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Families' perceptions of the contribution of intellectual disability clinical nurse specialists in  
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**Title** – Families perceptions of the contribution of intellectual disability clinical nurse specialists (ID-CNSs) in Ireland.

## **ABSTRACT**

**Aim and objectives.** To explore families perceptions of the contribution of clinical nurse specialists (CNSs) in intellectual disability nursing in Ireland.

**Background.** CNS roles have developed over the years and are seen as complex and multifaceted, causing confusion, frustration and controversy. 2001 saw the formal introduction of CNS roles in Ireland across nursing including intellectual disability.

**Design.** A exploratory qualitative approach utilising semi-structured one-to-one interviews with 10 family members regarding their perceptions of the CNS in intellectual disability.

**Methods.** Data were audio-recorded, transcribed and analysed using Burnard's framework. Ethical approval was gained and access granted by service providers.

**Findings.** The study highlights that intellectual disability CNSs contribute and support care deliver across a range of areas including; personal caring, supporting and empowering families, liaison, education and leadership.

**Conclusions.** CNSs have an important role and contribution in supporting families' and clients, and Ireland is in a unique position to develop knowledge regarding specialist care for people with intellectual disability that can be shared nationally and internationally.

**Relevance to clinical practice.** Ireland is in a unique position to develop knowledge regarding specialist care for people with intellectual disability that can be shared and adapted by other healthcare professionals in other countries that do not have a specialised intellectual disability nurses.

**Key words:** Clinical nurse specialist, intellectual disability, Ireland, families, service delivery

## **INTRODUCTION**

While CNS roles are recognised internationally (Kilpatrick *et al.* 2016) the role is broad, ambiguous and individualized (Colwill *et al.* 2014). Essential components within the CNS role include direct clinical, practice, education, consultation, research, professional leadership and ethical decision making (Sparacino 2005). In Ireland CNS roles developed in 2001 focusing on the core concepts of client focused, advocacy, audit/research, education/training and consultancy (National Council for the Professional Development of Nursing and Midwifery 2008). CNSs improve practice and service delivery by integrating their specialist knowledge, skill and research evidence (Lewandowski & Adamle 2009, Bryant-Lukosius *et al.* 2015), to support evidence based practice and improve quality of care (Begley *et al.* 2013) and provide safe effective care across a wide range of settings (Newhouse *et al.* 2011). CNSs spend varying amounts of time in each component of their role (Kilpatrick *et al.* 2013, Colwill *et al.* 2014). These variations in time spent within each component of their role may reveal how CNSs adapt their practice and respond to the needs of patients, organisations and health systems (Kilpatrick *et al.* 2016).

Evidence regarding CNS role effectiveness mainly relates to clinical aspects of their role and from acute care settings (Bryant-Lukosius 2010). However, little is known regarding their work with people with intellectual disability (ID) and in this incident Ireland is in a unique position as it holds the specialist discipline of intellectual disability nursing (training, education and practice) and CNSs within the discipline. This creates an opportunity to highlight the work of ID-CNSs, making their role visible

and contributing to the knowledge base, as CNS roles are often poorly understood by stakeholders, including decision makers, regulators and members of the healthcare team (DiCenso *et al.* 2010). This paper focuses on ten families' of persons with intellectual disability aged 4 to 19 years and their perceptions of ID-CNSs and their contribution to care/service delivery. Areas of practice families were in receipt of were; behavior, health promotion, school, early intervention and community CNSs.

## **BACKGROUND**

Given the fact many countries do not have specifically trained intellectual disability (ID) nurses the uniqueness of the ID-CNS role presents opportunities for research activity, knowledge creation and professional development. Accordingly given consideration to ID-CNS roles will increase clarity and common understanding of the role this then will support policy formulation and role implementation. This is essential to highlight the work of ID-CNSs and make their contribution visible as the development of the clinical career pathway of ID nursing has not occurred in a comparable manner as that of the other nursing disciplines (Doody *et al.* 2012).

With ID service provision models focused on the closure of congregated settings (HSE 2011) consideration needs to be given to families and their perspectives within the care process. ID-CNSs draw similarity to community learning disability nurses (CLDNs) in the United Kingdom (UK). However, unlike the UK, Irish ID-CNSs were predominantly based in congregated settings reflecting the traditional service model in operation, where people with ID lived at home and attended a day-service within a congregated setting or resided on campus. As we move towards community based services for people with ID in Ireland, there is a greater need today and in the future for more coordinated collaboration between various multi-professional groups and agencies (i.e. statutory,

voluntary, ID and non-ID providers) as a means of improving services. By improving services there will be natural improvements in the quality of life of the individual and families using such services. CNSs play a vital role in ID services and require strong leadership skills to coordinate groups of professionals to serve people with intellectual disability (Northway *et al.* 2006).

## **METHODS**

### **Aim**

To explore families perceptions of the contribution of intellectual disability CNSs in Ireland, through gaining insight, giving recognition and acknowledging the personal experiences of families and supporting a holistic view of CNSs contribution.

### **Research Design**

The purpose of the interviews were to explore families perceptions of service provided by CNSs in a dynamic and interactive manner (Schultze & Avital 2011). The results of previous phases of the study (CNSs, team members) guided the development of the interview guide and facilitated the discussion to remain focused on the particular topic under investigation (Holloway & Wheeler 2010).

### **Participants and recruitment**

A non-probability purposeful sample (n=10) of families of a person with ID (Table 1) in receipt of a CNS service was chosen as individuals with relevant information increase the understanding of the phenomenon under investigation (Newell & Burnard 2011). As services requested the researcher liaise directly with CNS to identify families, a letter was sent to 48 CNSs seeking their willingness to distribute research packs (information sheet, invitation letter, reply slip and a stamped addressed envelope). 21 CNSs responded and 38 research packs were distributed. 10 families responded and all agreed to participate (six mothers and four fathers) and each service provider represented within the

sample were informed of the families engagement in the study. Participants were afforded time to consider the information and their involvement prior to arrangements for interview date, time and venue been agreed.

### **Data Collection**

Qualitative semi-structured interviews were used to collect data as it allowed questions on topics to be asked with subsequent questions according to the participants' responses (Doody & Noonan 2013). All interviews took place in the participants own home, as the venue agreed based on neutrality, choice and what was socially acceptable to participants. Participants signed a consent form prior to commencing interviews which were audio-recorded, transcribed and lasted between 38 to 65 minutes (average 50min). Note taking and field notes were made after each session to facilitate data analysis and during interviews observation of body language, making eye contact, using gestures and verbal acknowledgements of understanding were used to establish a relationship of trust (Parahoo 2014).

### **Data Analysis**

Data analysis followed Burnard's (2011) framework involving 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. The narratives were thematically analysed, involving clustering of categories to capture the participants' perceptions and produce a detailed and systematic recording of the categories and issues addressed in the interviews. Linking these categories and interviews together under a reasonable exhaustive category system occurred (Burnard 2011).

### **Ethics**

Ethical approval was granted (University Research Ethics Committee) and access gained through services. Within the study, autonomy of participants was protected, participants were free to make an independent and informed choice to participate without coercion and they were free to withdraw at any stage (Guillemin et al. 2010). Confidentiality was upheld at all stages, pseudonyms were used and consent was a process rather than a one off event with agreement to participate in this study verified by both researcher and participant receiving a signed copy of the consent form. Participants were all afforded a choice of venues to be interviewed and the researcher was cognisant when entering the participants own home and was respectful of their time, space and experience. While the interview guide provided structure, probing was used to gain further explanation of the participants' responses. While the research topic is not a sensitive area, describing ones experience could result in past emotions arising so the researcher was observant for signs of distress/discomfort during the interviews. Participant were sent a thank you letter, afforded the opportunity for their transcripts to be returned to them and the main themes were identified for them to verify if they were an accurate interpretation of the interviews.

## **FINDINGS**

The findings are presented by incorporating a summary paragraph, selected quotes and a brief interpretation of the data. Participant profile and the five themes emerged from the data (table 1) highlighting the work and contribution of the ID-CNSs from a family's perspective: personal caring, supporting and empowering, liaison, education and leadership. Within the findings pseudonym are used when presenting participant quotations.

### **Table 1: Themes and essences**

#### **Personal Caring**

The personal caring aspect of CNSs work was expressed by all participants and this was indicative of the relationship that existed which formed a positive working relationship between CNS and the family. Within this relationship listening in a non-judgmental manner was a key attribute to the formation of a caring relationship.

*'It's the non-judgmental way she deals with us that is key ..... the CNS listens in a non-judgmental way and gives us relevant information and works with us' (Mary)*

This non-judgmental attitude created a sense that the CNS understood the families situation and circumstances.

*'The CNS treats us as individuals in the sense that we feel, this is new and we are going through it, I know it's not new to the CNS but she takes it as new for us and she will wait, she doesn't jump in with the answer or information, she will allow us to express it, discuss it, identify what we want, focus us on (name), her needs and wants or wishes' (Paul)*

These feelings of the caring provided were greatly supported by the CNSs presence throughout the care process and the sense of togetherness this created.

*'There's an ease for me knowing (named CNS) is there every day, and she has been with us all the time and any advice we want or need (named CNS) is there, she will link in and see how she can support you' (Pauline)*

Participants emphasised that the CNSs way of working created a true sense of togetherness in the caring process and supporting the family.



*'They're (CNSs) always with us if we need them it's not just a periodic visit. They support us, in times of stress, working directly with (named child) and us, show us what to do and is the only one who seems to be there directly for (named child) and us' (Joe)*

Key to caring was the aspect of knowing the person and this was not just from the point of view of the CNS knowing the client it also included the CNS knowing the family and this was reciprocal as it also involved the family and client knowing the CNS.

*'I like the fact that I have people that know the child and the family and it's not like when you go into a service, the CNS knows the family and how we work and we know them and about their family and this is important so everything can come together and we can work well together' (Marie)*

Participants acknowledged that this 'getting to know the person' seemed unique to the CNS within the team as they had little opportunity for a relationship or 'knowing' to occur with the other MDT members. Knowing the person enabled the CNSs to work effectively with clients highlighting their caring ability and knowledge. Participants also saw the CNS as having a more direct role in care and all care provision.

*'With the others (MDT) you don't get to know them you might have one appointment in six months so you don't open up and say much to them, but you have built up a rapport with the CNS and anyway they just see a problem or solution and put in on paper (MDT), but it's us and the CNS that have to do it so you don't get to or really need to get to know them (MDT)' (Tom)*

## **Supporting**

The support aspect of the CNS work was described by participants as a valuable and important component and one that assisted them in maintaining family life and bringing the family together. This support was first and foremost in the information CNSs provided which is tailored to the families need and to the particular needs at that time. In addition to providing information the actual understanding and putting that information into practice was supported by CNSs in their willingness to demonstrate and seek feedback from the family and be open to questions which assisted or guided the family in the care process.

*'she (CNS) is able to give the right information and the right amount but most of all she makes it relevant and she will check back with us in case we have any questions and ask us about what we have read, but more importantly she will give a hand when needed and show us or demonstrate how to do something and it's a very practical approach, then I can see how she did that and how I could do it and this reinforces the information she has given' (Claire)*

A key element of providing information and demonstration was the manner in which the CNS provides this support and been cognisant of the overall work of the family and the necessity to create normality within the family. By respecting that this may mean that not all tools can be dropped at a time when the CNS is there.

*'the information and demonstration is great and guided us as a family but it is also delivered in a manner that is considerate of the overall family function in the sense that I don't need to stand on foot while she talks me through it, I can do the normal family activities be it cooking or whatever and she will come into the kitchen and do it there as it's hard to get it all done' (Jill)*

Fundamental to supporting the family is the flexibility of the CNS and their willingness to conduct home visits. This was reported by participants as assisting them in maintaining a family/life balance and allowing the child to perform in their natural environment. Where the CNS could get a true and accurate account of their child's ability which is not often the case in clinics where both parent and child feel they have to perform.

*'the home visit is so important and helps so much and they (CNSs) will even make it evening time if we were working or morning if I had a late start, it's here they get to know the child and the family and see what will work for them and us and what's in the home environment that can be used and it's great as she (child) will cooperate here as she knows everything and is comfortable, whereas we all get stressed in the clinics with the MDT as I want her to perform and she must feel the spot light as she tends do little or nothing and they must think she has so little capabilities' (Rose)*

Support and home visits were further reinforced not only by the CNS flexibility but also by their accessibility as all families identified the CNS as their first point of contact and someone they called upon regularly not only regarding CNS care and service but the overall care and support required by the family as the CNS will actively engage with the other members of the team and come back to the family.

*'often I would text or email her (CNS) to say this is not working and she would come back to me or call out, she's our first point of contact and the one service we will always contact if there is an issue even if it's not their area we can discuss it and get their advice and they (CNSs) will advise us and follow up with the others (MDT) if they need to and come back to us' (Frank)*

Support was reported by participants as always resulting in a plan of action coming into place that was inclusive of the family and child. This support was always client focused and tailored to their specific needs and where these plans required specific interventions the CNS was on hand to support, demonstrate and provide training where necessary.

*'no matter what, there will be a plan and I did think what do we need it for at the start but I can see why now we all can see it and its clear how to do something or deal with something, when there're direct interventions she (CNS) will support us in supporting (child) be it with speech, movement, behaviour or whatever and she will always assist and give advice and new things to try and if we need it she will show us again and again' (Paul)*

These plans and interventions were of value to the families and the family participants stated they could see the benefits of them in the development, interaction, social or life skills of the individual.

*'the plan has made a huge difference, in his speech in his movement, in his behaviour and now that the conversation is going there are less tantrums, she (CNS) has worked on his social skills and now we can take him places and she would have supported us at home and in the school and did a lot of work on sensory integration' (Joe)*

However the families did report a shortfall in the preparation for the future and or transition planning such as moving from pre-school to primary school or between services such as child to adolescent.

*'they need to let the CNS into the school and the CNS needs to be talking to the special needs officers, teachers and special needs assistants, now they would have done it but it is an extra not a given, they work on a time period for example 0-4 and then they move to the next service but there is a lot going on and there needs to be a crossover between the services by the CNS*

*for a period of time to assist and support this process as they know the child so well, when you move you have to start the process all over again and the new person is losing out on all the knowledge and information the CNS has about the child and it's not the same if it's down on paper' (Tom)*

## **Liaison**

Within the CNS work participants clearly identified the aspects of referral, coordination, collaboration and bringing all plans together which overall represented the CNS liaison work and practice. Firstly the CNS worked in a manner to ensure the family was referred to the appropriate services and was open to the family seeking the CNS to refer them if they so wish.

*'she (CNS) will always ensure we are linked in with the other services we need by referring us but it's not just the ones she feels we need as if we come to her looking to be referred somewhere she will do that for us as well' (Mary)*

Within their work CNSs support and coordinates appointments for the family and assists them in gaining the appropriate services and effectively planning ahead so all are prepared for upcoming events.

*'they (CNSs) will link with the others so that I won't have to be coming in twice and make it as convenient as possible, or if the CNS felt a review was needed they would link in with the other specialists and get that done at the one visit, if I said I needed something she would come back to me and have coordinated it all, and she did the grant application and allowance application with us' (Marie)*

Participants identified the CNS as always been present and the coordinator between the whole service their child was receiving and this lead them to question the involvement of the other professionals and appreciate the work of the CNS.

*'the CNS is there in the background always, she (CNS) will link in and see how it's working, how she can support you at home, how it is going to be implemented at school, they are invaluable' (Rose)*

This coordination and collaboration work of the CNS created as sense that the CNS functioned effectively as part of the team but more importantly the CNS was seen as part of the family team as well as working within the health profession team.

*'the CNS is the link in the system that everything revolves around, without them the whole team would fall down as they are the ones that do the work and support us' (Claire)*

The CNS communicates their decisions to all concerned and ensures that all are aware in order to support effective collaborative working and where necessary was autonomous in decision making.

*'it's difficult for the CNS as they are trying to keep everyone involved and informed, it's the CNS who ties everyone together and decide what will work and try things out, this is done while she presents us with all the options and assists us to make a decision, but the decision is a collaborative effort between the CNS and us as a family and we trust her at times when an immediate decision has to be made' (Joe)*

Throughout the interviews participants discussed and identified the CNS as bringing the plans together and that without their involvement things would be fragmented, disjointed and open to failure.

*'the CNS will help us with (named child), she will carry out the steps or plans that others have given, along with whatever she is doing with us or wants to do with us, she's always aware of what's going on and how it is going to ensure everything is working and alright' (Jill)*

This bringing of the plans together was important for families as it supported them in the care process and enabled them to work more effectively with their child at home and adapt programmes to their family and home life more appropriately and reduce stress.

*'I find that the physio wants you to do this, the OT wants you to do that, the speech therapist wants you to do the other and the psychologist wants something different, but the CNS seemed to have an understanding of them all and in one session they could incorporate the elements of these four into their own work as the CNS will have joined them all with her own plan' (Mary)*

Of additional support to the family was the CNSs involvement in other support services for the family such as respite and summer camps. These facilities greatly supported family functioning and were often organised and run by the CNS. This was evidenced of further examples of the CNSs work to join all care together and liaise not only within the MDT but also with the family.

### **Education and knowledge**

Throughout the interviews the participants continually acknowledged the skill, knowledge and expertise of the CNS and that the CNS was able to utilise these attributes in an effective manner in order to support the family in an appropriate manner.

*'she (CNS) has years of experience and excellent knowledge and can share that with us, and to me this is what's effective for us' (Frank)*

Utilising their skills and knowledge meant that the CNS provided information to the family that was specific to their needs and appropriate to the care required. Inbuilt within information provision was also the creation of realistic expectations and planning ahead for all possibilities and that while the information was based on evidence it was tailor made to the individual and family.

*'she (CNS) always gives you the information that is useful at that time and share her experience, but it's the little things that make it, she will have the information in a pact with our and (child) names on it, starting with the date of the diagnosis and an explanation of what that means from (child) perspective, how it is affecting him and how he sees the word, how he communicates, how he may feel and his frustrations' (Pauline)*

Identified and discussed across all interviews was the educative role of the CNS as she not only delivered the information to each family she also built on that information by providing courses/training for the parents and extended family. This had a knock on effect for the parents in that their family were more understanding and supportive as a result.

*'she will educate others with or for us as well such as our family and it was great as the family are more understanding of (child) and our needs and have often popped in and given us a break now as a result' (Claire)*

Within the education aspect of the CNS work families also identified a team approach to education in both the delivery and receipt of education. This occurred in the sense that the CNS often worked with others in the delivery of the course but also attends educational programmes themselves.



*'she (CNS) delivers the course but sometimes she will bring in others for certain aspects and she is always telling us about something she has heard or learnt at a course she did herself'*

*(Tom)*

## **Empowering**

Within empowerment participants clearly identified the CNS as both client/person and family centered and that this team approach to care was created by the CNS acceptance of the families own expertise, individuality and choices.

*'when we met the CNS she was able to sit there and talk to us from the child's perspective and reassure us that a lot of the issues we were having were not about (child) but about people not been trained to support these specific needs, this was a relief as we are anxious to keep him at home and (CNS) would have looked at what we want and we sat down to see how we as a family could achieve this between us' (Frank)*

Intertwined within the CNS approach of working with the child and family was not only the acknowledgement of an individualised plan of care but also the acceptance of the role of the family in the decision making process. The role was supported, negotiated and encouraged so that family and child could claim ownership of the plans developed and appreciate their real value.

*'she (CNS) will develop and design an individual plan and be at all the meetings to support you, the plan will be done in a way that (child) and us can understand and she will get us all involved in what goes in and deciding what is the best way to do it' (Marie)*

Within the process the CNS also supported the family in attaining their rights and entitlements, advocating for them and the child where necessary and being present to support them advocate for themselves and their child within the care process or in seeking resources.

*'she (CNS) will ensure we have what we need and are entitled to even though it is not her job specifically, she will sit with you if needed and help us get them' (Pauline)*

While the CNS was effective in planning and delivering individual and family-centered care the families also identified that they were also planning much further in advance than just a year plan.

*'she (CNS) would have the year all mapped out and would have discussed it all with us, identified who we may need to be referred to and what we would like for the coming year, she would have the coming years also identified and put in other things that may or will occur' (Jill)*

However within this future planning the families began to identify problems and issues within service provision.

*'the CNS has been a great support to us in keeping our child at home, but there needs to be more of a focus when the child is moving into mainstream education, it seems that there's a lot of input then they're dropped when they start school, there should be some transition and the CNS was a big loss to us' (Paul)*

In addition families were clear in the kind of future service they wanted and this included the CNS even though they were very aware of the social model of care they were very assured of the role of the CNS or their desired role of the CNS.

*'the CNS is essential in the sense that you can have a referral to the psychologist or whoever and they give you a programme but to be honest it's the CNS who implements it, educates you, supports you and monitors how it is going, then after six months if it's working the psychologist will cross you off their books "there's a success", but with the CNS that programme is still going three years later, now not in the same manner but in a format that has changed and developed with the child, so for us the knowledge and skills the CNS has needs to be fostered into whatever new service or future service (child) will have, as the CNS is so observant and in tune with the needs of the individual and the family, I know you need both (health and social care) and that's fine but people can work with disability and support the social aspects or do activities but you need the nursing skills to be present also' (Rose)*

## **DISCUSSION**

Within this study families highlighted the personal relationship that had grown with ID-CNSs which was based on 'a getting to know each other'. This was fundamental to care provision in that; clients' comes first, clients' rights and needs are to the fore at all times and advocating for clients' needs in a respectful manner. While advocating can be difficult, relational continuity facilitated a trusting relationship, allowing CNSs to; get to know the person, facilitate equal partnership and promote autonomy, choice and empowerment. These elements of CNS practice are important in the provision of person-centred holistic care. Similar to Doody (2012) families reported a sense of equity among clients, who reported clients' were treated equally in the light of their needs. Thereby the philosophy of care employed by CNSs is based on an individualised approach to care in a holistic manner. The findings of this study confirm that the ID-CNSs fulfil the national health strategy (DoHC 2001) and its principles of accessibility, person-centredness, equity and accountability. Within this study relational continuity

was important in facilitating a trusting relationship allowing; CNSs to get to know the child and family, family get to know CNSs which facilitated an equal partnership between family and CNS. Continuity of relationships are important and equate to increased confidence about quality of care delivered (Kirk & Glendinning 2004, Heller & Solomon 2005). Continuity facilitated relationships characterised by mutual recognition of individual knowledge and expertise, encouraging sharing of expertise and information (O Halloran & Doody 2013). Often parents of children with intellectual disability define their relationships to include professionals who work with them and their child, subsequently professionals need to recognise the importance of interacting with families beyond the provision of direct services (Smith-Stepanek, 2008). The way in which professionals support children and their families can enhance or impede family outcomes (Dempsey & Keen 2008), within this study families reported a sense of support, advice, empowerment, empathy, respect, emotional support and an acknowledge of families' expertise and experience. Beside every client is their family and that their lives are intimately intertwined (Doody 2012). CNSs interacted with families' beyond direct services in aspect such as the personal relationship and this was achieved by CNSs willingness "to go the extra mile" or "walk the floor with you". However, this relationship may impact on empowering the family and creating co-dependency. Nonetheless this seems to be counteracted by the CNSs invitation and support of families' to be involved in care planning, decision making process and evaluation of the services provided.

Families' perception of supports and services provided is a critical factor influencing family quality-of-life (Summers *et al.* 2007, Werner *et al.* 2009). Focusing on family quality-of-life has been widely endorsed where increasingly the construct of family quality-of-life is being used to consider issues of family needs (Brown *et al.* 2009, Werner *et al.* 2009). Where families' needs are met and family

members enjoy their life together and have a chance to do things that are important to them (Park *et al.* 2003). Families' within this study appreciated CNSs involvement and support at a whole family and extended family level. Services and supports should both reduce the negative effects produced by the difficulties in situations (Summers *et al.* 2005) and strengthen the positive effects through interventions favouring family autonomy and empowerment (Soresi *et al.* 2007). This study highlights CNSs support families in decision making and care planning in a manner appropriate to their needs, supporting the overall care of their child. Ultimately it is the effects that such services and supports have on children and families' that determine the quality and effectiveness of any service or program.

Important to families' was having their needs assessed, and receiving appropriate and sufficient support so they could care for their child needs, and that CNSs worked with other healthcare professionals/agencies so that support delivered is meaningful for both child and family. This requires collaboration, liaison and consultation with other healthcare professionals/agencies and was positively reported. A commitment to partnership practice underpins Irish health and child care policy advocating a commitment to the principle of effective partnership with parents (DoHC 2002, 2004). The DoHC, (2004:15) proposes a bi-dimensional concept of partnership to include the relationship between; services and families', and agencies and disciplines in meeting families' needs. With regard to the former, effective partnership practice involves a commitment to the provision of information, practical arrangements and emotional support to parents engaged with services. This provision of information, practical arrangements and emotional support was very evident and articulated by families. The quality of parents' partnerships with service providers is a critical element of their overall quality-of-life (Blue-Banning *et al.* 2000), and crucial in achieving the best possible service delivery outcomes for children and families' (McIntosh & Runciman 2007). Research indicates that parents and professionals alike

define collaborative partnerships at least in part in terms of the quality of their interpersonal relationships with each other (Park & Turnbull 2003). Blue-Banning *et al.* (2004) propose six inter-related themes of collaborative family-professional partnership in the context of childhood disability including communication, commitment, equality, skills, trust and respect. Trust and respect were also identified as core features of family-professional partnerships by Fereday *et al.* (2010). Families' highlighted that CNSs accepted they had a different, but equally valid, point of view and knowledge of their child, which was respected. This empowered families' to become part of the decision making process. Professionals must be aware that their interactions can act to either increase or reduce parents coping (Hauskov-Grungaard *et al.* 2011) and this study indicates CNSs interactions are positive and supportive.

ID-CNSs were identified as a person whom the family can approach for advice and practical help with any problem related to their child and as the "first point of contact". The value of having a person who acts to coordinate the input to the family from the various agencies and services involved in care is well recognised (Cavet 2007, Hardie & Leary 2010). Watson *et al.* (2002) suggest that there is a continuum of joint working ranging from multidisciplinary to transdisciplinary working. Suggesting that transdisciplinary working is "a synthesis of services" (p.53) whereby packages of care and support are developed to meet the particular needs and aspirations of individual children and their families. While, this was not evident in this study, there was evidence of multidisciplinary working. However, families' reported little coordination, information and integration of services/agencies when their child was moving between services/agencies or transitions, with frustration due to bureaucracy and delays. While transdisciplinary working may not be evident families' noted that CNSs "brought all the plans together for them" in a workable manner and demonstrated and assisted where necessary. Health policy and

legislation, particularly in the context of disability services has an emphasis on person-centeredness (GoI 2005, DoHC 2006). However, at a time when all health policy is shifting focus towards community care (DoHC 2001a, 2001b, 2008), the case for addressing the needs of families (primary carers) seems obvious. It must be acknowledged that different families' react differently to the demands placed upon them and the lack of coordination between services can overwhelm parents (Hewitt-Taylor 2005). While the families' reported been well supported by CNSs and involved in the care and decision process and families' reported home visits as a means of assisting family life and provided a relaxed environment, opportunities to raise concerns, see progress and the child's true performance (Savage 2007).

This study highlights the positive role ID-CNSs have with families and while many of the aspects raised such as, listening, liaising, coordinating are fundamental within the ID nurses role families did value the specialist skills of the ID-CNS. As we move away from congregated setting in the coming years and see their closure (HSE 2011) the ID-CNS must take a leadership role in the profession and focus on health promotion, health education and health access/equality/disparities. Furthermore greater access to ID-CNSs needs to be considered and just as congregated setting as closed and people moving to alternative living arrangements so too will the ID-CNS have to develop new working arrangements beyond congregated setting and work across services, communities and agencies.

## **LIMITATIONS**

This study is unique in its investigation of the contribution of ID CNSs in an Irish context and despite the small sample the study provides the first overview of the contribution of ID CNSs from the families' perspective. However, no single study can capture all that might be learned or known about a

given topic. The sample of families was heavily in favour of child/adolescent based services and those residing at home. While this is beneficial it does not necessarily reflect the current service provision where residential care still predominates. However this model of service provision is due to be replaced with the closure of congregated settings (HSE, 2011) and thereby the findings may be more representative in the years ahead. The absence of data obtained from people with ID was disappointing even though they were afforded the opportunity to contribute or be interviewed with a family member. The study was one moment in time, and a further follow-up study would be needed to verify the results of this research. In addition, the challenge to the author of being both a researcher and nurse and how this may impact on the data collection and research process needs to be considered. However, through reflexivity the research team the researcher had an avenue in which to highlight potential biases. Despite these limitations this study was a seminal piece of research which should be viewed as a baseline for further research in exploring the current and potential roles of ID-CNSs in meeting the needs of people with ID and their families.

## **CONCLUSION**

The themes of caring, support, liaison, education and empowerment were clearly articulated and families' valued CNSs seeing them as an essential support to them and their child in their day-to-day caring role. CNSs provided education for family caregivers and clients and liaised across services/agencies, helping families' move from feeling a lack of control over their lives to being empowered. Research on appropriate interventions is largely lacking and there is an urgent need for additional research exploring the efficacy of different forms of intervention that support clients, and families' in their care-giving role. The views of family caregivers of people with intellectual disability are essential and this study gains a glimpse into the views of a small number of family carers. However,



essential to care provision is hearing their voices and views of people with intellectual disability. Thereby research needs to involve clients in participatory research approaches and avoid 'token' representation.

## **RELEVANCE TO CLINICAL PRACTICE**

This paper provides a clear picture of families perceptions of the contribution of ID CNSs within care and service provision in Ireland. To-date little evidence exists on families views of CNSs and this study highlights ID CNSs contribution in supporting families through caring, supporting, liaison, education and empowering.

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