and New Brunswick's Inclusion Support Program. Additionally, youth in the Inclusion Support Program are only eligible for the program if their parents are attending school or training. Youth are also eligible for the program if they are under 12 years of age, a New Brunswick resident, are enrolled in school, and provide a referral indicating intensive needs as determined by a support worker. Moreover, Alberta's Child and Youth Support Program is designed for situations where the parents or guardians are unable or unwilling to care for the child. The program also requires that the child is under 18 years of age, does not have an income higher than financial guidelines, is attending school or employed full-time, and resides with an alternative caregiver that is not their parents 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. Both New Zealand's Ministry of Children's individualized funding program and Newfoundland and Labrador's Special Child Welfare Allowance Program only allow youth or their families to access funding after all other government resources have been exhausted. Lastly, the Yukon's Family Supports for Children with Disabilities Program is distinct from other identified programs, as it does not require any form of formal diagnosis or demonstration of need.

Amount of funding provided and how it was determined

We found that the amount of funding available to youth and their families varied based on each program's purpose and unique characteristics, as well as the family's financial income or type and amount of support need required by the youth. New Zealand's Variety Children's Charity offers a one-time grant ranging from NZD $200–2000 to children and their families based on family income, while the U.S.'s Supplemental Security Income program provides monthly payments that are adjusted based on a family's net income. Funding for recipients of the U.K.'s personal health budgets are determined based on a child's preferences and needs.

Individualized funding models in Canadian provinces varied greatly in terms of funding amounts and needs assessments. The Canada Child Benefit offers monthly payments of up to $264.41, based on a family's net income, and in B.C., the Autism funding program can provide a maximum amount of $22,000 per year for each child. In addition to monthly payments of $105 and $148 for children ages zero to 11 and ages 12 to 17, respectively, families who are funded by the Alberta Child and Youth Support Program can possibly receive a supplementary $200 if they require additional medical coverage. The amount of funding provided is based on an assessment of the youth's income. Funding is also provided through Alberta's Child Health Benefit, which provides $500 per year, the Children Ability Fund, which provides a maximum grant of $10,000, and Cerebral Palsy Alberta, which provides some coverage of medical expenses to those demonstrating financial need. In Saskatchewan, Autism Services provides a maximum of $500 per year to those eligible, and Quebec's Supplement for Handicapped Children offers a fixed amount of $218 per month, regardless of financial need or type of disability.

In Ontario, Special Services at Home allocates funds based on the type and cost of services a child may need, support the family is already receiving, and additional help available in the community. The Assistance for Children with Severe Disabilities program offers monthly funding from $25–618 based on the size of the family, severity of disability, and cost associated with caring for the child. The Ontario Autism Program may offer $20,000 per year for children under the age of six, or $5,000/year for children six and older, based on the severity of diagnosis and required supports. Other individualized funding programs in Canada that provide funding based on assessment of financial need include the direct financial support program in Nova Scotia, P.E.I.'s AccessAbility Supports, Newfoundland and Labrador's Special Child Welfare Allowance (SCWA) Program and Yukon's Family Supports for Children with Disabilities Program.

How funds could be spent

Several individualized funding models we identified allowed funds to be spent on services to help manage the medical symptoms of youth with support needs. For example, B.C.'s Autism Funding program specifically funds behavioural interventionists and rehabilitation therapists for children with autism, and New Zealand's Ministry of Education provides support for educational services. Both the Variety Children's Charity in New Zealand and Newfoundland and Labrador's Special Child Welfare Allowance (SCWA) Program cover the cost of drug prescriptions and medical fees. Additionally, both Ontario's Special Services at Home and Alberta's Children Abilities Fund offer funding to cover medical related travel.

Many programs allow flexibility in spending to access social supports and promote meaningful engagement and community participation. For example, Australia's National Disability Insurance Scheme, the Cerebral Palsy Society of New Zealand, Saskatchewan's Autism Services, Newfoundland and Labrador's SCWA Program, and Cerebral Palsy Alberta offer funding for youth extracurricular activities, job supports and accessible transportation. Australia's National Disability Insurance Scheme, B.C.'s Autism Funding Program, Alberta's Children Ability Fund, Variety Children's Charity, Cerebral Palsy Alberta, and Saskatchewan's Individualized Funding for Home Care all aim to increase accessibility in the lives of youth with support needs by providing funds for assistive technology and home modification. Lastly, some programs also offer funding to support the entire family, such as B.C.'s Autism Supports and Alberta's Child Health Benefit permit spending on family counselling.

To help families navigate their budget, Australia's National Disability Insurance Scheme, the Ministry of Disabled People in New Zealand, NHS England's personal health budgets, and the U.K.'s Transforming Care Programme all offer the services of a local coordinator.

Reporting requirements

Information regarding the reporting requirements of individualized funding models across jurisdictions was limited. We found that some programs, such as Australia's National Disability Insurance Scheme, B.C.'s Autism Funding Program and Quebec's Supplement for Handicapped Children, require advanced quotes prior to spending. Alternatively, other programs including Cerebral Palsy Alberta and Saskatchewan's Individualized Funding for Home Care allow receipts and tax forms to be submitted for verification after spending. No information for denied claims are provided on either program's website.

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