# Understanding the contribution of intellectual disability nurses: Scoping research

## Volume 2 of 3: Scoping survey research report


**Professor Kay Mafuba**
**Dr Hazel M Chapman**
**Dr Joann Kiernan**
**Dorothy Kupara**
**Rebecca Chester**
**Chiedza Kudita**



UNIVERSITY OF WEST LONDON

RCNFoundation
Supporting nursing, improving care

University of Chester

Edge Hill University

NHS
Berkshire Healthcare
NHS Foundation Trust

**Authors' affiliations**

1. **Professor Kay Mafuba** (Principal Investigator) (University of West London)
2. **Dr Hazel M Chapman** (University of Chester)
3. **Dr Joann Kiernan** (Edge Hill University & Nurse Consultant, Alder Hey Hospital)
4. **Dorothy Kupara (**University of West London)
5. **Rebecca Chester** (Berkshire Healthcare NHS Foundation Trust & Chair United Kingdom Intellectual Disability Consultant Nurse Network)
6. **Chiedza Kudita** (University of West London)



©UWL / RCN Foundation 2021

**Contents**





©UWL / RCN Foundation 2021

**Abstract**

***Introduction***

This scoping research identifies nursing-led and or nursing centred interventions that are in place to address the changing needs of people with intellectual disabilities (ID).

***Aims***

The aim of the research is to identify nursing-led and / or nursing centred interventions that are in place to address the challenging and changing needs of people with ID. The research identifies interventions, that can be implemented by nurses working in multi-disciplinary teams. The research also identifies areas of good care delivery, innovative practices, and possible gaps in the provision of care for individuals with intellectual disabilities.

***Methods***

We undertook an online survey to collect quantitative and qualitative data. We used voluntary response sampling to collect data from 230 participants from 7 countries. Participants were primarily registered intellectual disabilities nurses working with people with ID. We used thematic, and content analyses to analyse qualitative data. We undertook descriptive and inferential statistical analyses of quantitative data, specifically we undertook Pearson correlations and Pearson Chi-square analyses.

***Results***

We identified 878 interventions from 7 countries. These interventions were 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 (19). 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*. We identified several case studies that demonstrate the positive impact of ID nursing interventions.



©UWL / RCN Foundation 2021

***Conclusions***

ID nurses implement a wide range of emerging interventions working in multi-disciplinary teams. They practice in a wide range of settings in the UK and other countries. More work is needed in order to better understand the reasons for the limited involvement of ID nurses with pregnant women with IDs and in end-of-life care. The variation in understanding the interventions undertaken by ID nurses between countries need to be further investigated.



©UWL / RCN Foundation 2021

## 1. Introduction

This is a report of a scoping research that investigated the contribution of ID nurses to improving the health and well-being of pregnant women, children, adults, and older people with intellectual disabilities (ID), as well as those receiving end of life care. The research was commissioned by the RCN (Royal College of Nursing) Foundation. The research project report is in three volumes; Volume 1 of 3: Scoping literature review report; Volume 2 of 3: Scoping survey research report (this volume); and Volume 3 of 3: Compendium of intellectual disabilities nursing interventions.

The overall aim of the scoping research is to identify nursing led and or nursing centred interventions that are in place to address the challenging and changing needs of people with ID. The research identifies interventions that can be implemented by nurses working in multi-disciplinary teams. The research identifies areas of good care delivery, innovative practices, and possible gaps in the provision of care for individuals with intellectual disabilities. The research covers interventions undertaken in all four countries of the UK, as well as Republic of Ireland, New Zealand, and Isle of Man. The scoping research covers all settings, and includes interventions undertaken in the NHS, the independent sector, charities, education, social care, and other organisations.

Poor uptake of health services amongst the population of people with ID is a longstanding issue (Allerton and Emerson, 2012; Robertson *et. al.,* 2014). It is therefore important to investigate how ID nurses make contributions to the health and healthcare needs of people with ID. Studies have shown that people with ID are likely to be passive participants in their health and healthcare, and that they are dependent on others for their health and healthcare outcomes (Campbell and Martin, 2009). ID nurses are expected to deliver effective nursing care to people with ID in challenging circumstances (Thomas and Kerr, 2011). It is therefore important to have clarity of the interventions they undertake, and the organisations and environments in which these professionals practice. The provision of health and healthcare services to people with ID is opportunistic,


©UWL / RCN Foundation 2021

despite evidence that point to a need for targeted activities in order to have positive outcomes (McIlfatrick *et al.*, 2011; Chauhan *et al.,* 2010; Robertson *et. al.,* 2014). Preventative nursing interventions such as health screening are effective in identifying the health needs of people with ID (Emerson *et al*., 2011; Robertson *et. al.,* 2014). There is limited research that identifies effective interventions undertaken by ID nurses (Mafuba *et al.,* 2020).

In this report we identify interventions undertaken by ID nurses that led to the development of a compendium of interventions for ID nurses. These interventions are essential for meeting the healthcare needs of people with ID. This collation of interventions improves the evidence base of our understanding of the contribution of ID nurses to improve the health and well-being of pregnant women with ID, children, adults, older people with ID, and people with ID at the end of life. This scoping research highlights areas requiring further research investment in ID nursing interventions and innovations that will improve patient care for people with ID. The findings of this scoping research will be disseminated through conference presentations, publications in peer reviewed journals, and contribute to textbook chapters. We hope that the findings of this scoping research will raise the profile and contribution of ID nurses to improving the health and healthcare outcomes for people with ID by engaging in nursing interventions and innovations that have a positive impact on the lives of people with ID.

### *Terminology*

For the purpose of this scoping research, we have used the term 'intellectual disabilities' as a way of acknowledging the international nature of the work we have undertaken. However, we are aware that in the United Kingdom a variety of terms are used in practice (Gates and Mafuba, 2016).



©UWL / RCN Foundation 2021

## 2. Objectives

There is a lack of clarity on effective interventions that can be carried out by ID nurses. It is no surprise that role expectations vary across the four countries of the United Kingdom, and internationally. Lack of clarity on effective nursing interventions can result in confused and ambiguous expectations among health and social care professionals. This is likely to result in reduced quality of health and healthcare experiences for people with ID. Clarity of role expectations for nurses will be beneficial because it will improve communication, flexibility, and responsiveness at every level of health policy implementation for people with ID.

The purpose of the scoping review of literature is to summarise the best evidence available on nursing led and or nursing centred interventions that are in place to address the needs of people with ID. The review focuses on multi-disciplinary team interventions across the lifespan which involve ID nurses.

### *Research questions*

The research sought to answer the following questions;

1. *What nursing led / nursing centred interventions are in place to respond to the changing needs of people with ID?*
2. *Are there examples of service redesign to meet future needs?*
3. *How could ID nurses better contribute to these interventions?*
4. *Where in the UK are these interventions taking place?*
5. *In which settings (example: private, NHS, charity care settings)?*
6. *What is the impact of these interventions?*



©UWL / RCN Foundation 2021

## 3. Background

It is estimated that there are currently 1.5 million people with ID in the UK and this population is changing and increasing, with approximately 2.16% of adults and 2.5% of children identified as having an intellectual disability (Mencap, 2020). Globally, the World Health Organisation (2011) estimated that there were 200 million people (2.6% of the global population) had ID. The avoidable disparity between the health, and the health needs of people with intellectual disabilities as compared to that of the general population has been acknowledged over many years (Kerr, 2004; Straetmans, *et al.,* 2007; 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, but could be improved through appropriate ID nursing interventions. What is not clear from existing research is a clear description of the roles undertaken by ID nurses to reduce these disparities in order to improve health and healthcare outcomes.

Truesdale and Brown (2017) noted that the life expectancy of people living with an ID is increasing, as well as the complexity of the health and social care needs and conditions of this population. Despite this increasing life expectancy there are persistent but avoidable disparities between the health, and the healthcare needs, of people with ID as compared to that of the general population (Kerr, 2004; van Schrojenstein Lantman-de Valk *et al*., 2007). People with ID are known to have much greater health needs than those of comparable age groups who do not have ID (Backer *et al*., 2009), and experience preventable higher mortality rates (LeDeR, 2020). Campbell and Martin (2009) have observed that people with ID are often or more likely to be dependent on others for their health and healthcare outcomes. In addition, Oullette-Kuntz (2005) concluded that healthcare outcomes for people with ID could be improved through appropriate ID nursing interventions. Given that people with ID are high and frequent users of all health and social care services, including primary care, child health services, acute healthcare services and



©UWL / RCN Foundation 2021

specialist ID services, the contribution of ID nurses to positive healthcare outcomes need to be clearly described.

Globally, people with ID are known to have much greater health needs than the general population (Backer, Chapman, and Mitchell, 2009; Savage and Emerson, 2016; Emerson *et al.,* 2016a; Emerson *et al.,* 2016b; Robertson *et. al.,* 2017). People with ID experience higher rates of mental health related disorders, higher rates of visual impairments, higher rates of epilepsy, hypertension and hypothyroidism, obesity, and are more likely to die from preventable causes (Llewellyn *et al.,* 2015; Emerson and Brigham, 2015) Mencap, 2007; Pawar and Akuffo, 2008; Heslop *et al.,* 2013; Heslop *et al*., 2014; Emerson *et. al.,* 2014. Robertson *et al*., 2015; Bakker-van Gijssel *et al.,* 2017). These health problems are commonly, and widely undiagnosed, misdiagnosed, and untreated (Mencap, 2007; DH, 2007; Heslop *et al.,* 2013; Heslop *et al*., 2014; Robertson *et al*., 2015). This means that although life expectancy has improved, it is still significantly lower, and 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). It is therefore important to clarify the interventions ID nurses can plan and undertake to improve health and healthcare outcomes.

There are longstanding and widespread concerns about the inequalities in health, and poor access to healthcare for people with ID (Melville *et al.,* 2006; Kavanagh *et al.,* 2016; Brown *et al.,* 2010). Clearly people with ID have complex health needs, and comorbidities are common. To effectively address these issues, require appropriate interventions by those at the frontline of healthcare delivery such as ID nurses. Recent publications have shown that some health inequalities experienced by people with ID are linked to poor access to appropriate healthcare provision (Michael, 2008; Mencap, 2012).

The barriers to health services experienced by people with ID contribute to the health inequalities they live with. The lack of clarity


©UWL / RCN Foundation 2021

of what ID do to address these barriers and inequalities has been consistently identified as one of the barriers (Mafuba, 2009, 2013; Mafuba and Gates, 2015; Mafuba, Gates and Cozens, 2016). ID nurses have an important role in meeting the health needs of people with ID but there is a lack of evidence as to the interventions they undertake in meeting these needs.

Children with multiple and complex ID are living into adulthood and the number of people with ID living into older age is also increasing. This has major implications for health and other services now and in the future (NICE, 2018). It also has significant implications on the interventions performed by ID nurses to support and meet the needs of this population. Consequently, it is important that these interventions are clearly defined and their impacts clearly described. It is also important to establish the evidence base for the most effective interventions for delivering nursing care to people with intellectual disabilities.

In the first phase of this scoping research, we categorised ID nursing interventions as: effectuating nursing procedures; enhancing impact of services; and enhancing quality of life (Mafuba *et al.*, 2020). These interventions were identified in a number of publications that highlighted the involvement of ID nurses in meeting the needs of people with ID across the lifespan. However, none of the publications included in the scoping review specifically sought to identify the interventions undertaken by ID nurses.

Evidence on the interventions undertaken by ID nurses in meeting the maternity needs of women with ID is very limited. McCarron *et al.* (2018) identified liaison in maternity services, providing psychosocial support, and health promotion as some of the interventions that could be undertaken by ID nurses. Northway *et al.* (2017) suggested that ID nurses can intervene by being involved in pre-natal screening and providing support in relation to diagnosis.


©UWL / RCN Foundation 2021

In relation to nursing interventions undertaken by ID nurses working with children with epilepsy, Quinn and Smolinski (2018) identified pain and assessment, objective clinical assessments, and parent consultation in school environments. In addition, it has been argued that ID nurses have important roles in promoting the health and wellbeing of children with intellectual disabilities in education settings (Marshall *et al.*, 2003; Delahunty, 2017; Northway *et al.*, 2017). Furthermore, Delahunty (2017) concluded that nurses can make important interventions when working with children by identifying children with potential intellectual disability, acting as a link between schools and other services, facilitating transition from nursery into school or transition into adult services, identifying children who should be prioritised for further intellectual disability assessment, and monitoring children's development. Marshall and Foster (2002) identified liaising with professionals and significant others such as parents and relatives, providing hygiene advice, providing dietary advice, and continence promotion were reported were important interventions performed by community ID nurses, and concluded that effective interventions by ID nurses need to engage all stakeholders at individual and population levels. Marshall *et al.* (2003) have emphasised the importance of combining health screening with health promotion when working with children living with obesity.

Existing publications have identified a number of interventions undertaken by ID nurses when working with adults living with ID (Pennington *et al*., 2019; Ring *et al.*, 2018; Brown *et al.*, 2016; MacArthur *et al.*, 2015; Dalgarno and Riordan, 2014; Lovell *et al.*, 2014; Llewellyn and Northway, 2007; Barr *et al.*, 1999; Llewellyn, 2005; Slevin and Sines, 2005; McKeon, 2009; Mason and Phipps, 2010; Campbell, 2011; Taggart *et al.,* 2011; Marsham, 2012; Brown *et al.*, 2012; Lee and Kiemle, 2014; Lloyd and Coulson, 2014; Lovell and Bailey, 2016; Drozd and Clinch, 2016). These interventions were undertaken by ID nurses with people with a wide range of conditions, in a wide range of settings and in a number of countries.


©UWL / RCN Foundation 2021

Pennington *et al*. (2019), Auberry and Cullen (2016) and Ring *et al.* (2018) identified clinical diagnosis, managing epilepsy and complex epilepsy, assessing and managing risk, patient assessment, medication management, ordering and interpreting investigations, providing education, and supporting and counselling patients and families, providing seizure telephone triage in the community, and providing seizure guidance to people with intellectual disability living in the community as the interventions performed by ID nurses working with adults with intellectual disability and epilepsy. Auberry and Cullen (2016) concluded that Learning Disabilities Nurses undertake important interventions in providing seizure guidance to people with intellectual disability living in the community.

ID nurses have been involved with supporting people with intellectual disabilities with mental illness, challenging behaviour and forensic history or offending behaviour for some considerable time. Lovell and Bailey (2016) concluded that intellectual disability nurses work with and support people with intellectual disabilities with complicated backgrounds. Interventions identified in existing studies include de-escalation and preventing crisis and the subsequent need for physical intervention, building and maintaining meaningful professional working relationships, provision of emotional support, supporting service users to problem solve, listening to offence histories, empowering service users, enabling development of skills, and undertaking risk assessments and management, cognitive behaviour therapy (CBT) training, facilitating multi-disciplinary working and inter-agency liaison, and record keeping, management of violence, control and restraint, control of medication, risk assessment and risk management, managing self-harm, implementing early interventions, implementing assessment strategies, offence-specific interventions, family therapy, and psychological interventions were the reported interventions performed by intellectual disability nurses (McKeon, 2009; Mason and Phipps, 2010; Lovell *et al.*, 2015; Campbell, 2011; Lee and Kiemle, 2014; Dalgarno and Riordan, 2014). The range of interventions suggest that the ID nurses' role is highly skilled


©UWL / RCN Foundation 2021

encapsulating a very wide range of behaviours, skills, attitudes and beliefs (Dalgarno and Riordan, 2014; Lovell *et al.*, 2014). Lovell *et al.* (2014) concluded that intellectual disability nurse competencies are transferable across settings.

In the UK, people with ID are expected to access generic healthcare services. However, often the nurses and other healthcare professionals who work in generic healthcare services are unable to work effectively with people with ID without the need for making reasonable adjustments. For example; Taua *et al.* (2017) has noted that ID nurses undertake this role by enabling creative communication, and modifying mental health interventions. Drozd and Clinch (2016) identified co-ordinating communications, making reasonable adjustments, undertaking mental capacity assessments, promoting greater independence, preparing patients for surgery, undertaking risk assessments, and managing risk as interventions performed by nurses. In addition, Brown *et al.* (2016) identified trouble shooting and matching information with capacity to understand as important ID nursing interventions in making reasonable adjustments. Furthermore, MacArthur *et al.* (2015), Marriott *et al.* (2015), and Lloyd and Coulson (2014) have described ID nursing interventions as facilitating reasonable adjustments, reasonable adjustments, developing easy to understand letters and information, training mainstream screening staff, sharing information relating to care needs, provision of communication advice, provision of psychological support, provision of carer educational support, undertaking pre-morbid baseline assessments, provision of eating and drinking advice and guidelines, and provision of diagnostic advice were identified as important interventions performed by intellectual disability liaison nurses. MacArthur *et al.* (2015) concluded that intellectual disabilities liaison nurses undertake important interventions that enhance the effectiveness of other healthcare services. Marriott *et al.* (2015), Lloyd and Coulson (2014) and Taggart *et al. (*2011) have described some of the interventions undertaken by ID nurses as supporting women with intellectual disabilities to manage


©UWL / RCN Foundation 2021

cervical screening, preparing women psychologically for cancer screening, and managing the challenges of supporting women with complex needs, raising breast awareness, provision of information on healthier lifestyles, supporting women to self-examine and report any abnormalities, developing health education material, and training health and social care staff. These interventions demonstrate that ID nurses play a significant role in enhancing the effectiveness of health interventions. It is therefore important that we have a clearer understanding of these interventions.

What is also clear from current studies is that ID nurses practice in a complex and non-condition specific clinical environment. Chapman (2015) has described ID nurse interventions as health consultation, health facilitation, making reasonable adjustments, and undertaking health checks. Doody *et al.* (2013) identified ID nurse roles in preparing other nursing specialisms to care holistically for people with ID, without which these other healthcare professionals will not be able to meet the health needs. On the other hand, Brown *et al.* (2012) have identified a complex array of interventions such managing risk, providing advice, educational support, providing psychological support, undertaking pre-morbid baseline assessment, producing guidelines and accessible information, mediating, facilitating, influencing, advocating, communicating, collaborating, and educating as key interventions performed by ID liaison nurses. It is clear that ID nursing interventions impact on clinical patient care as well as wider educational, practice development, and strategic organisational developments in the services and organisations in which they practice. Furthermore, Marsham (2012) illustrate the complexity of this role by describing how they manage complex long-term conditions, facilitate self-management, escalate treatment pathways, facilitate development of coping skills, reduce challenging behaviour, facilitate access to healthcare, and assess people's understanding of their needs as part of their daily activities.


©UWL / RCN Foundation 2021

Advocating for people with ID is an important role undertaken by ID nurses. Interventions in this role are wide ranging. For example; Llewellyn and Northway (2007) and Llewellyn (2005) have argued advocating for service users is an important intervention performed by ID nurses and that this is important in the delivery of health services to people with ID. Barr *et al.* (1999) concluded that the primary intervention of community ID nurses was raising the profile of the health needs of people with ID.

Mafuba *et al.* (2018), Mafuba, Gates and Cozens (2018), Mafuba and Gates (2013), Mafuba (2013) and Mafuba (2009) identified health surveillance, information sharing, assessment of need, facilitating access to mainstream services, facilitation of reasonable adjustments, promoting health, health education, assessing effectiveness of interventions, monitoring the effectiveness of treatments, enabling and supporting healthy lifestyle choices, and addressing determinants of health as some of the interventions ID nurses undertake. In addition, Taua, Hepworth and Nevill*e* (2012) identified ID nursing interventions as; assessment, advocacy, health promotion (including working with family), facilitating communication and risk management. Flagging and identifying needs, making reasonable adjustments, pre-admission support, identifying equipment and resources, facilitating specialist clinics, providing signage, providing parent support, facilitating transition, handling complaints, staff training, providing informal support and advice, restraint practice, positive behaviour support training, engaging other agencies, facilitating communication, mental capacity assessment, engaging senior managers, evaluation of care interventions and outcomes, implementation of care, provision of advice, education / training to families, making recommendations relating to client care and client care issues, supporting staff to develop practice, guidelines/policies, consulting with other services/agencies, referring clients to another service/ agency, and receiving referrals from another service/ agency have been previously identified as interventions performed by


©UWL / RCN Foundation 2021

intellectual disability nurses (Oulton *et al.,* 2019; Doody, Slevin and Taggart, 2019; Sheerin, 2012)).

Other roles identified in current studies include; reducing the impact of health inequalities, and supporting admissions and outpatients (Cope and Shaw, 2019); providing support and advice in primary care, liaison in palliative care, bereavement counselling (McCarron *et al.*, 2018); assessment of mobility decline in older people with intellectual disabilities, and supporting maintenance of optimal health (Nelson and Carey, 2016); reviewing and assisting with the withdrawal of antipsychotic medication, reducing prescribing of antipsychotic medicines, maintaining and enhancing the general physical health and well-being of people with intellectual disabilities, providing constipation advice, monitoring medication effectiveness, and improving communication between healthcare professionals in primary and secondary care (Adams and Shah, 2016); and, pre-admission screening, clinical assessment, advocating for people with intellectual disabilities, advising hospital staff on reasonable adjustments, assisting with capacity/risk assessments, advising on and providing a plan of care for complex admissions and discharge, educating people with intellectual disabilities, educating family members and carers, raising awareness of intellectual disabilities and autism, serving as a contact person for community and inpatient services, and providing advice on treatment options (Morton-Nance, 2015).

Studies identifying and describing ID nursing interventions with older adults is very limited. This is perhaps because in the UK there are likely to be very few or very limited specialist services for older adults with ID. Caregiving at mid-stage (eating and drinking) and at end stage (toileting and incontinence), pain management, behavioural support, problem solving when uncertainty around care exists, providing education for peers to develop an understanding of the changes caused by dementia, and providing environmental supports and staff training in the principles of person-centred dementia have been


©UWL / RCN Foundation 2021

reported as some of the interventions performed by intellectual disability nurses (Nelson and Carey, 2016; Jenkins, 2012; Doody *et al.*, 2013; Auberry and Cullen, 2016; Cleary and Doody, 2017; Cleary and Doody, 2017.

Another area with a paucity of evidence regarding the interventions undertaken by ID nurses is end of life or palliative care. Some of the nursing interventions identified and described in current studies are; baseline physical health assessments, assessing changing health conditions, interpreting complaints and symptoms, informing doctors and relatives, shaping the nature of end-of-life care and influencing end-of-life decisions, giving information, advance care planning, detecting deterioration, and supporting relatives and helping medical staff to make decisions (McCarron *et al.*, 2018; Wagemans *et al.*, 2015; Ng, 2011). In addition, Arrey (2014) described building relationships, facilitating communication, provision of insight into how people with communication difficulties and intellectual disabilities in palliative care settings communicate distress, sharing professional knowledge, training, and facilitating collaborative working were identified as key nursing interventions. Furthermore, Bailey *et al.* (2014) reported provision of information, supporting the family, supporting and advising staff, coordinating services, symptom management, making referrals within the MDT, pressure relief and skin care, assessing patients, diet and nutrition management, planning for end of life, home nursing care delivery, provision of palliative care, completing hospital / hospice referrals, managing end of life care, and finding resources for end of life care were identified as important nursing interventions in end of life care.

What is clear in the literatures discussed here is that ID nurses do not only work directly with people with ID, 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 ID. In order to effectively meet the health, healthcare, and social care needs of people ID, ID nurses need to engage in a wide


©UWL / RCN Foundation 2021

range of roles, and they need to assimilate emergent roles (Northway *et al.*, 2017). Research is therefore needed, not only to identify, describe, and explain the interventions undertaken by ID nurses. In this scoping research we identify some of these interventions.



©UWL / RCN Foundation 2021

## 4. Methods

In phase 1 of the project, we undertook a scoping literature review using the Joanna Briggs Institute's (JBI) scoping review protocols. We used the PRISMA-ScR process and JBI guidance to select the literature for review and to present the literature review report (Trico, *et al*., 2018; Peters, *et al*., 2017) (see volume 1 of 3). Thematic synthesis was used to generate analytical themes. Empirical (quantitative, qualitative, mixed methods) studies, synthesised evidence (literature reviews) and opinion papers, (*n* = 52) were included in the review (see volume 1 of the report).

Originally, in this phase (phase 2) of the project we proposed to adopt a sequential mixed method approach to the research and its evaluation, combining quantitative and qualitative methods and data (Creswell and Plano-Clark, 2011; Bradley, 2011). We had proposed to gather qualitative data from nurses who undertake nursing interventions for people with ID, and combine this with quantitative data that would give us a robust, as well as an authentic assessment of the parameters of impact of ID nursing interventions. We had also proposed to use focus groups, as well as a survey of nurses working with people with ID in the four countries of the UK. For the evaluation stage of the project, we intended to focus on the process we would have followed to undertake the scoping research and the potential impact of the identified interventions and outcomes. We also intended to evaluate whether outcomes and outputs of the scoping research would result in better understanding of the impacts of ID nursing interventions for people with ID across the lifespan. We envisaged that the findings of the scoping research would provide much needed evidence of the impact of ID nursing interventions in everyday practice of ID nurses working in a wide range of organisations and settings.

However, the outbreak of Covid-19, and the consequent social distancing rules resulted in our original proposed methodology being redundant. This meant that we were unable to hold focus groups to



©UWL / RCN Foundation 2021

collect qualitative data from ID nurse consultants, other senior nurses, service users and service user groups.

Following consultation with the RCN Foundation, we revised the research methodology and collected data from ID nurses using an online survey questionnaire (see appendix A). Here we describe the process we followed to collect qualitative data, quantitative data, case studies and their impact, and evaluation data using an online survey. While we were unable to hold focus groups with people with ID by using the online survey questionnaire, we were able to collect data from 230 ID nurse participants from 7 countries.

***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). We adopted the survey because we were able to collect appropriate data for describing the phenomenon of ID nursing interventions (Punch, 2003; Kelly *et al*., 2003; Fink, 2015). 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 ID nursing roles and interventions (Connelly, 2009; Creswell and Creswell, 2018). Using the survey method was also an attractive proposition because it offered us an opportunity to test some of the relationships between participants' background data and the interventions they were involved as part of the scoping research (see table 4, and appendix E). By using the online survey questionnaire, we were able to reach a large number of participants from multiple countries very quickly, economically, and easily (Kelly *et al*., 2003).

We however have to acknowledge the limitations of the survey method. Firstly, we realise that some of the qualitative responses lack


©UWL / RCN Foundation 2021

the detail and contextualisation we would have obtained through the use of focus groups. This is particularly important in this project, which sought to identify and describe the experiences of ID nurses in meeting the needs of people with ID (Kelly *et al.,* 2003). Secondly, we also need to acknowledge the poor response rates associated with survey research (Connelly, 2009). This was particularly important in the context of Covid-19, and this eventually influenced the approach we took to the sampling and participant recruitment methods we adopted.

*Survey questionnaire development*

We developed a scoping study questionnaire to identify ID nursing interventions, the impact of the interventions, and participants' understanding of their roles. The questionnaire was developed and pre-tested by four members of the scoping research team. The questionnaire took approximately 30 minutes to complete and included 20 items across six domains: 1) biographical information; 2) countries and type of organisations; 3) patient (service user) group and interventions undertaken; 4) examples of impacts of interventions; and 5) participants' understanding of ID nursing roles (see appendix A).

*Sampling and participant recruitment*

Participants were ID nurses or other nurses registered with a nursing regulator who worked exclusively with people with intellectual disabilities. Participants were recruited through professional networks (see appendix D). We used a combination of voluntary response sampling (McCombes, 2020) and snowball sampling (Creswell and Planko, 2017). Voluntary response sampling is a non-probability sampling method widely used in collecting data using online survey instruments (McCombes, 2020). Voluntary response sampling is where participants volunteer to take part in a research study to share their opinions and experiences (McCombes, 2020). In this scoping research we focussed on capturing the experiences of ID nurses in their roles in meeting the healthcare needs of people with ID, and therefore this


©UWL / RCN Foundation 2021

was an appropriate method. Blending voluntary response sampling with snowball sampling or chain-referral sampling provided an opportunity for recipients of the survey link and or participants to share the survey link with their colleagues and ID nurses in their own professional networks (Creswell and Planko, 2017).

After deciding on our sampling strategy, the next step was to calculate the size of the sample we needed for statistical analyses. A number of tools exist for estimating non-probability sample sizes for surveys. In addition to the guidance from Fink (2015), we consulted a statistician on sample size calculation. Following advice from the statistician, and given the approach to sampling, we used the G*Power sample size calculator (Heinrich State University, 2020). The input parameters we used for the calculation were influenced by the proposed tests (Pearson correlations and Pearson Chi-square). The appropriate sample size estimated was ($n$ = 225).

*Data collection*

After ascertaining the content and construct validity of the survey questionnaire we created the online version on the JISC Online Surveys platform (https://www.onlinesurveys.ac.uk/). The pre-testing referred to earlier was undertaken online. This provided us with an opportunity to assess the interactivity and functionality of the survey, as well as ascertaining the time required for participants to complete the survey. We opted to use the JISC Online Surveys platform because it is secure and data is stored in the UK.

Another reason for our choice of this platform, and perhaps the most important is its ability to analyse quantitative data and generate descriptive statistics. Another important utility of the JISC Online Surveys is that we were able to export the data onto an excel spread sheet, as well as import the quantitative data into SPSS 27 for statistical analysis.


©UWL / RCN Foundation 2021

Furthermore, we were able to export qualitative data into a .pdf file. We were able to upload the qualitative data file into NVivo 13 to aid thematic analysis. This was particularly useful because it eliminated the need for data transcription.

Participants were recruited through various local, national, and international networks for ID nurses (see appendix D). An e-mail containing information about the survey, consent, confidentiality, and a weblink to the survey site was sent to all potential participants (see appendices B1, B2 and C). During the period of data collection, we checked the website several times a day to ensure that it was functioning correctly, and to monitor the progress of the responses. The survey was open from 13 October 2020 to 31 December 2020.

*Quantitative data analysis*

We undertook descriptive and inferential statistical analysis of quantitative data (questions 1-8, 16-20) (see appendix A) using SPSS 27.0 (IBM, 2020). All quantitative questions were analysed descriptively (see figures 1-15).

As we said earlier, we also undertook two types of statistical analyses. Firstly, we analysed the data for Pearson correlations. The Pearson correlation coefficient (r) is the most common bivariate correlation statistic in analysing relationships between variables of categorical data (Pallant, 2007). This was important for us to observe any relationship between participant characteristic variables, and response variables related to the interventions ID nurses undertook for people with ID and evaluation data. For interpreting the Pearson correlation statistics, we followed the widely used guidance provided by Cohen (1988). Secondly, we undertook Pearson Chi-square tests on the data. The Chi-square test is intended to test how likely it is that an observed distribution is due to chance. It is also called a *"goodness of fit"* statistic, because it measures how well the observed distribution of data fits with the distribution that is expected if the variables are independent.



©UWL / RCN Foundation 2021

*Qualitative data analysis*

We adopted three approaches to analysing qualitative data. For questions 9-12 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 of themes. First, after identifying the interventions we organised them into themes across the lifespan (maternity, children, adults, older adults, all age groups, and end of life) (see table 1). Second, we generated analytical themes of the interventions (effectuating nursing procedures, enhancing ID services, enhancing mainstream services, enhancing ID nursing practice, and enhancing quality of life) (see table 1). We adopted the effectuating nursing procedures, and enhancing quality of life themes from phase 1 of the project.

Question 13 enabled us to collect qualitative data on the impact of interventions undertaken by the participants. We used thematic analysis to analyse data from this question (Braun and Clarke, 2006) We identified 13 themes of impacts of ID nursing interventions. These are;

1. *Having a voice,*
2. *Increased independence and choice,*
3. *Improved health and quality of life,*
4. *Improved access to health and social care services,*
5. *Improved standards, quality of care, and patient experience,*
6. *Improved awareness of the needs of people with intellectual disabilities, reduced health inequalities and risks,*
7. *Making reasonable adjustments*
8. *Improved transitions improved family life*
9. *Improved healthcare outcomes,*
10. *Increased community presence and inclusion, and*
11. *Improved mental health and reduced challenging behaviour.*

We collected case studies in question 14. We used case study analysis method (Houghton, *et al.,* 2014), and organised the case studies into 23 groups (assessment (all types) (subdivide by specialism); building relationships with others / community / services / families / service user, care co- ordination; end of life; child development support; co-



©UWL / RCN Foundation 2021

production; communication - including listening; crisis intervention; educating / training family members; educating / training professionals; empowerment including educating / training individuals; delivered person-centred services; sex education; health facilitation / acute liaison / AHCs / diagnostic overshadowing; health promotion; holistic care, inclusion / community presence / participation (O'Brien's principles); medication (STOMP and STAMP), and other - polypharmacy; mental health issues / wellbeing - reducing anxiety; bositive behaviour support (PBS); reasonable adjustments; resilience and capacity - supporting / building with individual, family / others /staff; safeguarding / human rights/ child protection; sleep; transition support).


©UWL / RCN Foundation 2021

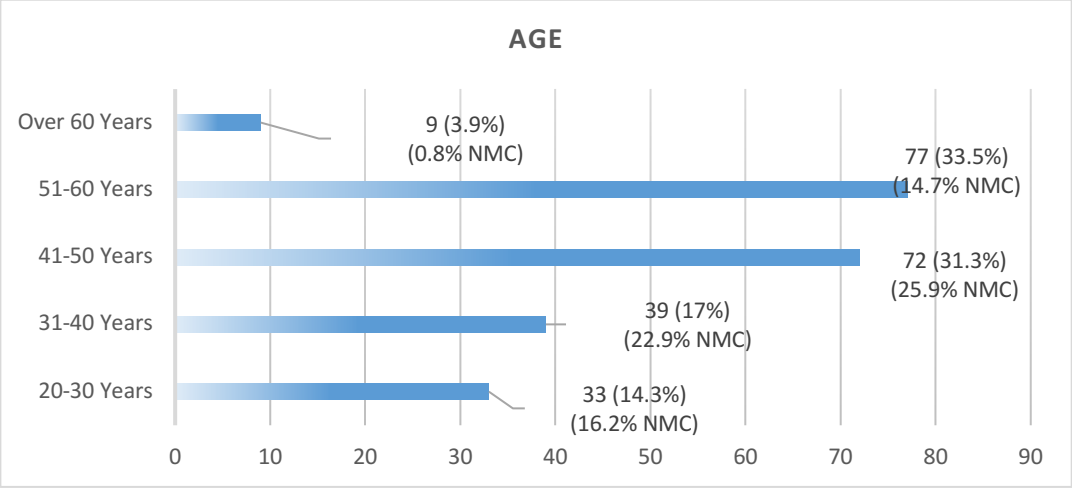
## 5. Findings and discussion

Here we present and discuss our findings. Each question we asked addressed specific elements of the project. We are therefore cognisant of the need to ensure that each set and subset of the findings are clearly presented. Because of this disparateness we present our findings and summary discussions under the following headings; participant profiles, interventions (effectuating nursing procedures, enhancing impact of ID services, enhancing impact of mainstream services, enhancing impact of ID nursing practice, enhancing quality of life, case studies, examples of impact, and evaluation.

### *Participant profiles*

Figure 1 illustrates the ages of participants. Data show that the age distribution 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 NMC registrants in 2020 (Michas, 2020, NMC, 2020). Perhaps what is more worrying is the proportion of ID 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 60s years old. As a proportion, there were 4.9 times more ID nurse participants (3.9%) as compared to 0.8% of total NMC registrants. It is more likely that this reflects the age profiles of entrants into ID nursing practice.

*Figure 1:* Age of participants






©UWL / RCN Foundation 2021

Figure 2 illustrates the gender distribution of participants. The participants were predominantly females at 85.2% as compared to 14.8% males. According to the NMC (2020) there were 10.8% males on the NMC register and 89.2% females. In addition, 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 ID nursing profession.

*Figure 2:* Gender of participants

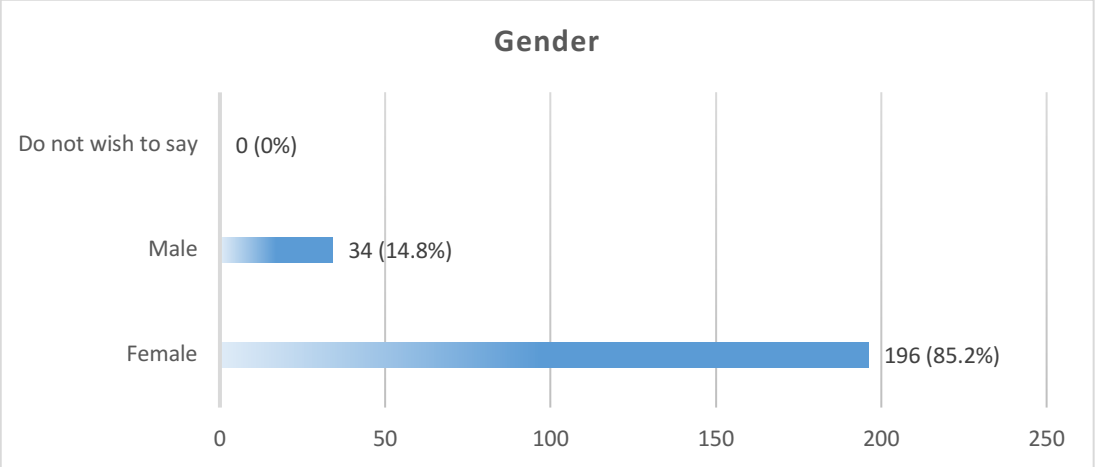
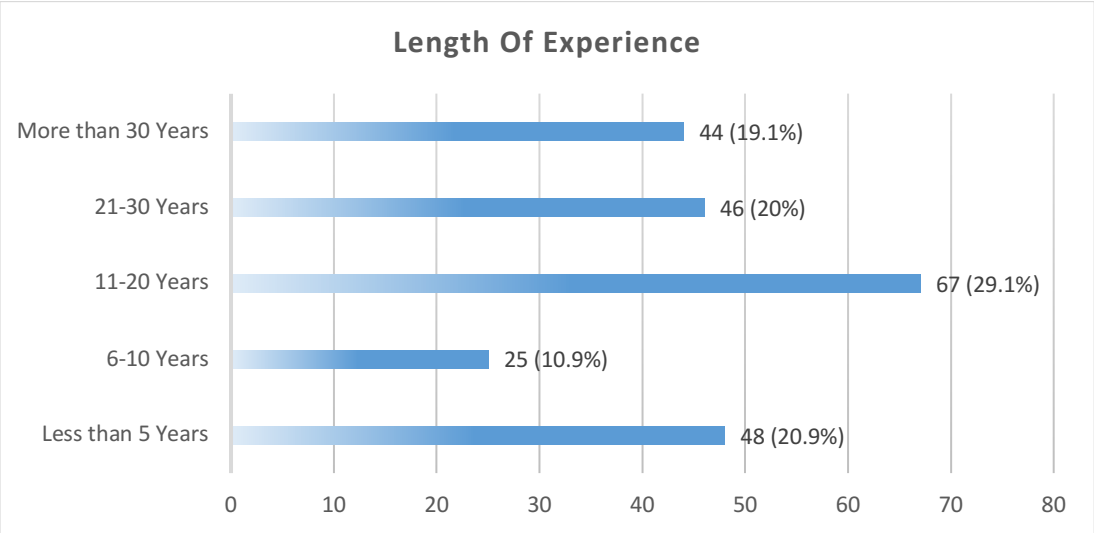



Figure 3 shows that 19.1% of participants have more than 30 years' experience. Most of these participants would more likely be entitled to retire. It is also important to note that 20% of participants have more than 20 years' experience and will be eligible for retirement in the next 10 years. Potentially, this means that 39.1% of ID 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 show that 53.5% of UK trained NMC registrants who left the register and participated in the survey were below the age of 60 years. Also, and perhaps what needs to be considered 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 ID nurses continue to practice.



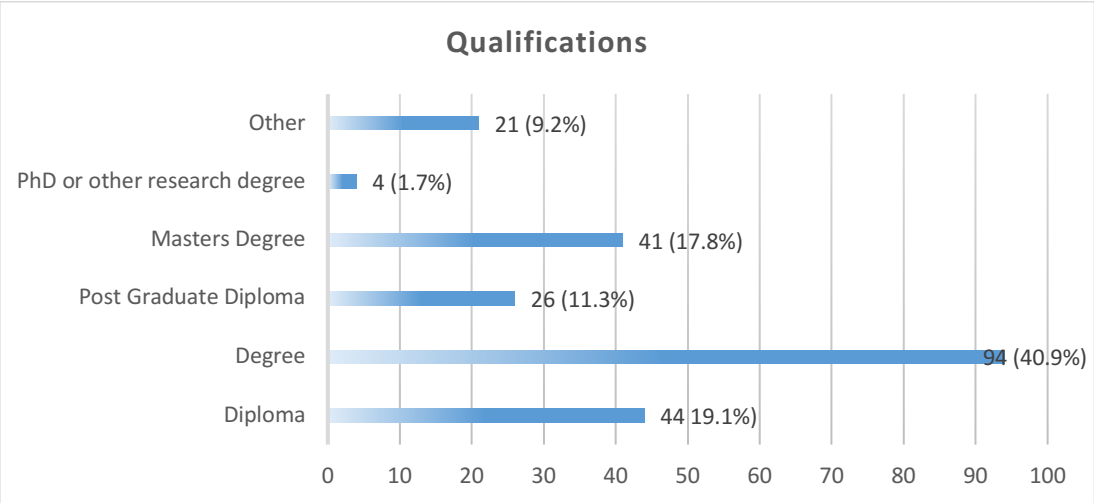
©UWL / RCN Foundation 2021

*Figure 3:* Participants' length of experience




In the UK, since the introduction of the *Standards for pre-registration nursing standards* (NMC, 2010), the minimum requirement for entry onto the register is a degree. 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.

*Figures 4:* Participants' qualifications



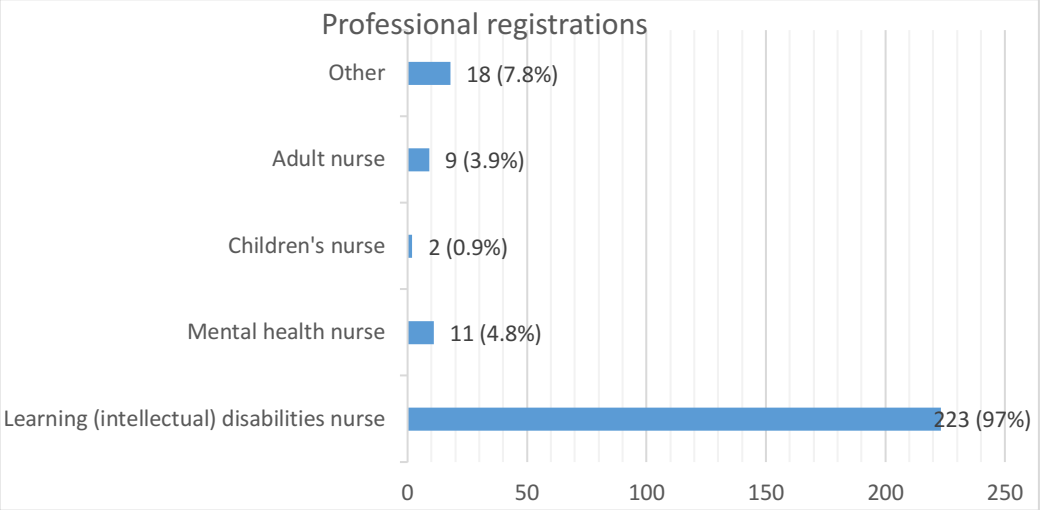

People with ID often have complex healthcare needs and having a nursing workforce with a wide range of skills is important. Having appropriate pre-registration, or post registration nurse training is



©UWL / RCN Foundation 2021

important to enable engagement in appropriate interventions. Of the 230 participants, 7 were not ID nurses, and it is unclear what training they have had to be able to understand the complex needs of people with ID.

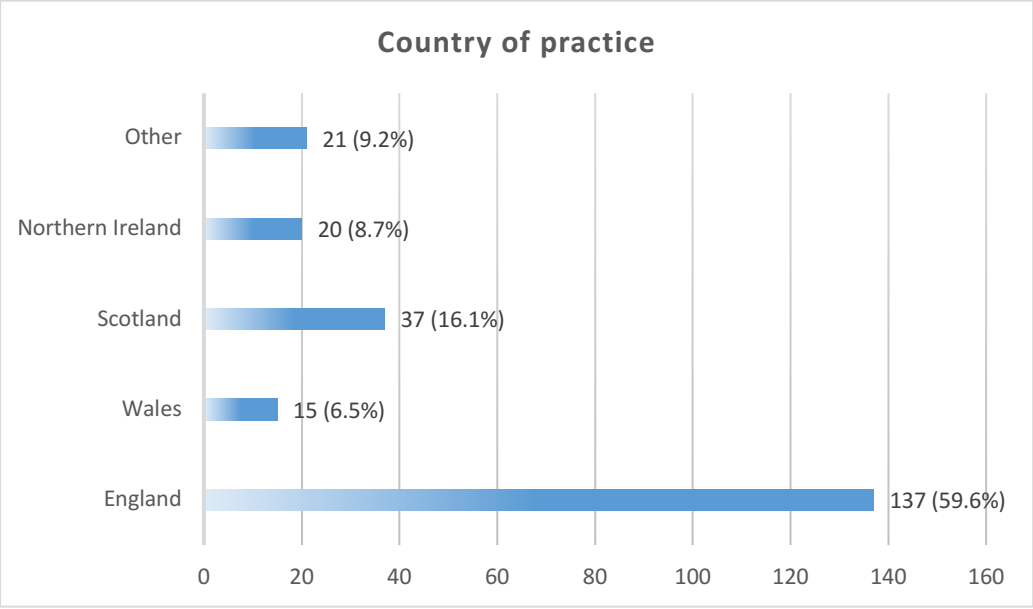
*Figure 5:* Professional registrations of participants




On the other hand, and perhaps what is more positive is that 38 (16.5%) participants reported that they were registered in other fields of practice.

*Where participants practice*

*Figure 6:* Countries where participants practice




59.6% of participants were practicing in England, followed by Scotland

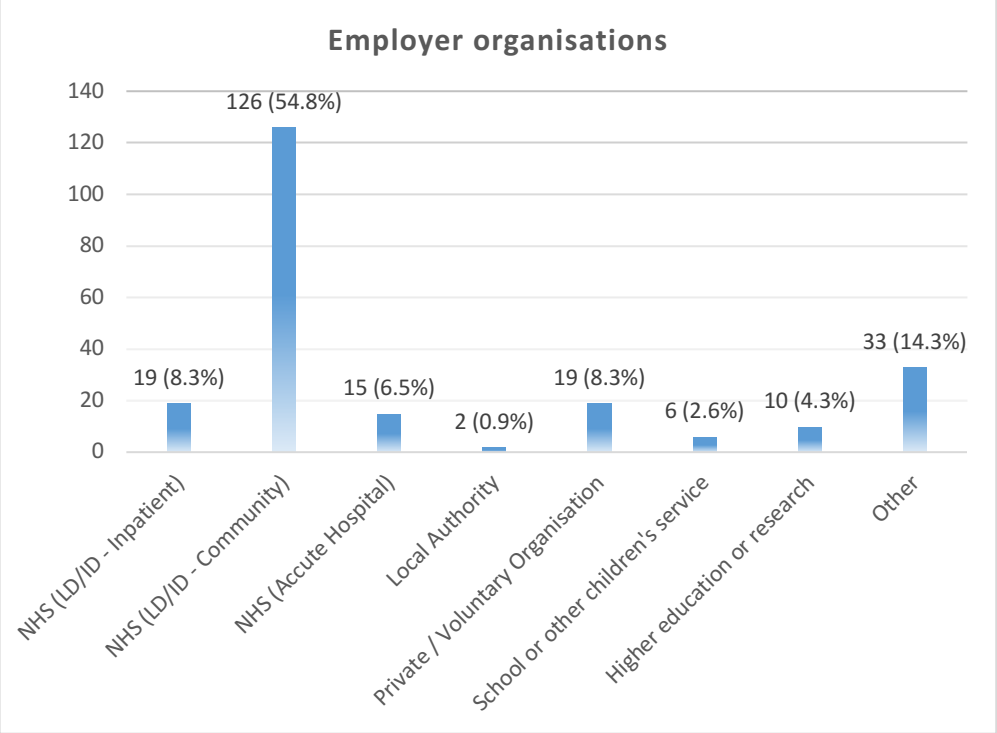


©UWL / RCN Foundation 2021

(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 show that most participants worked in the community (54.8%). The proportion of ID nurses who work in other organisations is significant at 14.3%. This proportion includes ID nurses working in; NHS England / Improvement, practice education, Health Education England, independent consultancy, prison nursing services, NHS commissioning - specialist provisions, New Zealand equivalent of the 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.

*Figure 7:* Participants' type of employer organisations.




It could be argued that the diversity of organisations and settings in which ID nurses who participated in this study work clearly demonstrates the complexity of the landscape in which ID nurses now practice. The proportion of ID nurses working in school nursing, and acute mainstream hospitals demonstrates emergent roles. Some of



©UWL / RCN Foundation 2021

these roles are likely to require ID nurses to develop advanced nursing practice skills in order to meet the needs of people with ID in these settings.

*Figure 8:* Distribution of age groups of people participants worked with

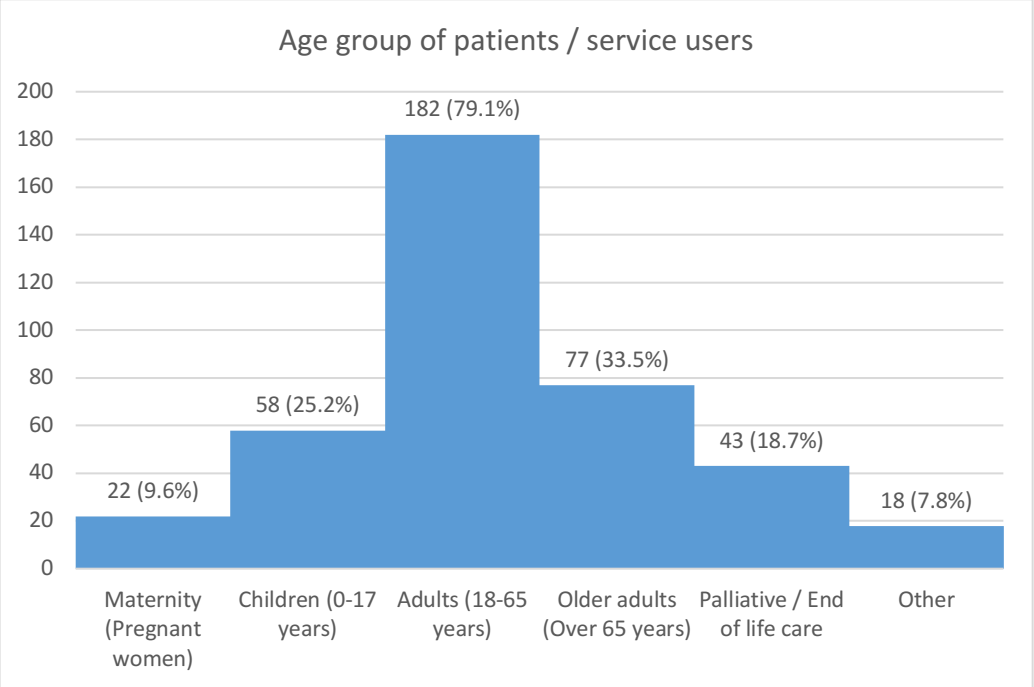



Figure 8 demonstrates that 79.1% of the interventions undertaken by participants involved adults with ID. In the UK, like in other countries pre-registration ID nurse education focuses on adults. What is clear here is the extent of ID nursing interventions across the lifespan; 9.6% of interventions undertaken by participants involved pregnant women, 25.2% involved children, 33.5% involved older adults, and 18.7% involved palliative (end of life care). What is also clear in the data is that ID nurses work across age groups. In the UK, this is inconsistent with the traditional organisation of mainstream healthcare services which are normally categorised as; maternity, children services, adult services, older adult services, and palliative care services. Working across age groups requires a significant repertoire of skills to undertake evidence-based interventions that result in positive outcomes for people with ID. Interventions in the 'other' category include; higher education, practice education, and transition services.



©UWL / RCN Foundation 2021

***Interventions***

We have identified 878 interventions from 7 countries. These interventions were 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 (19) (see figure 9, and table 1). The higher total from lifespan stages as compared to the identified interventions is accounted for by the fact that a significant proportion of the interventions are common across age groups. What is clear from the data is very limited involvement of ID nurses with pregnant women with ID. 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 ID choose to have children. An alternative explanation could be that midwifery is a separate profession from nursing, meaning that the skills required for ID nurses to be involved are beyond the scope of their practice. Perhaps what is more concerning are the limited specific interventions undertaken by ID nurses with respect to end-of-life care (2%). It might be that not many ID nurses practice in palliative care settings. The LeDer program, has consistently shown that people with ID are much more likely to die in hospital than the general population (for example, the 2017 report showed that 64% of the deaths notified to LeDer died in hospital as compared to 47% in the general population (LeDer, 2017). What needs to be understood here is how people with ID are supported, and by whom in the last days in hospital.



©UWL / RCN Foundation 2021

*Figure 9:* Distribution of interventions across the lifespan

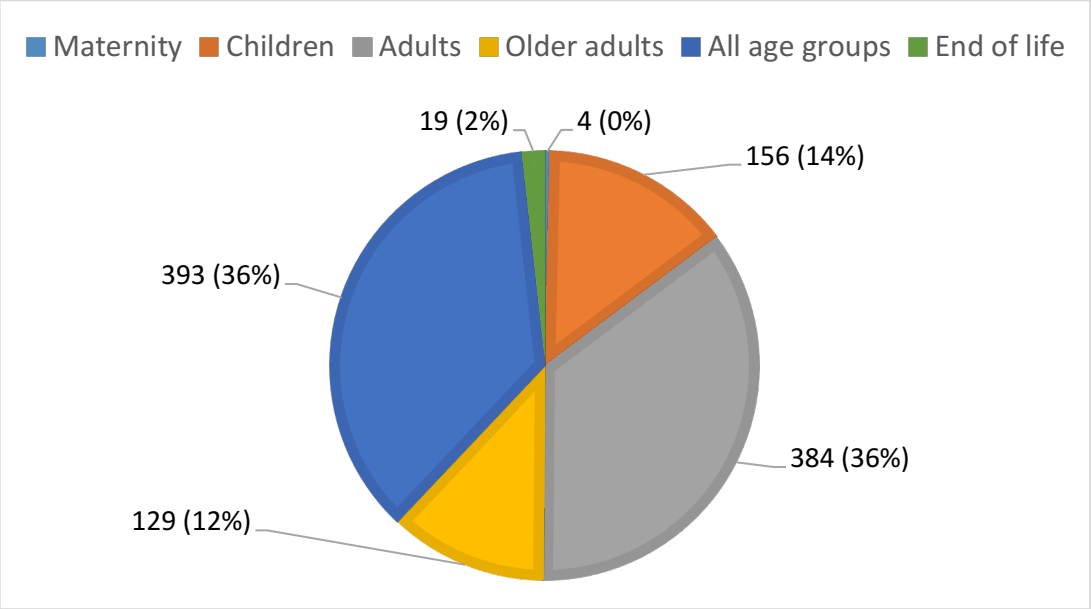
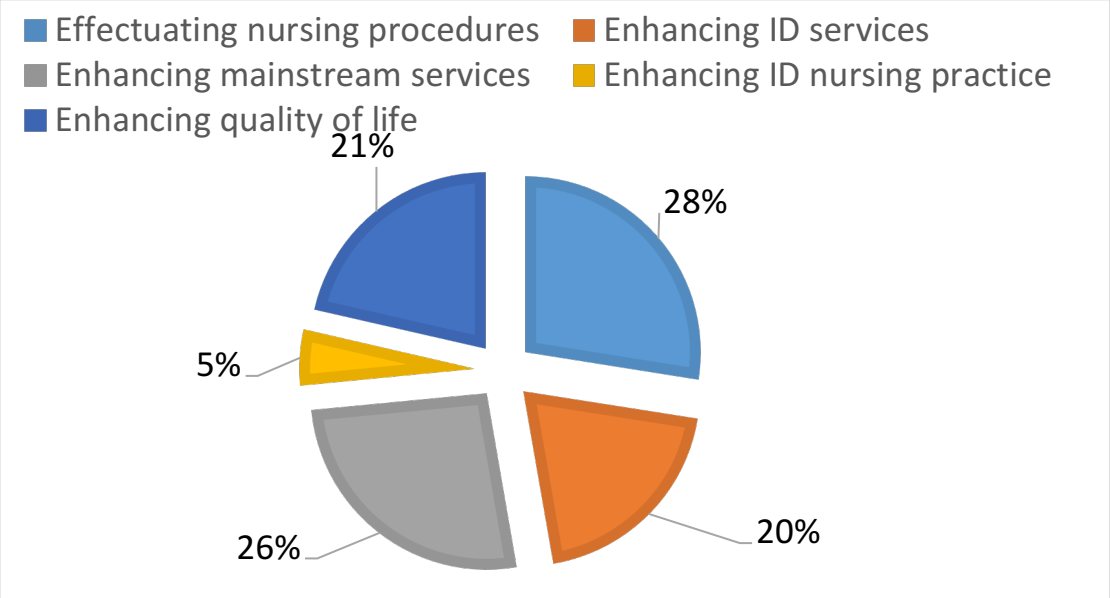



*Figure 10:* Distribution of interventions across the themes




We categorised the 878 interventions into five themes; *effectuating nursing procedures* (28%), *enhancing impact of ID services* (20%), *enhancing impact of mainstream services* (26%), *enhancing ID nursing practice* (5%), and *enhancing quality of life* (21%) (see figure 10, and table 1). We mapped ID nursing interventions to the stages of the lifespan, and to the emerging themes. What emerges is a very complex picture of ID nursing practice (see table 1). The *effectuating nursing procedures* interventions are ID nursing activities that involve



©UWL / RCN Foundation 2021

performing practical tasks with people with intellectual disabilities. The *enhancing impact of ID services* theme incorporates interventions directed at improving the work of organisations that specifically specialise on working with people with ID 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 ID nursing practice* (5%) theme incorporates activities undertaken by ID nurses to improve their own practice and the ID nursing profession. The *enhancing quality of life* theme incorporates interventions undertaken by ID nurses to promote the health and wellbeing of people with ID.

*Table 1:* Interventions

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 1. ABAS (adaptive behaviour system) assessments for children | | X | | | | | X | | | | |
| 2. ABC (antecedent behaviour consequence) charts monitoring during admission | | | X | | | | X | | | | |
| 3. Academic assessor role (all fields of nursing practice) | | | | | X | | | | | X | |
| 4. Accessible letters (produce templates) | | | | | X | | | X | X | | |
| 5. Act as a link between schools and other services | | X | | | | | | | X | | |
| 6. Acute healthcare acquired microbial infections prevention | | | | | X | | X | | | | |
| 7. Adapt communication for easy understanding | | | | | X | | | X | X | X | |
| 8. Adapt material for easy read | | | | | X | | | X | X | X | |
| 9. Adapt triage forms | | | X | | | | | | X | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| (prison service) | | | | | | | | | | | |
| 10. Adapt CBT (cognitive behaviour therapy) | | X | | | | | X | X | | | |
| 11. Adapt CBT for anxiety and depression for children | | X | | | | | X | X | | | |
| 12. Adapt environments | | | | | X | | | | | | X |
| 13. Adapt information for easy read | | | | | X | | | X | X | | X |
| 14. Adaptive communication | | | | | X | | X | X | X | | X |
| 15. Address determinants of health and health inequalities | | | | | X | | | | X | | X |
| 16. Address inequalities (constipation, dysphagia, aspiration, oral care) | | | | | X | | X | X | X | | X |
| 17. ADHD (attention deficit hyperactivity disorder) assessments | | X | X | | | | X | | | | |
| 18. ADHD clinics | | X | X | | | | X | | | | |
| 19. ADHD diagnosis | | X | X | | | | X | | | | |
| 20. Administer and manage medication | | | | | X | | X | | | | |
| 21. Administer of enemas | | | | | X | | X | | | | |
| 22. Administer oxygen | | | | | X | | X | | | | |
| 23. Admission avoidance | | X | X | | | | | | | | X |
| 24. Adult and child support and protection | | X | X | | | | | | | | X |
| 25. Advance care planning | | | | | | X | | X | X | | X |
| 26. Advise service users /carers | | | | | X | | | X | X | | X |
| 27. Advise and support commissioning teams | | | | | X | | | X | X | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 28. Advise parents | | X | | | | | | | | | X |
| 29. Advise acute hospital of individual needs | | | | | X | | | | X | | |
| 30. Advise CAMHS (child adolescent mental health service) colleagues | | X | | | | | | X | X | | |
| 31. Advise hospital staff on reasonable adjustments | | | | | X | | | | X | | |
| 32. Advise on and provide a plan of care for complex admissions and discharge | | | | | X | | | | X | | |
| 33. Advise others on working with people with ID | | | | | X | | | | X | | |
| 34. Advise providers and commissioners | | | | | X | | | X | X | | |
| 35. Advise social care services | | | | | X | | | X | X | | |
| 36. Advocate for ID inclusion at corporate level | | | | | X | | | | X | | |
| 37. Advocate for people with ID and / or their families | | | | | X | | | | X | | X |
| 38. Advocating for immunisation uptake | | X | | | | | | | | | X |
| 39. Advocacy (making referrals) | | | X | X | | | | | | | X |
| 40. Airway management (tracheostomy, ventilators) | | | | | X | | X | | | | |
| 41. Alcohol and substance (advise and support) | | | X | | | | | | | | X |
| 42. Alcohol or substance misuse work | | | X | | | | X | | | | X |
| 43. Alcohol/substance education | | | X | | | | | | | X | X |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 44. Anger management | | X | X | | | | X | | | | |
| 45. Annual health check | | | X | X | | | | | X | | |
| 46. Annual health checks monitoring | | | X | X | | | X | X | X | | |
| 47. Annual medication monitoring | | | | | X | | X | X | X | | |
| 48. Anti-psychotic medication review and monitoring | | | X | | | | X | X | X | | X |
| 49. Anxiety assessment | | | X | | | | X | | | | |
| 50. Anxiety management | | | X | | | | X | | | | X |
| 51. Anxiety support | | | X | | | | | | | | X |
| 52. Anxiety workbooks (produce and implement) | | | X | | | | | X | | | X |
| 53. Arranging health appointments | | | | | X | | | X | X | | |
| 54. Arranging reasonable adjustments | | | | | X | | | X | X | | |
| 55. ASD (autism spectrum disorder) diagnosis | | X | X | | | | X | | | | |
| 56. ASD liaison with specialists regarding sensory needs and sensory diets | | X | | | | | | | X | | |
| 57. ASD post diagnostic support | | X | X | | | | X | | | | X |
| 58. Assess changing health conditions and detecting deterioration | | | | | | X | X | | | | X |
| 59. Assessing and managing co-morbidities associated with ID, ASD, MH (mental health) | | | | | X | | X | | | | |
| 60. Assess effectiveness of interventions | | | | | X | | | | X | | |
| 61. Assess needs | | | | | X | | X | | | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 62. Assess people's understanding of their needs | | | X | | | | | | | | X |
| 63. Assess risk | | | | | X | | X | | | | |
| 64. Assessment for equipment | | | | | X | | X | | | | |
| 65. Assessment of mental health | | X | X | | | | X | | | | |
| 66. Assess mobility decline in older people with ID | | | | X | | | X | | | | |
| 67. Assist others to work with people with ID | X | | | | X | | | | X | | |
| 68. Assist with capacity/risk assessments | | | | | X | | | | X | | |
| 69. Asthma clinics | | | X | X | | | X | | | | |
| 70. Audit | | | | | X | | | X | X | | |
| 71. Audit (restrictive practices) | | | | | X | | | X | X | | |
| 72. Audit annual health checks | | | X | X | | | | X | X | | |
| 73. Audit clinical pathways | | | | | X | | | X | X | | |
| 74. Autism assessment | | X | X | | X | | X | X | X | | |
| 75. Autism awareness raising, training and education (staff / carers) | | | | | X | | | X | X | X | X |
| 76. Autism diagnosis | | X | | | | | X | X | | | |
| 77. Autism support (community) | | | | | X | | | X | X | | x |
| 78. Awareness training (ID) for service providers | | | | | X | | | X | X | | |
| 79. Baseline dementia assessments | | | | X | | | X | | | | |
| 80. Baseline observations | | | | | X | | X | | | | |
| 81. Behaviour analysis (observation and data analysis) | | | | | X | | X | | | | |
| 82. Behaviour and sleep management (child) | | X | | | | | X | | | | |
| 83. Behaviour | | | | | X | | X | | | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| assessment, planning and implementation | | | | | | | | | | | |
| 84. Behaviour family therapy | | X | X | | | | X | | | | X |
| 85. Behaviour management assessment | | X | X | | | | X | | | | |
| 86. Behaviour support during COVID-19 isolation | | | | | X | | X | | | | X |
| 87. Behavioural analysis | | | | | X | | X | | | | |
| 88. Behavioural assessments | | | | | X | | X | | | | |
| 89. Behavioural intervention and support | | | | | X | | X | | | | X |
| 90. Behavioural sleep interventions | | X | | | | | X | | | | X |
| 91. Benchmarking | | | | | X | | | X | X | | |
| 92. Bereavement counselling | | | | | X | X | X | | | | X |
| 93. Bereavement support | | | | | X | | | | | | X |
| 94. Bereavement workbooks (develop) for service users | | | | | X | | | X | X | | X |
| 95. Best interest assessments | | | | | X | | | X | X | | X |
| 96. Best interest meetings (chairing) | | | | | X | | | X | X | | X |
| 97. Blood glucose monitoring | | | | | | | | | | | |
| 98. Blood test (antipsychotic medication) (ordering and interpreting) | | | | | X | | X | | | | |
| 99. Blood tests | | | X | X | | | X | | | | |
| 100. Bowel care | | | X | X | | | X | | | | |
| 101. Bowel monitoring | | | X | X | | | X | | | | |
| 102. Bowel screening | | | X | X | | | X | | | | |
| 103. Bowel screening promotion | | | X | X | | | X | | | | X |
| 104. Brain injury | | X | X | | | | | X | X | X | X |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| education | | | | | | | | | | | |
| 105. Breast screening promotion | | | X | | | | | | X | | X |
| 106. Building positive and therapeutic relationships | | | X | | | | X | | | | X |
| 107. Cancer awareness training | | | X | | | | | | | | X |
| 108. Cancer screening promotion | | | X | | | | | | | | X |
| 109. Capacity for marriage education | | | X | | | | | | | | X |
| 110. Cardiometabolic assessments | | | X | | | | X | | | | |
| 111. Care assessments | | | X | X | | | X | | X | | |
| 112. Care coordination | | | | | X | | X | X | X | | |
| 113. Care planning | | | | | X | | X | | | | |
| 114. Caregiver education | | | | | X | | | X | X | | X |
| 115. Caregiving | | | | X | | X | X | | | | |
| 116. Carer assessment | | | | X | | | X | | X | | X |
| 117. Carer support | | | | | X | | | X | | | X |
| 118. Carer training for weight management | | | X | | | | | | | | X |
| 119. Carrying out urinalysis | | | X | X | | | X | | | | |
| 120. Case (caseload) management | | | X | X | | | X | X | X | | |
| 121. Catheter care | | | X | X | | | X | | | | |
| 122. Catheterisation | | | X | X | | | X | | | | |
| 123. Cervical screening promotion | | | X | | | | | | | | X |
| 124. Chair best interest meetings | | | X | X | | | | X | X | | |
| 125. Chairing care program approach (CPA) meetings | | | X | X | | | | X | | | |
| 126. Chairing CTR reviews | | | | | X | | | | X | | |
| 127. Challenging behaviour support (community) | | | | | X | | | X | | | X |
| 128. Challenging practice / unconscious discrimination | | | | | X | | X | X | X | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 129. CHC (continuing healthcare) assessment | | | X | | | | X | | | | |
| 130. Chest physiotherapy | | | X | | | | X | | | | |
| 131. Child and adult protection safety planning | | X | X | | | | X | | | | |
| 132. Child development monitoring | | X | | | | | X | | | | |
| 133. Child sex education | | X | | | | | | | | | X |
| 134. Child sex therapy | | X | | | | | X | | | | |
| 135. Clinical consultation and advice | | | X | X | | | X | | | | X |
| 136. Clinical diagnosis | | | X | X | | | X | | | | |
| 137. Clinical governance | | | | | X | | | X | X | | |
| 138. Clinical leadership | | | | | X | | | | | X | |
| 139. Clinical leadership (local, regional and national) | | | | | X | | | | | X | |
| 140. Clinical supervision | | | | | X | | | | | X | |
| 141. Clinical support | | | | | X | | | | | X | |
| 142. Co-ordinate care between teams in acute hospital | | | | | X | | | X | X | | |
| 143. Co-ordinate care/treatment pathways | | | | | X | | | X | X | | |
| 144. Co-ordinate multi-disciplinary reviews | | | | | X | | | X | X | | |
| 145. Co-ordinate communications | | | | | X | | | | | | |
| 146. Co-produce disability awareness literature/training | | X | X | | | | | | | | X |
| 147. Co-production | | | | | X | | | X | X | | X |
| 148. Coaching | | | | | X | | | | | X | |
| 149. Coaching (quality improvement methodology) | | | | | X | | | X | | | |
| 150. Cognitive behaviour therapy (CBT) | | | X | | | | X | | | | |
| 151. Cognitive decline assessments | | | | X | | | X | | | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 152. Collaborative working with other professionals | | | X | | | | | X | X | | |
| 153. Collecting MSU (midstream specimen urine) | | | X | | | | X | | | | |
| 154. Commission packages of care | | X | | | | | | X | X | | |
| 155. Commission changes to service provision | | | X | X | | | | X | X | | |
| 156. Communication (support with contacting statutory and other agencies) | | | X | X | | | | | | | X |
| 157. Communication assessments | | X | X | | | | X | | | | |
| 158. Community service restructuring | | | | | X | | | X | | | |
| 159. Complete ReSPECT (recommended summary plan for emergency care and treatment) forms | | | X | | | | X | | | | |
| 160. Completing MEWS (modified early warning score) charts | | | X | | | | X | | | | |
| 161. Complex discharge planning | | | X | X | | | X | | | | |
| 162. Complex epilepsy support | | X | X | | | | X | | | | X |
| 163. Compose and implement care regimes | | | X | | | | X | | | | |
| 164. Consultancy (worldwide) | | | | | X | | | X | X | | |
| 165. Consultation | | | X | X | | | X | X | X | | |
| 166. Consultation with CAMHS teams and SEN (special education needs) schools | | X | | | | | | X | X | | |
| 167. Continence assessment | | | | | X | | X | | | | |
| 168. Continence care | | | | | X | | X | | | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 169. Continence intervention planning and management | | | | | X | | X | | | | |
| 170. Continence training | | X | | | | | | | | | X |
| 171. Continence promotion | | X | | | | | | | | | X |
| 172. Continence review | | X | | | | | | | | | X |
| 173. Continence support | | X | | | | | | | | | X |
| 174. Contingency planning | | | | | X | | | X | X | | |
| 175. Continuing health care assessment | | | | | X | | X | | | | |
| 176. Continuing health care assessment (children) | | | | | X | | X | | | | |
| 177. Continuing healthcare care reviews (annual) | | | | | X | | X | | | | |
| 178. Continuing professional development | | | | | X | | | | | X | |
| 179. Contract, care and treatment plan monitoring | | | | | X | | X | | | | |
| 180. Contribute to EHCP plans | | X | | | | X | | | X | | |
| 181. Coordinate assessment process | | | X | X | | X | | X | X | | |
| 182. Coordinate clinical supports | | | | | X | | | X | X | | |
| 183. Coproduction of policy | | | | | X | | | X | X | | X |
| 184. Counsel patients and families | | | X | | | | | | | | X |
| 185. Court liaison | | | X | | | | | | X | | |
| 186. Court of protection applications | | | X | | | | | | | | X |
| 187. Covid 19 risk assessments | | | X | X | | | X | | | | |
| 188. COVID-19 education | | | X | X | | | | | | | X |
| 189. Covid-19 swabbing training | | | | | X | | | X | | | |
| 190. Covid-19 testing | | | X | X | | | X | | | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 191. Covid-19 vaccinations | | | X | X | | | X | | | | |
| 192. CPA coordination | | | X | X | | | X | X | | | |
| 193. CPD planning | | | | | X | | | | | X | |
| 194. CQC (Care Quality Commission) inspections | | | | | X | | | X | X | | |
| 195. Create and provide easy read information | | | | | X | | | X | X | | X |
| 196. Creating new roles (co-ordinator and named professional for safeguarding in fire service) | | | | | X | | | | | X | |
| 197. Create service specifications | | | | | X | | | X | | | |
| 198. Create new care pathways | | | X | | | | | | X | | X |
| 199. Criminal justice system work | | | X | | | | | | X | | X |
| 200. Crisis intervention | | | X | | | | | X | X | | |
| 201. Crisis planning | | | X | | | | | X | X | | |
| 202. Crisis prevention and response | | X | X | | | | X | X | | | |
| 203. De-congregation | | | X | | | | | X | X | | X |
| 204. De-escalate and prevent crisis | | | | | X | | X | | | | |
| 205. Decider skills therapy | | X | | | | | X | | | | |
| 206. Deliver health improvement programmes | | | X | X | | | | X | X | | X |
| 207. Dementia assessment (diagnostic) | | | X | X | | | X | | | | |
| 208. Dementia care | | | X | X | | | X | | | | |
| 209. Dementia care assessments | | | X | X | | | | X | X | | X |
| 210. Dementia in ID education (individuals, families and carers) | | | X | X | | | X | | | | |
| 211. Dementia review | | | X | X | | | X | | | | |
| 212. Dementia screening | | | X | X | | | X | | | | |
| 213. Dementia support | | | X | X | | | | X | X | | X |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| (community) | | | | | | | | | | | |
| 214. Dementia training | | | X | X | | | | | | | |
| 215. Dental hygiene awareness | | | X | | | | | X | | | X |
| 216. Dentistry liaison | | | X | X | | | | | X | | |
| 217. Deprescribe psychotropic medication | | | X | X | | | X | | | | |
| 218. Depression assessment | | | X | X | | | X | | | | |
| 219. DES (Directed Enhanced Service) training | | | X | X | | | | | X | | |
| 220. Desensitisation | | X | X | | | | X | | | | X |
| 221. Desensitisation (equipment, procedures, screening, blood tests) | | X | X | | | | | | X | | X |
| 222. Desensitisation to clinical procedures using visual aids | | X | X | | | | | | X | | X |
| 223. Determine funding | | X | X | | | | | X | | | X |
| 224. Develop and design tools to improve identification of physical health needs | | | X | | | | | X | X | | X |
| 225. Develop and implement training packages for community teams | | | X | | | | | | | X | |
| 226. Develop anxiety management plans | | | X | | | | X | | | | |
| 227. Develop assessments for G4S (prison service) | | | X | | | | X | | X | | |
| 228. Develop audit tools for ID services within prison settings | | | X | | | | | | X | | |
| 229. Develop business cases | | | X | | | | | X | | | |
| 230. Develop easy read material | | | | | X | | | X | X | | X |
| 231. Develop health | | | X | | | | | X | X | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| strategy for service delivery | | | | | | | | | | | |
| 232. Develop national policy and guidance | | | | | X | | | X | X | X | |
| 233. Develop new services | | | X | | | | | X | | | |
| 234. Develop parenting programmes | | X | | | | | | | | | X |
| 235. Develop pathways for better access to dementia services (dementia) | | | X | X | | | | | X | | |
| 236. Develop plans of care | | | X | | | | X | | | | |
| 237. Develop policy | | | | | X | | | X | | | |
| 238. Develop profound and multiple intellectual disability core and essential standards | | | | | X | | | X | X | | |
| 239. Develop school resources for children | | X | | | | | | | X | | |
| 240. Develop systems and processes to support national initiatives, e.g., STOMP | | | | | X | | | X | X | | |
| 241. Develop accessible health information | | | | | X | | | X | X | | X |
| 242. Develop admission pathways | | | X | | | | | X | X | | |
| 243. Develop behaviour management plans | | X | X | | | | X | X | | | X |
| 244. Develop and maintain care and treatment plans | | X | X | | | | X | | | | |
| 245. Develop and maintain PBS plans | | | X | | | | X | | | | |
| 246. Develop communication aids | | X | X | | | | | X | X | | X |
| 247. Develop coping strategies for the prisoners | | | X | | | | | | | | X |
| 248. Develop easy to understand letters, | | | X | | | | | | | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| guidelines and information | | | | | | | | | | | |
| 249. Develop epilepsy guidelines | | X | X | | | | | X | X | | X |
| 250. Develop Health Action Plans | | | X | | | | X | | | | |
| 251. Develop health education material | | | X | | | | | X | | | X |
| 252. Develop hospital care passports (within hospital) | | X | X | | | | | | X | | |
| 253. Develop hospital passports (between community and hospital) | | X | X | | | | | | X | | |
| 254. Develop ID referral system | | | X | | | | | X | X | | |
| 255. Develop regulation processes (HIQA) | | | | | X | | | X | | | |
| 256. Develop toolkits for healthcare professionals | | | | | X | | | X | X | | |
| 257. Develop and implement behaviour support plans | | | | | X | | X | | | | |
| 258. Developmental assessment | | X | | | | | X | | | | |
| 259. Diabetes monitoring | | X | X | | | | X | | | | |
| 260. Diabetes passports (develop) | | | X | | | | X | | X | | |
| 261. Diabetes support | | | X | | | | X | | | | X |
| 262. Diagnostic assessment (ID) | | X | | | | | X | | | | |
| 263. Diagnostic assessments | | | | | X | | X | | | | |
| 264. Dialectal therapies | | X | | | | | X | | | | |
| 265. Diet and nutrition assessment | | X | X | | | | X | | | | |
| 266. Diet and nutrition management | | | X | X | | X | X | | | | |
| 267. Diet planning | | | X | | | | X | | | | X |
| 268. Diet/fluid monitoring | | | | | X | | X | | | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 269. Digital rectal evacuation | | | X | X | | | X | | | | |
| 270. Disability analysis | | | X | | | | X | | | | |
| 271. Discharge follow up review meetings | | | X | | | | | X | X | | |
| 272. Discharge follow-up reviews with GPs | | | X | | | | | | X | | |
| 273. Discharge planning | | | X | | | | X | X | X | | |
| 274. Disseminate research findings | | | | | | | | | | | |
| 275. Distress assessment (DisDAT) (disability distress assessment tool) | | | X | | | | X | | | | |
| 276. DNACPR (do not attempt cardiopulmonary resuscitation) decisions | | | X | X | | | X | | X | | |
| 277. Dysphagia assessment and management | | | X | | | | X | | | | |
| 278. Eating intervention planning | | X | | | | | X | | | | X |
| 279. Educate health visitors | | X | | | | | | | X | X | |
| 280. Educate acute care staff | | | | | X | | | | X | X | |
| 281. Educate people with ID, family members, staff, and carers | | | | | X | X | | | X | | |
| 282. Educate primary care staff | | | | | X | | | | X | | |
| 283. Education, assessment and treatment of victims and perpetrators of abuse | | | X | | | | X | | X | | |
| 284. Education on IPC (infection prevention and control) audits | | | | | X | | | X | | | X |
| 285. Educate others to understand | | X | | | | | | | X | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| children's needs | | | | | | | | | | | |
| 286. Electrocardiogram (ECGs) (performing test) | | | X | | | | X | | | | |
| 287. Eligibility assessments | | | X | | | | X | | | | |
| 288. Emergency epilepsy medication (administration) | | | | | X | | X | | | | |
| 289. Emergency planning | | | | | X | | | X | X | | |
| 290. Emergency response de-escalation | | X | X | | | | X | | | | |
| 291. Emotional literacy training | | X | | | | | X | | | | X |
| 292. Emotional literacy (support / development) | | X | | | | | X | | | | X |
| 293. Employment (support with finding) | | | X | | | | | | | | X |
| 294. Empower families and children | | X | | | | | | | | | X |
| 295. Enable and empower | | | X | | | | | | | | X |
| 296. Enable and support healthy lifestyle choices | | | | | X | | | | | | X |
| 297. Enable creative communication | | | X | | | | | | X | | |
| 298. Enable GPs to offer annual health checks and health action plans | | | X | | | | | | X | | |
| 299. Enable things to happen | | | X | | | | | | X | | |
| 300. Encourage independence | | | X | | | | | | | | X |
| 301. Encourage physical activities | | | X | | | | | | | | X |
| 302. End of life advice for NHS staff | | | | | X | | | | X | | |
| 303. End of life care | | | | | X | | X | | | | |
| 304. End of life care (management of syringe driver) | | | | | X | | X | | | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 305. End of life support | | | | | X | | X | | | | X |
| 306. Engage other agencies | | X | | | | | | | X | | |
| 307. Ensure all care plan information is disseminated among staff teams | | | X | | | | | X | X | | |
| 308. Ensure good oral hygiene | | | | | X | | X | | | | |
| 309. Enteral feeding | | | | | X | | X | | | | |
| 310. Enteral management | | | | | X | | X | | | | |
| 311. Epilepsy assessment | | | | | X | | X | | | | |
| 312. Epilepsy awareness and emergency medication training | | | | | X | | | X | | | X |
| 313. Epilepsy care | | | | | X | | X | | | | |
| 314. Epilepsy education (individuals, families and carers) | | | | | X | | | X | X | | X |
| 315. Epilepsy management | | | | | X | | X | | | | |
| 316. Epilepsy monitoring | | | | | X | | X | | | | |
| 317. Epilepsy nursing assessment | | | | | X | | X | | | | |
| 318. Epilepsy review | | | | | X | | X | | | | |
| 319. Epilepsy support planning | | | | | X | | X | | X | | |
| 320. Facilitate access to education | | X | X | | | | | | X | | X |
| 321. Facilitate access (community, day service, health care, health screening, health services, mainstream services, primary & secondary care, reasonable adjustments, other services, health appointments) | | | | | X | | | | X | | X |
| 322. Facilitate access to social care | | X | X | | | | | | X | | X |
| 323. Facilitate ASD (autistic spectrum | | X | | | | | | | | | X |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| disorder) post diagnostic groups (child and parent) | | | | | | | | | | | |
| 324. Facilitate behaviour workshops | | X | X | | | | | | X | | |
| 325. Facilitate effective communication with GPs | | | X | | | | | | X | | |
| 326. Facilitate innovation | | | | | X | | | | | X | |
| 327. Facilitate optimum development (physical and emotional) | | X | | | | | X | | | | X |
| 328. Facilitate primary care professionals to work with people with ID | | | | | X | | | | X | | |
| 329. Facilitate social prescribing | | | X | | | | | | X | | |
| 330. Facilitate access to health services (Health facilitation) | | | | | X | | | | X | | |
| 331. Facilitate and attend MARMs (multi-agency response management system) | | | | | X | | | X | X | | |
| 332. Facilitate communication | | | | | X | X | X | X | X | | X |
| 333. Facilitate conferences | | | | | X | | | X | X | X | X |
| 334. Facilitate early discharge from mental health wards | | X | X | | | | | X | X | | X |
| 335. Facilitate informed choice | | | | | X | | | | | | X |
| 336. Facilitating mental capacity assessments | | X | X | | | | X | X | X | | |
| 337. Facilitate reasonable adjustments | | | | | X | | | X | X | | |
| 338. Facilitate service user groups | | | X | | | | | | | | X |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 339. Facilitate specialist clinics | | | | | X | | X | | | | |
| 340. Facilitate transitions | | | | | X | | | X | X | | |
| 341. Facilitate complex planned admissions | | | | | X | | | | X | | |
| 342. Family advice and support | | | | | X | | | | | | X |
| 343. Family intervention | | X | | | | | X | | | | X |
| 344. Family therapy / support | | X | X | | | | X | | | | |
| 345. FASD (foetal alcohol spectrum disorders) diagnosis | | X | | | | | X | | | | |
| 346. Feeding programs | | X | | | | | X | | | | X |
| 347. Feeds (PEG (percutaneous endoscopic gastrostomy), JEJ (jejunostomy) and blended) | | | | | X | | X | | | | |
| 348. Financial management | | | | | X | | | X | X | | |
| 349. Fire safety lead | | | | | X | | | X | | | |
| 350. Flu vaccinations (and promote uptake) | | | X | X | | | X | | | | X |
| 351. Forensic assessment | | | X | | | | X | | | | |
| 352. Forensic care planning | | | X | | | | X | | | | |
| 353. Forensic risk assessment | | | X | | | | X | | | | |
| 354. Forensic support liaison | | | X | | | | | | X | | |
| 355. Forensic team care co-ordination | | | X | | | | | | X | | |
| 356. Formulating service improvements | | | X | | | | | X | | | |
| 357. Functional analysis | | X | X | | | | X | | | | |
| 358. Functional assessments | | X | X | | | | X | | | | |
| 359. Funding decisions (agree/disagree) | | | | | X | | | | X | | X |
| 360. Gardening therapy | | | X | | | | X | | | | X |
| 361. Gatekeeping mental health assessments | | | X | | | | | X | X | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| for admission to hospital | | | | | | | | | | | |
| 362. Gemba walks | | | | | X | | | X | X | | |
| 363. Give information and advice | | | | | X | | | | X | | X |
| 364. GP outreach | | | | | X | | | | X | | |
| 365. GP practices ID awareness training | | | | | X | | | | X | | |
| 366. Group work on health advice/ sex education consent and capacity | | X | X | | | | | | | | X |
| 367. Growth monitoring | | X | | | | | X | | | | |
| 368. Guiding junior staff | | | | | X | | | X | X | X | |
| 369. Hand hygiene promotion | | | | | X | | | | X | | X |
| 370. Handle complaints | | X | | | | | | X | X | | X |
| 371. Hate crime reduction | | | X | | | | | | X | | X |
| 372. Health action planning | | | X | | | | X | X | X | | X |
| 373. Health assessments (respiratory, heart, neurological or abdominal abnormalities) | | | | | X | | X | | | | |
| 374. Health checks with GPs | | | | | X | | X | | | | |
| 375. Health coaching | | | | | X | | | | | | X |
| 376. Health education | | | | | X | | | | | | X |
| 377. Health education (condition specific) | | | | | X | | | X | X | | X |
| 378. Health education (medications) | | | | | X | | | X | | | X |
| 379. Health education for GP practices | | | | | X | | | | X | | |
| 380. Health facilitation | | | X | | | | | | X | | |
| 381. Health facilitation (LeDeR 9 (intellectual disabilities mortality review) action points) | | | X | | | | | | X | | |
| 382. Health improvement | | | X | | | | | | X | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 383. Health inequalities education | | | X | | | | | | X | | |
| 384. Health liaison | | | | | X | | | | X | | |
| 385. Health monitoring | | | | | X | | | X | X | | |
| 386. Health needs assessment | | | | | X | | X | | | | |
| 387. Health prevention | | | | | X | | | X | X | | X |
| 388. Health promotion (at GP surgeries, children, individual and group, keep fit, lifestyle, diet, obesity, diabetes, asthma, group sessions, healthy eating) | | | | | X | | | | | | X |
| 389. Health protection | | | | | X | | | | X | | |
| 390. Health screening | | | | | X | | X | | | | |
| 391. Health surveillance | | | | | X | | | | X | | |
| 392. Healthy eating advice (parents) | | X | | | | | | | | | X |
| 393. Healthy lifestyle advice | | | X | | | | | | | | X |
| 394. Healthy relationship groups | | | X | | | | | | | | X |
| 395. History taking | | | | | X | | X | | | | |
| 396. Homecare nursing | | | | | X | | X | | | | |
| 397. Hospital admission prevention | | | | | X | | | X | | | |
| 398. Hospital liaison | | | | | X | | | | X | | |
| 399. Hospital passport completion | | | X | | | | | | X | | X |
| 400. Hospital passports / traffic lights (developing and implementing) | | | | | X | | | | X | | X |
| 401. Hospital providers monitoring | | | | | X | | | | X | | |
| 402. Human rights education (service users) | | | | | X | | | X | X | | X |
| 403. ID awareness training (professionals, carers, primary care) | | | | | X | | | X | X | | X |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 404. ID GP DES (directed enhanced services) training | | | X | | | | | | X | | |
| 405. Identify children requiring further ID diagnostic assessment | | X | | | | | X | | | | |
| 406. Identify children subject to safeguarding | | X | | | | | | | X | | X |
| 407. Identify health inequalities (HEF) (health equalities framework) | | | | | X | | | | X | | |
| 408. Identify themes for service improvement | | | | | X | | | X | X | | |
| 409. Identify and support access to occupation and leisure activities | | | X | | | | | | | | X |
| 410. Identify equipment and resources | | | | | X | | X | | | | |
| 411. Implement HEF (health equalities framework) | | | | | X | | | | X | | |
| 412. Implement LAEP (local area emergency protocol) | | | | | X | | | | X | | |
| 413. Implement early interventions | | | X | | | | X | | | | |
| 414. Implement new local operating policies | | | | | X | | | X | X | | |
| 415. Implement the DAFNE (dose adjustment for normal eating) diabetes course | | | | | X | | | | | X | X |
| 416. Improve access to screening | | | X | | | | | | X | | |
| 417. Incident reviews | | | X | X | | | | X | X | | |
| 418. Independence (promoting) | | | X | | | | | | | | X |
| 419. Independent | | | X | | | | | | | | X |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| advocacy | | | | | | | | | | | |
| 420. Independent clinical reviews for CTRs (care treatment review) | | | X | | | | | X | X | | |
| 421. Independent medical prescribing | | | X | | | | X | | | | |
| 422. Individual education (physical/mental health diagnoses, health promotion, trauma, anxiety, coping strategies) | | | X | | | | X | | | | X |
| 423. Infection control | | | | | X | | X | | | | |
| 424. Infection control audits | | | | | X | | X | | X | | |
| 425. Inter-/intra-agency collaboration | | | | | X | | | X | X | | |
| 426. Intermittent catheterisation | | | X | | | | X | | | | |
| 427. Internet safety promotion and education | | X | | | | | | | | | X |
| 428. Interpret behaviour that challenges services | | X | X | | | | X | | | | |
| 429. Interpret complaints and symptoms | | | | | | X | X | | | | |
| 430. Introduce multi-agency working (adults and CYP (children and young people)) | | X | | | | | | X | X | | |
| 431. Investigate complaints | | | X | | | | | X | X | | |
| 432. Involvement in de-congregation process and supporting residents through same | | | X | | | | | X | | | |
| 433. Involvement in quality improvement | | | X | | | | | X | X | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| process | | | | | | | | | | | |
| 434. Last offices | | | | | | X | | X | X | | X |
| 435. Lead ID and ASD transforming care for CCG (clinical commissioning group) | | | X | | | | | X | X | | |
| 436. Lead multi-agency coordination care / meetings | | | X | X | | | | X | X | | |
| 437. Lead professional team | | | | | X | | | X | | X | |
| 438. Leadership (local work plans, national work plans, regional work plans) | | | | | X | | | X | X | X | |
| 439. Intellectual and development (lead) | | | | | X | | | X | X | X | |
| 440. Intellectual and skills building | | | | | X | | | X | X | X | |
| 441. Lecturing at university | | | | | X | | | | | X | |
| 442. LeDeR (intellectual disability mortality review) reviews | | | | | X | | | X | X | | |
| 443. Legislation review | | | | | X | | | X | X | | |
| 444. Liaise with GPs / consultants | | | | | X | | | | X | | |
| 445. Liaise with CCG regarding funding | | | | | X | | | | X | | |
| 446. Liaise with courts and solicitors | | | | | | | | | | | |
| 447. Liaise with health care professionals | | | X | | | | | | X | | |
| 448. Liaise (with acute neurology services, advocacy services, family and support, workers, genetic services, neurology services, paediatrics regarding diagnoses of ADHD (children), physical health services - especially neurology with | | | | | X | | | X | X | | X |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| regards to epilepsy(children), schools for children with additional needs and contribution to EHCP (children), police, housing, education)) | | | | | | | | | | | |
| 449. Lifestyle advice | | | X | | | | | | | | X |
| 450. Link nursing (GPs, primary care, secondary care, social services) | | | X | X | | | | | X | | |
| 451. Lobby management | | | | | X | | | X | X | | |
| 452. Make reasonable adjustments | | | | | X | | | X | X | | |
| 453. Make recommendations about interventions and supports | | | | | X | | X | X | X | | |
| 454. Make and facilitate reasonable adjustments | | | | | X | X | | | X | | |
| 455. Manage aggression | | X | X | | | | X | | | | |
| 456. Manage anxiety | | | X | | | | X | | | | X |
| 457. Manage anxiety through developing emotional literacy | | X | X | | | | X | | | | X |
| 458. Manage community housing strategy | | | X | | | | | | X | | X |
| 459. Manage epilepsy | | X | X | | | | X | | | | |
| 460. Manage resources | | | | | X | | | | X | | |
| 461. Manage staff | | | | | X | | | | X | | |
| 462. Management of NG (naso-gastric) tube | | X | X | | | | X | | | | |
| 463. Management of PEG (percutaneous endoscopic gastrostomy) | | X | X | | | | X | | | | |
| 464. Manage challenging behaviour | | | | | X | | X | | | | |
| 465. Manage complex patients | | | X | X | | | | X | X | | X |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 466. Manage DoLS (deprivation of liberty safeguards) | | | | | X | | | X | X | | X |
| 467. Manage end of life care | | | | | | X | X | | | | |
| 468. Manage epilepsy | | | X | | | | X | | | | |
| 469. Manage finance | | | | | X | | | X | X | | |
| 470. Manage long-term conditions | | | X | | | | X | | | | |
| 471. Manage mental health issues | | | | | X | | X | X | | | |
| 472. Manage Mental Health Act detentions | | | | | X | | X | X | X | | |
| 473. Manage hospital discharge | | | X | X | | | X | X | X | | |
| 474. Manage risk | | | X | | | | X | | | | |
| 475. Manage self-harm | | X | X | | | | X | | | | |
| 476. Manage the challenges of supporting women with complex needs | | | X | | | | X | | | | |
| 477. Manual handling risk assessment | | | X | X | | | X | X | | | |
| 478. Maternity care | X | | X | | | | X | | X | | X |
| 479. MDT (multi-disciplinary team) coordination | | | X | | | | | X | X | | X |
| 480. Meal planning | | | X | | | | | | | | X |
| 481. Measure vital signs | | | | | X | | X | | | | |
| 482. Medication (administration, management, audits, monitoring, education, review, assessment, initiation, filtration, decreasing, stopping, management reviews, physical health checks, side effects monitoring, and side effects review) | | | | | X | | X | | | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 483. Member of MAPPA (multi-agency public protection arrangements) | | | X | | | | | | X | | |
| 484. Mental capacity assessment | | | X | X | | | | X | X | | X |
| 485. Mental health advocacy | | | X | X | | | X | | X | | X |
| 486. Mental health and behavioural assessments of children (CAMHS) | | X | | | | | X | | | | |
| 487. Mental health assessment | | | X | | | | X | | | | |
| 488. Mental health care co-ordination | | | | | X | | X | X | X | | |
| 489. Mental health intervention | | | | | X | | X | | | | |
| 490. Mental health monitoring | | | | | X | | X | | | | |
| 491. Mental health promotion and support | | | | | X | | X | | | | X |
| 492. Mental health reviews | | | | | X | | X | | | | |
| 493. Mental health support | | | | | X | | | | | | X |
| 494. Mental health support groups (facilitating) | | | | | X | | | | | | X |
| 495. Mental health triaging in emergency department | | | | | X | | X | | X | | |
| 496. Mentor (students and new staff) | | | | | X | | | | | X | |
| 497. MHA (Mental Health Act) Section 117 reviews | | X | X | | | | X | X | X | | |
| 498. Mickey button changes | | X | X | | | | X | | | | |
| 499. Mindfulness (individual) | | | X | | | | X | | | | X |
| 500. Mindfulness classes | | | X | | | | X | | | | X |
| 501. Mindfulness for depression | | | X | | | | X | | | | X |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 502. Mobility assessment | | | X | X | | | X | | | | |
| 503. Modify health promotion materials (make them accessible) | | | | | X | | | | | | X |
| 504. Modify mental health interventions to suit people with ID | | | X | | | | | | | | X |
| 505. Monitor / review care packages | | | X | | | | | X | | | |
| 506. Monitor and evaluate care interventions | | | X | | | | | X | X | | |
| 507. Monitor effectiveness of medications and treatments | | | X | | | | X | | | | X |
| 508. Monitor vital signs | | | | | X | | X | | | | |
| 509. Mortality audits | | | | | X | | | X | X | | |
| 510. Mortality reviews as part of LeDeR | | | | | X | | X | X | X | | |
| 511. Moving and handling assessment | | | | | X | | X | | | | |
| 512. Moving and handling patients | | | | | X | | X | | | | |
| 513. Multisensory stimulation | | | | | X | | X | | | | X |
| 514. Musculoskeletal support and posture support | | | | | X | | X | | | | |
| 515. Music therapy | | | | | X | | X | | | | |
| 516. MUST (malnutrition universal screening tool) assessment | | X | X | | | | X | | | | |
| 517. Narrative therapies | | | X | | | | X | | | | |
| 518. Nebulization | | | | | X | | X | | | | |
| 519. Neighborhood relations building | | | X | | | | | | | | X |
| 520. Network with primary health care providers | | | X | X | | | | | X | | |
| 521. NEWS (national early warning score) | | | X | X | | | X | | | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| assessment of deterioration | | | | | | | | | | | |
| 522. Non-medical prescribing (mental health) | | | X | | | | X | | | | |
| 523. Nurse leadership and service improvement | | | | | X | | | X | | X | |
| 524. Nurse led clinics (run) | | | X | | | | X | | | | |
| 525. Nurse prescribing | | | X | | | | X | | | | |
| 526. Nursing assessment | | | | | X | | X | | | | |
| 527. Nutrition advice (provision of) | | | | | X | | | X | | | X |
| 528. Nutrition and dysphagia management | | | | | X | | X | | | | |
| 529. Nutrition and fluid support | | | | | X | | X | X | | | X |
| 530. Nutrition awareness training | | | | | X | | | X | | | X |
| 531. Nutritional management | | | | | X | | X | | | | |
| 532. Obtain samples for lab oratory analysis (urine, blood, sputum) | | | X | | | | X | | | | |
| 533. Offence-specific interventions | | | X | | | | X | | | | |
| 534. Offending behaviour interventions | | | X | | | | X | | | | |
| 535. Offending behaviour support | | | X | | | | X | | | | X |
| 536. Oral health care assessments | | | X | | | | X | | | | |
| 537. Oral suctioning | | | X | | | | X | | | | |
| 538. Order and interpret blood tests | | | X | X | | | X | | | | |
| 539. Order and interpret investigations | | | X | | | | X | | | | |
| 540. Organise social activities | | | X | X | | | | | | | X |
| 541. Outpatient clinics (physical health checks) | | | X | | | | X | | | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 542. Out of area visits | | | X | X | | | X | X | | | |
| 543. Oversee of packages of care | | | X | X | | | | X | | | |
| 544. Oversee the A&E (accident & emergency) department as a senior psychiatric nurse | | | X | | | | X | | | | |
| 545. Oxygen administration / therapy | | | | | X | | X | | | | |
| 546. Pain assessment | | | | | X | | X | | | | |
| 547. Pain management | | | | X | | | X | | | | |
| 548. Pain/distress traffic light planning | | | | | X | | X | | | | |
| 549. Palliative and end of life care | | | | | | X | X | | | | |
| 550. Palliative care | | | | | X | | X | | | | |
| 551. Palliative care in collaboration with hospice nurses | | | | | X | | X | | | | |
| 552. Parent support groups | | X | | | | | | | | | X |
| 553. Parent training (children) | | X | | | | | | | | | X |
| 554. Parental education during early diagnosis | | X | | | | | | | | | X |
| 555. Parenting interventions | | X | | | | | | | | | X |
| 556. Parenting support | | X | | | | | | | | | X |
| 557. Parent groups/workshops (facilitation of) | | X | | | | | | | | | X |
| 558. Parole hearings (prison) | | | X | | | | | | X | | |
| 559. Participation in adult protection cases | | | X | | | | | | X | | X |
| 560. Participate in NICE (National Institute for Health and Care Excellence) core group meetings | | | | | X | | | X | X | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 561. Peer reviewing research | | | | | X | | | | | X | |
| 562. Peer support | | | | | X | | | X | X | X | |
| 563. PEG balloon replacing / care | | | | | X | | X | | | | |
| 564. PEG management | | | | | X | | X | | | | |
| 565. PEG feeding | | | | | X | | X | | | | |
| 566. Performance (measurement and management) | | | | | X | | | X | X | X | |
| 567. Pharmacy liaison | | | X | X | | | | | X | | |
| 568. Pharmacological advice to GPs | | | X | X | | | | | X | | |
| 569. Phlebotomy | | | X | X | | | X | | | | |
| 570. Physical activity health checks | | | X | | | | X | | | | |
| 571. Physical and mental health programs monitoring | | | X | X | | | | X | X | | |
| 572. Physical deterioration assessment (RESTORE2) | | | X | X | | | X | | | | |
| 573. Physical health assessment (abdominal, respiratory, and cardiovascular auscultation, percussion and palpitation) | | | X | X | | | X | | | | |
| 574. Physical health monitoring | | | | | X | | X | | | | |
| 575. Physical intervention | | | X | X | | | X | | | | |
| 576. Physical wellbeing education (healthy eating/exercise) | | | X | X | | | | | | | X |
| 577. PIP (personal independence payment) assessments | | X | X | | | | X | | X | | X |
| 578. Placement (breakdown prevention, review) | | | X | X | | | | X | | | |
| 579. Placement support | | | | | X | | | | | X | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| for students (nursing, social work, trainee psychology, trainee nurse associate students) | | | | | | | | | | | |
| 580. Play skills training | | X | | | | | | | | | X |
| 581. Play stimulation | | X | | | | | | | | | X |
| 582. Play therapy | | X | | | | | X | | | | X |
| 583. Policies, procedures and guidelines (development, implementation, review) | | | | | X | | | X | X | X | |
| 584. Positive Behaviour Support (assessment, planning, intervention, and evaluation) | | | | | X | | X | | | | |
| 585. Positive behaviour support training | | | | | X | | | X | | | |
| 586. Postural drainage | | | X | | | | X | | | | |
| 587. Postural support | | | X | | | | X | | | | |
| 588. Practice education lead | | | | | X | | | | | X | |
| 589. Pre-admission screening | | | | | X | | X | | | | |
| 590. Pre-admission support | | | | | X | | | | X | | |
| 591. Preceptorship (provide) | | | | | X | | | | | X | |
| 592. Prepare evidence for court appearance | | | | | X | | | | X | | |
| 593. Prepare home for changed needs | | | | X | | | | | | | X |
| 594. Prepare reports for mental health review tribunals | | X | X | | | | X | X | X | | |
| 595. Prepare syringe drivers | | | | | X | | X | | | | |
| 596. Prepare women psychologically for cancer screening | | | X | | | | | | X | | X |
| 597. Prescribing | | | X | X | | | X | | | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 598. Prescribing (anxiety, OCD, low mood, agitated and aggressive behaviours, sleep) | | X | | | | | X | | | | |
| 599. Prescribing psychotropic medication | | | X | X | | | X | | | | |
| 600. Presenting at conferences | | | | | X | | | X | X | X | X |
| 601. Pressure care | | | X | X | | | X | | | | |
| 602. Pressure relief and skin care | | | | | | X | X | | | | |
| 603. Pressure sore risk assessment | | | X | X | | | X | | | | |
| 604. Prevent and manage violence and aggression | | | | | X | | X | | | | |
| 605. Prevent health care acquired infection | | | | | X | | X | | | | |
| 606. Prevention and management of violence and aggression (PMVA) training | | | | | X | | | X | X | X | |
| 607. Prevention of ulcers | | | X | | | | X | | | | |
| 608. Proactive support in relation to forced marriage | | | X | | | | | | X | | X |
| 609. Produce accessible format resources (domestic violence, end of life, mental capacity) | | | X | | | | | | X | | X |
| 610. Produce accessible health information | | | X | | | | | X | | | X |
| 611. Produce accessible information (treatment or scans) | | | X | X | | | | | X | | X |
| 612. Produce service user friendly resources for inpatient wards | | | | | X | | | | X | | |
| 613. Produce teaching/training | | | | | X | | | | X | X | X |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| packages | | | | | | | | | | | |
| 614. Produce Covid-19 passports | | | X | X | | | | | X | | X |
| 615. Produce hospital passports | | | | | X | | | | X | | X |
| 616. Produce visual aids (PECS) (picture exchange communication system) | | | | | X | | | | X | | X |
| 617. Professional leadership | | | | | X | | | X | | X | |
| 618. Professional leadership (consultant nurse) | | | | | X | | | X | X | X | |
| 619. Promote choice | | | | | X | | | | | | X |
| 620. Promote communication (social stories, pictorial timetables, communication strategies) | | | X | | | | | X | | | X |
| 621. Promote community involvement | | | X | | | | | | | | X |
| 622. Promote community presence | | | X | | | | | | | | X |
| 623. Promote early years development | | X | | | | | | | | | X |
| 624. Promote family contact | | | | | X | | | | | | X |
| 625. Promote healthcare equality | | | | | X | | | | X | | |
| 626. Promote healthy choices (eating) | | | | | X | | | | | | X |
| 627. Promote exercise | | | X | | | | | | | | X |
| 628. Promote human rights | | | | | X | | | | | | X |
| 629. Promote ID awareness | | | | | X | | | | X | | |
| 630. Promote ID nurse role in schools | | | X | | | | | | X | | |
| 631. Promote ID nursing practice | | | | | X | | | | | X | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 632. Promote individuality | | | | | X | | | X | | | X |
| 633. Promote life skills | | | X | | | | | | | | X |
| 634. Promote PBS approaches | | | | | X | | | X | | | |
| 635. Promote social activities | | | | | X | | | | | | X |
| 636. Promote uptake of annual health checks | | | X | X | | | | | X | | X |
| 637. Promote attendance at annual health checks | | | X | X | | | | | | | X |
| 638. Promote health checks and screening | | | X | | | | | | X | | X |
| 639. Promote independence | | | X | | | | | | | | X |
| 640. Promote personal and sexual relationships | | | X | | | | | | | | X |
| 641. Promote resilience | | | X | | | | | | | | X |
| 642. Provide consultation to colleagues in health, education and social care | | | | | X | | | X | X | | |
| 643. Provide education to HMIP (HM Inspectorate of Prisons) | | | X | | | | | | X | | |
| 644. Provide information and training to clients | | | X | X | | | | | | | X |
| 645. Provide information on transition to adult services | | | X | | | | | | X | | |
| 646. Provide psychosocial interventions | | | X | | | | X | | | | |
| 647. Provide specialist equipment | | | | | X | | | X | | | X |
| 648. Provide training to colleagues in | | | | | X | | | X | X | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| health, education and social care | | | | | | | | | | | |
| 649. Provide advice and guidance to other professionals | | | | | X | | | | X | | |
| 650. Provide behavioural advice | | | X | | | | | X | | | X |
| 651. Provide diagnostic advice | | | X | | | | | | X | | |
| 652. Provide dietary advice | | X | | | | | | X | | | X |
| 653. Provide emotional support to people with personality disorder | | | | | X | | | | | | X |
| 654. Provide information in easy read formats | | | | | X | | | | X | | X |
| 655. Provide information to carers and family | | | | | X | | | | | | X |
| 656. Provide leadership | | | | | X | | | X | | X | X |
| 657. Provide legal advice related to mental health | | | X | | | | | | X | | X |
| 658. Provide palliative care | | | | | | X | X | | | | |
| 659. Provide psychological support | X | | | | X | X | | | | | X |
| 660. Provide reasonable adjustments | | | X | X | | | | X | X | | |
| 661. Provide support and advice to service users | | | X | | | | | | | | X |
| 662. Provide support in primary care | | | | | X | | | | X | | |
| 663. Provide support to families | | | | | X | | | | | | X |
| 664. Provide support with decision-making | | | | | X | | | X | X | | X |
| 665. Psychological education | | X | X | | | | X | | | | X |
| 666. Psychological education for children and | | X | | | | | X | | | | X |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| families (parent groups) (children) | | | | | | | | | | | |
| 667. Psychological educational group facilitation for parents | | X | | | | | | | | | X |
| 668. Psychological interventions / therapies | | | X | | | | X | | | | |
| 669. Psychosocial crisis assessments | | | X | | | | X | | | | |
| 670. Puberty workshops (facilitating) | | X | | | | | | | | | X |
| 671. QABF (Questions about behavior function) assessment | | | X | | | | X | | | | |
| 672. Quality assurance | | | | | X | | | X | X | | |
| 673. Quality check residential placements | | | | | X | | | X | X | | |
| 674. Quality improvement | | | | | X | | | X | X | | |
| 675. Radically Open Dialectical Behaviour Therapy (RO DBT) | | | X | | | | X | | | | |
| 676. Raising awareness on the needs of people with ID | | | | | X | | | X | X | | |
| 677. RCN (Royal College of Nursing) ID Networking | | | | | X | | | | | X | |
| 678. Reasonable adjustments support and advice | | | | | X | | | | X | | |
| 679. Reasonable adjustments training (health professionals) | | | | | X | | | | X | | |
| 680. Reassurance and support | | | | | X | | | | | | X |
| 681. Receive referrals from another services / agencies | | | X | | | | X | | | | |
| 682. Recommend interventions to | | X | X | | | | | | X | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| support individuals with ASD | | | | | | | | | | | |
| 683. Record keeping | | | | | X | | | X | X | | |
| 684. Reduce diagnostic overshadowing | | | | | X | | X | X | X | | |
| 685. Reduce restrictive practices (work with PVI (private and voluntary) service providers) | | | | | X | | | X | | | |
| 686. Reduce SIDS (sudden infant death syndrome) | | X | | | | | | | | | X |
| 687. Reduce use of antipsychotic medicines | | | | | X | | | | | | X |
| 688. Refer clients to another services / agencies / professionals | | | X | | | | | | X | | |
| 689. Referral screening | | | X | | | | X | X | X | | |
| 690. Regional/ national networking (facilitating) | | | | | X | | | X | | X | |
| 691. Reinsertion of PEGs | | | X | X | | | X | | | | |
| 692. Relationship building with key stakeholders including commissioners | | | | | X | | | X | X | | X |
| 693. Relationship education (family) | | X | X | | | | X | | | | X |
| 694. Relaxation therapy | | | | | X | | X | | | | X |
| 695. Replace gastrostomy balloon and tubes | | | | | X | | X | | | | |
| 696. Report writing | | | | | X | | X | X | X | | |
| 697. Research and writing for publication | | | | | X | | | X | X | X | X |
| 698. Resources (produce) for non-ID colleagues | | | | | X | | | | X | | |
| 699. Respite nursing | | X | X | | | | X | | | | |
| 700. Resuscitation (paediatric | | X | | | | | X | | | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| resuscitation using bag valve mask and oxygen) | | | | | | | | | | | |
| 701. Review care packages | | | | | X | | X | X | X | | X |
| 702. Review and validate GP (general practice) registers for people with ID | | | | | X | | | | X | | |
| 703. Review national policy and guidance | | | | | X | | | X | X | | |
| 704. Review other services | | | X | X | | | | X | X | | |
| 705. Review quality of care | | | X | X | | | | X | X | X | |
| 706. Review bloods and ECGs | | | X | X | | | X | | X | | |
| 707. Review self-harm | | X | X | | | | X | X | | | |
| 708. Road safety training | | X | | | | | | | | | X |
| 709. Safeguarding | | | | | X | | | X | X | | X |
| 710. Safeguarding investigations and protection plans | | | | | X | | | X | X | | X |
| 711. Safety planning and training | | X | | | | | | | | | X |
| 712. School liaison | | X | | | | | | | X | | |
| 713. School nursing | | X | | | | | X | | | | |
| 714. Screening training with service users | | | X | | | | | | X | | X |
| 715. Self-advocacy (promoting) | | | X | | | | | | | | X |
| 716. Self-advocacy groups (supporting) | | | X | | | | | | | | X |
| 717. Self-awareness training | | | X | | | | | | | | X |
| 718. Sensory assessments | | X | X | | | | X | | | | |
| 719. Sensory modulation | | X | X | | | | X | | | | |
| 720. Sensory therapy | | X | X | | | | X | | | | |
| 721. Service and organisational redesign | | | X | X | | | | X | | | |
| 722. Service commissioning | | | | | X | | | X | X | | |
| 723. Service development | | | X | X | | | | X | X | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 724. Service development (new services) | | | | | X | | | X | | | |
| 725. Service evaluation | | | | | X | | | X | | | |
| 726. Service improvement | | | | | X | | | X | | | |
| 727. Service user education (medical conditions) | | X | X | | | | X | | | | X |
| 728. Setting standards | | | X | | | | | X | | X | |
| 729. Sex and relationships assessments and interventions | | X | X | | | | X | | | | |
| 730. Sex and relationships education /awareness (e.g., classes at local colleges and schools) | | X | X | | | | | | | | X |
| 731. Shape the nature of end-of-life care and influence end-of-life decisions | | | | | | X | | X | X | | X |
| 732. Shift management | | | | | X | | X | X | | X | |
| 733. Showcase practice improvements | | | | | X | | | X | X | | |
| 734. Signposting (e.g., housing, finance psychology, psychiatry) | | | | | X | | | | | | X |
| 735. Skills assessments | | | X | | | | | | | | X |
| 736. Skills building to promote independence | | | X | | | | | | | | X |
| 737. Skills training (ADL) (activities of daily living) | | | X | | | | | | | | X |
| 738. Skin integrity assessment | | | X | X | | | X | | | | |
| 739. Sleep assessment | | | | | X | | X | | | | |
| 740. Sleep clinics | | X | | | | | X | | | | |
| 741. Sleep hygiene promotion and management | | X | | | | | X | | | | X |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 742. Sleep interventions | | X | | | | | X | | | | |
| 743. Sleep programs (development) | | X | | | | | X | | | | |
| 744. Social and community integration | | | | | X | | | | | | X |
| 745. Social care liaison | | | X | X | | | | | X | | |
| 746. Social skills assessments | | | X | X | | | X | | | | X |
| 747. Social stories therapy | | | | | X | | X | | | | |
| 748. Source care providers | | | X | X | | | | X | | | |
| 749. Special needs school nursing | | X | | | | | X | | | | |
| 750. Specialised equipment provision | | | | | X | | | X | | | X |
| 751. Staff appraisal | | | | | X | | | | | X | |
| 752. Staff education /training (health/ medical needs) | | | | | X | | | X | | X | |
| 753. Staff management | | | | | X | | | X | | X | |
| 754. Staff recruitment | | | | | X | | | X | | | |
| 755. Staff supervision | | | | | X | | | X | | X | |
| 756. Stay well planning | | | | | X | | X | | | | X |
| 757. Step-up therapy (asthma) | | | X | X | | | X | | | | |
| 758. Stoma care | | | X | X | | | X | | | | |
| 759. Stop smoking (advice and support) | | | X | | | | | | | | X |
| 760. Stopping over medication of people with an intellectual disability, autism or both (STOMP) | | | X | | | | X | | | | |
| 761. Strategic committee membership | | | X | X | | | | X | | | |
| 762. Strategic planning | | | X | X | | | | X | | | |
| 763. Strategical level implementation of the health initiatives | | | | | X | | | X | X | | |
| 764. Student supervision | | | | | X | | | | | X | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| and support | | | | | | | | | | | |
| 765. Substance misuse support with accessing services | | | X | | | | | | X | | X |
| 766. SUDEP (sudden unexpected death) risk assessments (epilepsy) | | | | | X | | X | | | | |
| 767. Supervision of PSI (public service improvement) work | | | | | X | | | X | X | | |
| 768. Support access to health screening | | | | | X | | | X | X | | |
| 769. Support and supervise day-care staff | | | X | X | | | | | X | | |
| 770. Support around recognising and improving attachment with children (especially looked after children) | | X | | | | | | X | | | X |
| 771. Support assessments in A&E (accident and emergency) | | | X | X | | | X | | X | | |
| 772. Support care staff | | | | | X | | | | X | | |
| 773. Support children and their families with transition | | X | | | | | | | X | | |
| 774. Support community participation | | | X | | | | | | | | X |
| 775. Support complex health decision making | | | X | | | | | X | X | | X |
| 776. Support with DoLS applications | | | X | X | | | | X | | | |
| 777. Support GPs with annual health checks | | | X | X | | | | | X | | |
| 778. Support consultant psychiatrist with ID clinics | | | | | | | X | X | X | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 779. Support implementation of NICE guidance | | | | | X | | | X | X | | |
| 780. Support individuals to cope with diagnosis / symptoms | | | | | X | | | | | | X |
| 781. Support individuals to understand symptoms / diagnosis | | | | | X | | | | | | X |
| 782. Support key performance indicators being met | | | | | X | | | X | X | | |
| 783. Support local authority children services | | X | | | | | | | X | | |
| 784. Support mainstream school nursing services with immunisations | | X | | | | | X | | X | | |
| 785. Support patient engagement groups | | | X | | | | | | X | | |
| 786. Support patients, families and carers through the legal system | | | X | | | | | | X | | X |
| 787. Support pregnant women/parents with ID (including through child protection proceedings) | X | | | | | | X | | X | | |
| 788. Support psychiatrists with medication reviews | | | | | X | | X | | | | |
| 789. Support quality improvement projects | | | | | X | | | X | X | | |
| 790. Support SEN schools | | X | | | | | | | X | | |
| 791. Support service providers to develop | | | | | X | | | X | X | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| appropriate support plans | | | | | | | | | | | |
| 792. Support service providers/carers | | | X | X | | | | X | X | | |
| 793. Support social care staff to commission appropriate care and accommodations | | | X | X | | | | X | | | |
| 794. Support to make and maintain meaningful relationships | | | X | | | | | | | | X |
| 795. Support transitions from child to adult services | | X | | | | | | | X | | X |
| 796. Support with adult protection proceedings | | | X | X | | | | | X | | X |
| 797. Support with benefits | | | X | X | | | | | X | | X |
| 798. Support with completion of health action plans | | | X | X | | | X | X | X | | |
| 799. Support with criminal justice system | | | X | | | | | | X | | X |
| 800. Support with family life | | | X | | | | | | | | X |
| 801. Support with mental wellbeing | | | X | | | | X | | | | X |
| 802. Support with NIV (non-invasive ventilation) | | | | | X | | X | | | | |
| 803. Support young people to understand healthy relationships during puberty | | | X | X | | | | | | | X |
| 804. Support/advise carers | | | | | X | | | X | | | X |
| 805. Swabbing | | | X | X | | | X | | | | |
| 806. Syndromes and associated health risks education | | X | | | | | X | | | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| (individuals, families and carers) | | | | | | | | | | | |
| 807. Take part in CETRs (care, education and treatment review) | | X | | | | | | | X | | |
| 808. Talking therapy | | | X | | | | X | | | | |
| 809. Teach coping mechanisms | | | X | | | | | | | | X |
| 810. Teach student nurses (children with developmental disabilities) | | | | | X | | | | X | X | |
| 811. Teaching (how to promote health) | | | | | X | | | X | X | | X |
| 812. Teaching (legal issues in ID practice) | | | | | X | | | | | X | |
| 813. Teaching carers and professionals (autism, ID awareness, epilepsy, PBS) | | | | | X | | | X | | | X |
| 814. Teaching clinical skills (mobility and positioning, wound care, nutrition, aseptic technique, infection control) | | | | | X | | | | | X | |
| 815. Teaching distress tolerance skills | | X | | | | | | | | | X |
| 816. Teaching individuals to manage/cope with their own conditions | | | X | | | | X | | | | X |
| 817. Teaching ID nursing students | | | | | X | | | | | X | |
| 818. Teaching life skills | | X | X | | | | | | | | X |
| 819. Teaching nurses | | | | | X | | | X | X | X | |
| 820. Teaching nursing students (all fields) | | | | | X | | | X | X | X | |
| 821. Teaching prisoners about health and mental wellbeing | | | X | | | | | | | | X |
| 822. Teaching skin care | | | X | X | | | | X | | X | |
| 823. Teaching staff | | | | | X | | | X | X | X | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 824. Teaching talking mats | | | | | X | | | X | X | | X |
| 825. Telephone care (Telehealth) | | | | | X | | | X | | | X |
| 826. Toilet training / continence support | | X | | | | | | | | | X |
| 827. Toileting programs (developing) | | X | | | | | X | | | | |
| 828. Tracheostomy care | | X | X | | | | X | | | | |
| 829. Tracheostomy changes | | X | X | | | | X | | | | |
| 830. Training | | | | | X | | | X | X | X | X |
| 831. Training (enteral feeding) | | X | X | | | | | X | X | X | |
| 832. Training (PBS for new services) | | | X | | | | | X | | | |
| 833. Training (worldwide) | | | | | X | | | X | X | X | |
| 834. Training and assessing competencies | | | | | X | | | X | | X | |
| 835. Training and raising awareness | | | | | X | X | | X | X | | X |
| 836. Train care providers to improve direct care services | | | | | X | | | X | X | | |
| 837. Train GP practice staff | | | | | X | | | X | | | |
| 838. Train GP staff and care services about reasonable adjustments | | | | | X | | | X | | | |
| 839. Train health and social care professionals on Health Action Planning | | | X | X | | | | X | X | | |
| 840. Train ID nursing students | | | | | X | | | | | X | |
| 841. Train parents in PBS, ID, ASC | | | | | X | | | | | | X |
| 842. Train prison staff | | | X | | | | | | X | | |
| 843. Training regarding STOMP | | | | | X | | | | X | | |
| 844. Train school staff (gastronomy | | X | | | | | | | X | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| feeding, emergency oxygen, epilepsy and emergency medication, asthma, anaphylaxis) | | | | | | | | | | | |
| 845. Train school staff (ID and mental health) | | X | | | | | | | X | | |
| 846. Train service providers (mental health and ID) | | | X | X | | | | X | X | | |
| 847. Train staff | | | | | X | | | X | X | | |
| 848. Transition liaison | | X | | | | | | X | X | | |
| 849. Transition planning | | X | | | | | | X | X | | |
| 850. Trauma interventions (adapted EMDR) | | X | | | | | X | | | | |
| 851. Trauma work (including trauma therapy) | | | X | X | | | X | | | | |
| 852. Treat and manage epilepsy | | | | | X | | X | | X | | |
| 853. Treatment review | | | X | X | | | X | X | X | | |
| 854. Triage and intake of referrals | | | X | X | | | X | | | | |
| 855. Triage dementia clinics | | | X | X | | | X | | | | |
| 856. Triage psychiatry clinics and referrals | | | X | X | | | X | | | | |
| 857. Trouble shooting | | | X | | | | | X | X | | |
| 858. Vaccinate patients | | | | | X | | X | | | | |
| 859. Vaccinate staff | | | | | X | | X | | | | |
| 860. Venipuncture | | | X | X | | | X | | | | |
| 861. Venipuncture desensitisation | | | X | X | | | X | | X | | |
| 862. Ventilation care (long-term) | | X | | | | | X | | | | |
| 863. Weight loss guidance and support | | | X | X | | | | | | | X |
| 864. Weight management | | | X | X | | | X | | | | |
| 865. Weight monitoring and management clinics | | | | | X | | X | | | | |



©UWL / RCN Foundation 2021

| Intervention | Maternity (4) | Children (156) | Adults (546) | Older adults (130) | All age groups (362) | End of life (25) | Effectuating nursing procedures (28%) | Enhancing impact of ID services (20%) | Enhancing impact of mainstream services (26%) | Enhancing impact of ID nursing practice (5%) | Enhancing quality of life (21%) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| 866. Weight monitoring | | X | | | | | X | | X | | |
| 867. Wellbeing assessment | | | | | X | | X | | | | |
| 868. Wellbeing sessions for men (develop and deliver) | | | X | | | | X | | | | X |
| 869. Wellman health checks | | | X | | | | X | | | | |
| 870. Workforce design | | | | | X | | | X | | | |
| 871. Workforce planning | | | | | X | | | X | | | |
| 872. Working with MAPPA | | | | | X | | | | X | | |
| 873. Wound assessments | | | | | X | | X | | | | |
| 874. Wound care | | | | | X | | X | | | | |
| 875. Wound management | | | | | X | | X | | | | |
| 876. Write clinical pathways | | | | | X | | X | | | | |
| 877. Write guidelines protocols (e.g., preventing falls, bowel management, PRN) | | | | | X | | | X | X | | |
| 878. Write MDR (medical device reporting) reports | | | X | X | | | | | X | | |

*Maternity interventions*

Similar our findings in the scoping literature review (see volume 1), we only identified a limited number of interventions undertaken by ID nurses relating to maternity. Participants reported that they were involved in maternity care, supported pregnant women/parents with ID (including through child protection proceedings), assisted others to work with people with ID, and provided psychological support to expectant parents with ID. The interventions related to three themes; *effectuating nursing procedures, enhancing impact of mainstream services,* and *enhancing quality of life*. There were no ID nursing



©UWL / RCN Foundation 2021

interventions related the *enhancing impact of ID services theme*, or the *enhancing impact of ID nursing practice* theme.

As noted earlier, maternity practice is outside the competence scope of ID nursing practice, so it is likely that ID nursing interventions in relation to women will always be limited. However, it could be argued that the need for ID nurses to work with women with ID 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 disabilities may be unable to access appropriate maternity services. Furthermore, expectant mothers with ID are likely to face child protection issues and ID nurses can undertake important interventions to support them through these processes. Going through pregnancy is likely to be a challenging experience for most women, and it could be argued that the challenges are likely to be greater for women with ID. ID nurses are well placed to work directly with pregnant women with ID through supporting them psychologically. Such interventions are likely to be complex and varied and will require ID nurses to develop a complex repertoire of knowledge and skills.

*Interventions across all age groups*

We identified 393 interventions (see table 1) which ID nurses were involved in across all the age groups. This represents 36% of interventions undertaken by the participants. The interventions related to all the five themes.

A wide range of interventions across the lifespan and in a wide range of settings were in the *effectuating nursing procedures* theme. The participants reported involvement in undertaking a wide range of assessments. For example, some participants reported that they were involved in; assessing and managing co-morbidities associated with ID, autism, and mental health), assessing people for equipment, carrying out diagnostic assessments, and sleep assessments. These findings are



©UWL / RCN Foundation 2021

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; Bailey, 2014; Brown *et al.,* 2012; Sheerin, 2012; Ng, 2011; Mason and Phipps, 2010; McKeon, 2009; Slevin and Sines, 2005). People with ID live with complex and changing needs that require continuous assessment in order to maintain and improve their health and wellbeing.

Care planning, implementing care interventions and managing health conditions was widely reported. These are important interventions and they have been reported previously (Taua *et al.,* 2012; Dahm and Wadwnsten, 2008).

Other important nursing procedures identified in the survey related to health inequalities experienced by people with ID. For example, some participants undertook interventions to health inequalities associated with constipation, dysphagia, aspiration, and oral health. The importance of the ID nurse role in addressing the determinants and health inequalities experienced by people with ID has been previously highlighted (Cope and Shaw, 2019; Mafuba *et al*., 2018a; Sheerin, 2012). What is clear from these studies is the complexity and varied nature of the nursing procedures performed by intellectual disability nurses across the lifespan. Some participants reported that they; facilitated specialist clinics, facilitated communication, monitored developmental growth, managed pain, provided bereavement counselling, undertook de-escalation activities in order to prevent crises and admissions to hospital, carried out wound care, undertook airway management (tracheostomy, ventilators). This complexity requires ID nurses to be adaptable in order to deliver effective care to people with intellectual disabilities.

Interventions (some were previously reported) in the *enhancing impact of ID services* theme include; adapting communication for easy understanding, autism support (community), best interest


©UWL / RCN Foundation 2021

assessments, benchmarking, coaching (quality improvement), writing guidelines and protocols (e.g., preventing falls, bowel management, PRN), training (worldwide), epilepsy awareness and emergency medication training, promoting PBS approaches, ID awareness training (professionals, carers, primary care) (Oulton *et al.,* 2019; Doody *et al*., 2019; Cleary and Doody, 2017; Marriott *et al*., 2015; Arrey, 2014; Lovell *et al*., 2014; Taggart *et al.,* 2011; DoH, 2007), and support families (Cope and Shaw, 2019; McCarron, *et al.,* 2018; Doody et al., 2017; Northway et al., 2017; Bailey *et al.,* 2014).

This evidence demonstrates that ID nurses spend a significant amount of time focusing on ensuring that other ID staff, and voluntary and independent services effectively support people with ID. These interventions are at individual, organisational and strategic levels (Mafuba *et al.,* 2018). The evidence from the data demonstrates that the interventions performed by ID nurses can contribute to the impact of ID services when supporting people with ID. This is important because ID nurses need to support other healthcare and social care professionals who work directly with people with ID in the community across the lifespan.

In addition to interventions undertaken by ID nurses to enhance the impact of ID services, we identified interventions that focus on ensuring *enhancing the impact of mainstream services*. As in the enhancing impact of ID services theme these interventions are at individual, organisational and strategic levels. Some of the interventions were highlighted in previous publications, and include; assessing effectiveness of interventions (Mafuba *et al.,* 2018), addressing determinants of health and health inequalities, monitoring effectiveness of medications and treatments (Adams and Shah, 2016), facilitating access to health services (Mafuba *et al.,* 2018a; Mafuba *et al.* 2018b; Mafuba and Gates, 2013; Mafuba, 2013; Brown *et al.,* 2012; Mafuba, 2009; DoH, 2007), advising acute hospital of individual needs, co-ordinating care between teams in acute hospital, advise social care services, advocating for ID inclusion at corporate level, auditing annual


©UWL / RCN Foundation 2021

health checks, developing national policy and guidance, facilitating the making of and implementation of reasonable adjustments (Cope and Shaw, 2019; (Mafuba *et al.,* 2018a; MacArthur *et al*., 2015), facilitating transitions (Delahunty, 2017; Northway *et al.,* 2017), undertaking health liaison activities (Northway *et al.,* 2017; Morton-Nance, 2015), facilitating social prescribing, educating acute care staff, training GP practice staff, and strategic level implementation of the health initiatives. It is evident from this evidence that ID nurses undertake important interventions in enhancing the impact of mainstream services and healthcare professionals who work in these services. For example, working with main stream services to put reasonable adjustments in place, and training mainstream staff regarding the needs of people with intellectual disabilities. This is important because intellectual disability nurses need to support other healthcare professionals who work directly with people with intellectual disabilities across the lifespan.

It could be argued that like all other professions, the ID 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 ID nursing practice.* Participants reported that they; produced teaching/training packages, trained and educated staff (Oulton *et. al.,* 2019; Doody *et. al.,* 2019; Cleary and Doody, 2017; Marriot *et al.,* 2015; *Taggart et al.,* 2011), undertook research and writing for publication, provided clinical leadership (local, regional, and national), created new roles, were involved in coaching, facilitated conferences, and provided peer support among other activities. Interventions to enhance ID nursing practice only make up 5% of the interventions we identified. Clearly there is a need for more work in this area in order to improve how ID nurses assimilate and adopt new and emerging interventions that benefit people with intellectual disabilities.

ID nurses play an important role in improving the quality of life, health,


©UWL / RCN Foundation 2021

and wellbeing of people with intellectual disabilities. 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*., 2018), advising and advocating for people with ID 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 ID to make their own choices (Sheerin, 2012), educating people with ID 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, 2013; 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 ID nurse interventions are wide ranging across the lifespan.

*Interventions for children*

In the scoping literature review we found a limited number of studies that have identified interventions performed by ID nurses in the *effectuating nursing procedures* related to children and young people. In this scoping survey we have identified all the interventions in the scoping literature review, plus significantly more. For example, data show that ID nurses undertake a wide range of assessments (ABAS (adaptive behaviour system) assessments for children, communication assessments, ADHD (attention deficit hyperactivity disorder) assessments, ADHD diagnosis, behaviour management assessment



©UWL / RCN Foundation 2021

FASD (foetal alcohol spectrum disorders) diagnosis, identifying children requiring further ID diagnostic assessment, ID 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 ID nurses need to have skills to undertake complex assessments of children's needs. What is also emerging here is that ID nurses are assimilating significant new roles is nursing children with ID.

Other nursing procedures we identified include; growth monitoring, management of PEG (percutaneous endoscopic gastrostomy), prescribing (anxiety, OCD, low mood, agitated and aggressive behaviours, sleep), ventilation care (long-term), weight monitoring, behaviour family therapy, facilitating ADHD clinics, Adapt CBT (cognitive behaviour therapy), desensitisation, dialectal therapies, sex and relationships education /awareness (e.g., classes at local colleges and schools), syndromes and associated health risks education (individuals, families and carers). These interventions illustrate the spectrum and complexity of the interventions undertaken by ID nurses when working with children.

New ID nursing interventions that focus on *enhancing impact of ID services* that we identified in the data include; adapting CBT for anxiety and depression for children, advising CAMHS (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. For example; providing positive behaviour support training and handling complaints (Oulton *et al.*, 2019), providing dietary advice (Marshall and Foster, 2002), acting as a links between schools and other services (Delahunty, 2017). These interventions are significant to the health and healthcare outcomes of children with ID. It appears from the wide range of interventions reported in this survey that increasingly, ID nurses are taking on roles in mainstream services. This development is likely to


©UWL / RCN Foundation 2021

improve how ID services respond to the healthcare needs pf children with ID.

Some of the interventions we identified undertaken by ID nurses in the theme *enhancing impact of mainstream services* were wide ranging and include; ASD liaison with specialists regarding sensory needs and sensory diets, consultation with CAMHS teams, educating health visitors, SEN (special education needs) school nursing, desensitisation to clinical procedures using visual aids, and school liaison. Other roles we identified were previously reported, for example, Oulton *et al.* (2019) has previously identified the ID nurse roles in pre-admission support, and Delahunty (2017) previously reported that ID 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 ID nurses are assimilating new roles that focus on enhancing the impact of mainstream services. These new interventions are important because ID nurses are more often in regular contact with children ID, they support and therefore better placed to facilitate links between services. The data from this survey also seem to suggest that increasingly, ID nurses are taking on roles in school nursing services. This development is likely to improve how mainstream services respond to the healthcare needs pf children with ID.

As discussed earlier, overall, the data shows that ID nurses have limited involvement in *enhancing impact of ID nursing practice*. The pattern is the same in relation to children. We did not identify any activity that demonstrate involvement of ID nurses in *enhancing the impact of ID nursing practice*. Given the extent of the interventions undertaken by ID nurses in this area, there is need to ensure that there is appropriate ID nurse leadership and support in this vital emergent area of ID nursing practice.

We identified a wide range of interventions undertaken by ID nurses


©UWL / RCN Foundation 2021

which were not previously reported that focus on *enhancing quality of life* the quality of life of children with ID. For example, we found that ID nurses; undertake child support and protection interventions, advocate for immunisation uptake, undertake continence training and continence promotion, develop parenting programmes, deliver emotional literacy training, undertake internet safety promotion and education, facilitate psychological educational groups for parents and children, teach life skills, and teach distress tolerance skills. These interventions are significant, and important given the growing population of children with intellectual disabilities, 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 ID nurses that enhance the quality of life of children with ID. The emergent new interventions undertaken by ID nurses demonstrate that they are taking on new roles and developing new and often advanced skills and knowledge not previously associated with ID nursing practice.

*Interventions for adults*

Previous studies have identified ID nursing roles in *effectuating nursing procedures* (Pennington *et al*., 2019; Dalgarno and Riordan, 2014; Mason and Phipps, 2010; Taua *et al.,* 2017; Doody *et al*., 2019; Quinn and Smolinski, 2018; Barr *et al.,*1999; Drozd and Clinch, 2016). In this scoping survey we have identified an extensive array of assessment interventions undertaken by ID nurses, and these include; NEWS (national early warning score) assessment of deterioration, mental capacity assessments, anxiety assessments, assessment of mental health, assessment of people's understanding of their needs, ASD (autism spectrum disorder) diagnosis, behaviour management assessment, blood tests, bowel screening, cardiometabolic assessments, dementia care assessments, developing assessments for the prison service, dysphagia assessments, forensic assessments, physical health assessments (abdominal, respiratory, and



©UWL / RCN Foundation 2021

cardiovascular auscultation, percussion and palpitation), pressure sore risk assessment, psychosocial crisis assessments, sensory assessments, sex and relationships assessments, assessments in A&E (accident and emergency), triage in dementia clinics, and triage psychiatry clinics. These interventions demonstrate that ID nurses assess adults with diverse and complex needs. It is evident that these ID 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.

The data from this scoping survey show that ID nurses implement a wide range of complex interventions for people with ID. For example; 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). The range of the interventions identified in this survey extent those previously identified (Brown *et al.,* 2016; Pennington *et al*., 2019; Marsham, 2012; Pennington *et al*., 2019; 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*., 2015; 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 ID nurses manage a wide range of complex health and healthcare needs in a wide range of contexts and settings. Given this complexity, ID nurses are likely to constantly learn and develop new knowledge and skills essential for engaging in advanced ID nursing practice. The data suggests that ID nurses may have to switch between a wide range of activities in a day's work, and are likely to require well advanced multi-tasking skills.

Interventions we have identified in the *enhancing impact of ID services*


©UWL / RCN Foundation 2021

theme include; annual medication monitoring, anti-psychotic medication review and monitoring , chairing care program approach (CPA) meetings, develop epilepsy guidelines, organizing and facilitating hospital discharge follow up review meetings, formulating service improvement plans, overseeing packages of care, sourcing care providers, supporting service providers/carers, training (PBS for new services), and trouble shooting. The importance of the roles of ID nurses in supporting ID services, and developing appropriate guidelines for ID services to support people with ID better cannot be overemphasised. As noted earlier, ID nurses practice in complex environments which, are often multi-disciplinary and multiple-agency. This will require them to engage in creative communication to enable things to happen. Furthermore, there is a need for ID nurses to provide leadership in improving ID services through troubleshooting and other interventions.

Interventions identified in previous studies that focused on ID 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). Data from this scoping survey illustrate increasingly complex catalogue of activities. These include; coordinating the assessment process in multi-agency contexts, annual health checks monitoring, auditing annual health checks, chairing best interest meetings, dentistry liaison, developing audit tools for ID services within prison settings, supporting DNACPR (do not attempt cardiopulmonary resuscitation) decisions, forensic support liaison, gatekeeping mental health assessments for admission to hospital, involvement in quality improvement processes, pharmacy liaison, providing pharmacological advice to GPs, reviewing other services, and triaging in A&E (accident and emergency).

The interventions undertaken by ID nurses appear to be expanding at pace. In addition, it appears ID nurses are undertaking increasingly complex and advanced interventions. For people with intellectual disabilities, these interventions may mean the difference between


©UWL / RCN Foundation 2021

accessing appropriate mainstream services and support. To improve services and enhance their impact ID 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 ID nurse graduates in a unique position to assimilate these emerging roles in mainstream services.

As noted in the scoping literature review and reported earlier in this report, there is a dearth of evidence to illustrate activities undertaken by ID nurses that focus on *enhancing impact of ID nursing practice*. This is a particular concern in relation to post registration professional development. The activities undertaken by ID nurses we have identified here include; brain injury education, alcohol/substance education, developing and implementing training packages for community nurses, setting standards for ID practice, and skills training (e.g., skin care, enteral feeding). This is concerning given the ever-increasing list of interventions ID nurses are assimilating. This

Interventions identified in existing literature relating to ID nurse roles in *enhancing the quality of life* of people with ID related to promoting independence and advocacy, and health promotion activities (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). In this scoping survey, in addition to previously reported, we have identified new interventions for example; 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, ID nurses are engaging in much more holistic


©UWL / RCN Foundation 2021

interventions than previously reported in existing literature. This may suggest an improving understanding of the complexity of the lives of people with ID 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 we unearthed during the scoping literature review. These include; assessing mobility decline, behaviour management assessment, care assessments, carer assessments, cognitive decline assessments, dementia assessment (diagnostic), manual handling risk assessment, physical deterioration assessment (RESTORE2), physical health assessment (abdominal, respiratory, and cardiovascular auscultation, percussion and palpitation), pressure sore risk assessment, catheter care, diet and nutrition management, pain management, pressure care, and stoma care. Some of these interventions were previously reported (Drozd and Clinch, 2016; Brown *et al.,* 2012; Arrey, 2014; Nelson and Carey, 2016; Northway *et al.,* 2017; Cleary and Doody, 2017; Wagemans *et al*., 2015). What is emerging from these findings is that ID nurses are involved in working directly with older adults with ID. This may very well reflect that ID nurses are increasingly taking up new roles in dementia care services and nursing homes where older adults with ID may reside. For ID nurses working in the community, this may reflect an aging population that require assimilation of new and advanced skills in order to deliver appropriate interventions.

Evidence from this scoping survey demonstrate that ID nurses are involved in *enhancing the impact of ID services* in relation to older people with a wide range of complex needs in the community. Evidence show that ID nurses are involved in; 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


©UWL / RCN Foundation 2021

making reasonable adjustments, and supporting service providers and carers. These interventions suggest that ID nurses are working directly with older adults with ID, their families, community service providers, and staff.

In the literature review we identified only one intervention undertaken by ID nurses that focus on *enhancing the impact of mainstream services, i.e.,* coordinating services (Cleary and Doody, 2017; Bailey *et al.,* 2014). In this scoping survey evidence demonstrate that ID nurses are involved with; 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 ID.

As noted in the scoping literature review and reported earlier in this report, there is a dearth of evidence to illustrate activities undertaken by ID nurses that focus on *enhancing impact of ID nursing practice* involving older adults. We only identified one activity related to teaching a new skill to other ID nurses. With the increasing population of older adults with ID, and the need for ID nurses to assimilate new roles in this area, this lack of involvement in developing ID nursing practice will need to be addressed.

None of the publications we reviewed during phase 1 of this project (see volume 1 of the report) specifically identified interventions performed by ID nurses in addressing the determinants of health to *enhance quality of life* of older adults with ID (Mafuba *et. al.,* 2020). In this scoping survey we identified several interventions undertaken by ID nurses such as; bowel screening promotion, carer assessment, COVID-19 education, dementia support in the community, mental health advocacy, and preparing homes for changed needs. There are clearly interventions undertaken by ID nurses in this complex area. This is an important development given that older adults often have


©UWL / RCN Foundation 2021

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 a number of important nursing procedures effected by ID nurses that focus on ensuring that people with ID 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 of these interventions were previously reported (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; Arrey, 2014). The range of interventions in this very psychologically difficult and complex area illustrates the uniqueness of the knowledge and skills of ID nurses who work with people with ID across the lifespan with diverse backgrounds and needs at the most challenging time of their lives. As we concluded in our literature review report, the range of interventions require well developed direct care knowledge and skills, care co-ordination skills, as well as skills to deliver psychological support.

The interventions we identified in the scoping survey in relation to ID nurse roles in *enhancing impact of ID 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. Previous studies have reported that nurses working with people with ID at the end of life were involved in; advance care planning (Wagemans *et al.,* 2015), shaping the nature of end-of-life care and influencing end-of-life decisions (Wagemans *et al.,* 2015), making and facilitating reasonable adjustments (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;



©UWL / RCN Foundation 2021

Morton-Nance, 2015). This evidence demonstrates that the provision of end-of-life care for people with ID may be becoming increasingly a common occurrence in ID nursing practice.

We observed limited new interventions that have not been previously reported on that focus on e*nhancing the impact of mainstream services*, and these are; 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 secondary care (McCarron *et al.,* 2018; Marshall and Foster, 2002).

Current palliative care services in the UK are fragmented (Dening *et al*., 2018), and there is clearly a need for co-ordination of existing palliative care services for the needs of people with ID to be met. The evidence suggest that ID nurses undertake important interventions to address inequalities in care provision for people with ID who are at the end of their lives.

As noted in the scoping literature review, and reported earlier in this report, there is a dearth of evidence to illustrate activities undertaken by ID nurses that focus on *enhancing the impact of ID nursing practice* involving end of life care for people with ID across the lifespan.

We identified; providing psychological support, and training and raising awareness as some of the activities undertaken by ID 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. ID nurses appear to have an important role to play in


©UWL / RCN Foundation 2021

meeting the palliative care needs of people with ID.

***Impacts of ID nursing interventions***

We asked participants in the survey to tell us the impact of their interventions on services and quality of life of people with intellectual disabilities. Of the 230 participants, 213 responded to this question. The impacts identified related to ID nurses' interventions with children, adults, older adults and end of life. We did not identify any impact relating to ID nurse interventions with pregnant women with ID. We used Braun and Clarke (2006)'s framework to analyse the data and identified 13 themes (see table 2) of these impacts;

1. *Having a voice,*
2. *Increased independence and choice,*
3. *Improved health and quality of life,*
4. *Improved access to health and social care services,*
5. *Improved standards, quality of care, and patient experience,*
6. *Improved awareness of the needs of people with intellectual disabilities,*
7. *Reduced health inequalities and risks,*
8. *Making reasonable adjustments,*
9. *Improved transitions,*
10. *Improved family life,*
11. *Improved healthcare outcomes,*
12. *Increased community presence and inclusion,* and
13. *Improved mental health and reduced challenging behaviour*



©UWL / RCN Foundation 2021

*Table 2:* Impacts of ID nursing interventions

| **Theme** | **Impacts** |
|---|---|
| 1. Having a voice | a. *"All residents have a voice…,*<br>b. *…their rights are adhered to….,*<br>c. *…people who use our service are heard…,*<br>d. *…. their views matter and are included….,*<br>e. *Obtain better support and outcomes for them…,*<br>f. *People with ID are getting to die at home,*<br>g. *Patients receive the same services as the general population…,* and<br>h. *…enable access to other services/reduce and overcome barriers…."* |
| 2. Increased independence and choice | a. *"…client's new activities that will keep them safe and healthy… patient to be actively involved in planning their care…make an informed decision on their care,*<br>b. *… be part of their healthcare and be included in making decisions...,*<br>c. *… improved quality of life and access to community and other networks,*<br>d. *…live as full and independent a life as possible,*<br>e. *…services to better understand intellectual disability, which in turn leads to better outcomes,*<br>f. *… remain independent,* and<br>g. *… the person has a good understanding of what is happening with their care and support…"* |
| 3. Improved health and quality of life | a. *"… minimise health issues,*<br>b. *Improve people's physical and mental health,* |



©UWL / RCN Foundation 2021

| Theme | Impacts |
|---|---|
| | c. *Making a change and difference to their current need,*<br>d. *Improved physical health and confidence…,*<br>e. *Improvement in quality and access to acute services improves the health outcomes …,*<br>f. *Reduce premature mortality,*<br>g. *Improved quality of life,*<br>h. *…improved health and wellbeing which in turn leads to a better quality of life … people … die with dignity and in a pain free manner…,*<br>i. *We have improved the uptake of annual health checks and through the work of our primary care liaison nurse we have improved the quality of the checks,* and<br>j. *Reduced the length of stay for people in hospital ….and reduced the need for admission."* |
| 4. Improved access to health and social care services | a. *"… increased quality of service during admission, increased access to investigations and treatment if needed ……improved communication and continuity of care,*<br>b. *… people with ID are able to access health services,*<br>c. *… access fair and equitable healthcare,*<br>d. *… reduced health inequalities by supporting acute care services …,*<br>e. *… professionals provide a better service to people with ID,*<br>f. *in the period I have been employed as matron for intellectual disabilities, autism and complex needs service development* |



©UWL / RCN Foundation 2021

| Theme | Impacts |
|---|---|
| | *has improved, there are a number of policies and procedures introduced designed to improve patient care, having a specialist clinician in the acute setting has significantly improved the care provision for complex and vulnerable patients, colleagues have embraced and value the role of the intellectual disability nurse specialist and seek support and advice when supporting patients with intellectual disabilities and/or autism,*<br>g. *The work we do with GP practices enables people with intellectual disabilities to have equal and fair access to mainstream services,* and<br>*h. people with intellectual disabilities have a good quality of life, …feel included in their community."* |
| 5. Improved standards, quality of care, and patient experience | *a. "…improved safety, elimination of ground restraint, reduced waiting times, increased efficiency, improved morale…,*<br>*b. … services offer the most person centred, evidence based co-produced services and workforce in a sustainable manner…,*<br>*c. Non nursing staff are more confident about basic nursing care,*<br>*d. My students tell me I am inspirational,*<br>*e. …services become better and more informed, …improving physical and mental health…,*<br>*f. …the impact on services of relieving the pressure at home, sharing good practice, developing a model of care within a safe environment, describing what and support* |



©UWL / RCN Foundation 2021

| Theme | Impacts |
|---|---|
| | *is needed and offering training to help sustain placements,*<br>*g. Produce national strategy that positively impacts on quality and delivery of care across the country,*<br>*h. Improved experience in the hospital,*<br>*i. Individuals' lives are extended and quality of life is improved,*<br>j. *Better planned discharges from hospital,* and<br>*k. This role …ensures the care, treatment and safety of people who are placed in these services is appropriate."* |
| 6. Improved awareness of the needs of people with intellectual disabilities | *a. "…others understand patients' needs,*<br>*b. Improved awareness of changed needs for the person and the staff team that support them,*<br>*c. …support services to understand intellectual disabilities,*<br>*d. … improved understanding of how to meet their needs when they differ from the rest of the population,*<br>*e. …services to better understand intellectual disability, which in turn leads to better outcomes,*<br>*f. …understanding of situations of the person with ID,*<br>g. *Commissioners and providers adapt what they are doing to meet what local people have said is important to them,* and<br>*h. I am the only ID liaison nurse in the hospital I work, so I support and raise awareness of the needs of our intellectual disability patients."* |



©UWL / RCN Foundation 2021

| Theme | Impacts |
|---|---|
| 7. Reduced health inequalities and risks | *i. "… risks have reduced before discharging,*<br>*j. …have equal access to mainstream and specialist health and social care services when they need it,*<br>*k. … a prisoner got released 16 years after his tariff was up, by identifying he had autism, to supporting another prisoner to get a diagnosis of autism and he has now been released for over 1 year (never been out longer than 2 weeks in custody),*<br>l. *We have supported the prison to make reasonable adjustments to the IEP system and I have recently supported a prisoner to gain his enhanced status. Significantly improving his quality of life, his income, his amount of family visits he is allowed a month. He has been in prison 11 years and never achieved enhanced status. He also successfully had 2 teeth removed in the last month through health promotion and transitional work (visiting the dental room, building relationships with the dental team, easy read information). Prior to this work, he had recurring dental infections and ongoing dental pain for 3 years which resulted in more offending behaviour in prison. Overall, the intellectual disabilities team impact has reduced incidents in the prison (I have data that I am happy to share with yourselves if you require this),* and<br>*m. Reduced levels of offending and risk-taking behaviour due to increased awareness and understanding."* |



©UWL / RCN Foundation 2021

| Theme | Impacts |
|---|---|
| 8. Making reasonable adjustments | a. *"…health care staff are aware of the need for reasonable adjustments and have the knowledge and skills to apply these in their everyday practice,*<br>b. *… support services to make reasonable adjustments…,*<br>c. *… we have person centred services, that meets needs, if not we make reasonable adjustments to ensure bespoke packages of care are created to meet need,* and<br>d. *… needs are met in a timely fashion."* |
| 9. Improved transitions | a. *"… prevent gaps in care,*<br>b. *…transitions to mainstream services are seamless…,* and<br>c. *…maintain familiar relationships for continuity of care and develop life skills … opportunity to learn social norms."* |
| 10. Improved family life | a. *"Seeing the family happy with their care just knowing that their needs are met,*<br>b. *Individuals, families and carers have a better understanding of issues that affect them or their family members,*<br>c. *… families are given support in their home and medical needs are looked after, as well as trying to create a fun/ playful environment for the child,*<br>d. *people to stay in their own homes…,*<br>e. *…improved knowledge and confidence in how to effectively support their child…,*<br>f. *…keep families together, bring happiness to others, repair relationships…,* and<br>g. *Improved sleep for patients and carers."* |



©UWL / RCN Foundation 2021

| Theme | Impacts |
|---|---|
| 11. Improved healthcare outcomes | a. *"… increased access to investigations and treatment which can extend a person's life,*<br>b. *… people …cope with their diagnoses and manage their own mental health,*<br>c. *Improved health outcomes for clients,*<br>d. *Improved life expectancy,*<br>e. *Reduced inpatient admissions, improved access to healthcare…,* and<br>*f.* *…reduced deaths, reduced suffering/pain … service users have a voice and a good quality of life."* |
| 12. Increased community presence and inclusion | a. *"Improved quality of life and opportunities to participate in community,*<br>b. *…. improving quality of life and access to normal* (mainstream) *community services,*<br>c. *I have taken lead roles in forensic services to maintain great outcomes where the patient is able to maintain their community presence safely reducing the risks to others and to the patient's future liberty,*<br>d. *Support for people with an intellectual disability and their families/ carers to be engaged in activities that are meaningful for them and help them experience an ordinary life within their local communities,* and<br>*e.* *… access mainstream service with support reduce health inequality and support people to feel included in their community."* |
| 13. Improved mental health and reduced | a. *"We provide specialist mental health support to people with intellectual disabilities, whose needs cannot be* |



©UWL / RCN Foundation 2021

| Theme | Impacts |
|---|---|
| challenging behaviour | *appropriately met by mainstream adult mental health services. We do a full assessment of somebody's mental health and health needs and ensure they are met. We work on a biological, psychological and sociological framework, and work in partnership with other health teams. This helps people with intellectual disabilities access the same level of care as the general population and ensures that they can live fulfilling lives with good mental health,*<br>*b. Increase in self-confidence, assertiveness and self-esteem,*<br>*c. Reduced challenging behaviour and improves quality of life,*<br>*d. …reduced anxiety,*<br>*e. Reduced stress and distress,*<br>*f. … reduced …behaviours that challenge services, …enabled them to access services and the correct support,*<br>g. *Over the 2 years of being in post we have successfully reduced psychotropic medication of over 100 people. Results have shown weight loss, increased motivation, improved physical health, improved communication, improved mobility, the list goes on…,* and<br>*h. Better mental health and wellbeing."* |

ID nurses play an important role in problem solving and facilitating access to a wide range of health and social care services on two levels; directly for the services users, and indirectly by advocating for their families or carers. This advocacy ensures that professionals and



©UWL / RCN Foundation 2021

services make appropriate decisions that result in positive outcomes for people with ID. These decisions resulting from ID nursing advocacy mean people with ID; receive appropriately funded care, adequate levels of support, equal access to services just like the general population, have their rights respected, and their families and carers receive appropriate support.

ID nurse interventions improve the independence, and the ability to make choices by people with ID. The impact of this is that people with ID are able to make informed decisions about their health, healthcare, and lifestyles that result in improved and better quality of life. In addition, the ability to make appropriate and informed decisions is more likely to lead to improved quality of life in the community.

Preventative ID nursing interventions are central to improving the health and healthcare outcomes for people with intellectual disabilities. From the evidence from the participants in this survey, these interventions reduce health risks, improve the experience of care, improve physical and mental health, and reduce premature mortality among people with intellectual disabilities.

The role of ID nurses in supporting people with ID to access appropriate services is longstanding. What is apparent in the examples of impact provided here is of immense importance and significance to people with ID. The result of this is improved access to services is better assessments treatments, and person-centred supports resulting in improved healthcare experiences and outcomes.

The standards and quality of care are central to service user experience when people need healthcare interventions. For people with intellectual disabilities this may result in premature mortality. Nursing interventions undertaken by ID nurses improve patient safety, make mainstream services better informed about the healthcare needs of people with ID, and ensures that people with ID have better


©UWL / RCN Foundation 2021

experience of care. The result is that people with ID live longer lives in good health.

The health and healthcare needs of people with ID are complex and many mainstream services lack the awareness of these needs, and in many cases are unable to deliver the care that could be expected. ID nursing interventions can support mainstream services to become more responsive to the complex needs of people with ID. ID nurses have a key role in ensuring that healthcare staff, managers, and commissioners of healthcare services understand these complex needs.

People with ID experience health inequalities and inequities that are not experience by people without ID. This more often result in preventable illnesses, poor experiences of health and social care services, and some cases preventable early mortalities. The interventions undertaken by ID nurses to reduce health inequalities and risk of illness and death are central to the health and healthcare outcomes for people with intellectual disabilities.

Many people with intellectual disabilities are unable to access the services they more often need than the general population. The reasons are multiple and include the fragmentation of health and social care services in the UK that may result in people with ID '*falling through the cracks*.' The interventions undertaken by ID nurses are important in preventing people with ID from falling through these cracks.

People with intellectual disabilities often have long term or lifelong care needs. Family life is consequently a significant and important aspect of their lives. Examples of the case studies demonstrate that the interventions undertaken by ID nurses result in better supports for the families of people with ID. Improved family lives may lead to improved and better outcomes for people with intellectual disabilities.


©UWL / RCN Foundation 2021

Because of complex health needs associated with intellectual disabilities, people with ID are known to need healthcare interventions more often. Healthcare professionals in mainstream services often have the necessary experience to understand the complexity of the healthcare needs of this population, resulting in diagnostic overshadowing that often results in unintended consequences. ID nurses play an important role ensuring appropriate diagnoses and interventions that result in reduced inpatient admissions, improved healthcare outcomes, and reduced suffering and even premature death.

Mental ill-health and challenging behaviours are common among people with ID. The impact of interventions undertaken by ID nurses include; reduction in anxiety, reduction in stress and distress, reduction in challenging behaviours, and better mental health and wellbeing. These impacts are likely to result in improved overall health and quality of life.

The role of the ID nurse is central to the health and healthcare outcomes for people with intellectual disabilities.

***Case studies***

We read the case studies and extracted, where possible, the role, intervention and exemplars from them. These data were then analysed to produce different categories of intervention, resulting in a set of 23 groups of interventions that ID nurses identified that they carried out. Here we illustrate and discuss 51 case studies.

*1. Empowerment*

Under this theme, which was identified as part of their role by 51 participants, there was a consistent thread of promotion of autonomy, informed choice and using person-centred approaches to identify and support a positive life trajectory for people with ID. Service user groups included children and adults across all age groups including those with “challenging behaviour”, people with a diagnosed mental illness, people requiring palliative care, people with complex needs



©UWL / RCN Foundation 2021

and people with undiagnosed or unmet health needs. Activities that incorporated this theme included: developing life plans; providing assistance with activities of living, including planning holidays and other activities with social capital (see *Case study 1,* Case study example 4 (CSE4).

**Case study 1. Supporting adults who use wheelchairs with their activities of living**

*"…promoting social-role valorisation, including planning a cruise holiday, clothes shopping for it, socialising and taking photographs and making scrapbooks as a topic of conversation….[The cruise had a] great impact on his mental health and wellbeing"*

Other empowerment interventions included: integrating people into their local community; providing explanations of a child's needs to parents in order to empower them; and ensuring that people were given the information they needed to make decisions around their health care (*see Case study* 2, CSE18).

**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."*

Other activities in this theme included: ensuring that service users are on recruitment panels; providing sexual knowledge assessment and education; providing education on pregnancy and parenting; providing support with understanding official communications related to health and social care; supporting individuals to recognise abuse; developing supportive care plans for the multi-professional team (see *Case study* 3, CSE53A)

**Case study 3. Develop individualised pathways in a prison setting**

*"we developed a transgender pathway for people with ID in a prison setting"*



©UWL / RCN Foundation 2021

Co-production of care plans and life management was another common thread within this theme, highlighting the importance of being non-judgemental and *"getting to know people"* (CSE58) as part of the ID nurse's role. Throughout the case studies, empowerment underpinned many of the different roles, activities, service user group needs and interventions. It was particularly important in the event of behavioural changes, major life events and transitions and acute or unmet health needs, where it also linked to advocacy (see *Case study* 4, CSE101).

**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'."*

There were many examples in the other categories that could also be linked to empowerment and person-centred care (see *Case study* 5, CSE104).

**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".*

This aspect of the ID nurse's role is difficult to identify in any set of skills, but empowerment is fundamental to the philosophy and practice in the field. It is a key function of the ID nurse, whose knowledge of health inequalities, stigma and historical abuses enables them to empower individuals and groups of people with ID and their social support, to negotiate and access the care and lifestyle they have a right to.

### *2. Advocacy (human rights)*


©UWL / RCN Foundation 2021

There were many situations (identified by 32 participants) where ID nurses needed to act as advocates for the service users in their care. As one nurse put it (see *Case study* 6).

**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"*

Mental health advocacy was clearly necessary to *"prevent admission to a mental health institution under the Mental Health Act"* (CSE16) or to ensure that the human rights of people with ID were being met (see *Case study* 7, CSE99A).

**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".*

In one case, a person was detained under Section 3 of the Mental Health Act for nine years. The ID nurse worked with core groups and local teams, a forensic team and experienced social and community service workers, to progress care plans through a lengthy discharge process and transition plan to allow the person and the team to feel confident in the discharge process and outcome (see *Case study* 8, CSE11).

**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."*

Women with ID may be seen as a risk to their own child when they are pregnant and come under the purview of child protection. When one



©UWL / RCN Foundation 2021

ID nurse (CSE22) identified that the wording of a social services letter being sent to a pregnant woman about potential court proceedings and her baby being taken into care was negative, they advocated on behalf of the pregnant woman, explaining the impact of receiving such a letter in the post, resulting in changes to the wording and format (easy-read). They delivered the letter with the social worker to explain the letter and the importance of the baby's wellbeing, but also to highlight what was going well. The ID nurse carried out a similar role for another pregnant woman with a positive outcome (see *Case study* 9, CSE36).

**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."*

Advocacy, while subsumed within many more concrete interventions, drives the function of the ID nurse to save lives, to allow women to keep their children and look after them, to prevent the institutionalisation and deprivation of liberties that is a persistent threat to people with ID.

*3. Communication – including listening*

While it is arguable that communication is so fundamental to care that it is almost assumed to be part of the role, nonetheless, 23 participants identified this as an intervention in their responses, from collaborative, active listening (CSE104) to developing services in this aspect of care (see *Case study* 10, CSE71).

**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."*

Other Nurses identified their role as *"to support communication with abused child"* (CSE65) but also to aid communication between service users and their social support network (see *Case study* 7, CSE33).



©UWL / RCN Foundation 2021

| **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."* |

One ID nurse identified how, although they had initially used social stories to help make the transition from school to college more predictable for a young man with autism and associated anxieties, they were able to use this to communicate with him to negotiate difficult life events (see *Case study* 12, CSE14).

| **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"* |

Social stories were also a successful intervention (see Case study 12, CSE14) to allow a young man with ID and anxiety to have blood taken and attend health appointments without displaying *"behaviour that challenges".*

| **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".* |

The importance of modifying communication to meet the cognitive and self-actualisation needs of service users was also an important aspect of the work of the ID nurse (see Case study 13, CSE13).

| **Case study 13. Adapting communication** |
| --- |


©UWL / RCN Foundation 2021

*"I listen to my clients and talk to them in a way that is suitable to the individual. I will do easy read literature and look for activities that they want to do, not what society says they can do".*

Much of the time, communication is an assumed part of other interventions and nursing activities by the ID nurse, but these examples demonstrate the complexity of the skills used for communication and the centrality of adapted and individualised communication to meet a range of needs for the person with ID. Being supported by someone with expert listening and communication skills has a profound impact on the lives of people with ID.

*4. Assessment*

35 participants identified assessment amongst their interventions, including health assessment (CSE7A, 17, 18, 67, 72A,74). CSE2A (see *Case study 14*) illustrated how ID nurses educate other health professionals to assess the health needs of people with ID. Also included in assessment were identifying specific neurodiverse differences, such as autism (CSE24, CSE99B).

**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 ".*

Some health assessments were specific, for example, carrying out a continence assessment (CSE82), or a pain assessment (CSE56), while others were more generic and identified family assessment (CSE21) and working with families to assess the need for referrals to other agencies (31). Assessments were also discussed in terms of a holistic approach, to enable referrals to a number of different supportive specialists, for example speech and language therapists, and to co-ordinate the multi-professional team (see *Case study* 15, CSE25).

**Case study 15. Assessing health needs**

*"We work through observations, assessments, information gathering, pulling together multi-disciplinary teams, analysing and*



©UWL / RCN Foundation 2021

*being creative in our strategies and recommendations to meet the individual needs of the patient and their families".*

The assessment of risk (CSE94B) was identified by some participants as one of their interventions, particularly in relation to offending behaviours (see *Case study* 16, CSE67B).

**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 ."*

Risk assessments were also used to improve sexual health and reduce risky sexual behaviours (CSE36, 105). However, there was an emphasis on promoting understanding to promote wellbeing rather than on negative and potentially punitive interventions (see *Case study* 17, CSE30).

**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. "*

However, most ID nurses who assess and manage the needs of people with ID and mental ill health have specialist knowledge of pharmacological as well as psychosocial treatment options (CSE28). One ID nurse described how their assessment and support of a young man with ID and challenging behaviour enabled staff within a mental hospital to work successfully with him (see *Case study* 18, CSE9).

**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*



©UWL / RCN Foundation 2021

*with him and what had not. His transition back to the community was very successful and he continues to thrive. "*

Assessment is a very broad term that captures a wide variety of specialist skills and knowledge across a number of different professional arenas and services. ID nurses often use the terms holistic or biopsychosocial to indicate the importance of taking many factors into account when assessing any aspect of health and wellbeing for a person with intellectual disabilities, incorporating family, environmental cues and risks, functional analysis of behaviour, potential physical and mental health concerns, as well as potential safeguarding risks. This is essential in order to co-ordinate the input of other members of the multi-professional team and ensure it meets the specific and complex needs of people with intellectual disabilities. It is also essential to avoid diagnostic overshadowing (see category 11).

*5. Holistic care; biopsychosocial dementia*

17 ID nurses identified an aspect of their role as providing holistic or biopsychosocial care, a theme that was consistently discussed in relation to caring for people with intellectual disabilities and dementia and wherever support with achieving activities of living was a prominent aspect of care provision. It was also identified as an aspect of managing health needs (see *Case study* 19, CSE23).

**Case study 19. Facilitating holistic care**

*"We look at a person holistically and, using our contacts with other agencies, make necessary referrals to ensure reasonable adjustments are made to access appropriate health…"*

Dementia care was not only about providing direct care, but about supporting services to ensure care provision could be maintained when health became a concern, preventing placements from breaking down (CS26). Holistic care was also identified as important in identifying and meeting the needs of people with intellectual disabilities and mental ill health (CSE28, CSE61A, CSE57, CSE41, CSE40,


©UWL / RCN Foundation 2021

CSE45A) and people with epilepsy (CS75) in the assessment and management of needs (See *Case study* 20, CSE45A).

**Case study 20. Facilitating holistic care**

*"The result of this has been [the] person still has trust in me and services and is still engaging."*

Using a holistic approach was also an important component of health facilitation (CSE56, CSE47).

*6. Safeguarding / human rights/ child protection*

Safeguarding was important across a number of different areas of care (identified by 23 ID nurses), including placements (see Case study 21, CSE66).

**Case study 21. Raising concerns and monitoring quality of care**

*"Raising concerns around placements not meeting need. Highlighting when care staff have not received adequate training."*

Perhaps surprisingly to those who are not aware of the different skills in assessment acquired by the ID nurse, the need for safeguarding was evident even during acute hospital stays (see Case study 22, CSE35).

**Case study 22. Safeguarding adults**

*"She had been in the acute hospital for 9 days before I was informed of her admission and they were getting ready to discharge her. I noticed she also has 2 fractured hips. The hospital had failed to identify that this should be an ASP [Adult Support and Protection] query. My input resulted in a big investigation happening with nursing home and patient being placed somewhere else. It was highlighted possible neglect where she had been residing also. This resulted in the patient being kept safe from potential abuse/harm and being treated with more dignity as she nears the end of her life."*

This clearly highlights the importance of understanding the needs of the person with intellectual disabilities from the perspective of an ID nurse with specialist knowledge and awareness of safeguarding issues. Nurses also identified safeguarding in relation to keeping service users



©UWL / RCN Foundation 2021

with preventing people needing to be admitted to mental health facilities (CSE99, CSE9A, CSE97A) as well as maintaining their safety if they were admitted to acute services (CS94B). Safeguarding was also an important aspect of the role for those working with children and young people (CSE67as well as in protecting people who were at risk of offending (CSE67B). Again, awareness of the need for the person with intellectual disabilities to be protected from abuse becomes apparent with regard to relationships. For one woman who had been traumatised by an abusive relationship, the ID nurse provided a suite of interventions to support and protect her (see *Case study* 23, CSE52A).

**Case study 23. Awareness of needs**

*"I have been providing education around trauma and how these experiences still affect her, coping/redirection and grounding strategies, mental health monitoring, supporting contact with GP around physical health issues as required, emotional support."*

In conclusion, adult safeguarding for people with intellectual disabilities require advanced knowledge and understanding of their potential needs and a broad range of expert skills in addressing them.

*7. Sleep*

Sleep was specifically identified as an intervention or aspect of their role by three ID nurses, one of whom developed a sleep programme for weekly review in a sleep clinic to improve children's sleep patterns (CSE1A), and a second ID nurse set their role within a wide family remit of *"increased access to sleep"* (CSE44). For the third, it was part of a range of assessments and interventions carried out in their role working with children with intellectual disabilities (CSE25). The goal and impact of care was seen in terms of reducing distress for the child and their family, supporting the parents with education and improving the health and wellbeing of all parties through a number of different interventions ranging from cognitive, behavioural and pharmacological.



©UWL / RCN Foundation 2021

*8. Building relationships - with others / community / services / families / service user*

18 interventions had a focus on building relationships with others in order to provide individualised care that supported family, carers and the individual to improved health and wellbeing, across a number of different services and types of care need (see *Case study* 23, CSE5).

**Case study 23. Acute liaison**

*"Liaising with the hospitals provides a communication pathway between the 2 care areas to improve the experience for the person and ensure that the clinical needs are met and shared to the appropriate people."*

For example, one ID nurse, who had worked in the area for over 15 years, had to arrange a hospital admission for a 16-year-old showing early signs of schizophrenia, and identified the impact of their relationship on the person (see *Case study* 24, CSE20).

**Case study 24. Building therapeutic relationships**

*"I have been able to develop a positive therapeutic rapport which has helped 'anchor' him, particularly during times of increased wellness, and through numerous personnel changes".*

*9. Positive Behavioural Support (PBS)*

This was an important category, with 40 ID nurses identifying PBS interventions within their role. Since they worked closely with families and paid carers to assess and plan interventions to reduce distress in people who exhibited *"challenging behaviour"* (see Case study 25, CSE106B).

**Case study 25. Positive behaviour support**

*"Person with stressed behaviour whose placement was at risk. Worked with staff to understand the function of the behaviour for the individual. Developed support plan to enhance individual's quality of life."*

Other PBS interventions also focused on improving a person's quality of life (CSE11A and see *Case study* 26, CSE96).

**Case study 26. Positive behaviour support**



©UWL / RCN Foundation 2021

*"By training staff to understand, recognise and respond more effectively to the persons anxiety and adopting a person centred their quality of life significantly improved'.*

An important outcome of PBS, discussed in relation an adult who was assessed and treated for "*challenging behaviour*" that had led to a placement breakdown, was to shorten hospital stays and improve community settings and interventions (see *Case study* 27, CSE69).

**Case study 27. Positive behaviour support (adult)**

*"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."*

Similarly, during health facilitation (see category 11), practitioners who carry out positive behavioural support employ a wide variety of specialist skills and engage in a number of complex interventions that would merit further investigation.

*10.Health promotion*

Health promotion was identified in 20 interventions, and, while often part of health liaison or health facilitation, it was also distinct from other activities such as health assessment, referrals, advocacy, support with engaging with tests and care interventions and care planning. Health promotion was delivered in different ways. For example, in CSE8 (*Case study* 28), although a need was identified for one person with intellectual disabilities, group health promotion sessions were delivered:

**Case study 28. Promoting health**

*"An individual had a high BMI, type 2 diabetes - did not have a healthy balanced diet when attending day-care. Lunch would have included 3 packets of crisps and 4 bars of chocolate. I delivered health promotion sessions to the group room - which included*



©UWL / RCN Foundation 2021

*healthy eating, active lifestyles, diabetes. Through regular health promotion, this service user gradually reduced the amount of crisps, bars etc. His weight and BMI had reduced."*

Similarly, in their summer activities scheme, some ID nurses incorporated health promotion into a suite of offerings to support local children during the COVID-19 pandemic in 2020 (see *Case study* 29, CSE10).

**Case study 29. Positive behaviour support (adult)**

*"This summer due to the restrictions of Covid 19 all summer schemes and summer support were suspended. Myself and other nursing colleagues saw the need for family support and compiled a programme of activities weekly to meet the needs of the children, in keeping with Covid restrictions. We were able to complete health promotion work, medication monitoring and emotional regulation work as some of the children had not been out of the house for 3 months. Parents stated it made a massive difference for the family as children were able to interact with others. It helped relieve anxieties about children transitioning back into school. Also, toilet training was complete and children became fully continent."*

Health promotion also involved teaching health care skills and self-monitoring to individuals with health needs, to enable them to manage their own health care needs (CSE88).

*11. Health facilitation / acute liaison / AHCs / diagnostic overshadowing*

Health facilitation constituted the most frequently identified set of interventions for ID nurses, with many being involved in health assessments and referrals, as well as supporting with attendance at and tolerance of appointments for examinations, reviews, tests and treatments, including one where a woman had been referred because of behaviour that was a cause for concern in day services, preventing her from attending. The ID nurse identified that the family were struggling to cope, so supported her with all her health appointments including her annual health check and specialist dentistry referral and


©UWL / RCN Foundation 2021

optician review. Her health needs were assessed, investigated and met – with the ID nurse supporting her until she was able to tolerate a full dental check (see *Case study* 30, CSE18).

**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."*

One nurse described the health liaison role to explain that *"Liaising with the hospitals provides a communication pathway between the 2 care areas to improve the experience for the person and ensure that the clinical needs are met and shared to the appropriate people."* (CSE5), while another described it as *"...education of health needs, support during hospital admissions to ensure reasonable adjustments are made to promote effective delivery of care and treatment that is afforded to all patients"* (CSE100B). Some clarified that included mental as well as physical health (CSE97B) while others focused on the importance of capacity being included in the necessary reasonable adjustments (see *Case study* 30, CSE93A).

**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."*

It is worth noting that most registered ID nurses did not elaborate on the health facilitation role, perhaps considering that it is a well-defined and clearly understood suite of interventions. However, as these examples (and others that have been included in other sections) show, health liaison covers a great many different types of intervention, from graduated exposure to allow people to tolerate procedures such as blood tests (CSE21) to advocating for the rights of people with intellectual disabilities to be offered the same level of health screening as others in society (see CSE101 in category 1 (empowerment). It would be interesting to analyse the health facilitator role in greater depth in the future.


©UWL / RCN Foundation 2021

*12. Care co-ordination and end of life care*

Examples of co-ordinating care were described consistently throughout the case studies. Focussing on the individual and their needs, ID nurses worked across a range of services at operational as well as system level were clearly described (see *Case study* 31, CSE8A).

**Case study 31. Care coordination**

*"…. working closely with complex needs services to develop positive behaviour plan to reduce challenging behaviour, working with SALT to improve communication, liaising with tissue viability nurse to improve leg ulcers".*

Good quality assessment to ensure appropriate referral across agencies is a key skill of the nurse in ensuring holistic and person-centred care (see *Case study* 32, CSE82).

**Case study 32. Making referrals**

*"Assessed her continence needs in the first instance and checked she didn't need products prescribed and how much of the issue she understood. Identified training needs for the service and delivered bespoke training for them in continence, constipation and dignity in care. Advised the commissioners and CQC that they require their contracts to be looked at due to confusion around what 'care' they can and cannot deliver. Screened the young lady for any underlying health issues and ensured all health needs are being met - some minor things identified from our initial screening that have since been answered e.g. dental care, orthotics and epilepsy review - intervened with these where appropriate. Referred to community ID occupational therapy for further assessment around toilet routine and they are now working directly with her to increase her independence and skill set in this area, with the hope she can return to day services."*

Palliative and end of life care was mentioned in multiple interventions described by nurses in relation to their role in coordinating care. Working across multiple agencies and multi-professional groups



©UWL / RCN Foundation 2021

person centred care was advocated with and for individuals (see *Case study* 33, CSE81).

**Case study 33. Planning end of life care**

*"I have helped service users to plan end of life care…make decisions about their own care/support."*

*13. Medication (polypharmacy, STOMP, STAMP)*

The nurse's role in medication prescribed to people with intellectual disabilities was discussed in multiple ways. Supporting individuals to access, manage, and understand their needs as well as ensuring that appropriate prescribing and review patterns were supported with clinicians was highlighted in the case studies. The below example highlights assessment, monitoring, review and collaborative working with professionals as well as families and carers to ensure a therapeutic plan for the person and generalisation of knowledge across environments. This level of intervention relates directly to the principles of STOMP and STAMP with nurses clearly engaged in these agendas (see *Case study* 34, CSE74).

**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."*

Diagnostic overshadowing (see *Case study* 35, CSE87)) was identified associated with medication prescribed and the ongoing effects of these for individuals. Educating people and their families and carers appears fundamental to the nurse's role in ensuring that medication is appropriate and understood.

**Case study 35. Intellectual Disabilities Nursing – Child**



©UWL / RCN Foundation 2021

*"…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."*

*14. Reasonable adjustments*

Facilitating reasonable adjustments was one of the most prevalent interventions across the data. Nurses identified the importance of ensuring that the people they supported had equality of access through the application of the Equality Act 2010. The interventions were described in multiple examples of ensuring people's health care needs were met, that individuals could access appropriate information and give consent in an informed and supported way (see *Case study* 35, CSE61A).

**Case study 35. Supporting others and making reasonable adjustments**

*"I make a difference by helping all those who support the person to understand the unique nature of their needs and all the reasonable adjustments big and small, in a physical sense and a theoretical sense, that we have to make to even begin to make my client's access to health and wellbeing on a par to that of the wider population."*

Across all age groups examples of reasonable adjustments were discussed associated with empowerment and communication. Nurses report applying reasonable adjustments, facilitating others to utilise them for the benefit of individuals and also developing tools that are person-centred (see *Case study* 35, CSE73).

**Case study 35. Preparing children for hospital**

*"Helping children understand what may happen when they come to hospital, developed a 'Going To Hospital Book' with photos to explain procedures and what they may experience, help build their communication through 'Makaton' and feel empowered in the health choices and decisions made in their care."*



©UWL / RCN Foundation 2021

*15. Educating and training other professionals*

The role of the intellectual disability nurse in training staff teams and services was a common intervention discussed. The importance of training with people with intellectual disabilities and / or autism was considered in the below case study. Supporting individuals to undertake this important role and working in true partnership towards co-production evidences the power of the nurse in role modelling best practice (see *Case study* 36, CSE18).

**Case study 36. Co-production**

*"….is to provide training to services which support people with an LD to help them understand how autism can affect people and look at ways of supporting people. This has always been done with myself and an autistic person providing the training so they can articulate their experiences and answer any questions which is very helpful …"*

Positive behaviour support interventions and educating other professionals when working with adults and staff teams was highlighted by nurses as key to their roles. As well as enabling the understanding of individuals and their presentations it was also identified as supporting the national agenda associated with the reduction of restrictive interventions in people's care (see *Case study* 37, CSE34).

**Case study 37. Supporting staff**

*"…. staff debrief and support to better understand behaviour of concern and understand the function of the behaviour to be more empathetic to the person and reduce over restriction or restraint".*

*16. Educating and training family members*

Working alongside families and carers to support their loved ones was clear across multiple case studies. Improving the resilience of carers can maintain family units and avoid the need for individuals to leave home due to crisis or exhaustion. The below case study exemplifies this situation (see *Case study* 38, CSE33B).

**Case study 38. Developing and implementing PBS plans**

*"Young man living at home with dad, dad not managing him and police being called out. Dad doesn't want him to move into care.*



©UWL / RCN Foundation 2021

*Used PBS training to work with dad and write proactive and reactive strategies so dad could recognise the stages, prevent increased arousal and manage his son proactively."*

For children and young people, working alongside families, carers and providers of services, education features across the case studies considering the needs of children and young people. Positive Behaviour Support was again reported to be among the dominant interventions highlighted. Facilitating knowledge, understanding of function and the acquisition of new is an important area of intellectual disabilities nursing (see *Case study* 39, CSE30).

**Case study 39. Training families (children and young people)**

*"Provide specialist behavioural assessment and use this information to develop behaviour support plans in conjunction with children, their families and carers…. assist with the implementation of interventions. 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."*

*17. Mental health and wellbeing*

The intellectual disability nurse's role in supporting people's mental health needs was discussed across multiple interventions. General mental wellbeing was a recurrent theme identifying trauma, anxiety and distress as part of the care described. The ability to ensure that people are able to maintain their relationships with mainstream services is particularly important with Nurses identifying this as a positive result of the intervention (see *Case study* 40, CSE45A).

**Case study 40. Assessing mental health**

*"I have recently supported someone experiencing a decline in their mental health. Through appropriate support and advice, we were able to prevent hospital admission. Through the use of person-*



©UWL / RCN Foundation 2021

*centred care and reasonable adjustments. The result of this has been person still has trust in myself and services and is still engaging."*

Support during a mental health crisis was described within interventions associated with transitional care arrangements between environments, providing accessible information and the need to ensure care is person centred. Education and liaison with services is key to this role ensuring long term sustainable solutions for people with an intellectual disability and mental health issues (see *Case study* 41, CSE52).

**Case study 41. Supporting mental health recovery**

*"I met the patient and supported admission to the local mental health unit on the same day. I visited regularly whilst she was an inpatient to build a relationship and I continue to work with her now that she is home. I have been providing education around trauma and how these experiences still affect her, coping/redirection and grounding strategies, mental health monitoring, supporting contact with GP around physical health issues as required and emotional support."*

*18.Child development and support*

Working alongside children and young people and their families and carers is a key role of the intellectual disability nurse. Taking a holistic view of a child can enable the nurse to collaboratively work across services to enable and support treatment, development and appropriate developmental care. Describing care that had been based on an inappropriate diagnosis the below intervention enabled a young person to move forward with appropriate care based on child centred outcomes (see *Case study* 42, CSE65).

**Case study 42. Collaborating holistic care (children)**

*"(GP/A&E/social worker/school staff) believing this to be psychosis …. Over time use of medication and both narrative and EMDR therapy to help process the trauma and help (with carers) to reduce fear and regain skills and build new relationships."*



©UWL / RCN Foundation 2021

Working with children and young people for the intellectual disability nurse presents an opportunity to co-ordinate family centred care that can support real change in their ability to meet the needs of their child over time through developmental and transitional changes (see *Case study* 43, CSE67A).

**Case study 43. Family support (children)**

*"I am so pleased this family was allocated to me. It put me to the test for sure. I know this family still has the daily battles but I know I made a huge positive impact for them."*

*19. Community presence, relationships, choice, competence (O'Brien's 5 principles)*

Interventions described within the case studies often included and described the key principles of O'Brien's 5 Accomplishments (O'Brien and O'Brien, 1998). Integral to nursing practice in the field of intellectual disability nursing the five key elements were demonstrated across the narratives as a key rationale or result of the interventions described. Discussing how support had been altered due to the pandemic a participant highlighted how their role had been centred on assuring that the people who they supported had presence in discussions associated with access to treatment and quality of life discussions (see *Case study* 44, CSE60B).

**Case study 44. Inclusion**

*"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."*

Considering how an individual can be supported and how an intervention can affect change the below case study described impact in ensuring an individual experienced presence through a valued role increasing competence (see *Case study* 45, CSE48).

**Case study 45. Community presence**

*"For the person himself his self-esteem, pride and confidence continue to grow as he undertakes a role with real purpose."*



©UWL / RCN Foundation 2021

*20. Transition support*

Interventions focused on supporting transition for individuals with an intellectual disability featured across many of the case studies described by nurses. Transition across services, changes in provision, age related service changes were all described as part of the care that nurses co-ordinated for individuals. For one nurse working within an acute care setting transition was described as part of her role in ensuring health needs were met across departments and between appropriate hospitals (see *Case study* 46, CSE68).

**Case study 46. Supporting transitions to adult services**

*"I support transition to adult services, inpatients, out patients and elective surgery patients with intellectual disabilities and / or autism to ensure their contact with the trust is of a high standard, which meets their additional needs and ensures they get an equitable service."*

*21. Resilience and capacity*

This theme considered the nurse's role in supporting and building the resilience and capacity of those supporting individuals as well as people with an intellectual disability. This form of intervention was described in relation to services, families and staff and was considered as fundamental to the role of the nurse in facilitating holistic care. Considering the complex needs of a person who required extensive medical interventions one nurse described the wider role required to enable person centred care to be provided (see *Case study* 47, CSE90).

**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*



©UWL / RCN Foundation 2021

*one GA for multiple examinations and investigations to help maintain his health."*

Direct support of staff teams is referred to across the case studies as enabling the provision of holistic care associated with increased capability due to deeper understanding of the individuals they support (see *Case study* 48, CSE106B).

**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."*

For families and carers, the role of the nurse in the provision of interventions was evident throughout the case studies. Clear examples of positive change included the building of skills and confidence within an individual's family unit to help improve all round resilience and capacity (see *Case study* 49, CSE24).

**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."*

*22.Crisis intervention*

Crisis work was specifically mentioned across 4 of the case studies when the nurse was required to respond in a reactive way to a person's needs or situation. However, the need to be proactive and support people, families/carers and staff teams was identified in multiple case studies associated with placement breakdown, changes in care, implementation and facilitation of PBS plans. As in CSE69 (*Case study* 50), both during and post-crisis the nursing interventions focused on the support required to enable discharge and appropriate care support in a new placement area.

**Case study 50. Facilitating early discharge from hospital**



©UWL / RCN Foundation 2021

*"…. placement had broken down due to his challenging behaviour. He came into hospital for a short period …. supported his new care team during transition period to new setting and after discharge for 12 weeks. 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 his new placement... His transition back to the community was very successful and he continues to thrive."*

*23.Co-production*

Co-production was mentioned across multiple case studies associated with working and supporting individuals as partners in care. It was characterised by key interventions including ID nurses who created supportive and trusting relationships and co-ordinated true person-centred care.

The desire to ensure that where possible individuals were supported to understand and create their own plans of care that reflected their needs and wishes was seen across many of the case study examples, including CS60B (see *Case study* 51) and CS104 (see *Case study* 52).

**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."*

The desire to ensure that where possible individuals were supported to understand and create their own plans of care that reflected their needs and wishes was seen across many of the case study examples.

In summary, the case studies demonstrated that intellectual disabilities nurses are both specialist and generalist, sometimes within



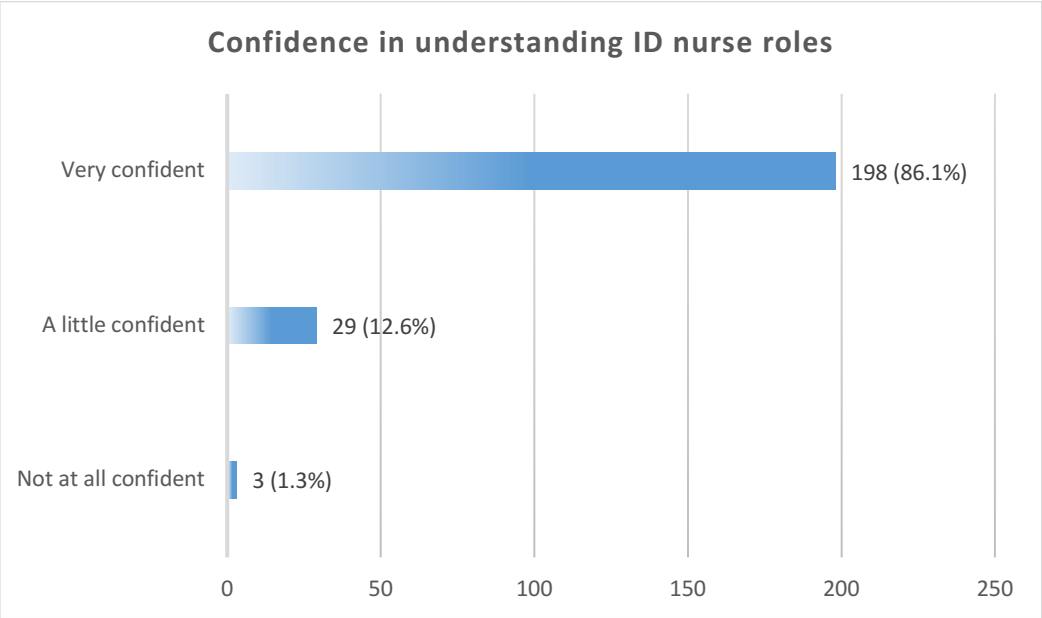
©UWL / RCN Foundation 2021

the same role. They are often working at an advanced practitioner level and frequently need to be involved in care delivery by other practitioners in order to ensure that health and social care, including engagement with legal frameworks, is adapted and augmented in order to meet the needs and human rights of people with intellectual disabilities.

***Evaluation***

We asked participants how confident they felt about their understanding of what all intellectual disabilities nurses do in their role in general. All 230 participants responded. Figure 11 illustrates that a significant proportion of the participants were not confident at all (1.3%), or had little confidence (12.6%) in their understanding of what the role ID nurses entail. This lack of clarity has been previously reported (Mafuba, 2013). It is concerning that such a significant proportion of participants lack confidence in their own roles.

*Figure 11:* Participants' confidence in understanding the ID nurse's role.



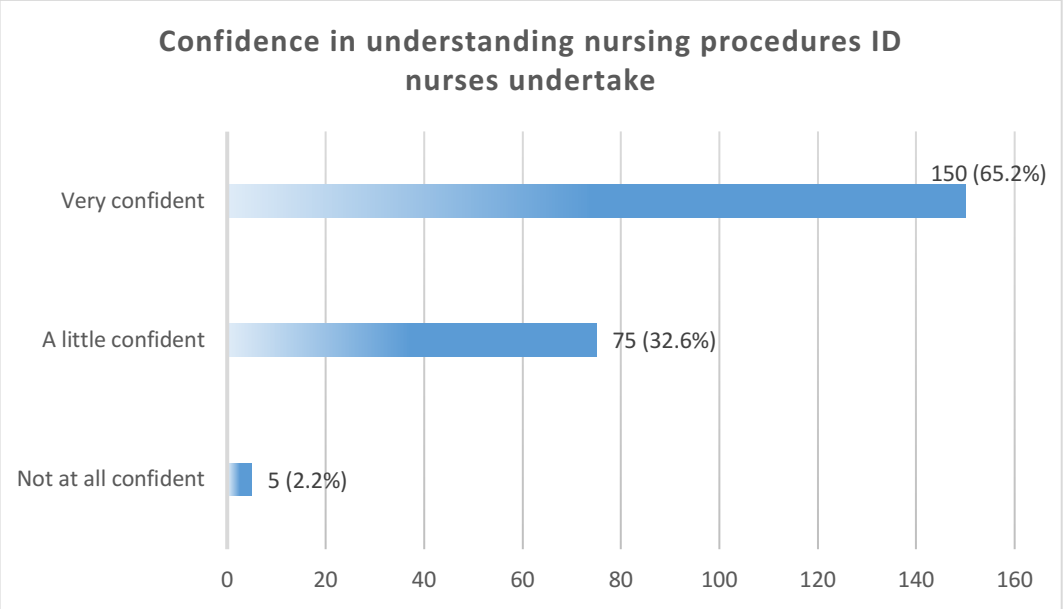

We asked participants how confident they felt feel their understanding of the nursing procedures ID nurses are expected to undertake. All 230 participants responded. Figure 12 illustrates that a significant



©UWL / RCN Foundation 2021

proportion of the participants were not confident at all (2.2%), or had little confidence (32.6%) in their understanding of the nursing procedures undertaken by ID nurses entail. It is concerning that such a significant proportion of participants lack confidence in their understanding of the nursing procedures they are expected to undertake in their work with vulnerable people with ID. This may mean that ID may have to depend on other professionals to undertake nursing procedures within their own sphere of practice. More worryingly, this may contribute to untreated conditions.

*Figure 12:* Participants' confidence in understanding ID nursing procedures

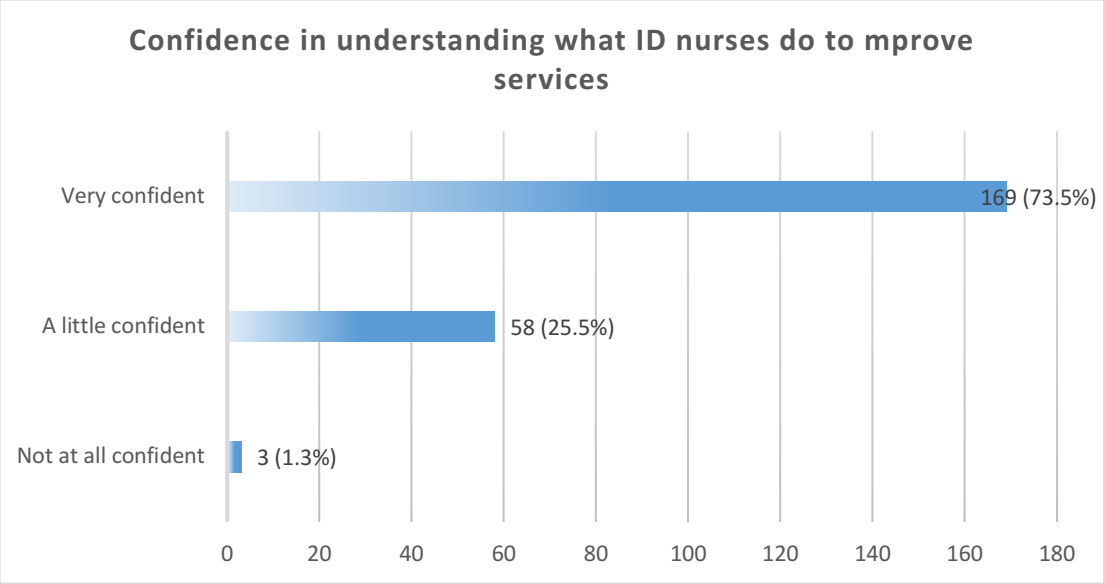



We asked participants how confident they felt in their understanding of all activities intellectual disabilities nurses are expected to undertake in order to improve how other services or healthcare professionals deliver effective care to people with intellectual disabilities. All 230 participants responded. Figure 13 illustrates that a significant proportion of the participants were not confident at all (1.3%), or had little confidence (25.5%) in their understanding of what interventions undertaken by ID nurses to enhance the impact of other services entail. It is concerning that such a significant proportion of participants lack confidence in what they can do to support other


©UWL / RCN Foundation 2021

professionals and services to work more effectively with people with. The consequence may be that people with ID fail to access the appropriate services they may require.

*Figure 13:* Participants' confidence in understanding ID nurse's role in enhancing impact of services.

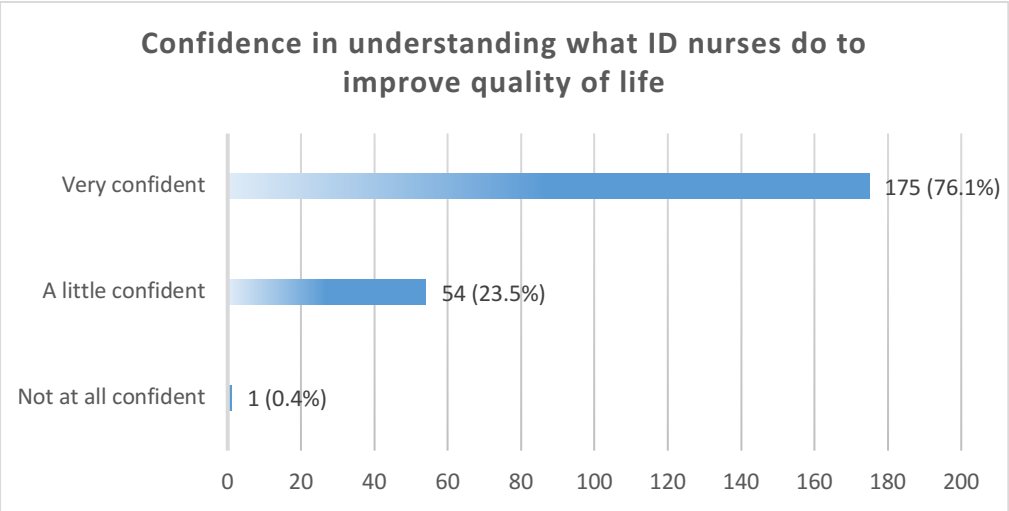



We asked participants how confident they felt in their understanding of all activities intellectual disabilities nurses are expected to undertake in order to improve the quality of life of people with intellectual disabilities.

All 230 participants responded. Figure 14 illustrates that a significant proportion of the participants were not confident at all (0.4%), or had little confidence (23.5%) in their understanding of what interventions undertaken by ID nurses to enhance the quality of life of people with ID entail. This may mean that people with ID may continue to experience health inequalities and inequities that should otherwise be addressed by ID nurses.

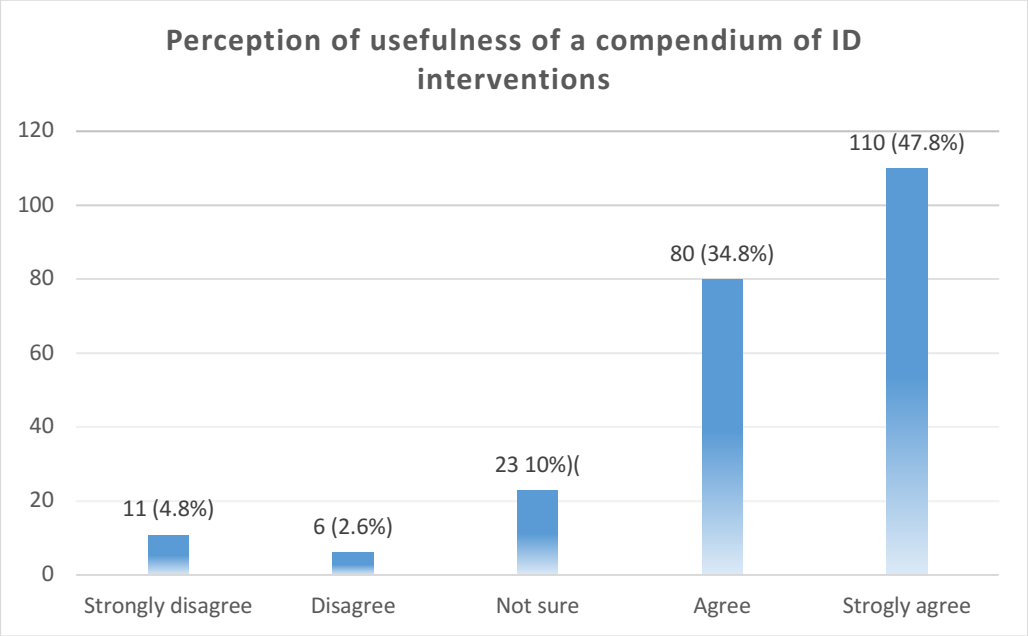

©UWL / RCN Foundation 2021

*Figure 14:* Participants' confidence in understanding ID nurse role in enhancing quality of life.




We asked participants their perception of the utility of a compendium that describe what intellectual disabilities nurses do as a guide for their own practice. All 230 participants responded. 4.8% strongly disagreed, 2.6% disagreed, 10% were not sure, 34.8% agreed, and 47.8% strongly agreed. These findings indicate that 82.6% consider a compendium of ID nursing interventions a useful development.

*Figure 15:* Participants' perceived value of a compendium of ID nursing interventions.




In light of the lack of role clarity detailed above and, in an effort, to



©UWL / RCN Foundation 2021

obtain a better understanding of ID nurses' understanding of the interventions they are expected to undertake and their attributes, we analysed the data to ascertain any relationships between a number of variables.

*Table 3:* Interpretation of relationships between variables

| **Pearson correlations (N = 230)** | ***r =*** | ***Significance*** | **Interpretation (Cohen, 1988)** |
|---|---|---|---|
| Age and experience | .68 | p<0.01 (*Sig*. = .000, *n* = 230, *p*<0.05) | Large |
| Age and qualifications | .17 | p<0.01 (*Sig*. = .005, *n* = 230, *p*<0.05) | Small |
| Experience and qualifications | .22 | p<0.01 (*Sig*. = .000, *n* = 230, *p*<0.05) | Small |
| Qualifications and type of organisation | .18 | p<0.01 (*Sig*. = .003, *n* = 230, *p*<0.05) | Small |
| Qualifications and understanding of ID nurse roles in enhancing impact of services | .15 | p<0.01 (*Sig*. = .010, *n* = 230, *p*<0.05) | Small |
| Qualifications and understanding of ID nurse roles in enhancing quality of life | .15 | p<0.01 (*Sig*. = .012, *n* = 230, *p*<0.05) | Small |
| Country of practice and type of organisation | .13 | p<0.01 (*Sig*. = .030, *n* = 230, *p*<0.05) | Small |
| Country of practice and understanding of ID nurse roles | -.22 | p<0.01 (*Sig*. = .000, *n* = 230, *p*<0.05) | Small |
| Country of practice and understanding of ID nurse roles in enhancing impact of services | -.13 | p<0.01 (*Sig*. = .028, *n* = 230, *p*<0.05) | Small |
| Country of practice and understanding of ID nurse roles in enhancing quality of life | -.15 | p<0.01 (*Sig*. = .014, *n* = 230, *p*<0.05) | Small |
| Type of organisation and understanding of ID nurse roles | -.11 | p<0.01 (*Sig*. = .045, *n* = 230, *p*<0.05) | Small |
| Understanding of ID nurse roles and understanding of ID nurse roles in effectuating nursing procedures | .44 | p<0.01 (*Sig*. = .000, *n* = 230, *p*<0.05) | Medium |



©UWL / RCN Foundation 2021

| **Pearson correlations (N = 230)** | ***r =*** | ***Significance*** | **Interpretation (Cohen, 1988)** |
|---|---|---|---|
| Understanding of ID nurse roles and understanding of ID nurse roles in enhancing impact of services | .45 | p<0.01 (*Sig*. = .000, *n* = 230, *p*<0.05) | Medium |
| Understanding of ID nurse roles and understanding of ID nurse roles in enhancing quality of life | .39 | p<0.01 (*Sig*. = .000, *n* = 230, *p*<0.05) | Medium |
| Understanding of ID nurse roles in effectuating nursing procedures and understanding of ID nurse roles in enhancing impact of services | .56 | p<0.01 (*Sig*. = .000, *n* = 230, *p*<0.05) | Large |
| Understanding of ID nurse roles in effectuating nursing procedures and understanding of ID nurse roles in enhancing quality of life | .50 | p<0.01 (*Sig*. = .000, *n* = 230, *p*<0.05) | Large |

Firstly, we calculated Pearson correlations (one-tailed). We interpreted the Pearson correlations using Cohen (1988)'s interpretation guide; Small (*r* = +-.10 to +-.29), Medium (*r* = +-.30 to +-.49), Large (*r* = +-.50 to +-1.0). Table 3 highlights variables with significant relations (see appendix E).

Of particular interest to us was to ascertain whether there was a correlation between; participants qualifications and their understanding of ID nurse roles in enhancing impact of services, *r* = .15 p<0.01 (*Sig*. = .012, *n* = 230, *p*<0.05), participants' qualifications and understanding of ID nurse roles in enhancing quality of life, *r* = .15 p<0.01 (*Sig*. = .012, *n* = 230, *p*<0.05), country of practice of participants and the type of organisation they worked in, *r* = .13


©UWL / RCN Foundation 2021

p<0.01 (*Sig*. = .030, *n* = 230, *p*<0.05), country of practice of practice of participants and their understanding of ID nurse roles, *r* = -.22 p<0.01 (*Sig*. = .000, *n* = 230, *p*<0.05), country of practice of participants and their understanding of ID nurse roles in enhancing impact of services, *r* = -.13 p<0.01 (*Sig*. = .028, *n* = 230, *p*<0.05), country of practice and understanding of ID nurse roles in enhancing quality of life, *r* = -.15 p<0.01 (*Sig*. = .014, *n* = 230, *p*<0.05), and type of organisation in which participants practiced in and understanding of ID nurse roles *r* = -.11 p<0.01 (*Sig*. = .045, *n* = 230, *p*<0.05). These findings clearly demonstrate that significant relationships exist between variables. We were also interested in ascertaining the statistical significance of the relationship between a lack of confidence in understanding the ID nurse's role and the types of interventions. We observed significant correlations between ID nurses' broader understanding of their role and their understanding of ID nurse roles in effectuating nursing procedures, *r* = .44, p<0.01 (*Sig*. = .000, *n* = 230, *p*<0.05), between ID nurses' broader understanding of their role and their understanding of ID nurse roles in enhancing the impact of services, *r* = .45 p<0.01 (*Sig*. = .000, *n* = 230, *p*<0.05), and between ID nurses' broader understanding of their role and their understanding of ID nurse roles in enhancing quality of life, *r* = .39, p<0.01 (*Sig*. = .000, *n* = 230, *p*<0.05).

Secondly, we applied the Pearson chi-square ($\mathcal{X}^2$) statistical test to the data applied. The chi-square test determined a significant association between participants' age and their qualifications, ($\mathcal{X}^2$) (value = 69.39, df = 24, *N* = 230, Sig. = .000, p =.05) (see table 4).

*Table 4:* Age and qualifications response distributions

| Qualifications | | Diploma | Degree | Post Graduate Diploma | Master's Degree | PhD or other research degree | Other | Total |
|---|---|---|---|---|---|---|---|---|
| Age | 20-30 years | 0.4% | 11.3% | 0.9% | 0.9% | 0.0% | 0.9% | 33 (14.3%) |



©UWL / RCN Foundation 2021

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | 31-40 years | 2.2% | 7.0% | 3.0% | 4.3% | 0.0% | 0.4% | 39 (17.0%) |
| | 41-50 years | 11.3% | 7.8% | 5.2% | 5.2% | 0.9% | 0.9% | 72 (31.3%) |
| | 51-60 years | 4.8% | 13.5% | 2.2% | 5.7% | 0.9% | 6.5% | 33.5% |
| | Over 60 years | 0.4% | 1.3% | 0.0% | 1.7% | 0.0% | 0.4% | 3.9% |
| **Total** | | 44 | 94 | 26 | 41 | 4 | 21 | 230 |
| | | 19.1% | 40.9% | 11.3% | 17.8% | 1.7% | 9.1% | 100.0% |

The chi-square test determined a significant association between participants' age and their length of experience, ($\mathcal{X}^2$) (value = 200.06, df = 16, *N* = 230, Sig. = .000, p =.05) (see table 5).

*Table 5:* Age and experience response distributions

| | Experience | Less than 5 years | 6-10 years | 11-20 years | 21-30 years | More than 30 years | Total |
|---|---|---|---|---|---|---|---|
| Age | 20-30 years | 52.1% | 28.0% | 1.5% | 0.0% | 0.0% | 14.3% |
| | 31-40 years | 16.7% | 44.0% | 29.9% | 0.0% | 0.0% | 17.0% |
| | 41-50 years | 18.8% | 12.0% | 43.3% | 65.2% | 2.3% | 31.3% |
| | 51-60 years | 12.5% | 16.0% | 22.4% | 32.6% | 84.1% | 33.5% |
| | Over 60 years | 0.0% | 0.0% | 3.0% | 2.2% | 13.6% | 3.9% |
| **Total** | | 48 | 25 | 67 | 46 | 44 | 230 |
| | | 100.0% | 100.0% | 100.0% | 100.0% | 100.0% | 100.0% |

The chi-square test determined a significant association between the participants' country of practice and their understanding of ID nursing roles, ($\mathcal{X}^2$) (value = 24.57, df = 8, *N* = 230, Sig. = .002, p =.05) (see table 7). Of particular significance in these results are the proportions of the distributions of participants who have little confidence in their understanding of ID nurse roles. Participants from Northern Ireland constituted 9.1% of participants, and those from Scotland constituted 16.1%. There is disproportionate percentage of participants from Northern Ireland (24.1%) and Scotland (20.7%) who reported that they had little confidence in their understanding of the ID nurse role (see table 6 and figure 16).

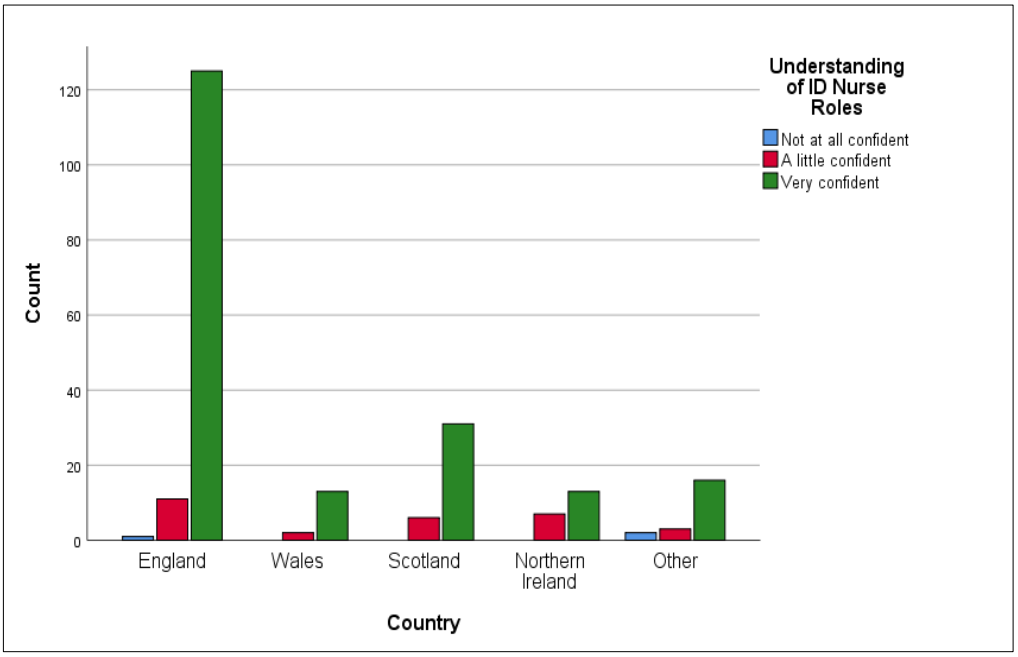


©UWL / RCN Foundation 2021

*Table 6:* Country of practice and participant understanding of ID nursing roles response distributions

| Understanding of ID nurse roles | | Not at all confident | A little confident | Very confident | Total |
|---|---|---|---|---|---|
| Country | England | 33.3% | 37.9% | 63.1% | 137 (59.6%) |
| | Wales | 0.0% | 6.9% | 6.6% | 15 (6.5%) |
| | Scotland | 0.0% | 20.7% | 15.7% | 37 (16.1%) |
| | Northern Ireland | 0.0% | 24.1% | 6.6% | 20 (8.7%) |
| | Other | 66.7% | 10.3% | 8.1% | 21 (9.1%) |
| Total | | 3 | 29 | 198 | 230 |
| | | 100.0% | 100.0% | 100.0% | 100.0% |

*Figure 16:* Country of practice and understanding of ID nursing roles




The chi-square test determined a significant association between participants' country of practice and their understanding of ID nursing roles in enhancing the quality of life of people with ID, ($\mathcal{X}^2$) (value = 15.96, df = 8, *N* = 230, Sig. = .043, p =.05). What is important to note in these findings are the overall proportion of participants who had little confidence in their understanding of the ID nurse role in enhancing the quality of life of people with ID (23.5%). The distribution between country of these participants is also disproportionate, England (48.1%), Scotland (24.1%), Northern



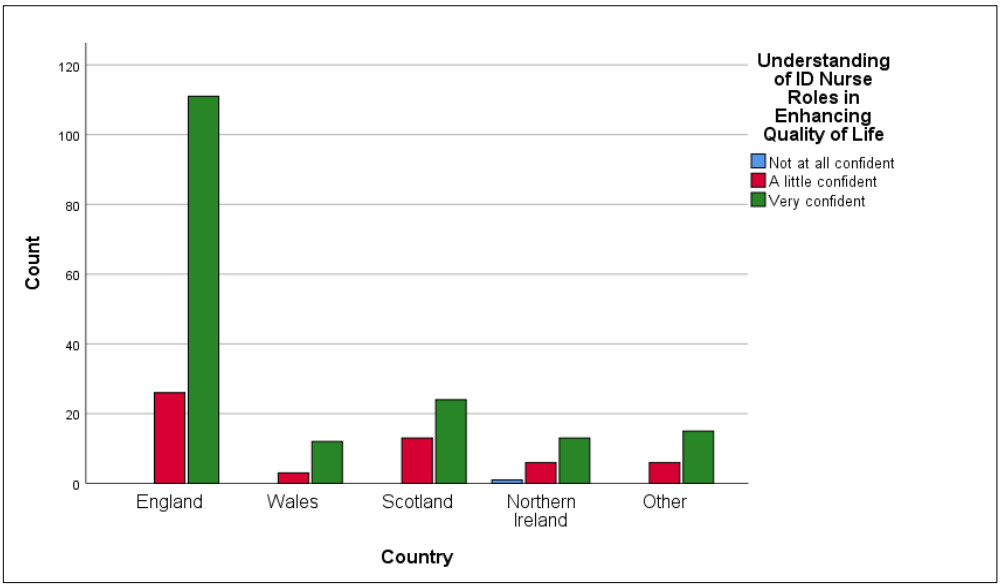
©UWL / RCN Foundation 2021

Ireland (11.1%), Other countries (11.1%), and Wales (5.6%) (see table 7 and figure 17).

*Table 7:* Country of practice and participant understanding of ID nursing roles in enhancing quality of life response distributions

| Understanding of ID nurse roles in enhancing quality of life | | Not at all confident | A little confident | Very confident | Total |
|---|---|---|---|---|---|
| Country | England | 0.0% | 48.1% | 63.4% | 137 (59.6%) |
| | Wales | 0.0% | 5.6% | 6.9% | 15 (6.5%) |
| | Scotland | 0.0% | 24.1% | 13.7% | 37 (16.1%) |
| | Northern Ireland | 100.0% | 11.1% | 7.4% | 20 (8.7%) |
| | Other | 0.0% | 11.1% | 8.6% | 21 (9.1%) |
| Total | | 1 | 54 | 175 | 230 |
| | | 100.0% | 100.0% | 100.0% | 100.0% |

*Figure 17:* Country of practice and participant understanding of ID nursing roles in enhancing quality of life




The chi-square test determined a borderline association between the type of organisation participants worked in and their understanding of ID nursing roles in enhancing the quality of life of people with ID, ($\mathcal{X}^2$) (value = 23.24, df = 14, *N* = 230, Sig. = .056, p =.05). Overall, 13.5% of participants had no, or had little confidence in their understanding of ID nursing roles in enhancing the quality of life of people with ID. Also, it is important to note the disproportionate



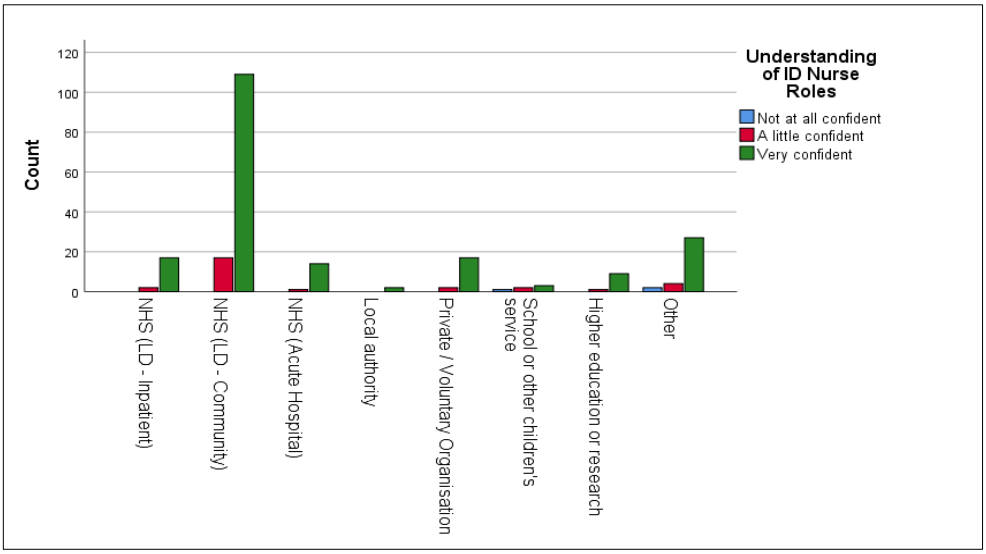
©UWL / RCN Foundation 2021

distribution participants who had little confidence in their understanding of ID nurse roles in enhancing the quality of life of people with ID between types of employer; NHS (ID inpatient) (6.9%), NHS (ID community) (58.6%), private / voluntary sector organisations (6.9%), schools / children services (6.9%), and other employer organisations (13.8%) (see table 8 and figure 18).

*Table 8:* Type of organisation and participant understanding of ID nursing roles in enhancing quality of life response distributions

| Understanding of ID nurse roles in enhancing quality of life | | Not at all confident | A little confident | Very confident | Total |
|---|---|---|---|---|---|
| Type of Organisation | NHS (ID - Inpatient) | 0.0% | 6.9% | 8.6% | 19 (8.3%) |
| | NHS (ID - Community) | 0.0% | 58.6% | 55.1% | 126 (54.8%) |
| | NHS (Acute Hospital) | 0.0% | 3.4% | 7.1% | 15 (6.5%) |
| | Local authority | 0.0% | 0.0% | 1.0% | 2 (0.9%) |
| | Private / Voluntary Organisation | 0.0% | 6.9% | 8.6% | 19 (8.3%) |
| | School or other children's service | 33.3% | 6.9% | 1.5% | 6 (2.6%) |
| | Higher education or research | 0.0% | 3.4% | 4.5% | 10 (4.3%) |
| | Other | 66.7% | 13.8% | 13.6% | 33 (14.3%) |
| Total | | 3 | 29 | 198 | 230 |
| | | 100.0% | 100.0% | 100.0% | 100.0% |

*Figure 18:* Type of organisation and participant understanding of ID nursing roles in enhancing quality of life




The lack of role clarity of the professionals working with people with



©UWL / RCN Foundation 2021

intellectual disabilities has been consistently identified as one of the most common barriers to accessing appropriate services (Thornton, 1996; Powrie, 2003; NHS Health Scotland, 2004; Phillips *et al*., 2004; Melville *et al*., 2005; Mafuba, 2009). More recently, in the UK, Mafuba (2013), Mafuba and Gates (2015), and Mafuba, Kupara, Cozens *et. al.* (2015) highlighted the lack of role clarity among ID nurses themselves. This scoping survey included a significant proportion of participants from outside of the UK. This suggests that this lack of clarity may very well similar in other countries where ID nurses practice.

Findings from this study demonstrate that a significant proportion of participants from the UK and elsewhere were not very confident in understanding what the role ID nurse's entails. In addition, a significant proportion of the participants were also not very confident in their understanding of what nursing procedures were undertaken by ID nurses, or in their understanding of interventions undertaken by ID nurses to improve the impact of services in meeting the needs of people with intellectual disabilities, and were not confident in their understanding of the role of ID nurses in enhancing the quality of life of people with ID. What is also clear from these findings is that there appear to be correlations between lack of role clarity and the types of employer organisations and countries of the participants. Despite a significant proportion of participants being unclear about ID nurse roles and interventions which impact the lives of people with ID, it is surprising that; 4.8% of participants strongly disagreed, 2.6% of participants disagreed, and 10% with the idea of a compendium of ID nursing interventions that could be used as a guide for their own practice. Without clarity of what the expectations are for their own role it is no surprise other healthcare professionals will have varying interpretations resulting in further ambiguities. This lack of clarity of the interventions they can effectively undertake is likely to have negative impact on the health and healthcare outcomes for people with ID.


©UWL / RCN Foundation 2021

The chi-square test determined a significant association between the participants' country of practice and their understanding of ID nursing roles ($\mathcal{X}^2$) (value = 24.57, df = 8, *N* = 230, Sig. = .002, p =.05) (see table 7). Of particular significance in these results are the proportions of the distributions of participants who have little confidence in their understanding of ID nurse roles. Participants from Northern Ireland constituted 9.1% of participants, and those from Scotland constituted 16.1%. There is disproportionate number of participants from Northern Ireland (24.1%) and Scotland (20.7%) who reported that they had little confidence in their understanding of the ID nurse role (see table 6 and figure 16).

The chi-square test determined a significant association between participants' country of practice and their understanding of ID nursing roles in enhancing the quality of life of people with ID, ($\mathcal{X}^2$) (value = 15.96, df = 8, *N* = 230, Sig. = .043, p =.05). What is important to note in these findings is the overall proportion of participants who had little confidence in their understanding of the ID nurse role in enhancing the quality of life of people with ID (23.5%). The distribution by country of these participants is also disproportionate, England (48.1%), Scotland (24.1%), Northern Ireland (11.1%), Other countries (11.1%), and Wales (5.6%) (see table 7 and figure 17).

The chi-square test determined a borderline association between the type of organisation participants worked in and their understanding of ID nursing roles in enhancing the quality of life of people with ID, ($\mathcal{X}^2$) (value = 23.24, df = 14, *N* = 230, Sig. = .056, p =.05). Overall, 13.5% of participants had no, or had little confidence in their understanding of ID nursing roles in enhancing the quality of life of people with ID. Also, it is important to note the disproportionate distribution participants who had little confidence in their understanding of ID nurse roles in enhancing the quality of life of people with ID between types of employer; NHS (ID inpatient)


©UWL / RCN Foundation 2021

(6.9%), NHS (ID community) (58.6%), private / voluntary sector organisations (6.9%), schools / children services (6.9%), and other employer organisations (13.8%) (see table 8 and figure 18).



©UWL / RCN Foundation 2021

## 6. Conclusions and recommendations

The overall aim of the scoping research was to identify nursing led and or nursing centred interventions that are in place to address the challenging and changing needs of people with ID. The research has identified a wide range of emerging interventions that are implemented by ID nurses working in multi-disciplinary teams across a wide range of settings in the UK and other countries. The research has identified a wide range of case studies and innovative practices that illustrate good care delivery.

**Recommendation 1**

We recommend that more work be undertaken to further develop the compendium of ID nursing interventions. We recommend that further work focuses on developing guidance for implementing the interventions, linking each intervention to evidence and appropriate resources.

We have also identified possible gaps in the provision of care for individuals with intellectual disabilities. Of significant concern are the very limited interventions related to maternity and end of life care. It is likely that the limited involvement is reflective of the limited number of women with ID who choose to have children. The second significant gap relates to frailty and end of life care. Although people with ID are more likely to die in hospital settings, it is unclear why there is limited ID 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.

What is clear from this scoping research is the wide range of interventions that ID nurses undertake in a complex sphere of practice. It is clear from the extent of these interventions that ID nurses need to constantly adapt and engage in a wide range of roles, and that they need to constantly assimilate emergent roles (Northway *et. al.,* 2017). What also emerges from this research are the complexities and changing needs of people with ID, the



©UWL / RCN Foundation 2021

changing environments in which ID nurses are practising, and the increasing expectation for ID nurses to meet health, healthcare and social needs of people with ID across the lifespan.

**Recommendation 2**
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 disabilities, we recommend that further research is undertaken to collect more data on ID nurse interventions, more specifically in relation to maternity, frailty, and end of life care.

We have collected a wide range of case studies and examples of ID nurse interventions that demonstrate the impact of these interventions. What we have not ascertained is the effectiveness of these interventions. The lack of evidence to demonstrate the impact and effectiveness of interventions performed by ID nurses pose a challenge for these nurses and the profession, and their contribution to the wider healthcare economy remain ambiguous.

**Recommendation 3**
We recommend that further work be undertaken to promote and publicise the impact and contributions of ID nurses. Importantly we recommend that some of this work focus on the unique contributions made by ID nurses to mainstream services and agencies. This is important for planning and resource allocation for future service provision.

This survey demonstrated that a worrying proportion of ID nurses who participated were over 50 years (37.4%) as compared to 15.5% of all NMC registrants. While this is likely to be reflective of the age profiles of entrants into ID nursing practice. The implication of this is that ID nurses are likely to have a much shorter career than their peers in other fields of nursing practice. In addition, the fact that


©UWL / RCN Foundation 2021

19.1% of participants had more than 30 years is suggestive of an impending crisis if this statistic is reflective of the profession as a whole and these nurses decide to retire.

**Recommendation 4**

We recommend that more targeted work be undertaken to promote the image of ID nursing in schools, colleges and all formative education settings. Particularly colleges that provide health and social care courses.

In the UK, since 2010 the minimum requirement for entry onto the NMC register is a minimum of a degree. Further changes to pre-registration nursing standards in the UK in 2018 now require ID nurses to be proficient with a new array of nursing procedures that were previously only associated with the adult nursing field of practice. Following these significant changes, the expectation is that when such changes are made nurses are supported to undertake further study in order to meet the new professional requirements, practice safely, and assimilate the new knowledge and skills expected by the professional body. It is rather surprising that more than ten years since the 2010 change 28.3% of participants in this survey had a diploma or less as their highest qualification. What this may mean is that these nurses may very well be functioning at an academic level that is below what is expected by the professional body. This is even more important given the extent of the interventions which are being undertaken by ID nurses, some of which are considered as advanced practice. In England, the proposed advanced clinical framework is an important development and there is need for this to focus on all areas of ID nursing practice (Skills for Health and Health Education England, 2020).

**Recommendation 5**

We recommend that further work be undertaken to develop learning opportunities for ID nurses to improve their knowledge and



©UWL / RCN Foundation 2021

skills. We are cognisant of the limited capacity in services and universities to make such opportunities widely available regionally. We recommend that this work include assessing opportunities for distance learning, apprenticeships, and use of simulation at all levels of ID nurse education.

Some of the interventions performed by ID nurses in this survey could be considered as advanced practice. It is unclear what training these ID nurses have had in order to evidence that they practice these interventions safely. In addition, there are non-ID nurses who work in specialist ID services, and it is unclear what training they have had to be able to practice safely when working with people with ID. What has also emerged from this survey is the increasing expectation that ID nurses work across age groups, services and settings. The current NMC standards for specialist education and practice are being reviewed but date back to 2001. These are unlikely to reflect the current advanced practices performed by contemporary ID nurses.

**Recommendation 6**

We recommend that further work be undertaken to consult senior practitioners, employers, and academics to consider the development of an adaptive advanced practice course that captures the interventions identified in this survey, as well as any emerging advanced practice ones. Such as none medical prescribing.

The evidence from this survey demonstrate that ID nurses support other healthcare, social care, and education professionals who work directly with people with ID in the community and acute sectors across the lifespan. What is also evident is that ID 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



©UWL / RCN Foundation 2021

ID services at strategic level by policy makers and commissioners of services.

The interventions undertaken by ID nurses make a real difference to the health and healthcare outcomes for people with ID. The impact of these roles include; preventing people with ID from suffering with undiagnosed conditions, improving the healthcare experiences and outcomes of people with ID, improving patient safety in mainstream hospitals and other services, making mainstream services better informed and deliver better care to people with ID, supporting services to become more responsive to the complex needs of people with ID, ensuring that commissioners of healthcare services understand the complex needs of people with ID, facilitating transitions between services, and reducing the health inequalities experienced by people.

The evaluation data from this survey suggested and demonstrated a lack of clarity among ID nurses of the interventions they can effectively be undertaken by ID nurses. What is also clear from our findings is that there appears to be correlations between lack of role clarity and the types of employer organisations and countries. This is likely to have negative impacts on the health and healthcare outcomes for people with ID.

**Recommendation 7**

We recommend that further work be undertaken by nurse leaders in these countries in order to ascertain and address the reasons for the lack of clarity.

***Limitations***

This scoping survey research has limitations. The sample was not random and consequently it can be argued that it is unrepresentative. However, the sample size as compared with previous studies in this area provides a significant contemporary 'snapshot' of ID nursing practice in the 21st century. Therefore,



©UWL / RCN Foundation 2021

although our findings are not generalisable and need to be understood from the context of participants who took part in the survey, they provide an important starting point for future work. Covid-19 restrictions impacted on the process of data collection, and this affected our ability to verify some of the case studies and examples of the impacts that were reported.

**Funding**

This scoping review of literature was funded by the Royal College of Nursing (RCN) Foundation. The funders of the scoping review did not play any role in how it was conducted.



©UWL / RCN Foundation 2021

## 7. References


Adams, D. and Shah, C. (2016) 'Prescribing of psychotropic medicines: the role of learning disabilities nurses'. *Learning Disability Practice,* 19(8), pp. 21-25. doi: 10.7748/ldp.2016.e1763.

Allerton, L., and Emerson, E. (2012). British adults with chronic health conditions or impairments face significant barriers to accessing health services. *Public Health,* 126(11), pp.920-927.

Arrey, S.K. (2014) *Lived experiences of registered learning disability nurses and palliative care professionals in caring for people with communication difficulties and an intellectual disability experiencing distress in palliative care settings: a hermeneutic phenomenological study.* ProQuest Dissertations Publishing. Available at: https://search.proquest.com/docview/1783893689 (Accessed: 24th May 2018).

Auberry, K. and Cullen, D. (2016) 'Implementation of an evidence-based seizure algorithm in intellectual disability nursing'. *Journal of Intellectual Disabilities,* 20(1), pp. 55-64. doi: 10.1177/1744629515598216.

Backer, C., Chapman, M. and Mitchell, D. (2009) Access to secondary healthcare for people with intellectual disabilities: A review of the literature. *Journal of Applied Research in Intellectual Disabilities,* 22 (6), p.514-525.

Bailey, M., Doody, O. and Lyons, R. (2014). Surveying community nursing support for persons with a learning disability and palliative care needs. *British Journal of Learning Disabilities,* 44(1), pp.24-34. https://doi.org/10.1111/bld.12105.

Bakker-van Gijssel, E.J., Lucassen, P.L.B.J., Hartman, T., van Son, L., Assendelft, W.J.J., and van Schrojenstein Lantman-de Valk, H.M.J. (2017) Health assessment instruments for people with intellectual disabilities - A systematic review. *Research in Developmental Disabilities,* 64, pp.12-24.

Barr, O., Gilgunn, J., Kane, T. and Moore, G. (1999) 'Health screening for people with learning disabilities by a community learning disability nursing service in Northern Ireland', *Journal of*




©UWL / RCN Foundation 2021

*Advanced Nursing,* 29(6), pp. 1482-1491. doi: 10.1046/j.1365-2648.1999.01036.x.

Blair, J. (2013) Everybody's life has worth – Getting it right in hospital for people with a learning disability and reducing clinical risks. *Journal of Patient Safety and Risk Management,* 19(3), pp. 58-63.

Bradley, E. (2011). Mixed methods evaluation of in-hospital nurse prescribing finds similar care standards and provision between nurses and doctors. *Evidence-Based Nursing,* 14, p.121-122.

Braun, V. and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology,* 3(2), pp77-101.

Brown, M., Chouliara, Z., MacArthur, J., McKechanie, A., Mack, S., Hayes, M., & Fletcher, J. (2016). The perspectives of stakeholders of intellectual disability liaison nurses: a model of compassionate, person-centred care. *Journal of Clinical Nursing,* 25(7-8), pp.972-982. doi:10.1111/jocn.13142.

Brown, M., MacArthur, J., McKechanie, A., Hayes, M. and Fletcher, J. (2010) Equality and access to general healthcare for people with learning disabilities: Reality or rhetoric? *Journal of Research in Nursing,* 15 (4), p.351-361.

Brown, M., MacArthur, J., McKechanie, A., Mack, S., Hayes, M. and Fletcher, J. (2012) 'Learning disability liaison nursing services in south-east Scotland: a mixed-methods impact and outcome study'. *Journal of Intellectual Disability Research,* 56(12), pp. 1161-1174. doi: 10.1111/j.1365-2788.2011.01511.x.

Campbell, A.K. (2011). Nurses' experiences of working with adults who have an intellectual disability and challenging behaviour. *The British Journal of Development Disabilities,* 57(112), pp.41-51. DOI: 10.1179/096979511798967179.

Campbell, M. and Martin, M. (2009) Reducing health inequalities in Scotland: the involvement of people with learning disabilities as national health service reviewers. *British Journal of Learning Disabilities*, 38 (1), p.49–58.

Chapman, H.M. (2015). *The health consultation experience for people with learning disabilities: A constructivist grounded theory*



©UWL / RCN Foundation 2021

*study based on symbolic interactionism.* Chester: University of Chester, Unpublished PhD Thesis.

Chauhan, U., Kontopantelis, E., Campbell, S., Jarrett, H. & Lester, H. (2010) Health checks in primary care for adults with intellectual disabilities: how extensive should they be? *Journal of Intellectual Disability Research,* 54 (6), p.479-486.

Clarke, V., Braun, V., Terry, G & Hayfield N. (2019). Thematic analysis. In Liamputtong, P. (Ed.), *Handbook of research methods in health and social sciences* (pp. 843-860). Singapore: Springer.

Cleary, J. and Doody, O. (2017) 'Nurses' experience of caring for people with intellectual disability and dementia'. *Journal of Clinical Nursing,* 26(5-6), pp. 620-631. doi: 10.1111/jocn.13431.

Cohen, J. (1988) *Statistical power analysis for the behavioral sciences* (2nd edn.). New Jersey: Lawrence Erlbaum Associates.

Connelly, L.M. (2009) Survey methods. *MEDSURG Nursing*, 18 (2), p.114-115, 133.

Cope, G. and Shaw, T. (2019). *Capturing the voices of learning disability nurses and people who use services.* London: Foundation of Nursing Studies.

Creswell J.W. and Cresswell, J.D. (2018) *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches.* 5th edn. London: Sage.

Creswell, J.W. and Plano Clark, V.L. (2017). *Designing and conducting mixed methods research.* Revised 3rd ed. London: Sage.

Dahm M.F. and Wadwnsten, B. (2008) Nurses' experiences of and opinions about using standardised care plans in electronic health records – a questionnaire study. *Journal of Clinical Nursing,* 17(12), pp. 2137-2145. https://doi.org/10.1111/j.1365-2702.2008.02377.x.

Dalgarno, M.F. and Riordan, S.A. (2014). Forensic intellectual disability nursing: what's it really like? *Journal of Intellectual Disabilities and Offending Behaviour,* 5(4), pp.167-177. https://doi.org/10.1108/JIDOB-11-2014-0017.



©UWL / RCN Foundation 2021

Delahunty, L. (2017) 'Understanding the nurse's role in identifying children with intellectual disability'. *Nursing Children and Young People,* 29(6), pp. 33-36. doi: 10.7748/ncyp.2017.e863.

Dening, K.H., Sates, C. and Lloyd-Williams, M. (2018) Palliative care in dementia: A fragmented pathway? *International Journal of Palliative Nursing,* 24(12), pp. 585-596. DOI: 10.12968/ijpn.2018.24.12.585.

DoH (2007). *Good practice in intellectual disability nursing.* London: Department of Health.

DoH & SC (2018) *Prevention is better than cure.* London: Department of Health and Social Care.

Doody, C., Markey, K. and Doody, O. (2013). Future need of ageing people with an intellectual disability in the Republic of Ireland: lessons learned from the literature. *British Journal of Learning Disabilities,* 41(1), pp. 13-21. https://doi.org/10.1111/j.1468-3156.2011.00716.x.

Doody, O., Slevin, E. and Taggart, L. (2019). A survey of nursing and multidisciplinary team members' perspectives on the perceived contribution of intellectual disability clinical nurse specialists. *Journal of Clinical Nursing,* 28(21-220, pp.3879-3889.

Doody, O., Slevin, E. and Taggart, L. (2017) 'Focus group interviews examining the contribution of intellectual disability clinical nurse specialists in Ireland'. *Journal of Clinical Nursing,* 26(19-20), pp. 2964-2975. doi: 10.1111/jocn.13636.

DRC (2006) *Equal treatment: Closing the gap.* Stratford Upon Avon: Disability Rights Commission.

Drozd, M. and Clinch, C. (2016). The experiences of orthopaedic and trauma nurses who have cared for adults with a intellectual disability. *International Journal of Orthopaedic Trauma Nursing,* 22, pp.13-23. doi: 10.1016/j.ijotn.2015.08.003.

Emerson, E. and Brigham, P. (2015). Exposure of children with developmental delay to social determinants of poor health: Cross-sectional case record review study. *Child Care, Health and Development,* 41(2), pp.249-257.



©UWL / RCN Foundation 2021

Emerson, E., Copeland, A. and Glover, G. (2011) *The uptake of health checks for adults with learning disabilities: 2008/9 to 2010/11.* (Online). Available at: http://www.karentysonspage.org/Emerson%202011%20Health%20Checks%20for%20People%20with%20Intellectual%20Disabilities%202008-9%20%202010-11.pdf (Accessed: 6 October 2020).

Emerson, E., Hatton, C., Baines, S. and Robertson, J. (2016a). The physical health of British adults with intellectual disability: Cross sectional study. *International Journal for Equity in Health,* 15(1), pp.1-9.

Emerson, E., Robertson, J., Baines, S. and Hatton, C. (2016b). Obesity in British children with and without intellectual disability: cohort study. *BMC Public Health,* 16(1), pp.1-10.

Fink, A. (2015). *How to conduct survey – A step by step guide*. 6th edn. London: Sage.

Hatton, C. and Emerson, E. (2015). Health disparities, health inequity, and people with intellectual disabilities. *International Review of Research in Developmental Disabilities,* 48, pp.1-9.

Heinrich State University (2020). *G* Power 3.1.* Dusseldorf: Heinrich State University.

Heslop, P., Blair, P.S., Fleming, P., Hoghton, M., Marriott, A., and Russ, L. (2014) The confidential inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *The Lancet,* 383(9920), pp. 889-895.

Heslop, P., Blair, P.S., Fleming, P., Hoghton, M., Marriott, A., and Russ, L. (2013) *Confidential inquiry into premature deaths of people with intellectual disabilities (CIPOLD)* - Final report. Bristol: Norah Fry Research Centre. https://doi.org/10.1111/jocn.14990.

Houghton, C., Murphy, K., Shaw, D. and Casey, D. (2014). Qualitative case study data analysis: an example from practice. *Nurse Researcher,* 22 (5), pp. 8-12. doi: 10.7748/nr.22.5.8.e1307.

Gates, B. and Mafuba, K. (2016) Use of the term "learning disabilities" in the United Kingdom: Issues for international



©UWL / RCN Foundation 2021

researchers and practitioners. *Learning Disabilities: A Contemporary Journal*, 14(1), p.9-23.

Jenkins, R. (2012) 'Meeting the health needs of older people with intellectual disabilities'. *British Journal of Nursing,* 21(8), pp. 468-473. doi: 10.12968/bjon.2012.21.8.468.

Kavanagh, A., Aitken, Z., Emerson, E., Sahabandu, S., Milner, A., Bentley, R., LaMontagne, A., Pirkis, J. and Studdert, D. (2017). Inequalities in socio-economic characteristics and health and wellbeing of men with and without disabilities: a cross-sectional analysis of the baseline wave of the Australian longitudinal study on male health. *BMC Public Health,* 16(Supplement 3), pp.23-31.

Kelly, K., Clark, B., Brown, V. and Sitzia, J. (2003) Good practice in the conduct and reporting of survey research. *International Journal for Quality in healthcare*, 15 (3), p.261-266.

Kerr, M. (2004) Improving the general health of people with learning disabilities. *Advances in Psychiatric Treatment,* 10, p.200-206.

Krippendorff, Klaus (2004). *Content Analysis: An Introduction to Its Methodology* (2nd ed.). Thousand Oaks, CA: Sage. p. 413. *ISBN 9780761915454*.

LeDeR (2020). *The learning disability mortality review – Annual report.* Bristol: University of Bristol Norah Fry Centre for Disability Studies.

LeDeR (2017). *The learning disability mortality review – Annual report.* Bristol: University of Bristol Norah Fry Centre for Disability Studies.

Lee, A. and Kiemle, G. (2014). 'It's one of the hardest jobs in the world': The experience and understanding of unqualified nurses who work with individuals diagnosed with both intellectual disability and personality disorder. *Journal of Applied Research in Intellectual Disabilities,* 28(3), pp238-248. https://doi.org/10.1111/jar.12125.

Llewellyn, G., Vaughan, C. and Emerson, E. (2015). Discrimination and the health of people with learning disabilities. *International Review of Research in Developmental Disabilities*, 48, pp.43-72.



©UWL / RCN Foundation 2021

Llewellyn, P. (2005) *An investigation into the advocacy role of the learning disability nurse.* Unpublished PhD thesis. University of Glamorgan, UK.

Llewellyn, P. and Northway, R. (2007) 'An investigation into the advocacy role of the learning disability nurse'. *Journal of Research in Nursing,* 12(2), pp. 147-161. doi: 10.1177/1744987106075626.

Lloyd, J.L. and Coulson, N.S. (2014) 'The role of learning disability nurses in promoting cervical screening uptake in women with intellectual disabilities'. *Journal of Intellectual Disabilities,* 18(2), pp. 129-145. doi: 10.1177/1744629514528829.

Lovell, A. and Bailey, J. (2016). Nurses' perceptions of personal attributes required when working with people with a learning disability and an offending background: a qualitative study. *Journal of Psychiatric and Mental Health Nursing*, 24(1), pp. 4-14. https://doi.org/10.1111/jpm.12326.

Lovell, A., Bailey, J., Kingdon, A. and Gentile, D. (2014). Working with people with learning disabilities in varying degrees of security: nurses' perceptions of competencies. *Journal of Advanced Nursing,* 70(9), pp. 2041-2050. https://doi.org/10.1111/jan.12362.

MacArthur, J., Brown, M., McKechanie, A., Mack, S., Hayes, M. and Fletcher, J. (2015) 'Making reasonable and achievable adjustments: the contributions of learning disability liaison nurses in 'Getting it right' for people with intellectual disabilities receiving general hospitals care'. *Journal of Advanced Nursing,* 71(7), pp. 1552-1563. doi: 10.1111/jan.12629.

Mafuba, K. (2009) 'The public health role of learning disability nurses: a review of the literature. *Learning Disability Practice,* 12(4), pp. 33-37.

Mafuba, K. (2013) *Public health: community learning disability nurses' perception and experience of their roles: an exploratory sequential multiple methods study*. ProQuest Dissertations



©UWL / RCN Foundation 2021

Publishing. Available at: https://search.proquest.com/docview/1937411950 (Accessed: 6 October 2020).

Mafuba, K., Forster, M., Chapman, H., Kiernan, J., Kupara, D., Kudita, C. and Chester, R. (2020). *Understanding the contribution of learning disability nurses: Scoping research. Volume 1 of 3 – Scoping literature review report*. London: University of West London / RCN Foundation.

Mafuba, K. and Gates, B. (2015) 'An investigation into the public health roles of community learning disability nurses', *British Journal of Learning Disabilities,* 43(1), pp. 1-7. doi: 10.1111/bld.12071.

McCombes, S. (2020). *Understanding Different Sampling Methods.* Retrieved from: https://www.scribbr.com/methodology/sampling-methods/ on 24 December 2020.

Gates, B. and Mafuba, K. (2016) Use of the term “intellectual disabilities” in the United Kingdom: Issues for international researchers and practitioners. *Intellectual Disabilities: A Contemporary Journal*, 14(1), p.9-23.

Kelly, K., Clark, B., Brown, V. and Sitzia, J. (2003) Good practice in the conduct and reporting of survey research. *International Journal for Quality in Healthcare*, 15 (3), p.261-266.

Mafuba, K., Forster, M., Kupara, D. and Gates, B. (2018a) *Mixed methods literature review on improving the health of people with a learning disability – a public health nursing approach. Final Report.* London: University of West London / Public Health England.

Mafuba, K., Gates, B. and Cozens, M. (2018b) 'Community learning disability nurses’ public health roles in the United Kingdom: An exploratory documentary analysis'. *British Journal of Learning Disabilities*, 22(1), pp.61-73. doi: 10.1177/1744629516678524.

Mafuba, K., Kupara, D., Cozens, M. and Kudita, C. (2015) The importance of role clarity in community learning disability nursing – A critique of the literature. *Learning Disability Practice,* 18(8), p.28-31.



©UWL / RCN Foundation 2021

Mallett, J and Dougherty, L. (2000) *The Royal Marsden Hospital Manual of Clinical Nursing Procedures, 5th Edition.* London: Wiley-Blackwell.

Marriott, A., Turner, S., Ashby, S. and Rees, D. (2015) 'Cancer screening for people with learning disabilities and the role of the screening liaison nurse'. *Tizard Learning Disability Review,* 20(4), pp. 239-246. doi: 10.1108/TLDR-07-2015-0027.

Marshall, D. and Foster, I. (2002) 'Providing a healthcare input to children in special schools'. *British Journal of Nursing,* 11(1), pp. 28-35. doi: 10.12968/bjon.2002.11.1.9320.

Marshall, D., McConkey, R. and Moore, G. (2003) 'Obesity in people with learning disabilities: the impact of nurse-led health screenings and health promotion activities'. *Journal of Advanced Nursing,* 41(2), pp. 147-153. doi: 10.1046/j.1365-2648.2003.02522.x.

Marsham, M. (2012) 'An exploration of community learning disability nurses' therapeutic role'. *British Journal of Learning Disabilities,* 40(3), pp. 236-244. doi: 10.1111/j.1468-3156.2011.00702.x.

Mason, T. and Phipps, D. (2010). Forensic learning disability nursing skills and competencies: A study of forensic and non-forensic nurses. *Issues in Mental Health Nursing,* 31(11), pp.708-715.

McCarron, M., Sheerin, F., Roche, L., Ryan, AM., Griffiths, C., Keenan, P., Doody, O., D'Eath, M., Burke, E., McCallion, P. (2018) *Shaping the Future of Intellectual Disability Nursing in Ireland*. Dublin: Health Services Executive, Ireland.

Mcilfatrick, S., Taggart, L. and Truesdale-Kennedy, M. (2011) Supporting women with intellectual disabilities to access breast cancer screening: a healthcare professional perspective. *European Journal of Cancer Care,* 20 (3), p.412-420.

McKeon, M. (2009) 'A survey of clinical nursing skills in intellectual disability nursing', *Journal of Intellectual Disabilities,* 13(1), pp. 31-41. doi: 10.1177/1744629509103517.

Melville, C.A., Cooper S.A., Morrison I. J., Finlayson J., Allan, L., Robinson N., Burns E. and Martin, G. (2006) The outcomes of



©UWL / RCN Foundation 2021

an intervention study to reduce the barriers experienced by people with intellectual disabilities accessing primary healthcare services. *Journal of Intellectual Disability Research,* 50 (1), p.11-17.

Mencap (2007) *Death by indifference. Following up the Treat me right report.* London: Mencap.

Mencap (2012) *Death by indifference: 74 deaths and counting.* London: Mencap.

Mencap (2020) Children – research statistics. Online. Available at: https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/children-research-and-statistics (Accessed on: 06 October 2020).

Messent, P.R., Cooke, C.B. and Long, J. (1999). Primary and secondary barriers to physically active healthy lifestyles for adults with learning disabilities. *Disability and Rehabilitation,* 21(9), pp. 409-419. https://doi.org/10.1080/096382899297396.

Michael, J. (2008) *Healthcare for All: Report of the independent inquiry into access to healthcare for people with intellectual disabilities.* London: Department of Health.

Michas, F. (2020). Number of nurses, midwives and nursing associates registered in the United Kingdom (UK) in 2020, by age group. (Online). Available at: https://www.statista.com/statistics/1007465/registered-nursing-staff-united-kingdom-by-age/#:~:text=This%20statistic%20displays%20the%20number,between%2041%20and%2050%20years. Accessed: 17 February 2021.

Morton-Nance, S. (2015) 'Unique role of learning disability liaison nurses'. *Learning Disability Practice,* 18(7), pp. 30-34. doi: 10.7748/ldp.18.7.30.e1627.

Morton-Nance, S. and Schaler, T. (2012). End of life care for people with a learning disability. *Nursing Standard,* 27(10, pp 40-47. PMID: 23082363 DOI: 10.7748/ns2012.09.27.1.40.c9270.

Nelson, S. and Carey, E. (2016) The role of the nurse in assessing mobility decline in older people with learning disabilities.



©UWL / RCN Foundation 2021

*Learning Disability Practice,* 19(9), pp. 19-24. doi: 10.7748/ldp.2016.e1776.

Neuendorf, K.A. (2011) Content analysis: A methodological primer for gender research. *Sex Roles – A Journal of Research,* 64(3-4), pp276-289. DOI 10.1007/ s11199-010-9893-0.

Ng, J. S. W. (2011) *Knowing the patient well: intellectual disability nurses' experiences of caring for terminally ill people with profound intellectual disabilities in residential care settings.* PhD thesis, University of Greenwich.

NHS Health Scotland (2004) *Health needs assessment report: People with learning disability in Scotland.* Glasgow: NHS Health Scotland.

NICE (2018). *Learning disabilities and behaviours that challenges: service design and delivery.* (Online). Available at: www.nice.org.uk/guidance/ng93. Accessed: 27 March 2021.

NMC (2020). *NMC register, September 2020 UK data table.* (Online). Available at: https://www.nmc.org.uk/about-us/reports-and-accounts/registration-statistics/. Accessed: 27 March 2021.

NMC (2018). *Future nurse: Standards of proficiency for registered nurses*. London: NMC.

NMC (2010) *Standards for pre-registration nurse education.* London: Nursing and Midwifery Council.

Northway, R., Cushing, K., Duffin, S., Payne, T., Price, P. and Sutherland, K. (2017) 'Supporting people across the lifespan: the role of learning disability nurses'. *Learning Disability Practice,* 20(3), pp. 22-27. doi: 10.7748/ldp.2017.e1841.

ONS (2011). *2011 Census.* (Online). Available at: https://www.ons.gov.uk/census/2011census. Accessed: 27 March 2021.

Ouellette-Kuntz , H. (2005) Understanding health disparities and inequities faced by individuals with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities,* 18 (2), p.113-121.

Oulton, J., Wray, Hassiotis, A., Kenten, C., Russell, J., Tuffrey-Wijne, I., Whiting, M., and Faith Gibson, F. (2019) Learning disability



©UWL / RCN Foundation 2021

nurse provision in children's hospitals: hospital staff perceptions of whether it makes a difference. *BMC Pediatrics,* 19:192. https://doi.org/10.1186/s12887-019-1547-y.

Pallant, J. (2007) *SPSS survival manual.* 3rd edn. Maidenhead: Open University Press.

Pennington, M., Ring, H., Howlett, J., Smith, C., Redley, M., Murphy, C., Hook, R., Platt, A., Gilbert, N., Jones, E., Kelly, J., Pullen, A., Mander, A., Donaldson, C., Rowe, S., Wason, J. and Irvine F. (2019). The impact of an epilepsy nurse competency framework on the costs of supporting adults with epilepsy and intellectual disability: findings from the EpAID study. *Journal of Intellectual Disability Research,* 63(12), pp. 1391-1400.

Peters, M., Godfrey, C.M., Khalil, H. and Mcinerney, P. (2017). Chapter 11: Scoping reviews. In: *2017 Guidance for the Conduct of JBI Scoping Reviews.* Adelaide: JBI.

Phillips A., Morrison J. and Davis R. W. (2004) General practitioners' educational needs in intellectual disability health. *Journal of Intellectual Disability Research*, 48 (2), p.142-149.

Powrie E. (2003) Primary healthcare provision for adults with a learning disability. *Journal of Advanced Nursing*, 42 (4), p.413-423.

Punch, K. (2003) *Survey research: The basics.* London: Sage.

Quinn, B.L., and Smolinski, M (2018). Improving school nurse pain assessment practices for students with intellectual disability. *The Journal of School Nursing,* 34(6), pp.480-488.

RCN (2012) *Going upstream: nursing's contribution to public health: Prevent, promote and protect - RCN guidance for nurses.* London: Royal College of Nursing.

Ring H., Howlett, J., Pennington, M., Smith, C., Redley, M., Murphy, C., Hook, R., Platt, A., Gilbert, N., Jones, E., Kelly, J., Pullen, A. Mander, A., Donaldson, C., Rowe, S., Wason, J. and Irvine, F. (2018). Training nurses in a competency framework tosupport adults with epilepsy and intellectual disability: the EpAID cluster RCT. *Health Technology Assessment,* 22(10). DOI: 10.3310/hta22100.



©UWL / RCN Foundation 2021

Robertson, J., Chadwick, D., Baines, S., Emerson, E., and Hatton, C. (2017). Prevalence of dysphagia in people with intellectual disability: A systematic review. *Intellectual and Developmental Disabilities*, 55(6), pp.377-391.

Robertson, J., Hatton C., Emerson, E. and Baines, S. (2014) The impact of health checks for people with intellectual disabilities: An updated systematic review of evidence. *Research in Developmental Disabilities,* 35(10), pp. 2450-2462.

Robertson, J., Hatton, C., Emerson, E. and Baines, S. (2015) Mortality in people with intellectual disabilities and epilepsy: A systematic review. *Seizure,* 29, pp.123-133. https://doi.org/10.1016/j.seizure.2015.04.004.

Sandelowski, M., Voils, C.I., Leeman, J. and Crandell, J. (2012) Mapping the mixed methods–mixed research synthesis terrain. *Journal of Mixed Methods Research,* 6(4), pp. 317–331. doi:10.1177/1558689811427913.

Savage, A., and Emerson, E. (2016). Overweight and obesity among children at risk of intellectual disability in 20 low- and middle-income countries. *Journal of Intellectual Disability Research*, 60(11), pp.1128-1135.

Sheerin, F.K. (2012) ' Learning disability nursing – responding to health inequity', *British Journal of Learning Disabilities,* 40(4), pp. 266-271. doi: 10.1111/j.1468-3156.2011.00705.x.

Skills for Health and HEE (2020). Advanced Clinical Practice: Capabilities framework when working with people who have a learning disability and / or autism. (Online). Available at: https://www.skillsforhealth.org.uk/images/services/cstf/ACP%20in%20LDA%20Framework.pdf. Accessed: 27 March 2021.

Slevin, E. and Sines, D. (2005) 'The role of community nurses for people with intellectual disabilities: working with people who challenge'. *Journal of Nursing Studies*, 42, pp. 415-427.

Straetmans, J.M.J.A.A., van Schrojenstein Lantman-de Valk, H.M.J., Schellevis, F.G., and Dinant, G.J. (2007) Health problems of people with intellectual disabilities: The impact for general practice. *British Journal of General Practice* 57, (534), p.64-66.



©UWL / RCN Foundation 2021

Taggart, L., Truesdale-Kennedy, M. and McIlfatrick, S. (2011) 'The role of community nurses and residential staff in supporting women with intellectual disability to access breast screening services'. *Journal of Intellectual Disability Research,* 55(1), pp. 41-52. doi: 10.1111/j.1365-2788.2010.01345.x.

Taua, C., Hepworth, J. and Neville, C. (2012) 'Nurses' role in caring for people with a comorbidity of mental illness and intellectual disability: A literature review'. *International Journal of Mental Health Nursing,* 21(2), pp. 163-174. doi: 10.1111/j.1447-0349.2011.00779.x.

Taua, C., Neville, C. and Scot, T. (2017). Appreciating the work of nurses caring for adults with intellectual disability and mental health issues. *International Journal of Mental Health Nursing,* 26(6), pp.629-638. https://doi.org/10.1111/inm.12291.

Thobaity, A.A.I, Plummer V. and Williams B. (2017). What are the most common domains of the core competencies of disaster nursing? A scoping review. *International Emergency Nursing,* 31, p.64-71. https://doi.org/10.1016/j.ienj.2016.10.003.

Thomas, G. and Kerr, M.P. (2011). Longitudinal follow-up of weight change in the context of a community-based health promotion programme for adults with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 24 (4), p.381-387.

Thomas, J. and Harden, A. (2007) *Methods for the thematic synthesis of qualitative research in systematic reviews.* London: ESRC National Centre for Research Methods.

Thornton, C. (1996) A focus group inquiry into the perceptions of primary healthcare teams and the provision of healthcare for adults with learning disability living in the community. *Journal of Advanced Nursing*, 23 (6), p.1168-1176.

Timmins, F. and McCabe, C. (2005) How to conduct an effective literature search. *Nursing Standard*, 20(11), pp.41-47.

Tricco, A. C., Lillie, E., Zarin, W., *et al.* (2018). PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Annals of Internal Medicine,* 169(7), pp.467-473. doi: 10.7326/M18-0850.



©UWL / RCN Foundation 2021

Truesdale, M. and Brown, M. (2017). *People with Learning Disabilities in Scotland: 2017 Health Needs Assessment Report.* Edinburgh: NHS Health Scotland.

*Van* Schrojenstein Lantman-de Valk H. M. J., Metsemakers J. F. M., Haveman M. J. and Crebolder, H. F. J. M. (2007) Health problems in people with intellectual disability in general practice: a comparative study. *Family Practice,* 17 (5), p.405-407.

Wagemans, A.M.A., van Schrojenstein Lantman-de Valk, H.M.J., Proot, I.M., *et al.* (2015) 'End-of-life decision-making for people with intellectual disability from the perspective of nurses. *Journal of Policy and Practice in Intellectual Disabilities,* 12(4), pp.294-302. doi: 10.1111/jppi.12140.



©UWL / RCN Foundation 2021

## 8. Appendices

*Appendix A* - Self-completed online questionnaire

Onlinesurveys

# Understanding the contribution of intellectual (intellectual) disability nurses to improving the health and well-being of children, adults and older people with intellectual disabilities, now and for the future: Scoping research

1. **INVITATION AND GUIDANCE**

You have been invited to participate in this scoping study which, is funded by the RCN Foundation because we believe that you are the most appropriate person to approach for assistance. We also believe that you would make essential and valuable contribution to the findings of the study. This study is open to NMC registered intellectual disability nurses.

The study is being conducted in England, Wales, Scotland, and Northern Ireland. The scoping research *investigates the contribution of intellectual (intellectual) disability nurses to improving the health and well-being of children, adults and older people with intellectual disabilities, now and for the future.*

We would like you to tell us;

1. About yourself,
2. Where you work and what you do,
3. Any examples of what you do that makes a difference, and
4. What you think about what intellectual (intellectual) disability nurses do.

Most questions are multiple choice, and the questionnaire will take about 30 minutes to complete.

**2. CONSENT**



©UWL / RCN Foundation 2021

By completing this questionnaire, you are giving your consent for your responses to be used in this research study. You are also confirming that you have understood that your participation is voluntary and that you are free to discontinue at any time, without giving any reason.
You can be assured that all information collected as part of this study will be treated in the strictest of confidence and will not be used for anything else other than for the purposes of this research. NO PERSONAL INFORMATION about yourself and where you work will be identified in the data collected or in any published results.

**3. RESEARCHERS**
If you have any questions please contact:
Professor Kay Mafuba (Principal Investigator) College of Nursing, Midwifery and Healthcare, University of West London
Dr Marc Foster, University of West London
Dr Hazel Chapman, University of Chester
Dr Joann Kiernan, Edge Hill University & Nurse Consultant, Alder Hey Hospital
Dorothy Kupara, University of West London
Chiedza Kudita, University of West London
Rebecca Chester MBE, Berkshire Healthcare NHS Foundation Trust & Chair United Kingdom Intellectual Disability Consultant Nurse Network

**4. FUNDING** - This project is funded by the RCN Foundation.

## About me

1 How old are you?

1. 20-30 years
2. 31-40 years
3. 41-50 years
4. 51-60 years
5. Over 60 years

2 Gender

1. Female
2. Male
3. Do not wish to say


©UWL / RCN Foundation 2021

3Years of experience as a registered intellectual (intellectual) disabilities nurse

1. Less than 5 years
2. 6-10 years
3. 11-20 years
4. 21-30 years
5. More than 30 years

4 My highest qualification

1. Diploma
2. Degree
3. Post Graduate Diploma
4. Master's Degree
5. PhD or other research degree
6. Other

a If you selected Other, please specify:

5 I am registered with the professional body as (Select all that applies);

1. Intellectual / intellectual disabilities nurse
2. Mental health nurse
3. Children's nurse
4. Adult nurse

Other (Please specify)

a If you selected Other, please specify:

## Where I work and what I do

6 Country where I practice

1. England
2. Wales
3. Scotland



©UWL / RCN Foundation 2021

4. Northern Ireland
5. Other

a If you selected Other, please specify:

7 Type of organisation I work for

1. NHS (LD – Inpatient)
2. NHS (LD – Community)
3. NHS (Acute Hospital)
4. Local authority
5. Private / Voluntary organisation
6. School or other children's service
7. Higher education or research
8. Other

a If you selected Other, please specify:

8 The age group(s) of people I work with (Select all that applies)

1. Maternity (pregnant women)
2. Children (0-17 years)
3. Adults (18-65 years)
4. Adults (Over 65 years)
5. Palliative / End of life care (could be any age)
6. Other

a If you selected Other, please specify:

9 List all nursing procedures you undertake (these are activities you practically do, e.g., administering medication; managing aggression).



©UWL / RCN Foundation 2021

10 List all activities you undertake to improve how other services or professionals deliver effective care to people with intellectual disabilities (e.g., making reasonable adjustments).

11 List all activities you undertake to improve the quality of life of people with intellectual disabilities (e.g. health promotion).

12 List any other activities you undertake you have not described above.

13 Tell us the impact of what you do on services and quality of life of people with intellectual (intellectual) disabilities.

## Example(s) of what I/we do which makes a difference

14 Describe the person (people) and their need(s). Tell us what you did (do) which made (makes) a difference? How did (does) what you do make a difference to the person (people) you support?



©UWL / RCN Foundation 2021

15 We would really want to get more information on what you do. If you would like us to contact you please provide us with details (Name and E-mail address)

## What you think about what intellectual (intellectual) disability nurses do.

16 How confident do you feel in your understanding of what all intellectual (intellectual) disabilities nurses do?

1. Not at all confident
2. A little confident
3. Very confident

17 How confident do you feel in your understanding of all the nursing procedures intellectual (intellectual) disabilities nurses are expected to perform in roles?

1. Not at all confident
2. A little confident
3. Very confident

18 How confident do you feel in your understanding of all activities intellectual (intellectual) disabilities nurses are expected to undertake in order to improve how other services or professionals deliver effective care to people with intellectual (intellectual) disabilities?

1. Not at all confident
2. A little confident
3. Very confident

19 How confident do you feel in your understanding of all activities intellectual (intellectual) disabilities nurses are expected to undertake in improving the quality of life of people with intellectual (intellectual) disabilities?

1. Not at all confident
2. A little confident
3. Very confident



©UWL / RCN Foundation 2021

20 A compendium describing what intellectual (intellectual) disabilities nurses do would be a useful resource for my practice.

1. Strongly disagree
2. Disagree
3. Not sure
4. Agree
5. Strongly agree

## Final page

That was the last question. We want to thank you again for taking time to participate in this research. We will share with you the findings of this research.

In the meantime, if you have any questions please contact:

Professor Kay Mafuba (Principal Investigator)
College of Nursing, Midwifery and Healthcare
University of West London
Paragon House
Boston Manor Road
Brentford
Middlesex TW8 9GA
Tel: 0208 209 4217
Mob: 0797 363 5793
E-mail: kay.mafuba@uwl.ac.uk



©UWL / RCN Foundation 2021

*Appendix B1* – Participant invitation e-mail

Dear ALL

I am writing to you with regard a study being undertaken by the University of West London, University of Chester, Edge Hill University and Berkshire Healthcare NHS Foundation Trust, and is funded by the RCN Foundation.

The scoping study is being conducted in England, Wales, Scotland, and Northern Ireland. The scoping research focuses on *understanding the contribution of nurses to improve the health and well-being of children, adults, and older people with intellectual disabilities, now and for the future.*

You can be assured that all information collected as part of this research study will be treated in the strictest confidence. **NO PERSONAL INFORMATION** about participants and their organisations will **NOT be identified** in the data collected or in any published results.

If you are willing to participate please **CLICK HERE.**

Thanks very much for agreeing to take part and supporting this very important study.

May we request your assistance and forward this e-mail to all your colleagues and members of your professional networks.

Yours sincerely

Professor K Mafuba



©UWL / RCN Foundation 2021

*Appendix B2:* Invitation letter

**What impact do intellectual (intellectual) disabilities nurses have?**

**RE: Calling on ALL intellectual (intellectual) disability nurses to participate in an RCN Foundation funded research project.**

Dear Colleague,
The RCN Foundation is funding a study which aims to identify nursing led and or nursing centred interventions undertaken by intellectual (intellectual) disability nurses to address the changing needs of people with intellectual (intellectual) disabilities across the lifespan and in all settings. The research will make explicit what intellectual (intellectual) disability nurses do. This research will also highlight areas of further research investment in nursing interventions and innovations that will further improve patient care for people with intellectual (intellectual) disabilities.

We are requesting all registered intellectual (intellectual) disability nurses to participate in a survey to further develop this work. The survey takes 20-30 minutes to complete.
**To complete the survey**, click here. Alternatively copy and paste this link into your internet browser:
https://uwl.onlinesurveys.ac.uk/understanding-the-contribution-of-intellectual-disability

Please forward this e-mail to as many colleagues as you possibly can. If you have any questions please contact Professor Kay Mafuba: kay.mafuba@uwl.ac.uk.

**Title of Study**
*Understanding the contribution of nurses to improving the health and well-being of children, adults and older people with intellectual (intellectual) disabilities, now and for the future.*


©UWL / RCN Foundation 2021

**Investigators**

1. Professor Kay Mafuba (Principal Investigator), University of West London
2. Dr Marc Foster, University of West London
3. Dr Hazel Chapman, University of Chester
4. Dr Joann Kiernan, Edge Hill University and Nurse Consultant, Alder Hey Hospital
5. Rebecca Chester MBE, Berkshire Healthcare NHS Foundation Trust & & Chair United Kingdom Intellectual Disability Consultant Nurse Network
6. Dorothy Kupara, University of West London
7. Chiedza Kudita, University of West London



©UWL / RCN Foundation 2021

*Appendix C*: Consent form

Dear Colleague,

**Title of Study: Understanding the contribution of nurses to improve the health and well-being of children, adults and older people with intellectual disabilities, now and for the future.**

**Investigators: Professor Kay Mafuba** (Principal Investigator), University of West London; **Dr Marc Foster**, University of West London; **Dr Hazel Chapman**, University of Chester; **Dr Joann Kiernan**, Edge Hill University; **Dorothy Kupara**, University of West London; **Chiedza Kudita**, University of West London; **Rebecca Chester**, Berkshire Healthcare NHS Foundation Trust.

Please read and complete this form carefully. If you are willing to participate in this study, then ring the appropriate responses, and sign and date the declaration at the end. If you do not understand anything and would like more information, then please ask.

1. I have had the research satisfactorily explained to me in verbal and, or, written form by the researcher/s. YES / NO

2. I understand that the research will involve an audio taped semi-structured interview lasting approximately 30 minutes. YES / NO

3. I understand that I can withdraw from this study at any time without having to give an explanation. YES / NO

4. I understand that all information about me will be treated in confidence, and that I will not be named in any written work arising from this study. YES / NO

5. I understand that any audiotape material of me will be used solely for research purposes and will be destroyed on completion of the research. YES / NO



©UWL / RCN Foundation 2021

6. I understand that the researcher/s will be completing a report for the RCN Foundation, and publishing papers about this work. YES / NO
   I give my consent to participate in this research study, and have been given a copy of this form for my own information.

Name:…….

Signature: ……

Date: ……..



©UWL / RCN Foundation 2021

*Appendix D:* Networks

| Network | Contact |
|---|---|
| A2A National Network | **Rick Robson**<br>Rick.Robson@sssft.nhs.uk |
| All Wales Senior Nurse Advisory Group (LD) | **Stephen Hughes**<br>Stephen.hughes@nww-tr.wales.nhs.uk |
| National Network for Intellectual Disability Nursing (NNLDN) | **Michael Brown**<br>Michaelj.brown@nhs.net |
| Profound & Multiple Intellectual Disability Networks | **Beverley Dawkins**<br>Beverley.dawkins@mencap.org.uk<br>www.PMLDnetwork.org |
| National Health Facilitation Network | **Mark Bradley**<br>Mark.Bradley@oxleas.nhs.uk |
| Mental Health in Intellectual Disabilities Network | **Steve Hardy**<br>Steven.hardy@kcl.ac.uk |
| National Intellectual Disability & Ethnicity Network | **Bridget Fisher/Pam Smith**<br>Bridget.fisher@arcuk.org.uk<br>www.lden.org.uk |
| National Network for Palliative Care for Children with a Intellectual Disability | **Linda McEnhill**<br>LindaMcEnhill@natnetpald.org.uk |
| National Network for Palliative Care for People with a Intellectual Disability (NNPCPLD) | **Linda McEnhill**<br>LindaMcEnhill@natnetpald.org.uk |
| RCN Intellectual Disability Forum | Anne.norman@rcn.org.uk |
| Nurse Consultants Network | rebecca.Chester@berkshire.nhs.uk |



©UWL / RCN Foundation 2021

| Network | Contact |
|---|---|
| UK Health and Intellectual Disability Network | **Janet Cobb**<br>jcobb@fpld.org.uk<br>www.intellectualdisabilities.org.uk/ldhn |
| UK CAMHS and Intellectual Disability Network | **Janet Cobb**<br>IntellectualDisability@camhs.org.uk<br>www.jan-net.co.uk |
| UK Forensic and Intellectual Disability Network | **Janet Cobb**<br>janet@jan-net.co.uk<br>www.jan-net.co.uk |
| UK Continuing Care Network (Intellectual Disability) | **Janet Cobb**<br>janet@jan-net.co.uk<br>www.jan-net.co.uk |
| UK Epilepsy Network | **Janet Cobb**<br>janet@jan-net.co.uk<br>www.jan-net.co.uk |
| NHS Networks | www.networks.nhs.uk |
| **Regional Networks** | |
| A2A West Midlands Regional Network | **Dawn Harborne /Karen Breese**<br>Dawn.harborne@solihull-ct.nhs.uk<br>Karen.breese@sssft.nhs.uk |
| A2A East Midlands Regional Network | **Marianne Duffy/Laura Summers**<br>Marianne.Duffy@northants.nhs.uk<br>laura.summers@lcrpct.nhs.uk |
| A2A South East Network | **Sarah Lalljee**<br>Sarah.lalljee@sabp.nhs.uk |


©UWL / RCN Foundation 2021

## *Appendix E: Pearson correlations*

| Pearson correlation (r). Sig. (1-tailed) | | Q1 | Q2 | Q3 | Q4 | Q5 | Q6 | Q7 | Q16 | Q17 | Q18 | Q19 | Q20 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Q1 - Age | *r* | 1 | .083 | .682** | .168** | -.007 | -.014 | -.048 | .025 | .032 | .100 | .085 | -.035 |
| | Sig. | | .106 | .000 | .005 | .458 | .418 | .236 | .355 | .314 | .064 | .099 | .301 |
| Q2 - Gender | *r* | | 1 | -.026 | .003 | .074 | -.092 | -.019 | .068 | .013 | .038 | -.076 | -.038 |
| | Sig. | | | .348 | .483 | .133 | .082 | .388 | .154 | .421 | .285 | .126 | .284 |
| Q3 - Experience | *r* | | | 1 | .219** | .007 | .090 | .027 | .056 | .023 | .050 | .059 | -.010 |
| | Sig. | | | | .000 | .456 | .086 | .340 | .200 | .366 | .224 | .188 | .439 |
| Q4 – Qualifications | *r* | | | | 1 | -.037 | .053 | .178** | .085 | .080 | .153* | .148* | -.041 |
| | Sig. | | | | | .290 | .211 | .003 | .098 | .114 | .010 | .012 | .270 |
| Q5 – Professional registration | *r* | | | | | 1 | .093 | -.075 | -.068 | -.076 | .056 | .017 | -.018 |
| | Sig. | | | | | | .080 | .128 | .151 | .124 | .199 | .399 | .395 |
| Q6 – Country of practice | *r* | | | | | | 1 | .125* | -.219** | -.047 | -.126* | -.145* | -.029 |
| | Sig. | | | | | | | .030 | .000 | .239 | .028 | .014 | .332 |
| Q7 – Type of organisation | *r* | | | | | | | 1 | -.112* | .016 | -.025 | .063 | .066 |
| | Sig. | | | | | | | | .045 | .404 | .353 | .169 | .161 |
| Q16 – Understanding of ID nurse roles | *r* | | | | | | | | 1 | .442** | .446** | .389** | .004 |
| | Sig. | | | | | | | | | .000 | .000 | .000 | .475 |
| Q17 – Understanding of ID nurse roles in effectuating nursing procedures | *r* | | | | | | | | | 1 | .562** | .495** | .020 |
| | Sig. | | | | | | | | | | .000 | .000 | .381 |
| Q18 – Understanding of ID nurse roles in enhancing impact of services | *r* | | | | | | | | | | 1 | .528** | .094 |
| | Sig. | | | | | | | | | | | .000 | .078 |
| Q19 – Understanding of ID nurse roles in enhancing quality of life | *r* | | | | | | | | | | | 1 | .059 |
| | Sig. | | | | | | | | | | | | .185 |
| Q20 – A compendium of ID nursing interventions is a useful resource | *r* | | | | | | | | | | | | 1 |
| | Sig. | | | | | | | | | | | | |

**. Correlation is significant at the 0.01 level (1-tailed).



©UWL / RCN Foundation 2021

For further details contact:
Professor Kay Mafuba (Principal Investigator)
College of Nursing, Midwifery and Healthcare
University of West London
Paragon House
Boston Manor Road
Brentford
Middlesex TW8 9GA
Tel: 0208 209 4217
Mob: 0797 363 5793
E-mail: kay.mafuba@uwl.ac.uk

March 2021