



## Developing curricular-content and systems-related impact indicators for intellectual disability awareness training for acute hospital settings: A modified International Delphi Survey

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## **Developing curricular-content and systems-related impact indicators for intellectual disability awareness training for acute hospital settings: A modified International Delphi Survey**

### **Abstract**

**Aim:** To identify, and reach consensus on, curricular-content and delivery methods, as well as ways to maximise the impact of intellectual disability awareness training programmes in acute hospital settings.

**Background:** With the continuing evidence of avoidable deaths and unwarranted variations in the quality of care to people with an intellectual disability in acute hospitals, it could be purported that current training provided to hospital staff appears to be making minimal difference in the care provided to this population.

**Design:** A two-round modified Delphi survey was conducted between June 2020-Jan 2021.

**Methods:** International experts from primary healthcare and hospital settings, and intellectual disability health fields participated in the survey. Initial curricular-content items were developed from the literature, and based upon the combined clinical and academic experience base of the authors. Items were evaluated in terms of agreement/consensus, importance, and stability of responses. There were 57 expert responses in Round 1 and 45 in Round 2.

**Results:** Consensus was reached with regard to 55 of 65 curricular-content indicators relating to Aims, Design, Content, and Delivery. Ten curricular-content indicators failed to be agreed upon relating to mode of training delivery. With regard to systems-related impact indicators, 28 out of 31 reached consensus. The expert panel identified and agreed on seven system barriers that could obstruct the successful implementation of the awareness training programmes within acute hospital settings.

**Conclusions:** This is the first international Delphi survey to agree 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.

**Impact:** In order to maximise 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.

**Keywords:** intellectual disability, Delphi survey, awareness training, nurses, acute hospital

### **Why is this research or review needed?**

- Children and adults with an intellectual disability remain more likely to die younger and avoidably than non-disabled peers in acute hospitals.
- Acute hospitals often struggle to make individualised adjustments to usual pathways for the provision of care, treatment, and support; there is evidence of a lack of knowledge and skills concerning intellectual disability amongst acute hospital staff.
- There is no clear consensus or evidence regarding the curricular content and mode of training delivery and its consequent impact upon clinical practice.

### **What are the key findings?**

- Using a modified Delphi survey, an international panel reached agreement on curricular content regarding Aims, Design and Content.
- Variations of opinion were found regarding the proposed modes of training delivery.
- A number of systems-related impact indicators were agreed upon relating to resources, inputs, and outcomes to be implemented within acute hospitals.
- The expert panel identified and agreed on seven potential systemic barriers that could obstruct the successful implementation of the awareness training programmes that the acute hospital settings need to address.

### **How should the findings be used to influence policy / practice / research / education?**

- The curricular content and systems-related impact indicators of the intellectual disability awareness training could also be applied to other cognitively impaired populations across acute hospital settings, thereby leading to further improvements in equity of health provision and quality of care.
- While this study has prospectively identified curricular content and systems-related impact indicators, based on existing literature and expert opinion, which are likely to be associated with maximising the impact of intellectual disability awareness training, an evaluation of training based on their adoption and implementation will be required to confirm their effectiveness.

## **1 INTRODUCTION**

Whilst globally the life expectancy of people with a learning or an intellectual disability has increased, children and adults with disability remain more likely to die younger and avoidably than non-disabled peers. People with an intellectual disability are also more likely to develop a range of physical and mental health comorbidities, leading to poorer quality of life. These health inequalities have been linked to: difficulties accessing appropriate healthcare; failures to make individualised adjustments to usual pathways for the provision of care, treatment, and support; and a lack of knowledge and skills amongst frontline healthcare staff. Research suggests there is a fundamental need for intellectual disability awareness training for acute hospital staff. Currently however, there is no clear consensus or evidence regarding the idealised curricular content and mode of delivery for such training, nor how to assess its consequent impact upon clinical practice.

The aim of this study was to identify, and reach a consensus agreement upon, key curricular content, and systems-related impact indicators, for an intellectual disability awareness training programme for acute hospital settings. This study was part of a wider project undertaken by The National Development Team for Inclusion (NDTi) in England with the aim of supporting the development of more sustainable intellectual disability awareness training for healthcare staff.

## **2 BACKGROUND**

Intellectual disability awareness training is a key priority for healthcare staff in the United Kingdom and in other international countries. Health Education England (HEE) published the 'Learning Disabilities Education and Training Framework', and updated in 2019 'Learning Disability and Autism Training for Health and Care Staff' (Dept of Health & Social Care, 2019a), which focused on core skills that the broader healthcare workforce needs to have in order to effectively support this population. This framework describes three tiers of core skills and knowledge: general awareness training for those who occasionally interact with children and adults with an intellectual disability (Tier 1); for those staff in more regular contact with people with an intellectual disability (Tier 2); and for those staff providing direct care for this population (Tier 3) (see Figure 1). Although core knowledge and skills are identified, HEE (2016) and the Dept of Health & Social Care (2019a) provide little information about how such training programmes should be delivered or the effectiveness of delivery assessed. This study will focus on Tier 1 core skills and knowledge of the Framework.

### **INSERT FIGURE 1 HERE**

The National Development Team for Inclusion (NDTi) (Marriott and Harflett, 2020) undertook a review of published and unpublished literature from 2009 pertaining to the most effective and sustainable methods for the provision of intellectual disability awareness training programmes (Tier 1 as described above) for primary healthcare

and acute hospital staff. Marriott and Harflett identified 24 papers: 11 research articles that focussed on evaluating awareness training programmes for healthcare staff, 8 articles that focused on awareness training or education for student healthcare workers, two articles that identified the training needs for primary healthcare and acute hospital staff, and three unpublished reports that had completed similar evaluations. Marriott and Harflett used the Kirkpatrick's Four-Level Training Evaluation Model to assess the efficacy of these intellectual disability awareness training programmes: 1) reaction (staff enjoyment from course), 2) learning (staff gained new knowledge, skills, and confidence), 3) behaviour (staff applied the learning into clinical practice) and 4) results (evidence of better outcomes for people with intellectual disabilities receiving care and treatment).

Marriott and Harflett (2020) found that some reports of intellectual disability awareness training noted improvements in staff *knowledge* (Hatton, 2008; Heneage et al., 2010; Buchanan, 2011; Read & Huston, 2013; Harwood & Hassiotis, 2014; Watkins & Colgate, 2016; Piper & Alazzi, 2017; Mengoni & Redman, 2019), *attitudes* (Harwood & Hassiotis, 2014; Billon et al., 2016; Dagnan et al., 2018), *confidence* (Hatton, 2008; Heneage et al., 2010; O'Boyle-Duggan, 2010; O'Boyle-Duggan et al., 2012; Billon et al., 2016; Dagnan et al., 2018), and *skills* (Tomas et al., 2014; Billon et al., 2016). There was also evidence that people with an intellectual disability who co-delivered training, reported a positive experience (Attoe et al., 2017), and of this leading to an opportunity of employment, thereby improving financial independence, self-esteem, and well-being (Metcalfe & Colgate, 2019).

However, Marriott & Harflett (2020) found that many of these studies were methodologically weak with small samples, no comparison groups, no randomisation, lack of standardised scales used for pre/post measurement, or lack of follow-up and they raised concerns about the quality of the evidence. None of the intellectual disability awareness training programmes reviewed were underpinned by a theoretical framework and many of training programmes differed in aims, design, content, and delivery thereby making comparison difficult. Some studies failed to report the content of training programmes. Amongst the more recent papers that were reviewed there was no evidence of training being aligned to HEE's (2016) 'Learning Disabilities Core Skills Education and Training Framework' and the 'Learning Disability and Autism Training for Health and Care Staff' (Dept of Health & Social Care, 2019a).

More worryingly, Marriott & Harflett (2020) found that no studies measured or evaluated the longer-term impact of awareness training, on the care and treatment of people with an intellectual disability accessing primary healthcare or acute hospital settings. Many studies failed to identify 'what worked' and 'what didn't work'. This has to be critically contrasted with the recent avoidable deaths of Oliver McGowan, Richard Handley and Laura Booth in the UK, and other accounts of avoidable deaths and continued poor care of children and adults with an intellectual disability in acute hospitals across the UK (MENCAP, 2007; Dept of Health, 2014; Glover et al., 2017;

O'Leary et al., 2018; Heslop et al., 2019). This need is not limited to the UK with other international studies echoing similar failings: Australia (Iacono et al., 2014; Brameld et al., 2018; Troller et al., 2017), Canada (Stankiewickz et al., 2018), Finland (Arvio et al., 2016); Ireland (McCarron et al., 2015) and the USA (Lauer & McCallion, 2015). It could be argued that conventional approaches to intellectual disability awareness training programmes in primary healthcare and acute hospital settings appear to have made minimal difference to the care provided to this population and the outcomes they experience.

If we are to improve the quality of healthcare provision, and reduce avoidable deaths of people with an intellectual disability (and other cognitive disabilities), then a fundamental review and reformulation of training approaches is urgently required. This paper seeks to address this gap, and is the first of its kind to confirm a consensus position regarding both curricular content and systems-related facilitators that are prerequisites to the development and delivery of effective intellectual disability awareness raising training programmes.

### **3 THE STUDY**

#### **3.1 Aims**

The aim of this study was to identify, and reach a consensus agreement upon, key curricular content, and systems-related facilitators (actions that could maximise the potential implementation of learning points), for an intellectual disability awareness training for acute hospital staff.

## **4 Design**

### **4.1 Study design**

A two-round modified Delphi survey was conducted between June 2020-Jan 2021. A Delphi survey is an iterative methodology for reaching a consensus on a given topic amongst a panel of experts (Mulhall et al., 2018). The process typically involves a predetermined series of 'rounds' in which the panel are asked to rate a series of items using a Likert-style scale. The aim is to reach a predetermined level of agreement, or consensus, amongst the panel on each item. In a 'standard' Delphi survey an open-ended question is presented to the panel such as 'What do you think are the most important items to include in an awareness raising training?' Responses to this question would then be sculpted into a series of items and re-presented for rating in Round 2.

This current Delphi survey is considered 'modified' as the items were devised before presentation to the panel from a) a review of the existing literature (see Marriott and Harlett, 2020 in section 4.3, below) and b) the clinical and academic experience of the authors. This approach has been used extensively in the medical, social, and behavioural sciences (Uphoff et al., 2012; Quyen, 2014) and in the development of training priorities for medical students (Kizawa et al., 2020; Viljoen et al., 2020).

**INSERT TABLE 1 HERE**

### **4.2 Sample/Participants**

Panel members needed to have good clinical, and/or academic/research knowledge, and expertise in the health of people with an intellectual disability and experience in disability awareness training programmes to make meaningful contributions (Balasubramanian & Agarwal, 2013; Weise et al., 2017). Table 1 details the profiles of the international panel consisting of 57 experts from mainstream primary healthcare and acute hospital settings, and intellectual disability health professionals. The panel included experts from Australia, Canada, Japan, New Zealand, Netherlands, New Zealand, Norway, South Africa, Sweden and the four countries of the UK (England, Northern Ireland, Scotland, and Wales).

UK panel members from a number of primary healthcare and acute hospital settings (such as the NHS) from across England, Northern Ireland, Scotland, and Wales were invited to participate within the Delphi survey. International panel members were invited from: the Health Section of the International Association of the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD); Special Olympics International; and the American Academy of Developmental Medicine & Dentistry (AADMD).

### 4.3 Initial Item Creation: Identification of curricular content and systems-related items

Marriott and Harflett (2020) summarised the curricular content of a number of intellectual disability awareness training programmes. These included: general information about what an intellectual disability is, the physical and mental health of children and adults with an intellectual disability, health inequalities experienced by this population, stigma, communication, hospital processes, legal issues, and profession-specific needs. The curricular content components identified by Marriott & Harflett (2020) were combined with items from HEE (2015, 2016, 2019), and items from the authors' clinical and academic experience. Together these were used to create 96 items which were presented to the panel in Round 1. The wording of each item was checked for readability within the research team throughout the pre-administration stage.

From the evidence presented above, appropriate curricular content is essential for the development of any disability awareness training programme (Aims, Design, Content, Delivery). However, it is unrealistic to expect curriculum content alone to have a significant or sustainable impact on staffs' knowledge, attitudes, skills, confidence and more importantly changing clinical practice. Pawson & Tilley's (1997) '*context, mechanism and outcome*' framework was used to conceptualise and formulate wider whole service, system-related structural and process factors that are critical to maximising the impact of intellectual disability awareness training programmes. This paper goes beyond '*what works*' to ask, '*what it is about a [intellectual disability aware training] programme that works for whom, in what circumstances, in what respects, over which duration*' (Pawson, 2013, p.15). Pawson & Tilley's (1997) framework is based within '*realism*'.

'Realism' or '*realist evaluation*' is '*underpinned by an understanding of how the world is and how it works (ontology), and an understanding of the nature of knowledge (what we can know and how we can know it (epistemology))*' (Emmel et al. 2018, p.43). Traditional research seeks to identify if a social programme such as awareness training '*works*': is it effective. However, these types of studies have come under criticism from '*realists*' (Pawson & Tilley, 1997; Bhaskar, 2008), as they have failed to understand the training awareness programme's '*mechanisms*' that cause the programme to lead to changes in the identified outcomes. For example, in what '*context*' is the awareness training programme delivered (ie. population, setting, time), and what are the '*causal mechanisms*' (ie. the underpinning theories of the specific components of the awareness training, who is delivering the training, resources, fidelity of programme delivery), that makes It is beyond the scope of this reflective paper to offer readers a comprehensive explanation of the philosophical foundations of '*realism*', but we refer readers to the seminal work of Pawson & Tilley (1997) and Bhaskar (2008).



Focussing on the curricular content only fails to understand the ‘*context*’ within which awareness training programmes are delivered, the ‘*mechanisms*’ that mitigate against or in favour of behaviour change in training recipients, and the short, medium and long-term ‘*outcomes*’ of the programme on the individual and on the system/organisation. These systems-related impact indicators were reviewed alongside the authors team’s own academic, research and clinical experience and were further incorporated into items presented within Round 1. In summary, items were devised for three key components of curriculum content, systems-related facilitating factors, and outcome indicators for this study.

In total, 96 items within seven headings were developed: 65 items related to curricular content (i.e., Aims, Design, Content, Delivery) and 31 systems-related impact indicators (Resources, Outputs, Outcomes).

## **4.4 The Delphi Survey**

### **4.4.1 Data collection**

A two-round modified Delphi survey was conducted with a panel of 57 international experts from mainstream primary and acute healthcare settings, and intellectual disability health fields.

### **4.4.2 Delphi Round 1**

An invitation e-mail was sent to a number of primary healthcare and acute hospital settings, and intellectual disability organisations from across the UK. They were asked to identify key personnel in their organisations who had engaged in intellectual disability awareness training and who could also act as panel members and to forward the invitation e-mail. Likewise, international organisations (IASSIDD, AADMD), were also asked to identify appropriate personnel who could act as panel experts, and to forward the invitation e-mail. The e-mail explained the purpose of the study and provided the participant with a Qualtrics link to the online Delphi survey. Expert panel members completed their consent online, along with several demographic questions. They were then asked to rate the importance of a number of items relating to the training curricula (Aims, Design, Content, Delivery) and systems-related impact indicators (Resources, Outputs, Outcomes). The survey took approximately 30-40 minutes to complete. Experts were also asked to make additional comments/suggestions to several open-ended questions after each section. Responses to the open-ended questions were used to devise additional indicators, which were presented in Round 2. A four-week deadline for completion was given with two reminders e-mailed, if required, two weeks apart.

### **4.4.3 Delphi Round 2**

In Round 2, those items that did not reach the 70% consensus target were re-presented to the panel for review, along with individualised feedback. For example: “*In the previous Round you rated this item [insert participant’s rating]. The overall group*

*ratings were: 1= Unimportant - 5%; 2= Little importance – 10%; 3= Neutral – 60%; 4= Important – 20%; 5 =Very Important – 5%. Please re-submit a rating for this item (you can use your previous rating or change to a new rating). How important do you think it is to include this item in .....?”* Panel members then had the opportunity to either return the same rating they selected from Round 1 or amend their rating. The same timeframe as above was used.

#### **4.5 Analysis, Consensus and Stability**

Despite the growing number of Delphi surveys being undertaken, there is still no agreed standard for consensus or agreement levels in the literature (Jorm, 2015). Consensus levels have ranged from 66%-90%, with most studies selecting 70%.

Each item was rated by the expert panel member using a five-point Likert-type Scale (1= Unimportant, 2= Little importance, 3= Unsure, 4=Important, 5= Very Important). It was agreed to conduct two rounds and to use a consensus target of 70%, meaning that items for which at least 70% of the panel rated as important or very important would be retained and used to inform the content and delivery mode of the training. As is standard Delphi practice, items which did not achieve the target consensus level in Round 1 were re-presented in Round 2 along with targeted feedback, and the option for each respondent to change their rating.

Responses were exported from Qualtrics software platform into SPSS for Windows (Version 26). Items were deemed to have achieved the pre-set consensus level if 70% of the panel rated the item as ‘4 – Important’ or ‘5 - Very Important’. Items at Round 2 were also assessed for ‘stability of agreement’ using a weighted-Kappa. The term ‘agreement’ refers to the stability of responses to an item by each individual respondent from Round One to Round Two. There are no set standards for interpreting a Kappa statistic. In this survey we followed Mulhall et al (2018), who in turn followed guidance from Landis & Koch (1977) who suggested: a Kappa value of 0.0 - 0.2 = Slight agreement; 0.21-0.4 = Fair agreement; 0.41 – 0.6 = Moderate agreement; 0.61 – 0.8 = Substantial agreement; 0.81 – 1 = Almost perfect agreement. Items which do not achieve the target level of consensus in Round 2, but which achieve substantial agreement, were to be included with a cautionary note.

The data were analysed using Qualtrics and SPSS (V.26). Qualitative comments to the open-ended questions at the end of each sub-section and system barriers were copied and pasted into MSWord and were read alongside their indicators developed by the first author (LT), and checked and agreed by the research team in the first round only.

#### **4.6 Ethical Review**

As this work did not require a review by an NHS REC (as indicated by the NHS HRA decision making tool) or any other external ethical approval, it was reviewed by NDTi’s internal, independent Ethics Review Committee which works to an ethical

framework based on the Social Research Association ethical guidelines. All participants provided informed consent to take part at the beginning of the process as part of the online survey. We purposely asked participants to provide their name and e-mail address in Round 1 so we could contact them for Round 2, therefore complete anonymity of responses could not be given, however pseudo-confidentiality was assured as respondents were not aware of the number, or the identities, of other respondents. All data were handled in accordance with UK data protection regulations.

## **5 RESULTS**

### **5.1 Completion/Retention Rate**

In total, 69 experts completed the Round 1 Delphi survey, however, 12 surveys were partially completed and therefore not used within the analysis. Likewise, 49 experts completed the Round 2 Delphi survey although 4 surveys were only partially completed and not used within the analysis. This is a strong retention rate of 79%.

**INSERT TABLE 2a HERE**

### **5.2: Curricular content (Aims, Design, Content, Delivery)**

#### **5.2.1: Aims and Design**

At Round 1, the panel were presented with five items regarding potential aims of the intellectual disability awareness training. All five items reached the target consensus level (>70% rating the items as important or very important). Three new items were devised from the responses to the open-ended questions in Round 1, and these were later presented to the panel in Round 2. All three items subsequently reached between 93.4%-97.8% consensus agreement. From Table 2a it can be observed that the highest levels of agreement amongst the aims related to: understanding the health needs and health inequalities of this population (100%), the need for reasonable adjustments and how people with an intellectual disability may present with unmet needs (100%), the need for improved communication (100%), promoting positive interaction (96.5%), and the identification of children/adults with an intellectual disability (93%).

Six items regarding the Design of the intellectual disability awareness training were presented to the panel in Round 1. All these items reached between 89.5%-96.5% agreement. One new indicator was devised from the responses to the open-ended questions in Round 1, and this was later presented to the panel in Round 2 and achieved a consensus level of 93.4%. From Table 2a it can be observed that the highest levels of agreement amongst the design-related items were related to: having a partnership with people with an intellectual disability and their family carers (98.2%), the training being designed with input from primary and acute healthcare staff and staff from intellectual disability services input (98.2%), having a focus on the specific barriers children/adults with an intellectual disability have in accessing health services and target personal barriers that acute hospital staff may experience (e.g. knowledge, skills, motivation to change) (96.5%), the awareness training should also have a theoretical underpinning (94.7%), and further bespoke training on the disability awareness training should be provided to different professional groups (91.1%).

**INSERT TABLE 2b HERE**

### **5.2.2: Content**

The Content section comprised five sub-sections (Medical Conditions and Care, Communication, Pain, Ethical Standards, and Information/Resources) which were presented to the panel of international experts.

*Medical Conditions:* The panel agreed that the content of an awareness training programme should include the following ten medical conditions/issues: 'diagnostic overshadowing' (96.5%), fear and anxiety (96.5%), reasons for the greater number of health inequalities amongst people with an intellectual disability (94.8%), recognising and managing behaviours that challenge (91.2%), constipation (91.1%), nutrition and hydration (89%), epilepsy (84.4%), dysphagia (87.7%), postural care (79%), and respiratory problems (79%) (see table 2b). One new indicator suggested in Round 1 was that the awareness training should also focus on the premature deaths of children and adults with an intellectual disability: this achieved 91% agreement in Round 2.

*Communication:* Three items were presented to the panel relating to Communication, all of which achieved >70% consensus target set: effective communication strategies with family/paid supporters (100%), effective communicative strategies with children and adults with an intellectual disability who have limited communication skills (98.2%), and communicating effectively using non-verbal communication (e.g. Makaton) (77.2%) (see Table 2b).

*Pain:* One indicator was presented to the panel in Round 1 on recognising, controlling and minimising pain in children/adults with an intellectual disability and this reached a 98.2% consensus agreement. A further indicator on using scales to measure pain was suggested by the panel in Round 1 and this reached 77.3% consensus at Round 2 (see Table 2b).

*Ethical Standards:* Five items were presented to the expert panel on Ethical Standards in Round 1; all the items reached between 87.7%-100% agreement. These were: safeguarding issues and how to ensure the rights of this population (100%), people with an intellectual disability being listened to rather than relying upon only the views of carers (98.2%), assessing capacity to consent (98.2%), using best interests and obtaining the views of people with an intellectual disability in assessment and treatment (98.2%) and reference should be made to the UN Convention on the Rights of People with Disabilities (87.7%) (see Table 2b).

*Information/resources:* Six items were presented to the experts in Round 1 relating to the awareness training information/resources: the need to inform staff about supports within the hospital (e.g. champions, acute liaison nurse) (100%), informing staff about hospital passports (98.2%) and communication passports (96.4%), where to get user accessible information (94.6%), where to get user accessible information on

hospital procedures (92.8%) and the role of the community intellectual disability team (92.8%) (see Table 2b).

### **5.2.3: Delivery**

Twenty-one items regarding how the training should be delivered were presented to the panel in Round 1 (see Table 2b). The target consensus level was reached for eleven of these items (52.4%): that the awareness training should be mandatory (92.2%) and target all front-line staff (i.e. out-patients, Accident & Emergency Dept, acute hospital wards, paramedics) (94.7%), the training should be adapted for different groupings of staff (75.1%), it should include videos showing specific hospital scenarios with children and adults with an intellectual disability should be used (96.5%), e-learning material should be made available on-line (98.2%), and resource materials (handouts, case stories) given out (75%). The panel reached consensus that the awareness training should be refreshed every 3 years (73.3%), and that staff should be assessed on the learning outcomes of the training using an online assessment tool (75%).

However, expert panel members did not reach the set consensus target on items relating to the delivery mode of the awareness training. Specifically, the panel could not reach consensus on whether the training delivery should use a blended approach of face to face and e-learning, face to face delivery only, or on-line only. Likewise, the panel members did not reach the target consensus level regarding whether the training should be delivered over a full day, a half-day, or over 1 - 2hrs.

Those items that did not reach the consensus target at Round 2 were assessed for response stability. Three items were found to have substantial stability (Weighted Kappa >0.61), meaning that although the overall group did not reach consensus, those who did rate these items as important or very important were consistent in this view across both rounds: 'the awareness training should last a full day' (0.71); 'the awareness training should be delivered by a professional trainer from an acute hospital setting' (0.68); 'the awareness training should be delivered by a professional trainer from the local community intellectual disability services' (0.65).

Two new items were devised from the responses to the open-ended questions in Round 1 and these were later presented to the panel in Round 2. One item, that the awareness training should be delivered online via Zoom, did not reach the agreed target (59.1%). The other indicator, that the awareness training should be delivered collaboratively by people with an intellectual disability, carers, disability, and hospital staff, did reach the agreed consensus (91.1%).

**INSERT TABLE 3 HERE**

### **5.3: Systems-related facilitators (Resources, Outputs, Outcomes)**

#### **5.3.1: Resources**

Panel experts were asked to rate the importance of seven resource-related items that would be required within the acute hospital setting to facilitate the staff to implement the intellectual disability awareness training. All seven items reached between 71.1%-94.6% consensus in Round 1: use of accessible information made available (94.6%), staff offered on the job training and supervision from senior management (91.2%), hospital (79.7%) and communication (86.4%) passports should be used with this population, explicit mention of children and adults with an intellectual disability in policy indicators (86%), people with an intellectual disability electrically flagged within the hospital (76.8%) and there should be a social marketing strategy to promote equity of care for people with an intellectual disability (71.1%) (see Table 3). The experts suggested an additional indicator in Round 1 that the awareness training should include positive experiences of children/adults with an intellectual disability -this reached consensus (80.9%) at Round 2.

#### **5.3.2: Outputs**

Four items were presented to the expert panel relating to outputs, all of which achieved the target consensus level: out-patients and hospital admissions should proactively pre-plan making reasonable adjustments for children and adults with an intellectual disability (100%), hospitals should employ an Acute Liaison Intellectual Disability Nurse (89.5%), hospitals should provide on the job training for staff in caring for this population (89.5%), and the hospital should appoint an Intellectual Disability Champion/named person (84.1%) (see Table 3). One further item was suggested by the panel in Round 1 pertaining to hospitals using desensitisation to support children and adults with an intellectual disability to diminish their anxiety. At Round 2, 72.8% of the panel agreed this was an important or very important recommendation.

#### **5.3.3 Outcomes**

A series of items were presented to the panel regarding potential short (1-2yrs), medium (3-5yrs) and long-term (10yrs plus) outcomes that hospitals should measure to examine the efficacy of such intellectual disability awareness training.

##### **5.3.3.1 Short-term**

Six items were presented to the panel relating to short-term outcomes. These items all reached between 85.7%-100% agreement in Round 1 items: hospitals should monitor complaints (100%) and critical incidents (96.5%) and respond appropriately, feedback should be sought from people with an intellectual disability (96.5%) and their family/paid supporters (94.7%), the awareness training content and delivery be re-evaluated annually (86%), and hospitals having a record of all staff attending the training in the last 12-months (85.7%) (see Table 3). One new indicator was devised from the responses to the open-ended questions in Round 1. N

Namely that the hospitals should monitor, and respond appropriately, to all critical incidents involving people with an intellectual disability. This reached 91.1% consensus agreement at Round 2.

### **5.3.3.2 Medium-term**

Seven items were presented relating to medium-term outcomes of the intellectual disability awareness training. Six of the items obtained consensus between 79.4%-98.2% in Round 1: the number of deaths of people with an intellectual disability should be reviewed every year (98.2%), hospitals should develop further inter-disciplinary intellectual disability education modules for all staff (89%), hospital staff should ask for hospital and communication passports from people with an intellectual disability when arriving into out-patient appointments and hospitals (82.4%), a reduction in hospital re-admissions (82.1%) and reduction in non-attendance (79.4%), and there should be a reduction in the number of elective admissions that are planned and subsequently cancelled (whether by the hospital or the person with an intellectual disability and/or their carers) (73.3%) (see Table 3). One indicator relating to staffs' knowledge, attitudes, and skills of working with children and adults with an intellectual disability being assessed every 3-5 years did not achieve sufficient consensus in Round 1, but did when re-presented in Round 2 (70.5%).

### **5.3.3.3 Long-term**

Panel members were asked to rate the importance of four items regarding the long-term (10yrs) outcomes of the awareness training. Only one indicator, that there should be a reduction in avoidable deaths in people with an intellectual disability, reached the agreed consensus (96.5%) in Round 1. The other three items did not reach the set 70% target for consensus in both rounds, and only one of these three items achieved sufficient stability – 'There should be a reduction in A&E admissions for people with an intellectual disability' (Weighted Kappa = 0.71) (see Table 3).

**INSERT TABLE 4 HERE**

## **5.4 Systems Barriers to Implementing the Intellectual Disability Awareness Training**

In Round 1, the expert panel members were asked to identify any potential barriers or challenges in implementing the intellectual disability awareness training in clinical practice. Seven items were developed from these responses which were then presented to the expert panel in Round 2. All seven items reached a consensus agreement above the set target of 70% (72.1%-95.4%): a lack of policy and clear guidelines in how to support children and adults with an intellectual disability in out-patient and hospital settings (95.4%); lack of resources/technology on the ward (Acute Liaison Nurse, Intellectual Disability Champion) (88.3%); a lack of understanding of family/paid supporters and their roles (86%); culture of the hospital/senior managers not providing the support front-line staff need to make reasonable adjustments (83.7%);



people with an intellectual disability not being a priority within the organisation/system (79%); staff not having regular contact with people with an intellectual disability (75.8%); hospital staff workloads being a barrier to implementing reasonable adjustments (72.1%); and not all staff receiving the awareness training (70.5%) (see Table 4).

## 6 Discussion

People with an intellectual disability have been found to have more unmet health needs, a greater inequity of healthcare provision, longer-stays within hospital, and to die prematurely in hospital of deaths that can be avoided (Emerson & Hatton, 2013; Iacano et al., 2014; O’Leary et al., 2018; The Learning Disability Mortality Review (LeDeR) Programme, 2019). Moloney et al. (2021) in an international scoping review found a lack of research on the implementation of ‘*reasonable adjustments*’ within acute hospital settings, ensuring children and adults with an intellectual disability have fair access to and use of health services. Within this paper an international panel of experts in the field have agreed an extensive series of points concerning the curriculum content and delivery mechanisms for intellectual disability awareness trainings for acute hospital staff. They have also agreed on a range of potential barriers and facilitators to maximising the implementation of the key knowledge and skills developed from such a training. Lastly, a set of short, medium, and long-term outcome measures have been proposed by which the impact of such trainings can be assessed. This paper is a call for action.

### **Aims, Design and Content of awareness training**

There has been a strong consensus among the experts regarding the desired Aims, Design and Content of an intellectual disability awareness training programme, which could quite easily be used internationally within different healthcare systems. The core aims of this training centre upon understanding the health needs of this population, the need for reasonable adjustments, and improved communication between staff and service users/carers (see Table 2a). Likewise, there was agreement concerning the Design of the awareness training, proposing a partnership approach with contributions from people with an intellectual disability, their family carers, primary and acute healthcare staff, and from staff in intellectual disability services. The training content should address specific barriers that people with an intellectual disability face when accessing health services and those experienced by acute hospital staff when trying to provide services (e.g. knowledge, attitude, skills, motivation to change) (see Table 2a). Given the international composition of the expert panel, and the high levels of consensus achieved, these issues, and the proposals by the panel, are of international relevance and are likely to be applicable to a range of health care systems.

There was also universal agreement among all the experts regarding the specific content of this awareness training focusing on core medical conditions/issues (constipation, nutrition and hydration, dysphagia, epilepsy, respiratory problems, postural care), communication, pain, ethical standards, and the information/resources needed (see Table 2b). These findings echo the concerns highlighted by a range of reports and national policy documents proposing mandatory standards across English healthcare settings for people with an intellectual disability (Disability Rights Commission, 2006; Dept of Health, 2008; 2013; HEE, 2015, 2016; Dept of Health & Social Care, 2019a).

## Delivery of awareness training

There was less consensus reached amongst the panel concerning the delivery mode of proposed trainings. Twenty-one delivery-related items were presented to the panel in Round 1, of which only 11 (52.4%) reached the 70% agreed consensus target. Although the panel agreed that the awareness training should be mandatory; the training should be delivered collaboratively between people with an intellectual disability, family carers, and disability and hospital staff; and the training should be provided to all front-line staff (i.e., out-patients, A&E, acute hospital wards, paramedics): the experts also believed the training should be adapted for different groupings of staff. The panel agreed that the awareness training should be refreshed every 3 years, however, they did not agree as to whether the training should be delivered using a blended approach of face to face and e-learning, face to face delivery only, or on-line only. Likewise, the panel members did not agree whether the training should be delivered over a full day, a half-day, or over 1-2hrs.

This lack of agreement of the delivery mechanism is not unexpected given the diverse range of health professionals who participated in the Delphi survey. It could be argued that different health professionals (medical doctors, nurses, allied health professionals, administrative staff, domestics, porters, etc.) may expect the training to be tailored more to their profession, and also across primary healthcare settings as well as social care settings. Equally, various professionals may have different prior experience of different modes of delivery (more used to on-line training). However, it must be remembered that this data was collected at the beginning of the COVID-19 pandemic when many people were struggling to adjust to increase online working arrangements.

Given the diverse needs and ability levels of people with an intellectual disability, Mulhall et al. (2018) proposed that information provided to this population should be developed with different versions, each addressing different needs and ability levels. So too, it may be with awareness training for different staff providing services to people with an intellectual disability, they too may require information provided in different ways that meet their individual (professional) needs. Hemm et al. (2015) in a systematic review of the training needs for mainstream healthcare professionals reported that the core training needs of professional groups were: '*general communication, knowledge/information and professional specific needs*'. Hemm and colleagues have stated '*that it may be possible to produce a core training package, suitable across professionals with elements that are profession specific*' (p.98). This study has clearly illustrated the agreed consensus across an international group of experts of the core curricular content which could then be adapted to meet the needs of the professionals receiving the training.

The HEE (2016) published the 'Learning Disabilities Education and Training Framework' and the Dept of Health & Social Care published the 'Learning Disability and Autism Training for Health and Care Staff' (2019a) that focused on the core skills

that the broader workforce will need for working with people with an intellectual disability. There are three Tiers or levels of core skills and knowledge as described in the framework in Figure 1 above. This study has evidently shown the agreed curricular content that a general awareness training programme for those who occasionally interact with children and adults with an intellectual disability needs to include. This is in addition to a range of systems-related barriers, facilitators, and impact indicators (resources, outputs, outcomes) that have not been previously highlighted in many of the published policy guidance and mandatory standards.

We would strongly argue that the findings of our study regarding the curricular content and systems-related impact indicators could also be modified and applied to healthcare staff working across the wider primary healthcare settings and social care settings. Furthermore, these systems-related impact indicators as proposed and agreed upon within this study by the international expert panel, would create a strong foundation to help implement the learnings from Tier 2 and Tier 3 training as described in the framework in Figure 1 (HEE, 2015, 2016; Dept of Health & Social Care, 2019a).

### **Systems-related impact indicators**

If programme designers focus on the curricular content only, they will fail to attend to the *'context'* in which the awareness training programme is delivered, the *'mechanisms'* that influence behaviour change, and *'outcomes'* of the programme on the individual and on the system/organisation. There is growing evidence to highlight that disability awareness training programmes themselves are not complex, but they are generally provided and implemented within complex systems/organisations. Therefore, greater emphasis should be placed not just on *what* to include but also upon *how* to implement these disability awareness programmes within complex acute hospitals in order to maximise their impact (Moore et al., 2012; 2019; Jamal et al., 2015; Moore & Evans, 2017).

There is growing evidence of need for the systems-related suggestions identified in this study to be addressed through wider policy guidance alongside mandatory training standards (HEE, 2015, 2016; Dept of Health & Social Care, 2019a). Likewise, there is growing evidence of the clinical effectiveness of a number of these systems-related suggestions. For example, Bur et al. (2020) in a recent integrative review of the UK and Ireland literature reported that acute liaison intellectual disability nurses held *'expert knowledge and skills that contribute to the development of effective systems and processes'* within acute hospitals. Another example is provided by Heifetz & Yunsy (2018) in Canada who evaluated the effectiveness of the hospital passport for adults with an intellectual disability within the A&E Dept. The authors reported that hospital passports *'can effectively support communication between people with an intellectual disability and hospital staff.'* Another example is offered by Waight & Oldreive (2020) who found that providing accessible information (i.e., easy-read materials, videos, computer programmes and websites) in a format that children and adults with an intellectual disability can understand *'encourages them to engage with*

*their health and with healthcare services, thereby contributing to reduce the health inequalities they encounter*'. The National Institute of Clinical Excellence (NICE) for people with an intellectual disability who present with behaviours that challenge (NICE, 2015), for people with an intellectual disability and mental health problems (NICE, 2016), and for older people with an intellectual disability (NICE, 2018), all recommend the use of hospital and communication passports and also making information accessible.

The results of this paper support the HEE (2016) 'Learning Disabilities Education and Training Framework' and Dept of Health & Social Care 'Learning Disability and Autism Training for Health and Care Staff' (2019a) offering acute hospital settings clear direction on how to develop, deliver, and assess the impact of intellectual disability awareness training.

### **Barriers to implementation**

The contributing experts agreed on seven potential barriers or challenges in implementing the intellectual disability awareness training in clinical practice. These included: a lack of policy and clear guidelines; lack of resources/technology; a lack of understanding of family/paid carers; culture of the hospital/senior managers who do not provide the staff needed to make the reasonable adjustments required; children and adults with an intellectual disability not a priority within the organisation/system; staff not having regular contact with people with an intellectual disability; hospital staff not able to implement the individual reasonable adjustments; and not all staff receiving the awareness training. This is the first time that these barriers to awareness trainings in this field has been collated. This is of benefit to policy makers, those who commission training programmes, hospital management, trainers, and clinical staff in acute hospital settings who need to be acutely aware of such barriers and offer policy commitments, fiscal arrangements (i.e., ring-fence budgets), and training guidelines to overcome such challenges.

### **Other cognitive disability populations**

Similar findings have been reported in two recent systematic reviews concerning other cognitively impaired populations. Abley et al. (2019) reviewed nine dementia awareness training programmes for staff working in acute hospital settings, and found some training programmes to be associated with increased staff knowledge and immediate post-training gains in reported staff confidence. However, the training programmes differed in curriculum, content, and delivery modes; and used differing outcome measures and were found to be generally of low quality. Moreover, *there was insufficient evidence to conclude that these educational interventions for staff lead to improved patient outcomes*' in this population (p. 201). Scerri et al. (2017) in their systematic review of 14 dementia awareness training programmes delivered in acute hospitals, reported similar results concerning variations in curriculum, content, different modes of delivery and use of different outcome measures. Studies overall

were found to be methodologically weak, with no changes reported in the clinical care of older adults with dementia.

There is also growing research that children and adults with autistic spectrum disorder have also unmet substantial health needs leading to health inequalities and poor care in acute hospitals. For example, Bradshaw et al. (2019) undertook a systematic review of 23 research studies that explored the healthcare needs of autistic adults without an intellectual disability. Bradshaw and colleagues highlighted three types of barriers to good quality care: 1) patient-level factors (i.e., communication, sensory issues, anxiety, etc), 2) provider-level factors (i.e., a lack of provider knowledge, a lack of staff training, etc.) and 3) system-level factors (i.e., accessibility of health-care facilities and limited referral pathways, etc.).

The curricular-based and systems-related impact indicators identified in the current study could also be applied to other cognitively impaired populations such as those with dementia, autistic spectrum disorders, acquired brain-injury, and other marginalised groups within acute hospital settings. Health systems who target all cognitively impaired disability populations, approx. 15% of the total population, may be able to bring about greater changes within the acute hospital sector thereby leading to improvements in the health of this population (Cacari-Stone et al., 2014).

### **Mandatory Training Implications**

The findings of this study are timely and provide the necessary level of detail to support the development of Tier 1 trainings, as per the HEE (2016) and Dept of Health & Social Care (2019a). But they also provide valuable detailed guidance for other UK-specific attempts to improve service provision to people with intellectual disability. In 2018 NHS published the national 'Learning Disability Improvement Standards for NHS Trusts' across England (NHS, 2018) with the aim of improving outcomes and experiences of people using NHS services and reducing unwarranted variations in service quality. The improvement standards reiterated expectations associated with a range of national legislative and policy imperatives and required all NHS Trusts in England to put in place a range of improvement measures. These included: having a designated lead for people with an intellectual disability; having mechanisms to identify and flag people with an intellectual disability who use services; making reasonable adjustments to pathways of care; and empowering people to exercise their rights. With regard to healthcare workforce, the improvement standards required all NHS Trusts to ensure their staff received mandatory training, that was routinely refreshed, in the delivery of care and support to people with an intellectual disability in a way that takes account of their unique needs and health vulnerabilities and the importance of making individualised adjustments to how services are delivered.

More recently, the UK government published their response to the consultation on the mandatory intellectual disability and autism training for health and care staff (The 'Right to be Heard', Dept of Health & Social Care, 2019b). Alongside this, the NHS

'Long Term Plan' (NHS, 2019) committed the NHS in England *'to ensuring all people with a learning disability, autism, or both can live happier, healthier, longer lives'*. The findings of this study offer further exemplars of which systems-related impact indicators are needed in order to ensure the disability awareness training can now be effectively delivered, and evaluated, within clinical practice thereby leading to better clinical care. Our findings complement the 'Learning Disabilities Education and Training Framework' (HEE, 2016), 'Core Capabilities Framework for Supporting People with a Learning Disability' (HEE, 2019a) and also the new 'Core Capabilities Framework for Supporting Autistic People' (HEE, 2019b).

## **Policy and Practice Implications**

The findings of this study have important implications for policy makers, those who commission training programmes, hospital management, trainers, and clinical staff in acute hospital settings in how they can plan and deliver future intellectual disability, and other cognitively disabled populations, awareness training. Many aspects of current intellectual disability awareness training frameworks are supported by the findings of the study, especially with regard to their aims, design and content. However, given the lack of consensus regarding optimal training delivery approaches, any awareness training being developed, delivered or trialled, should include measures to enable future evaluation of delivery approaches.

The consensus regarding the need for continued attention to wider organisational context and mechanisms, that would otherwise serve as barriers, suggests it would be naïve of healthcare providers to solely rely on making awareness training programmes available in order to improve the outcomes and experiences of people with an intellectual disability. A series of critical areas are highlighted, that healthcare providers need to address, in order to maximise the impact of intellectual disability awareness training programmes.

## **Limitations**

A Delphi survey is a validated and robust framework that has been used extensively in the development of training programme content in various medical and nursing fields, including robotic surgery training (Collins et al., 2019), disaster preparedness for hospital nurses (Noh et al., 2018), and the development of nursing quality care process metrics and indicators for intellectual disability services (Doody et al., 2019). To the best of our knowledge, this is the first time that the Delphi survey framework has been used to determine the curricular-based and systems-related impact indicators of an intellectual disability awareness programme for acute hospital staff.

This study has nevertheless several limitations not least selection bias, based upon the opinions of experts and the small number of participants from certain countries

and professions. The participants within this study were international experts in primary and secondary healthcare, and the health of people with an intellectual disability, who had a broad range of experiences, knowledge, and perspectives who could make meaningful contributions in order to generate more robust results (Jorm, 2015). Although not all participants within this study were affiliated with these international organisations. While this study has produced a number of agreed curricular-based and systems-related impact indicators underpinned by evidence and clinical practice, a full evaluation of their implementation is required to consider their effectiveness.

This study did not seek the views of '*experts by experience*' and future studies might be improved by seeking the service users' voices enhancing our understanding of these curricular-based and systems-related impact indicators.

## **7 CONCLUSION**

This was the first international Delphi survey to identify curricular content and systems-related barriers, as well as potential impact indicators for intellectual disability awareness trainings for acute hospital settings. Over fifty international experts from mainstream primary healthcare and acute hospital settings, and intellectual disability health professionals, participated. This study has identified curricular-based and systems-related impact indicators that if fully implemented in acute hospital settings, could lead to people with an intellectual disability experiencing avoidable deaths and unwarranted variations in quality of care. The findings of this study have important implications for policy makers, those who commission training programmes, hospital management, trainers, and clinical staff in acute hospital settings in how they can plan and deliver future intellectual disability, and other cognitively disabled populations, awareness training.

The provision of intellectual disability awareness training to all acute hospital staff will be a significant step in addressing the discrimination which continues to exist in many health systems, despite the espoused rights of equal citizenship for this population (UN Convention on the Rights of Person with Disabilities, 2006). It will be important to test the effectiveness of awareness training so that future investment in education will be founded on the evidence that such training can make a difference to the quality of care of the children and adults with an intellectual disability, and their family carers. Acute hospitals need to invest in staff education, in order to bring about the desired outcomes for people with an intellectual disability, and other cognitive impairment, their family carers, and service improvement. However, investment in education will need to be accompanied by system changes regarding the governance of service provision for people with an intellectual disability.



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