

Moving from a long-stay institution to a community-based residential programme for persons with intellectual disability: The views of families.

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Introduction:

It is important to review the developments of intellectual disability nursing in order to understand the changes that have led to current practice within the profession today. Traditionally, the care of people with intellectual disability revolved around long-stay hospital care, but the negative effects of institutional living eventually led to social and political pressures to move towards community care. As politicians, professionals and the general public debated the ways in which people with intellectual disability should be cared for, their opinions influenced both service provision and delivery. Historically people with intellectual disability were negatively viewed, with the use of terminology that is now considered derogatory in the English language. The labelling of people with intellectual disability has adapted in line with changing care philosophies, service provision, public perception and, more importantly, the views of people with intellectual disability themselves.

On the establishment of the Irish state in 1922 there was only one centre dealing specifically with intellectual disability, which meant such persons were catered for, to a large extent in mental hospitals and in county homes (which succeeded the institutions provided under the Poor Law 1834). Today however there is a wide range of service providers for persons with intellectual disability and a substantial move from institutional to community-based care has taken place. The aim of this shift has been to see people in the mainstream of life: living in ordinary houses, in ordinary streets, with the same range of choices as any citizen and mixing as equals with others” (King’s Fund Centre, London, 1980, p.5).

The change in service provision has also meant a change in the role of the intellectual disability nurse - from providing little more than custodial care, to enabling people with intellectual disability to live as independently as possible - in an environment

that maintains the privacy and dignity of each individual and provides support to enable them to reach their maximum potential in all areas of their life (Department of Health 1997a). This change in care philosophy and practice was not only influenced by government reports but also by the field of psychology. The publication of Wolfensberger's theories on normalisation (1982, 1972) and social role valorisation (2000, 1994, 1985), which also supported community living, had a vast impact on contemporary attitudes and practices. In addition, these theories describe care philosophies that should underpin care delivery and promote valuing people with intellectual disability and thereby facilitating their value as individuals within society and the community in which they live.

Background of the study:

Family's perceptions of persons with an intellectual disability who leave institutional care to live in community programmes are often included as a component of a study, rather than being considered in themselves. The present study focused, in the Irish context, on the views of families of persons with an intellectual disability who left a long stay psychiatric institution to live in a near by intellectual disability community-based programme. The clients involved had initially been inappropriately placed, and they were transferred as a result of the recognition of the fact, and because of current government policy. The 36 clients involved in the move were all of severe to profound disability, ranging in age from 34-74 and had resided in the long-stay institution for a period of 16-46 years.

Methodology:

The research was conducted with ten participants who met the criteria for this study. In order to allow for a balanced view of the move and to reflect the true perceptions of families, all the participants who were selected had two years of contact prior to the client's transfer of residence and continued contact after the move had occurred. Six interviews were conducted with individual family members and two were conducted with two members of a family. The participants comprised six sisters, one brother, one niece, one brother-in-law and one mother. The ten participants were interviewed in a venue of their choice, for a period lasting one-hour at a minimum. A phenomenological approach based on Husserl was chosen and data was

collected through interviews, which were transcribed and analysed using Colaizzi's (1978) procedural steps.

Findings:

Overall, the participants viewed the change in service and service environment as being a positive transition. Initially participants had been made aware of the move, but some did comment on the lack of information at times. For families, the client mix and compatibility with co-residents (Browning and Jones, 2002) were a general concern in the planning of the move. Families identified environmental changes (such as client independence, individual rooms, increases privacy and personal belongings) as being evident (Leff, 1993). They also felt the clients were in an environment that was relaxed and welcoming, with pleasant surroundings (Donnelly et al, 1994). Participants expressed a sense of gratitude for the service their family member now receives, but there was little awareness that this was within their right to equal participation in society, as declared internationally (United Nations Human Rights, 1987) or asserted in Ireland (Department of Health and Children, 2001; Department of Health, 1994). Accessibility and openness had increased for families and communication between family and staff increased. Families were given access to details of care plans and personal accounts (as reinforced by the Freedom of Information Act, 1997b). The expression of ownership inasmuch as clients have their own room and personal belonging, was deemed important, but families still felt they were a vulnerable group in relation to the security of service and were concerned that services might not always be available to them.

Good communication and family togetherness were identified as being important; this was encapsulated by a feeling that staff members were now seen as part of the family. The participants also acknowledged that the staff seemed to see the client as part of their family as well. All families especially appreciated social gatherings and events that provided more opportunities to meet, as this allowed them to bring their own children and to further developed family ties to the next generation. Participants noted that staff members often attend these events even if they are not on duty at the time, and they might bring along their own children. These factors helped develop a greater sense of a family environment. The clients have developed better communication

networks with their own family, for example by linking more frequently with greeting cards, photos of holidays, etc.

The study participants also highlighted the issue of stigma. They felt that the actual institutional environment, and its physical and ecological aspects, had exacerbated stigma, which had now been considerably lessened. They were also conscious of social stigma associated with the institution, which had been viewed by some people in the area as a 'mad house'. As Pert et al, (1999) highlighted, situational factors may lead to heightened awareness of stigma.

Participants perceived that there had been 'a new breed' of nurses trained in recent times, and in their attitudes to care. There was an acknowledgement of the respect and dignity clients receive and the overall approach to care. Consistency of staff, and their familiarity with their family member, was highlighted as important to families. This was seen not only in the care of the client, but also in the creation of the relaxed atmosphere for everyone.

Overall the care received by the clients was seen as equitable and suited to the needs of the client. Families were now treated as important people too, included in care delivery and planning, as well as being involved in such areas as 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 also very evident in relation to the annual plans, which the participants identified, where all people from the family, staff and multidisciplinary team were involved.

Conclusion:

Overall the findings of the study are positive and sit well with the principles of normalisation and social role valorisation. Among the findings, communication and the inclusion of families in the planning and delivery of care were seen as essential. Also, the general philosophy of care based on respect for the individuality of each client (as evidenced in individual care plans and mission statements) was important to families.

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