

POLICY BRIEF

INDIVIDUALISED FUNDING for people with a disability



Context

With the Irish Government poised to introduce new funding mechanisms for persons living with a disability, this policy brief will present: 1) a **background** to the origins of individualised funding; 2) trends from national data relating to **traditional service provision**; 3) findings of evaluative research carried out on **four pilot projects in Ireland**; and 4) international evidence on the **effectiveness of individualised funding** at improving health and social care outcomes. Overall this brief endorses Individualised Funding by outlining the benefits of individualised funding while presenting recommendations focussed on successful implementation.

Individualised funding, since it is based on one persons needs and aspirations, has the flexibility to quickly change and adapt to the changing landscape of a persons life, something that is very difficult, if not impossible, within a group-based setting. Critics of individualised funding have raised concerns about the potential adverse implications of commodifying care and of turning disabled people into consumers of basic life needs. However, the vast majority of evidence available indicates many benefits to individualised funding and self-directed support.

Control – Opportunity - Flexibility

The idea of individualised funding grew from the Independent Living Movement that originated in the US and Canada in the 1960s / 70s. The Community Care Act 1990, followed by the Direct Payments Act 1996, saw the first large scale pilots of individualised funding in the UK. This quickly spread to other parts of Europe, North America, Australia and New Zealand. The UN endorsed Individualised Funding, in 2006, as a means to achieve self-determination for disabled people. Irish policy began to reflect the concept of individualised supports in various policy documents including: Time to Move on from Congregated Settings (2011), New Directions (2012), Value for Money and Policy Review (2012). In 2016, on foot of mounting international evidence and advocacy group demands, the Department of Health committed to assemble a taskforce on the implementation of personalised budgets in Ireland.

Freedom - Community Integration

Background

Individualised funding is an umbrella term to describe various models of self-directed supports for disabled individuals and/or their support networks. These models are facilitated by an individual budget. In short it is about empowering the disabled person to decide how they are supported, when they are supported and who supports them. In the past, service providers made these decisions for disabled people by offering a selection of options, usually delivered in a group setting that was separated from the wider community. This was based on professional-led services that were relatively easy to deliver in a group setting. However, preferences change - levels of ability vary – past experiences can dictate future interests.

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Method

In order to inform the imminent policy decisions, a body of research was undertaken to:

 **1)** look at day-service trends over a 15 year period by analysing national secondary data;

 **2)** evaluate four pilots of individualised funding in Ireland, specifically focussing on the successes and challenges related to implementation within the Irish context, by a largely qualitative in-depth case study approach ; and

 **3)** synthesise the international evidence on the effectiveness of individualised funding at improving health and social care outcomes, as well as summarising the experiences of participants, by means of a Campbell Collaboration systematic review.



Findings

Study 1) Over a 15 year period, 1998-2013, day services in Ireland did not change substantially and often did not reflect demand. Government funds should support individualised models, more adaptive to changing trends. National databases need flexibility to respond to policy and user demands. Future research should focus on day service utilization of younger people and the impact of rurality on service availability, utilization, quality and migration.

Fleming, P., McGilloway, S., & Barry, S. (2016a). Day Service Provision for People with Intellectual Disabilities: A Case Study Mapping 15-Year Trends in Ireland. *Journal of Applied Research in Intellectual Disabilities*, 30(2), 383–394. doi:10.1111/jar.12249



Recommendations

★ Individualised funding should not be forced to function within existing systems, processes and procedures that were developed for a different time, society, perspective and understanding of disability. It should instead be facilitated by a needs-led, person-focussed, aspirational resource allocation system that is flexible and adaptive to various, dynamic and changing contexts.

★ Introduce individualised funding on an incremental (step-by-step) basis, starting with school leavers and, in time, moving to a whole society approach including disabled children and (where appropriate) adults and older people receiving supports within traditional services.

★ Provide the necessary resources, (human, time and financial) to facilitate the transition from traditional paternalistic model of service provision to one that is truly person-focussed, needs led and focussed on full community integration. This should include training opportunities for all stakeholders.

Study 2) Exemplified by independent-skills development and community integration, the individualised funding pilots in Ireland have been welcomed as a progressive development beyond traditional service provision, with perceived improvements across a range of organisational, personal, health and social care domains. The research explored the importance of ‘natural supports’ and how overly protective behaviour may unintentionally act as a barrier to full implementation. The findings also indicate that unnecessarily complex systems can lead to individual burnout. Furthermore, a national resource allocation system working in partnership with existing social care professionals and the wider community is recommended, as is learning from overly simplified, group-based ideologies.

Fleming, P., McGilloway, S., & Barry, S. (2016b). The successes and challenges of implementing individualised funding and supports for disabled people: an Irish perspective. *Disability & Society*, 31(10), 15. doi:10.1080/09687599.2016.1261692

Fleming, P. (2016). *How personal budgets are working in Ireland: Evaluating the implementation of four individualised funding initiatives for people with a disability in Ireland*. In G. Trust (Series Ed.), www.genio.ie, (pp. 24). Retrieved from www.genio.ie/personal-budgets



Study 3) Seven studies with eligible quantitative data were identified, demonstrating statistically significant improvements for people utilising individualised funding in terms of quality of life, satisfaction levels and safety, with fewer adverse effects compared to the control group. Cost-effectiveness data was inconclusive. Sixty-nine studies with eligible qualitative data highlighted the many benefits of individualised funding, in addition to implementation successes and challenges.

Fleming, P., McGilloway, S., Heron, M., O’Doherty, S. (RIP), Furlong, M., Keogh, F., & Stainton, T. (2017 – under review). Individualised funding interventions to improve health and social care outcomes for people with a disability: a mixed-methods systematic review Retrieved from <http://campbellcollaboration.org/lib/project/350/>.



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