An evaluation of personalised supports to individuals with disabilities and mental health difficulties

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Context

Internationally, increased attention is focused on the provision of personalised supports to people with disabilities and enduring illness. Personalised or individualised supports are those which address the unique needs of the individual focusing on their strengths and abilities, which are chosen by the person and which are delivered in the community fostering inclusion and participation. Recent Irish policy documents have also described and recommended a way of supporting people with disabilities which involves a reframing of provision from services towards individualised supports. The *Value for Money and Policy Review of Disability Services*[1] recommends that the goal of full inclusion and self-determination for people with disabilities be pursued "through access to the individualised personal social supports and services needed to live a fully included life in the community."

Aims of the evaluation

In this context this evaluation was concerned with identifying:

1. The outcomes for people with disabilities and mental health difficulties receiving individualised supports; particularly on indicators of social inclusion and quality of life but also in relation to their individual aspirations, including assessing changes over time as people move from congregated settings to more personalised arrangements;
2. The processes which have led to effective change and transition in terms of personal outcomes and the delivery of individualised supports;
3. The direct costs of providing the personalised support for service users and how these costs have changed as a result of the changes in support provided;
4. The implications for the further development of personalised services in an Irish service context.

The sample

Twenty four projects took part in the evaluation[2]; thirteen involved people with intellectual disabilities, eight involved people with mental health difficulties and three projects involved people with physical disabilities. Both voluntary organisations and HSE-managed services were involved. All the projects were working to provide personalised supports to people with disabilities or mental health difficulties, and the main focus for most projects was on supporting individuals to move to supported independent living in the community.

Two hundred and sixty individuals were invited to participate in the evaluation. 18% declined or dropped out. These findings are based on 197 people who participated and this represents 81% of active participants.

Participants varied in terms of their demographic characteristics and disabilities/mental health difficulties which resulted in a very heterogeneous sample. Slightly more females than males were included; three-fifths of the sample was over 40 years of age (total age range 16 to 73 years); nearly two-thirds had attended ordinary schools although fewer than half held an educational qualification; nearly all were single with few non-Irish nationals. One hundred and sixteen participants had an intellectual disability, 64 had mental health difficulties and 17 had a physical disability. Almost one third (32%) were described as having high support needs, 26% as having some support needs and 43% as having low support needs. One fifth (21%) had epilepsy and 10% had a diagnosis of autism or autism spectrum disorder.

In the course of the evaluation, five groups emerged which categorised the sample according to whether they had moved or not and to which setting. This included those who:

1. moved from congregated settings to personalised arrangements,
2. moved from congregated settings to group homes,
3. remained in congregated settings,
4. remained with their family in the course of the evaluation
5. had already moved to personalised arrangements and who remained in them for the course of the evaluation.

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[1] Department of Health (2012) Value for Money and Policy Review of Disability Services in Ireland. Dublin, Department of Health.

[2] 23 were projects grant-aided by Genio and one was a non-Genio project that was also working in a personalised way to support people with disabilities.

Headline findings

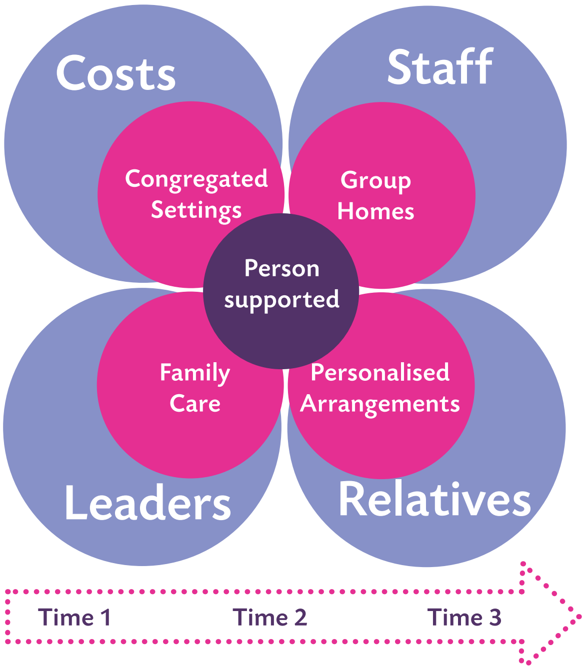
The main findings of the evaluation, which are summarised below indicate that:

Personalisation produces better outcomes than congregated care	across a range of outcomes
Quality of Life improvements are evident	quality of life is poorest for those in congregated settings
Personalisation can save on costs but not for everyone	congregated settings were generally the most expensive
People living with families have some of the best outcomes	and support can lead to better outcomes over time
Group homes do not offer personalised accommodation or support	it is possible to move directly from congregated settings to personalised arrangements
Relatives initial concerns are often not borne out	and can be overcome with active involvement and open communication
Personalisation slowly changes people's lifestyle	it can take at least a year to see certain changes
Personalised housing and support options are feasible to implement in Ireland	across people with a variety of disabilities and mental health difficulties and with different levels of support need
Community engagement and social relationships need intensive support	building links to the community takes time and should be seen as an essential part of the support provided
Personalised housing and support options can take different forms	a range and variety means individual needs can be better met
New roles for support staff	that can bring greater satisfaction as well as some challenges
New arrangements take time to set up	this needs to be built into planning moves to the community
Longer-term follow-up is needed	particularly to identify the sustainability of changes

Methodology

Figure 1 shows the conceptual framework for the evaluation, with the person supported as the central focus. The aim was to obtain a rounded picture of their lives primarily through their own words but also the reflections of the support staff who knew them best (their 'key-workers') and their relatives. A second major focus of interest was the type of accommodation in which people resided and the supports they received. This can be typified into four broad categories although within each there were variations in terms of the number of co-residents, the facilities available and staffing arrangements. The accommodation links with support, for example the term personalised accommodation is used throughout to indicate independent, supported accommodation with individualised supports.

Figure 1: The conceptual framework for the evaluation



A third focus related to the service context providing the support to the person. Four aspects were highlighted: the accommodation and support costs associated with the person, the role of staff supporting the individual especially in personalised arrangements, the contribution of leaders and managers in making change happen and the engagement and experience with relatives during accommodation moves.

The fourth dimension was changes over time in all of the foregoing and especially contrasting those who moved to new support and accommodation arrangements before and after the move but also with those who remained in the same settings.

Information gathered

Detailed information using structured questionnaires and mostly face-to-face interviews was collected at three time points from people supported by the projects, their key-workers and, if available and willing, the relatives of the people with disabilities or mental health difficulties. In addition the experiences of service managers and project leaders were obtained. Information was gathered on demographic characteristics, the nature and type of supports received, and outcomes on a range of indicators. In addition, ratings scales were used to gauge the extent of individualised support the person received and ratings of their overall quality of life. For each person, information was also obtained on the costs they had incurred on direct support staff costs, their use of community services and of hospital services costs, plus their income from social security benefits.

The core of the evaluation is comparisons among the five groups in the sample over a 20 month period on a range of domains reflecting service arrangements and quality of life (see Figure 2).

Figure 2: Domains of change

The domains and indicators were selected from a literature review, consultations with local stake-holders and pilot studies. Statistical procedures then identified the 16 indicators that best discriminated the groupings. They included items such as having a key to the house, choice of own support staff, friends visiting for a meal, in paid employment, reporting less anxiety and participating in sports, leisure and fitness.

Qualitative data

At each time point the people supported were individually interviewed using a series of structured prompts that were adjusted according to whether or not they had changed their accommodation. Similar interviews were separately conducted with nominated key-workers and a relative if they were available. From this rich source of qualitative data it was possible to create the personal stories of participants in the evaluation with quotes of their actual words. Moreover a substantial and unique archive of material that has been assembled, that could be used to investigate particular themes around the lives of people with varying needs.

Focus groups and interviews were held with senior staff in participating services who had been responsible for managing the Genio supported projects. The aims were to identify the factors that contributed to successful outcomes, the barriers that prevented the project achieving its goals and the added-value that Genio grants had brought to the participating services.

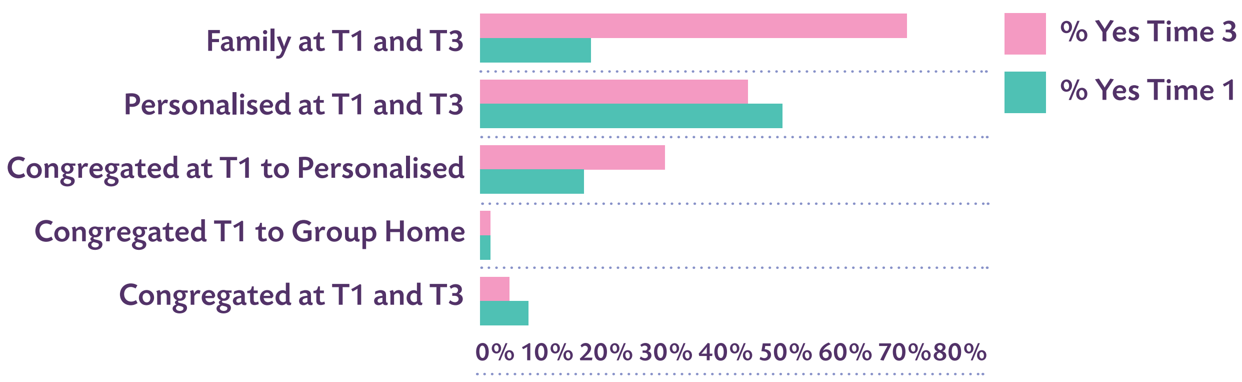
Detailed findings

Changes in accommodation and support

The evaluation took place over 20 months from Oct 2011 to May 2013. It took place under real-life conditions so that a number of people had already been supported to move to personalised arrangements by the time the evaluation could get underway, while projects that commenced late in 2011 took some time to get fully underway. Thus over the time frame of the evaluation several groups of movers and non-movers emerged, as projects and individuals within them moved at a different pace. The five groups that emerged and the numbers involved were those who were in:

- Congregated settings at first interview (T1) and moved to personalised arrangements by their third interview (T3) n=23
- Congregated settings at T1 and moved to group homes at T3 n=35
- Remained in congregated settings in the course of the evaluation n=42
- Remained with their family in the course of the evaluation n=20
- Already moved to personalised arrangements at T1 and who remained in them for the course of the evaluation n=40.

Figure 3: The percentage of people in each grouping who chose their own support staff at Time 1 and again at Time 3.



Males were more likely than females to move to new settings. Older people were more often found in congregated settings and people with mental health difficulties were more likely to move to personalised arrangements rather than to group homes whereas it was the converse for people with intellectual disabilities.

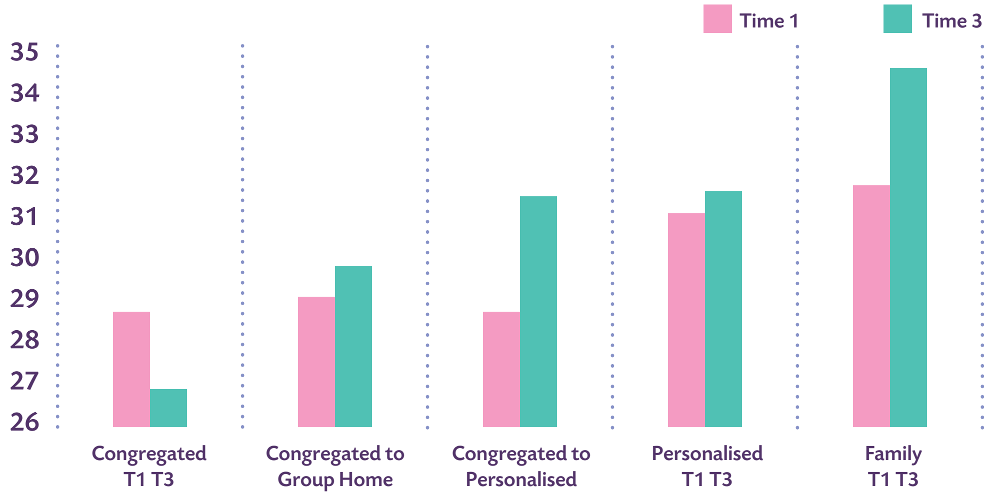
The majority of projects had either achieved their goals in relocating people or were close to doing so. However the time-scale for doing this seemed to be more protracted for some, with a minority of projects who had moved very few people up to 18 months after the commencement of funding. This demonstrates the challenging nature of this work, particularly where individuals had lived in institutions for many years. Both HSE services and voluntary organisations had progressed their goals.

Changes in outcome indicators and quality of life

Almost all participants were pleased with their move. Two people reported that it had made life worse for them. Figure 3 shows an example of the differences among the five groupings and the changes over time in the percentage of people who chose their own support staff, which was an indicator of greater choice and control for participants. Similar profiles were found for the other indicators that were examined, with participants in the personalised and family groups generally reporting better outcomes than those in the congregated groups.

Figure 4 shows the mean ratings of quality of life made by participants across the five groups, with those living with families reporting the highest ratings of quality of life, followed by those living in personalised arrangements. The lowest self-rating of quality of life were for those in congregated settings.

Figure 4: The mean scores on the Quality of Life Scale completed by people supported in each grouping at Time 1 and again at Time 3.



Taken together, the data points towards personalised arrangements producing better outcomes for the people supported irrespective of their impairments and level of functioning than for those who continued to live in congregated settings or in group homes. Similarly people who were supported by projects while living with family carers also reported better outcomes.

The cost of services

Overall personalised options are much less costly for the same people than when they resided in congregated settings although there were a few instances when these arrangements resulted in higher monthly costs. Thus when a move to personalised supports and accommodation is made, it will be less costly for some, roughly the same cost for others and for people with high support needs it may be a more expensive option. However, the data indicate that the cost reductions for the majority seem to more than offset the increased costs for the fewer numbers with higher support needs. Staff support costs were generally highest in congregated settings for both people with disabilities and mental health difficulties.

Within each accommodation and support grouping, there was wide variation in the costs calculated for individuals included in that grouping. This was especially so when people moved. The reasons were varied but they included: people had differing support needs; they lived in different styles of accommodation options; and supports were provided in different ways across projects and individuals.

Personal stories

Each person had a unique story to tell not only about the outcomes for them but also their experiences of the process as they prepared to move and when they made the move.

Some key messages echoed throughout the stories. People were in general delighted with the new accommodation and they were happy with the support they were receiving.

> The security, the independence, the privacy, the location [...] the serenity because it is in a lovely location and it is peaceful, okay, there is loneliness but the good thing about it is the privacy and the serenity really.
>
> (Person Supported)

Generally the planning for the move to other accommodation was individualised and involved the person. However, the extent of this varied across projects and even from person-to-person within projects. Choices were not always provided to people or people were not necessarily involved in looking at possible accommodation.

> All the people from the house moved to different places. I've moved up here. The place is working out great. Now the staff work with me one to one. I made it my own place. I'm happy.
>
> (Person Supported)

While some connections had been made in the community, social networks and community participation did not seem to have flourished for many people, probably because of the limited time they had lived in the locality.

Reactions of relatives

Around 50% of the people supported had on-going contact with relatives who were agreeable to be interviewed. Relative's initial concerns and misgivings are often not borne out when people changed their accommodation options. Indeed relatives can become strong proponents of the new arrangements and readily name the benefits for the person as well as for themselves.

Relatives also can play an important advocacy role on behalf of the people in these new arrangements. They mentioned some of the same areas for improvement mentioned by others - such as friendships and community engagement - but also added others that are especially pertinent to their relative.

Figure 5: Service leaders' perception of the engine driving change

Role of support staff

The role of support staff was also explored further in their interviews. The similarity of responses was striking from staff across the range of services in both mental health and disability. Their work was largely the same whether the employer was the HSE or a large or small voluntary organisation. Also staff transferring to new arrangements as well as those who were newly recruited gave comparable accounts. Likewise the role of staff appeared very similar with people who had differing disabilities and mental ill-health.

Providing one-to-one support was a model that worked well for the key workers, they agreed that people should live in the community and many advocated for the person with whom they worked in accessing supports and other resources. Staff also named a variety of personal benefits that the new working arrangements had brought them, as well as improvements that could be made.

Making change happen

The data from the focus groups with service leaders led to the development of a process model that described the key drivers in making change happen (see Figure 5). The metaphor of an engine was used to integrate the various themes that were identified.

The central driver was the organisation with four other main drivers identified: support from Genio, staff, clients and relatives. Four more minor drivers were: communication; finances; housing and community contacts. For each driver a number of sub-themes were evident as shown in Figure 5. The systems model that emerged was applicable to services serving three different client groups – intellectual disability, mental health and physical disability.

Discussion of findings

Strengths and limitations of the evaluation

This evaluation is unique in an Irish context and has certain strengths. It includes a sizeable sample of people with intellectual disabilities and those with mental health difficulties thus there is shared learning across two client populations that traditionally have been viewed separately. A second strength is the longitudinal nature of the study which allowed comparisons to be made for the same individuals before and after major changes in their lives. Although comparable data is available internationally there is limited information available for Irish services.

Thirdly, every effort was made to obtain information from people themselves rather than rely on third party reports from staff and relatives. Moreover information was gathered across a range of domains to capture a holistic picture of people's lives.

Fourthly, multiple perspectives were captured, with information from key-workers, relatives and service leaders as well as the people supported.

Information was gathered primarily through face-to-face interviews and although some people chose not to take part, response rates were high and people were retained within the sample across the time points. The evaluation has resulted in an evidence base that arises from, and is especially relevant to, the Irish service context.

However, there were limitations to the evaluation. Perhaps the over-riding one is the paradox that lies at the heart of this endeavour. The goal was to personalise the support and accommodation options available to individuals and yet the evaluation is predicated on finding differences among groupings of people who experienced apparently similar changes in their support arrangements. The rationale for doing this is laudable and indeed the group differences found represent a strong effect albeit not holding for everyone. Equally though, there could well be real changes for certain people in particular situations that are not present for others in the grouping but these are masked by a failure to find changes for the group as a whole. Much larger samples would be needed to identify these types of changes further.

Most of the services involved represent 'early adopters'; some had already commenced working in a personalised way and had sought grant funding to accelerate or scale up that process within a larger service. The individuals involved were generally those who wanted to move to more independent living arrangements. Therefore the model of process characterised above (Figure 5) remains to be tested in services that did not receive or seek Genio funding.

Although the total sample size is large, when split across the five groups the numbers became relatively small, thus the effects of the moves across the indicators and quality of life measures were not very pronounced. For some people supported, they had moved shortly before their final interview and had little time to settle into their new arrangements and begin to form connections in their communities. Both of these limitations could be addressed in future evaluations.

Although this data suggests that cost savings could be made through greater use of personalised arrangements, these savings may not be realised to the same extent when applied to a wider population of people in need of support. However, it is likely that the money currently invested will buy greater benefits for individuals than those they currently receive from what is a substantial annual investment of staff resources of close to €100,000 per person in congregated settings.

While important insights were gained from staff on their changing roles, a detailed examination of these changes was not possible within the resources of the evaluation. This area is worth exploring in future evaluations.

The wider implications of the findings are discussed in the full report around four key concepts underpinning the personalisation of service supports; namely, personalisation is a process not a product; it applies to everyone; it is based on self-determination and personalisation creates identity.

Thus far, personalised support has been couched within specialist services (in this instance for people with a disability and mental health problems). An alternative perspective would be to view it within the perspective that applies to most Irish citizens: i.e. through their use of generic health services and the person's own social networks of support, that of family, friends and neighbours. However, these are not two opposing systems but rather in the case of people with disabilities and mental health difficulties they should be complementary and hence co-ordinated. Indeed, this was the ambition underpinning the Genio projects. The potential for this to happen remains to be fully realised within wider disability and mental health services.

In essence personalisation of service supports demands a societal response underpinned by cross-Government initiatives and collaborative working among specialist and community agencies. It is a truly transformative agenda.

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Genio

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