



Engaged Research Case Study Template

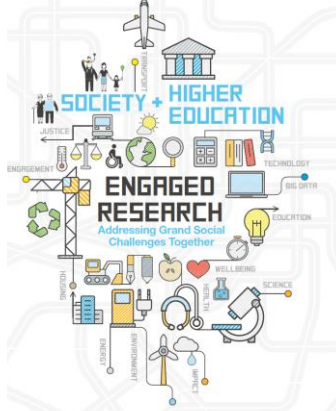
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| Project Title (8 words max) | An evaluation of the development and implementation of individualised funding for people with a disability |
| Health and wellbeing | |
| Project synopsis (100 words max) Please give a very short description of the societal challenge, the action taken, and the intended/ achieved result. | <p>Individualised funding aims to achieve independence and self-determination for people with a disability by enabling personalised and self-directed supports. Such supports have become globally recognised as a viable alternative to traditional group-orientated and centre-based ‘service provision’.</p> <p>The collective findings from this research suggest that individualised funding should not be shoehorned into existing systems, processes and procedures that have been developed for a time when societal perspectives and understanding of disability were very different from those that are in evidence today. These initiatives should, instead, be facilitated by a needs-led, person-focused, aspirational resource allocation system that is flexible and capable of adapting to various, dynamic and changing contexts.</p> <p>With regards to policy and practice insights; individualised funding should perhaps be introduced on an incremental basis, starting with school leavers and, in time, moving to a ‘whole society’ approach, including disabled children, adults and older people receiving supports within traditional services. Implementation should be accompanied by the provision of necessary resources, (human, time and financial) to facilitate the transition from a traditional paternalistic model of service provision to one that is truly person-focused, needs led and community-based. This should include educational and training opportunities for all stakeholders.</p> <p>Ideally, implementation should also be supplemented with robust, mixed-methods evaluations which focus, not only on outcomes over time but also the context of, and mechanisms for, success into the future.</p> <p>This research is particularly timely and important given the plans that are currently underway for national roll-out, as evidenced by unique policy dialogue opportunities involving, for example, the National Taskforce on Personalised Budgets and a high level of interest from, and consultations with, the Health Research Board and the Department of Health in Ireland.</p> |
| Higher Education Institution: | Maynooth University |
| Engaged Research Partners (civic, civil society organisations, Social enterprises, public or professional service or product users, policy makers, members of the public). | <ul style="list-style-type: none"> • People with a disability and their support networks • Genio • HRB • Several disability support services (Possibilities Plus, HSE, The AT Network, National Learning Network) • National Disability Authority • Inclusion Ireland |



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| <p>Engagement (research method or activity) (100 words max)</p> | <ul style="list-style-type: none"> • Department of Health Taskforce on Personalised Budgets <p>Three separate but related studies were conducted using mixed methods approaches within a pragmatic framework. Study One was retrospective in nature and used secondary national data to examine day-service utilisation in Ireland during a 15-year period (1998 to 2013). Study Two involved an in-depth national evaluation of four individualised funding pilot initiatives in Ireland. Using exploratory and participatory methods, this study incorporated an extensive documentary analysis, in-depth interviews, secondary analysis of qualitative data and a participatory workshop. Study Three involved a mixed-methods systematic review of international data from 1985 – 2016, comprising a narrative analysis of quantitative data and a meta-synthesis of qualitative data.</p> |
| <p>Project outputs and outcomes: (600 words max) Please describe briefly the target audience and activities that occurred and short terms results. This information could include:</p> <ul style="list-style-type: none"> • who you worked with; • issue to be addressed • what actions you took; • the geographical location; • any shorter-term outcomes or changes in local situation and circumstances, knowledge and skills attitudes or behaviour, policy, practice, organisational development etc, decision-making. | <p>This research was conducted in a very timely manner, in the lead up to the formation of a National Taskforce on Personalised Budgets. As such, much interest was being generated through the participatory approach taken to the study, but also in terms of outputs, such as peer reviewed papers, publications of professional interest, media interviews, and national and international presentations. As a member of the advisory and consultative arm of National Taskforce on Personalised Funding, the lead investigator was ideally placed to feed research findings into the early implementation process, by attending and actively contributing to the taskforce. Ultimately the taskforce recommended that the Department of Health and the HSE should establish demonstration projects to test the delivery of personalised budgets with a view to identifying the best approach to the national roll-out of these payment models.</p> <p>Furthermore, the participatory approach adopted in Study Two, meant that the findings were directly informed and verified by the individuals participating in the pilots, their family and friends and the organisations implementing individualised funding. The research participants reportedly gained useful insights by participating in the initial data collection, but also the participatory workshop where they had the opportunity to network and share key lessons learned with others implementing and receiving individualised funding. This was a unique opportunity that would not have otherwise taken place, had the research project not brought these key stakeholders together. This ‘casting of the net’ meant that research findings were being disseminated, not only by the researcher (as is the convention), but also by the various stakeholder groups, thereby having a potentially more tangible and lasting effect.</p> <p>Overall, the findings from this study represent an important and useful addition to the literature while also providing comprehensive evidence on the effectiveness and implementation of individualised funding in countries across the world including Australia, Belgium, Canada, England, Germany, Ireland, Northern Ireland, Scotland, Wales, and the USA. As such, the findings provide an important resource for those implementing individualised funding both in</p> |



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| | <p>Ireland and elsewhere, whilst also providing an important ‘toolkit’ for policy and practice more generally.</p> <p>Individualised funding has been shown to have considerable benefits over traditional models of service delivery but any national roll-out must be accompanied by robust, participatory, collaborative and evaluative research to provide much needed quantitative data and especially in the view of the dearth of outcomes data when compared to the length of time individualised funding has been in existence.</p> <p>Lastly, the collective findings presented as part of this multi-strand research, suggest that government, policy makers, practitioners and end-users alike, should advocate for, and support, implementation in their respective jurisdictions, providing opportunities for improved outcomes and a progressive and shared reconceptualisation of disability supports throughout the world.</p> <p>Outputs include 12 publications in total:</p> <ul style="list-style-type: none"> • 3 peer reviewed journal articles • 1 systematic review (in submission) • 8 publications of professional interest and scholarly interest: <ul style="list-style-type: none"> ○ Research report ○ 2 articles in Frontline – an Irish quarterly magazine published from 1989 to 2015 for people with intellectual disability, allied staff and families at the front line of intellectual disability ○ Policy brief ○ Short articles in SPHeRE Network quarterly publication • 10 national / international conference presentations. |
| <p>Longer term anticipated areas for Impact (Choose from below): Economic Policy & Public Service Societal Engagement Health & Wellbeing Professional services Environmental New knowledge Human Capacity</p> | <p>Economic Policy & Public Service Societal Engagement Health & Wellbeing Professional services New knowledge Human Capacity</p> |
| <p>Funding source:</p> | <p>This work was funded by Genio and conducted as part of the HRB Scholar Programme in Health Services Research (SPHeRE) under Grant No. PHD/2013/1</p> |
| <p>For more information contact:</p> | <p>Dr. Pádraic Fleming, (HSE), (Principle Investigator)</p> <p>Co-investigators: Professor Sinéad McGilloway (Centre for Mental Health and Community Research, Department of Psychology and Social Sciences Institute, Maynooth University) (Principal Supervisor) Dr Sarah Barry, Centre for Health Policy and Management, TCD (Co-supervisor)</p> |

