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Focus group interviews examining the contribution of intellectual disability clinical nurse
specialists in Ireland

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Title - Focus group interviews examining the contribution of intellectual disability clinical nurse specialists in Ireland.

ABSTRACT

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

Background. While CNSs exist since the 1940's they have only been a reality in Ireland since 2001. While the role of CNS has developed over the years, it still however is often seen as a complex multifaceted role that causes confusion, frustration and controversy.

Design. A exploratory qualitative approach utilising focus groups with Irish intellectual disability CNSs (n=31).

Methods. Five focus group interviews were conducted to gather qualitative data to gain insight into the attitudes, perceptions and opinions of the participants. Data were audio-recorded, transcribed and analysed using Burnard's (2011) framework. Ethical approval was gained from the researcher's university and access granted by the national council for the professional development of nursing/midwifery Ireland.

Results. The study highlights that intellectual disability CNSs contribute and support care deliver across a range of areas including; client focused and family centered care, staff support, organisation support, community support and supporting other agencies.

Conclusions. Overall, the study shows the importance of intellectual disability CNSs and their contribution across a range of services, care environments and the support they offer to clients/families/staff/multidisciplinary team members and outside agencies.

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,

INTRODUCTION

Since the development of Clinical Nurse Specialist (CNS), many attempts have been made to clarify their role, functions and defining characteristics. However, CNS remains a complex multifaceted role with many components creating confusion, frustration and controversy (Doody & Baiely 2011, Edwards 2011; Charbachi *et al.* 2012). This confusion stems from role ambiguity; individual interpretation; variation in educational preparation; title confusion; lack of authority; lack of support; loss of clinical role and insufficient research regarding the role (Doody & Baiely 2011, Roberts *et al.* 2011). Within Ireland, registered intellectual disability nurses (RNIDs) have existed and grown as a discipline since 1972 (Doody *et al.* 2012a). While many countries don't deliver intellectual disability (ID) nurse education, Ireland and the United Kingdom (UK) continue to. Since 2001 Ireland has developed CNSs across all disciplines of nursing/midwifery creating an opportunity for ID CNSs to lead the discipline and make their knowledge, practices and contribution visible (Doody *et al.* 2012b). This opportunity is also noted by Fulton (2013) call for making the outcomes of CNS specialist practice visible. Thereby there is a need for nurses to divulge their practice and research into the public domain through practice and research based publications (Doody *et al.* 2012a,b).

BACKGROUND

The roots of Irish CNSs evolved in 1980 (Department of Health, 1980) however, sometime later the Government of Ireland (GoI) recommended the establishment of a national council for the professional development of nursing/midwifery (NCPDNM) and recognised the need to promote nursing as a career (GoI 1998). The NCPDNM developed a National framework for CNSs, defined CNS, identified areas of specialty and described five core concepts of the CNS role (client focus, client advocate, education/training, audit/research and consultancy) based on an adaptation of Hamric's (1989) role components. Each of the five core concepts need to be enacted in order for the nurse to be considered a CNS (Doody and Bailey 2011).

While CNS roles have gained support in recent years it is the least clearly defined (Dowling *et al.* 2013, Kilpatrick *et al.* 2013). With many countries re-examining their CNS roles or educational curricula (Wong *et al.* 2010, Arslanian-Engoren 2011, Baldwin *et al.* 2013, Kleinpell *et al.* 2014, Jokiniemi *et al.* 2015). Thus, the pace of and readiness for role implementation vary from country to country (Bryant-Lukosius & DiCenso 2004, Sheer & Wong 2008), leading to variation in CNS practice and lack of uniform policies regulating CNS representing barriers to the accurate identification and optimal functioning of CNSs (Furlong & Smith 2005, Patten & Goudreau 2012, Kilpatrick *et al.* 2013). The CNS role has been defined by individual organisations, creating the emergence of unnecessary variation in roles and thus compelling the need for national role conceptualisation and standardisation (Jokiniemi *et al.* 2014). Therefore, consideration is required to increase clarity and common understanding related to CNS roles to support policy formulation and role implementation.

The number of ID CNSs has grown but not at the pace of its other nursing counterparts (Begley *et al.* 2010) and activities of ID CNSs have rarely been explored. Evidence that exists regarding ID CNSs comes from the NCPDNM own evaluations of the role across all disciplines in nursing. The NCPDNM (2004) evaluation report highlights that the CNS has an active role in client care, education, and

advocacy but there is limited evidence of the research role. The clinical component were rated the most important (63%) followed by advocacy (26%), education and training (20%), consultancy (8%) and audit and research (4%). In 2010 a further evaluation of the CNS role in Ireland was conducted by Begley *et al.* (2010). Highlighting that the education and health promotion role of CNSs were viewed as contributing to the maintenance of quality standards of care and serving as a role model and that the CNS impacted on broader outcomes related to quality of life for clients and families (Begley *et al.* 2010). However, both evaluations only achieved an 8% response rate and results have to be considered in relation to representation of the findings and the fact there is disparity across services unlike acute care services which are largely similar across acute care hospital.

METHODS

Aim

To explore ID CNSs contribution to care provision in Ireland.

Research Design

In line with the study aim, an exploratory qualitative approach was chosen as pre-existing information regarding the contribution of ID CNSs is limited with no available literature specific to the field. An exploratory qualitative approach is useful in summarising and understanding an area of interest where little is known (Polit and Beck 2014).

Participants and recruitment

A non-probability purposeful sample was chosen as individuals with relevant information increase the researchers understanding of the phenomenon under investigation (Ryan *et al.* 2006). A recognised technique for identifying participants is via already established membership lists (Kingry *et al.* 1990) and the NCPDNM held the list of CNSs in Ireland. Ethical approval was granted by the Research

Ethics Committee of the researcher's university and upon approval access was sought through the NCPDNM. Invitation letters and information sheets were distributed by the NCPDNM on behalf of the researcher to all ID CNSs presently working (n=105). 49 CNSs responded and when the focus group interview dates, location and times were arranged 31 CNSs across 5 focus groups participated. Written informed consent was gained, confidentiality guaranteed and participants' had the right to withdraw at any time.

Data Collection

Qualitative semi-structured interviews were used to collect data in a centrally agreed venue. Focus group interviews were audio-recorded, transcribed and lasted between 75 and 95 minutes. The intended aim of using focus groups was not to develop consensus, but to produce qualitative data that would provide insight into the attitudes, perceptions and opinions (Doody *et al.* 2013a,b) of participating CNSs through a focused discussion.

Data Analysis

The process of data analysis followed Burnard's (2011) data analysis framework which 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. The narratives were thematically analysed, involving clustering of categories to capture the contribution of ID CNSs and produce a detailed and systematic recording of the categories and issues addressed in the focus group interviews. Linking these categories and interviews together under a reasonable exhaustive category system occurred (Burnard 2011, Polit & Beck 2014).

RESULTS

CNSs were very willing to discuss the various aspects of their role and while certain components were specific to individual roles there were general agreement even though they had different specialist areas and workloads. Although specific roles were identifiable CNSs did not always refer to these roles by name and a considerable amount of discussion revolved around the clinical component of their role and this encompassed the greatest weighting of time. Data pertaining to the participant profile is presented in Table 1. Through analysis it was possible to identify the main components of their role and six key themes regarding the ID CNSs contribution. The concepts, subthemes and themes are highlighted in Table 2 and some of the themes may have overlapping elements, and some of the statements may highlight more than one theme as narrative material is generally nonlinear (Polit & Beck 2014).

Table 1 Participants profile

Gender	3 Male 28 Female
Year experience in role	Range 2-8 years
Age	30 – 59 years
Employment	20 Full time 11 part time/job sharing
Duty Rota	24 Monday-Friday 7 seven day rota
Specialist cert	17
Diploma	15
Degree	7
Post graduate diploma	12
Masters Degree	3
Service	Residential 6, Community 12, Residential and community 13
Specialist areas represented	12 Behaviour, 6 Early intervention, 5 Community, 4 Creational diversional and recreational activities, 2 Health promotion, 2 Older person,

Table 2 Data analysis concepts, subthemes and themes

Concepts	Sub theme	Theme
Experience Valuing experience Being known	Assessment Design programmes Implementation Evaluation Monitoring progress Advocating for client	Client care

Being known First point of contact Listen and aware of needs Up-to-date information Develop relationship Assist	Home care Home visit Support for family Design booklets or packages Education Resource person	Family care
Role model Peer support Team members Being known First point of contact Aware of role	Education Support Collaboration Create ownership Advise Informal and formal advice	Staff support
Insider knowledge Autonomy In-service education Induction Team member/work Service plan Best practice	Collaboration Caseloads Referrals Audits Policies/guidelines/ service plan Other roles (management) Support Advise Education	Service support
Getting out there Sharing knowledge Letting them know we exist Undertake further study Research skills	Presentation Conferences, Publications Research Education formal/informal Time/support	Community support
Work across services Work across agencies Being accessible Being available Being known Working together	Collaboration Referrals Consulting Supporting Advising Policies	Other agencies support

Client focused

Within all focus groups there were a clear focus on CNSs clinical role and supporting clients within their care. Traditional aspects of assessing, planning, implementation and evaluation of care were identified. CNS's focused on different areas depending on the nature of their speciality and workload although specific roles were identifiable in their discussion, CNS's did not always refer to them by name. In addition the aspect of advocating on clients behalf and supporting clients in times of need were emphasised. These were reinforced by CNSs prior experience in the practice area and having worked in the service prior to taking up a CNS post, thereby most likely haven known or previously worked with the clients. All CNS's saw their primarily function as been there for the client and that the

client came first and care delivery was based on working with the client and staff to devise a specific person-centred programme.

Certainly the client is the focus of everything and we focus on everything going on around them (FGI 3)

I ensure there's an individual programme for each client within the service I'd carry out an assessment of where they are at present and find the best way of working for them. I'd go back then and monitor it to see how it is going. (FGI 2)

As in any job there is always constraints and participants acknowledged that been truly client focused is difficult as creating independence creates risk, but no matter what they must continue to advocate for the client at all times. Balancing this risk is often difficult and CNSs previous experience as an RNID and creditability assisted them to introduce plans for clients.

When you are given clients independence you have to know there's a risk and I find the service doesn't want to take a risk. You are trying to put the client first and their desire and how this will bring independence but it is a challenge (FGI 5)

Because we were RNIDs for many years before we took on the CNS position our practical experience on the ground and our ability to apply theory, enables us to be an expert as we can bring it to life for them as we know what we're talking about and they believe its credible (FGI 4)

Family centred

Within their work CNSs support families in the home through offering support, guidance, educational support, providing resources and been the first point of contact and a constant figure present for the family. All CNSs regardless of the level of contact with families saw themselves as a source of support to the family and depending on their role this may involve going to the family home.

My primary work would be in working with families in helping them to support the client (FGI 3)
I go into the family home to do interventions and you do your observational sessions and you talk to the mum and dad. This is where you have to be honest and upfront with each other as you get to see the real life and real environment (FGI 1)

In working with the client and family in a supportive way the CNS need to consider the full picture in a manner that meets both their needs.

We're looking at everything to be sure that the family is fully supported, that they have all that they need for training, for information, for support, for advice, we're looking at everything you have to have a holistic view and be very practical (FGI 5)

In providing support for the families resources were identified by the groups, be it providing a copy of the individuals plan of care or items such as booklets, as just important as the direct support and interventions provided.

I developed a booklet for families and given out videos or other materials that would be of use as families don't want to hear that they are coming in for a lesson and I've got feedback on what they thought of them (FGI 2)

As part of the support for families CNSs all felt education was a major component in order support the client and family in the long-term.

We try to enable parents so that they can maintain the family unit for as long as possible and this could involve promoting good health to enable children to stay within their home environment (FGI 5)

In working with and supporting the family the CNS becomes a regular and familiar person to the family and one that they often rely on.

You seem to be a constant figure in a family's life, and the parents will look for you, they will seek out the CNS, maybe it's because we seem to stay, maybe it's because you're a constant figure and you've understanding and give sound advice and you have a relationships with the family, so you can be the first point of contact for them (FGI 3)

CNSs were very willing to discuss the various aspects relating to supporting the family and were in the true belief that the family and client lives are intimately intertwined and cannot be seen in isolation.

CNSs did focus on different areas depending on their area of practice with the community based and child services having more immediate contact with family. CNSs working in residential services with

the older person did acknowledge that there is less family contact but still regarded it as essential to keep the family informed and up-to-date at all times along with trying to develop ties to the next generation of family members.

Supporting staff

This theme encompassed the aspects of clinical, educational, supportive and collaborative working with staff, been the first point of contact for staff, providing education and support for staff both on a formal and informal basis along with trying to remove oneself by create ownership among the staff. Within supporting staff CNS's saw themselves as the first and last point of support for staff and one aspect was that they were accessible.

If they want anything they will go to the CNS before anyone else, we are more easily accessible, I am the first and last person to arrive (FGI 3)

All CNS's identified that central to their role was the aspect of supporting staff as beside the staff is a client and vice-a-versa and this support was mainly given in the form of education, training or advice.

Ultimately the nurse is there for the nurse now within that, the nurse is standing beside a client and the family so for the implementation purposes it is vital to educate staff and co-workers on what's happening. It can be a very simple in relation to communication something, but it's the staff and the person that needs to be educated (FGI 2)

CNSs saw the aspect of training and education as taking a large amount of their time and while they acknowledged it as important there was some concern regarding what they perceived as their clinical focus.

I spend a lot of time particularly around education and a supportive role and now into staff training it's a big role and I would be scared about that because I think our focus should be clinical. If anything our clinical should be more than anything else because our main purpose is to be there for other nurses and clients on the ground and the beauty of the role is that we are at the end of a phone (FGI 5)

As part of the education process CNSs identified the importance of being hands-on at the beginning to facilitate staff to become educated and skilled to carry on the programme/intervention by themselves.

Initially I would be hands-on and then I would be training the staff up on the programme and care plans but you would initially be doing a lot you know it would be part of your training and education of staff and you would be hands on initially then in and out to visit as you need to step back and enable them to continue without you (FGI 2)

However, while CNSs provide education and training CNSs within the focus group highlighted a large proportion of their support is provided on an informal basis to nursing and non-nursing staff.

I go through it with them and go back to them again, most would be informal on the units or I talk to staff and ask do you want me to come up if you do I will or people ask me or say I'm having problems, it can either be over dinner or it can be wherever it's informal (FGI 3)

One aspect raised by all groups was support for CNS's themselves as they felt there could be more on offer to them to support their practice and each other. Within the discussion CNSs began to identify what they might do themselves to rectify this and one group had just commenced a local area network group having had their first meeting one week prior to the focus group.

I'd love a kind of a network of where people pose questions to each other as we never really shared information about what went wrong or what went right or how this was done I'm sure there's an answer out there somewhere for me, if we had a thing for CNSs where we could meet and maybe even just once a year share knowledge, meet people from different places, I think we're missing out on that, I think we should start ourselves at a local base and once we have our local base we could develop as we all have connections everywhere and we all know some other CNS (FGI 1)

Supporting the organisation

This theme comprised of the aspects relating to collaborative working with team members and managing caseloads. Specifically mentioned were the aspects of non-nursing grades, students, referrals, audits and organisation policies. One factor identified by the groups was the differences in the way they

deliver services with some CNSs having independent/supernumary status whereas others may have to be fulfilling other roles. There was a sense of uneasiness regarding caseloads in the sense of the struggle between quality versus quantity and this was further complicated by the aspect of client complexity. CNSs saw themselves as a part of the multidisciplinary team and having a valuable role to play in supporting and advising others within the team.

'We are very involved in the MDT and we continue to be nurse led and we act as consultant to the team, I find the CNS is the person that pulls the rest of the team together and continues to chase them to pull and lead the team around somebody with very complex needs.' (FG 3)

However, CNSs did report a slight distrust in relation to the working of the team at times while others worked in the absence of a MDT and had to deliver services and care in their absence.

'I do a report three to four pages every month and it takes a lot of my time when I am off duty because I feel it's important, when I consult with the physiotherapist or the OT or whoever I record what my advice was, and when something comes up at a later date, I will know I've made reference to it and it is still outstanding, as we don't have a MDT and I have co-ordinated care in the absence of a MDT and get on with it.' (FG 2)

A critical component of service delivery was a team approach between day and night services where CNSs would educate and support them directly but the nurse management system has a vital role in ensuring care is delivered.

'I have come into night staff as it's a 24 hour care system Monday to Monday, and if there isn't the motivation to fully implement what you've spent an awful long time coming up with it's going to fall flat on its face, and the managers and people responsible for monitoring need to ensure the interventions are rolled out.' (FG 1)

Within the team approach the ability of CNSs to receive referrals and to refer clients to other team members was highlighted as important. However, the issue of teamwork was identified as a stumbling block as not always is the CNS seen as autonomous or within their role to refer clients. Furthermore

with referrals comes an additional work/caseload and this can be difficult to manage but is decided upon based on priority of need.

'We take a referral and see it through to the end and refer to others when needed but some people don't see us as autonomous, but we can't put a cap on our case load, we go on priority, there are different levels of complexities within your caseload we look at the needs of the client and who can fulfil the needs for that client and their family.' (FG 4)

Across the focus groups audits were identified and while an audit is a tool to evaluate their service CNSs saw it as a means to priorities their service also. These audits were conducted through existing mechanisms in each organisation and sent to their director of nursing (DoN), however some CNSs acknowledge that they have not audited their service but do send an annual report to the DoN.

'I've done a review and an audit report so I have numbers that could be looked at and prioritised, I did the audit and evaluation through the quality control system in the services and send it to the director of nursing every year.' (FG 5)

CNSs saw themselves as supporting the organisation through their involvement in the development of policy guidelines and supporting student education where possible.

'I have reviewed and written behavioural policy for the organisation and redone the restraint policy and written the student policy in dealing with behaviour and have an input around policy development and service planning' (FG 3)

However, delivering a service across the whole organisation is a struggle and this was impacted upon by the fact that they were either assigned to a unit or service, the nature of disability and resource provided.

'We are stretched across the whole service, I don't have the resources and I've been looking for them for a long time, I feel that I am not providing the very best service because clients aren't getting the volume of intervention that they require because I don't have the resource and because of the complexity and nature of disability we cross traditional boundaries and it's hard to keep skilled, with the range of conditions and disabilities from severe to profound right up to borderline and adapt to all people.' (FG 4)

In addition some CNSs identified that they fulfil other roles such as a manual handling instructor or held a shared post of CNS or nurse manager. While they felt this was supporting the organisation in some manner it was not of benefit to their role as CNS or supporting their area of practice.

'I have a CNM role and if I take annual leave I may take it in the CNS days because we're so short.' (FG 2)

On the other hand, some CNSs reported that they were still holding a staff post in addition to a CNS post as non-replacement had occurred. This had two effects, where CNSs had to continue their role of a staff nurse and delivering a CNS service to a limit group or the CNS role was an addition to their unit role and they struggled to deliver a CNS service to the whole organisation as they still remained part of the staff complement on the specific unit.

'I'm in a unit and hands on all the time waiting for the opportunity to be supernumerary and do my CNS role.' (FG 4)

However, those who were free to perform their CNS role in an independent/supernumerary capacity did identify that they had to be careful not to be pulled in a direction that they did not want as they felt that the organisation often sees them as been free and thereby call upon them to contribute in areas that may not be related to their CNS practice.

'Sometimes you would be called upon as we're supernumerary, they think you can drop all and sometimes you are brought into things that don't require you and it generates more work and takes your time.' (FG 4)

Supporting the community

This theme emerged from the open and frank discussion within each focus group regarding CNSs role which identified their support to the nursing community. The aspects of presentations, conferences, practice publications, research and been invited to deliver on academic or professional courses were

specifically mentioned. However CNSs did identify that time and support for their own professional development and research is warranted as they found it difficult to balance the need to be research active and develop evidence from their practice with their daily work commitments. CNSs identified their contributing to the wider education of nurses, students and others involved in caring for persons with ID through delivering education both formally and informally.

'I teach (named university) and for (named a professional organisation) as they have spotted there is a gap and we can support them and its good as when people come looking for information, you'd be a resource for literature and knowledge for them.' (FG 5)

One factor highlighted as hindering CNSs contribution in this area was the CNSs own education background. While CNSs were willing to engage in further education they did identify that knowledge pertaining to their specific specialities would be the driving force and not the desire to have additional qualifications and when courses are not available the CNS avails of other means to remain professionally relevant or travel to do specific specialist courses.

'I don't want to do a degree just to have a degree, I want something relevant for what I'm doing everyday and there are no Diplomas or Degrees in (named specialist area) so I attend courses and stay up-to-date and if they setup something I'd do it.' (FG 2)

For those who did not have a specialist course available, their course selection was based on relevance to practice and client group and others felt when such courses are available they would engage with them.

'Courses have to be applicable, it has to help us in our role, if I was to do my Masters or a course, it must benefit the people in my service I think that's important, I'd hate to spend a lot of time doing a course that I can't apply, it would only be to get the letters after my name and it would be a waste of time, I'd prefer to do a collection of things that would really benefit the people I'm working with.' (FG 3)

In order to contribute more CNSs recognised the necessity to engage in research in a more meaningful way as part of their role and for those who were engaged in formal studies they could identify its benefits.

'I am doing a piece of research at the minute around (named area) and that has impacted on my professional work as there's a lot of our skills that are hard to put down in paper but it was only when I was trying to explain them to somebody else that I realised what we have developed.' (FG 3)

However having the opportunity and actually doing were two different things for most CNSs and this seemed to stem from the historical position of nursing been subservient and lacking in confidence and the perceived lack of support to assist them in research.

'Nurses are doers, and it's only in recent years that nurses have now got their degree and maybe masters, I've often talked about sitting down and doing some research and it's the getting started that's the issue I don't have that experience or confidence, you need a mentor, getting ethical approval took so much out of me and I tried to educate myself but as I had little support it fell by the wayside because it didn't become a priority.' (FG 3)

CNSs reported their contribution to the community through disseminating at conferences, poster presentations or writing for publication and there was an acknowledgement of the value of the process and that research had contributed to practice.

'A lot of our work goes out on conferences or posters and all that we do we try and push it, we're actually very close to the whole publishing aspect, we would disseminate the information on work done, so probably one extra step is the whole publishing aspect...I personally feel research is what actually developed me as a CNS, the research and the literature reviews and I suppose I had an in-depth insight and experience into what I did and I now have the evidence to back up my practice' (FG 4)

While the research component of the CNS role was gaining impetus among the participants the aspect of time seemed to be the greatest barrier along with support within the organisation.

'I have to say, its time I would love to be able to sit down and say right I'm going to do this research and get it published but the minute I start something takes you and you never get to give it

the time and nobody's going to come after you and say well that's good, you should publish that.'
(FG 1)

While time and support were discussed as obstacles to research, the true barrier was related to their struggle to balance the aspects of their role and maintain their core philosophy of been client focused/centred. However, CNSs indicated awareness that they may be the barrier in preventing the creation of a workable balance between the components of the role.

'I think there is a certain amount of guilt, that research takes away from the client's we're working with, and the client focus and that would be one of the things lying in the back of my brain, as the individual is the priority the last thing in my mind is that I must publish this or research this, I'm just glad to walk away knowing that his life has improved and where will I go next, who's next on my list, so research or publishing it's not a priority.' (FG 4)

Within the discussions CNSs identified providing educational talks/seminars within their community and supporting community projects. However, the necessity to value ones expertise and knowledge and not sell oneself short was highlighted. Participants commented that they would not charge for their service while other professionals would and the saw this as a negative in relation to their perceived value.

'If somebody asked us to go and do a talk, we would do it and not charge but others are charging therefore if we don't charge we obviously don't have a value, we are not valuing ourselves so we actually put ourselves down.' (FG 2)

Supporting other agencies

This theme included the aspects of CNSs working with and across other agencies both as a component of their work or a collaborative aspect of their role. Specifically mentioned were consulting, supporting, providing advice and opportunities now and into the future. The specific aspects identifiable in the discussion did transcend across CNSs area of practice, however the community based CNSs had greater opportunity to link with and support other agencies. The residential CNSs

support other agencies on occasions through advice and information but were not openly available from their perspective due to employment arrangements. All CNSs reported supporting other agencies even if there were difficulties in doing so. These agencies ranged from governmental agencies such as education, policing, other hospital service (general, maternity, mental health) to voluntary agencies and families.

'I work closely with a nurse practice team but also external people like consultants, voluntary bodies who ring up and say I have a problem, how do I go about that and I get called into (schools) for students with problems or the general hospital or HSE and they mightn't be even a formal referral, but I insist a formal referral be made so my work is visible.' (FG 4)

The main support provided was in the form of advice but some CNSs did work directly with other agencies in providing services to persons in the community.

'People would come to me for advice or guidance and support, anyone can come like the police, education, social workers, families or other health professionals, there is a whole range, they ring to consult with you or ask advice and if advice is not enough I will go out to meet with them and assess.' (FG 5)

Although CNSs were providing support to other agencies they also saw a need for further development specifically in supporting people with ID who are vulnerable.

'There are people with ID that end up particularly in the prison system with communication problems and they need support, also I see people in the community and they shouldn't have to go into services due to ageing or lack of support especially after integration occurring we need to support them you don't want to see them move into a residential service because the proper facilities aren't there, so that makes it important for us to be able to support and offer support early.' (FG 1)

Also identified was the aspect of supporting general health services such as primary care teams and general hospitals.

'A major role for ID CNSs is on the primary care team, in the first instance it's the first point of contact for a person, so the ID CNS should be sitting on the primary care teams as a standard national policy also there's room for the CNS to expand their services within general hospitals and

throughout the community and our role has provided an opportunity, other professionals can see the importance of our role like GP's ringing and they're coming back more and more to us.' (FG 2)

CNSs recognized that to support outside agencies they needed greater autonomy and better inter-agency working between/across health and social services. The aspect of employment by organisations and predominately voluntary organisations rather than statutory agencies was identified as a factor that needed to be considered and lead the CNSs to question their future and the value their service could bring if utilised appropriately.

'I'm actually employed by a service, and that's a difficulty as there isn't great inter-agency working here or in the other services and that's something that needs to occur, where's the future of CNS role when you have a service holding on to you and doesn't want you to go outside the gates because they own you and pay for you, I think agencies are very reluctant to share the expertise that they have built up, whereas we could be out there looking after all the agencies, be it education, advice or consultancy but they are very reluctant to let us do that.' (FG 1).

DISCUSSION

Within this study CNSs spoke of the relationship that had grown over the years with clients, staff and families. This relationship was based on 'a getting to know each other' and was supported by the fact all CNSs had worked with the client population during their staff nurse experience. In addition their expert knowledge enabled the CNS to be best suited to deal with issues/problems as they arose. This was reinforced by the CNSs knowledge, which was broader than medical/nursing knowledge and included how the present issue may affect the client, what supports are necessary and the design of an individualised plan of care. These findings draw similarities to Savage, (2007) study on cystic fibrosis CNSs in Ireland which also identified that CNS's had a practical know how, expert knowledge, practical knowledge and that everyone knew each other so well. The complexity and nature of conditions within ID was highlighted as requiring a high level of skill and differentiation of people with ID from the general population. This has been recognised within the overall realm of the field of

disability where, academics within the disability rights movement have appraised the social model of disability, debating its generalisability and proposing potential alternatives to the social model (Burchardt, 2004; Gabel and Peters, 2004). A reconceptualisation of the social model has relevance within the present study, as in practice the unique skills of the ID CNS and their bio-psycho-social-educational model of care provision (Doody and Doody, 2012) is evident. These skills are utilised to perform an individualised assessment of need, plan of care, support implementation of the plan and monitor and evaluate its performance and suitability for the individual in order to provide a holistic person-centred approach to care. While these skills are promoted in ID nursing the high rate of consultation between staff nurses, family and MDT members in this study indicates that these skills are beyond that of a staff nurse and that the CNS operates at a level of expert practice, skill and knowledge.

Fundamental to care provision is that the client comes first and this was widely identified by the CNSs in the focus groups. Within this aspect advocating was identified but can be difficult; however, relational continuity was a factor which CNSs reported as assisting to advocate for clients (Heller and Solomon 2005). This relational continuity was important in facilitating a trusting relationship; allowing the CNS to get to know the person which facilitates a more equal partnership, promoting autonomy, choice and empowerment. These aspects are important for the provision of person-centred holistic care and enabling the CNS advocate on behalf of the client. Previous research has focused on quality-of-life for the individual and this has been widely endorsed in the ID field to consider issues of needs (Brown *et al.* 2009; Werner *et al.* 2009). However, this study identifies that in advocating and promoting quality-of-life, CNSs noted the difficulty that it may create in the sense that increased independence also increases risk and that this is a difficult aspect for staff working within organisations and families to balance. Often what is right is replaced by what is convenient, or the avoidance of risk can be

justified by debating issues related to client safety without truly weighing all issues against the rights, autonomy and independence of the client. Thereby the CNS has a key role in supporting the client and advocating on their behalf to reconcile this risk.

Working with families and assisting them care for their family member with ID was seen as a key aspect of the CNSs work. This is an essential role as services provided to families have been identified as a critical factor influencing family quality-of-life (Brown *et al.* 2009; Werner *et al.* 2009). As when family needs are met and family members enjoy life together and have the chance to do things that are important to them caring becomes less burdensome (Soresi *et al.* 2007). Supports provided should both reduce the negative effects produced by the difficulties if the situation (Summers *et al.* 2005) and strengthen the positive effects through interventions favouring family autonomy and empowerment (Soresi *et al.* 2007). This is evident in the CNSs involvement with families through providing support and education and in the decision making and care planning process. Specific to the CNS family relationship was the importance of continuity as it equates to increased confidence about the quality of care delivered (Heller and Solomon, 2005) and this relationship is characterised by mutual recognition of individual knowledge and expertise which encourages sharing of expertise and information and service satisfaction.

Within this study the CNSs were available to staff, MDT members, students and other agencies who could refer clients or consult with the CNS. Overall CNSs seem to be the first point of contact for all, be it nursing colleagues, families, healthcare professionals, students or other agencies. While these consultations were often informal they also resulted in developing practice guidelines and making recommendations for practice. This collaborative practice allows for resources to be pooled together to

ensure high quality care and create open effective communication based on mutual respect (Edwards 2011, Mcnamara *et al.* 2011). Overall the CNS has become a prominent figure as is the case in many international healthcare contexts (Campbell & Profetto-McGrath 2013). CNSs are an important source of information, and people prefer the experiential and clinical knowledge of peers over research articles (Sellars & Mayo 2013). This is evident in CNSs making research findings accessible and user-friendly to base their care and care recommendations on the findings and evidence from research (Gettrust *et al.* 2016). This is achieved by the CNS functioning as a role model where the CNS shares their specialist knowledge to improved patient care. While the focus on the clinical component of the CNSs role is clear and well recognised (Roberts *et al.* 2011) growth in the research role needs to be further supported and developed (Profetto-McGrath *et al.* 2010). Challenges included balancing CNS role demands and shifting priorities for the CNSs in their work and there needs to be support provided including a formal networking system to allow CNSs to share evidence, developing a credible research repository specific to CNSs' needs and organisational support (Profetto-McGrath *et al.* 2010). Collaboration and teamwork could be other methods of increasing CNS research activity. However, it would be important to ensure that such collaboration would generate research where the CNS research activity would be visible.

One aspect that needs to be addressed as highlight within the findings of this study is the autonomy of CNSs which cannot be achieved where CNSs are utilised in a shared role (CNS and nurse manager or CNS and staff nurse). Where some CNSs are also fulfilling a nurse management role and this dual role seems to arise out of the fact that both roles are at the same pay grade. The ability to fulfill both roles is an impossibility as management issues arise and occupy time. Therefore, a distinction needs to be made between leadership within the CNS role and nurse management, where service providers need to

distinguish between fulfilling a management role as related to unit management or their CNS role and cease utilising CNSs in a dual role. In addition, the use of CNSs as staff members and not attaining supernumerary status to take on a CNS caseload needs to be addressed. This may be as a result of the recent economic downturn and fiscal climate, where CNSs were appointed but not replaced.

Addressing these issues could afford CNSs the opportunity to champion change, collaborate and lead the profession (Gurzick & Kesten 2010).

CONCLUSION

This study offers a unique opportunity to highlight the contribution of ID CNSs where CNSs have much to offer for the benefit of patients, families, staff and services but they are a resource that needs to be used to its full potential and utilised within a CNS role only. Care provision is never static and within ID there are many complexities thereby there is a need for CNSs to highlight their work. As care provision continues to evolve, the demands and requirements of CNSs will also change. However, CNS must contribute to such changes and take an active role in service planning (Doody and Bailey 2011, Doody *et al* 2012b). The CNS is a valued resource in health care and has the potential to make a positive impact on patient care, particularly complex patient care. The skills and contribution of ID CNSs were clearly evident throughout the focus group discussions. However, CNSs need to be competent and active in many roles, as different roles are used at different times, with overlap occurring between roles. Here the difficult is that it may be unrealistic to be active in all areas at the same time. Within the focus groups, whether novice or expert CNSs recognised their need for professional and personal development. However, there is a need for CNSs to highlight their educational and training needs in order for the potential of CNSs to be attained. This study is unique in its investigation of the contribution of ID CNSs in an Irish context and has the opportunity to add to the literature base on the topic area. This knowledge

may support practice by highlighting the contribution of ID CNSs and create greater awareness of the role leading to greater collaboration/consultation in the future. Despite the small population of ID CNSs in Ireland the study provides the first overview of the contribution of ID CNSs. However, no single study can capture all that might be learned or known about a given topic. Thereby, the study can be viewed as a baseline for further research in exploring the current and potential roles of ID CNS's in meeting the needs of people with ID, their families and co-workers.

Relevance to clinical practice

This paper provides a clear picture of the contribution of ID CNSs within care and service provision in Ireland. To-date little were known about the contribution of ID CNSs and this study explores the views of ID CNSs identifying their contribution to a range of areas within practice, community, service provision and across services.

What does this paper contribute to the wider community

- This paper identifies the contribution of ID CNSs in Ireland.
- The findings of this study can be utilised by other CNSs working with the ID population.
- Opportunities and barriers to CNS practice are identified.

Contributions

Study design: OD, ES, LT; data collection: OD; data analysis: OD, ES, LT and manuscript preparation OD, ES, LT.

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