

## **Promoting mutuality in a family-centred service.**

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### **Abstract**

Fostering mutual relationships, where the expertise of all parties is valued and promoted, is central to providing a supportive environment in a family-centred service. In this article, the nurse manager of a home support and respite service reflects on her working relationship with families to illustrate an example of the complexity of family-centred care and its application in practice.

**Keywords** Family-centred, intellectual disability nursing, mutuality, person-centred, reflection

### **Introduction**

There is a requirement in person-centred care for the formation of particular relationships often described as ‘therapeutic relationships’ between professionals, patients and others who are significant in the patient’s life. These relationships are built on mutual trust, understanding and a sharing of collective knowledge (Dewing 2004). This notion is consistent with McCormack’s and McCance’s (2010) work, which refers to ‘all those involved in a caring interaction and therefore encompasses patients, clients, families and carers, nursing colleagues, and other members of the multidisciplinary team’.

A principal element of person-centred care is mutuality, which acknowledges and supports parents’ competency in the care of their children. As a result, nursing care is provided in the context of the family, where values are known and choices are made (Curley 1997). In a mutuality approach, people and their families are helped to reach their full potential and maximise their abilities to achieve an improved quality of life (Nolan et al 2004).

Person-centred care originated from Florence Nightingale, who deviated from common medical practice by focusing on patients rather than disease. According to Binnie and Titchen (1999), as a result of the evolution of science and medicine, patients became less important than models of impersonal and ritualised activities, which leave little room for addressing and responding to patterns of personal need. The person-centred care approach, in which the person is placed at the centre of family-centred care, is a cornerstone of modern healthcare

services (Shields et al 2006). A person-centred care approach is a philosophy in which the family is viewed as a unit and it is assumed that children with disabilities will progress if the needs of whole families are addressed (Graham et al 2009).

### **Psychosocial educational model**

Since the 1980s, the emphasis of intellectual disability nursing has moved to a biopsychosocial educational model (Sheerin 2004, Doody and Doody 2012) and, as a result, intellectual disability nurse training has moved from a traditional medical-oriented model of nurse education, which has affected the identity and development of intellectual disability nursing (Mitchell 2004, Doody et al 2012). Freshwater and Stickley (2004) argue that a form of education that focuses on rational issues, but ignores the value and development of the emotions, denies the central purpose of the art of nursing.

In the 1980s, intellectual disability public policy in Ireland moved towards community-based services (Department of Health (DoH) 1990, 1996, National Federation of Voluntary Bodies 1996, Government of Ireland 2004, Health and Safety Executive (HSE) 2011). Since then, the range of care settings has expanded, while the value of partnership between service users and their families has been emphasised. However, while about 75 per cent of people with intellectual disabilities reside at home or in community care settings, about 75 per cent of intellectual disability nurses work in a residential institution for people with intellectual disabilities (Sheerin 2004). These figures highlight the need for a shift in how intellectual disability nurses are employed and emphasises the importance of supporting the needs of families of people with intellectual disabilities.

This article explores how an intellectual disability nurse manager responded to the needs of families in a community-based service by promoting mutuality and enabling a family-centred service to operate effectively. The article includes quotes from families, which were recorded during a quality improvement initiative designed to assess parents' and carers' opinions of the service. The body of the article was written from the point of view of the principal author, who was nurse manager of the service, while the introduction, conclusion and overall drafting were carried out jointly by both authors.

### **Service provision**

The service provided home support and respite to families and their children who had physical and sensory disabilities, autism spectrum disorder (ASD) and intellectual disabilities, in the form of:

- Community participation, enabling children to attend mainstream community activities with a staff member on a one-to-one basis.
- Short in-home breaks to assist activities of daily living (ADLs).
- Group activities.

- Residential respite care in the form of sleepover clubs.

As a nurse manager working in the west of Ireland for a voluntary agency, I was employed to develop and deliver the services mentioned above to families in line with best practice in the area. The agency was funded by the HSE to develop and deliver the services.

### **Families' needs**

Some families had children with severe physical disabilities who need a high level of support in all their ADLs. Other families required support because their children had multiple and complex needs, such as epilepsy, enteral feeding and respiratory difficulties requiring ventilation. Other families required support because of their child's ASD and, as a result, had been kept awake when their children became upset because their daily routines had been changed. In other cases, children had communication difficulties that caused frustration, at times leaving families struggling to identify what their child was communicating to them. Some children showed challenging behaviours that sometimes caused fear and upset, and in other families children had rare conditions and had to attend hospital appointments on a regular basis. Some families had attempted to get their children involved in clubs but were faced with a situation where the child would not be allowed to join unless they had one-to-one supervision at all times. Other children needed 24-hour care because of their medical needs that resulted in physical and emotional strain on the family.

To tailor the service to the needs of each family I had to fully engage with family members through an open communication process to explore their requirements. The service involved options for families based on their assessed need. These options entailed:

- Providing a staff member who could ensure the inclusion of children in community activities with one-to-one support on a weekly basis.
- Offering support to families to carry out ADLs.
- Encouraging children's attendance at summer camps with the support of a staff member.
- Providing families with time to spend with other family members while a member of staff attended to care needs.
- Offering full nursing care to families whose children had multiple and complex needs.
- Enabling a child to join a sleepover club that they would attend on a monthly basis.

Parents' comments on the service included:

- 'Without our respite worker we could not survive the demands of our special needs child, which are very stressful at times.'
- 'My caregiver is very flexible. She fits in around my child's hospital appointments and his general health.'

This was a new service, so all forms, including referral forms, assessment forms and service agreement forms, were developed in line with best practice and were sensitive to, and inclusive of, the needs of families with children with intellectual disabilities. From the start of the service, I aimed to include families in all aspects of service delivery where mutuality was fostered and encouraged.

## **Self-referral**

My relationship with the families began after structures that helped parents to self-refer had been set up. Referral leaflets including an overview of the service, its aims and objectives, mission statement and my contact details had been distributed to all disability services, support groups, special schools and stakeholder groups in the area. Referral forms were attached to the leaflets so that families could self-refer or refer with the support of a professional in the area. On receipt of their referral forms, families were contacted within 24 hours by the lead author. I then:

- Introduced myself as the person running the service.
- Took families through the assessment and service delivery process.
- Answered families' questions about the service and the options available to them.
- Arranged to meet families at locations and times convenient to them to complete their initial assessments.

To receive a service, families had to complete an obligatory assessment. I called this the 'gathering of information' after a conversation with a parent who spoke with dread about assessments. I was aware of the amount of paperwork families had to complete and tried to make the process as user friendly as possible. I did this by allaying fears about the process, gathering most of the information by talking to the family member and gently probing when I needed more information. I also spent time with the family, showing interest and concern for the needs of their children and other family members. Through active listening, I encouraged members of the family to share their concerns and discuss openly how the service could best suit their needs.

- One parent said: 'The service is instrumental in the ongoing wellbeing of our child and our other children.' Parents were then asked to read the completed assessment forms and highlight changes or adaptations to the information they had given. These initial meetings with families usually paved the way for continuing relationships based on mutual respect for each other's expertise. After I had gathered information from families on their and their children's needs, a planned service based on the information gathered and the assessed need of each family was implemented. From the outset, families were fully informed about how the service would work for them. They were given my contact details and were assured that I would be available to answer their queries at any time. Subsequently, two parents made the following comments:

- ‘She is always at the other end of the phone. I only phone her when I really need help.’
- ‘The nurse co-ordinator is extremely willing to communicate and be contacted because she provided her mobile phone number.’

I also assured families that, once the service began, I would be linking in by phone and home visits on a regular basis in an effort to continually evaluate the effectiveness of the service to the family. This contact would also help me to build trusting relationships and assist in the identification of shared goals in relation to the needs of the family. By engaging with families and actively listening to their needs in these ways, I could determine the skill set of staff required to support the family and ultimately meet those identified needs. One parent said:

- ‘The staff member is so friendly and all my child’s needs while out of my care are met. His worker has a great understanding of my son’s needs.’

## **Engagement**

More than 150 families now receive a range of services. The structures that were initiated when the service started have also grown and developed. What began as, in some respects, an experimental service delivery based on a limited knowledge of the philosophy of person- and family-centred care, has grown and developed through engagement with families, continued education and a belief system that promotes and fosters the expertise of families as they raise their children and respond to their needs. Less than a month after the service had been launched, more than 40 referrals had been received either through self-referrals or collaborative referrals from families and healthcare providers working together and identifying a need for support. This level of referral indicates how much support is required by families in raising children with disabilities. It also reflected the lack of practical support available to families at a time when we were experiencing the closure of congregated settings and moving more towards community-based support. One parent said:

- ‘This service was provided to my son when we had no support at all and it helped us all. My son became more confident and we coped better.’

During this time, I also became aware how much congregated settings had acted as a buffer system for me as a nurse practitioner. The system had protected me from realising fully the effect children with disabilities can have on how families function. This realisation reaffirmed my decision to engage fully with the process, learn from families and share expertise in an effort to create a service where mutuality was fostered and promoted. Budget constraints had a huge impact on service delivery and, as a result, as a clinical practitioner, I needed to be creative and imaginative within these constraints. By listening to, and engaging with, families we were able to be proactive within the allocated resources, thereby creating services appropriate to the needs of each family. Being present and listening to families allowed this process to develop and my ability to become intuitive to the requirements of

families was enhanced. Throughout the process I continued to question my own engagement with families and reflect on my interactions with them:

- Was I doing enough?
- How could I do better?
- Was the service relevant to the families' needs?

I was also aware that to provide a quality service for families meant that staff working in the area needed to be supported, appropriately trained and encouraged to be the best that they could be. Some of the training provided was mandatory to all staff members, including safer moving and handling of people, first aid and child protection. Other training was tailored to the needs of the family and included:

- Autism awareness.
- The Picture Exchange Communication Systems.
- Lámh, or Irish sign language.
- Epilepsy awareness.
- Positive programming, managing behaviour that challenges.
- Applied behaviour analysis.

I also needed to ensure that I was available for staff to address their concerns, guide them in the service delivery and provide the appropriate training so that staff could engage fully in their roles as family support workers. This process required collaboration between all professionals so I set about fostering those relationships by meeting with early intervention team members, child and mental health team members, and teachers in the special educational facilities, where I discussed the aims and objectives of our remit as a service. There were also times when I thought I would become overwhelmed with the system because of lack of resources, lack of time and an inability to 'fix all'. I realised that some families experienced difficulties beyond our remit where the support we were providing was not enough to meet their diverse needs.

One such family, which acknowledged the effort we were making but was experiencing difficulties, described our service as a 'Band-Aid service' because the support we provided did not match what the family thought it needed at the time. We could only agree. I therefore worked as an advocate with families who had expressed a need for more support, in part by liaising with the HSE and intervention services. Reflecting on my work, there were always instances where I could have dealt with situations better, such as increased collaboration with other care providers to ensure better co-ordination of services to families. The power of reflection allowed me as a practitioner to assess and reassess my interactions with people. Each situation has allowed me to grow as a person and clinician. I intended to create a service that was based on mutual respect with families and my remit was to provide a home support and respite service.

At times, there was conflict and disagreement as my desire to meet the needs of families was not always feasible. However, as a practitioner I did not allow these constraints to affect my

relationship with families and continued to engage and advocate with them regarding their children's needs. These constraints did not always lead to a happy ending, but whether or not I could have dealt with these better is a matter for debate. As a practitioner, my commitment to families remained constant. I enjoyed meeting them, hearing their stories and being with them. I took time and made an effort to get to know families and showed genuine interest in them. I enjoyed being part of their journey as their child grew and moved through life. I continued my commitment to engagement and included families in all aspects of the service. I encouraged and respected their expert knowledge of their child and learned from that knowledge. I was also available to families 24 hours a day, seven days a week to meet and discuss any issues in an effort to promote an open and transparent service.

## **Mutuality**

During the initial stages of the service, I was aware of the philosophy of person- and family-centred care, and a desire to run the service based on mutuality. This awareness was based on reading published literature and research on these areas. As a philosophy, mutuality allowed me to question my beliefs and values in respect of the family, and put these beliefs into practice while engaging with families. I had always considered myself to be a person-centred or family-centred practitioner but did not experience the true meaning of being person-centred or family-centred until I really started working with families. I have learned from families the true essence of 'centredness' and now integrate person and family-centredness in all aspects of my life.

Over time, through my involvement with further education, professional development and engagement with families, I began to bridge the theory-to-practice gap and was able to become a more skilled practitioner, using my knowledge to provide better services to families. This involvement made me more confident and self-aware, and allowed me to deliver services to families holistically. As a registered nurse in intellectual disability (RNID) I had worked mainly in congregated settings but I had the chance to work directly with families. Being invited into families' homes allowed me the opportunity to experience directly the impact a child with disabilities can have on the family. There were expressions of joy and sorrow, there was fun, laughter, tears and sadness. The families I met were at all stages of their journeys with their children, from receiving their initial diagnosis, through transitional periods and into adulthood. I became aware of the frustration families experienced while caring for their child when they told their stories. I listened to the impact on siblings and on parent-family member relationships, both positive and negative. I met families whose children had multiple and complex needs, communication and behavioural difficulties, and families of children with high technology needs, who were all striving to provide the best for their children.

I was often struck by the families' drive to put whatever structures were needed in place for their children and the time that took. I had a mixture of feelings in relation to the service. Staff and families were always respectful of my out of office hours and would only contact

me when a situation needed immediate attention. In general, I was always available to take calls and I worked with team members who were also committed to providing a quality service to families. They could deal with day-to-day enquiries and were able to direct more serious concerns to senior managers in the region in my absence. I wanted to support families caring for their children with disabilities and I wanted to make an impact on that caring role. I was often struck by the fragmentation of services to families where services worked in isolation and I worked at supporting greater co-operation and co-ordination between the various groups. As a result of their child's needs, some families had a large number of professionals accessing their home. Bringing a sense of normality into these homes was a huge struggle for families. The number of appointments some had to attend left little time for self and others. When I reflect on the support provided, I think we helped families to:

- Achieve therapeutic goals supported by therapists, including physiotherapists and occupational therapists.
- Access community-based activities for their children and supported them so they could attend.
- Spend time with other family members by taking over some of their caring needs.
- Try new things, such as introducing children with ASD to activities including swimming and horse riding.

Families were included in all goal-setting activities and were always respected for their knowledge and expertise. The service grew quickly and this stretched resources because the available budget did not match that expansion. This meant I had to make decisions with families about the best use of the service and, at times, draw back on service provision. I found myself constantly on-call to families to fulfil my commitments. But my beliefs and values remained the same in including families in all aspects of service delivery. I had learned so much from them and was continually humbled by their resilience and strength. My intuitive skills had increased and my knowledge of the needs of families was also enhanced. I became frustrated at times when I was unable to meet the needs of families and was always truthful when communicating those frustrations. The budget constraints had an impact on service delivery and were a concern for families because they had come to rely on the service. At the beginning of each year, family needs were reviewed in line with our budget allocation, and this always proved stressful for families. I never made decisions about allocations without first consulting families and they articulated their concerns: 'The fear of losing our respite worker and also the fear of losing or having any hours cut from our allocation 'I live in dread of both as our service is genuinely a lifeline for us.'

This experience of developing the service has changed my knowledge as a nurse and reinforced my belief in the value of the RNID. My skill set, experience and education allowed me to move from working in a congregated setting to a community-based service leading teams of staff. In addition my:

- Nursing intuition allowed me to be creative in helping to meet the needs of families.
- Knowledge of the broad spectrum of intellectual disability enabled me to plan and implement services appropriate to the needs of families.



- Empathic nature as a nurse allowed me to step into the shoes of families and support them on their journey.
- Engagement in reflective practice allowed me to look back on situations in a humanistic way and learn from that reflection.

I continue to believe that parents are the experts in their child's care and that we, as nurses, can learn and grow from listening to families, supporting them in caring for their children and advocating for them. I believe RNIDs are in an ideal position to take leading roles in community-based services working towards inclusive practice, equality and participation for people with intellectual disabilities.

## **Conclusion**

Families of children with an intellectual disability find themselves on a different journey to the one we all hope for and dream when we have children. To be family-centred practitioners, intellectual disability nurses should educate themselves in the philosophy of person- and family-centred care, and question their own beliefs and values in relation to its practice. Reflection is an important element to being person and family-centred and should therefore become an integral part of the intellectual disability nurse's practice. Continued education is also an integral part of the development of family-centred practitioners. As nurses, we need to recognise that each family we meet is different, and has strengths, abilities, coping styles and coping mechanisms. We should learn about how each family functions and take their lead to support their ways of coping. We should also get to know families and their children. To avoid 'Band-Aid' services we should encourage and embrace collaboration between family members, their local community and other service providers, thereby becoming truly person and family-centred in our approach.

In Ireland, the National Disability Strategy Towards 2016 – Strategic Document (Department of Health and Children 2009) has as a high-level, long-term objective: to acknowledge and support carers in their caring role. For this to occur, we need to work in a family-centred way with mutuality as a core principle of our practice. While Ireland has recognised a lack of individualised service provision (Expert Reference Group on Disability Policy 2011), there is a greater emphasis on community services in recent years. In addition, Time to Move on from Congregated Settings: A Strategy for Community Inclusion (HSE 2011) identifies a need to move beyond congregated settings in Ireland and adopt a new model of support driven by values of equality, the right of individuals to be part of their community, to plan for their own lives and make their own choices, and to get the personal support they need for their independence.

Such expectations are underpinned by legislation, policy and person-centred planning tailored to individual's needs, where wishes and choices are advocated. The DoH (2012) recently published Value for Money and Policy Review of Disability Services in Ireland, which proposes a fundamental change in approach to the governance, funding and focus of disability services provision from the traditional approach predominantly centred on group-

based service delivery, to a model of person-centred and individually chosen support. This recommended model of support should be underpinned by a more effective method of assessing need, and allocating and monitoring resources used, thereby supporting individuals to remain in their communities and upholding their rights. Fundamental to upholding the rights of people with disability is having a truly person-centred service accompanied by a family-centred approach that enables the person with disabilities to fulfil their wishes and dreams

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