

# How personal budgets are working in Ireland

Evaluating the implementation of four individualised funding initiatives for people with a disability in Ireland

Research brief, May 2016

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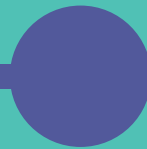
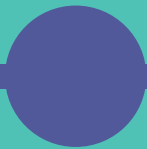
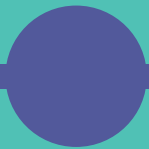
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## Focus of this research brief

This document is aimed at anyone who is interested in the practicalities, successes and challenges of implementing individualised funding initiatives in Ireland. Those who may be interested include:

- ➔ People living with a disability.
- ➔ Those providing informal supports for people with a disability, such as family members, friends, members of the wider community.
- ➔ Personal assistants / key workers and other paid support for individuals with a disability.
- ➔ Staff members currently implementing individualised funding initiatives.
- ➔ Service providers considering moving to an individualised funding model or incorporating an individualised funding arm into their current service model.
- ➔ Researchers.
- ➔ Funders.
- ➔ Policy makers/drivers such as civil servants and elected members of government.
- ➔ The Health Service Executive (HSE) and other health service staff.

There were four organisations involved in this evaluation. The briefing document will present a summary of the main lessons learned according to the key people involved in these four individualised funding initiatives, including individuals with a disability who participated in the initiatives, family members,

paid and unpaid advocates; and staff members from within the four organisations.

A number of recommendations will be made at the end of the briefing document. These are based on the key lessons presented and are intended to inform, challenge and promote discussion among the readership.

## Introduction: Individualised funding

Individualised funding is an umbrella term for various different funding mechanisms that aim to provide personalised and individualised support services for people with a disability. Many other descriptors which vary across contexts are captured within the umbrella term of 'individualised funding' (see Table 1). Indeed, new terms continue to emerge, as organisations attempt to implement this relatively new model, each striving to meet the individual needs of people with a disability.

While the terminology around individualised funding differs, the principles are consistent, based on self-determination, choice, control and, very often, person-centred planning. The initiatives generally aim to place the person with a disability at the centre of the decision making process, with a view to recognising people's strengths, preferences and aspirations. This can empower people to shape public services, including health and social care, by allowing those in receipt of such services to identify their needs, and to make choices about how and when they are supported (Fleming, Furlong, et al., 2016).

## Historical context

The disability sector is complex with considerable variation internationally in terms of progress and models of service delivery, and is often deeply influenced by policy and practices from the past. Historically in Ireland, as in many other countries, family- and advocate-led organisations became the driving force for change, eventually forming voluntary organisations and semi-autonomous non-governmental-organisations (NGOs), funded largely by the Government. These became the main provider of vocational training, sheltered work and other activities for people with a disability, and continue to deliver services within geographical designated areas to this day.

During the 1960s, the medicalised model of service provision became increasingly 'specialised' with professionals recommending the necessary services to

address the health care needs of people with a disability. However, in more recent years, a shift in international policy began to move the disability sector towards an individualised and person-centred model, drawing on a more holistic view of what is required to live a fulfilled and healthy life, including personal and social care needs. In Ireland, a number of policy documents based on international best practice have been developed (Department of Health, 2012; Health Service Executive, 2011, 2012). Most recently, the "Value for Money and Policy Review of Disability Services in Ireland" (2012) – currently used as the benchmark for achieving disability sector improvements - recommends, amongst other things, the provision of 'supports' rather than 'services', using person-centred plans, individualised supports and personal budgets to bring Ireland in line with the global changes within the disability sector (Fleming, McGilloway, & Barry, 2016).



Table 1 - Terminology used to describe individualised funding

Country	Terms used	Source of money	Support / Care mechanism
<b>U.S.A</b>	<ul style="list-style-type: none"> <li>➔ Self-Determination programs</li> <li>➔ Cash and Counseling</li> <li>➔ Consumer Directed Care / Support</li> </ul>	Medicaid waivers at State level	<ul style="list-style-type: none"> <li>➔ Independent consultant</li> <li>➔ Fiscal intermediary services</li> </ul>
<b>U.K.</b>	Direct Payments	Local Authority	Personal assistant
	Individual Budget	Local Authority	Package of care from multiple sources
	Block funding from the Social Care budget	Social Care budget	Residential costs and associated care costs
	Independent Living Fund	Department for Social Security	Care from agency OR personal assistant
	<i>Other terms used:</i> <ul style="list-style-type: none"> <li>➔ Recovery Budget</li> <li>➔ Personal Budget</li> <li>➔ Personal Health Budget</li> <li>➔ Microboard</li> </ul>	<i>Other funding sources:</i> <ul style="list-style-type: none"> <li>➔ Supporting People fund</li> <li>➔ Access to work funding</li> <li>➔ Disabled Facilities Grants</li> </ul>	
<b>Netherlands</b>	Person-centred budget	Dutch Welfare State	Package of self-determined care. Assisted by employed care worker (Often Informal (family) carers).
<b>Ireland</b> (Presented in this report)	Independent Support Broker / Brokerage	<ul style="list-style-type: none"> <li>➔ Innovation funding for pilot</li> <li>➔ Ongoing funding from HSE</li> </ul>	Package of care from multiple sources / residential costs
	Direct payments	<ul style="list-style-type: none"> <li>➔ Innovation funding for pilot</li> <li>➔ Ongoing funding from HSE</li> </ul>	Package of care from multiple sources / residential costs
	Self-management model	Innovation funding for pilot	Community Connector

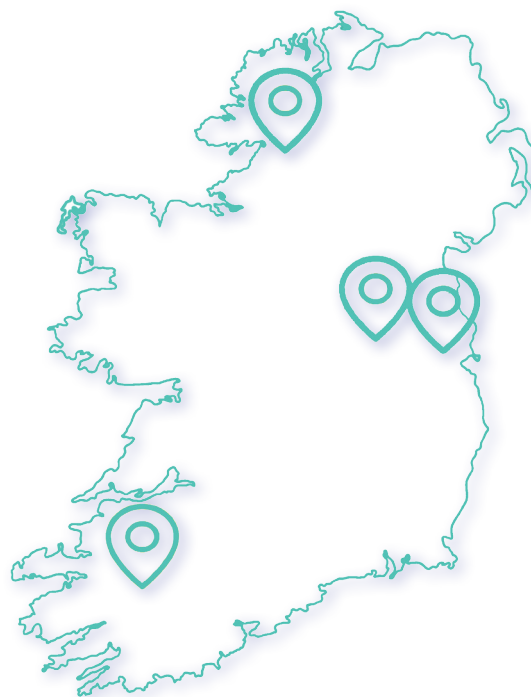
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Country	Terms used	Source of money	Support / Care mechanism
Canada	Direct Payment / Direct Funding	Community Living British Columbia (CLBC)	Supports and services for the individual as agreed to by the individual, agent and CLBC facilitators and CLBC analysts
	Host Agency Funding	Community Living British Columbia	
	<i>Other terms used:</i> ➔ Self-managed care ➔ Individualised funding program ➔ Support for Interdependent living		
Australia	➔ Microboard ➔ Self-directed funding ➔ Consumer-directed care ➔ Local Area Co-ordination Program ➔ Shared management model ➔ Self-management (direct payments)		
<b>Other terms used internationally</b>	Indicative allocation, Individual service fund, Managed account, Managed budget, Notional budget, Personalised care, Pooled budget, Self-directed care, Self-directed support, Virtual budget, Cash-for-care.		

Data sourced from: (Carter Anand et al., 2012; Fleming, McGilloway, & Barry, 2015b; Power, 2010; Webber, Treacy, Carr, Clark, & Parker, 2014)

## Overview of four Irish initiatives

In response to these policy recommendations, Genio provided innovation funding for organisations to pilot individualised funding initiatives in four locations throughout Ireland. These initiatives, which may be categorised in different ways, are described below:



How personal budgets are working in Ireland

Model	Population	Funding Mechanism	Supports	Status
<p><b>Direct Payment</b> Provided to people with different disabilities (&amp; their families) in Ireland to enable people to purchase their own services, mainly Personal Assistance. Run by the ÁT Network, Dublin.</p>	<p>Mainly people with physical disabilities but also includes people with other disabilities.  20 members at time of evaluation.</p>	<p>Individual sets up own company whereby they manage finances, hire necessary staff &amp; purchase services directly from providers..</p>	<p><b>1. Staff</b></p> <ul style="list-style-type: none"> <li>➔ Act as Intermediary between individual &amp; HSE.</li> <li>➔ Support person to use Direct Payment including: <ul style="list-style-type: none"> <li>o Resources.</li> <li>o Training.</li> <li>o Research &amp; Innovation.</li> <li>o Communication / Events</li> </ul> </li> </ul> <p><b>2. Circle of Support</b></p>	<p>Exited pilot stage &amp; is receiving HSE funds on person by person basis. National expansion underway.</p>
<p><b>Direct Payment using Broker</b> Provided support to young adults with disabilities to arrange &amp; access services, to meet their training needs in a community setting. This is a pilot called 'Bridging the Gap', run within a HSE service in Donegal.</p>	<p>People with physical, intellectual &amp; developmental disabilities.  11 individuals participated in the pilot.</p>	<p>Direct payment was held centrally &amp; managed on behalf of participant using pre-existing systems. The broker &amp; client developed a PCP (person-centred plan), identified &amp; costed various elements of plan.</p>	<p><b>1. Broker</b></p> <ul style="list-style-type: none"> <li>➔ Negotiated price of services</li> <li>➔ Liaised with organisational staff &amp; review group.</li> </ul> <p><b>2. Governing / Monitoring</b></p> <ul style="list-style-type: none"> <li>➔ Facilitated meetings</li> <li>➔ Developed admin forms</li> <li>➔ Financial review Group <ul style="list-style-type: none"> <li>o reviewed PCP</li> <li>o approved expenditure</li> <li>o monitored progress</li> </ul> </li> </ul>	<p>No mechanism was available to unbundle existing funding when innovation funding ended. On hold until funding mechanism is put in place.</p>



Model	Population	Funding Mechanism	Supports	Status
<p><b>Independent Support Broker</b></p> <p>Supporting people with disabilities to live self-directed lives by negotiating with HSE to release funds usually allocated to traditional service providers for use as personal budget. This is called PossibilitiesPlus, run from within a service provider organisation in County Kildare.</p>	<p>People with physical, intellectual &amp; developmental disabilities. 9 individuals participating in pilot at time of evaluation.</p>	<p>Finances &amp; human resources were managed centrally by the 'brokerage service' - utilising pre-existing systems within the organisations traditional service arm. All other mechanisms were separate. Cash provided to individuals for daily expenses.</p>	<p><b>1. Staff</b></p> <ul style="list-style-type: none"> <li>➔ Intermediary between individual / their family &amp; HSE to determine: how much money allocated; is it adequate to meet needs; &amp; is it available to use as personal budget.</li> <li>➔ Get to know the individual &amp; their support structure - formalise or develop circle of (informal) supports.</li> <li>➔ Recruit support worker to work with individual</li> </ul> <p><b>2. Encourage Circle of Support to:</b></p> <p>Think creatively, network &amp; try out new experiences.</p>	<p>Exited pilot stage &amp; is receiving HSE funds on a person by person basis. HSE has commenced referring individuals to the service.</p>
<p><b>Self-management model</b> where individuals planned &amp; managed their training, work, education &amp; recreational activities with the help of a 'Community Connector'. This is a pilot called ConnectAbility, run from within the National Learning Network in Kerry.</p>	<p>Young adults (18 – 25) with intellectual / developmental disabilities or mental health problems. 5 individuals</p>	<p>Finances were held centrally &amp; managed by the organisations pre-existing systems. However individuals, with help from the community connector, decided how &amp; where the money was spent.</p>	<p><b>Community Connector</b></p> <ul style="list-style-type: none"> <li>➔ Assisted individuals to design their own program, choosing activities &amp; providers that met their needs best</li> <li>➔ Community based training activities were identified to help individuals manage community participation e.g. money management skills, driving lessons.</li> </ul>	<p>No mechanism was available to unbundle existing funding when innovation funding ended. Project ended.</p>

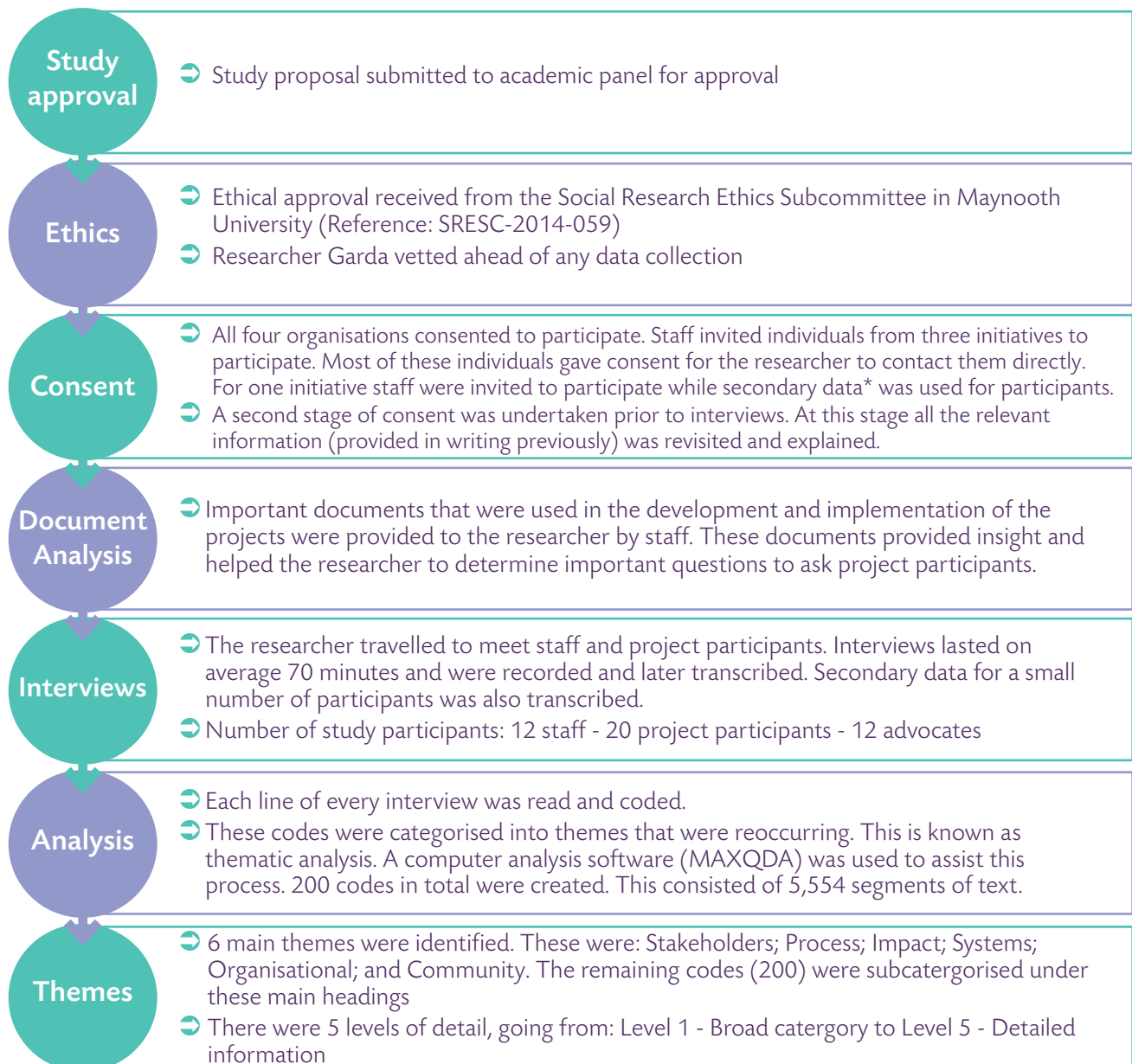
## Study aims and objectives

The principal aim of this research evaluation was to identify and explore the successes and challenges of implementing individualised funding initiatives within an Irish context.

## Methods

Four organisations were involved in the evaluation. Those who participated in the research included: people with a physical, intellectual or developmental disability; their

family members and other advocates; and staff from the four organisations. In total there were twenty people with a disability, twelve family members/advocates and twelve staff involved. International literature and organisational documents were initially examined. These helped the researcher develop a set of questions to ask research participants during in-depth interviews. All interviews were analysed together to identify common themes that emerged within the four pilots. Further detail on the methods can be seen in the flowchart below:



\*Note: Secondary data consisted of video files publicly available on the internet, in which participants were discussing their experiences of the individualised funding scheme in question.

## Findings

The evaluation was primarily interested in the successes and challenges of implementing individualised funding initiatives within the Irish context. As a result the facilitators of successful implementation and the barriers to successful implementation will be presented below under the 6 main themes identified in the evaluation.

### 1. The role of stakeholders

One of the main influences on the implementation of individualised funding was the nature of the stakeholders involved. The key stakeholders identified in the evaluation were:

- ➔ People with a disability – physical, intellectual, developmental or related to mental health.
- ➔ Advocates
  - Natural supports – extended family, partners, friends, neighbours, work colleagues, and members of wider community.
  - Paid supports – Personal assistants, key workers, independent support broker, mentor, allied health professionals, administrative & other organisational staff, educators, disability managers within HSE, service providers.

#### Facilitators of successful implementation

The availability of a ‘circle’ of natural supports provided significant benefits for participants in terms of helping them learn to actively engage with the community, especially when

learning new social, decision-making and independent living skills. Where no circle of support existed, formal supports (e.g. organisational staff, broker, key worker or mentor) worked hard to identify and engage with potential advocates. Supporters who worked best within this new and evolving environment were described as practical, amenable, friendly and encouraging in their approach. Other personal attributes that were important included having: vision; innovation; personal experience of disability; a willingness to challenge stakeholders and an active role in the community. Essential for all stakeholders was an appreciation of an individual’s abilities, passions and interests.

#### Barriers to successful implementation

While family members and other paid and unpaid supports were integral to successful implementation, there were certain behaviours/attributes which limited the extent of these successes. These included: treating the individual with a disability as a child rather than an adult; assuming an incapacity to undertake certain tasks based on past experience, or the disabling effects of the traditional paternalistic model of service provision; doing simple and more complex tasks on behalf of the individual; and being over-protective due to previous negative experiences or fears/anxiety associated with the unknown. These appeared to be due, at least in part, to damaged relationships with traditional service providers and health professionals as a result of previous hardships / negative experiences.

## 2. Process-related factors

The process of developing a personal budgeting initiative began with the host organisations (three pre-existing, traditional service providers & one voluntary group of individuals with a disability) intensively researching international experiences of implementing individualised funding initiatives. In some cases, this involved visiting programmes in the UK and the US. Such site visits were particularly useful due to the absence of any individualised funding initiatives in Ireland previously. The next step was to recruit and, in some cases, train independent support brokers / community connectors, after which the recruitment of participants began. This varied across all four initiatives but involved either informal word-of-mouth or formal HSE referrals via the host organisation. For one of the organisations, the first participants became the future directors/board members of the individualised funding initiative. There were achievements in terms of accessing HSE funds, with the amount of money provided usually based on the cost of traditional day or residential services.

### Facilitators of successful implementation

Essential to the process was giving 'a voice' to the individual with a disability, listening to them and acting upon their wishes. For many individuals who had previously participated in a very structured and prescriptive support environment, decision-making did not come easily. Therefore, considerable time was required to get to know the individual (this is applicable for close relatives also who needed to re-evaluate what they thought they knew about their relative with a disability).

This involved identifying the best means of enabling that individual to express their preferences. It was also considered very important to have an organic and informal process, with a flexibility to change and adapt to the individuals' new and emerging independent life.

The process also benefited from being needs-led and innovative, harnessing community spirit. For example, the hosting of participatory meetings with the new and growing circle of support worked well in terms of: involving the person with a disability; exploring their preferences; identifying activities within the community; and actively involving the support network in the persons' life plan and goal aspirations. During the early stages of implementation, it was also useful to have formal supports (support brokers/community connectors) more actively involved and leading these meetings if necessary. Over time, this leadership role and responsibilities were transferred to the individual with a disability and their new support network. Lastly, it was considered important to have the role of formal paid supports clearly outlined from the beginning so that a trusting and sustainable relationship could be developed whilst the provision of an easy and equitable access route to individualised funding was also critically important, with access routes being developed and formalised during the pilot initiatives.

### Barriers to successful implementation

One of the most challenging aspects of implementation for all four initiatives was access to funding. With no national resource allocation system in place, each individual

case was different and required a very time consuming and often very difficult process to get funds released from the block grants of service providers or directly from the HSE. Two initiatives never managed to get funds reconfigured by the HSE so that they could be used on an ongoing basis after the pilot. As an alternative, they used pre-existing staff and systems to support and resource implementation, while the Genio innovation funding was used to provide the actual individual budgets for the duration of the pilot.

For the other (more sustainable) initiatives, meetings were held between the HSE disability manager, support staff, family members, and in some cases the individual with a disability. In many cases, the individual funds, as allocated from the HSE, were tied up in another day or residential service provider, even if the individual no longer attended those services. This challenging and overly burdensome process had the potential to lead to burnout for the individual, their family and support services. Participants reported that the time and energy invested by advocates in negotiating the release of funds could have been better spent in overcoming other person-specific issues related to the supports they needed to live a full life, such as identifying activities / pursuits, educational or job opportunities.

The lack of a national resource allocation system also meant that the route to accessing individualised funding was not clear. In other words, many people did not know that the option existed. If they did know about the pilot initiatives, there was no application process or apparent eligibility criteria. The

initial recruitment of individuals in two initiatives was informal in nature whilst a HSE referral or a mix of informal and formal recruitment was utilised by the other two initiatives. The lack of transparency was flagged by participating individuals as being unequal and inequitable. However, the pilot initiatives made good progress over time in addressing these kinds of teething difficulties and in developing and formalising this process by: generating informational materials (text and video); hosting public information events; and creating websites that included eligibility criteria, contact information and an application form in one case.

### 3. Impact

Individualised funding initiatives aim to improve the lives of people with a disability by giving them more control and choice over what they do with their lives and how they are supported. Ultimately, the goal is to move toward a self-determined life. With that in mind, the pilot initiatives were reported to have had many positive impacts on the lives of the individuals with a disability and their support network. There were also challenges identified and the research findings shed light on potential ways to successfully manage those challenges. As a result of the individualised funding and associated activities, individuals described themselves as more **successful – confident – adaptive – skilled - empowered - independent - in control** – and with a **greater sense of purpose**. However, without the appropriate support mechanisms and social and interpersonal skills in place, there was the potential for individuals to become overwhelmed with their new life

circumstances. A fear of isolation for these participants was also in evidence, having left many life-long friends behind in the traditional centre-based services. This fear, among other things, occasionally led to anxiety, lack of trust, defensiveness and a defeatist, apathetic mentality whereby the person focussed on their disability rather than their abilities. However, it should be noted that this was the exception rather than the rule, but still a potential risk to highlight, should these initiatives be rolled-out into the future.

### **Facilitators of successful implementation**

It was acknowledged by all of the initiatives involved that undertaking a journey of discovery alongside the individual with a disability was an excellent starting point. If following a certain 'discovery' model, it was important to have the flexibility to change direction, turn back, skip a section, take a break or restart the journey if necessary. The initiatives utilised, and in some cases developed, various tools to facilitate this journey of discovery. For example, the Social Role Valorisation model was one such approach which helped to take people out of the devalued roles they previously occupied and put the steps in place for a more valued social position (Blakely & Dziadosz, 2015). Here, a number of factors were important in improving people's outcomes. These included: providing opportunities to develop independent life skills, social and community supports and engagement with new opportunities and experiences. Appendix one (p.20) outlines how pilot participants decided to spend their allocated funds to achieve these outcomes. The associated benefits

were often unexpected and substantial. The available evidence indicated further that changes in the 'mind-set' of paid support and natural supports - to focus on ability rather than disability - had enabled people with a disability to trust their instincts, to voice their preferences / concerns and to challenge the status quo.

### **Barriers to successful implementation**

An important observation during this research was that people with a disability (particularly an intellectual or developmental disability) have a tendency to want to please, which often translates to doing what they think others want them to do. However, a potential for less positive or negative outcomes arose if this tendency went unchecked or worse still, if it was enabled. A further barrier arose in relation to informal supports who had over-protective or paternalistic relationships with the individual. For example, where an individual had made progress in terms of developing independent travel skills, the opportunity to practise these new life skills was avoided due to anxiety and fears on behalf of family members. Indeed, such risk adverse behaviour was recognised among family members themselves during the research. This was not helped by future uncertainty in terms of whether individualised funding coupled with a fair and equitable resource allocation system, would be rolled out nationally.

## **4. Systems-related factors**

The four organisations implementing individualised funding also developed, tested, revised and rolled out operational systems. Some worked within the constraints of pre-existing organisational processes

and procedures, whilst another was given 'a blank canvas'. These new systems were deemed acceptable by participants and their advocates, thereby representing an improvement on traditional services. The systems put in place aimed to formalise processes around: 'de-bundling' money from the 'block grant' within the HSE; getting funds released from other service providers no longer providing services; governance; allocation of funds to individuals; reporting to HSE; training and mentoring for individuals and their support network; recruitment of clients; recruiting and training staff; monitoring progress; health and safety checks; and administrative / legal / accounting support for those managing their own business. Similarities across initiatives were most evident around the mechanisms used to engage and develop informal support networks.

### **Facilitators of successful implementation**

With perceived improvements across a range of personal, health and social care domains, the new systems were championed by many individuals with a disability and their family members/informal supports. Staff working within the four organisations had long standing relationships with HSE senior staff members and local disability offices. This created a sense of trust and assurance for HSE staff who were otherwise cautious about releasing funds to individuals. Governance issues were of less concern due to the presence of an 'intermediary body', in this case the organisations piloting the individualised funding initiatives. These pre-existing relationships led to successes around the 'de-bundling of money' and subsequent

flexibility around the allocation and use of funds. The strong and transparent reporting systems also helped to reassure HSE officials.

### **Barriers to successful implementation**

While there was considerable flexibility provided to individuals engaging with the individualised funding initiatives, there were also potential barriers to success when it came to systems. The most striking was the anxiety and uncertainty due to the lack of a national resource allocation system. The need to consult with HSE officials on a person-by-person basis caused unnecessary burden for both organisational staff and individuals seeking to release funds. Against a reported backdrop of constantly having to 'fight the system' (for families and individuals), this overly complex system posed a real risk of demotivation, disengagement and burn-out. Alternative systems of money allocation and monitoring of spending led to considerable administrative burden for individual support networks. This was an important deterrent particularly for individuals with an intellectual disability. Without national systems in place, sustainability was constantly being scrutinised. This uncertainty posed a challenge for individuals and families to completely disengage with traditional service providers, often making informal arrangements to return if and when the individualised funding initiatives ceased.

For staff members, the system of de-bundling money was reported to have adversely impacted the amount of time left to develop other aspects of the programme. For example, some processes around 'getting to know individuals' and 'building community connections' were standardised in order to

save time and make processes more easily replicable. There was a risk here of losing the individuality that lies at the core of these new initiatives and this is something that perhaps staff could be aware of going forward. For example, the use of 'petty cash' for one person was a source of great independence whilst for another it caused unnecessary confusion, anxiety and fear.

Collectively, these findings suggest that a national resource allocation system is an important prerequisite for these initiatives to be ultimately successful. Importantly, the National Disability Authority (NDA) has carried out a significant body of work on possible resource allocation systems, although there is no conclusion as yet (National Disability Authority, 2015). However, international experience from Canada and the UK warns against becoming overly focussed on the systems because this has the potential for stakeholders to lose sight of the personal and social values that inspired individualised funding in the first place (Fleming, McGilloy, & Barry, 2015a, 2016 (Under Review)).

## 5. Organisational factors

Our findings indicated that the organisations that embarked upon this innovative journey of implementing individualised funding schemes had a steep learning curve and many associated rewards and challenges. There was a real sense of accomplishment and pride among these early adopters, with a perception that they were paving the way forward in a dynamic and changing sector. Nevertheless, with slower than anticipated progress and a certain amount of resistance experienced along the way, the path to success was not smooth and indeed the challenges are ongoing.

## Facilitators of successful implementation

Frontline staff seemed to be motivated by senior staff members who were passionate about individualised funding. In fact, it was cited by one staff member as one of the most impactful interventions that he witnessed over his entire career, with real tangible benefits for the individuals with a disability. For many, these motivational factors stemmed from seeing, first hand, the perceived improvements in the quality of life, personal achievements and circumstances of participating individuals and their families. Often this was reflected in the commitment demonstrated by individuals who had previously been apathetic about traditional services. Staff appeared to be motivated by observing how real value for money could be achieved, both in terms of cost savings when purchasing services, and by achieving more 'bang for your buck' socially and personally through the enhanced quality of services. This sense of accomplishment was enriched through personal storytelling and celebrating the successes associated with challenging the status quo. While these factors seem simple they had a real impact, enabling a positive work culture in what was otherwise a difficult path to follow at first.

## Barriers to successful implementation

It was very important for organisations to ensure that they had buy-in from staff members and individual support networks. Where people were overly cautious or too afraid to relinquish the traditional way of doing things, success was more difficult to achieve. This sense of cautiousness was present for most people involved, even those championing individualised funding.



Participating individuals had engaged with traditional services, some over years, others for decades and changing human behaviour takes time. Once again these insecurities were associated with the sustainability of individualised funding, with no tangible governmental commitments in evidence, beyond policy documents.

At an organisational level, there was also an apparent resistance to change both internally and externally. For one project, senior staff members (somewhat removed from implementation of the new initiative) were mistrusting of the national policy move towards individualised funding, suspecting that it was a money saving measure on behalf of funding bodies. There also appeared to be an underlying degree of mistrust around organisational changes in governance and the associated power shift from service provider towards service recipient. These misgivings subtly appeared to transcend the ranks, and ultimately had a demotivating effect on frontline staff. Others perceived the funding bodies in question to be disengaging with the new individualised funding model outlined in national policy.

At a more practical level, there were other potential barriers to success for those implementing the pilot initiatives. These included: staff limitations in terms of manpower and time management (particularly around de-bundling money while building a strong circle of support for individuals); an over-emphasis on the monitoring process; confusion and misinformation about what other pilot initiatives were doing; identifying resources and building trusting relationships within the

community; maintaining the health and safety of those participating in the initiatives and people management (particularly in relation to over-protective, resistant or sceptical family members). Key recommendations can be seen at the end of this report, which go some way to address these potential barriers.

## 6. The role of the community

Community integration is one of the key goals of individualised funding and is also one of the most substantial differences between historically institutionalised service provision and also with the current traditional model of group, segregated and centre-based service provision. Research participants, when explaining the key advantages of the new individualised funding model, very often compared their new and improved circumstances to those previously experienced in traditional arrangements. Community-based benefits were consistently reported in relation to the individualised funding model although there were also obstacles to overcome, such as ensuring individuals develop their social skills while maintaining personal safety. These formed part of the learning experience for all stakeholders including members of the general public.

### Facilitators of successful implementation

The opportunity to engage with activities and services that are provided to the general public was one of the greatest successes of these initiatives in terms of community. For participants, they were exposed, sometimes for the first time (on an individual basis), to businesses, civil society groups, recreational

and leisure facilities. Any initial apprehensions or anxiety were quickly overcome; indeed such anxieties would be expected of anyone undertaking a new experience for the first time. Members of the general public who actively engaged with individuals appeared to become more understanding and more aware with regard to the fact that no exceptional or additional effort is required to provide services or to meet the needs of individuals with a disability when compared to the general population. Where specific needs (e.g. one-to-one teaching rather than a group teaching environment) arose, these were generally easy to accommodate.

The paid support (broker/support worker/community connector) acknowledged that it was generally good practice to notify service providers (e.g. tutors in adult community courses) of specific needs or behaviour traits to be expected, particularly if it was their first time mentoring a person with a disability (as was often the case). This was person-specific and generally such pre-emptive practices were not required. The arrangement of one-to-one service provision was another facilitator of success. Unlike a group-based setting, this ensured a personalised service that moved at the appropriate pace. It also provided some time and space for everyone involved to become accustomed to the new dynamic. However, immediate integration into group activities was the preference of others thereby increasing opportunities for social interaction and the associated benefits for all involved. Friendships often blossomed from community integration, leading to a natural expansion of the informal circle of support.

### **Barriers to successful implementation**

For many people with a disability, it was their first time to independently engage with services within the general community. This often required assistance at the beginning while learning important independence and social skills. One of the most basic and often challenging skills was money management (i.e. paying for items and taking change). For some, acquiring these new skills was a steep learning curve and was somewhat overwhelming. As always, the pace at which community integration progressed needed to be tailored to individual need. Some people were more cautious, while others sometimes 'threw caution to the wind' in order to enthusiastically embrace this new sense of independence. For those implementing the initiatives, the latter approach highlighted potential health and safety concerns. There was also the risk of overwhelming members of the community who were otherwise open, for example, to providing work experience opportunities. As a result, there was the need to manage expectations around the receptiveness of the wider community. While generally there were no problems, there was a small risk of an adverse reaction from members of the public. Balancing the paternalistic instinct to protect the individual with a disability, and acknowledging the need for some degree of positive risk-taking, was a major challenge for the support networks. Such over-protectiveness had the real potential to hamper progress for individuals.

The findings from this research suggest a number of ways in which the process of implementing individualised funding might be improved if rolled out in Ireland. These suggested recommendations are outlined on the next page.

## Recommendations for the implementation of individualised funding

For individualised funding to be successful in Ireland, it is important to:

- ➔ Focus on an individual's abilities, passions and interests and encourage independence and personal responsibility by avoiding paternalistic behaviour. Over-protective instincts should be constantly assessed by anyone who is actively engaging with people with a disability.
- ➔ Provide an easy and transparent access route from the outset for people who wish to avail of individualised funding; this should include information around eligibility and what is expected as part of the 'sign-up' process.
- ➔ Provide targeted training for support workers / personal assistants etc. including:
  - A discovery process framework that includes: Facilitating decision-making - People management skills - Facilitating behaviour change
- ➔ Provide training and real-life opportunities around decision-making for individuals with a disability; this should include considerations about how they expect the decision to change their current situation, why that is important and who will be affected by the decision.
- ➔ Retain individuality - avoid standardised procedures as much as possible (e.g. the use of petty cash should not be rolled out across the board, but rather offered on a case-by-case basis).
- ➔ Be clear about roles and responsibilities as early as possible; this avoids misunderstandings at later stages when paid supports become less involved.
- ➔ Ensure social contacts and friendships are maintained with those with whom individuals once shared the centre-based services; new community-based friendships should also be encouraged and facilitated.
- ➔ Assess whether individuals prefer group environments or one-to-one arrangements.
- ➔ Advocate for a national resource allocation system, but do not become overly focussed on these systems; whilst not ideal, evidence suggests that much can be achieved within the current framework.
- ➔ Use existing relationships with staff within disability offices to build a sustainable and equitable system.
- ➔ Ensure that senior staff members within organisations implementing individualised funding positively champion and promote individualised funding, particularly during challenging periods.
- ➔ Share stories and celebrate achievements - use social networks, blogs, print, video and other media to highlight success stories and grow momentum.
- ➔ Develop collaboration and build a unified network of advocates in order to strengthen the national presence. Valuable lessons have been learned by several organisations and many individuals over the past three years. It is important that these people engage and network in order to share ideas, top tips and pitfalls whilst focusing on shared goals rather than organisational differences.

## Appendix 1

How did people decide to spend their money?\*

### Activities of daily living

(e.g. mobility assistance, shopping assistance, driving, booking holidays)

- ➔ Personal assistant hours

### Education / Classes

- ➔ Cooking skills (one-to-one mentoring)
- ➔ Forklifting course
- ➔ Literacy classes (free in local adult education centre)
- ➔ Numeracy / Money management skills
- ➔ Nutrition course
- ➔ One-on-one mentoring for 'Driving theory test'
- ➔ Pedestrian training (using pedestrian crossing, understanding road signs)
- ➔ Personal development course
- ➔ Pottery class (evening classes)
- ➔ SafePass (health and safety in construction industry)
- ➔ Teagasc (agricultural and food development) course
- ➔ Welding course

### Equipment

- ➔ Laptop / other hardware & software programmes for college course
- ➔ Pen friend (to assist with writing)
- ➔ Slow cooker
- ➔ Specialised cooker and microwave particularly suited to people with a visual impairment

- ➔ Specialised equipment to enable independent cooking (e.g. safe chopping utensils)

- ➔ Specialised table

### Exercise / Gym / Sport

- ➔ Paid support to accompany / assist at gym
- ➔ Paid support to participate in outdoors pursuits e.g. hill walking / visiting caves
- ➔ Swimming coach / personal trainer
- ➔ Swimming in local pool
- ➔ Yoga class
- ➔ Zumba class

### Health and Social Care needs

- ➔ Counselling (for main informal supporter to deal with transition)
- ➔ Hydrotherapy pool sessions
- ➔ Key worker hours (independent living skills)
- ➔ Occupational therapy hours (one-to-one)
- ➔ Physiotherapy
- ➔ Private vision test and 'National Council for the Blind' consultation
- ➔ Speech therapy hours (one-to-one)

### Leisure activities

(generally requires paid support to assist and ensure safety precautions in place)

- ➔ Aqua Park
- ➔ Attending farmers market
- ➔ Attending nail bar (manicure)
- ➔ Body boarding
- ➔ Bowling (with others in group home)

- ➔ Fishing equipment
- ➔ Horse riding
- ➔ Segway tour
- ➔ Set dancing

### Residential

- ➔ Group home costs (with ongoing training for independent living)
- ➔ Paid support to assist with organising and managing family home renovation to enable independent living
- ➔ Paid support to assist with purchasing own home (independent living)

### Social activities

- ➔ Meeting friends for tea/coffee in local café
- ➔ Paid support for community integration activities (e.g. working front of house in local theatre)
- ➔ Paid support for leisure travel abroad
- ➔ Paid support to accompany to cinema
- ➔ Paid support to attend concert
- ➔ Paid support to attend football match in national stadium
- ➔ Social club (evenings)

### Transport

- ➔ Bicycle (for leisure and practical purposes)
- ➔ Driving test
- ➔ Mobility Scooter
- ➔ One-to-one mentoring for independent travel skills (e.g. using public transport)
- ➔ Taxi (usually in evening when public transport unavailable or unsafe)

### Work / Job

- ➔ Administrative support for running own business (e.g. accounts, tax, contracts, HR)
- ➔ Materials to support organisation of support (circle of support meetings)

\***Note:** Some purchases were once-off, while others may have been ongoing (e.g. personal assistance - accounting for a large percentage of the total spend). However in some cases the smaller items or once-off purchases had a significant impact on an individual's personal gains (e.g. mobility scooter opened up many opportunities which were otherwise unattainable)

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