Article

Relocating people with intellectual disability to new accommodation and support settings: Contrasts between personalized arrangements and group home placements

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Abstract

Internationally the relocation of people with intellectual disability from institutions has brought significant gains to their quality of life. This study contrasted three groups of persons in Ireland who moved either to personalized arrangements ($n = 29$) or to community group homes ($n = 31$) with those who remained in congregated settings awaiting relocation ($n = 29$). Persons moving to rented accommodation with personalized support tended to be younger and had fewer support needs than those in group homes. They had greater control and choice in their lives, more community engagement and increased personal relationships compared to residents in group homes but those remaining in congregated settings fared worse of all. However, average staff costs were significantly higher in the latter settings. The implications for the future provision of group living arrangements are discussed along with the need for further longitudinal research to assess the sustained impact of personalized arrangements and their funding.

Keywords

intellectual disability, group homes, personalized support, quality of life, personal outcomes

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Introduction

The move from institutional to community care is ongoing in many European countries. Improved quality of life for people with intellectual disability has been a well-attested outcome of these relocations, such as gains in material well-being, increased opportunities for choice, greater involvement in leisure activities and increased interactions with staff and other residents (Chowdhury and Benson, 2011; Kozma et al., 2009). Nonetheless in many countries – Ireland included – large numbers of people with intellectual disability remain in a variety of congregated living arrangements such as hospital-style wards, clusters of houses in campus-style settings, and in residential or nursing homes accommodating 16 or more persons (Mansell et al., 2010).

Community-based alternatives can take different forms, although a common model internationally is 'shared living', such as 'group homes', that accommodate up to six or eight persons in ordinary housing with support staff available day and/or night depending on residents' needs. In the Republic of Ireland, for example, 9032 persons were recorded on the National Intellectual Disability Database as availing of residential services in 2013 (Kelly and O'Donohue, 2014). In all, 47% were resident in community group homes, 40% in special residential (congregated) centres with only 13% in independent or semi-independent accommodation.

Although small group living was an improvement on institutional care as noted above, it can have its own shortcomings not least in the carry-over of a staffing culture that could retain control over people's lives (Bigby et al., 2012). Moreover, a growing literature documents the aspirations of people with an intellectual disability to have their own home along with having more friendships and opportunities for paid employment (Garcia Iriarte et al., 2014; Miller et al., 2008). Family carers too aspire for their relatives to have support in their own home rather than in group settings (Taggart et al., 2012).

Thus, in recent years there has been a shift away from shared living towards more individualized accommodation and support options, in which the person with intellectual disability rents or owns a property and receives personalized support. The arguments in favour of this approach are based mainly around human rights, better quality of life, increased self-determination and cost-effectiveness (Fisher et al., 2007). In the United States, for example, there has been a 58% increase in the number of persons supported in individualized housing and support options during the decade 2001–2011 and this model now accounts for over 30% of persons with intellectual disability in all forms of residential accommodation across the United States (Larson et al., 2013). Likewise, in the United Kingdom there has been a marked increase in similar –'supported living' – arrangements (Emerson et al., 2012).

Latterly, these developments have been spurred on by the expansion of new funding arrangements, such as individualized budgets in the United Kingdom, that permit support to be tailored to the needs of individuals and in some instances to enable people to employ their own support staff (Spicker, 2013). Although Government policy in the United Kingdom and Ireland is firmly supportive of personalized services (Department of Health, 2012; HM Government, 2009), the evidence remains sparse that such arrangements can deliver better outcomes for people with intellectual disability than the group living settings that are still the dominant form of residential provision in many countries (Glendinning et al, 2008; Harkes et al., 2012). However, studies in the United States suggest that people with mild and moderate intellectual disability have more control over everyday choices when living in their own homes, as do those with more severe and profound disabilities who live in small group settings of three or fewer persons (Stancliffe et al., 2000; Tichá et al., 2012).

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It was against this background that the present evaluative study was conceived. The Genio Trust was established in 2010 as an Irish registered charity with funding from Atlantic Philanthropies, the Health Services Executive and the Department of Health and Children. Providers of residential services for persons with disability or mental health problems could apply for grants from Genio to facilitate their service-users in an individualized way to move either from congregated settings to community alternatives or to more personalized arrangements in the community where they were living. An evaluation was then commissioned by Genio of the impact of these moves on people's lives (see McConkey et al., 2014 for full details).

This article compares people with intellectual disability who had moved to group homes with those who moved to personalized accommodation and support arrangements. At this time point, some persons continued to live in congregated settings and were waiting for new arrangements to be set up. Thus this 'natural experiment' provided the opportunity to identify the characteristics of persons with intellectual disability who were placed in the three types of settings and to contrast the outcomes for individuals across these different accommodation options with particular reference to choice and control of their living and support arrangements, daily activities and relationships with others. These had been identified as key concerns of Irish persons with intellectual disability (Garcia Iriarte et al., 2014) and they feature in many quality of life measures and outcome indictors (e.g. McCormack and Farrell, 2009). In addition, information would be gathered on the costs of support staff in the three types of settings.

All of the participants in the study were drawn from a pool of persons who had been identified by their service providers for relocation and who would mostly continue to be served by these providers in the new arrangements. This reduced a possible confound in past research where the different types of accommodation and support arrangements were provided by different agencies to differently recruited groups of persons with intellectual disability. Indeed this evaluation aimed to illustrate the impact on people's lives when service providers changed their model of residential supports. Other articles from the evaluation examine the role of staff (Garcia-Iriarate et al., in this volume) and the changes needed in organizational culture and management (McConkey and Keogh, 2014).

Participants

In all 11 different service providers – 9 non-statutory and 2 statutory – from across Ireland were grant-aided by Genio Trust in 2010 and 2011 to facilitate the relocation of persons from congregated and group living settings to more personalized accommodation and support arrangements. A person-centred planning approach was used involving the individual, relatives (if available) and support staff known to and preferably selected by the person. Genio provided training courses for service personnel on supported, self-directed living (see: http://www.genio.ie/learning-skills/formal-training/ssdl-training-overview).

In all, 89 individuals were nominated by the services and at the time of the follow-up – on average around 12 months after people moved – 29 persons had moved to personalized arrangements and 31 to group homes with a further 29 remaining in congregated settings awaiting relocation.

Personalized arrangements. Typically these arrangements took the form of rented accommodation in ordinary houses or apartments with people either living alone ($n = 28$) or with a friend of their choosing ($n = 1$). The tenants often chose the property and location as well as deciding on

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furnishings. Most had support staff visiting their home at agreed days and times for a set number of hours per week in accordance with their needs but a few individuals with higher support needs had staff available to them on a 24/7 basis. Prior to the move, 15 persons had lived in a group home, 9 in congregated settings and 5 with family carers. Two-thirds of the persons in these settings reported that new staff were supporting them.

Group homes. These were ordinary housing in the community shared by up to six persons with support staff available during daytime hours or on a 24-h basis. However, these residents typically had limited choice of co-residents. Prior to the move, 27 of these residents had lived in congregated settings, 3 in another group home and 1 with a family carer. In all, 79% of the people reported that new staff were supporting them in their new home.

Congregated settings. These included campus accommodation of separate bungalows and houses on a shared site as well as hospital wards. In such settings people had little choice over whom they lived with; they shared communal bathing facilities, dining and sitting rooms and even though some had their own bedroom, others shared sleeping arrangements in ward-like accommodation. Staff were available 24 h a day although different staff may work across the various housing units and wards.

Table 1 summarizes the demographic characteristics of the sample across the three settings. Although there were no gender differences across the three settings, younger people were most likely to be placed in personalized arrangements with older persons the most likely to remain in congregated settings.

Support needs were assessed based on 13 items related to daily life, such as doing household chores, using public transport, shopping for groceries and filling in forms. A three-point scale was used ranging from 'no support required', 'some support' and 'always needs support'. A count was then made of the number of items for which support was 'always needed' with high scores indicative of needing more support. The maximum possible score was 13. Persons resident in group homes had the highest mean score followed by those in congregated settings and then personalized arrangements. Nonetheless people with high support needs were also accommodated in the latter settings as indicated by the standard deviation on these scores.

Additional information was collected on further characteristics of the participants and their support needs as shown in Table 1. People with a history of epilepsy were more commonly placed in group homes and to a lesser extent in personalized arrangements but few people in congregated settings had epilepsy. On other indicators of additional support, the differences across the three options were not statistically significant but in general people with autism and a reputation for challenging behaviour were more likely to be placed in group homes or personalized arrangements than in congregated settings.

In addition, of the 89 study participants, all but 4 were Irish and all but 1 were single.

Procedures

Ethical approval was obtained from Ulster University. An easy-to-read Information Sheet describing the evaluation was prepared along with a consent form. These were sent to projects prior to the commencement of data gathering in the hope that they would be distributed to people supported, their relatives and key workers ahead of the interview. This did not always happen.

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Table 1. The characteristics of participants within each of the accommodation and support options.

	Personalized ($n = 29$)	Group homes ($n = 31$)	Congregated ($n = 29$)	Statistical tests
Gender – males	13 (45%)	17 (55%)	11 (36%)	χ^2 1.75 NS
Mean (SD) age in years	40.6 (12.3)	50.2 (11.7)	55.0 (11.6)	$F = 8.71 < 0.001$
Support needs: mean (SD) score	7.1 (4.0)	10.6 (3.7)	8.8 (3.1)	$F = 7.0$ $p < 0.005$
Support with medications	16 (59%)	22 (82%)	11 (55%)	χ^2 4.5 NS
Epilepsy	7 (33%)	13 (48%)	2 (9%)	χ^2 8.6 $p < 0.05$
A medical condition affecting daily life	6 (29%)	12 (43%)	9 (33%)	χ^2 1.2 NS
Autism	3 (14%)	7 (26%)	1 (3%)	χ^2 4.2 NS
Challenging behaviour	9 (31%)	14 (45%)	4 (14%)	χ^2 8.6 NS
Feeling down/depressed	5 (17%)	6 (19%)	4 (14%)	χ^2 2.6 NS

Hence all participants were talked through the Information Sheet and signed consent was obtained before the interview commenced.

In consenting, it was made clear to participants that they could refuse to answer any questions without giving a reason and they could terminate their participation at any time. They were assured that all their information would be kept private and no one, and no service would be identified in any reports. The support they receive would be unaffected by their decision to participate or not.

A structured interview schedule was prepared based on the literature, the evaluation aims and through consultation with an advisory group of service-users. It was further revised after piloting.

A team of eight research associates was recruited and police clearance was obtained for them. They were trained to interview the persons with intellectual disability, their key worker and an available relative. The interviews were usually conducted in a private room in the person's residence. The person supported had the option of a member of staff being present or a relative as they wished. The interviews generally took around 2 h with breaks as needed but they could extend to nearly 4 h.

For the 89 interviews, 36% were undertaken with the person alone, 39% with the person and key worker but with 25% of persons, the key worker was the main informant (although the person was physically present for some if not all of the interview). The number of responses to each item varied as small numbers of people were unsure of the answer or felt the question did not apply to them.

The interview data were transferred to SPSS version 22 for statistical analysis. Comparisons across the three accommodation and support options were made using χ^2 tests or one-way analysis of variance as appropriate.

Results

Ratings of change

People who had moved were asked to rate how things had changed for them since their move to new accommodation. Four options were provided using pictograms of smiling faces plus words: 'better; same; worse; not sure'. Of those moving to personalized arrangements ($n = 29$), 90% chose better, 5% no change and 5% were not sure. Comparable percentages for group homes were ($n = 31$): 81% better, 3% same, 3% worse and 13% not sure.

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Table 2. The number and percentage of persons in the three settings by features of their accommodation and support.

	Personalized ($n = 29$)	Group homes ($n = 31$)	Congregated ($n = 29$)	Statistical tests
Accommodation is rented	23 (85%)	11 (38%)	0 (0%)	χ^2 38.0 $p < 0.001$
Person has key to house	25 (86%)	10 (32%)	0 (0%)	χ^2 42.8 $p < 0.001$
Person is free to come and go	25 (86%)	15 (48%)	13 (52%)	χ^2 10.7 $p < 0.005$
24-h staffing available	10 (37%)	25 (81%)	29 (100%)	χ^2 26.8 $p < 0.001$
Person chose support staff	12 (50%)	1 (3%)	1 (4%)	χ^2 23.7 $p < 0.001$
Person chose key worker	12 (44%)	5 (19%)	1 (5%)	χ^2 11.5 $p < 0.05$
Individual personal plan	21 (78%)	16 (62%)	10 (44%)	χ^2 6.2 $p < 0.05$
Circle of support	15 (58%)	8 (29%)	2 (8%)	χ^2 14.2 $p < 0.001$

Choice and control

Table 2 summarizes the characteristics of the accommodation and support provided to the persons with intellectual disability across the three settings. The general pattern to emerge is that on the indicators noted, personalized arrangements contrast markedly with congregated settings with group homes falling between these two options. In personalized arrangements, nearly all persons lived in rented accommodation and had a tenancy agreement; they had a key to the property and were free to come and go. These features applied to fewer proportions of people in group homes and least of all to those resident in congregated settings. Indeed, the freedom of these residents to move was likely confined to the campus setting in which they lived.

Congregated settings provided 24-h staffing and this was also available to most persons in group homes but also to around one-third of those in personalized arrangements. This mirrors the support needs of persons as noted earlier. However, the option of choosing support staff and key workers was more commonly available to people in personalized settings although not to all of them.

People in personalized arrangements were more likely to have an Individual Personal Plan and to have a circle of support than were people in group homes and congregated settings.

There were other features of accommodation that did not discriminate across the three groupings, namely, people having their own bedroom, feeling safe and having special equipment assistive devices available. Hence, these features were present in all the accommodation options.

Daily activity

Participants were asked about the daily activities in which they took part and their responses are summarized in Table 3. People living in personalized arrangements were most likely to have played sports, gone swimming or attended fitness classes in the past 4 weeks compared to those living in other settings. They were also more likely to be in paid employment, attending education or training courses and less likely to attend a sheltered workshop as they were more engaged in the local community.

However, there were no differences across the three options in terms of people engaged in voluntary work or in attending day centres although the nature of these might differ in that for persons in congregated settings, these are likely to be on the campus rather than in a community setting as used by people in personalized accommodation. Also the use of community facilities in

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Table 3. The number and percentage of persons in the three settings by daytime activity.

	Personalized ($n = 29$)	Group homes ($n = 31$)	Congregated ($n = 29$)	Statistical tests
Played sports in community settings in past four weeks	15 (52%)	8 (28%)	4 (17%)	χ^2 7.9 $p < 0.05$
Paid employment	8 (33%)	2 (8%)	0 (0%)	χ^2 12.4 $p < 0.005$
Education or training courses	8 (30%)	5 (19%)	1 (3%)	χ^2 7.3 $p < 0.05$
Voluntary work	5 (18%)	5 (16%)	2 (8%)	χ^2 1.2 NS
Sheltered workshop	1 (4%)	3 (10%)	8 (28%)	χ^2 9.8 $p < 0.01$
Day centre/drop-in centre	8 (31%)	4 (13%)	9 (36%)	χ^2 4.5 NS

Table 4. The number and percentage of persons in the three settings by relationships with others.

	Personalized ($n = 29$)	Group homes ($n = 31$)	Congregated ($n = 29$)	Statistical tests
Friends/relatives visited for meal	19 (76%)	9 (29%)	4 (16%)	χ^2 21.1 $p < 0.001$
Friends/relatives stayed for weekend	9 (36%)	2 (6%)	0 (0%)	χ^2 16.0 $p < 0.001$
Received help from neighbour	13 (52%)	6 (19%)	2 (10%)	χ^2 11.2 $p < 0.005$
Gave help to neighbour	10 (42%)	2 (7%)	1 (5%)	χ^2 13.9 $p < 0.001$
Made new friends in past year	12 (48%)	6 (21%)	5 (28%)	$\chi^2$4.8 NS
See relatives more often	13 (46%)	18 (58%)	4 (14%)	χ^2 14.6 $p < 0.01$

the past 4 weeks, such as cafes, pubs and cinemas, was similar across all three settings and these tended to be used by a minority of persons in each type of accommodation.

Relationships

Table 4 summarizes the contacts that people had with others. Personalized arrangements gave people greater opportunities to invite friends or relatives to their home for a meal or to stay overnight. Likewise, people in these settings were more likely to get help from or give help to neighbours. They were also more likely to have made new friends in the past year. Some residents in group homes experienced similar relationship opportunities but they were fewer in number, although more of them had increased their contact with relatives since they moved to the group home as the services had engaged with families as part of the relocation process. People in congregated settings had least contact with friends, families and neighbours.

Staff costs

From the details provided by informants, the monthly costs were calculated of the support staff involved with the individuals in the three types of settings. In group living and congregated settings, these costs were divided among the number of persons supported by the same staff team. However, cost information could not be ascertained for nine individuals in personalized accommodation, three in group homes and three in congregated settings. The mean monthly costs along with the range of staff costs are given in Table 5.

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Table 5. The mean and range of monthly staff costs for persons in the three settings.

	Personalized ($n = 20$)	Group homes ($n = 28$)	Congregated ($n = 26$)	Statistical tests
Mean monthly cost	€3892	€6967	€8512	χ^2 25.77 $p < 0.001$
Range	€380–16,496	€3648–7365	€7365–10,348	

The difference in staff costs was statistically significant, with personalized arrangements having the lowest average costs. This represents a major saving in support costs from when these individuals resided in congregated settings. However, the range of costs was highest in personalized settings, which likely reflect the greater support needs of a few individuals. In both groups and congregated settings these higher support costs are masked when costs are equally apportioned across individuals rather than in terms of the extra supports required by certain individuals.

Discussion

This study provided a unique comparison of three accommodation and support options for persons with intellectual disability. The participants were drawn from the same cohort of service providers; they had been identified as requiring a change in their present accommodation; and funding had been sought to facilitate their relocation. Training in individualized supports had also been provided to redeployed and newly recruited staff. Around 24 months later, two-thirds had moved to either personalized arrangements or to group homes with a further one-third awaiting relocation. From the information gathered – mostly from the people supported themselves – the new living arrangements seemed to produce better outcomes for them compared to the lives of their peers who continued to live in congregated settings. This confirms much of the international literature reviewed earlier. However, people who moved to personalized arrangements generally seemed to fare better than those who moved to group homes. This confirms and extends the reports of other studies of personalized arrangements although these lack the comparative element provided here (Sims and Gulyurtlu, 2014). Moreover, there were significant reductions in staff costs across personalized arrangements and to a lesser extent in group homes compared to congregated settings, which confirms previous research (Robertson et al., 2004).

That said, the size of the sample was limited, which precluded more detailed statistical analyses that controlled for possible confounding variables such as support needs and age differences. Also, there may be some biases in the sample that arose from how the projects and their participants were selected. It is likely that the services that sought funding from Genio differ in some important respects from similar services that had the option to apply but chose not to do so. For example, most of the applicant services already had a greater commitment to personalization and were comfortable with creating and managing change (McConkey and Keogh, 2014). Likewise, the participants were mostly given the choice about moving and they too may represent a biased sample of more eager and possibly more suitable persons for the new options. They also tended to be younger than those who moved to the group homes. Thus, the information obtained is indicative rather than representative data pertaining to Irish services. Furthermore, some of the significant statistical differences reported may have arisen by chance because of the number of tests carried out on the full range of indicators included in the study. Nonetheless, the findings do illustrate the positive impact that moving to new accommodation and support arrangements can have on people

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with an intellectual disability and which should be replicable by other Irish support services as well as those elsewhere.

The degree of support required by people with intellectual disability has often been the basis on which decisions about residential options have been made. This is illustrated to some extent in the findings of this study in that persons who always required support with daily living tasks were most likely to be placed in group homes rather than in personalized settings. Surprisingly, those who continued to live in congregated settings needed less support perhaps because they were a selected group of people who were waiting to move whilst more dependent persons were not considered for relocation (Kozma et al., 2009). However, it is worth noting that some persons in personalized arrangements had high support needs as indicated by the standard deviations on the measure of support (see Table 1) and they had additional staffing allocated to them as shown by the costs in Table 5. Equally there were no significant differences across the three settings in terms of other potential support needs such as medical conditions, administering medications, challenging behaviours and feelings of depression. Also people with a history of epilepsy were more likely to be placed in personalized arrangements or group homes. At a minimum then this study confirms that people requiring higher levels of support can be accommodated in settings other than specialist residential homes or centres but it also demonstrates the possible gains to be had when they are relocated.

The study had a certain irony within it. Just over half of the people who moved to personalized arrangements had previously lived in group homes whilst most of those living in congregated settings were relocated to group homes. One reason given was that the move to group homes facilitated the service agencies to speedily close outdated institutions. Moreover, the difficulties in accessing suitable housing had been a major reason for people continuing to live in congregated settings. Further justification for people moving to community-based group homes comes from the gains that at least some people experienced on moving as evidenced in these findings and as other studies had noted previously (e.g. Chowdhury and Benson, 2011). But the associated risk is that people may not have the opportunity to move on from the group home to more personalized arrangements on the grounds of avoiding further upset to them. Nonetheless, the services involved in this study had made it possible for people to move from group homes to more personalized arrangements and the findings illustrate the extra gains that can accrue for individuals in these settings. All of which raises the possibility of relocating people directly from congregated settings into personalized housing and support arrangements. International experience in countries such as Norway has demonstrated that it can be done (Tøssebro et al., 2012) although the availability of suitable housing is a requisite that can take time to put in place (Kirkpatrick, 2011).

More fundamentally though, these findings question the future of group homes in a post-deinstitutional era. Based on these data, people currently living with family carers would be better advised to seek personalized support arrangements rather than group home placements although the reservations of parents around safety, supervision and support for their relatives will have to be addressed (Curryer et al., 2015). Also for service commissioners and funders, the analysis of staffing costs indicates that personalized supports may provide better value than group home placements given the better outcomes that can be achieved.

Hence, we may see a decline in the number of people living in existing group homes in the coming years in line with Government policy and might we ultimately see the demise of group living as has happened with institutional care? Or perhaps the future demand for placements may be such that group living remains and even expands as seems to be happening in Norway (Tøssebro et al., 2012). In this scenario, hopefully, group homes would be reinvented to suit the particular

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needs of certain individuals and the findings relating to personalized arrangements in this study provide some indications as to how this might be done through choice of support staff and key workers, having an individual support plan and a personal circle of support. Moreover, individualized formal and informal support arrangements need to be created to ensure comparable outcomes are obtained for residents in group homes as those resulting from more personalized arrangements. It is likely too that staff and management cultures will need to change (McConkey and Keogh, 2014).

Recently, concerns have been expressed about how personalization is being implemented in times of austerity and the strength of the commitment by service commissioners and providers to promote self-determination for persons with intellectual disability who usually require lifelong support (Duffy, 2011; Spicker, 2013). Thus the 'snap-shot' data presented in this study need to be extended to examine how people in these different support arrangements fare in future years but especially those in personalized options and the quality of support that they receive (Cocks and Boaden, 2011). Past research suggests that gains apparent soon after moving may not be sustained in the longer term once initial enthusiasm wanes (Chowdhury and Benson, 2011). Future articles arising from the evaluation will report on a follow-up of these individuals 1 year later (McConkey et al., 2014) but longer term longitudinal studies would be valuable, especially of persons who move directly into these arrangements from family care and who have not experienced group living.

Additionally, both the concept and operation of personalized services deserve more critical scrutiny in relation to people with intellectual disability than has happened thus far; particularly, in relation to the quality of support offered, the promotion of self-determination, and the sustainability of these models when people's need for support increase. Thus far, the outcomes achieved through personalization seem impressive but there is much still to learn.

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