

A Message from the Co-Chair

By Yona Frishman

It is with great excitement that I will be sharing with you my recently acquired knowledge about this comprehensive study on individualized funding.

The study is called:

Individualized funding interventions to improve health and social care outcomes for people with a disability: A mixed-methods systematic review

- This study is a review of 73 studies on individualized funding for people with disabilities. They include 4 quantitative studies, 66 qualitative and 3 based on a mix-methods design.
- The data refers to a 24 - year period from 1992 to 2016, with data for 14,000 people.
- The review authors searched for studies up to the end of 2016. Studies that were carried out in Europe, the US, **Canada** and Australia.
- This review was published in January 2019.

The aim of this review was to examine the effects of individualized funding on a range of health and social care outcomes. It also presents evidence on the experiences of people with a disability, their paid and unpaid supports and implementation successes and challenges from the perspective of both funding and support organizations.

The review provides an up-to-date and in-depth synthesis of the available evidence over 25 years. It shows that there are benefits of the individualized funding model. This finding suggests that practitioners and funders should consider moving away from skepticism, towards opportunity and enthusiasm. Policy makers need to be aware of the set-up and transitional costs involved. Investment in education and training will facilitate deeper understanding of individualized funding and the mechanisms for successful implementation.

The World Health Organisation estimates that 15% of the world's population live with a disability and that this number will continue to grow into the future, but with the attendant challenge of increasing unmet need due to poor access to health and social care (WHO, 2013).

Historically, the types of supports available to people with a disability were based on medical needs only. More recently, however, the importance of social care needs, such as keeping active and socializing, has been recognized. There is now an international policy imperative for people with a disability to live autonomous, self determined lives whereby they are empowered and as independent as possible, choosing their supports and self-directing their lives.

One way to achieve self-determination is by means of a personal budget (United Nations, 2006). Personal budgets are just one example of many terms used to describe individualized funding - a mechanism to provide personalized and self-directed supports for people with a disability, which places them at the center of decision-making around how and when they are supported. Individualized funding - which is rooted in the Independent Living Movement - has evolved to take many forms. These include, for example, direct-payments, whereby funds are given directly to the person with a disability who then self-manages this money to meet their individual needs, capabilities, life circumstances and aspirations. Alternatively, a micro board, brokerage model, or 'managed' personal budget provide a similar amount of freedom for the person with a disability, but an intermediary service assumes responsibility for administrative tasks, while sometimes also providing support,

guidance and information to enable the person to successfully plan, arrange and manage their supports or care plans.

The population of interest included: adults aged 18 years and over receiving a personal budget, with any form or level of lifelong disability (physical, sensory, intellectual or developmental disability, level of mental health problem, disorder or illness, or dementia), residing in any country and any type of residential setting (own home, group home, residential care setting, nursing home, hospital, institution). Studies in any language were included.

Minors and older people without a lifelong disability (i.e., no disability in 10 years prior to reaching the age of 65) were excluded, as were privately funded individualized funding interventions. Other types of models also exist, largely guided by country-specific contexts, such as social benefits systems.

For the purposes of this review, the intervention included any form of individualized funding regardless of the name given, provided it met the following criteria:

(a) it must be provided by the state as financial support for people with a lifelong physical, sensory, intellectual, developmental disability or mental health problem;

(b) the recipient must be able to freely choose how this money is spent in order to meet their individual needs;

(c) the individual can avail of 'intermediary' services or any equivalent service which supports them in terms of planning and managing how the money is used over the lifetime of the funding period;

(d) the recipient can also independently manage the individualized fund, in whatever way is feasible;

and (e) the individualized fund may be provided as a 'once-off' pilot intervention for a defined period of time (minimum 6 months), or it can be a permanent move from more traditional forms of funding arrangements that exist nationally or regionally.

Overall, the evidence suggests positive effects of individualized funding with respect to quality of life, client satisfaction and safety.

Recipients particularly value: flexibility, improved self-image and self-belief; more value for money; community integration; freedom to choose 'who supports you'; 'social opportunities'; and needs-led support. Many people chose individualized funding due to previous negative experiences of traditional, segregated, group-orientated supports.

Successful implementation is supported by strong, trusting and collaborative relationships in their support network with both paid and unpaid individuals. This facilitates processes such as information sourcing, staff recruitment, network building and support with administrative and management tasks. These relationships are strengthened by financial recognition for family and friends, appropriate rates of pay, a shift in power from agencies to the individual or avoidance of paternalistic behaviour.

Challenges include long delays in accessing and receiving funds, which are compounded by overly complex and bureaucratic processes. There can be a general lack of clarity (e.g., allowable budget use) and inconsistent approaches to delivery as well as unmet information needs. Hidden costs or administrative charges can be a source of considerable concern and stress.

Staff mention involvement of local support organizations, availability of a support network for the person with a disability and timely relevant training as factors supporting implementation. Staff also highlight logistical challenges in support needs in an individualized way including, for example, responding to individual expectations and socio-demographic differences.

Due to the considerable and growing interest in individualized funding as a means to improve the lived experience of people with a disability and their wider network of support (paid and unpaid), this review provides a comprehensive synthesis of evidence for future governments, funders, and policy makers. Commentators have previously criticized governments for proceeding with individualized funding initiatives without carefully considering the evidence. This review, therefore, provides an up-to-date repository of such evidence, particularly for countries at the early stages of planning or implementation. Not only does it present the most robust effectiveness data available, but it also specifically highlights implementation successes and challenges.

The evidence suggests that practitioners and funders need to shift their focus from one of skepticism, often grounded in fears, to one of opportunity and enthusiasm. Many of the fears, such as fraud/misuse of funds, job losses, recipients flooding the system, are not based on evidence. Funders and practitioners should be guided by the many examples of good practice outlined in this review, whilst working collaboratively toward, and appreciating the consistently reported benefits of, individualized funding. Greater investment is needed in education and training in order to facilitate stakeholder buy-in and generate a better understanding of individualized funding and the philosophy and ethos and the associated mechanisms required for its successful implementation. Finally, policy makers need to be cognizant of the inevitable set-up and transitional costs involved such as capital funding for education and training, as well as redevelopment of assessment, review and other governance systems. In order to facilitate this spending, policy need to be put in place to allow the release of funds from block grants, if implementation is to be cost-effective in the longer term.

This review clearly highlights and synthesizes the extensive and rich qualitative evidence from studies conducted in many countries - across changing social, political, economic, social care and healthcare landscapes – and over a considerable period of time. It also points to the inherent difficulties associated with collecting quantitative data on complex social interventions of this nature, with a subsequent lack of robust effectiveness data. The complexities around set-up and attendant delays, highlighted in the qualitative data, suggest necessary changes in any future collection of quantitative outcomes. And would encourage the adoption of mixed-methods approaches in further systematic reviews when assessing the effectiveness of complex ‘real-world’ interventions in the field of health and social care.

Note: Dr. Tim Stainton from UBC School of Social Work & Centre for Inclusion and Citizenship, Vancouver, BC, Canada was one of the 6 researchers of this study.

Note: With so much on our minds during this pandemic, this is a message for people and families to be thinking about for the future. At the start of the new fiscal year in 2021, we hope to fulfill the plans we had in place for April 2020 - partnering on a gathering with people and families, including bringing new and inspiring information that may help people think about the future with more hope.

Read the full review at: <https://onlinelibrary.wiley.com/doi/full/10.4073/csr.2019.3>

Fleming, P., McGilloway, S., Hernon, M., Furlong, M., O'Doherty, S., Keogh, F., & Stainton, T. (2019). Individualised funding interventions to improve health and social care outcomes for people with a disability: a mixed-methods systematic review. *Campbell Systematic Reviews*, 3.

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