Original Research

Understanding the contribution of intellectual disability nurses. Paper 2 of 4 - Survey

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Abstract

The objective was to identify ID nursing interventions and their impact on the health and healthcare of people with IDs. Data was collected using an online survey questionnaire from a voluntary response and snowball sample of 230 participants. Thematic, descriptive statistical, and inferential statistical analyses were undertaken. We identified 878 interventions that could be undertaken by ID nurses from 7 countries. We categorised the interventions into five themes: effectuating nursing procedures, enhancing impact of ID services, enhancing impact of mainstream services, enhancing quality of life, and enhancing ID nursing practice. Findings demonstrate that ID nurses play important roles in improving the health and healthcare experiences of people with IDs.

Keywords

intellectual disability, effectuating nursing procedures, enhancing impact, enhancing quality of life, nursing procedures

Introduction and background

This is part 2 of a 4-part series. The overall aim of the research was to identify nursing led and or nursing centred interventions that are in place to address the challenging and changing needs of

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Data Availability Statement included at the end of the article

people with intellectual disability. Paper 1 reports the findings from the scoping literature review that was undertaken between 1 February 2020 and 31 May 2020. This paper (paper 2) reports the findings from an online cross-sectional survey of intellectual disability nurses that identified 5 major themes of nursing interventions; effectuating nursing procedures, enhancing impact of intellectuality disability services, enhancing impact of mainstream services, enhancing quality of life, and enhancing intellectual disability nursing practice. Paper 3 reports the findings from evaluation questions of an online survey of intellectual disability and other nurses working with people with intellectual disabilities of how they understood these interventions. Paper 4 reports the impacts of intellectual disability nursing interventions and other nurses working predominantly with people with intellectual disabilities.

There are an estimated 1.5 million people with intellectual disability in the UK (Mencap, 2020). People with intellectual disability experience avoidable disparity in health and health care (Kerr, 2004; Straetmans, et al., 2007; van Schrojenstein Lantman-de Valk et al., 2007; Backer et al., 2009; Hatton and Emerson, 2015; Kavanagh et al., 2017; LeDer, 2020). These disparities result from poor access to health services, limited options in lifestyle, and poor living standards. What is not clear from existing research is a clear description of the roles undertaken by intellectual disability nurses to reduce these disparities.

The life expectancy of people with intellectual disability is increasing (Truesdale and Brown, 2017). They have greater health needs than the general population (Backer et al. 2009; Savage and Emerson, 2016; Emerson et al., 2016a; Emerson et al., 2016b; Robertson et. al., 2017; Llewellyn et al., 2015; Emerson and Brigham, 2015; Mencap, 2007; Heslop et al., 2013; Heslop et al., 2014; Robertson et al., 2015; Bakker-van Gijssel et al., 2017). Their health problems are commonly undiagnosed, misdiagnosed, and untreated (Mencap, 2007; DH, 2007; Heslop et al., 2013; Heslop et al., 2014; Robertson et al., 2015). Mortality rates remain significantly higher, than those of the general population (Heslop et al., 2013; Heslop et al., 2014; Robertson et al., 2015; Bakker-van Gijssel et al., 2017). People with intellectual disability are more likely to be dependent on others for their health and healthcare outcomes (Campbell and Martin, 2009), and their healthcare outcomes could be improved through appropriate intellectual disability nursing interventions (Oullette-Kuntz, 2005).

People with intellectual disability experience poor access to healthcare (Melville et al., 2006; Kavanagh et al., 2017; Brown et al., 2010), and poor uptake of health services amongst this population is a longstanding issue (Allerton and Emerson, 2012; Robertson et. al., 2014). Evidence points to a need for targeted interventions to have positive outcomes (McIlfatrick et al., 2011; Chauhan et al., 2010; Robertson et. al., 2014). Intellectual disability nurses are expected to deliver effective nursing care to people with intellectual disability in challenging circumstances (Thomas and Kerr, 2011). Preventative nursing interventions are effective in identifying the health needs of people with intellectual disability (Emerson et al., 2011; Robertson et. al., 2014). However, there is limited research that identifies effective interventions undertaken by intellectual disability nurses (Mafuba et al., 2020).

Existing studies have identified some important interventions undertaken by intellectual disability nurses, for example, they enable creative communication (Taua et al., 2017), they make reasonable adjustments (Drozd and Clinch, 2016), they trouble shoot (Brown et al., 2016), they train mainstream health care staff (MacArthur et al., 2015); Lloyd and Coulson, 2014; Doody et al. 2013), they enhance the effectiveness of other healthcare services (MacArthur et al., 2015), and they provide information on healthier lifestyles (Lloyd and Coulson, 2014; Taggart et al., 2011). In addition, intellectual disability nurses are reported to undertake health checks (Chapman, 2015), provide advice (Brown et al., 2012), manage complex long-term conditions (Marsham, 2012),

advocate for people with intellectual disability (Llewellyn and Northway, 2007; Llewellyn, 2005), and raise the profile of the health needs of people with intellectual disability (Barr et al., 1999). Furthermore, intellectual disability nurses play an important role in addressing determinants of health for this population (Mafuba et al., 2018a; Mafuba et al., 2018b; Mafuba and Gates, 2015; Mafuba, 2013; Mafuba, 2009), promote health (Taua et al., 2012), flag and identify needs (Oulton et al., 2019; Doody et al., 2019; Sheerin, 2012).

Other interventions identified in current studies include; reducing the impact of health inequalities (Cope and Shaw, 2019), bereavement counselling (McCarron et al., 2018), assessment of mobility decline in older people (Nelson and Carey, 2016), reviewing and assisting with the withdrawal of antipsychotic medication (Adams and Shah, 2016), providing advice on treatment options (Morton-Nance, 2015), pain management and problem solving (Nelson and Carey, 2016; Jenkins, 2012; Doody et al., 2013; Auberry and Cullen, 2016; Cleary and Doody, 2017), helping medical staff to make decisions (McCarron et al., 2018; Wagemans et al., 2015; Ng, 2011), and facilitating collaborative working (Arrey, 2014).

What is clear from current literature is that intellectual disability nurses do not only work directly with people with intellectual disability, but more importantly play significant roles in the delivery of effective interventions by supporting other health and social care professionals who work directly with people with intellectual disability. To effectively meet the health, healthcare, and social care needs of people with intellectual disability, intellectual disability nurses need to engage in, and assimilate a wide range of emergent roles (Northway et al., 2017). Research is therefore needed to identify, describe, and explain the interventions undertaken by intellectual disability nurses.

Methods

The survey method

We use the term '*survey*' to describe our method, our data collection method, and our data collection tool (Creswell and Creswell, 2018). By using the survey method, we were able to collect information on participants' biographical information, countries in which participants practiced in, and the types of organisations they worked for, patient (service user) group, and interventions undertaken by the participants, case studies, and examples of the impacts of the interventions undertaken by the participants, and participants' understanding of intellectual disability nursing roles and interventions. Using the survey method offered us an opportunity to test the relationships between participants' background data and the interventions they were involved in. By using an online survey questionnaire, we were able to reach many participants from multiple countries.

Survey questionnaire development. We developed an online survey questionnaire to identify intellectual disability nursing interventions, the impact of the interventions, and participants' understanding of their roles. The questionnaire was developed, and pilot tested for reliability and validity.

Sampling and participant recruitment. Participants were registered nurses in their own countries, were practising during the data collection, and worked exclusively with people with intellectual disability. Ethical approval was obtained through the lead organisation. Participants were recruited through professional networks. We used a combination of voluntary response sampling (McCombes, 2020) and snowball sampling (Creswell and Planko, 2017). Blending voluntary response sampling with snowball sampling/chain-referral sampling provided an opportunity for participants to distribute the survey to their colleagues in their professional networks. Consent was obtained through the online

survey form. We used the G*Power sample size calculator (Heinrich State University, 2020), and the appropriate sample size suitable for Pearson correlations and Pearson Chi-square tests was estimated at $n = 225$.

Data collection. We used JISC Online Surveys platform (https://www.onlinesurveys.ac.uk/) to collect data. The survey was open from 13 October 2020 to 31 December 2020.

Quantitative data analysis. We undertook descriptive analysis of quantitative data using SPSS 27.0 (IBM, 2020). Quantitative data analysis was undertaken by the lead researcher. Two members of the research team were involved in the qualitative data analysis with the aid of NVivo 12 (QSR International, 2020). The lead research and the rest of the research team members acted as reviewers to agree emerging themes.

We adopted three approaches to analysing qualitative data. For questions 9-12, that we are reporting in this paper, we adopted qualitative content analysis (Neuendorf, 2011). Using this method enabled us to identify the interventions undertaken by the participants, as well as organise them into themes. After identifying the interventions, we organised them into clusters across the lifespan (maternity, children, adults, older adults, all age groups, and end of life). We generated analytical themes of the interventions (*Effectuating nursing procedures, Enhancing intellectual disability services, Enhancing mainstream services, Enhancing intellectual disability nursing practice,* and *Enhancing quality of life)* (see Figure 10).

Findings and discussion

Here we present our findings and discussions under the following headings: participant profiles, emerging interventions across the lifespan (maternity, children adults, older adults, all age groups, and end of life.

Participant profiles

Figure 1 shows that the age of participants presents a significant workforce challenge in the next few years. Data show that 68.7% of participants were over 40 years. This compares with 41.4% of the total number of Nursing and Midwifery Council (NMC) registrants in 2020 (Michas, 2020; NMC, 2020).

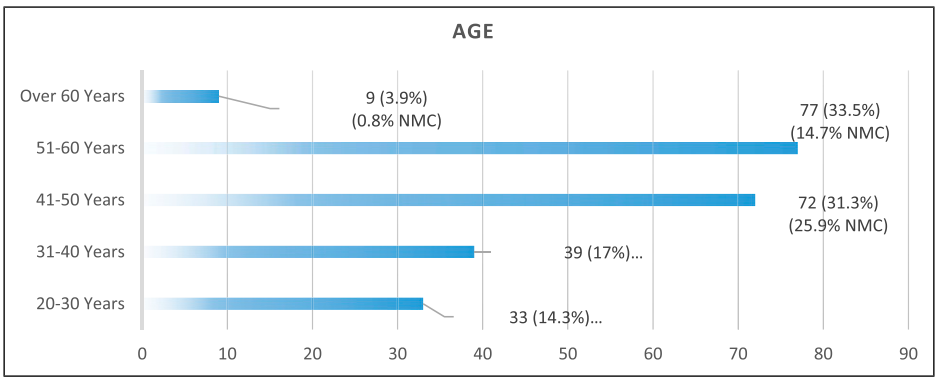


Figure 1. Age of participants.

Perhaps what is more worrying is the proportion of intellectual disability nurses who are between 51-60 years (33.5%) as compared to the NMC register (14.7%). The statistics appear to be extreme in those over 60 years old. As a proportion, there were 4.9 times more intellectual disability nurse participants (3.9%) as compared to 0.8% of total NMC registrants.

The participants were 85.2% females and 14.8% males (see Figure 2). This compares with 89.2% females and 10.8% males on the NMC register (NMC, 2020). This compares with 51% (females) to 49% (males) in the most recent UK population census (ONS, 2011). There is clearly a need for more males to join the intellectual disability nursing profession.

Figure 3 shows that 19.1% of participants have more than 30 years' experience. Most of these participants would more likely be entitled to retire. It is also important to note that 20% of participants have more than 20 years' experience and will be eligible for retirement in the next 10 years. Potentially, this means that 39.1% of intellectual disability nurses may be able to retire in the next 10 years. These statistics need to be understood in the context of the NMC leavers' survey (NMC, 2020), which showed that 53.5% of UK trained NMC registrants who left the register and participated in the NMC survey were below the age of 60 years. Also, and perhaps what needs to be considered in the NMC survey is that 9.4% of the respondence were below the age of 50 years. The most common reason cited was 'too much pressure' and 'poor mental health'. These realities are also likely to influence whether intellectual disability nurses continue to practice.

In the UK, since 2010, the minimum requirement for entry onto the register is a degree. Figure 4 shows that a significant proportion of participants (19.1%) were educated to diploma level, and (9.2%) had other qualifications such as advanced diploma and enrolled nurse certificate. This means that 28.3% of participants do not have the academic qualification required to enter the NMC register if they were to apply for registration today.

Having appropriate pre-registration, or post registration nurse training is important to enable engagement in appropriate interventions. Of the 230 participants, 7 were not intellectual disability nurses (see Figure 5), and it is unclear what training they have had to be able to understand the complex needs of people with intellectual disability.

The number of professional registrations in Figure 5 is more than 230 because some participants had more than one registration.

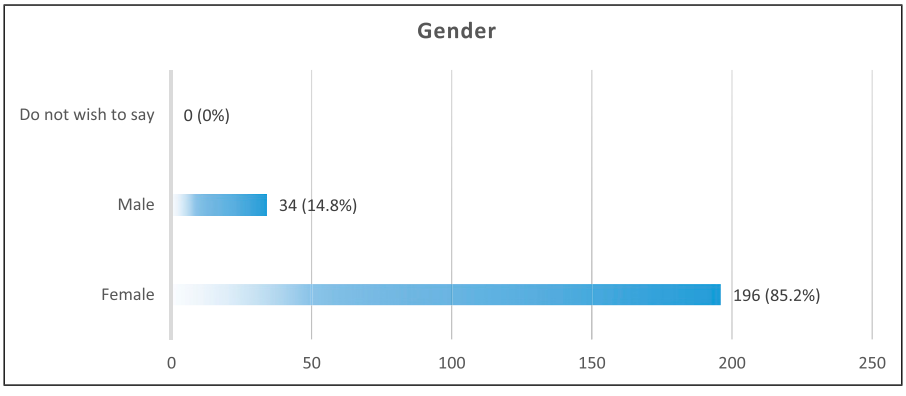


Figure 2. Gender of participants.

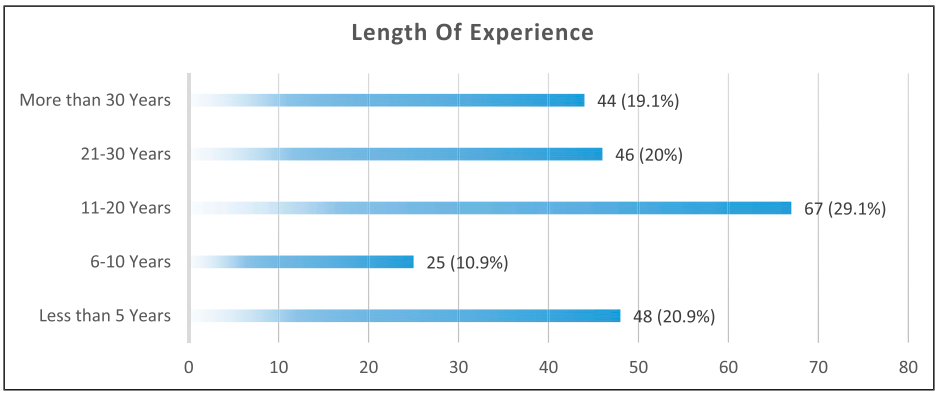
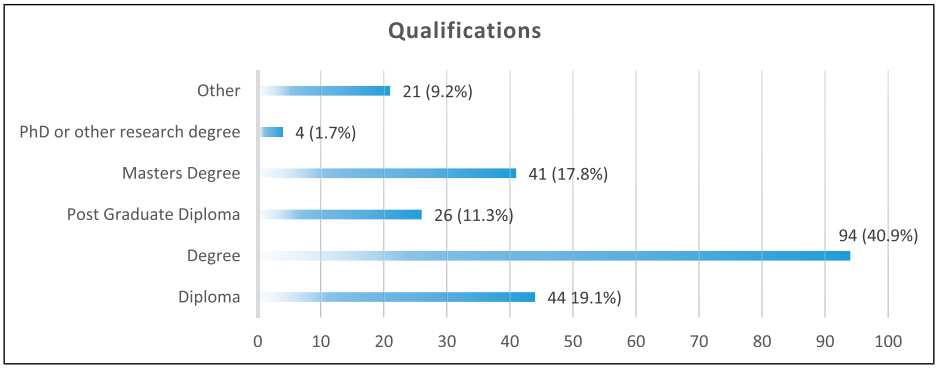


Figure 3. Participants' length of experience.



Figures 4. Participants' qualifications.

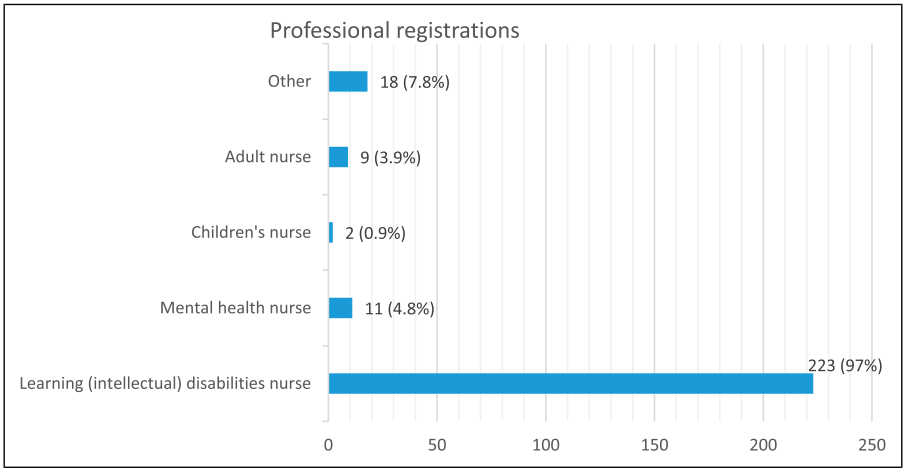


Figure 5. Professional registrations of participants.

Where participants practice. 59.6% of participants were practicing in England, followed by Scotland (16.1%), other countries (9.2%), Northern Ireland (8.7%), and Wales (6.5%) (see Figure 6). Participants from other countries were from the Republic of Ireland, New Zealand, and Isle of Man.

Figure 7 shows that most participants worked in the community (54.8%). The proportion of intellectual disability nurses who work in other organisations is significant at 14.3%. This proportion includes intellectual disability nurses working in improvement services, practice education, health education commissioning, independent consultancy, prison nursing services, health care commissioning, New Zealand equivalent of the UK NHS, Department of Health and Social Care (Isle of Man), Health Service Executive (Republic of Ireland), Clinical Commissioning Groups, Department of Works and Pensions (DWP), and Care Quality Commission.

It could be argued that the diversity of organisations and settings in which intellectual disability nurses who participated in this study work clearly demonstrates the complexity of the landscape in which intellectual disability nurses now practice. The proportion of intellectual disability nurses working in school nursing, and acute mainstream hospitals demonstrates emergent roles. Some of these roles are likely to require intellectual disability nurses to develop advanced nursing practice skills to meet the needs of people with intellectual disability in these settings.

Figure 8 demonstrates that intellectual disability nurses work across the lifespan with 79.1% of participants working with adults, 9.6% of interventions involved pregnant women, 25.2% involved children, 33.5% involved older adults, and 18.7% involved palliative (end of life care). Working across age groups requires a significant repertoire of skills to undertake evidence-based interventions that result in positive outcomes for people with intellectual disability.

Emerging interventions across the lifespan

We have identified 878 interventions undertaken in a wide range of settings and across the lifespan (maternity (4), children (156), adults (384), older adults (129), all age groups (393) and end of life

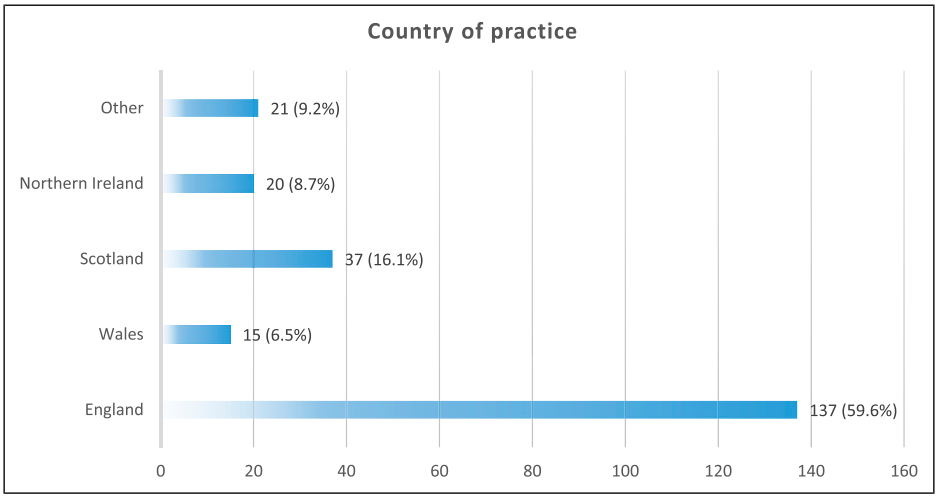


Figure 6. Countries where participants practice.

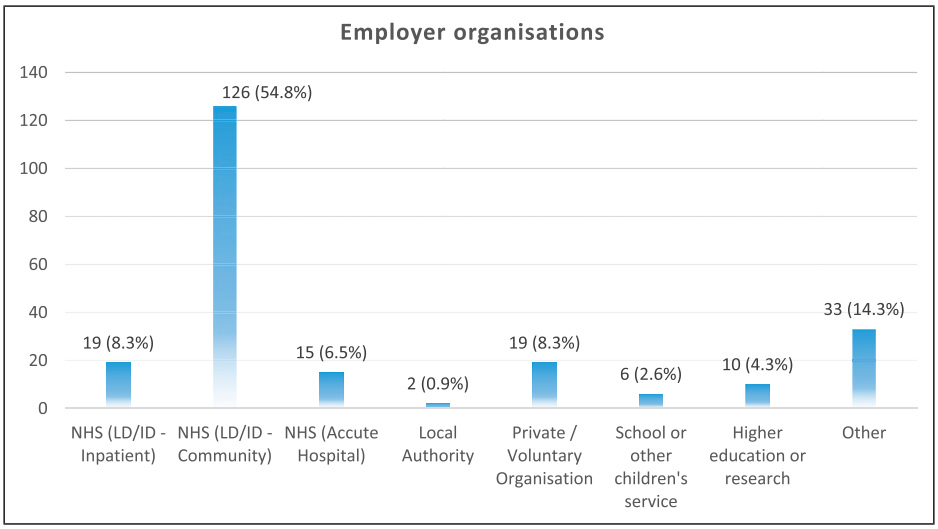


Figure 7. Participants' type of employer organisations.

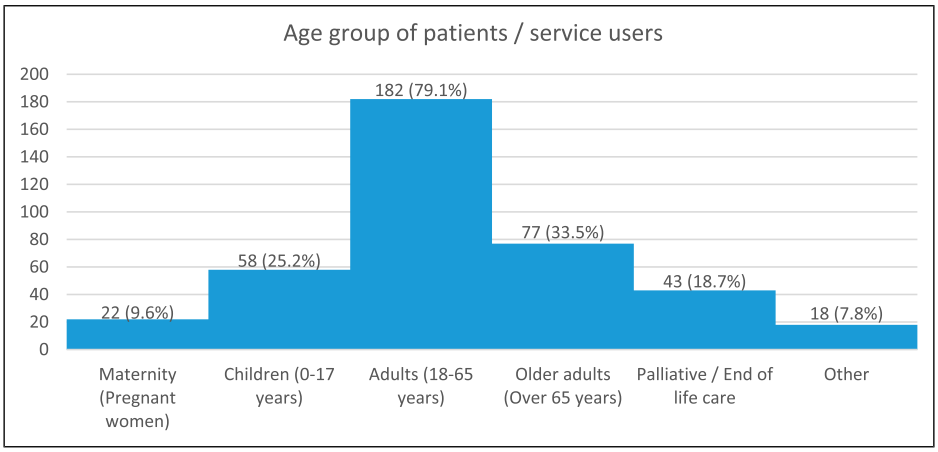


Figure 8. Distribution of age groups of people participants worked with.

(19) (see Figures 9 and 10). The higher total from lifespan stages as compared to the total number of interventions is accounted for by the fact that a significant proportion of the interventions are common across age groups. We discussed these under a separate theme, 'all age groups' to distinguish them from those interventions that are unique to each stage of the lifespan.

We categorised the 878 interventions into five themes; *effectuating nursing procedures* (28%), *enhancing impact of intellectual disability services* (20%), *enhancing impact of mainstream services* (26%), *enhancing intellectual disability nursing practice* (5%), and *enhancing quality of life* (21%). The *effectuating nursing procedures* interventions are intellectual disability nursing activities that involve performing practical tasks with people with intellectual disabilities. The *enhancing impact of intellectual disability services* theme incorporates interventions directed at

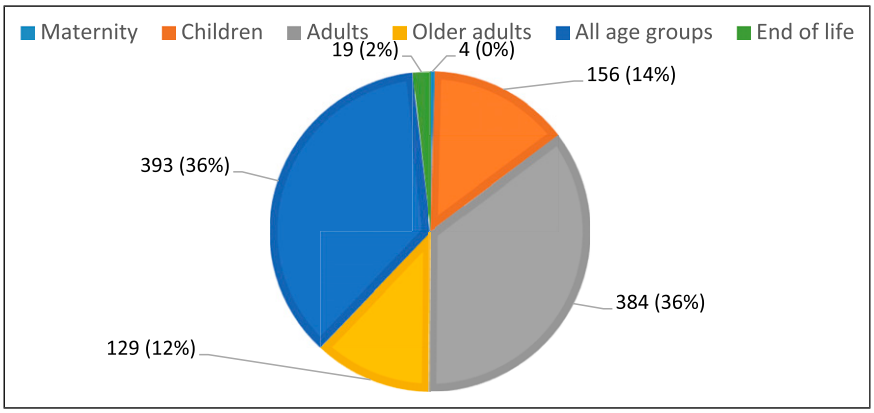


Figure 9. Distribution of interventions across the lifespan.

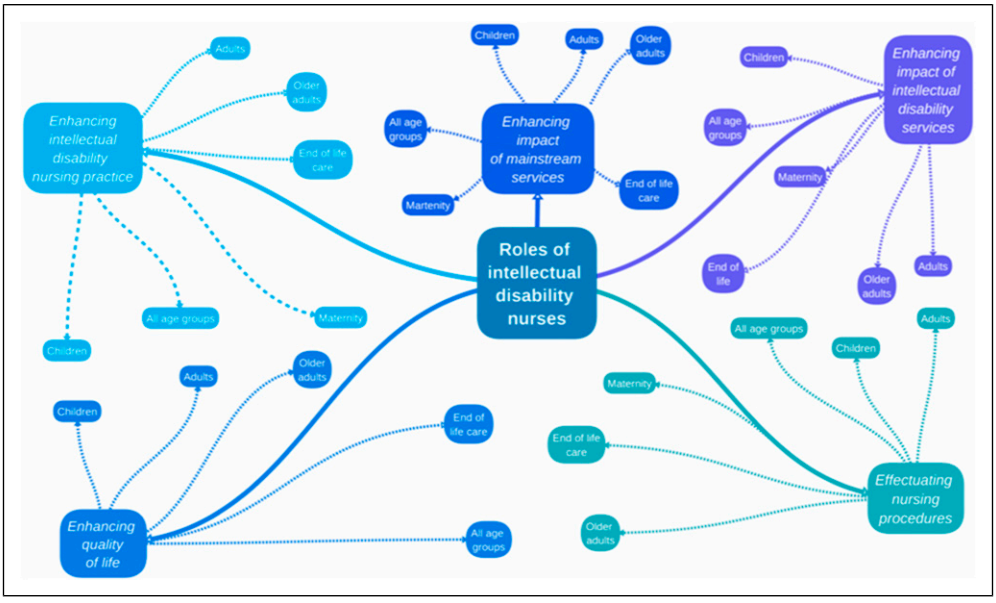


Figure 10. Roles of intellectual disabilities nurses.

improving the work of organisations that specifically specialise on working with people with intellectual disability such as residential home services. The *enhancing impact of mainstream services* theme incorporates interventions directed at improving the work of mainstream healthcare organisations. The *enhancing intellectual disability nursing practice* (5%) theme incorporates activities undertaken by intellectual disability nurses to improve their own practice and the intellectual disability nursing profession. The *enhancing quality of life* theme incorporates interventions undertaken by intellectual disability nurses to promote the health and wellbeing of people with intellectual disability.

Our findings show a very limited involvement of intellectual disability nurses with pregnant women. This is consistent with our findings in the literature review stage of this project (Mafuba et. al., 2020). This may be because not many women with intellectual disability choose to have children. An alternative explanation could be that midwifery is a separate profession from nursing, meaning that the skills required for intellectual disability nurses to be involved are beyond the scope of their practice. Perhaps what is more concerning are the limited specific interventions undertaken by intellectual disability nurses with respect to end-of-life care (2%) (see Figure 9). It might be that not many intellectual disability nurses practice in palliative care settings. The LeDer program, has consistently shown that people with intellectual disability are much more likely to die in hospital than the general population (LeDer, 2017). What needs to be understood here is how people with intellectual disability are supported, and by whom in the last days in hospital.

Maternity interventions. As noted earlier, maternity is outside the competence scope of intellectual disability nursing practice, so it is likely that intellectual disability nursing interventions in relation to pregnant women will always be limited. However, it could be argued that the need for intellectual disability nurses to work with women with intellectual disability to access maternity and pre-natal screening services is important (Marriott, et. al., 2015; McCarron et al., 2018). Also, providing this support is important because without such support it is likely that pregnant women with intellectual disability may be unable to access appropriate maternity services. Furthermore, expectant mothers with intellectual disability are likely to face child protection issues and intellectual disability nurses can undertake important interventions to support them through these processes. Going through pregnancy is a challenging experience for most women, and it could be argued that the challenges are likely to be greater for women with intellectual disability. Intellectual disability nurses are well placed to work directly with pregnant women with intellectual disability through supporting them psychologically. Such interventions are likely to be complex and varied and will require intellectual disability nurses to develop a complex repertoire of knowledge and skills.

Interventions across all age groups. In the survey some participants reported that they were involved in; assessing and managing co-morbidities associated with intellectual disability, autism, and mental health, assessing people for equipment, carrying out diagnostic assessments, and sleep assessments. These findings are consistent with previous studies (McCarron et al., 2018); Quinn and Smolinski, 2018; Doody et al., 2017; Delahunty, 2017; Sutherland, 2017; Nelson and Carey, 2016; MacArthur et al., 2015; Morton-Nance, 2015; Chapman, 2015; Brown et al., 2012; Sheerin, 2012; Ng, 2011; Mason and Phipps, 2010; McKeon, 2009; Slevin and Sines, 2005).

Care planning, implementing care interventions and managing health conditions was widely reported and these have been identified previously (Taua et al., 2012; Dahm and Wadwnsten, 2008). The importance of the intellectual disability nurse role in addressing the determinants of health and health inequalities experienced by people with intellectual disability is an important one and has been previously highlighted (Cope and Shaw, 2019; Mafuba et al., 2018a; Sheerin, 2012). What is clear from our findings is the complexity and varied nature of the interventions performed by intellectual disability nurses across the lifespan. This complexity requires intellectual disability nurses to be adaptable to deliver effective care to people with intellectual disability.

Our evidence demonstrate that intellectual disability nurses spend a significant amount of time focusing on ensuring that other intellectual disability staff, and voluntary and independent services effectively support people with intellectual disability. These interventions are at individual, organisational and strategic levels (Mafuba et al., 2018a). This is important because intellectual

disability nurses need to support other healthcare and social care professionals who work directly with people with intellectual disability in the community across the lifespan.

In addition to interventions undertaken by intellectual disability nurses to enhance the impact of intellectual disability services, we identified interventions that focus on ensuring *enhancing the impact of mainstream services*. Some of the interventions we identified were highlighted in previous publications (Mafuba et al., 2018b; Adams and Shah, 2016; Mafuba et al., 2018a; Mafuba et al. 2018b; Mafuba and Gates, 2015; Mafuba, 2013; Brown et al., 2012; Mafuba, 2009; DH, 2007; Cope and Shaw, 2019; (Mafuba et al., 2018a; MacArthur et al., 2015; Delahunty, 2017; Northway et al., 2017; Northway et al., 2017; Morton-Nance, 2015). It is evident from our evidence that intellectual disability nurses undertake important interventions in enhancing the impact of mainstream services and healthcare professionals who work in these services. This is important because intellectual disability nurses need to support other healthcare professionals who work directly with people with intellectual disability across the lifespan.

It could be argued that like all other professions, the intellectual disability nurses owe it to themselves and the people they support to ensure that they develop and implement interventions that have a positive impact. It is in this context that we are surprised at the limited number of activities that focus on *enhancing the impact of intellectual disability nursing practice,* and these findings reflect previous studies (Oulton et. al., 2019; Doody et. al., 2019; Cleary and Doody, 2017; Marriot et al., 2015; Taggart et al., 2011), Interventions to enhance intellectual disability nursing practice only make up 5% of the interventions we identified. Clearly there is a need for more work in this area to improve how intellectual disability nurses assimilate and adopt new and emerging interventions that benefit people with intellectual disability.

Intellectual disability nurses play an important role in improving the quality of life, health, and wellbeing of people with intellectual disability. We found a wide range of interventions that focus on enhancing the quality of life across the lifespan, and some of these have been previously identified, and these include; enabling and supporting healthy lifestyle choices and diet (Mafuba et al., 2018a), advising and advocating for people with intellectual disability and their families (Cope and Shaw, 2019; McCarron et al., 2018; Ring et al., 2018; Doody et al., 2017; Brown et al., 2016; Morton-Nance, 2015; Dalgarno and Riordan, 2014; Taua et al., 2012; Brown et al., 2012; Llewellyn and Northway, 2007; Llewellyn, 2005), enabling, empowering and educating people with intellectual disability to make their own choices (Sheerin, 2012), educating people with intellectual disability and their families and carers about health and healthy lifestyles and how to cope with diagnoses and symptoms (Mafuba et al., 2018a; Mafuba and Gates, 2015; Mafuba, 2013; Taggart et al., 2011; Mafuba, 2009; Cleary and Doody, 2017; Morton-Nance, 2015; MacArthur et al., 2015; Dalgarno and Riordan, 2014; Northway et al., 2017; Brown et al., 2012; Slevin and Sines, 2005), human rights education (service users), supporting social connectedness and community integration (McCarron et al., 2018), supporting individuals to remain in their home (Northway et al., 2017), adapting environments, adapting information for easy read, developing accessible health information, producing hospital passports, and producing Covid-19 passports. The extent of these interventions clearly demonstrate that intellectual disability nurse interventions are wide ranging across the lifespan.

Interventions for children. Our data show that intellectual disability nurses undertake a wide range of behaviour assessments for children, communication assessments, attention deficit hyperactivity disorder assessments, attention deficit hyperactivity disorder diagnosis, behaviour management assessment foetal alcohol spectrum disorders diagnosis, identifying children requiring further attention deficit hyperactivity disorder diagnostic assessment, attention deficit hyperactivity

disorder diagnostic assessments. In the review of literature only two interventions related to this were identified by Northway et al. (2017) and Delahunty (2017). What emerges from the evidence is that attention deficit hyperactivity disorder nurses need to have skills to undertake complex assessments of children's needs. What is also emerging here is that attention deficit hyperactivity disorder nurses are assimilating significant new roles is nursing children with attention deficit hyperactivity disorder.

Intellectual disability nursing interventions that focus on *enhancing impact of intellectual disability services* that we identified in the data include advising child adolescent mental health service colleagues, developing epilepsy guidelines, brain injury education, facilitating early discharge from mental health wards, transition liaison, and transition planning. In addition, some of the interventions we identified were previously reported (Oulton et al., 2019; Marshall and Foster, 2002; Delahunty, 2017). These interventions are important to the health and healthcare outcomes of children with intellectual disability. It appears from the wide range of interventions reported in this survey that increasingly, intellectual disability nurses are taking on roles in mainstream services such as primary care services, acute hospital services, and school nursing services. This development is likely to improve how mainstream services respond to the health and social care needs of children with intellectual disability, as intellectual disability nurses play an increasing role in these settings.

Some of the interventions we identified undertaken by intellectual disability nurses in the theme *enhancing impact of mainstream services* were wide ranging and include with specialists regarding sensory needs and sensory diets, educating health visitors, special education needs school nursing, and school liaison. Other roles we identified were previously reported, for example, Oulton et al. (2019) has previously identified the intellectual disability nurse roles in pre-admission support, and Delahunty (2017) previously reported that intellectual disability nurses play important roles in acting as a link between schools and other services. Marshall and Foster (2002) reported that intellectual disability nurses were involved in providing dietary advice. The interventions we have identified appear to suggest that intellectual disability nurses are assimilating new roles that focus on enhancing the impact of mainstream services. These new interventions are important because intellectual disability nurses are more often in regular contact with children with intellectual disability, they support and therefore better placed to facilitate links between services. The data from this survey also seem to suggest that increasingly, intellectual disability nurses are taking on roles in school nursing services. This development is likely to improve how mainstream services respond to the healthcare needs of children with intellectual disability.

Our data shows that intellectual disability nurses have limited involvement in *enhancing impact of intellectual disability nursing practice* in relation to children. Given the extent of the interventions undertaken by intellectual disability nurses in this area, there is need to ensure that there is appropriate intellectual disability nurse leadership and support in this vital emergent area of intellectual disability nursing practice.

We identified a wide range of interventions that focus on *enhancing quality of life* the quality of life of children with intellectual disability, and these include undertaking child support and protection interventions, facilitating psychological educational groups for parents and children, and teaching distress tolerance skills. These interventions are significant, and important given the growing population of children with intellectual disability, who often have complex and enduring health needs which may impact on their ability to lead healthy and active lifestyles. In the literature review we only identified continence promotion (Marshall and Foster, 2002), and provision of informal support and advice (Oulton et al., 2019) as interventions undertaken by intellectual disability nurses that enhance the quality of life of children with intellectual disability. The emergent

new interventions undertaken by intellectual disability nurses demonstrate that they are taking on new roles and developing new and often advanced skills and knowledge not previously associated with intellectual disability nursing practice.

Interventions for adults. In this survey we have identified an extensive array of assessment interventions undertaken by intellectual disability nurses, including National Early Warning Score assessment of deterioration, mental capacity assessments, anxiety assessments, assessment of mental health, assessment of people's understanding of their needs, autistic spectrum disorder diagnosis, behaviour management assessment, blood tests, bowel screening, cardiometabolic assessments, dementia care assessments, developing assessments for the prison service, dysphagia screening, forensic assessments, physical health assessments (abdominal, respiratory, and cardiovascular auscultation, percussion and palpitation), pressure sore risk assessment, psychosocial crisis assessments, sensory assessments, sex and relationships assessments, assessments in accident and emergency, triage in dementia clinics, and triage psychiatry clinics. These interventions demonstrate that intellectual disability nurses assess adults with diverse and complex needs. It is evident that these intellectual disability nurses require knowledge and competence to use a wide range of assessment tools, as well as knowledge of different and often unrelated health care needs.

Data shows that intellectual disability nurses implement a wide range of complex interventions for adults with intellectual disability such as behaviour family therapy, catheterisation, chest physiotherapy, deprescribe psychotropic medication, manage self-harm, monitor effectiveness of medications and treatments, run nurse led clinics, order and interpret investigation, tracheostomy care, talking therapy, venipuncture, wellbeing sessions for men (develop and deliver) and are beyond what was previously identified by (Brown et al., 2016; Pennington et al., 2019; Marsham, 2012; Drozd and Clinch, 2016; Dalgarno and Riordan, 2014; Brown et al., 2012; Taua et al., 2012; Mason and Phipps, 2010; Ring et al., 2018; Northway et al., 2017; Adams and Shah, 2016; Lloyd and Coulson, 2014; Barr et al., 1999; Lovell et al., 2014; Cleary and Doody, 2017; Arrey, 2014; Lee and Kiemle, 2014; Lovell et al., 2014; Ring et al., 2018; Northway et al., 2017; Adams and Shah, 2016; Doody et al., 2019). What is evident from the scope of these interventions is that intellectual disability nurses manage a wide range of complex health and healthcare needs in a wide range of contexts and settings. Given this complexity, intellectual disability nurses are likely to constantly learn and develop new knowledge and skills essential for engaging in advanced intellectual disability nursing practice. The data suggests that intellectual disability nurses may have to switch between a wide range of activities in a day's work and are likely to require well advanced multitasking skills.

Interventions we have identified in the *enhancing impact of intellectual disability services* theme include annual medication monitoring, anti-psychotic medication reviews and monitoring, developing epilepsy guidelines, formulating service improvement plans, overseeing packages of care, and sourcing care providers. The importance of the roles of intellectual disability nurses in supporting intellectual disability services and developing appropriate guidelines for intellectual disability services to support people with intellectual disability better cannot be overemphasised. As noted earlier, intellectual disability nurses practice in complex environments which, are often multidisciplinary and multi-agency. This will require them to engage in creative communication to enable things to happen. Furthermore, there is a need for intellectual disability nurses to provide leadership in improving intellectual disability services through troubleshooting and other interventions.

Interventions identified in previous studies that focused on intellectual disability nurse roles in *enhancing impact of mainstream services* tended to relate to acute health liaison and health facilitation activities (Northway et al., 2017; Morton-Nance, 2015; Chapman, 2015). Evidence from

this study show an increasingly complex catalogue of interventions undertaken by intellectual disability nurses such as coordinating the assessment process in multi-agency contexts, auditing annual health checks, chairing best interest meetings, gatekeeping mental health assessments for admission to hospital, providing pharmacological advice to general practitioners, reviewing other services, and triaging in accident and emergency. In addition, it appears intellectual disability nurses are undertaking increasingly complex and advanced interventions. For people with intellectual disability, these interventions may mean the difference between accessing appropriate mainstream services and support. To improve services and enhance their impact intellectual disability nurses need to work collaboratively to improve access to mainstream services as well as take up direct care roles in mainstream services. The introduction of the *Future nurse* (NMC, 2018) standards places future intellectual disability nurse graduates in a unique position to assimilate these emerging roles in mainstream services.

The activities undertaken by intellectual disability nurses we have identified in the *enhancing impact of intellectual disability nursing practice* theme include brain injury education, alcohol/substance misuse, education, developing and implementing training packages for community nurses, setting standards for intellectual disability practice, and skills training (e.g., skin care, enteral feeding). This is concerning given the ever-increasing list of interventions intellectual disability nurses are assimilating.

In this survey, in addition to previously reported (Marsham, 2012; Taggart et al., 2011; Cope and Shaw, 2019; Mafuba et al., 2018b; McCarron et al., 2018; Northway et al., 2017; Doody et al., 2019; Doody et al., 2017; MacArthur et al., 2015; Wagemans *et al.,* 2015; Morton-Nance, 2015; Bailey et al., 2014; Brown et al., 2012), we identified new interventions such as hate crime reduction, internet safety promotion and education, neighborhood relations building, support with criminal justice system, anxiety support, behaviour family therapy, dementia support (community), and proactive support in relation to forced marriage. These findings suggest that in addition to dealing with barriers to living healthy active lifestyles, intellectual disability nurses are engaging in much more holistic interventions than previously reported in existing literature. This may suggest an improving understanding of the complexity of the lives of people with intellectual disability by policy makers, public health agencies, commissioners of health services, and healthcare providers.

Interventions for older adults. In the *effectuating nursing procedures* theme, we identified significantly more interventions than previously reported by Drozd and Clinch (2016), Brown et al. (2012), Arrey (2014), Nelson and Carey (2016), Northway et al. (2017) Cleary and Doody (2017) and Wagemans et al. (2015). For example, assessing mobility decline, behaviour management assessment, care assessments, carer assessments, cognitive decline assessments, dementia assessment (diagnostic), manual handling risk assessment, physical deterioration assessment (RESTORE2), pressure sore risk assessment, catheter care, pain management, and stoma care. What is emerging from these findings is that intellectual disability nurses are involved in working directly with older adults with intellectual disability. This may very well reflect that intellectual disability nurses are increasingly taking up new roles in dementia care services and nursing homes where older adults with intellectual disability may reside. For intellectual disability nurses working in the community, this may reflect an aging population that require assimilation of new and advanced skills to deliver appropriate interventions.

We found evidence to demonstrate that intellectual disability nurses are involved in *enhancing the impact of intellectual disability services* in relation to older people with a wide range of complex needs in the community including commissioning changes to service provision, providing dementia support in community, leading multi-agency coordination care / meetings, managing hospital discharges, mental

capacity assessment, overseeing packages of care, placement breakdown prevention as needs change, supporting making reasonable adjustments, and supporting service providers and carers. These interventions suggest that intellectual disability nurses are working directly with older adults with intellectual disability, their families, community service providers, and staff.

We found evidence to demonstrate that intellectual disability nurses are involved *enhancing the impact of mainstream services* through reviewing quality of care, social care liaison, supporting and supervising day-care staff, and supporting service providers among other interventions. Given the increasing complex landscape of services for older adults in the UK as the population increases, these interventions are vital to healthcare outcomes for older adults with intellectual disability.

We only identified one activity related to *enhancing impact of intellectual disability nursing practice* through teaching new skills to other nurses. With the increasing population of older adults with intellectual disability, and the need for intellectual disability nurses to assimilate new roles in this area, this lack of involvement in developing intellectual disability nursing practice will need to be addressed.

We identified several interventions undertaken by intellectual disability nurses that *enhance quality of life* of older adults with intellectual disability such as bowel screening promotion, carer assessment, COVID-19 education, dementia support in the community, mental health advocacy, and preparing homes for changed needs. No previous study has identified any intervention in this area (Mafuba et. al., 2020). This is an important development given that older adults often have complex and enduring health needs which may impact on their ability to lead healthy and active lifestyles (Emerson et al., 2011).

End of life interventions. We identified several nursing procedures effected by intellectual disability nurses that focus on ensuring that people with intellectual disability of all ages experience good quality end of life care. These include assessing changing health conditions and detecting deterioration, interpreting complaints and symptoms, diet and nutrition management, managing end of life care, performing last offices, pressure care assessment and care, bereavement counselling, care giving, and facilitating communication. Some were previously reported by Ng (2011), Wagemans et al. (2015), Bailey et al. (2014), McCarron et al. (2018), Oulton et al. (2019), Northway et al. (2017), Adams and Shah (2016, Wagemans et al. (2015), Morton-Nance (2015), and Arrey (2014). The range of interventions in this very psychologically difficult and complex area illustrates the uniqueness of the knowledge and skills of intellectual disability nurses who work with people with intellectual disability across the lifespan with diverse backgrounds and needs at the most challenging time of their lives.

Interventions we identified in relation to intellectual disability nurse roles in *enhancing impact of intellectual disability services* include coordinating the assessment process, facilitating communication, undertaking last offices, shaping the nature of end-of-life care, and influencing end-of-life decisions. This evidence demonstrates that the provision of end-of-life care for people with intellectual disability may be becoming increasingly a common occurrence in intellectual disability nursing practice. These findings add to previous findings by Wagemans et al. (2015), Cope and Shaw (2019), Mafuba et al. (2018a), Northway et al. (2017), Cleary and Doody (2017), Drozd and Clinch (2016), MacArthur et al. (2015), Marriott et al. (2015), and Morton-Nance (2015).

We identified new interventions that focus on e*nhancing the impact of mainstream services*, and include facilitating communication, and facilitating reasonable adjustments. Other findings confirm what was previously reported, for example, facilitating collaborative working (Arrey, 2014), educating healthcare professionals and staff (Cleary and Doody, 2017; Morton-Nance, 2015; MacArthur et al., 2015; Dalgarno and Riordan, 2014; Brown et al., 2012; Slevin and Sines, 2005), providing information (Bailey et al., 2014), sharing information with other professionals (Mafuba

et al., 2018a; Wagemans et al., 2015), and liaising with secondary care (McCarron et al., 2018; Marshall and Foster, 2002). Our evidence suggest that intellectual disability nurses undertake important interventions to address inequalities in care provision for people with intellectual disability who are at the end of their lives.

We did not find any evidence to illustrate activities undertaken by intellectual disability nurses that focus on *enhancing the impact of intellectual disability nursing practice* involving end of life care for people with intellectual disability across the lifespan.

We identified, providing psychological support, and training and raising awareness as some of the activities undertaken by intellectual disability nurses in *enhancing the quality of life* of people with intellectual disabilities at the end of their lives. End of life experiences are likely to be physically and emotionally debilitating for those facing end of life and those around them. Intellectual disability nurses appear to have an important role to play in meeting the palliative care needs of people with intellectual disability.

Conclusions

The research has identified a wide range of emerging interventions that are implemented by intellectual disability nurses working in multi-disciplinary teams across a wide range of settings in the UK and other countries. It is clear from the extent of these interventions that intellectual disability nurses need to constantly adapt and engage in a wide range of roles, and that they need to constantly assimilate emergent roles. What also emerges from this research are the complexities and changing needs of people with intellectual disability, the changing environments in which intellectual disability nurses are practising, and the increasing expectation for intellectual disability nurses to meet health, and social needs of people with intellectual disability across the lifespan.

Some of the interventions performed by intellectual disability nurses could be considered as advanced practice. It is unclear what training these intellectual disability nurses have had to evidence that they practice these interventions safely. In addition, there are non- intellectual disability trained nurses who work in specialist intellectual disability services, and it is unclear what training they have had to be able to practice safely when working with people with intellectual disability. What has also emerged from this survey is the increasing expectation that intellectual disability nurses work across age groups, services, and settings.

What is evident from this research is that intellectual disability nurses are now working in mainstream services such schools and other children's services, general hospital wards such as accident and emergency departments, and a wide range of strategic services. These developments are welcome and need to be acknowledged and investments made to create career structures within non-traditional intellectual disability services at strategic level by policy makers and commissioners of services.

There are gaps in the provision of care for individuals with intellectual disability. Of significant concern are the very limited interventions related to maternity care for pregnant women with intellectual disability. The second gap relates to frailty and end of life care. Although people with intellectual disability are more likely to die in hospital settings, it is unclear why there is limited intellectual disability nurse involvement in this area given that it is likely that these people will be in receipt of health and social care support from health or social care services.

Implications and recommendations for practice

The interventions undertaken by intellectual disability nurses make a real difference to the health and healthcare outcomes for people with intellectual disabilities. The implication of this that by

undertaking these roles intellectual disability prevent people with intellectual disabilities from suffering with undiagnosed conditions, improve the healthcare experiences and outcomes of people with intellectual disabilities, improve patient safety in mainstream hospitals and other services, make mainstream services better informed and deliver better care to people with intellectual disabilities, support services to become more responsive to the complex needs of people with intellectual disabilities, ensure that commissioners of healthcare services understand the complex needs of people with intellectual disabilities, facilitate transitions between services, and reduce the health inequalities experienced by people with intellectual disabilities.

Given the well documented complexity of the health needs, poorer health, higher rates of co-morbidity, inequalities in health, poor access to health services and higher rates of premature mortality experienced by people with intellectual disability, intellectual disability nurses need to undertake further research to validate the effectiveness and impact of their interventions, more specifically in relation to maternity, frailty, and end of life care.

Intellectual disability nurses need to take responsibility for promoting and publicising the impact and contributions to meeting the complex health and social care needs of people with intellectual disability. Specific work needs to focus on the unique contributions made by intellectual disability nurses to mainstream services and agencies. This is important for planning and resource allocation for future service provision.

There is need for continued collaboration between intellectual disability senior clinicians, policy holders, commissioners, and academics to develop adaptive courses that capture emerging interventions such as those identified in this survey.

Limitations

We acknowledge the limitations of the survey method. We realise that some of the qualitative responses lack the detail and contextualisation we would have obtained using focus groups or interviews. This is particularly important in this project, which sought to identify and describe the experiences of intellectual disability nurses in meeting the needs of people with intellectual disability.

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Ethical statement

Ethical approval

We confirm that Ethical Committee approval was sought from the University of West London (Approval No: 01032) and is acknowledged within the text of the submitted manuscript.

Informed consent

We confirm that guidelines on participant consent have been met and any details of informed consent obtained are indicated within the text of the submitted manuscript.

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Data Availability Statement

Raw data were generated at the University of West London. Data supporting the findings of this study are available from the corresponding author Professor Kay Mafuba (kay.mafuba@uwl.ac.uk) on request. Data will be retained for at least 5 years.

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