The contribution of intellectual disability clinical nurse specialists in Ireland: focus group interviews

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ID Nursing Context

- 1959 ID nurse education.

- Evidence regarding utilisation of nursing skills in Irish ID services is limited.

- Clinical career pathways developed in 2001 across all disciplines of nursing in Ireland.

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Research Aim

- To explore ID CNSs' contribution to care provision in Ireland.

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Research Process

- Exploratory qualitative approach.
- Ethical approval from the researchers university.
- Access through the National Council NM.
- Participants and recruitment - nonprobability purposeful sample via National Council list.
- Invitation letters and information sheets were distributed by the National Council to all ID CNSs presently working (n = 105).

Research Process continued

- Forty-nine CNSs responded.

- Dates, location and times were arranged.

- 31 CNSs across five focus groups participated.

- Written informed consent and participants had the right to withdraw at any time.

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Research Process continued

- Focus group interviews audio-recorded, were transcribed and between 75-95 minutes.

- Burnard's (2011) data analysis framework utilised.

- Six key themes regarding the ID CNSs' contribution.

Contribution to Client care

- Clear focus on CNSs' clinical role and supporting clients.

- Assessing, planning, implementation and evaluation core roles - risk management, environmental, needs, pain, distress, behavioural, functional and health assessments.

- Advocating and client came first.

Contribution to Client care

- Reinforced by CNSs' prior experience in the practice area and having worked in the service.

- Care delivery was based on working with the client and staff/family to devise a specific person-centred programme.

- Complexity and nature of conditions requires a high level of skill and differentiation of people with ID from the general population.

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Contribution to Client care

- Rights and needs of the client were to the fore – with all clients treated equally in the light of their needs.

- Relational continuity supported the CNS to advocate for clients and facilitated; a trusting relationship, knowing the person, partnership, autonomy, choice and empowerment.

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Contribution to Client care

- Creating independence creates risk which staff/families can find difficult to balance.

- Often what is right is replaced by what is convenient, or avoidance of risk is justified by debating issues related to client safety without truly weighing all issues against rights, autonomy and independence.

- CNS work to support carers reconcile risk.

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Contribution to Family

- CNS s worked families in a supportive way and in the home where necessary.

- Offered support, guidance, educational support, and were the first point of contact and a constant figure present for the family.

- Providing resources such as copy of plans and booklets.

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Contribution to Family

- Education was a major component to support the client and family in the long term.

- Regular and familiar person to the family and one that they often rely on.

- Lives are intimately intertwined and cannot be seen in isolation.

- Keep the family informed and up-to-date at all times along with trying to develop ties to the next generation of family member.

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Contribution to Staff

- Contribution focused on; clinical, educational, supportive and collaborative working with staff.

- Provided education and support on both a formal and informal basis - remove oneself to create ownership.

- First and last point of contact/support they were accessible.

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Contribution to Staff

- Beside every staff is a client and vice versa and support was mainly given in the form of education, training or advice.

- Training and education took a large amount of their time
  - hands-on at the beginning to facilitate staff to become educated and skilled to carry on the programme/intervention by themselves.
  - informal basis to nursing and non-nursing staff.

Contribution to the Service/Organisation

- Through collaborative working with team members and managing caseloads.

- Working with non-nursing grades and students, referrals, audits and organisation policies.

- Some independent/supernumerary status whereas others may have to be fulfilling other roles.

- Uneasiness regarding caseloads in the sense of the struggle between quality vs. quantity, complicated by the aspect of client complexity.

Contribution to the Service/Organisation

- Part of the MDT team and having a valuable role to play in supporting and advising others within the team.

- Team approach between day and night services, CNSs would educate and support them directly.

- CNSs receive referrals and refer clients to other team members.

- Stumbling block not always seen as autonomous or within their role to refer clients.

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Contribution to the Service/Organisation

- Referrals - additional caseload, difficult to manage but is decided upon based on priority of need.

- Conducted an audit of service or evaluated their service as a means to prioritise their service (DoN).

- Where not audited/evaluated send an annual report (DoN).

- Development of policy and practice guidelines and supporting student education.

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Contribution to the Service/Organisation

- Delivering their service across the whole organisation was a struggle.

- Held other roles such as a manual handling instructor, or a shared post - nurse manager/staff nurse due to non replacement and recruitment.

- Need to be careful not to be pulled in different directions, the organisation often sees them as being free and thereby call upon them.

Contribution to the Community

- Contributed in areas such as presentations, conferences, practice publications, research, deliver on academic or professional courses.

- However, need time and support for their own professional development and research.

- Difficult to balance the need to be research-active and develop evidence from their practice with their daily work commitments.

Contribution to the Community

- Active in education of nurses, students and others involved in caring both formal and informal.

- Hindered by own education level but willing to engage in further education pertaining to their specialist area to remain professionally relevant.

- Saw a necessity to engage in research in a more meaningful way to contribute to their role, and those engaged in formal studies, identify its benefit.

Contribution to the Community

- Saw research opportunity and actually doing research as different things, they lacked confidence and perceived a lack of support to assist them.

- Evidence of disseminating at conferences, poster presentations or writing for publication.

- Research had contributed to practice.

- Time seemed to be the greatest barrier along with support within the organisation.

Contribution to the Community

- True barrier was related to their struggle to balance the aspects of their role and maintain their core philosophy of being client-centred.

- Identified providing educational talks/seminars within their community and supporting community projects.

- However needed to value ones expertise and knowledge and not sell oneself short, perceived value as compared to others.

Contribution to Other Agencies

- Worked with and collaborated across other agencies.

- Consulting, supporting, providing information and advice.

- Governmental agencies such as education, policing, other hospital service (general, maternity, mental health, palliative) to voluntary agencies and families.

Contribution to Other Agencies

- Will to provide advice to those providing services to persons in the community.

- Identified further development specifically in supporting people with ID who are vulnerable.

- Need to support general health services such as primary care teams and general hospitals.

- To support outside agencies, they needed greater autonomy and better interagency working between/across health and social services.

Conclusions

- As current health policy advances the primary care model and the move to community based settings there is a need for the CNS to move beyond a unit/service based post.

- There is also a need to support CNSs to engage with academic work and develop areas for future research in collaboration with Universities or through the pursuit of Master's degree programmes.

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Conclusions

- CNSs should be accessible to mainstream and health services that people with ID use such as; general hospital, respite services, primary care teams, mental health services, palliative care, pre-mainstream schools, maternity and non-nursing agencies and open up their education and training opportunities to the public.

- There is a need to consider regional allocation of CNSs rather that service allocation to enable the CNS move beyond a service based post.

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