The experiences of registered intellectual disability nurses caring for the older person with intellectual disability

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Abstract

Aim and objectives. To explore the experiences of registered intellectual disability nurses caring for the older person with intellectual disability.

Background. Increased longevity for the older person with intellectual disability is relatively a new phenomenon with social and medical factors having significantly increased the lifespan. The ageing population of people with intellectual disability is growing in Ireland, and they are outliving or expected to outlive their family carers.

Design. A qualitative Heideggerian phenomenological approach allowed the researcher become immersed in the essence of meaning and analyse how registered intellectual disability nurses working with the older person perceive, experience and express their experience of caring.

Methods. After ethical approval was granted, data were collected through semi-structured interviews from seven participants and were transcribed and analysed thematically using Burnard’s framework for data analysis.

Results. Three key themes were identified: ‘care delivery’, ‘inclusiveness’ and ‘client-focused care’. The study highlights the need for effective planning, an integrated approach to services and that the registered intellectual disability nurse needs to be integrated into the care delivery system within the health service to support client and family carers in the home environment.

Conclusions. Overall, the study shows the importance of teamwork, proactive planning, inclusion, attitudes, individualised care, knowing the person and best practice in providing care for older people with intellectual disability.

Relevance to clinical practice. This paper reports on the findings of a study which explored the experiences of caring for the older person with intellectual disability. Teamwork, proactive planning, client-centred approach and supporting clients living at home are important as ageing is inevitable.

Key words: ageing, intellectual disability, nurses experience, older person

Introduction

Ageing with a lifelong disability is relatively a new phenomenon illustrated by dramatic changes in life expectancy for people with intellectual disability (Carter & Jancer 1983, Bigby 2004). This phenomenon was first highlighted in the United States in the 1980s because of the growing number of older people with intellectual disability outliving their family carers (Fisher 2004). This increased longevity is resulting in nurses coming into contact with ageing people with intellectual disability, and the need for information about
ageing for adults with intellectual disability is intensifying (Service & Hahn 2003). Knowledge of age-related change is vital to mobilise action to slow its occurrence or minimise its impact through appropriate individual or environmental adaptation and compensation. However, often general assumptions are made that physical decline or poor health is attributable to the impact of ageing, thereby little cognisance of the fact that individuals with intellectual disability are more likely to suffer from health problems than persons in the general population (O’Hara et al. 2010). Therefore, the responsibility shifts onto RNIDs to recognise atypical symptoms such as challenging behaviour that could be indicative of an underlying health problem and support people with an intellectual disability maintain their health.

**Background**

In Ireland, 26,066 people were registered on the National Intellectual Disability Database (2009) by Kelly et al. (2010) an increase of 37% since the 1974 Census. Proportionately, the number of people over 35 with intellectual disability has increased from 29% in 1974 to 49% \( (n = 12,773) \), reflecting an increased lifespan (Kelly et al. 2010). This changing age profile has implications for service planning, including a demand for full-time residential services, support services for ageing caregivers and services designed specifically to meet the needs of older people with intellectual disability (Bigby 2004). Irish government policies have highlighted the need for appropriate services for individuals suited to their needs (Commission of Inquiry on Mental Handicap, Government of Ireland 1965; Planning for the Future, Government of Ireland Department of Health 1984; Needs and Abilities, Government of Ireland Department of Health 1990; Shaping a Healthier Future, Government of Ireland Department of Health 1994; Quality and Fairness, Government of Ireland Department of Health & Children 2001). However Jacobzone (2000) and Tolson et al. (2005) recognise that meeting the health and social-care needs of the ageing population is challenging, particularly those requiring long-term care. RNIDs have a multifaceted and crucial role in meeting care needs (Alaszewski et al. 2001, Sheerin 2004) and have the potential to become agents of inclusion as they work at the very heart of initiatives to develop services for people with intellectual disability (Gates 2006). Within the RNID role direct care, care management and administration, liaison work and educational activity are underpinned by the promotion of client autonomy (Long & Kavarian 2008). However, while there is a call for evidence-based care (Moulster & Turnbull 2004), there is a dearth of studies on the experiences of RNID particularly in caring for older person. Additionally, Gates (2006) identifies people with
intellectual disability view the RNID as possessing specialist knowledge, and appropriate knowledge, skills and attitudes are vital in providing a holistic person-centred approach to care delivery. Given that intellectual disability nursing is unique to Ireland and the UK, nurses within the discipline need to create a sound accessible research base highlighting the needs and effective care strategies (Griffiths et al. 2007). Therefore, the essence of intellectual disability nursing should be to endeavour to capture and illuminate the very heart and kernel of care to create an evidence-based quality service worthy of underpinning care (Doody et al. 2012). To fulfil this, it is essential that RNIDs working with older people identify the growing complexities and challenges working with this population group and provide strong leadership to remain viable as a profession and continue to serve people with intellectual disabilities (Northway et al. 2006).

Methods
Aim
The study aimed to explore the experiences of RNIDs caring for older people with intellectual disability.

Research design
In accordance with the study aim, a qualitative phenomenological approach was chosen, as it is considered appropriate in examining the qualities of human experience (Balls 2009). Within the phenomenological approach, the participant is recognised as the expert in relation to the phenomenon under enquiry, and while the researcher may know the literature and theories, they do not know the relevant dimensions of the experience being reported by the participant (Giorgi 2006), thereby allowing the researcher access the participant’s lifeworld to gain a deeper understanding of their experience (Balls 2009). Ethical approval was obtained from the Ethics Research Committee of the organisation, and access was sought from the director of nursing to the research site.

Participants and recruitment
A purposive sample of RNIDs working in a long-established voluntary service providing community and residential services (n = 20) were mailed an information leaflet and invitation letter to participate in the study. All participants were qualified over two years and had at least one year’s experience working with the older person with seven participating in the study. The participants comprised of men and women, of nurse and nurse management grades and day and night staff. Written informed consent was obtained, and confidentiality was protected; participants’ had the right to withdraw at any time without prejudice. Table 1 lists the demographic details of the participants.

Table 1 Demographic details of the participants

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<th>Education</th>
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<td>Nursing Certificate (RNID) and a certificate in palliative care</td>
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<td>Nursing Certificate (RNID) and a certificate in management</td>
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<td>Nursing Diploma (RNID) two participants</td>
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<td>Nursing Degree (RNID) two participant</td>
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Nursing Post-Graduate Degree (RNID) one participant

| Experience                                      | Ranging from 10–25 years in caring for people with intellectual disability  
|                                               | Ranging from 3–10 years caring for older people with intellectual disability |
| Gender                                         | Two males (James and Mike)  
|                                               | Five females (Ann, Mary, Joan, Marie and Jackie) |
| Position/grade                                 | Two nurse managers  
|                                               | Four staff nurse (day duty), One staff nurse (night duty) |

**Data collection**

Data were collected by interviews using a semi-structured qualitative approach in a venue of the participant’s choice, lasting 60–90 minutes and audio-recorded to allow for transcription. Interviews were aimed at exploring the participant’s experience of caring for older people with intellectual disability and were transcribed verbatim and as analysis progressed questions related to emerging themes were added. However, it is worthy to recognise that data may have been influenced by the fact participants were known to the first author.

**Data analysis**

The first author conducted the interviews, and the process of data analysis followed Burnard (2006) thematic analysis framework that is widely used in nursing research. This involved six steps: taking memos after each interview, reading transcripts and making notes of general themes, repeated reading and generating open-coding headings to describe all aspects of the data, reducing the codes under higher order headings, returning to the data with the higher order codes and collating the organised data for reporting. Two members of the research team reviewed the transcripts independently, and findings were compared and discussed until consensus was reached.

**Results**

Three key themes emerged from the data: ‘care delivery’, ‘inclusiveness’ and ‘client-focused care’. Themes were formulated by placing meaning on the participants’ statements and organising the meanings into themes. The themes and subthemes are highlighted in Table 2. Some of the themes have overlapping elements, and some of the statements may highlight more than one theme as narrative material is generally nonlinear (Polit & Beck 2010).
Table 2 Research themes and essences

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<th>Theme</th>
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<td>Care delivery</td>
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<td>Inclusiveness</td>
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<td>Attitudes to clients with intellectual disability</td>
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<td>Services for older people with intellectual disability</td>
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**Care delivery**

Participants expressed the importance of teamwork, proactive planning and family involvement as crucial components of caring for the older person.

**Teamwork**

Teamwork was seen as essential by participants in the provision of quality care, and all acknowledged the pivotal role the RNID plays in that process:

If you get new staff in the team they need to be cosseted along and most crucial is that the RNID spear head the team. (Ann)

However, some participants felt their input in care planning was not valued, and RNIDs need to be more involved in care planning:

The RNID is with the person, whereas other team members haven’t the same twenty-four hour service, so the RNID plays a big part and needs to be involved more rather than been overlooked by the team, it’s frustrating when the person is declining and your opinion is not considered, nor listened to, it took a doctor (named location) to say that what I was saying was right and now all systems are in place. (Joan)

This frustration was identified as something that can affect confidence in practice leading the RNID to question their knowledge and skills in practice:

You think am I too pushy, am I going way too quickly with this and you think maybe I’m a bad practitioner because I want to talk about death when the person is still alive, and then
someone comes in and reinforces you’re on the right track, you can become de-skilled from working in that environment, it takes your confidence. (Jackie)

This frustration and lack of recognition often lead to feeling angry, but participant recognised the team has a significant role to play in providing care:

When you’ve seen something in the elderly person and brought it to the attention of the team you’re often turned aside, it makes me angry because I trained as an RNID, I’ve years of experience, I see them regularly, but while it’s a battle the input required from the multidisciplinary team is more as they age and we recognise this. (Mary)

**Proactive planning**

While smaller numbers and homelike environments are incorporated into today’s services, participants felt services do not always focus on the inevitability of ageing clients:

Mobility is a big thing it’s decreasing as one gets older and there are certain aspects that really need to be looked at before it’s too late, service is blind to the fact they are ageing. So we all have to think of what’s happening now and what’s going to happen down the line as facilities weren’t put in to allow for someone ageing so you constantly trying to adapt the environment. (Mike)

The RNID is a valuable resource to consult with relating to future planning; however, there is a concern that this is not occurring:

I’ve never had the experience that I would have been involved in planning the environment, or planning for the future needs, I feel they don’t consult nurses who know the clients. (Marie)

Participants articulated that the older clients present with more complex healthcare needs: I worked with a younger age group and there wouldn’t be quarter of the health issues that we would see with the older clients and you need to plan and anticipate more. (Ann)

**Family involvement in care**

Participants identified the support from family members and their input as fundamental in care provision, highlighting the importance for healthcare professionals to encourage effective communication with the family during care planning:

Family input is vital, we welcome and applaud it and keep families informed of everything, we acknowledge what they do and try to keep all doors of communication open, their input can sometimes get things done so much faster, if they push, it happens. (James)
Family input was highlighted as having a visible impact on the client’s emotional well-being:

They have a reason for perking up and been brighter it’s for family and you know they are delighted to see them. (Mary)

**Inclusiveness**

Participants viewed inclusion within society as a crucial element in being valued members of their community. Consequently, this familiarity and presence may improve societal attitudes. Participants also expressed that services need to be age-appropriate, develop supports in retirement, loss and bereavement, thereby allowing for normal life course. Conversely, services need to embrace community support as a two-way process facilitating the RNIDs integration into community services and supporting family carers.

**Inclusion**

All participants commented on inclusion as a major part of their role in promoting the clients integration within society, relating to activities and using aged services:

They should do normal things that any elderly person does, go out for meals, go to concerts, go to bingo, those types of activities and pastimes and be brought in more with other elderly people. (Joan)

However, participants acknowledged that there were many potential barriers to inclusion such as staffing levels and expressed frustration regarding reduced staffing levels as it prevents staff incorporating positive initiatives that promote inclusion:

If you have a large group with fewer staff, you have less opportunities for going for walks, going to different social venues, maybe joining a gym, joining clubs, meeting different people, their whole life changes socially with that one aspect. (Jackie)

Participants wanted a greater emphasis to be placed on preparing other nursing specialisms to care holistically for clients, given there is a greater potential for older people with intellectual disability to access acute services. They saw student nurse training as an area that could be developed to allow greater exposure to people with intellectual disability:
Student nurses only come here for a week if they are lucky it’s not enough, our students do so many weeks in a general hospital and mental health placements then those students should be doing the same in intellectual disability. (James)

Participants identified that the RNID role needs to develop to support clients living at home been cared for by aged carers:

There are clients at home and even though they’re getting the best of care and their parents are brilliant with them the help of an RNID would open pathways and support them. (Marie)

Attitudes to clients with intellectual disability Participants commented on the importance of seeing the person rather than the disability expressing that this was not always the case in society at large:

Anything the normal community has, intellectual disability elderly people should have, allowed or join and there wouldn’t be this fear, this dread of a house being built/bought in the middle of the community for people with disability. (Mike)

However, participants acknowledged that there have been some improvements in attitudes of people to clients with intellectual disability:

I think there’s a perception you can change attitudes but it takes literally generations to change attitudes and today’s attitudes are better than they were twenty years ago. (Mary)

However, there was frustration with the lack of knowledge and understanding of some healthcare professionals within the healthcare sector, where healthcare professionals only see the disability and have no desire to learn about caring for the older person with intellectual disability:

They look at their disability and the person behind the disability is not seen they don’t give the time or wish to understand the client. (Ann)

However, these negative attitudes can have a positive outcome for the individual:

They view our ladies as been more prone to having complications and that’s why, we get the care as soon as we need. (Jackie)
The RNID holds a unique attitude regarding dignity, respect and personhood of the individual which is seen as the cornerstone of care. In caring, the RNID respects each individual and always sees the person as separate from the problem or behaviour leading to a positive unconditional regard:

They all have their good days and bad days. You don’t blame them for being in bad form; they can always take out their bad form on us that’s not a problem. (Mary)

Participants also identified a unique sense of pride and commitment to the care and a willingness to explore all avenues to meet the individual’s needs:

‘We’ve not rigid in our care, we’ll try anything. We will take service users anywhere, anything for new experiences, anything to try help with whatever difficulties arise. (Marie)

**Services for older people with intellectual disability**

Participants identified that service provision needs to differ for older individuals and activities need to be implemented at a slower pace, age appropriate and meaningful:

The elderly are a different group, things need to be slower we have to think would you do that with your mother or granny, so we think age appropriateness we have to think activities, maybe slower mundane activities and they will let you know if it’s suitable as they must gain enjoyment from the activity. (Joan)

Retirement was seen as an important aspect to aged services but not fully in operation at present. Participants acknowledged that retirement should be an active process rather than a withdrawal from activities and guided by the service user’s abilities:

There comes a time when you wind down and if you have an intellectual disability it isn’t any different. They should retire but still do things, retired people do things, they go travelling, bowling, for nice walks and other things. (Mike)

The value of reminiscence was identified as a positive aspect of caring for the older client and could contribute to the life of an individual:

Certain clients would be able for reminiscence therapy, just even sit down and have a one to one chat, where they came from and their family. This means more to them and the family and a group could be really fostered in that setting. (Ann)
It was identified that as life is a cycle from the cradle to the grave, the RNID has a valued role and important role to play in interpreting the needs of the individual in this area. One factor acknowledged was the aspect of loss that the person with intellectual disability may experience and while it is difficult to truly have an insight into the person’s feelings/experiences one does need to be always aware of all possibilities:

As they age and either visits home are less frequent or the parents have passed away, we see the knock-on affect of that daily because they cannot understand where the family connection has gone. We will never truly realise how it affects them, a normal person grieves, but you need to think how they grieve and we can miss out on that, there should be more on bereavement because we don’t really know whether it’s a physical ailment or a loss as to why there’re going downhill. (James)

**Client-focused care**

The aspect of client-focused care was expressed by participants who acknowledged that knowing the person assisted them to tailor care to meet the needs of the individual. Although person-centeredness was acknowledged as desirable, participants felt restricted in its implementation.

**Individualised care**

The aspect of individuality was a core concept of caring expressed by participants identifying that the client always comes first:

I always deal with everyone as one person I think that comes with experience. (Ann)

Service provision and environmental aspects to care have developed to enable an individualised approach to be fostered, incorporating personal aspects that allow for individuality such as personal belongings. However, while services have developed in the light of individuality, it remains an insidious process with not all areas benefiting equally:

Coming from big wards with clients all together they did not have personal clothing or personal belongings and may not have had activities. They have now been given the chance in life to have some ownership of their lives. They have their, own rooms, own belongings, own clothes, own routine. They have a say in careplanning and their families are able to visit them in this nice environment but there’re units that don’t have this. (Joan)

Central to the aspect of individuality was individual programme plans (IPPs) used across the service in conjunction with each client’s individual care plan. While care plans give structure
to care through assessment, planning, implementation and evaluation, the value of IPPs is in ensuring the individuality of each client and bringing team members together starting with the client, their family, nurses and MDT members:

We set goals during the IPP that the client would be able to achieve, it is invaluable as it brings the people who look after him/her together, the family, MDT, nurses once in the year and the client will be there and part-take. (Marie)

While person-centredness is fundamental and desirable, participants acknowledged the limitations that exist while implementing person-centred care, such as client numbers, and the fact that nurses on their own cannot deliver on person-centredness without a whole service approach:

We’re only touching the tip of the iceberg in relation to person-centeredness. We do our utmost in choice, in documentation, in family involvement, but we would need ten times more staff to do what possibly could be done for each service user to fulfil their dreams, we do the best we can with person centeredness at the core. (James)

One participant acknowledged the lack of understanding about person-centred care as a potential barrier to its implementation, suggesting the need to adopt a universal approach across the organisation:

One of the greatest barriers is the lack of understanding of personcenteredness. People think that the nurses are the only people to be person-centred but everybody from the maintenance man, cook, household staff and the team all have to be person-centred. (Ann)

**Knowing the person**

A central aspect raised during the interviews was the aspect of knowing the person. This was deemed essential in identifying asymptomatic signs of ill-health, identifying needs and interpreting non-verbal communication:

Their health is determined by the staff being observant and knowing them, because if you have new staff, they’re not going to know that the outburst they had today is completely different to what they had a month ago, or the person sitting there doesn’t always sit that way, if you don’t have familiar staff small things slip through the net, they don’t get picked up, be they health issues or otherwise you need familiarity. (Mike)

However, participants identified staff turnover as having a negative impact on client care:
I know you have to move, but I think they should consider the elderly person when they’re moving staff because it can be a loss and like a depression in a way, it should be done on a gradual basis and they should always have one or two staff that are solid, that are permanent, that have been with them and knows them inside out, because it makes a difference. (Joan)

The aspect of knowing the person as unique and privileged was acknowledged by participants:

It is a unique, privileged position to be in and I suppose for me that’s why I stick with this type of nursing, because that’s inherent in it and I think it’s really because we are RNIDs that we’ll stick with a thing because we know the client and what’s right for them and we don’t lose sight of that. (Jackie)

However, the diversity in the range of disabilities and care situations is vast and varied as people with intellectual disability may have complex multiple health needs that need to be addressed from a holistic perspective encapsulating the bio-psycho-social educational model of care:

You have the spectrum in every area that you go, you get the whole spectrum from the; client, family, emotional, mental health, communication issues whereas when you are working in a general area you’re dealing mainly with physical ailments. (Mary)

**Best practice**

It was acknowledged that best practice is a goal that all RNIDs strive for and is something that is endless as one tries to deliver care:

Evidence based practice plays a big role, first of all it safeguards the nurse but we are the people that are starting the new practice because we have the older clients, everything has to be evidence based especially now with the new format for training students and for accountability. (Mike)

While best practice is a constant aim, participants feel they will continue to be guided by experience and then grounded by education and research literature:

It’s a combination of your academic study on that person, your professionalism in getting to know that person. But really and truly it is your day-to-day work, working with that person on a physical, intellectual and intimate level. (Mary)
It was also articulated that many opportunities exist to create best practice and action needs to be taken to capture these opportunities by engaging in further research on the care need of the older person with intellectual disability:

The amount of studies in the area are small, it’s an area that needs looking at and the more it is studied the more use you will get out of it and we have to start selling our uniqueness and stick to it; we know the clients better and we shouldn’t just sit back. Nurse managers have to be more proactive, people get bogged down in the day-to-day work and there’s not enough scope for academia and not enough opportunities given to nurses to do training. (James)

Discussion
People with intellectual disability are living longer with factors such as better health care, evidence-based medicine and environmental factors contributing to their increased longevity (Emerson & Ramcharan 2010). With increased longevity come additional health needs and multiple chronic conditions, often requiring increased collaborative interventions (World Health Organisation 2003). While Jenkins et al. (2006) identify a wide range of professionals involved in the provision of services, Hickman et al. (2007) recognise families know the person best and their involvement results in a wealth of information that positively influences care provision. Additionally, the findings of this study reiterate the positive effects of family involvement in care, emotional well-being and advocating for services. Therefore, family’s perspectives should be acknowledged and valued as an integral and valuable part of care planning. This teamwork involving family, client and healthcare professionals is essential in providing quality care, meeting individual needs and providing a seamless service for the client (Thompson & Pickering 2001). RNIDs need to support families at home as family carers play an essential role in care provision, thereby safeguarding the health and well-being of the family as a caregiver unit (Jeon 2004). This is essential as families who have not needed support in the past need considerable help and input at home as family carers age (Gilbert et al. 2008). The support of an RNID in the community would assist generic services who lack the knowledge and experience of caring for people with intellectual disability (Doody et al. 2011). The health of this population can only be improved by a combination of primary prevention, early detection, treatment and a willingness for health and disability sectors to work together to achieve positive health outcomes (Webb & Stanton 2009). However, for a team to be effective, all members need to be a valued member, and personal contact is not enough to facilitate effective working relationships, rather there needs to be equal status between members (Jenkins et al. 2006). The RNID is vital in the collaboration of
care and needs to be reflected in attitudes, practices and partnerships with others, and therefore, continuity of care and effective teamwork requires more proficient communication with the RNID adopting a leading role in collaboration and care planning (Hart 2002, Gates 2006), with service providers acknowledging the inevitability of an ageing client group (Bigby 2010a) and not been tempted by short-term, inexpensive solutions (Proctor 2000).

Successful ageing must be prepared for long in advance; a happy old age is the criterion and reward of a well-conducted life (Ouwehand et al. 2007). The RNID should ensure each person has a tailored made health plan that identifies their health status and risks, based on their individual needs, which is updated at regular intervals or transition points (Department of Health 2001). For this to occur, RNIDs need to engage the client and their family in designing the health plan and address aspects such as ageing in place, which considers future plans for care provision and support (Forbat 2006, Bigby 2010b). This is essential as older people with intellectual disability remain vulnerable to premature and often inappropriate admission to residential aged facilities (Bigby 2010b). Here, the RNID operates within a person- and family-centred approach, ensuring they advocate for the needs and desires of the individual along with empowering the client and family within decision-making.

Recent literature to define health indicators for people with intellectual disability includes the Pomona Project in Europe (Walsh 2008) and the National Core Indicators (NCI) project in the United States (Bradley & Moseley 2007). Health checks have been recommended internationally, and RNIDs need to ensure health checks are conducted with this vulnerable group. While health checks from the general population have been used or adapted such as the Comprehensive Gerontological Assessment (CGA) and others have been devised for adults with intellectual disability such as the Cardiff checklist (Baxter et al. 2006) and the Comprehensive Health Assessment Program (CHAP) (Lennox et al. 2004), the RNID continually needs to consider these in relation to their applicability to the range of disability and cognitive function of the individual been assessed. Others such as Ruddick and Oliver (2005) developed a self-reporting health status measure for people with intellectual disability, and Fender et al. (2007) developed a health assessment based on the CHAP to include self-defined health and consider functional age. However these tools need further evaluation before assertions of general applicability can be made.
The mission of the RNID workforce is to meet the needs of an increasingly diverse population in an ever-changing healthcare environment, thereby intellectual disability nursing will always need to redefine and redesign itself to ensure its practice is meeting the changing needs of individuals and their carers (Department of Health & Children 2002). Gates (2006) suggests this may be achieved through person-centredness that focuses on what is important for the person now and for the future and acting upon this in collaboration with the person’s family and friends. Society and clients demand high-quality care based on evidence requiring an urgent development of various strategies for the implementation of evidence-based practice (EBP), implying challenges for several key groups including the RNIDs who have an important task to develop organisational strategies to realise EBP (Bostrom et al. 2006). As nurses, the RNID needs to enhance health status, longevity, functional ability and quality of life of ageing adults with intellectual disability. This can only be achieved by increasing information resources and staff reading habits, and despite the noted phenomenon of the ageing population, old age has only recently been conceptualised as a separate and distinct life stage for people with intellectual disability. Thereby, the RNID is often limited to evidence regarding physical health issues based primarily on generalisations form clinical and research findings on the general population and adults and children with intellectual disability (Prasher & Janicki 2002). Nevertheless, the RNID can use evidence from a range of other academic disciplines (Gates & Atherton 2001, Mitchell 2004), but the benefits of having a defined body of knowledge in nursing the older person with intellectual disability include better client care, enhanced professional status for nurses and guidance for research and education (Newell & Burnard 2006).

This study highlighted the aspect of individuality as a core concept of caring. McCormack (2003) emphasises that the nurse must be able to particularise the person, who that the person is, the relationship that exists between them and the client and the understandings and expectations implicit in the relationship. Turnbull (2004) and Brewster and Ramcharan (2010) recognise knowing the person as a central aspect of nursing practice and constitute a unique contribution to quality client care where clients are recognised and treated as individuals, which is a strongly held value of the RNID. Thus, knowing the client evolves from the interrelationship of competent communication and accuracy of understanding that are crucial and a vital component of everyday nursing (Finch 2004), which is crucial in predicting a client’s pattern of clinical responses, thereby enabling nurses to make accurate clinical decisions (Morrison 2011) and implement nursing interventions in a supportive
manner that positively affect client outcomes (Simmons et al. 2003). Individual programme plans play a vital role in care delivery, and regular evaluation of care is vital to good practice (Turnbull 2004). Measures of progress can be evaluated, which consequently instil a sense of enthusiasm in families while also revitalising and motivating the nurse. However, limitations such as environment and staffing have a significant impact on care delivery despite an intention to consider client and nursing values (McCormack et al. 2002, Rycroft-Malone et al. 2002). At a time when nurses stretch their professional efforts given the nursing shortages and numerous understaffing issues, it is more significant than ever that nurses understand the importance of their communication (Finch 2004). Transformation of practice is not just a matter of changing individual practitioners alone but discovering, analysing and transforming the social, cultural and environmental conditions under which their practice occurs (Carr & Kemmis 2005,). This study identifies that best practice was a goal that RNIDs strive for and that experience and research were facets that complement each other in that process, also highlighting the need for RNIDs to value practice and create evidence from the networking of information with others. Many nursing issues impact on the quality of care of the older person including nurse’s attitudes, lack of expertise and lack of nursing education in older person care (Lewis & Stenfert-Kroese 2010). However, given the current economic climate/environment, the on-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, and thereby, the RNID has a vital role in developing and supporting the older person and publishing their efforts. In addition, there has been a review of disability services under the value for money and policy review initiative 2008–2011 in Ireland, and given the current economic downturn, one may be concerned that such improved outcomes may not be valued against financial savings (Doody 2012). 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). Thereby, 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), thus reinforcing the RNID role in care provision for the older person.

There is a necessity for active retirement rather than traditional approaches where, as one ages, they were treated as vulnerable, non-productive adults requiring care (Llewellyn et al. 2004), thereby promoting their rights to retire and lead a more relaxed lifestyle (Bigby 2010a). While loss and bereavement support is essential, McEvoy et al. (2010) identify that
healthcare professionals may think they have the skills and resources to support someone who has been bereaved but in practice find it is an area with which they are unfamiliar. Services may have to consider referral to bereavement counselling services where the specialist skills of trained bereavement counsellors are acknowledged. Additionally, while understanding the feelings and experiences in coping with loss is dependent on familiarity and knowing the person, Hollins and Tuffreu-Wijne (2010) recognise that sensitive and timely support is possible but only achieved if everyone works closely and actively together with the individual at the heart of all initiatives. This collective working is vital as people with intellectual disability may express symptoms behaviourally rather than in words, and grieving is recognised as lasting up to two years.

**Conclusion**

Healthcare for older people with intellectual disability will present enormous challenges for services. To considerably improve clients’ quality of life, services need to carefully consider a pragmatic view of the issues and develop realistic, proactive and responsive strategies. However, this is achievable only if RNIDs are enabled to take a leadership role and provide direction for new strategies. Nevertheless, the RNID needs to focus on breaking down professional boundaries and the issues involved in collaboration with different agencies, with the ultimate aim of providing a seamless service that is needs based. Service philosophies have encouraged people with intellectual disability to cast off their dependent state by developing a variety of skills and adopting valued social roles; however, if services fully embrace the principles, then one would expect this client group to use ordinary generic services. However, intellectual disability is a complex condition with many associated pathologies. Most integrated care initiatives have a disease-specific approach that may not be directly translatable to individuals with multiple needs. Therefore, generic services will need to be informed, supported and have access to specialist support to inform these services of the complex range of health issues in the older person with intellectual disability.

**Relevance to clinical practice**

- People with intellectual disability are living longer.
- This research explores the experiences of registered intellectual disability nurses caring for the older person with intellectual disability.
- Teamwork and proactive planning is essential as ageing is inevitable.
• Supporting clients living at home places an onus and responsibility on services to facilitate home visits.
• Client-centred approaches to care based on best practice are warranted.

References


