Families' views on their relatives with intellectual disability moving from a long-stay psychiatric institution to a community-based intellectual disability service: an Irish context.

Owen Doody

Accessible summary
• This research explores families' perceptions of resettlement.
• Clients were moved from a long-stay psychiatric institution.
• To a campus-based residential setting within an intellectual disability service.

Summary
The pattern of residential services for people with intellectual disability in Ireland has seen many positive developments in recent years, with more places made available in residential homes within both community- and campus-based accommodation. This paper reports on the findings of a study which explored families' views regarding the movement of people with intellectual disability from a long-stay psychiatric institution to campus-based accommodation within a local intellectual disability service. A Husserlian phenomenology was chosen, ethical approval was granted, eleven participants were interviewed and data transcribed. Through Colaizzi's (1978) procedural framework for data analysis two key themes were identified. The positive transition resulting from the move and the enlightened thinking that has developed as a consequence of the move. Overall, the study indicates the importance of; care and care delivery from the family's perspective, the interaction of staff with families and families knowing the staff.

Keywords
Campus-based accommodation, families' perceptions, resettlement, Ireland, intellectual disability

Introduction
On the establishment of the Irish Free State 1922, there was only one institution/hospital specifically providing services for people with an intellectual disability. As a consequence, people with an intellectual disability were cared for in psychiatric hospitals. In the ensuing years, Irish government policy documents highlighted the need for appropriate services for people with an intellectual disability (Department of Health, 1990, 1984, Government of Ireland, 1965). Currently, there are an estimated 100 service providers for people with intellectual disability in Ireland (Health Service Employer Agency, 2003). Given that the continued care for people with an intellectual disability in long-stay psychiatric facilities is inappropriate. Reports recommended a transfer of clients to services that enable clients to receive the skilled and specialised care not generally available in psychiatric hospitals (Government of Ireland, 2002). While the Irish government has been committed to supporting the programme of resettlement, the more recent Disability Act (2005) indicates that services will be provided based on governments ability to fund such services.

As a consequence to government policy and legislation regarding the care of people with intellectual disability, there has been a shift from hospital/institutional care to

community care. This shift was influenced by philosophies that promoted normalisation, equality, inclusion and the rights for people with intellectual disability to live as others do in society (O'Brien 1987; King's Fund Centre, 1980, Wolfensberger 1972; Nijre 1969). A common goal of such policies is 'ordinary living' for people with intellectual disability (Kim et al. 2001). Recognising that resettlement and living in an environment that is free from negative impacts is a right for people with intellectual disability (Cho & Kim 2006; Kim et al. 2001). The closure of long-stay hospitals and subsequently transferring the provision of care for people with intellectual disability to the community aimed to benefit clients through reducing the negative factors associated with institutional living (Barr & Fay 1999).

In recent years, major changes have occurred in the provision of services for people with intellectual disability (McConkey et al. 2005). Institutional care has given way to services that are based on smaller groupings of people living in domestic style housing, often in community settings (Braddock et al. 2001). In Ireland, the favoured model has been the development of a complex of houses within a specialised campus setting (Department of Health, 1990) offering residents access to a range of services and health professionals. Internationally considerable effort has been made to close and downsize institutions resulting in a dramatic expansion in the number and range of community care options as alternatives to institutional care. Examples include United States (Prouty et al. 1996; Larson & Lakin 1989), United Kingdom (Emerson et al. 1996; Emerson & Hatton 1996a) and Australia (Dunt & Cummins 1990). While the term deinstitutionalisation did not appear until 1975 and not in a paper title until 1976 (Doll 1976), it has been perhaps the most important development in the way services have been organised in Western Europe and North America over the last 30 years. Although the ongoing participation of families is regarded as a key element to achieving successful deinstitutionalisation, it would appear that little attempts have been made to examine families' perceptions and attitudes regarding institutionalisation and deinstitutionalisation (Tabatabainia 2003).

Additionally, changes in Irish psychiatric care provision have seen large reductions (80%) in the number of inpatient residents in psychiatric institutions and units between 1963 and 2002 (Walsh & Daly 2004). Since the first report from the National Intellectual Disability Database (NIDD) in 1996, the number of people with intellectual disability accommodated in psychiatric hospitals has decreased by 68% (Kelly et al. 2008), with 188 of these individuals identified as needing to transfer from these locations to more appropriate accommodation (Kelly et al. 2008). While deinstitutionalisation has occurred and will continue, few studies have been published with minimal research from a families' perspective in Ireland.

Methodology
This study aimed to explore families' views of moving people with an intellectual disability from a long-stay psychiatric institution to a campus-based residential service. The research site, a long-established voluntary service for people with intellectual disability in the west of Ireland, provides both community and residential services to over three hundred people with intellectual disability. The client group involved in the transfer consisted of 36 individuals who moved to six campus-based bungalows within the service. The sample consisted of family members who met the inclusion criteria of having regular contact over the past 5 years to give a balanced view of the move. Diversity within the sample was important, and the invitation to

participate was open to the family as a whole. The population who met the criteria were mailed an invitation letter and information leaflet inviting them to participate in the research. All respondents were afforded the opportunity to participate. Of the eleven participants, seven were sisters, one a mother, one a brother, one a niece and one a brother-in-law of the clients. As the focus of the study was from a family's perspective, no clients were interviewed. A Husserlian descriptive phenomenology approach was chosen as the focus of the study was on description of the families' views rather than on the interpretation of their views. This method focuses on the human experiences (Polit et al. 2001), seeking to describe the participants' views while acknowledging that only they who experience the phenomena are capable of communicating it to the outside world (Parahoo 2006; Higginbottom 2004). Additionally, it is often used when little is known about a topic and accumulate evidence from a fresh perspective (Lo Biondo-Wood & Haber 2006; Higginbottom 2004).

A total of seven interviews were conducted with individual family members, and two interviews were conducted with two family members present. Interviews were conducted in a venue of the participant's choice, and each lasted a minimum of one hour. The interviews were audio-recorded to allow for transcription, and analysis was guided by (Colaizzi 1978) framework. This framework is widely used in nursing and involves verbatim transcription of the interview followed by reading the transcripts, extracting significant statements and phrases, formulating meaning of the significant statements, organising meanings into themes, integrating results into a rich description of the experience, formulating a structure of the phenomenon and seeking validation form the research participants who compare the descriptive results with their lived experience. Ethical approval for the study was granted by the ethics review group of the service provider. Throughout the study, the families were aware that they were free to withdraw at any stage and were afforded the opportunity to look over their transcripts and a copy of the findings prior to final write up. The researcher was aware of the demands of the study, and the aspect of spending time with the families after the interviews was an important issue along with the families having the researcher's contact details so that they could contact the researcher to discuss any aspect of the study. Table 1 identifies the demographic details of the client group, and Table 2 identifies the family group involved in this study.

Table 1 Demographic details of clients group

Age profile	Youngest 34, eldest 74
Length of stay in the psychiatric hospital	Shortest 16 years, longest 46
Degree of disability	All diagnosed with a severe to profound disability

Table 2 Details of the Families group involved in this study

Age profile	Youngest 28, eldest 78
Relationship with the client	One brother, one mother, one niece, one brother-in-law and seven sisters

Findings

Through analysis, two key themes emerged from the data, positive transition and enlightened thinking. These themes were formulated by placing meaning on the participants' statements and organising the meanings into themes. The themes and essences are highlighted in Table 3, which were validated by the participants who were afforded the opportunity to confirm and/or comment on the findings.

Table 3 Research themes and essences

Theme	Essences
Positive Transition	Evolution of care
	Independence
	Homely environment
	Gratefulness
	Accessibility
	Openness
	Transparency
	Equality
	Forming relationships
	New roles
	Extended families
	Less stigma
Enlightened thinking	'New breed' of nurse
	Regaining respect/dignity
	Government funding
	Knowing your client
	Important people
	Individual plans
	Integrated people
	Versatile interactive people

The positive transition theme emerged from the participants describing the development and changes in care over the years, where now the client is seen to have more independence and live in a more homely environment. The care providers were seen to have gone through a transition also now operating a more open and transparent systems that the participants felt they could be a part of. This enabled them to form a new relationship with the client and bring in other family members to visit and meet the client, thus allowing families develop a new and more involved role which was supported by the perceived reduction in stigma as a result of moving to the community. The enlightened thinking theme emerged from the participants describing what they perceived as a 'new breed' of nurses which they felt were trained differently and were focused on preserving the dignity and integration of the client into society. Also acknowledged was government commitment by funding the move from institutions to community-based accommodation. Of most importance to the participants was the expression that they and the client were now seen as important people and actively encouraged and supported to have an active role in planning care. Of vital consideration for the participants was the aspect of knowing the person from

both their point of view and the clients' point of view as without this, the environment and interaction was hampered.

Positive transition
Overall, the change in environment and the families' view of the service had lead to a positive transition. Initially, participants were aware of the move but did comment on the lack of information at times, client mix and compatibility with co-residents as a general concern for their families.

> *'They were like a family and you would not want to split them up'*

However, there was an expression of a free from 'jail/asylum card' among participants with a sense of relief or a weight being removed.

> *'Its made my life as well, I have gained from it because I used to worry about Jack and I don't worry now, I don't have sleepless nights, I know he is in good hands, I could not give him the good life he has now, he is enjoying his life now and so am I'*

Participants identified environmental changes such as client independence, individual rooms, increased privacy and personal belongings. They also felt that the clients were in a relaxed environment that was welcoming with pleasant surroundings which all created a homely atmosphere as compared to the old institution style accommodation.

> *'It's so homely the whole atmospheres is so homely and you really feel at ease, they have their own rooms, he's got his own TV and radio, he's got everything he needs and it's the welcome and the feeling of hope I suppose being a mum myself the focal point is always the kitchen its so warm and welcoming and a feeling of caring there'*

Within the transition participants expressed a sense of gratefulness for the service they now have.

> *'They are now getting what they deserve because they did not get it before and that's great but when they cant speak for themselves its hard to get what they deserve'*

However, there was little awareness that this service was the right of individuals with intellectual disability as they have the right to equal participation in society (Quinn & Degener 2002).

> *'I would have some concerns about how long this would continue, will it always be there for him and what would we do if it wasn't, now maybe it's an irrational fear but it's always in the back of my mind'*

The expression of ownership through clients having their own room and personal belonging was important, but most important participant felt that there was an equitable service for all clients and that the client was treated as equals by all staff.

> *'They do everything for him like they do everything for everyone else no exceptions made, they're all treated the same they do their best for them all, they're treated as equals'*

The openness and communication with families had a unifying effect and creating a sense of family togetherness as a consequence of the move, and this was encapsulated by the sense of who was involved in that network. The move has aided increased

contact with family and enabled additional development of relationships between family, other clients and staff.

> *'I didn't know Mary until she went to the house I would have gone at Christmas and Easter time because I felt obliged and because dad told me I had to, but now I have got to know Mary and the other clients since the move'*

> *'I go every Sunday now I don't need an excuse, we go out and its not because we have to or feel we have to, we want to and I have a daughter in college and she will pop over to see him and sit down and watch TV with him, I called one evening and they were all sitting down watching some music show even the staff and the fire was lighting and it had the warmth of a real home and a real family'*

Additionally, a positive development has been the fact that families have come together and are provided with opportunities to meet.

> *'It's just since the move we would have met most of the other relatives on some occasion or just during a visit, I would never have met any of them in the psychiatric hospital and there would be no events to go in for'*

Families saw the staff as part of the family and acknowledged that the staff see the client as part of their family as well.

> *'They're our extended family, their minding our brother and they seem to feel the same way and when there is anything on they will all be there, the last time Connie was there and she was out on maternity leave and Carmel was there with her kids'*

The clients have new roles within the family as well, linkage in relation to sending cards, photographs of holidays all aid greater communication networks to develop between the family and client.

> *'They took him away and they would take photographs of him on the beach and he would have his own photo album so when I go in I can see the photographs and Mike, the staff and I can talk about the trip, he also sends me cards at Christmas and that, but that was the first time ever I got anything from Mike and if he is on holidays he will buy me a gift, now I know it is the staff that initiate this but Mike can now do that now that he has been given the idea and chance'*

Central within the research was an acceptance by the family of a change in their role concerning their involvement in care and the decisions made relating to the planning of care for their family member. While this was a positive aspect, some remorse was expressed regarding their past involvement.

> *'We are all involved all the time and they ring us, they have our mobile numbers and if I'm away or cant answer they will ring another member, they know every move we make and we know every move they make, but I do regret I wasted so many years when I was not involved at all but here it was automatic that I would be asked and no decision would be made without us knowing'*

Stigma was also highlighted; this was perceived as being removed, but it was the actual environment that seemed to create the stigma as participants commented on the physical and ecological aspects of the old style institution. They were also conscious

of social stigma associated with the institution, as there was a social view that institutions were 'a mad house' or there was the social expression of 'been under the clock'.

> *'There was a stigma attached and that implied as much to the people going in to visit as it did to the people in there, there was probable more dignity attached to visiting the jail, you did not tell anyone where you were going, it was so old, the corridors were cold and some of the windows had bars on them and whether we like it or not institutions have a legacy and it was a major institution'*

Enlightened thinking

Participants perceived that there seemed to be a 'new breed' of nurses in relation to the training and attitudes to care. There was an acknowledgement of the respect and dignity clients receive and the overall approach to care. 'There is a 'new breed' of nurses now they speak to Mary the way they would speak to you or I, it's the training the staff have, they're obviously more expert and there is a pursuit of excellence throughout all the different aspects that are involved in caring for the person'

> *'There is this great undertaking to look after Peter, his everyday needs, his social needs, his medical needs and his psychological needs, I think the word holistic sums it up for me'*

The aspect of government funding was identified by families in the sense that the clients had their own allowance and that they had the facilities, but some did comment on the past and the insufficient funding that was available and the guilt for the people left behind.

> *'Obviously the funding was not there and the nurses were not given the recognition for the work they were doing but there seems to be more funding now so they can do some of the things they would have liked to have done I presume in the psychiatric hospital, I would say that this trend will save the government a fortune in the long run because now the nurses understand the problems and treat them with dignity but I do think of the people left in the psychiatric hospital and I feel guilty'*

Consistency of staff was highlighted as important to families as knowing the person is important. This was seen not only in the care of the client but also in the creation of the relaxed atmosphere, which allowed communication and caring between all persons develop.

> *'The staff are the key they understand each person and are able to give each person what they need and adjust in such a way as to put them at ease, but if your only somewhere temporary you don't get to know them as well or the relief staff while they do a great job and their care is excellent it's the small little things that come form been there and knowing the clients that creates the warm welcoming atmosphere and interaction with and among clients'*

Two families commented on the clients that had moved as been 'VIP's, and a further two referred to them as 'royalty'. Trying to identify what created this opinion families referred to the activities the clients were engaged in, the care planning process that was individual to each client and the professionalism of the nurse. Participants commented on the past and that social contact was limited and clients were hidden

whereas now families are seeing clients having more social contact with society and partaking in normal valued activities leading to more visibly integrated people.

> *'He belonged to a group of people who were locked away but now they go shopping, I see them out regularly, they go to various places where anyone else would go, such as parks, concerts or whatever and they go on holidays they stayed in a hotel'*

Families were now treated as important people themselves as they are now part of the care planning and delivery, as well as being involved in developing mission statements for the houses. The team approach to care delivery and the good communication system behind this was seen to be the key. Teamwork was evident in the annual plans, which participants identified as; where all people from the family, staff and multidisciplinary team were involved leading to individual plans been developed.

> *'There is good teamwork and anyone of the nurses could tell you what's going on and we know what's going on all the time as they keep us informed, there is a pursuit of excellence throughout all aspects they are involved in and everything is done with a purpose, but they let us know and want us to make decisions, be involved and at the end of the year we would meet all the team and look at the progress over the past year and everything that has happened in his life and it would all be down in writing and I get the report to take with me and I would have been involved, they don't do anything without asking me or me discussing it with them'*

Families commented on the versatility of the nurse and the high level of communication between themselves and the nurse leading to versatile interactive professionals.

> *'One of the nurses asked me what music he loved when we were kids and they play that music for him and he remembers, I appreciate the person who is willing to go to the trouble because it's a stretching of oneself and it is the staff who is the catalyst in that process that makes the quality of life better for us all and everyone is open and genuine and they can say to you if they are having a bad day but you can nearly see the caring shine through them, and knowing the person who is caring for your brother, sister, son or daughter is important as you can feel at ease with them and it helps you to relax and know that they are cared for and cared for very well'*

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Discussion
The relocation of people with intellectual disability from large institutions to community-based settings has been an important advancement (Bigby & Fyffe 2006; Mansell & Ericsson 1996) and further supported by this study. Prior to relocation, many factors are considered important from a family's point of view, which include client mix and client compatibility with coresidents in living situations Browning & Jones 2002; Donnelley et al. 1994). This is important as the right client mix promotes household harmony (Borbasi et al. 2008) as even people with severe intellectual disability will have formed attachments to people, aspects of the environment or familiar routines (Barton 1998).

Families highlighted institutions as often having problems, such as cleanliness, poor repair, age of buildings, lacking basic conditions for privacy and care of personal

possessions (Shepherd et al. 1996), whereas now families saw the community homes as clean, pleasant and more homely that any institutional ward/unit (Shepherd et al. 1996). This was reinforced for families by clients having their own personal items (Kay et al. 1995), independence in adaptive skills, lifestyle and personal happiness (O'Brien et al. 2001; Emerson & Hatton 1996a,b; Holland & Meddis 1993). This concurs with other research that identifies the key features for families associated with these positive outcomes, including architecture (Robertson et al. 2001), client privacy (Donnelley et al. 1994; Leff 1993) pleasant surroundings (Donnelley et al. 1994) a relaxed and welcoming atmosphere (Shepherd et al. 1996; Weber & Fritsch 1999) and having personal possessions (O'Brien et al. 2001; Apgar et al. 1998), all relating to general satisfaction. Emerson et al. (1996) highlight that national parent's groups appear to have played a less important role in promoting institutional closure than professional and managerial led endeavours. Nonetheless, while the welfare of people with intellectual disability remains paramount, their rights must be protected. The opinions and feelings of relatives whose lives are 'intimately intertwined' with those of service users also deserve consideration (Latib et al. 1984) and must not be overlooked. In relocating clients, this study is in keeping with Young et al. (2001) who identify that families feel their relative receive a greater opportunity for a life similar to non-disabled people, thus creating equity. However, within this study, families also noted equity among clients within the home where they felt they were all treated equally in the light of their needs.

Families within the study indicated that choice and ownership had increased for both the client and themselves as all information was accessible and they were involved in the care process (Borbasi et al. 2008; Cho & Kim 2006; Cambridge et al. 2002; Kim et al. 2001; Simic 1994;). Similar to McConkey et al. (2003) and Stancliffe & Lakin (2006), these factors all supported increased contact for clients with their families and increased contact of staff with families (Cho & Kim 2006; Kim et al. 2001; Young et al. 1998; Emerson & Hatton 1996a,b). This increased contact enhanced the development of relationships between all concerned and was further facilitated by not only the availability of staff but how they go about their job (McConkey 2000). This concept is important as we move to a broader definition of care and accept a holistic view (O'Brien et al. 2001) acknowledging that beside every client is their family and that their lives are intertwined (Latib et al. 1984). Through the nurses' approach to care which is focused on the individual and their needs, he/she promotes client autonomy and rights (Mansell & Beadle-Brown 2004; Robertson et al. 2001). This can be seen where active and intimate supports of others provide life purpose, responsibility and esteem (Cummins & Lua 2004). As through the support and contact with nurses, the client receives more social contact (Ager et al. 2001; Apgar et al. 1998) and access to resources, including skill and knowledge (Reid et al. 1989; Repp et al. 1987). In the current economic climate and in an environment of non-replacement of staff and staff embargos, it is vital that we remain focused on the support we provide and the impact this has on our clients and their families. As within the findings communication and the inclusiveness of families within care planning and delivery were seen as essential, which emerged from the general philosophy of care, based on respect and individuality of each client as evidenced in individual care plans and practice areas mission statements and the participants' perceptions of the nurses' attitude.

Overall, families expressed positive thoughts about the move to the community houses believing life was better for clients in the community compared to the institution expressing their preference to remain in the community setting and an intention of 'not going back' to the former congregate care facility. Families appreciated the setting as more flexible and responsive to their individual preferences. They liked that their relative was able to 'access the outside world', 'attend functions' and 'do ordinary things' such as go shopping. Family members also described the benefits of community living as 'nice house', 'nice environment', 'more homely' and 'not so institutionalised'. While the findings of the study are positive and sit well with the principles of normalisation and social role valorisation (Wolfensberger 1983), we continuously need to strive beyond the closure of institutions to individualised support of people with intellectual disability and ensure we do not just replace one institution with another or one set of buildings with another.

Conclusion
While the leaders in this field are arguably from Sweden and Norway, where all institutional provision has been replaced and where the law enshrines the right to community services (Tossebro 2004; Ericsson 2002). Ireland is well placed to learn from the mistakes of other countries and not just repeat them. We need to ensure community-based services are of good quality from the start and for everyone, not just the most able. Success will require a focus on demonstrating improvement in the quality of life of people with intellectual disability (Mansell 2006). This will involve more than simply changing the locus of care (Mansell & Beadle-Brown 2010) to service planning that is tailored to the needs of each individual (Lamb & Bachrach 2001). Accommodation should be designed for the individuals rather than a standard design, and clients should be afforded the choice with whom they live (Bigby & Fyffe 2006), changing the role of staff to provide more facilitative, enabling support for individuals, especially those with the most severe or complex needs (Mansell 2006). Conflict can regularly occur between the needs of staff and the needs of service users as reprovision is designed around staff to make it easier for them to get to work, move from one service to another, etc. (Bigby & Fyffe 2006). A culture of engagement in meaningful activity at home and in the community needs to be created (Clement & Bigby 2010; Bigby & Fyffe 2006). While people with intellectual disability may be present in the community, they may not be considered part of that community (Rapley 2000). Even though many activities supported by staff result in community presence, they are highly unlikely to lead to community participation. While people with intellectual disability make use of ordinary places or facilities, their lives can still be described as socially excluded (Clement & Bigby 2010).

From an Irish perspective, relocation from institutions to services in the community requires a mandate for a detailed vision of the future care system based on user and family involvement. Ideally, the relocation from institutions to services in the community will have a national mandate. At the very least, there needs to be local agreements between all potential service providers. This plan should not just specify that an institution will close and indicate the target date, but should include a detailed vision of the future care system. The international legal framework sets out the right of disabled people to live in the community. The United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006), which came into force in May 2008, recognises this right through Article 19, which entails the provision of a range of in-home, residential and other community support services, including

assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community (Mansell & Beadle-Brown 2010).

Relocation to a new setting will inevitably involve 'dislocation', and there can be an anticipated period of adjustment (Barton 1998). However, most families involved in this process do not feel adequately informed through official channels, and poor communication tends to raise false hopes or fuel unnecessary anxieties (Barton 1998). Consultation should be all inclusive, with service users and family involvement throughout. Although other actors (organisations and service providers) will play an important role, the responsibility for planning, coordinating and managing the process will rest with government. Thereby, there needs to be vision and leadership by government, working in close collaboration with representatives of service users, their families and service providers. Currently in Ireland, we are awaiting a report on congregated settings to be published, and national media has indicated the report calls for the closure of all institutions for people with intellectual disability within the next 7 years. If this report is acted upon and institutions are to be closed, it is important to effectively plan the relocation and involve family at every stage of the process.

However, new care arrangements (such as community-based care) could be more expensive than the arrangement it is replacing (such as long-stay hospital provision). Consequently, they may be more cost-effective as it leads to better outcomes for service users and their families. These improved outcomes should be valued sufficiently highly enough to justify the higher expenditure. For this to occur future planning requires a comprehensive long-term perspective considering all costs and benefits of relocation to make the appropriate decisions. Currently in Ireland, there is a review of disability services under the value for money and policy review initiative 2008–2011, and given the current economic downturn, one may be concerned that such improved outcomes may not be valued against financial savings. However, it is clear that 'one size fits all' approach to health and personal care services will not produce the desired results (National Disability Authority, 2010). It will be necessary to develop an approach that takes into account the differences between groups such as age, type or degree of disability when planning and delivering community living systems and practice (National Disability Authority 2010).

Through the process of inductive analysis, insights and explanations of a group of Irish families, their views have been presented. This provides service providers, residents, families and others as readers the opportunity to reflect on this study and findings to inform their own practice and possibly service and policy development.

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