Evidence Brief: Learning disabilities

Contents

Produced by the Knowledge Management team Evidence Briefs offer an overview of the published reports, research, and evidence on a workforce-related topic.

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Key publications – the big picture

Learning disability and autism workforce Skills for Care (2021/2022)
This report provides an overview of the adult social care workforce supporting people with learning disabilities and/or autism. This report is based on data from the National Minimum Dataset for Social Care (NMDS-SC). This report shows that were an estimated 665,000 jobs in the adult social care learning disabilities and/or autism workforce in 2017/18. 57,600 were in the local authority sector and 575,000 were in the independent sector.

Interim NHS People Plan NHS, June 2019
Our Interim NHS People Plan, developed collaboratively with national leaders and partners, sets a vision for how people working in the NHS will be supported to deliver that care and identifies the actions we will take to help them. See p. 30 “Tackling the nursing challenge” - “Undertake a detailed review across all branches of pre-registration nursing, including a strong focus on the steps needed in mental health and learning disability nursing to support growth in these areas.”

Learning disability and autism training for health and care staff: a consultation February 2019, Department of Health & Social Care
This consultation considers how we can ensure staff working in health and social care have the right training to understand the needs of people with a learning disability and/or autism and the skills to provide the most effective care and support. All staff can make a difference to the health and wellbeing outcomes of people with a learning disability and autistic people. The 2nd annual report of the Learning Disabilities Mortality Review Programme (LeDeR) recognised this in its sixth recommendation: that mandatory learning disability training should be provided to all staff, delivered in conjunction with people with learning disabilities and their families. The Government published its response to the report on 12 September 2018. In response to recommendation six, the Department of Health and Social Care committed to consulting on mandatory learning disability training for all relevant staff.

NHS Long Term Plan NHS, January 2019
As medicine advances, health needs change and society develops, the NHS has to continually move forward so that in 10 years’ time we have a service fit for the future. The NHS Long Term Plan is drawn up by frontline staff, patient groups, and national experts to be ambitious but realistic. See Chapter 3 “Further progress on care quality and outcomes”. Section 3.3 covers what the Long Term plan says about Learning Disabilities and Autism

Safe, sustainable and productive staffing: An improvement resource for learning disability services NHS Improvement, 2018
This improvement resource for community and inpatient learning disability services has been developed in the context of reducing health inequalities and increasing the life-expectancy of people with learning disabilities, as well as enabling sustainability and transformation plans in the NHS. It is designed to help providers of NHS-commissioned services to develop, review and sustain safe and effective, person-centred specialist health services for people with learning disabilities, who have a wide range of needs and varying levels of disability. It recognises the significance of the context of care due to the many different service models and providers of such services.

Facing the Facts, Shaping the Future: a draft health and care workforce strategy for England to 2027 NHS, December 2017
The NHS needs radical action to improve working conditions, boost training and retention and become a ‘model employer’ for

staff, a report on the future of the health and care workforce has concluded. See p. 64 for "Learning Disabilities"

The adult social care workforce supporting people with learning disabilities and/or autism Skills for Care, December 2018
This report provides an overview of the adult social care workforce supporting people with learning disabilities and/or autism. This report is based on data from the National Minimum Dataset for Social Care (NMDS-SC).

Children and Young People Transforming Care Workforce (CYP TCW) – Report and Recommendations NHS, May 2018
This document is the result of a programme of work commissioned by Health Education England (HEE) to begin to address challenges for the workforce caring for children and young people with learning disabilities (LD), autism (ASD) or both, displaying challenging behaviour. This is a key part of the Transforming Care programme focusing on improving care and support services to enable more people to live in the community, with the right support, and close to home. This work is specifically responding to recommendations 5 and 10 of the review by Dame Christine Lenehan; These Are Our Children2. In short these can be taken as follows:
1. Recommendation 5: To clarify the responsibilities of medical and other professionals for children and young people with a mental health condition, autism, challenging behaviour and/or a learning disability and develop jointly owned guidance.
2. Recommendation 10: To identify skill gaps in respect of caring for children and young people with a mental health condition, autism, challenging behaviour and/or a learning disability.

Building the right support LGA, ADASS and NHS England, October 2015
A national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition.
See also the "Transforming Care" programme.

Learning Disabilities: Meeting Education Needs of Nursing Students January 2015, Council of Deans of Health
This report presents a project by the UK Learning and Intellectual Disability Nursing Academic Network (LIDNAN) and the UK Council of Deans of Health (CoDH) that has addressed the specific question of how to best promote LD competence in other fields of nursing preregistration education. Deans and senior staff of higher education institutions that are members of CoDH were invited to take part in a survey to identify barriers to the delivery of learning disability-related education across all nursing programmes. In addition, the project undertook a literature and policy review and collated good practice examples, highlighting activity being undertaken by HE institutions in relation to learning disability nursing in pre-registration education.

Learning disabilities: making a difference toolkit Health Education England, 2014
Supporting access to health care wherever it is delivered, albeit in the community, at the GP surgery, or in generic hospital services. For many people, accessing the healthcare system remains a frightening experience - they are confronted by new environments, meet unfamiliar people, and don't know what to expect. These fears may be compounded when the person coming into hospital already has other needs, such as a mental health condition, dementia, or a learning disability. Such conditions can affect the person's perceptions or understanding of hospital experiences. This toolkit brings together a range of resources to promote understanding about what it's like to live with a learning disability, allowing healthcare professionals to

adjust the care they deliver and helping people with a learning disability accesses the services they need.

How-to guide 8: training the workforce – for people with profound and multiple learning disabilities Mencap and PMLD network, May 2013
It is based on the following recommendations:
- In fulfilling their responsibilities for developing and training the social care workforce, local authorities should ensure that sufficient numbers of personal assistants are available, trained in person-centred approaches to communication and support that meet the needs of adults with PMLD through training that involves families and adults with PMLD in its delivery.
- Agencies should offer subsidised or free places to families and personal assistants on any training courses they run which are relevant to adults with PMLD. Individual budgets should include provision for training of personal assistants.

Workforce development and people whose behaviour challenges: a review of the evidence Skills for Care/Institute of Public Care, November 2012
This review was commissioned by Skills for Care's Workforce Innovation Programme which explores how people's care and support needs change and how the workforce has to adapt to meet, the challenges that change can present. The key questions that the evidence review aimed to address with reference to people whose behaviour challenges and the social care workforce were:
- What are current reported practices to support workforce intelligence, planning and development?
- What works, and what does not work, in current practice to support workforce intelligence, planning and development?
- What are the key characteristics of effective practice in workforce intelligence, planning and development?
- Is there any relevant international evidence

Using generic role templates for the delivery of learning disability services in a community setting: a how to guide for commissioners and service providers Health Education England (no date)
To support the government's Transforming Care Programme, Health Education England (HEE) has commissioned Skills for Health to identify the components required for the health workforce to deliver effective support to people with learning disabilities in a community setting. The current delivery of community health services to people with learning disabilities across the country is diverse and wide ranging. It is anticipated that this will continue as regions design new and different ways of delivering care and support that has to date often only been available in specialist hospital settings.

Learning Disability Workforce Health Education England, (no date)
Making sure there are the right number of trained learning disability staff, now and in the future.
- Careers in learning disability
- Learning disability nurses
- Allied Health Professionals in learning disability and autism settings

Case Studies

Peter's story: I feel safe and happy NHS Long Term Plan, January 2019
This video case study shows Peter's story about his journey to living independently in the community, and how this has transformed his life.

Health centre makeover helps people with a learning disability and dementia NHS Long Term Plan, January 2019
Vital funding from NHS England has been used to help improve access for people with a learning disability and dementia in Evesham.

Youngsters in Ealing benefitting from an intensive therapeutic and short break service NHS Long Term Plan, January 2019
A service for young people with a learning disability, autism or both is helping keep them at home with their families and communities.

The Star for workforce redesign

More resources and tools are available if you search **"Learning Disabilities"** in the Star

Statistics

You can find relevant statistics on the Health and Care Statistics Landscape under **"Health and Care"** (search for **"learning disabilities"**).

There is also a tool from NHS Digital which covers the "Mental Health and Learning Disabilities workforce in the NHS"

Tools

Social Care Calculator for staffing within a locality based on the level of care that people requiring care packages will need.

Generic staff roles templates – to design new and different roles in learning disability community teams and services. They contain the core skills needed; the relevant competences can be chosen based on the type of role that is being designed. Visit the Learning Disability useful resources page.

An accompanying user guide provides further information.

Transition role templates – to design new roles working with young people in transition from children's services to adult services.

National Data Programme

Workforce, Training and Education staff can look at the National Data Warehouse (NDL) SharePoint site to find out more about datasets and Tableau products.

Published Peer Reviewed Research

Skills and competencies

Building high-quality interpersonal staff-client relationships with people with severe to profound intellectual disabilities and challenging behavior: Insights of professionals and relatives
Journal of Intellectual Disabilities, 2022
The present study reports the perspectives of professionals and relatives on what affects inter-personal staff-client relationships in people with severe to profound intellectual disabilities and challenging behavior. The research makes implicit, practice-based knowledge of professionals and relatives explicit and scientifically underpinned. A thematic analysis of focus groups and interviews with professionals and relatives identified four

principal themes: 1) components of interpersonal relationships, 2) staff factors, 3) involvement of relatives, and 4) context.

Attributional styles of support staff working with people with intellectual disabilities exhibiting challenging behaviour Journal of Applied Research in Intellectual Disabilities, November 2019 *(Athens log-in required*)*
In summary, the results of this study indicate that, in addition to differences in attributions of support staff regarding causal dimensions of three types of CB (i.e. aggressive behaviour, SIB and SCB), attribution styles also differ with regard to these types of CB. It is interesting to note that attributions are likely to shape the behaviour of support staff members, as well as their ideas of possible causes of and preventive options for CB (e.g. Hill & Dagnan, 2002; Stanley & Standen, 2000). Training and coaching support staff to understand their own attributions and related behaviour—and, more specifically, to understand their influence on the existence and maintenance of CB—is therefore likely to help improve the effectiveness of support staff in reacting to CB.

Cultural competence in lifelong care and support for individuals with intellectual disabilities Ethnicity & Health, March 2019 *(Athens log-in required*)*
Five cultural competencies were explored: awareness, knowledge, skills, motivation, and encounters. A thematic analysis of the interviews revealed that professionals providing lifelong care and support used all cultural competencies in their care practices. Moreover, our analysis suggested that these competencies could be categorized as either practical or analytical cultural competencies. Although these competencies were conditional in order to make cultural adaptations to care practices, the presence of cultural competencies did not automatically lead to these cultural adaptations. All five cultural competencies were used by professionals in lifelong care and support. Our analysis revealed that both practical and analytical cultural competencies were essential in providing culturally sensitive lifelong care and support. We additionally suggest that the cultural competence of professionals is necessary, but not sufficient, for making cultural adaptations to lifelong care and support for individuals with intellectual disabilities. In many cases, other factors also played a role in a professional's final decision to adapt their care practices.

What makes generalist mental health professionals effective when working with people with an intellectual disability? A family member and support person perspective Journal of Applied Research in Intellectual Disabilities, May 2018 *(Abstract only*)*
Generalist mental health professionals are inadequately equipped to meet the rights of people with intellectual disability. A better understanding of the attributes of effective professionals may assist in the development of workforce capacity in this area. Twenty-eight family/support persons of people with intellectual disability participated in four focus groups. Thematic analysis was undertaken applying the Intellectual Disability Mental Health Core Competencies Framework. Participants described attributes that aligned with current professional expectations such as working together and new attributes such as differentiating between behaviour and mental health. An unexpected finding was the need for professionals to be able to infer meaning by interpreting multiple sources of information. Participants also wanted professionals to acknowledge their professional limitations and seek professional support. Family/support persons identified a range of attributes of effective mental health professionals to support people with intellectual disability. Further research is necessary, particularly from the perspective of people with intellectual disability.

Workforce development: perspectives from people with learning disabilities Tizard Learning Disability Review, 2018 *(Abstract only*)*

Research into the skills and competencies required by staff working with people with learning disabilities has concentrated on staff views. The purpose of this paper is to explore what people with learning disabilities want from the workforce supporting them. People with learning disabilities value a workforce with a positive attitude, with staff who are skilled in supporting people to gain independence and have a voice. Findings are relevant to staff recruitment, matching of staff to services and staff training. Although there is some previous research around service user views, this evaluation had a larger sample size. The findings were similar to previous studies, particularly around the kind of qualities required from staff, which were the ability to listen, have trust and be able to learn specific skills. Although the highest representation was from young people and young adults, participants ranged from 12 to over 65 years. Differences in views according to participant age ranges are also noted.

Establishing core mental health workforce attributes for the effective mental health care of people with an intellectual disability and co-occurring mental ill health Journal of Applied Research in Intellectual Disabilities, December 2017 *(Abstract only*)*

People with intellectual disability experience high rates of mental ill health but multiple barriers to access to quality mental health care. One significant barrier to access is a generalist mental health workforce that lacks capacity, and consensus on what constitutes core workforce competencies in this area. As such, the first step in developing a comprehensive strategy that addresses these barriers is to define the core mental health workforce attributes. The results highlighted specific attributes in all areas of clinical practice, especially for communication (e.g., utilizes assistive communication technology), assessment (e.g., assess contributing factors to behaviours) and intervention (e.g., uses integrative interventions). A comprehensive strategy is required to facilitate the generalist mental health workforce to obtain these attributes.

Development and dissemination of a core competency framework Journal of Mental Health Training, August 2017 *(Abstract only*)*

The purpose of this paper is to describe and critique the methodology used to develop a core competency framework for mental health professionals working with people with an intellectual disability and co-occurring mental ill health. This framework can be utilised by mental health workers including clinicians, managers, service developers, and educators, from multiple professional backgrounds. The approach taken can also be used by others to develop similar frameworks. This is the first core competency framework, to the authors’ knowledge, specifically designed for public mental health professionals from varied backgrounds working with people with an intellectual disability. Consulting with multiple stakeholders, not just experts, elicited new information that may otherwise have been overlooked.

Demographics and trends

What encourages care workers to continue working in intellectual disability services in England? Interview findings Journal of Intellectual Disabilities, March 2021 *(Abstract only*)*

The article reports research aimed at identifying factors relating to retention in English intellectual disability services, drawing on a study of the social care workforce. The research involved two rounds of interviews with social care managers and staff between 2009 and 2014. The study uses social exchange theory, particularly the idea of 'reciprocity' and the mechanism of 'hope', as a conceptual framework to aid interpretation of the themes relating to retention identified in the interview analysis: 'pay', 'support', 'morale', and 'training' (related to reciprocity) and 'improving quality of life' and 'supporting personal development' (related to hope). Both groups of themes are identified as being particularly appropriate to intellectual disability services. The study concludes that reciprocity and hope seem to interact in factors related to staff retention, although the study suggests that reciprocity rather than hope is directly connected with retention.

Strategies to boost the mental health and learning disability nursing workforce British Journal of Nursing, February 2021 *(Abstract only*)*
Emeritus Professor Alan Glasper, from the University of Southampton, discusses two recent policy reports which indicate a potential crisis in mental health and learning disability nursing.

Building workforce capacity in Australia and New Zealand: a profile of psychiatrists with an interest in intellectual and developmental disability mental health Australasian Psychiatry, December 2018 *(Abstract only*)*
To describe the characteristics of psychiatrists working in the area of intellectual and developmental disability mental health (IDDMH) across Australia and New Zealand. A secondary analysis of data collected by the Royal Australian and New Zealand College of Psychiatrists 2014 workforce survey. Characteristics of the IDDMH workforce (n=146 psychiatrists) were compared with those of the broader psychiatry workforce (n=1050 psychiatrists). The IDDMH workforce were more likely than the broader psychiatry workforce to be working across both the public and private health sectors, be engaged in outreach work, endorse specialty practice areas pertinent to IDDMH, treat younger patients and work more clinical hours per week. Part-time status and retirement plans of the IDDMH workforce matched those of the broader psychiatry workforce. While some elements of the IDDMH workforce profile suggest this workforce is tailored to the needs of the population, the potential shortage of IDDMH psychiatrists highlights the need for the development of a specific training programme and pathway in this area.

The adult day care workforce in England at a time of policy change: implications for learning Journal of Intellectual Disabilities, June 2010 *(Abstract only*)*

More people will receive personal budgets to pay for social care services in England. Such people may or may not continue using services such as adult day care centres. Many day centres are under threat of closure. These trends will affect those working in adult day care. This article examines the profile of this workforce, using recent NMDS-SC data and applying multinomial statistical modelling. We identified nearly 6000 adult day care workers, over half supporting adults with learning disability. The results of the analysis show significant variations between the adult day care, residential care and domiciliary workforces. At the personal level, day care workers are significantly older and less ethnically diverse than other workers. They tend to have been working in the sector for longer, and their work patterns are more stable. The findings are discussed within the context of policy changes affecting learning disabilities and social care workforce strategies.

When a workforce strategy won't work: critique on current policy direction in England, UK Journal of Intellectual Disabilities, December 2010 *(Abstract only*)*

This editorial is based on findings from a regional review of educational commissioning, and workforce issues for one Strategic Health Authority in England. Known as the ‘Valued People Project’ (VPP) it commenced in May 2008 and was undertaken in response to expressed concerns by regional key stakeholders regarding education commissioning specifically of pre-registration learning disability nursing, and the contribution of the specialist learning disability health workforce more generally

(Gates, 2009). This work was also undertaken as a consequence of the scale and cumulative effect of changes to education, workforce, professional regulation
and central health and social care policy that has affected people with learning disabilities and the services and personnel that support them.

Support workforce

Training support workers about the overmedication of people with intellectual disabilities: an Australian pre–post pilot study Journal of Intellectual Disability Research, March 2023 *(Athens log-in required*)*
This study showed that staff knowledge of psychotropic medications can be increased, and retained, using a targeted and specialised training programme. Future research should continue to explore ways that staff training in this area can be enhanced in a way that translates to positive change at the practice level and leads to better outcomes for people with IDs.

Do Degrees Matter? Rethinking Workforce Development for Youth with Intellectual Disabilities and Mental Health Challenges, Global Implementation Research and Applications, March 2023 *(Athens log-in required*)*
In this era of workforce shortages, regardless of reason, task-shifting strategies have become more accepted practices across all human service disciplines (Rotheram-Fuller et al., 2017). However, it is yet to be determined if task shifting will be fully embraced by hierarchical systems designed to organize the workforce based on degree completion. Future research should examine the role of education but also staff background when adopting deviations to EBP models for specific population needs. While formal education explains some differences in core knowledge variation, it may also influence knowledge acquisition of trained materials and implementation of EBP adaptations. In addition, further exploration of informal education and experience should also be examined to determine their impact on training protocols. Lived experiences with family members, relatives, or friends with an intellectual disability, past volunteering experiences, and prior work in parallel fields may prove useful when educating and implementing EBP adaptations in the field. For instance, studies have shown that paraprofessionals learn and effectively implement EBP strategies when working in classrooms with students with Autism (Sam et al., 2022). Individuals with such backgrounds may possess a higher knowledge of EBPs and implement modifications more effectively or require less guidance given their prior experience. All of these factors offer a more comprehensive understanding of staffing factors that influence implementation of adaptive EBPs models.

Perspectives on delivering health promotion for the intellectual disability population British Journal of Nursing, June 2022 *(Abstract only*)*
The qualitative study reported in this article set out to develop an understanding of how staff supporting individuals with intellectual disabilities deliver health promotion in their practice. The aim was to determine how social care managers working within an intellectual disability care setting in Ireland perceived health promotion and their role within it. Semi-structured interviews were conducted to collect the data. Participants perceived health promotion to be a priority for this population group that should be tailored to meet individual needs. Study participants recognised that they have a role in supporting and providing health promotion for this population, but also that they themselves required more training and education on the issue. Health promotion enablers identified in the study for this client group need to be enhanced and ways to reduce the barriers to access identified. The results reflect observations reported in the literature and indicate a need to prioritise health promotion with

this population by establishing policies and practices in the organisation to promote it. A requirement for relevant training and education for social care managers—and other staff, as appropriate—was identified, as were areas for further research.

How Implementation of Cognitive Assistive Technology in Home-Based Services for Young Adults with Intellectual Disabilities Influences Support Staff`s Professional Practice Journal of Intellectual Disabilities, April 2022
The implementation of technology in home-based services takes place in contextualised socio-material practices negotiated through interactions between a diversity of actors. Prerequisites for succeeding in this process are time and competence, and that use of the technology is experienced as meaningful, for both the support staff and the resident. In this article, we investigate how implementation of cognitive assistive technology (CAT) in home-based services for young adults with intellectual disabilities influences the support staff`s professional practice. The participants are eight support staff members, five women and three men. Data were collected through two group interviews, the second one 8 months after the first one. The data were analysed according to a systematic text condensation (STC) approach. Implementation of CAT is a demanding process, revealing different perspectives on professionalism and changing power relations, and entails a new way of working for the support staff.

The Nuts and Bolts of Health Care: Evaluating an initiative to build direct support professional capacity to support the health care of individuals with intellectual disabilities Journal of Applied Research in Intellectual Disabilities, March 2022 *(Athens log-in required*)*
This study has demonstrated the value of a collaborative approach to improve DSP capacity to support the health and health care of people with intellectual disabilities through training, health care communication tools and resources. Although change is always difficult, the implementation process was supported by extensive DSP engagement and involvement in the process. Incorporating resources into DSPs' workflow was important for successful uptake. The primary barrier encountered was perceived resistance of health care providers. An important next step is to work together with all stakeholders, including DSPs, people with intellectual disabilities and health care providers, to ensure the tools are valuable and feasible for everyone involved in the health encounter. System level changes are also needed to ensure DSPs and health care providers operate within a system that facilitates their roles in supporting the health care of individuals with intellectual disabilities. Finally, a culture shift is necessary to fully empower DSPs to reimagine their role as health care facilitators and be acknowledged as an important member of the health care team.

Experiences of mental health professionals providing services to adults with intellectual disabilities and mental health problems: A systematic review and meta-synthesis of qualitative research studies Journal of Intellectual Disabilities, June 2021 *(Athens log-in required*)*
This paper focused on the experiences of MHPs providing services for adults with intellectual disabilities and mental health problems. Findings of the meta-synthesis identified three main themes: (1) understanding the person beyond their diagnoses (2) therapeutic relationship and interactions with people with intellectual disabilities when working with them and lastly (3); organisational barriers and recommendations to improve the mental health services to this population.

MHPs reported that mental health symptoms were sometimes misattributed to their clients’ intellectual disabilities and not promptly treated. Reiss et al. (1982) termed this misattribution bias ‘diagnostic overshadowing’ which may influence the treatment of adults with intellectual disabilities and may lead to negative perceptions or stigmatising attitudes towards them (Jopp and Keys, 2001).

Due to the complexity of presenting problems, MHPs reported taking longer and needing more resources when working with people with intellectual disabilities, which they did not often have, especially when working in mainstream services. As a result, they were at times overwhelmed and MHPs acknowledged that psychotropic medication is often used as the first treatment of choice. Some MHPs may view the mental health problems solely from a medical treatment model perspective and consider the problem to lie with the person with intellectual disabilities for being unable to adjust to their environment (Williams and Heslop, 2005). This may explain the feelings of frustration when MHPs struggle to make progress and lead them to view their clients as untreatable.

Staff member's views and attitudes to supporting people with an Intellectual Disability: A multi-method investigation of intimate relationships and sexuality Journal of Applied Research in Intellectual Disabilities, May 2021 *(Athens log-in required*)*
Multidirectional significant differences were noted on staff attitudes to sexuality based on demographic factors, that is, age, education, as well as non-demographics, for example, attendance at training, and active practising of religion. Qualitatively, three themes emerged: “Unsupported and Frustration”; “Taboo Subject Matter” and “Vulnerability and Access to Education”. Staff reported a lack of service supports, dominant conservative cultures and people with an intellectual disability's vulnerability.

Outcomes and costs of skilled support for people with severe or profound intellectual disability and complex needs Journal of Applied Research in Intellectual Disabilities, January 2021 *(Athens log-in required*)*
In this paper, we explore the impact of consistently good active support on a wider range of quality of life outcomes for people with severe intellectual disability and complex needs than had previously been explored. In addition, we wanted to look at, for the first time, whether working in this way was likely to require more resources than not doing so.

Direct support workforce supporting individuals with IDD: current wages, benefits, and stability Intellectual and Developmental Disabilities, October 2014 *(Abstract only*)*
Direct support professionals (DSPs) and frontline supervisors (FLSs) play an integral role in the lives of people with intellectual and developmental disabilities (IDD) and are often the individuals directly responsible for assisting people with IDD to live and fully participate in their communities. These two groups of workers have typically been employed at lower wages with limited access to fringe benefits, contributing to high rates of turnover compared to a similarly skilled worker in the United States. This article summarizes findings and is the first investigation in several years to systematically examine the wages, fringe benefits, and stability of the DSP and FLS workforces supporting individuals with IDD. Findings suggest that a typical DSP may expect to earn about $11.25 per hour, while FLSs may expect wages of about $15.45 hourly. Of concern, however, is that fringe benefit provision was quite limited in this sample. Implications, including relation to past reports of DSP workforce development, are discussed.

Status and trends in the direct support workforce in self-directed supports Intellectual and Development Disabilities, October 2010 *(Abstract only*)*

Self-directed programs that allow individuals with intellectual and developmental disabilities to exercise greater control over their finances have become increasingly common in recent years. At the same time, challenges in the recruitment, retention, and training of direct support workers in the field have grown more acute. In this article, the authors investigate the status of the direct support workforce for people using self-directed supports in 1 Midwestern state, based on the results of a statewide survey of service users. Although additional research is needed, the results of this study suggest that people who use self-directed funding options are satisfied with their ability to direct staffing, though challenges remain. Among these challenges, the presence of higher than expected wages but lower than expected benefits provision compared with traditional services may have serious policy and staff retention ramifications that affect the long-term viability of self-directed funding options. In addition, staff training remains a challenge, with service users in this sample reporting low rates of training beyond a general skill set. Implications of these findings are discussed.

Leadership

Practice Leadership at the Front Line in Supporting People with Intellectual Disabilities and Challenging Behaviour: A Qualitative Study of Registered Managers of Community-based, Staffed Group homes Journal of Applied Research in Intellectual Disabilities, May 2016
The front-line management role in services for people with intellectual disabilities remains rather under-researched. The aim of this study was to examine the experiences of registered managers in services for adults with intellectual disability who exhibit challenging behaviour. Five groups of themes emerged: monitoring staff performance, supporting new ways of working, shaping staff performance, influence of external and employing agencies, and importance of participants' personal values and experiences. The themes identified contribute to a conceptual framework for thinking about front-line management/practice leadership. The limitations, and potential implications, of the findings are discussed.

Education and training

Access, understanding, promotion and maintenance of good health: Evaluation of knowledge transfer of people with intellectual disabilities to bridge the health information and disease prevention in public health Frontiers in Public Health, September 2022 *(Athens log-in required*)*
The importance of patient empowerment among people with intellectual disabilities (ID) is steadily growing, yet multiple health and health literacy challenges still make this population more vulnerable to health disparities. Inadequate access to essential health and other basic services and the lack of involvement in health and educational research are some of the most crucial factors contributing to this inequality. A greater effort must be made to include people with ID in health literacy and communication research, preliminary focusing on language, including pictorial language. This community case study aimed to document the experiences of answering a pilot questionnaire to evaluate the problems of people with mild to moderate ID, 6A00.0 and 6A00.1 according to ICD-11. Our results show that most patients acquire health information from their physician or a medical professional. In preparing appropriate questionnaires, special education teachers can give valuable insight. However, participants were easily distracted and needed support in focusing on the questionnaire. Easy-to-read language, a simple format, big fonts and the presence of confidential caretakers are needed. This indicates, that semi-structured interviews with a trained interviewer might be most suitable for measuring the knowledge transfer of people with ID. The results of this case study highlight the need to develop an appropriate questionnaire and emphasize the need for a continued dialogue between people with ID and healthcare providers.

Training Healthcare Professionals to Work With People With Intellectual and Developmental Disabilities Intellectual and Developmental Disabilities, December 2021 *(Athens log-in required*)*
Ultimately, to become fully competent in treating people with disabilities, it may be necessary to experience both hands-on clinical training and specific, disability-related didactics. This combination recalls a classic idea, borrowed from the world of cognitive psychology, of how many human achievements feature both a “hot” (i.e., emotional, affectively laden) and a “cold” (intellectual, cognitive) component (Lepper, 1994). In this case, comfort might be considered the hot or emotional component, the one most fostered by increased contact and experience. But aspects of cold components might also operate when providing healthcare to people with disabilities; it might also be important to take classes, attend talks, and in other ways receive IDD-specific information. Additional continuing-education resources that could further knowledge of people with disabilities include tip sheets, modules, and/or webinars. Each provides initial interaction tips, appropriate communication, and common misconceptions to foster health professionals to have positive experiences with these patients. Many national and international initiatives already exist to provide professionals with beginning information as it relates to healthcare for people with disabilities (Smith et al., 2020). Such initiatives, however, are probably not widely known by most community-based healthcare professionals.

Supporting the delivery of good maternity care for parents with learning disabilities Midwifery, November 2021 *(Athens log-in required*)*
This study contributes to our understanding of ‘good practice’ in maternity care for parents with learning disabilities through the views and experiences of parents with learning disabilities, their informal supporters/carers, and the health and social care professionals who support them. Building on this understanding, resources to support the workforce to deliver good maternity care to parents with learning disabilities were co-produced, piloted and are free and accessible for use [https://www.surrey.ac.uk/research-projects/together-project-supporting-delivery-good-practice-maternity-services-parents-learning-disabilities]. Further evaluation will explore acceptability and perceived impact of these resources in maternity services.

Caring for Persons With Intellectual Disabilities and Challenging Behavior: Staff Experiences With a Web-Based Training Program Frontiers in Psychology, January 2021 *(Athens log-in required*)*
The benefits of web-based training for workplace learning clearly included the strengthening of professional care for persons with IDs and CB. The staff claimed to have gained novel insights about how to care for clients as well as about the importance of interaction in encounters with their clients. For instance, they allowed themselves to take a step back, giving clients the room and time to express themselves when they were experiencing an emotional outburst.

Our findings illustrate the complexity of providing staff training for the workplace through web-based training program. Beyond the benefits of web-based training for workplace learning, some challenges also emerged. We conclude that web-based training, workplace organization, and individuals' opinions each have an important impact on the learning outcome. To reach the best possible outcome, however, resources need to be invested in all three parts concurrently. This knowledge can contribute to the development of competence provision in municipal health and social care services more generally, where similar circumstances in terms of a notable downward trend in competence provision prevail, a pattern which could ultimately jeopardize the quality of care.

Supporting people who need care and support to have meaningful and safe relationships Skills for Care, 2021
Skills for Care and Supported Loving have developed a package of training materials to help social care employers develop the skills and knowledge needed to support people who draw on services with personal relationships.

The training resources have been developed for social care training providers and in-house training departments of social care employers to use to embed learning around supporting the personal and sexual relationships of people drawing on care and support.

Staff training in positive behaviour support for behaviour that challenges in people with intellectual disability: cost-utility analysis of a cluster randomised controlled trial BJPsych Open, March 2020 *(Athens log-in required*)*
This study adds to the evidence base for the cost-effectiveness of health staff training in PBS to treat adults with intellectual disability who display behaviour that challenges. Despite the lack of clinical effectiveness, there was a positive impact on health-related quality of life and less burden on informal care as shown by the sustained reduction in hours of care over time in the intervention arm. Decisions about health resource allocation should be based on the relative benefits and costs of interventions although these cannot be the sole criteria used. In light of the study finding that staff training in PBS did not reduce challenging behaviour above TAU, it is essential that services, trainers and policymakers reach consensus as to whether PBS ought to be delivered by specialists or whether other ‘light touch’ approaches may be acceptable. Despite the 85% probability of being cost-effective at £30 000 WTP per QALY gained, training in PBS is unlikely to tackle serious organisational barriers that practitioners need to overcome if PBS skills are to be properly implemented.

Best Practice Principles When Working With Individuals With Intellectual Disability and Comorbid Mental Health Concerns Qualitative Health Research, March 2020 *(Abstract only*)*
Working with individuals with dual disabilities can be a complex process in the presence of limited evidence base to guide clinical practice. The aims of this qualitative study were to investigate perceptions of best practices of Australian psychologists who work with this specialist population. Thirty-eight Australian psychologists working in the intellectual disability field participated in eight semistructured focus groups. Perceptions of evidence-based practice for individuals with intellectual disabilities and in relation to mental health assessment were explored. Psychologists demonstrated resourcefulness in adapting to limits in available evidence-based practice and in modifying mainstream practice to suit the needs of individuals with dual disabilities. Findings suggest the necessity of practice-based evidence in contributing to the evidence base, and person-centered approaches in relation to best practice for people with intellectual disabilities. Implications for strengthening psychologists' clinical competency and bridging the research and practice gap are discussed.

The impact of behavioural skills training on the knowledge, skills and well-being of front line staff in the intellectual disability sector: a clustered randomised control trial Journal of Intellectual Disability Research, May 2019 *(Abstract only*)*

Staff with varying backgrounds and educational qualifications can be effectively trained to implement procedures in line with evidence-based practice. Behavioural skills training (BST) is a competency-based training model used to effectively educate a broad selection of professionals, including front line staff, in a range of work-related skills. However, BST has yet to be evaluated in a large group-based experiment.

Participants in the intervention condition demonstrated statistically significant improvements in their knowledge scores over the study period. Participants in the control condition showed no change or a statistically significant decrease in their knowledge scores. No statistically significant changes to well-being were observed for either group. There was clear evidence of knowledge maintenance, as well as skill acquisition and subsequent generalisation to the workplace environment, among participants in the intervention condition. Participants also evaluated the BST intervention positively. Results support BST as a method for disseminating evidence-based practice to front line staff working with adults with intellectual and developmental disabilities.

Trainer and support staff experiences of engaging with the Who’s Challenging Who? challenging behaviour training course Journal of Intellectual Disabilities, 2019 *(Athens log-in required*)*
Being trained by people with ID and CB appears to encourage support staff to reflect on their own practice, and the impact that they have on the behaviours of the people they support. The trainers with ID saw both material and personal benefits from working as expert trainers, both of which were of great value to them. There were some discrepancies between how the trainers and trainees perceived the role of the trainers as experts, and this incongruence may undermine the impact of having valued contact with people with ID to engender attitude change, a core principle of Contact Theory (Allport, 1954) and an important aspect of the WCW training. Efforts must be made to counteract this perception, and to place greater value on the expertise of people with ID about their care and support provision, in line with current policy recommendations (Department of Health, 2012).

Peer support systems and professional identity of student nurses undertaking a UK learning disability nursing programme Nurse Education in Practice, May 2018

This practitioner-based action research examines the implementation of the peer assisted study scheme (PASS) and individual peer mentoring in a cohort of first year undergraduate nursing students. It arose out of the desire of a small number of students in one UK university to transfer from the learning (intellectual) disabilities nursing field to other fields. The number of learning disabilities nurses is falling in England, and nursing shortages and student nurse retention generally is an international concern. The peer support was evaluated by 21 completed questionnaires. All the students had found the sessions they attended useful. Four themes emerged from the study. Students reported gains in knowledge around academic skills, placements and their chosen field of nursing; students felt more confident as a result of attending the sessions; students felt supported, and the importance of the peer mentor's interpersonal skills was highlighted; and finally students had valued meeting other students in their chosen field. These findings are discussed with reference to relevant literature.

Intellectual disability health content within nursing curriculum: An audit of what our future nurses are taught Nurse Education Today, October 2016
Individuals with intellectual disability experience chronic and complex health issues, but face considerable barriers to healthcare. One such barrier is inadequate education of healthcare professionals. Despite significant unmet health needs of people with intellectual disability, there is considerable variability in the teaching of key intellectual disability content, with many gaps evident. Equipping nursing students with skills in this area is vital to building workforce capacity.

Models of care

Intensive support teams for adults with intellectual disabilities displaying challenging behaviour: the IST-ID mixed-methods study Health and Social Care Delivery Research, November 2022
The study describes the operation of intensive support teams in England and identified two distinct models. We did not find advantages or disadvantages associated with clinical outcomes between models, nor did we find cost differences. On this basis, we recommend that local services decide which model best suits their circumstances.

Relationships and power: An exploration of person-centredness in an intellectual disability service in Ireland Health & Social Care in the Community, October 2022 *(Abstract only*)*
This study aims to explore how adults with intellectual disability living in residential services and staff experience the professional caring relationship and the framework of person-centredness. The study was based on a phenomenological approach using thematic analysis which enabled six adults with intellectual disability and six staff to participate through one-to-one interviews. The thematic analysis resulted in three main themes: (1) Conflict within the relational dynamic between service users and staff. (2) Challenges to delivering person-centred care. (3) Shared needs. Participants reported that there was conflict within the relationship between service users and staff influenced by relational and cultural issues. Participants also experienced challenges in delivering person-centred care within the service. This study revealed that as a result of wider organisational and cultural influences, person-centred cultures, which are vital to underpin changes in power imbalances, were often undermined. This research highlights that it is not enough to have a system of quality of care guided by the principles of person-centredness alone to ensure a shift in culture and safeguard against abuse of adults with intellectual disability. Rather, consideration of the relational and cultural factors that impact their lives also needs to be built into the values and practices of services offered to adults with intellectual disability.

A model for fostering community capacity to support adults with intellectual disabilities who engage in challenging behaviour: A scoping review Journal of Intellectual Disabilities, July 2022 *(Abstract only*)*
Developmental support agencies support many adults with intellectual disabilities in the community. Unfortunately, these adults often exhibit high rates of challenging behaviou, which present significant pressures on these service providers. Agencies need to develop effective means of increasing their capacity to provide quality support. Previous systematic reviews found that training staff in positive behaviour supports can improve outcomes; however, the factors facilitating training's effects, long-term effectiveness, and outcomes for service users have yet to be determined. We conducted a scoping review of 98 journal articles and book chapters to develop a model for fostering capacity development drawing from Organizational Behaviour Management and Knowledge Translation theories. Some relevant factors include features of the inner and outer organizational contexts, training approaches (e.g., behavioural skills training & in-situ coaching), ongoing support and feedback. This model may lead to more effective and enduring treatment programs and improved support for adults with intellectual disabilities.

Setting up a new team of support staff for people with mild intellectual disability or borderline intellectual functioning and severe challenging behaviour: A concept mapping study Journal of Applied Research in Intellectual Disabilities, 2022
The aim of this study was to identify what service users, support staff, and supporting professionals consider important when

setting up a new team of support staff for service users with mild intellectual disability or borderline intellectual functioning and co-occurring psychopathology, who display severe challenging behaviour, when an orthopedagogical approach is used. To this end, we generated and described a concept map for each group. The concept maps were based on the statements that every group gave, clustered and prioritised. All three participant groups mentioned factors that referred to the relation between the service user and support staff. More specifically, they all named characteristics that support staff should have to enhance feelings of safety and trust among service users. For example, they reported that support staff need to be experienced (life as well as work experience), confident, have a low level of expressed emotions (e.g., show no fear), and stay calm in case of tension. These characteristics are in line with research about support to service users with intellectual disability who display challenging behaviour (Nijs et al., 2021; Willems et al., 2016). Nearly all the statements of service users applied to activities and interpersonal relations with a direct impact on the service user, described by Bronfenbrenner as the microsystem (Bronfenbrenner, 1994). On the other hand, few statements from support staff related to their direct relationship with service users. Next to staff and team characteristics, support staff hardly mentioned any other statements about the service users' microsystem. Their statements mainly referred to the relation between support staff with each other and with supporting professionals, and to preparations that should be made. In other words, support staff especially highlighted factors in the mesosystem (Bronfenbrenner, 1994). Statements of supporting professionals concerned both the microsystem and mesosystem, but also the exosystem (i.e., social relations that involve people who do not regularly interact with service users, such as interactions between upper management and support staff; Bronfenbrenner, 1994). Taken together, the three groups came up with different kinds of statements, all from their own angle. This underlines the relevance of involving different participant groups in research. Overall, our results confirm outcomes of research that it is important to invest in building relationships between service users and support staff (e.g., Nijs et al., 2021; Olivier-Pijpers et al., 2020a). This includes respect, trust, and getting to know each other well. Our study adds to previous studies that organisations should invest in building relationships from the start. Next to this overall finding, we will highlight four core outcomes into more detail.

Development and psychometric properties of a team formulation measure in intellectual disabilities services Journal of Applied Research in Intellectual Disabilities, May 2020 *(Athens log-in required*)*
This article describes the development and use of the Formulation Understanding Measure to evaluate team formulation with staff supporting people with intellectual disabilities. A quantitative design with an opportunistic sample was used to evaluate the psychometric properties of the Formulation Understanding Measure (FUM) including pre- and post-administration at case formulation workshops. The measure was developed based upon experience of delivering case formulation workshops and was administered alongside case formulation workshops with 347 staff team members. The measure was found to have acceptable psychometric properties with good internal reliability, a single principal component, and associations with training and demographic factors. It was also sensitive to changes resulting from case formulation workshops with the measure showing that staff increased in their understanding of the person with intellectual disability following a formulation workshop.

Intensive support for adults with intellectual disability and behaviours that challenge: a survey of provision and service

typologies in England BJPsych Open, March 2020 *(Athens log-in required*)*
The study describes a comprehensive survey of ISTs for adults with intellectual disability and/or autism and behaviours that challenge in England and obtained a high completion rate (91%). It expands on recent data of intensive services produced by the NHS Benchmarking Network Learning Disabilities (NHSBNLD)17 contributing to an invaluable insight into IST eligibility criteria, staff mix, interventions and other domains considered important to the functions of an IST. The study also has limitations, including being subject to possible respondent social desirability bias. We may have omitted other elements of functions relating to ISTs that could be of importance but not captured in the survey. For example, we did not ask specifically about integration with other local mental health services, gatekeeping role, information sharing or record keeping. Finally, the teams surveyed were those identified during screening and potentially, we may have over/under-ascertained ISTs and therefore the typology may lack precision. As a result of the data available we were only able to include six variables in the cluster analysis. We argue that the resulting typology has an empirical basis and clinical face validity based on clinician experience of such services. However, it has no theoretical basis on literature relating to intellectual disability but has largely adopted functions and indicators from existing literature on mental health crisis care. This may account, to an extent, for both the substantial overlap as well as the variation between clusters on some of the variables.

Models of community based integrated care for people with a learning disability and/or autism: evaluation findings from a national implementation programme International Journal of Integrated Care, August 2019 *(Abstract only*)*
In 2015, following successive scandals relating to abuse and poor quality of care, the NHS in England initiated the Building the Right Support national plan, which sets out an integrated service model to reduce dependence on hospital care. Local partnerships were established to oversee integrated working between health and social care commissioners, and specialist and community providers of care, support and housing, so that people could be supported closer to home. To understand the implementation process a national, three year evaluation was commissioned by NHS England to identify good practice, and understand the success factors and barriers that lie behind consistent implementation of the service model. The evaluation has directly engaged people with lived experience and their families through workshops and focus groups and has also sought perspectives from local and national representative groups and forums. We found that despite common endorsement of the integrated service model: There are continued gaps in care and support: receiving integrated care was not a common experience of most people and their families. Autistic people with mental health conditions, and children, are particularly poorly served. Many more people than expected remain dependent on hospital care. Implementation difficulties arose in areas that did not have a shared understanding of what was required to introduce the service model and a willingness to collaborate differently to achieve it. Conversely, local areas that had inherited and/or sought to develop a shared culture and trustbased relationships between commissioners and providers (as opposed to transactional ones) were most successful. Good quality co-design is critical to implementation, so that the priorities of local services match the needs of people and their families. The time and effort required for this was not usually prioritised, despite national and local commitments to do so. Progress in implementing the model after the end of the formal programme period in March 2019 is at risk due to constrained budgets (especially in social care), recruitment and retention difficulties within the care workforce, and a loss of momentum, should the policy focus change. Therefore, while the service

model is based on a widely supported model of integration, the blend of incentives, guidance, resources and compulsion has not led to consistent implementation. Honest appraisal of the scale of cultural and societal change required was somewhat overlooked, especially regarding ways that national and local bodies could work together to fund, manage and evaluate care.

Report of a mixed methods systematic review of literature to inform the development of 'sustainable safe staffing' improvement resource in learning disability (LD) services for NHS Improvement NHS Improvement, 2016
Without an appropriate service model of healthcare provision that includes clear healthcare policy implementation strategies, clearly defined professional roles, clearly defined collaboration or integration arrangements and meaningful stakeholder and service user engagement processes; sustainable, safe and effective care may very well be difficult to achieve. It is also imperative that healthcare providers have clear standards of care that incorporate processes for understanding of the context of care, delivery of effective care, facilitation of effective communication, and care evaluation to ensure high standards of care. The importance of how healthcare providers deploy resources cannot be emphasised. Healthcare providers need to ensure that processes for managing resources, systems for developing professional competence, and implementation of values-based recruitment and retention strategies are in place for sustainable, safe, effective and efficient staffing to be achievable.

Nursing

Co-design and delivery of a relational learning programme for nursing students and young people with severe and complex learning disabilities Nurse Education Today, December 2022 *(Athens log-in required*)*

A co-designed programme for nursing students and young people with severe and complex ILDs can benefit student knowledge and skills and reduce fears and anxieties between nurses and young people with ILDs. With adequate planning and resources, the programme could be adopted by multidisciplinary partnerships between other universities and special schools.

Supporting women with learning disabilities in infant feeding decisions: UK health care professionals' experiences Maternal & Child Nutrition, September 2022 *(Athens log-in required*)*
The findings of our interviews with health professionals suggest that women with learning disabilities can make and put into practice infant feeding decisions if they have access to the right support at the right time. Health professionals may have a crucial role in viewing themselves as part of the woman's support network and adopting a genuine person-centred approach when providing support. The necessity to challenge cultural and historical ideas and conceptions continues, particularly it appears with regard to breastfeeding being considered a viable option for all women. Our study suggests one challenge in discussing infant-feeding choices early in pregnancy might be due to competing priorities along with limited accessible resources. Our recommendation is to develop a suite of resources to enable a more flexible and individualised approach to supporting women to make infant-feeding decisions.

Developing curricular-content and systems-related impact indicators for intellectual disability awareness training for acute hospital settings: A modified International Delphi Survey Journal of Advanced Nursing, July 2022 *(Abstract only*)*
This is the first international Delphi survey to agree on curricular-content and identify systems-related facilitators for intellectual disability awareness training. Potential system barriers have been highlighted which could be addressed by systemic improvement. Implications for developing, and robustly testing

the efficacy of, intellectual disability awareness training programmes are discussed, as are the implications for other cognitively impaired populations. In order to maximize the impact, investment in acute hospital staff education will need to be accompanied by wider changes to systems and structures concerning the governance of service provision for people with an intellectual disability.

Nurses' attitudes and emotions toward caring for adults with intellectual disability: An international replication study Journal of Nursing Scholarship, February 2022 *(Athens log-in required*)*
Negative attitudes of health care providers have been suggested as an implicating factor in health inequities (Scior, 2011), including the belief among some nurses that a life lived with intellectual disability is not worth living (Michael & Richardson, 2008). Knowledge about and familiarity with people with intellectual disability can help to reduce negative perceptions of people with intellectual disability amongst health care professionals; however, some nurses have reported a lack of contact and subsequent unfamiliarity with adults with intellectual disability (Applegren et al., 2018). Furthermore, some nurses have reportedly held stereotypical perceptions of adults with intellectual disability as being non-compliant or uncooperative with treatment, exhibiting aggressive behavior, or being easily distressed when receiving care (Lewis & Stenfert-Kroese, 2010). Nurses have reportedly lacked confidence and experienced more stress about caring for adults with intellectual disability compared to caring for people with a physical disability only or people with no disability at all (Lewis & Stenfert-Kroese, 2010). A lack of knowledge about people with intellectual disability, the presence of stigmatizing perceptions, and feelings of fear about providing care for people with intellectual disability can lead health care professionals to treat people with intellectual disability differently than those without intellectual disability (Pelleboer-Gunnink et al., 2017).

Past, Present and Future: Perspectives on an Oral History of Intellectual Disability Nursing Journal of Intellectual Disabilities, February 2022 *(Athens log-in required*)*
A number of oral histories have been used to account for and extrapolate key findings that highlight the challenges these intellectual disability nurses have experienced within changing societal contexts and have identified the internal and external supports that were helpful to them. Additionally, the nature of intellectual disability services and the nursing role has been examined. In offering a new perspective on intellectual disability nursing, it is evident that there are key aspects that are important for intellectual disability nurses working with individuals which should include the maintenance of core competencies through continuing professional education. So too must intellectual disability nurses be responsive to the changing landscape of service provision and requirement for contemporary new roles in order to meet the changing needs of individuals with intellectual disabilities. This research contributes to filling a gap in understanding the historical perspectives of intellectual disability nurses and acknowledges the value of the experiences that these nurses have accrued over the years. It also highlights the importance of those experiences as they were shared with people with intellectual disabilities.

Fourth year intellectual disability student nurses’ journey and future work intention: a qualitative study BMC Nursing, 2022 *(Athens log-in required*)*
Intellectual disability service provision is in a time of major change for people with intellectual disabilities in Ireland [97]. This change and reconfiguring in the absence of a clear pathway for the intellectual disability nurse role within primary and community care teams creates confusion and role ambiguity. Growing numbers of social care workers are now recruited into the intellectual disability sector with demand outstriping supply [100],

while important for care provision social care workers cannot replace the clinical care an intellectual disability nurse can provide. While there has been a national review of intellectual disability nursing which highlights the need for intellectual disability nurses [6], there is a vacuum which has been created in the absence of a visible and communicated plan for the professional work group. Such an absence seems to be creating an apathy and uncertainty regarding intellectual disability nursing. In addition, the absence of national identifiable intellectual disability nurse leaders and awareness of their role is affecting the level of undergraduate students' entering and remaining in the intellectual disability nursing profession. Within the intellectual disability nursing students, the current ambiguity is affecting their future career choices and visions for nursing careers. Where some can see a pathway to advanced and community practice, others question the opportunities available and development of the profession that will occur if they stay within the profession.

Improving recruitment and retention in learning disability services Nursing Times, March 2021 *(Abstract only*)*
Nurses are increasingly becoming involved in the support of people with learning disabilities in social care settings. Recent policies have identified the need for an increased social care workforce, but many organisations have difficulty recruiting and retaining staff. Our review of the evidence found that many factors influence recruitment and retention directly and indirectly, including: gender and age; factors that contribute to staff stress and burnout; and organisational factors, such as supervision, training and culture. We suggest several areas that should be evaluated to inform an evidence-based approach to increasing the workforce that provides care for people who have an intellectual disability.

Learning disability nursing: how to halt the decline Nursing Times, April 2019
As learning disability nursing celebrates its 100th anniversary this year, the profession faces two key challenges, according to leading figures in the sector. Simon Jones, chair of the Royal College of Nursing's Learning Disability Nursing Forum, identified the "biggest concern" as the "steady decline" in the number of learning disability nurses in practice and "considerable drop-off in the number going into training". Linked to this is another major issue, which he said was an ongoing lack of awareness of what learning disability nurses did and the difference they made. "If you don't know what somebody does, it's very easy to say 'we don't need them'," he said. Health Education England is warning of a 30-35% shortfall in learning disability nurses by 2020."

Nurse AMHPs: an exploratory study of their experiences The Journal of Mental Health Training, Education and Practice, 2019 *(Abstract only*)*
Mental health and learning disability nurses have been eligible to become approved mental health professionals (AMHPs) since 2008, when the Mental Health Act 2007 was implemented. Despite this, there have been proportionally low numbers of these nurses pursuing the AMHP role. The purpose of this paper is to explore the experiences of these nurse AMHPs of training and practice. The participants highlighted the need to navigate personal, cultural and structural factors relating to accessing and applying for the training, difficulties with agreeing contracts terms, gaining comparative pay and undertaking the role.

This study has led to gain a greater understanding of the experiences of nurse AMHPs. The results from this study will assist employing local authorities, and NHS consider the barriers to mental health and learning disability nurses becoming AMHPs.

An exploration of the practice, policy and legislative issues of the specialist area of nursing people with intellectual disability: A scoping review Nursing Inquiry, October 2018 *(Abstract only*)*
The specialist field of intellectual disability nursing has been subjected to a number of changes since the move towards deinstitutionalisation from the 1970s. Government policies sought to change the nature of the disability workforce from what was labelled as a medicalised approach, towards a more socially oriented model of support. Decades on however, many nurses who specialise in the care of people with intellectual disability are still employed. In Australia, the advent of the National Disability Insurance Scheme offers an apt moment to reflect upon these decades of specialised nursing care as the context of this nursing care will continue to evolve. A review of the published literature was conducted to explore what has shaped the field in the past and how this might inform the future of this speciality area under new policy and service contexts. People with intellectual disability have specific health and support needs that require a specialised workforce. Specialist nurses continue to be needed for people with intellectual disability.

Assisting Individuals With Intellectual Disabilities: Do We, as Nurses, Still Have a Role? Journal of Psychosocial Nursing & Mental Health, October 2018 *(Abstract only*)*
According to an official analysis by Health Education England, the National Health Service will face “up to a 35% shortfall in learning disability nurses by 2020 unless action is taken to address the current education and recruitment ‘crisis’” (Stephenson, 2018, para. 1). Given that individuals with intellectual disabilities often have complex needs and poorer health, it is clear that intellectual disability clinical nurse specialists (CNSs) are too valuable to be in non-health-focused roles. [...]intellectual disability CNSs need to refocus their activities on health-related areas and support social care through delivering education, support, advice, and consultancy to primary, acute, and secondary health care providers, thereby enhancing their ability to work with individuals with intellectual disabilities and promote a more inclusive service.

LD nurse numbers decline by 40% in past eight years: RCN warns of return to 'Victorian' institutional care Learning Disability Practice, September 2018 *(Abstract only*)*
The RCN believes inadequate staffing could return learning disability nursing to a 'Victorian' model of institutional care. Workforce figures from NHS Digital show the number of learning disability (LD) nurses is down from 5,368 to 3,247 since 2010 -- a drop of 2,121 posts.

Looking after people with learning disabilities part three: who will care? Learning Disability Practice, April 2016 *(Abstract only*)*
In our previous articles we outlined the various challenges to learning disability nursing as a separate professional registration and considered the experiences of some recent graduates who have a dual learning disability nursing and social work qualification. It seems that as the concept of learning disability as a medico-legal category has undergone revisions, so too has the role, scope and function of those professionals who provide care for this group of people. Where there were once 'imbeciles and idiots' warehoused in asylums in the nineteenth century, the more contemporary notion of community care and individualised planning has ushered in new practices and the profession has adapted to meet contemporary challenges. People with learning disabilities as service users and their professional carers continue to demonstrate resilience in the face of sometimes provocative and unhelpful social and economic circumstances. But what happens next?

Workforce planning

“Look, all our hard work is paying off”: A qualitative evaluation of a system-wide, workforce development model to promote positive behavioural support Journal of Applied Research in Intellectual Disabilities, June 2020 *(Athens log-in required*)*
In conclusion, the results indicate that an evidence-based PBS programme that is underpinned by a systemic WFD model was perceived by a number of senior stakeholders as having resulted in changes that had a positive effect on staff knowledge, confidence and practice; resulting in wider organizational benefits, such as improved strategy and policies, and team stability; and improving the quality of life of those being supported. An important area for future research is to explore what the specific mechanisms were that helped promote these changes.

Challenging times: building a health, housing and social care local workforce strategy Housing, Care & Support, July 2018 *(Abstract only*)*
The purpose of this paper is to stimulate a wider debate around the coordination of workforce planning in non-statutory services (in this case, specialist housing for older people or those with long-term health and social care needs, such as learning disabilities). The authors argue that current NHS reforms do not go far enough in that they fail to include specialist housing and its workforce in integration, and by doing so, will be unable to optimise the potential efficiencies and streamlining of service delivery to this group. The paper highlights some potential limitations to the current NHS reforms: by integrating non-statutory services, planned efficiency savings may be optimised and service delivery improved.

Burnout

The challenges of mental health of staff working with people with intellectual disabilities during COVID-19 – A systematic review Journal of Intellectual Disabilities, October 2022 *(Athens log-in required*)*
Future research should also build on research findings from the first wave of COVID-19 in order to determine the impact of ongoing waves and lockdowns on staff working in healthcare. Consideration should be taken on the impact of long-COVID, whether the effects of the pandemic on mental health factors such as anxiety have changed over the course of the pandemic, and whether better supports have been developed and if healthcare systems are “building back better” in a manner that protects the mental health of HWs. Research employing structured questionnaires to assess mental health should endeavour to use similar measures as those employed in the general population.

Staff mental health while providing care to people with intellectual disability during the COVID-19 pandemic British Journal of Learning Disabilities, February 2022 *(Athens log-in required*)*
Staff working with people with intellectual disability suffer from the same work overload, the sudden change, the constant adaptation, and the impact of the pandemic on their mental health, as other health and social care workers. Due to the specific conditions of their work, and the needs of those whom they are supporting, the impact of the pandemic appears to be significant with solutions needed to address the mental health of health and social care workers across personal, institutional and policy levels.

At an individual level, coping strategies should be encouraged such as availing of support from peers and managers, as well as availing of more structured mental health supports. At an institutional level, appropriate levels of timely information about COVID-19 and available supports should be provided to staff, with clear communication between staff directly providing care and management staff. At a broader level, sufficient resources should be made available for PPE, staff mental health support, and staffing levels more generally, to avoid burnout associated with working excessive hours. At time of writing, lockdown restrictions are easing in Ireland, with very high uptake of COVID-19 vaccinations. Nonetheless, as one of our participants noted, the full mental health impact of this pandemic may not be fully known for some time to come.

Exposure to challenging behaviours and burnout symptoms among care staff: the role of psychological resources Journal of Intellectual Disability Research, December 2020 *(Athens log-in required*)*
Of the psychological resources found to be associated with reduced risk of burnout symptoms, staff self-efficacy and access of staff to supervisor social support seem to be the factors that can be influenced best. These factors thus may be of importance in reducing the risk of developing burnout symptoms and improving staff well-being, even though the current study was not designed to demonstrate causal relations between psychological resources and burnout symptoms.

Workplace stress, burnout and coping: a qualitative study of the experiences of Australian disability support workers Health & Social Care in the Community, May 2017
Disability support workers (DSWs) are the backbone of contemporary disability support services and the interface through which disability philosophies and policies are translated into practical action. DSWs often experience workplace stress and burnout, resulting in a high turnover rate of employees within the non-professional disability service workforce. The full implementation of the National Disability Insurance Scheme in Australia is set to intensify the current challenges of attracting and retaining DSWs, as the role becomes characterised by greater demands, ambiguity and conflict. The aim of this study was to explore DSWs' perceptions of enjoyable and challenging aspects of disability support work, sources of stress and burnout and the strategies they use to cope when these issues arise.

Twelve DSWs workers providing support for adults living with intellectual and physical disabilities were interviewed. Thematic analysis revealed a superordinate theme of 'Balance' comprising three sub-themes: 'Balancing Negatives and Positives', 'Periods of Imbalance', and 'Strategies to Reclaim Balance'. Participants spoke of the rewarding and uplifting times in their job such as watching a client learn new skills and being shown appreciation. These moments were contrasted by emotionally and physically draining aspects of their work, including challenging client behaviour, earning a low income, and having limited power to make decisions. Participants described periods of imbalance, wherein the negatives of their job outweighed the positives, resulting in stress and sometimes burnout. Participants often had to actively seek support and tended to rely on their own strategies to manage stress. Findings suggest that organisational support together with workplace interventions that support DSWs to perceive the positive aspects of their work, such as acceptance and mindfulness-based approaches, may help to limit experiences of stress and burnout. The further development and evaluation of emotion-focused workplace therapies, and interventions that consider organisational (macro) factors is suggested.

Role of technology

Understanding the possibilities and limitations of assistive technology in health and welfare services for people with

intellectual disabilities, staff perspectives Disability and Rehabilitation: Assistive Technology, August 2021 *(Athens log-in required*)*
The current study provides new knowledge of how healthcare staff define and understand AT in welfare services for people with ID. It also highlights the various possibilities, concerns, and obstacles to use AT. Although healthcare staff expressed a positive attitude, our findings indicate that they perceived uncertainty and ethical concerns towards using AT. The findings show that not only providing equipment and organisational support but also personal interests and attitudes of healthcare staff play essential roles in the successful implementation of AT. The staff need to receive more training and technical supports from their workplace. The year of using AT was positively associated with the positive attitude and use of AT among the staff. This study's findings may also indicate that disability nurse education should provide general knowledge for using AT in services for people with ID.

Competency Frameworks

Generic Service Interventions Pathway: a competency framework to support development of the learning disabilities workforce Health Education England (no date)
The framework has particular relevance for:

- Learning Disability Service Managers – who can use the framework to better understand the development needs of the workforce. It will help them understand how to maximise the contribution of the existing workforce and identify new ways of working within a framework that is person-centred and focused on improving health and care outcomes. It will help identify the need for, and development of, new roles
- Education Commissioners – who can use the framework to support competency based curriculum development activities
- People with a learning disability (and their carers) who wish to contribute to the development of care services
- Service Commissioners – who will gain an insight into competency based workforce development approaches and can use the tool to help describe service models and assurance activities that underpin the delivery of effective services.

Learning Disabilities Transition Pathway Competency Framework Health Education England (no date)
This document was commissioned by Health Education England to support the development of people working in services with young people with learning disabilities as they lead up to and make the transition from children's to adults' service provision.

The framework has particular relevance for:

- managers of services working with young people with learning disabilities at transition, who can use the framework to:
    - better understand the development needs of the workforce
    - help maximise the contribution of the existing workforce
    - identify new ways of working within a framework that is person-centred and focused on improving health and care outcomes
    - help identify the need for, and development of, new roles
    - develop the multi-agency team.
- education commissioners – who can use the framework to support competency based learning and development programmes
- people with a learning disability and their carers who wish to contribute to the development of care services

- service commissioners and workforce development leads, who can use the framework to:
    - gain an insight into the competency based workforce development approach
    - help describe service models
    - develop specifications and assurance activities that underpin the delivery of effective services.

Supporting psychological wellbeing in adults with learning disabilities: an educational framework on psychological interventions for practitioners working with adults with learning disabilities in Scotland NHS Education for Scotland (2017)
Health Education England (HEE) commissioned the Tavistock & Portman NHS Foundation Trust to develop a competency framework for all those who work with people in the perinatal period, their families and loved ones.

Learning Disabilities Core Skills Education and Training Framework 2016, Skills for Health, Skills for Care, Health Education England
This Learning Disabilities Core Skills Education and Training Framework was commissioned and funded by the Department of Health and developed in collaboration by Skills for Health, Health Education England (HEE) and Skills for Care. The framework supports workforce development in accordance with the HEE Mandate (2015-16)1 which states: “HEE continues to play its part in fulfilling pre-existing public commitments including Transforming care: A national response to Winterbourne View Hospital, the Winterbourne View Concordat , Positive and Proactive Care: reducing the need for restrictive interventions and the Mental Health Crisis Care Concordat: Improving outcomes for people experiencing mental health crisis. The Winterbourne View Concordat sets out that HEE will work with the Department of Health, providers, clinical leaders, and other partners to improve the skills and capability of the workforce to respond to the needs of people with learning disabilities and challenging behaviour” (HEE 2015 p15). The aim of the framework is therefore to support the development and delivery of appropriate and consistent cross-sector learning disabilities education and training.

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