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The successes and challenges of implementing individualised funding and supports for

disabled people: An Irish perspective

Abstract

‘Individualised funding’ which is rooted in the Independent Living Movement, has formed part of a global paradigm shift in support services for disabled people. Against the backdrop of international experience, a political system aligned with the UK and emergent critics of individualised funding, this paper presents findings from an evaluation of four pilot programmes in Ireland. Exemplified by independent-skills development and community integration, these initiatives 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. This paper explores 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 burn-out. 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.

Keywords

Disability, individualised funding, self-directed support, circle of support, implementation, resource allocation system

Introduction

The development of individualised funding, person-centred plans and self-directed supports has been at the leading edge of a global paradigm shift within the disability sector. These all aim to place the [disabled](#) individual at the centre of the decision making process, recognising their strengths, preferences and aspirations. Thus, they are designed to empower individuals to shape public services including their social care and support, by allowing them to identify their needs, and to make choices about how and when they are supported (Carr 2010).

Individualised funding is an umbrella term for a wide range of international descriptors that, based on country specific cultural and political contexts, have emerged to describe various processes of personalised funding and the attendant supports required, for [disabled](#) individuals (or their network of support). Various initiatives can be found, for example, in Canada, the US, the UK, Australia, Germany, the Netherlands, Finland and Sweden (Lord and Hutchison 2003, Moseley, Gettings, and Cooper 2005, Carr and Robbins 2009, Laragy et al. 2015, Eriksson 2014, Wiener, Tilly, and Evans Cuellar 2003, Clevnert and Johansson 2007). There are several types of individualised funding, the most common of which, in the UK and Ireland, involve a direct payment or a brokerage service. A direct payment, as its name suggests, involves funds being given directly to the [disabled](#) person, who then self-manages this money to meet their individual needs and life circumstances. This may include the employment of a personal assistant to help with everyday tasks and/or the purchase of services from private, voluntary or community service provider organisations (Carter Anand et al. 2012). A brokerage model or ‘managed’ personal budget, on the other hand, provides for a similar amount of freedom for the [disabled](#) person around

choice and control of services utilised, but the broker takes responsibility for administrative tasks, and also offers support, guidance and information to enable the person to successfully plan, arrange and manage their support services or care plans (Carr 2010). The 'Cash and Counselling' model is another example, found predominantly in the US, which allows the user the flexibility to choose between a self-managed account and a professionally managed/assisted account, thereby representing a combination of the direct payment and brokerage models (National Resource Center for Participant-Directed Services 2014). In Western Australia a similar model called 'shared management' has also been developed and found to be well received by end users (Western Australia's Individualised Services 2012). As the concept continues to grow throughout Europe, and indeed globally, the list of terms continue to proliferate accordingly (Fleming 2016).

Person-centred planning is generally utilised in individualised funding models and refers to a range of approaches used to individualise and organise supports for [disabled](#) people. It aims to enable individuals to lead the planning and development of collaborative supports that focus on community integration and participation while simultaneously building positive relationships, respect and skills (Dowling et al. 2006, Claes et al. 2010). Person-centred approaches were first highlighted in the work of Carl Rogers (1958), but their importance grew during the de-institutionalisation of [disabled](#) people in Canada and the US from the 1970s onwards (Dowling et al. 2006).

Individualised funding was developed to build the capacity of individuals, their families and communities and was made possible by a global shift towards self-determination and community involvement (Lord and Hutchison 2003). This shift was

rooted in the Independent Living Movement and the associated Independent Living Fund, whereby disabled people began to self-direct their support by hiring a personal assistant, thereby gaining more control over their lives and services (Fleming et al. 2016). While the first independent living movements were based in the US and Canada, the concept of an Independent Living Fund originated in the UK during the 1980s. However, during this time, only the more progressive authorities were providing the funding mechanisms for people to self-direct their lives. The campaign for legislative change to facilitate individualised funding, by UK-based authorities, was started in 1989 by the BCODP¹ Independent Living committee, which was formed in response to the broader European Network on Independent Living (ENIL). The direct payments Act 1996 was subsequently implemented in 1997 as a continuation of the ground-breaking Community Care Act 1990 which emphasised individual need and the importance of disabled people living in their own homes. (Evans 2003)

Following this emergent global trend, a national consultation in the UK (Whittaker and McIntosh 2000) concluded that, despite progress in de-institutionalisation and the large-scale movement of disabled people into the community, the vast majority still spent their time in congregated settings where their lifestyles were dictated by a menu of limited ‘special’ services. Subsequently, individualised funding was widely adopted throughout the UK, beyond those involved with the Independent Living Movement, with many positive outcomes reported (Rabiee, Moran, and Glendinning 2009, Glendinning et al. 2008, Duffy 2012). The UN Convention on the Right of Persons with Disabilities subsequently recognised individualised funding as one way to achieve self-determination, whilst many also acknowledged that it was only one way to achieve such goals (United Nations 2006).

¹ British Council of Organisations of Disabled People

Not unexpectedly, there have also been some criticisms of individualised funding throughout the UK social care sector. For example, Peter Beresford, a leading social work academic, raised concerns from the outset about the lack of input from service users into the shaping of such initiatives and the dearth of evidence-based management plans for the transition from outdated 'one-size-fits-all' services toward the government's national implementation of individualised funding (Beresford 2008). Indeed, Beresford continued to convey the suspicions of key stakeholders ('service users, practitioners and carers) that individualised funding would not close the gap between policy-based aspirations and the lived experience of those requiring supports (Beresford 2009). Furthermore, he and a number of others (Ungerson 1997, Pedlar and Hutchinson 2000) have argued that individualised funding is turning service users into consumers, thereby commodifying care and, in turn, directing large profits to service providers at the expense of quality for the end user (Beresford 2014).

Others still have argued that perhaps UK evaluations are flawed in that they are geared toward a neo-liberal ideology based on consumerist notions of choice; indeed, a number of authors have suggested that focusing on the funding mechanism over-simplifies the factors that influence user control (Askheim 2005, Slasberg and Beresford 2015). Instead they argue that the key lessons drawn should have focussed on the successes related to needs-based planning, carried out in a person-centred way - arguably the real triumph of individualised funding in the UK (Slasberg and Beresford 2015).

Regardless of such criticism and related challenges facing the UK, Ireland seems set to follow suit due to growing public demand for individualised funding, based on policy recommendations and attendant government commitments (Department of the Taoiseach 2011, 2016). Historically, Ireland is similar to the UK in terms of disability policy and practice, albeit generally lagging behind in terms of implementation. Large religious-run institutions dominated the landscape from the late 19th century. The Health Acts of 1953 and 1970 empowered the Department of Health to offer financial support to family and advocate-led organisations which eventually became the principal mechanism for providing activities, vocational training and sheltered work for [disabled](#) people. A segregated culture of ‘specialised’ services became embedded in service provision during the 1960s, with a range of specialised professions emerging to provide therapy and services to people with an intellectual impairment. A landmark Green Paper on Services for Disabled People (Department of Health & Social Welfare 1984) was seen by many as the start of more progressive and inclusive policies in Ireland based on international best practice and promoting community integration of housing and services. The European Social Fund and consequently the European Regional Development Fund (1970 - present), enabled specialist infrastructures to be put in place in Ireland to provide vocational skills training. The UN Standard Rules on the Equalisation of Opportunity for the People with Disability (1993) critically influenced the development of the ‘Commission on the Status of People with Disabilities’ in the latter part of the same year - now the ‘National Disability Authority’ (NDA). (Fleming, McGilloway, and Barry 2016)

The NDA is an independent state body providing expert advice to the Irish government on disability policy and practice. It has commissioned and supported a number

of key evidence-based policy documents, which have seen the disability sector in Ireland align itself more closely with international best practice, including the deinstitutionalisation of people with a wide range of disabling impairments. (Fleming, McGilloway, and Barry 2016) This transition is, however, still ongoing with 3,200 people (7.3% of those registered with the national disability database) remaining in congregated settings in 2013 (Health Service Executive 2014), with many promoting individualised funding as a mechanism to accelerate the process. Advocacy groups in Ireland, on behalf of disabled people and their support networks, are demanding that the newly formed government (2016) live up to past and current commitments to implement policy-based recommendations for individualised funding. Indeed the current Minister of State for Disability has publically committed to the implementation of individualised budgets, with plans to assemble a taskforce to oversee implementation. (Inclusion Ireland 2016) Furthermore, the Value for Money and Policy Review of Disability Services in Ireland (2012) – which is currently used, by the aforementioned advocates and others, as the benchmark for achieving disability sector improvements - recommends, amongst other things, the provision of ‘supports’ rather than ‘services’ to reflect the transition from an institutionalised to a personalised model. Notably, the report cautioned against a ‘drift’ towards individualised supports, and specifically recommended the piloting and testing of individualised funding prior to any full transition.

To this end, the NDA, whose research informed current policy recommendations, has also commissioned a body of research to explore and test the feasibility of four different resource allocation tools with the view to recommending the most appropriate system to facilitate national implementation in Ireland (National Disability Authority 2015). To complement that body of work, this current study was undertaken as part of a larger multi-

component international evaluation of individualised funding (Fleming, McGilloway, and Barry 2016, Fleming et al. 2016).

The objectives of the study were to assess if individualised funding was: (1) perceived to be effective at improving health and social care outcomes in Ireland; (2) acceptable and feasible within the Irish context; and (3) an appropriate mechanism for supporting disabled people to gain independence and self-determined lives, fully integrated within the community. Four individualised funding pilot initiatives, grant funded by an Irish NGO called Genio², were evaluated as part of this study. These pilots consisted of three brokerage and one direct payment model(s) and were based on international best practice and policy (Table 1).

Methods

Participants and settings

A total of 24 interviews were conducted with 35 individual participants and in some cases, project participants and advocates were interviewed together (Table 1). Eight secondary data files pertaining to 9 individuals were also analysed. The largest proportion (45%) of individuals involved had some form of intellectual, physical or mental health impairment.

[INSERT TABLE 1 ABOUT HERE]

² A non-profit funding organisation whose mission is to develop, test, and scale, cost-effective ways of supporting people who are disadvantaged to live full lives in their communities. Currently Genio works to improve the lives of disabled people, people with mental health difficulties and dementia.

Through a process of purposive sampling, four organisations (cases) were invited, and subsequently consented, to participate in the research. Recruitment was facilitated by a staff member within each organisation who acted as gatekeeper, distributing an information pack (containing written invitations, information sheets, consent forms and participation forms) to prospective project participants and their advocates. Project participants were given the option to have an advocate present with them during the interview which took place either in their home or the offices of the host organisation.

Method

The four individualised funding initiatives that were the focus of this study were at a very early stage of development and, as a result, only a small number of disabled people were involved in each of the initiatives. Additionally, little was known about the structures, processes, funding mechanisms, or successes and challenges underpinning the various initiatives. Therefore, an exploratory mixed methods approach was used and applied within a 'critical realism' framework (Gilson, 2012), including documentary analysis, in-depth interviews, secondary data analysis and a participatory workshop. A broader implementation science framework was also used to explore the various stages of the implementation process, namely: Exploration and Adoption; Programme Installation; Initial Implementation; Full operation; Innovation; and Sustainability (Fixsen et al. 2005). The study received ethical approval from the Social Research Ethics Subcommittee at Maynooth University.

A documentary analysis was initially carried out using a series of documents identified by the organisations as integral to the development and implementation of the

projects. These included, amongst others: minutes of meetings; administrative forms; correspondence; annual reports; strategic documents and action plans; policies; contracts and agreements; person-centred plans and weekly schedules; presentations and other informational materials. These documents provided the researcher with important insights into key concepts to explore, such as sustainability, conflict of interest, and organisational change. This process also helped to inform, in part, the development of the interview schedules, separate versions of which were devised for staff and project participants. Interview schedules were adapted to explore emergent themes, an approach which worked well with the overall framework of critical realism.

Interviews were audio recorded, with consent, using a digital dictaphone and lasted approximately one hour, on average. In addition to face-to-face interviews, secondary data were used for a small number of participants who were unavailable for interview; these data comprised publicly available online video files in which these individuals were discussing their experience of the individualised funding initiative. The content was prepared in advance and each video was of approximately 8 minutes' duration. While additional participants and staff members were available to be interviewed in most organisations, data collection ceased once saturation point was reached and no new themes were emerging. Primary and secondary data were transcribed verbatim and anonymised.

Analysis

A thematic analysis was used to identify recurring themes and was facilitated by the use of MAXQDA qualitative data analysis software. The interpretive coding (Mason 2002) related to the ontological and epistemological perspective of Critical Realism. Thus, the aim

was to generate theories that explain social phenomena and, in particular, to identify the mechanisms underpinning outcomes (Gilson 2012). On completion of the analysis, the validity and acceptability of the findings was tested by soliciting feedback from key stakeholders as part of a participatory workshop involving disabled people, family members, advocates and staff members from the four individualised-funding initiatives. Such participatory approaches are recommended for population based research and in particular to improve the ethics of disability related research (Good 2009).

Findings

A total of six superordinate themes were identified, within which all other themes were subcategorised, with up to 5 levels of detail (from macro (Level 1) to micro (Level 5)) (see Figure 1). A selection of the key themes and sub-themes is described here.

[INSERT FIGURE 1 ABOUT HERE]

In terms of stakeholders and outcomes (Figure 1), the findings clearly endorsed individualised funding as a means of securing improvements on a wide range of personal, health and social care domains. Disabled individuals perceived themselves as more successful, confident, adaptive, skilled, empowered, independent, in control and with a greater sense of purpose.

'I felt I got more confident than when I ended (traditional day service) you kind of meet the real me' (Project Participant CS4)

'The new responsibilities, the new way of seeing yourself, the new position that you're occupying ... and for a role in life, in the community, I think that's massive and it's changing perceptions as well from the outside' (Project Participant CS2)

These successes were supported by increased opportunities to develop independent life skills, social and community supports and engagement with new opportunities and experiences. A change in the mind-set of paid support and natural supports (family, friends and wider community) enabled individuals to have a voice in the decision making process which allowed them to identify and trial various activities:

'...traditionally we've had a porridge society, a porridge menu, so we've fed porridge all our lives to individuals, then we give them an à la carte menu and we say: "What do you want to do?" and they say: "I'll have porridge", you know that's not choice... but by finding out from the individual what they actually want to be doing with their life, and funding them accordingly.' (Staff CS1)

The kind of attitudinal changes seen in family members of **disabled** reflected a move from fear and anxiety related to their **impairment** toward an appreciation of their abilities, passions and interests. Individuals were, for the first time, afforded opportunities to move freely within the community, also facilitated by the option to purchase assistive technology which was not readily available through the traditional funding model.

'..but I say they [the participant's parents] were frightened... I'd say they would be concerned but ... as the weeks went on ... I'd say they weren't that worried at all. They knew I could handle it.' (Project participant CS1)

In terms of support processes and community (Figure 1), the availability of a 'circle of support' for project participants was an important factor in the successful implementation of individualised funding. This consisted of paid supports (e.g. broker, personal assistant, mentor, educators from community based courses) and natural supports (immediate and extended family members, neighbours, friends, colleagues, and community members). An organic/informal process was deemed most appropriate; that is, one that was needs-led, innovative and which harnessed community spirit and peer support as well as using existing (and often free) resources within the community.

'I couldn't have achieved these things without my company board and circle of support. These people are motivated, conscientious and willing to assist me in gaining more autonomy in my life.' (Project participant CS2)

Paid supports often played a crucial role in identifying and building this circle of support, particularly when none existed. As such, staff needed a broad set of skills and attributes including: a practical yet amenable and friendly approach; vision; innovation; personal experience of disability; and an active role in the community. In the 'Initial Implementation' of the new model of service delivery, paid supports were more actively involved in supporting individuals and their natural supports because they were better equipped with the tools and hands-on experience of the desk-based and field research

which they had conducted in the earlier 'Exploration and Adoption' and 'Programme Installation' phases of the implementation process. This involved resource intensive visits to individualised projects in the UK and US to harness their experiences and to adapt relevant administrative materials. Having developed the process and the roles and responsibilities of paid and natural supports, staff members were then able to focus on the expansion and the sustainability of individualised funding.

One of the key challenges that emerged for the four initiatives was access to funding which was very much hampered by existing systems and organisational impediments.

'The biggest single problem, and the biggest single delay has been trying to get the funding, and that comes in under a couple of headings. One is decoupling funding from a block grant'³... (Staff CS4)

Since there is currently no national resource allocation system in place, the pilot projects relied heavily on informal arrangements with disability managers on a person-by-person basis, often relying on pre-existing personal or organisational relationships. Furthermore, this often involved negotiating with another traditional service provider where individuals' funds were tied up, even if the individual was no longer availing of those services. This often led to overly-complex processes and attendant high levels of stress and frustration for individuals and families, who found it difficult to engage with the process at times.

³ Block funding to service providers whereby previous annual spend for a service provider is used to estimate the required funding for the upcoming year (National Disability Authority 2011)

'...a lot of these families are fragile enough and you can't have that process [being] so difficult that it breaks people....' (Parent CS4)

Pilot project staff members were, however, successful in negotiating more formalised arrangements with the Health Service Executive⁴ and were also able to reflect value for money, both real and conceptual.

'...our definition of value for money is going to be financial, but it's also going to incorporate the social, personal value, which is really important...a more holistic view...' (Staff CS2)

Participants reported a new appreciation for money, money management and the benefits garnered from the flexibility of 'shopping around' or deciding how much and when support is needed, thereby serving as an incentive to motivate them to become more independent and to help make the funds go further to meet additional needs.

'...she's given a wee bit more freedom with money because, before this she didn't realise the value of money, she would go in and spend whatever, buy whatever, hand over money and not wait for her money, her pennies [change] back...' (Parent CS1)

'No you have the PA [in traditional service] and that's it.... It can be, either / or [with individualised funding], it can be like - theres 6 hours of PA to help

⁴ Health Service Executive (HSE) provides all of Ireland's public health services in hospitals and communities.

you prepare your meals and then get the [specialised chopping] board to help you do more and as you get more confident then 6 [PA hours] could become 5 ... It also creates a bit of independence for a person. Like knowing that you're not going to get everything you ask for. And you're going to have to take out your finger and do a bit yourself' (Project participant CS1)

The challenge of releasing funds, however, was further compounded by organisational disengagement at a local level where the shift in power to individuals and families was met with some suspicion.

'You need the flexibility from the funding streams ... and my big concern for the budget is ... I think it's a cheap way of you know dealing with [individuals], "There you are, there's your 10 grand, there's your 20 grand, now you're finished with the government for the rest of your life almost". And that's not good enough either' (Staff CS3)

A source of greater concern perhaps, at national level, was the perceived view of senior staff from within the Health Service Executive and State ministers who, according to some participants had distanced themselves from discussions related to national roll-out. This had a demotivating and demoralising knock-on effect on project staff.

'[The senior health manager said]...it won't be here for another four or five years", and I said: "Personalised payments? They'll be here long before that",

and she says: "No it wouldn't" ... When you've got somebody in a position like that there coming out with that...you kind of think: "Why bother?"" (Staff CS1)

Another complex challenge related to the tendency of family members to be overprotective, largely out of a fear and anxiety for their family member and disillusionment, to some extent, with the health and social care system. In parallel there was a fear of losing the security of long-standing traditional service provision or the potential for social isolation once separated from these congregated settings. This challenge was identified by individuals, staff and also family members themselves and appeared to be rooted in traditional and paternalistic service provision which reportedly reinforced individuals' [impairment](#), rather than enhanced their abilities.

'...parental interference and control. So that was a challenge. So right down to, let's say, the individual would have liked to experience independent living, even respite... but the parent wouldn't let go...' (Staff member CS1)

'...you can build up your responsibility that...the child can do nothing without you, ... and it gives you an excuse for maybe not doing a lot of things yourself.' (Parent CS1)

Furthermore families felt overburdened with administrative tasks, had a tendency to be suspicious of certain tools or terminology, such as person-centred plans, since they had witnessed such initiatives failing in the past. Unchecked, these potential deterrents could lead to burn-out or disengagement with the new model.

'...I've seen it within the PCP process, not here, whereby people have just duplicated what's gone on six months ago, or three months ago, and that's nonsense...' (Parent CS1)

For project staff, the need to manage family cynicism while moving forward with the new model was also challenging. This required careful planning, time and people management skills and highlights a clear need for training for all support network members, paid and unpaid.

Discussion

The findings from this study reflect a perceived improvement in a range of personal, health and social care domains. The new system was reported to be acceptable, whilst also representing an improvement on the traditional services to which [disabled](#) individuals were previously accustomed. The organisations implementing the initiatives also experienced a number of benefits including: a perceived sense of accomplishment, paving the way for future generations; progress in de-bundling money from the block grant; a sense of freedom from the restrictions imposed by the Health Service Executive; and a more enabling work culture which led to greater commitment and enthusiasm from project staff and participants alike.

Participants also reported a new appreciation for the meaning and value of money - arising from their new experiences, having 'shopped around' to seek out the 'cheapest' option, in an effort to make savings and put cash back into their service fund. These tangible

monetary observations ranged from cost neutrality to considerable savings. Similar findings have been reported in Wales (Stainton, Boyce, and Phillips 2009) and more recently in a New Zealand study, which indicated that individualised funding can lead to significant cost reductions in the delivery of disability services over time (Field 2015). In addition, there were considerable personal and social benefits. As expected with the implementation of pilot initiatives, some key challenges and lessons emerged, but these were, by and large, overcome by creative and innovative, individually tailored solutions. For example, in one instance, a mobility scooter was funded which, somewhat counterintuitively, falls outside the eligibility criteria within the traditional medicalised model, where a substantially more expensive electric wheelchair is the only option.

Collectively, the findings from the present study highlight several other potential barriers to success including: staff limitations in terms of time and knowledge acquisition; administrative burden for families; uncertainty around money allocation and sustainability; fear of losing traditional support if new models cease; family burn-out due to long history of fighting the system and overly complex processes related to the new model; time and effort required to build a 'circle of support' where none exists; and the potential for individuals to become disengaged with the process, or socially isolated due to lack of skills required to deal with their new life circumstances. With regard to the last of these, some would argue that community connectedness is easier to achieve within settings where people are grouped together based on similar impairments, rather than in the general community which can be difficult and stressful (Cummins and Lau 2003). The evidence from this study, however, would suggest that the traditional congregated model of service provision has led

to a lack of social awareness, skills and attributes - the very cause of stress and difficulties related to community integration.

Likewise, a recent study in Canada indicated many similar reasons for low uptake of its individualised funding scheme including: inadequate information delivery leading to a limited understanding of the new system; peer influences (i.e. following the crowd); a lack of staff training; fear of isolation; frustration with regard to the amount of paperwork involved; families risk-aversion and fear of losing security associated with traditional services; and a perception that the wider community was generally unwelcoming (Bahadshah et al. 2015). The last of these is interesting because it is at variance with the present study which found that the wider community in Ireland was not perceived to be 'unwelcoming', although personal safety fears were associated with unsupervised community interaction.

There is considerable scope to address these kinds of barriers through the continued development of systems in Ireland and similar countries (e.g. Finland) and regions therein (e.g. remote parts of Canada and Australia) which are in the early stages of implementing individualised funding schemes. A key message/lesson emerging from the current study (as in the work by Bahadshah et al (2015)) focuses on the need for information to alleviate fears/confusion and to be delivered in an accessible and transparent way. Information dissemination could start with the basics of how state funding mechanisms work within a country, how much is currently allocated per person, where this funding currently resides and how to access that funding, if at all possible. Our findings indicate that people have very little understanding of how money is allocated and the processes involved in gaining access

to such support, whilst there is also a need to promote a greater sense of ownership of that process.

The findings from our study suggest that supporting individuals and their advocates to gain access to all available information will further promote a (necessary) shift in power from service provider to recipient; a resistance to this power shift was identified here as a potential barrier to successful implementation. For many countries, such as Ireland, national systems may not be in place and, therefore, early adopters must often find a temporary solution, usually with the help of an advocate who has pre-existing and trusted relationships with the health service. Once empowered with this information, individuals can then explore the options available to them and plan which model best meets their needs and how best to utilise the allocated funds in a positive and constructive manner.

The need for strong family/natural support was also identified within the current study where a lack of such support was seen to lead to participant drop-out or as a potential deterrent for organisations interested in facilitating individualised funding. Likewise, Curryer (2015) found that family members provided a fundamental source of practical and emotional support as well as a key role in the decision making process. Kyle, Chiapetta and Hannah (2015) further argue that such support is necessary for successful implementation, the lack of which was also seen as challenge in Finland where, similar to Ireland, a history of institutionalisation has separated families from their [disabled](#) relatives (Rajalahti 2015).

However, the lines between support and adverse interference are often blurred to the extent that some individuals may compromise to meet the wishes of their family

(Curryer 2015). In the current study, family interference, whilst clearly present in some cases, was often paternalistic, unintentional or even unrecognised. The impact of such anxiety-based control from families who feel responsible for the protection of their disabled family member – and especially where individual preferences do not align with family values or norms or involve some level of risk - has not yet been assessed (Curryer, Stancliffe, and Dew 2015). Marshall (2015) also argues that advocates, paid and unpaid, must accept a degree of risk in favour of the individuals' perspective, albeit within the parameters of personal safety, even if this causes discomfort.

The above findings suggest a need for appropriate training for both paid and natural supports in order to facilitate a culture of equality, where everyone is a valued citizen and where disabled people not expected to compromise. 'Social role valorisation' is one such model which has been found to increase the status of disabled people, whilst exploring and developing relationships that help these individuals to achieve their desired tasks and outcomes (Peipman and Vermeij-Irvin 2015, Duffy 2015). Such training can also overcome some of the other issues identified in this study and also during the early implementation phase in other jurisdictions including Scotland; these include: how and where to access proper support, advice and training; how to ensure flexibility to adapt to individual and changing needs; and how to carry out a person-centred assessment (Ridley and Jones 2003).

The lack of a standardised national resource allocation system was identified in the current study as a key barrier for those attempting to implement individualised funding initiatives in Ireland. This was seen as impacting all stages of the implementation process including, in particular, sustainability and was compounded by a degree of resistance to

organisational change both amongst practitioners and also managers within the national health service. This has also been found to pose a significant challenge for other countries in the early stages of individualised funding implementation (Rajalahti 2015). Importantly however, countries with several decades of experience with individualised funding, such as Canada, Australia and the UK, have warned against over-emphasising the development of such systems as they can often divert attention away from the kinds of personal and social values that inspired individualised funding in the first place (Kendrick, Stainton, and Duffy 2015).

Rather than becoming entangled in the debates around the ‘best’ type of needs assessment to inform resource allocation systems (e.g. medicalised model of assessment versus the social model versus self-assessment), our evidence suggests that there is considerable scope to collaborate in partnership with social workers, who have the advantage of knowledge and experience. Assessors could share their skills and teach [disabled](#) individuals how to assess their needs, in a systematic and transparent way, whilst taking on board, the types of social and environmental barriers that need to be tackled in addition to other health care needs (Renshaw 2008).

Conclusion

This study represents a valuable addition to the international literature and was based on a meticulously applied qualitative approach which involved a reasonable sample of [disabled](#) people, their advocates and staff at different stages of life and from a wide range of geographical and socio-demographic backgrounds. While not without its limitations (e.g. in terms of the small number and scale of the projects involved), the in-depth nature of the

methodology, grounded in a framework of critical realism and guided by an implementation science framework, ensured robust findings.

Despite the political, procedural and cultural challenges and restrictions, the individualised funding model was considered to be feasible in Ireland, with perceived improvements across a range of domains for disabled people, their families, advocates and the organisations with whom they engaged. Whilst the study illuminates factors which facilitated the implementation of the four initiatives, it also highlights potential barriers to success. These provide important lessons not only within an Irish context, but also internationally for other countries that are in the early stages of implementation/change. For example, careful consideration and planning needs to be undertaken in order to guide the complex transition from traditional paternalistic settings to an independent, community-based life. Furthermore, remaining within the 'easier', one-size-fits-all, group-based settings is, arguably, no longer acceptable or appropriate.

The experience of countries which are at a more advanced stage with respect to the implementation of individualised funding, (e.g. Canada, the US, Australia, New Zealand and the UK), suggests that the development of robust and efficient systems should not detract from the personal, social and health gains possible from individualised funding. These values must guide all policy and practice decisions involving ongoing consultation with recipients of individualised funding. Additionally, information dissemination needs to be carefully planned and piloted with the target audience in order to address potentially low uptake due to knowledge gaps, confusion and concerns.

Advocates, whether paid or natural, should be offered training opportunities to obtain the theoretical and practical skills to deliver meaningful person-centred support. Service providers and advocates also need to actively control their urge to 'protect', thereby empowering individuals to take ownership over their individualised funding and the decisions associated with full active citizenship. Further research is needed to explore the complex and delicate balance between controlling this impulse whilst also identifying and supporting individuals who may be overwhelmed with the challenges associated with suddenly having choice and control, or those who need guidance to navigate their way through this new and often complex process.

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Table 1. Profile of study sample

Study involved 44 individuals	Staff (12)		Project Participants (20)		Advocates (12)	
	Male	Female	Male	Female	Male	Female
Case Study 1 ^(CS1)	2	1	3	2	2	4
Case Study 2 ^(CS2)	1	1	4	3	0	2
Case Study 3 ^(CS3)	1	3	3	1	0	2
Case Study 4 ^(CS4)	1	2	1	3	0	2
Total n	5	7	11	9	2	10
(%)	(11%)	(16%)	(25%)	(20%)	(5%)	(23%)

^{CS1} Brokerage service supporting 11 individuals with a physical or intellectual **impairment***

^{CS2} Direct Payment service supporting 20 individuals with a physical or sensory **impairment***

^{CS3} Brokerage service supporting 5 individuals with an intellectual or mental health **impairment***

^{CS4} Brokerage service supporting 9 individuals an intellectual or developmental **impairment***

*Services were not limited to these **impairments** but reflected majority of participating individuals

Figure 1. Example of coding structure (including number of codes per level)