



Understanding the Contribution of Intellectual Disabilities Nurses: A Scoping Review

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Human Rights and Health Inequalities for People with Intellectual Disabilities

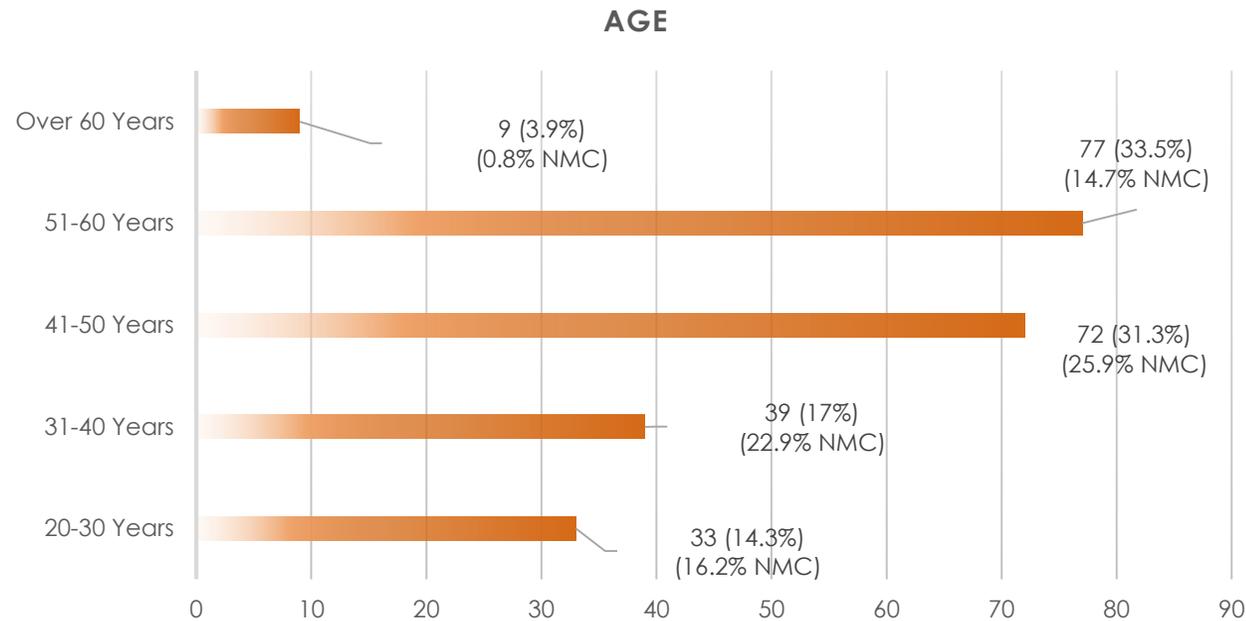
- 1.5 million people in the UK (1.5% adults, 2.5% children) have intellectual disabilities (Mencap, 2020)
- In 2019, 85% of the UK population who died were 65 or over; 2018-19, 38% of the people with intellectual disabilities who died were 65 or over (LeDeR, 2020)
- Early deaths associated with being of Asian / Asian British ethnicity (9.2 x greater than white British person) and other BAME groups (LeDeR, 2020)
- 73% of people who died had a DNACPR decision in place- 71% were deemed to be correctly completed (LeDeR, 2020)
- 42% of reviewers felt the person's care had not met good practice standards (LeDeR, 2020)

- Professor Kay Mafuba and team were commissioned by the Royal College of Nursing to carry out a study into the contribution of intellectual disabilities nurses
- A literature review outlining specific roles / interventions was carried out, identifying 154
- We carried out an online survey – 230 participants (intellectual disabilities nurses) from 7 countries identifying 878 interventions
- We also asked for case studies from the nurses' working lives

Context of Study –
What do Intellectual
Disabilities Nurses
Do? (and does it
make a difference?)

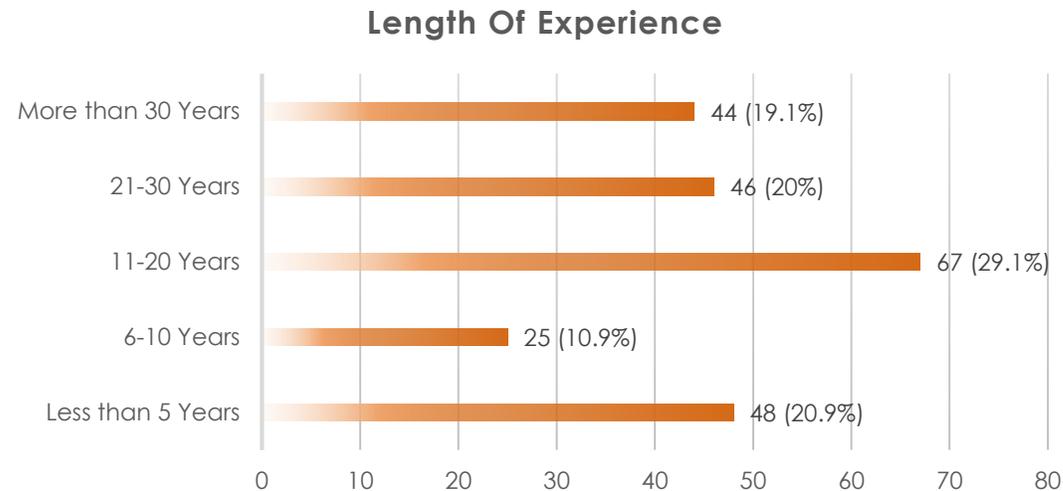
Participants by Gender and Age

- 85.2% female (compared with 89.2% on NMC register, 51% in general population)
- 68.7% over 40 years old



Qualifications and Experience

- Over 40% had a degree, with 31% having postgraduate qualifications, but over 28% would not be able to enter the NMC register if they applied now.
- 39% of the participants are eligible to retire, or will be in the next ten years



Participants' Employer Organisations



51 Case Studies, 23 Intervention Groups

1. Empowerment

Case study 5. Supporting and advocating for adults with ID

“Empower the person to have some control and input and say in their lives. Work collaboratively with the person and whoever is important to them”.

Case study 2. Informed consent to cataract procedure given. Enabled person to tolerate that procedure and the later one on the other eye.

“they would not have gone ahead had I not been there to support him through the procedure, subsequently less anxious when having the other cataract removed as had a positive experience the first-time round.”

Case study 4. Health facilitation

“I challenged a staff team who contacted me to ask how they 'could get it signed off that [a lady] doesn't have to have a mammogram'.”

Case study 3. Develop individualised pathways in a prison setting

“we developed a transgender pathway for people with ID in a prison setting”

2. Advocacy (Human Rights)

Case study 7. Mental capacity assessment

“Ensuring mental capacity and best interest decisions are made prior to any procedures and reinforcing that it is the law”.

Case study 8. Community life

“This person is now living within the community. Though he has some restrictions he is living the life that he likes, doing things he loves in a community and not within hospital. This is something the person has hoped for a long time and is enjoying having a life, being able to see family and do the things they love.”

Case study 6. Community nursing (adults)

“I hold people on my caseload with varying degrees of intellectual disability... I support for accessing health screening, I fight for equality in the access to health. I have saved lives by challenging decisions to not treat people due to their illnesses being put down to behavioural issues. I advocate on behalf of my patients that are unable to do so themselves”

Case study 9. Intellectual Disabilities Nursing

“Pregnant lady with unborn child under child protection procedure. Education on pregnancy and parenting given. Acted as an advocate at child protection meetings, 1 year on and both parent and child are thriving together.”

3. Communication – Including Listening

Case study 11. Facilitating communication

“We ensured residents were able to FaceTime relatives, we sent newsletters out to relatives which entailed pictures of activities we have been doing since lockdown. Providing relatives with reassurance whilst they are unable to visit. We ensured the information about covid restrictions was applicable to resident's needs, i.e., easy read and pictures format. This had a huge impact on both residents and relatives, reducing stress and anxiety.”

Case study 12. Communicating bad news

“This also worked really well during the lockdown when he could not go in and also when his mum found out she had cancer”

Case study 10. Children and young people

“I provide ID input for the organisation, developing and improving the service to reflect a more holistic approach to care, bringing expertise in areas such as behaviour support or communication.”

Case study 12. Using social stories

“[if he] does not know what is happening he can display behaviours, which has led to him being excluded from several health services....[we] developed a social story to let the gentleman know what exactly was going to happen and who would be performing the task. This was a huge success”.

4. Assessment

Case study 14. Teaching others about assessing needs

“I teach student nurses and health professionals about working in a person-centred way, assessing health needs of people with ID and meeting those health needs”.

Case study 16. Assessing risk

“I work with people with intellectual disabilities who offend or at risk of offending. I provide assessment and interventions to support individuals to change their behaviour and reduce their risk .”

Case study 18. Challenging behaviour

“This made the period he spent in hospital shorter and ensured the new care team felt supported by staff with good knowledge and relationships with the young man while he settled into new placement. We could share PBS plans and advise what worked well with him and what had not. His transition back to the community was very successful and he continues to thrive. ”

Case study 15. Assessing health needs

“We work through observations, assessments, information gathering, pulling together multi-disciplinary teams, analysing and being creative in our strategies and recommendations to meet the individual needs of the patient and their families”.

Case study 17. Children and young people with ID who present with behaviours of concern

“The support I provide makes a difference as it gives an understanding as to why the person with an intellectual disability performs behaviours of concern, taking account of all existing/underlying biopsychosocial issues. The focus of intervention is on proactive strategies and teaching of new skills. ”

11. Health Facilitation / Acute Liaison / AHCs / Diagnostic Overshadowing

Case study 30. Health liaison

“....she had 17 rotten teeth, abscess and infection. All rotten teeth extracted and antibiotics given for infection. Supported with aftercare, and behaviours stopped at day service.”

Case study 30. Adapting information

“Provision of easy read/accessible information give the patient information in a format that enhances understanding and increases the potential for the patient to consent themselves. ensuring the required reasonable adjustments are made to enhance care provision.”

13. Medication (Polypharmacy, STOMP, STAMP)

Case study 34. Medication (assessment and monitoring)

“An individual with food intolerance and changing bowel habits for a year. Implemented bowel charts and spoke with parents for assessment. Took information to GP with concerns of constipation. GP prescribed laxative. Through monitoring we achieved a therapeutic dose for the individual which allows them to have regular bowel movements. Throughout this I supported parents and provided information on the medication to reassure their concerns. The individual now has a bowel management plan in place involving parents, college and respite.”

Case study 35. Intellectual Disabilities Nursing – Child

“...I have seen children on multiple medications which were causing side effects that people weren't recognising or ignoring because the person was nonverbal. I have worked with families to enable them to understand the role of medications and non-pharmacological interventions, so that we could manage the anxieties about reducing and withdrawing medication.”

21. Resilience and Capacity

Case study 47. Facilitating and coordinating transitions

“My involvement in facilitating other professionals to be involved, liaison with GP supported this service user having as many investigations as possible whilst under GA [general anaesthetic]. I ensured everyone talked to each other and reiterated useful information about presentation of the person to help decision making. I supported the family and carers emotionally and reassured staff who were unsure on next steps when plan did not work in a straightforward way. Flexibility in approach and knowledge supported the process and this service user had only one GA for multiple examinations and investigations to help maintain his health.”

Case study 48. Staff development in ID services

“Involved staff in its development. Increased staff knowledge and understanding. Outcome - more informed staff team, quality of life improved, attitudinal change, placement secured.”

Case study 49. Family support (adult)

“This family appeared lost in how to support their son as usual parenting rules didn't seem to work. They lacked confidence and were often tearful and frustrated. Now they have the tools and confidence to be able to move forward as a family unit and embrace whatever happens in the future with sound skills and knowledge.”

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1. *Empowerment*
 2. *Advocacy (human rights)*
 3. *Communication – including listening*
 4. *Assessment*
 5. *Holistic care; biopsychosocial dementia*
 6. *Safeguarding / human rights/ child protection*
 7. *Sleep*
 8. *Building relationships - with others / community / services / families / service user*
 9. *Positive Behavioural Support (PBS)*
 10. *Health promotion*
 11. *Health facilitation / acute liaison / AHCs / diagnostic overshadowing*
 12. *Care co-ordination and end of life care*
 13. *Medication (polypharmacy, STOMP, STAMP)*
 14. *Reasonable adjustments*
 15. *Educating and training other professionals*
 16. *Educating and training family members*
 17. *Mental health and wellbeing*
 18. *Child development and support*
 19. *Community presence, relationships, choice, competence (O'Brien's 5 principles)*
 20. *Transition support*
 21. *Resilience and capacity*
 22. *Crisis intervention*
 23. *Co-production*

Final Thoughts

Case study 51. Advocating

“...to advocate for people with an intellectual disability. Ensure inclusion and human rights are upheld. Increase quality of life through care we provide and ensure the person is in the centre of everything we do.”

“Empower the person to have some control and input and say in their lives. Work collaboratively with the person and whoever is important to them.”

Any Questions?



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