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Prifysgol De Cymru

EVALUATION OF THE LEARNING DISABILITY ACUTE CARE BUNDLE

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February 2024

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1. Introduction

In 2022 Improvement Cymru issued a tender for an evaluation of the Learning Disability Acute Care Bundle (Bowness, 2014) that had been introduced into practice across Wales in 2014. The purpose of the evaluation was to determine whether the care bundle should:

- Continue in its present form,
- Be modified, or
- Be discontinued.

The views of four groups of stakeholders were to be sought:

- Learning disability acute care liaison nurses
- Senior nurses in learning disability services
- Secondary care staff from varying clinical areas
- Senior nurses in secondary care with responsibility for implementation of the care bundle

The University of South Wales were successful in securing the contract to undertake this piece of work and this report sets out the process followed, the results obtained, conclusions drawn, and the recommendations made.

2. Background and context

The Learning Disability Acute Care Bundle (Bowness, 2014) (hereafter referred to as the 'acute care bundle') was introduced in 2014 following the death of Paul Ridd, and several reports detailing inequalities in health and premature / avoidable deaths amongst people with learning disabilities (for example Michael, 2008; Heslop et al, 2013). It was developed jointly by the Public Health Wales 1000 Lives Programme and staff from Abertawe Morgannwg University Health Board, and aimed to assist acute health care services:

> *'…to be consistently alert to, and to respond to, the needs of people with learning disabilities, and their families and carers, when they access general hospital services'*

The care bundle comprised 4 key elements namely:

- The early recognition of patients with learning disabilities.
- Effective communication with patients, carers, family members and clinicians.
- Dignified, person centred care and treatment.
- Effective review and discharge planning.

In each area key actions to support these elements of care were identified.

Since 2014, however, there have been many changes in both policy and practice. For example, there has been an increase in the number of learning disability acute liaison nurses such that 6 of the 7 health boards now have such posts. The Health Profile was introduced in 2020 as a unified health communication tool to try and promote safe, timely and effective health care for people with learning disabilities. To support the provision of improved care within acute care settings learning disability champion training has been rolled out across Wales such that many wards and departments now have champions in place. In addition, more recently, the foundation level of the Paul Ridd Mandatory Training has been implemented providing all healthcare staff with key knowledge and understanding of the needs of people with learning disabilities.

Digital healthcare has also advanced since 2014. The Welsh Patient Administration System (WPAS) and Welsh Clinical Portal (WCP) have been rolled out across Wales and the Welsh Nursing Care Record (WNCR) has been introduced. Each of these has impacted on systems of communication and transfer of information within health services in Wales.

It is also important to note that over the period since the acute care bundle was introduced pressures on health care services have also increased. The Covid pandemic presented additional challenges and, post Covid, waiting lists for treatment have increased. Challenges in social care provision in the context of economic constraints have also led to pressures on hospital beds, delayed discharges, and pressures on healthcare staff.

It can thus be seen that the context in which the acute care bundle is delivered has changed significantly since its introduction in 2014. Also, during this period, the evidence regarding healthcare inequities and premature deaths experienced by people with learning disabilities has continued to expand alongside increased evidence relating to interventions developed to address such inequities. It is beyond the remit of this report to provide a comprehensive literature review. However, key studies are of relevance and worthy of note.

People with a learning disability have higher rates of acute care admissions than their non learning-disabled peers (Glover et al, 2019). However, such admissions vary between specialisms with a higher number of admissions to medical and paediatric care than to surgical areas. Glover et al also note that the admission of women to gynaecology and obstetrics is lower than their non-disabled peers and that rates of admission for dental care are higher for both men and women with learning disabilities. Caution is expressed, however, that the number of admissions reviewed in the study may be fewer than the actual number of admissions of people with learning disabilities. This is due to the data being based on a system of GP identification and GP records are often not complete in their identification of patients with a learning disability (Glover et al, 2019).

It has also been noted that people with a learning disability have a high rate of preventable admissions due to ambulatory care sensitive conditions that should be amenable to treatment in primary care (Glover et al, 2020). It can thus be seen that people with a learning disability are more likely to use acute healthcare services than their non-disabled peers. Given the health inequities they continue to experience it is thus important to assess the quality of their experience.

McCormick et al (2020) published a systematic review of the experiences of people with learning disabilities in acute care settings. Three key themes emerged from the studies they reviewed: communication, information sharing, and compassion and respect. They note continued poor communication between hospital staff and people with a learning disability but also that the support of a learning disability acute care liaison nurse and the use of a hospital (communication) passport significantly improve patient experience. Despite the existence of legislation mandating equality and the provision of reasonable adjustments, however, they conclude that there is still a need for improvement, and that increased use of hospital passports along with expansion of the liaison nurse role might lead to future improvements.

Similar concerns regarding a lack of reasonable adjustments in healthcare have been expressed by Heslop et al (2018). They point to the gap between legislation/ guidance and their implementation in practice. In an Irish study Moloney et al (2023) interviewed parents of individuals with learning disabilities regarding their experience of accessing acute care services.

Experiences were found to be mixed with the implementation of reasonable adjustments being limited or non-existent. A failure to make reasonable adjustments was identified as having a negative impact on individuals with a learning disability, their families and healthcare staff. The authors therefore call for the implementation of reasonable adjustments at a strategic level in healthcare services to ensure that person-centred care can be delivered (Moloney et al, 2023).

One reasonable adjustment (that also details how further adjustments can be made to ensure person-centred care) is use of a communication tool. In the context of Wales, a recent review of the Health Profile (Northway et al, 2023) concluded that, where the Health Profile is used, it is felt to promote safe and effective person-centred care. However, there remains a need to improve awareness of the tool across all stakeholders and some minor modifications to the format may be required. These findings are similar to those of a Canadian study which concluded that health passport tools have the potential to provide useful information and to enhance communication. However, 'continued efforts' are required to ensure that the tools are maintained and that healthcare staff are willing to use the information contained in the documents (Heifetz and Lunsky, 2018). These authors further suggest that fitting such tools into existing structures and practices is likely to be most successful since staff may be reluctant to engage in what is perceived as 'extra' work.

When the acute care bundle was launched acute care liaison services in Wales were in the early stages of development. Nonetheless, it did cite examples of some health boards where holders of such posts were contributing to elements of practice such as flagging of patients, coordination of care, and the provision of advice. It is, therefore, relevant to consider how evidence in concerning this role has developed since 2014.

In relation to the role of the learning disability acute liaison nurse it is interesting to note that NHS England have commissioned the organisation 'Changing Our Lives' to develop a competency framework and tool kit for this group of practitioners. The title of the project 'A Uniform Approach' (Changing Our Lives, 2023) suggests that the role has developed in different ways in different settings and that there is a desire for greater uniformity. Indeed, the project website indicates that the role is currently commissioned and supported in different ways across England. The first stage of this project has comprised a literature review from which the authors conclude that there is some evidence to support the view that acute liaison nurses have a positive impact on both patient safety and quality of care (Changing Our Lives, 2023). This position has also recently been restated in a report by the Health Services Investigation Agency (HSSIB, 2023) which recommends that best practice and workforce guidance relating to the role of the acute liaison nurse be developed for all acute hospitals to ensure appropriate support for people with a learning disability is available, as well as support for those providing care.

It is also relevant to note that research has been undertaken in Wales (Rees and Northway, 2022) focused on the role of the community learning disability nurse in supporting access to acute healthcare for people with a learning disability. This showed that even where acute care liaison nurses are in post, community learning disability nurses also play a significant role in enabling such access. This is relevant in the context of the acute care bundle given that it highlights the need to liaise with community learning disability teams.

Whilst not comprehensive, this brief review of the literature highlights issues of identification, communication, reasonable adjustments, and person-centred care all of which form important elements of the acute care bundle. Along with the practice and policy developments within

Wales since 2014 this evidence provides a context within which the subsequent evaluation has taken place. It will also provide the context for discussion of the findings later in this report.

3. Method

A two-stage process was adopted for this evaluation to gain breadth of information as well as to facilitate more in-depth discussion and clarification.

3.1 Online survey

To promote maximum participation within the short timescales required, an on-line survey using the JISC on-line survey software was utilised. Participants were sought from each of the four stakeholder groups identified by Improvement Cymru namely:

- Learning disability acute care liaison nurses
- Senior nurses in learning disability services
- Secondary care staff from varying clinical areas
- Senior nurses in secondary care with responsibility for implementation of the care bundle

Separate surveys were created for each of the above groups to reflect their different positions and perspectives. However, many questions appeared in each of the four surveys.

Basic demographic data in relation to health board and position were sought from participants to enable the representativeness of the responses to be assessed. The rest of the survey sought respondent views and experiences regarding each of the different elements of the acute care bundle (identification, communication, person-centred care planning, review and discharge). Most questions were fixed response but, in each section, respondents were invited to comment in open text format regarding what they felt was currently working well and what they felt needed to be improved.

Prior to distribution the survey was shared with Improvement Cymru to ensure that it encompassed all the required areas (face validity).

The invitation to participate in the survey was primarily distributed through each of the health boards. Direct emails inviting participation, and including the link to the survey, were sent to the acute care senior nurses, the learning disability liaison nurses, and the learning disability senior nurses. In relation to the acute care nurses then arrangements were made with the individual health boards to distribute an email template to acute care nursing staff within their organisation. The method of distribution of this email varied according to the individual health board.

In addition to the above, the survey for the acute care nurses was also advertised on social media and through the Paul Ridd Foundation to try and maximise participation.

As will be seen below in the section regarding ethics, the length of time it took to agree arrangements for distribution within the health boards varied. However, once agreement had been reached then 3 – 4 weeks were provided within each health board for survey responses to be submitted.

The JISC online survey tool allows for data to be exported to support analysis and provides descriptive statistics. This facility was used to analyse the quantitative data. The responses to the open questions were downloaded and transferred into a Word document then thematically analysed. This analysis was deductive rather than inductive in that the framework used comprised the different elements of the care bundle.

3.2 Focus groups

To 'sense check' the findings of stage one, and to enable issues to be discussed in more depth, stage two comprised a series of on-line focus groups. Respondents in stage one were invited to contact the lead researcher if they would be willing to participate in a stage two focus group. In addition, key members of Improvement Cymru staff were invited to participate. The intention was to conduct three focus groups – one with acute care staff, one with learning disability liaison nurses, and one with Improvement Cymru staff.

Each group followed the same procedure in which a PowerPoint presentation of the main results from stage one were presented. At the end of each section (relating to the elements of the care bundle) participants were asked to discuss them in relation to the following areas:

- How do the findings compare with their experience?
- Based on their experience what is working well?
- Based on their experience what needs to change?
- Why do they feel this?

In addition, at the end of the focus group participants were asked to consider whether the acute care bundle should be:

- Retained in its current form.
- Modified, or
- Discontinued

With the permission of participants, the focus groups were recorded, and a transcript developed using the transcribing facility within Teams. Following each group these transcripts were 'cleansed' to remove errors of transcription arising from voice recognition issues. These transcripts were then thematically analysed with most themes being deductive (linked to the elements of the acute care bundle and issues identified in the survey) and some inductive (themes that arose from the discussion). The analysis was undertaken by the first author and checked by another member of the team who was also present during the focus groups.

4. Ethics and governance

Ethical approval was secured from the Faculty of Life Sciences and Education Ethics Committee at the University of South Wales.

Participation in the project was voluntary and full information was provided to assist potential participants with decision making concerning their participation. In relation to the survey, submission of the survey response was taken as indication of consent for the data provided to be included in the study. In relation to the focus groups a signed consent form was required before an invitation to a participate focus group was forwarded. Permission to record the focus group was also checked again with participants at the beginning of each group.

The names of individuals were not requested in relation to the survey, only position and health board. In writing this report the names of individual health boards are not directly linked to data, with each health board being assigned a letter for identification purposes. In relation to focus groups participants were assigned a participant number. These measures were included to promote anonymity and confidentiality and to encourage open and honest responses.

Securing ethical approval was, however, only the first stage of the process. Since this is a service evaluation which seeks to collect data from health staff it was necessary to secure approval from each health board for the service evaluation to proceed within their area. This proved to be a complex and lengthy process with each health board having a different procedure. Issues that arose included:

- Identifying the appropriate point of contact within the health board to initiate the approvals process.
- Health boards seeking to locate responsibility for oversight of the acute care bundle with the learning disability directorate rather than the acute care directorate(s).
- One health board required the lead researcher to secure a full research passport despite this being a service evaluation.
- Some health boards required online documentation to be completed but the system was only accessible to health board staff. In one instance this led to a delay in completing the information as the researcher was reliant upon the timescales of the health board member of staff who was not familiar with the process.
- Delays in the application for approval being considered by the relevant health board committee.

However, it was deemed essential that staff in all health boards had the opportunity to participate in this evaluation. Therefore, after discussion with Improvement Cymru staff it was agreed to extend the timeline of the project.

Data collection in each health board commenced as soon as approvals had been secured. Approval from the final health board was secured in late August 2023, However, further delays in distribution of the survey within the health board meant that the deadline for submission of survey responses had to be extended to the end of September.

5. Results

5.1 Stage one – survey

The results of the on-line survey are presented here in relation to each of the elements of the acute care bundle with the quantitative data being presented first and then the open comments. These comments detail both areas where respondents felt things are currently working well and also those where they feel improvement is needed. First, however, the demographic information is provided.

5.1.1 Participant characteristics

Overall, 67 participants completed the surveys and the number completing each of the individual surveys is detailed below in Table 1.

Participant group	Number of responses
Acute care senior nurses	4
Acute care nurses	49
Learning disability senior nurses	7
Learning disability acute care liaison nurses	7
Total	**67**

Table 1: Respondent numbers by survey group

Responses were received from each of the 7 health boards in Wales as detailed below in Table 2:

Health board	Number of responses
A	8
B	12
C	11
D	14
E	11
F	5
G	6
Overall	67

Table 2: Respondent numbers by Health Board

Responses were also received from nurses employed at all pay bands from 3 – 8 as detailed in Table 3 below:

Staff banding	Number of responses
3	6
4	1
5	12
6	14
7	10
8	24
Overall	67

Table 3: Respondent numbers by pay band

The 49 responses from nurses working in acute care settings were received from a range of clinical backgrounds as detailed in Table 4 below:

Clinical area	**Number of responses**
Outpatients	3
Day surgery	2
Accident and emergency	7
Minor injuries	1
Intensive therapy unit	2
Medical assessment unit	5
General medical	5
General surgical	4
Cardiology	1
Oncology	1
Gastro-intestinal	1
Respiratory	1
Neurology	3
Theatres and recovery	1
Care of older people	3
Children	1
Other	8
Overall	**49**

Table 4: Respondent numbers by clinical specialty

Despite offering orthopaedics and maxillo-facial as areas of clinical specialism no respondents indicated that they were working in these areas.

Respondents from the acute care nurses' group were also asked a number of additional questions regarding their experience and training. All 49 respondents answered these questions, and their responses are detailed in Table 5 below:

	Yes	No	Unsure
Have you provided care for patients with a learning disability in your clinical area in the past 12 months?	46 (93.9%)	2 (4.1%)	1 (2%)
Are you aware of the Learning Disability Care Bundle?	37 (75.5%)	7 (14.3%)	5 (10.2%)
Are you aware of where information can be found in your clinical area regarding the Learning Disability Care Bundle?	36 (73.5%)	10 (20.4%)	3 (6.1%)
Does your clinical area have learning disability champions?	34 (69.4%)	6 (12.2%)	9 (18.4%)

Table 5: Respondent experience in relation to care provision and awareness of the Acute Care Bundle

Respondents were asked whether they had undertaken the foundation level of the Paul Ridd Mandatory Training. Thirty-three (67.3%) said they had whilst 16 (32.7%) indicated they had not. In relation to the Paul Ridd Learning Disability Champions training 20 (40.8%) had undertaken the training whilst 29 (59.2%) had not.

5.1.2 Identification of patients with a learning disability

For the acute care bundle to be implemented it is essential that patients with a learning disability are identified when they attend/ are admitted to an acute care setting. The survey thus asked respondents about the existence of a system for achieving this (often referred to as 'flagging') and the effectiveness of such a system.

All four respondent groups were asked whether there is a system in place in their clinical area/ health board to identify when patients with learning disabilities are admitted to acute care settings. Their responses are detailed in Table 6 below:

Within your hospital is there a system for identifying (flagging) patients with a learning disability when they attend/ are admitted?			
	Yes	No	Unsure
Acute care senior nurses (n=4)	4 (100%)		
Acute care nurses (n=49)	41 (83.7%)		8 (16.3%)
Learning disability senior nurses (n=7)	6 (85.7%)	1 (14.3%	
Learning disability liaison nurses (n=7)	7 (100%)		
Total (n=67)	**58 (86.5%)**	**1 (1.5%)**	**8 (11.9%)**

Table 6: Frequency of 'flagging' system

However, having a system in place, and that system working effectively, can be two different things. Therefore, respondents were also asked (if a system is in place) to rate how effective it is. Their responses are detailed in Table 7 below:

If there is a system how effective is it?				
	Very effective	Effective	Partially effective	Not effective
Acute care senior nurses (n=4)	2 (50%)		2 (50%)	
Acute care nurses (n=44)*	6 (13.3%)	21 (46.7%)	16 (35.6%)	2 (4.4%)
Learning disability senior nurses (n=7)	2 (33.3%)	1 (16.7%)	3 (50%)	
Learning disability liaison nurses (n=7)		5 (71.4%)	2 (28.6%)	
Total (n=62)	**10 (16.1%)**	**27 (43.5%)**	**23 (37%)**	**2 (3.2%)**

Table 7: Perceived effectiveness of the 'flagging' system

* Five respondents did not answer this question as they were not aware of a flagging system being in place

The learning disability liaison nurses were also asked how often they had to initiate the flagging process. One (14.3%) responded 'always' whilst the other 6 (85.7%) responded 'sometimes'.

Some respondents took the opportunity to make comments in the open question sections relating to systems for identifying patients with a learning disability. From the perspective of acute care senior nurses, it was felt that some systems (such as patient notification systems and safe to start meetings) were working well. However, it was also felt that improvements were still needed where different systems are used in different parts of a hospital. A patient notification system introduced in one health board to alert staff to patients registered as having a learning disability with their GP practice was felt to be much more effective than reliance on acute care staff to identify patients with a learning disability. Nonetheless, it was also noted that this did not work for patients not registered with a GP and those admitted from out of area.

Acute care nurses also identified several things that they felt were working well. These included pre alerts and alerts along with discussion at daily site wide meetings. Various tools (such as special folders, pain assessment tools, magnets, and stickers) were identified as being helpful. Like the senior nurses they also identified the acute are liaison nurse as playing a key role and, where the post was currently vacant, the negative impact of this was noted:

> *'Unfortunately, very limited support due to no LD nurse cover hospital'* (Respondent 2595)

Several areas for improvement were also identified by the acute care nurse respondents. These included the need to increase awareness of the care bundle and, in particular, it was noted that agency and bank staff are often not fully aware of systems. Even though learning disability awareness training is now mandatory it was noted that this is not occurring in one health board.

Some learning disability liaison nurses commented that the flagging system was working well and providing daily alerts and that the use of stickers / icons to promote better identification was helpful. However, problems were identified in relation to the transfer of information between services and flagging systems only applying to inpatient admissions.

5.1.3 Effective communication with patients, carers, family members and clinicians

Survey questions relating to the ‘communication’ element of the acute care bundle included issues relating to use of the Health Profile, communication with patients and their families, and communication between professionals.

When an individual with a learning disability is admitted / attends an acute care setting it is important that all the staff team are aware of their needs. Respondents were therefore asked whether this occurs. Their responses are detailed below in Table 8:

When an individual with a learning disability attends/ is admitted to your clinical area are all clinical staff informed that the individual has a learning disability?					
	Always	Often	Sometimes	Never	Unsure
Acute care senior nurses (n=4)	2 (50%)	1 (25%)	1 (25%)		
Acute care nurses (n=44)*	22 (44.9%)	16 (32.7%	10 (20.4%)		1 (2%)
Learning disability senior nurses (n=7)	2 (28.6%	1 (14.3%)	3 (42.9%)		1 (14.3%)

Table 8: Communication regarding individuals with learning disabilities

The Health Profile contains key information to promote safe and effective care of individuals with a learning disability and aims to enhance communication. Introduced in 2020, on an all Wales basis, its use has been promoted to people with learning disabilities, their families and paid carers, and health professionals. The acute care senior nurses, acute care nurses and learning disability senior nurses were asked how frequently patients with a learning disability brought their Health Profile with them when they attend/ are admitted to acute care hospitals. Their responses are detailed in Table 9 below:

When patients with a learning disability attend/ are admitted to an acute care setting in your health board/ clinical area how often do they take their Health Profile with them?					
	Always	Often	Sometimes	Never	Unsure
Acute care senior nurses (n=4)		1 (25%)	2 (50%)		1 (25%)
Acute care nurses (n=49)	3 (16.1%)	4 (8.2%)	37 (75.5%)	2 (4.1%)	3 (6.1%)
Learning disability senior nurses (n=7)	1 (14.3%)	2 (28.6%)	3 (42.9%)		1 (14.3%)
Total (60)	**4 (6.7%)**	**7 (11.7)**	**42 (70%)**	**2 (3.3%)**	**5 (8.3%)**

Table 9: Frequency of patients with a learning disability bringing their health profile to health appointments

The learning disability liaison nurses were asked a similar question, but this was split into outpatient and inpatient attendances / admissions. Their responses are detailed in Table 10: below:

When patients with a learning disability attend/ are admitted to an acute care setting in your health board/ clinical area how often do they take their Health Profile with them?					
	Always	Often	Sometimes	Never	Unsure
Outpatient appointments			6 (85.7%)	1 (14.3%)	
In-patient admissions		1 (14.3%)	6 (85.7%)		

Table 10: Frequency of patients with a learning disability bringing their health profile to health appointments (acute care liaison nurses)

The guidance for health professionals relating to their use of the Health Profile stresses that they should ask to see an individual's Health Profile if it is not offered to them. If the individual does not have such a document, they are asked to encourage completion of one and/ or to support this activity. The acute care senior nurses and the acute care nurses were, therefore, asked if this occurs in their hospital / they do this. Their responses are detailed in Table 11 below:

		Always	Often	Sometimes	Never	Unsure
When a patient with a learning disability attends/ is admitted do you ask to see their Health Profile if they do not offer it to you?	Acute care senior nurses	1 (25%)	1 (25%)	1 (25%)		1 (25%)
	Acute care nurses	14 (28.6%)	15 (30.6%)	10 (20.4%)	6 (12.2%)	4 (8.2%)
How often do you need to prompt or assist individuals with a learning disability, their family/ carers, to complete a Health Profile?	Acute care senior nurses	1 (25%)	2 (50%)			1 (25%)
	Acute care nurses	5 (10.2%)	10 (20.4%)	20 (40.8%)	6 (12.2%)	8 (16.3%)

Table 11: Frequency of acute care staff requesting to see the Health Profile and supporting individuals to complete a Health Profile

The learning disability liaison nurses and the learning disability senior nurses were also asked about the extent to which they or the learning disability nurses they manage prompt individuals, their families and carers to complete a Health Profile. Their responses are detailed in Table 12 below:

How often do you need to prompt or assist individuals with a learning disability, their family/ carers, or clinical staff to complete a Health Profile?					
	Always	Often	Sometimes	Never	Unsure
Learning disability liaison nurses	1 (14.3%)	4 (57.1%)	2 (28.6%)		
Learning disability senior nurses	3 (42.9%)		2 (28.6%)		2 (28.6%)

Table 12: Frequency of learning disability nursing staff prompting/ assisting individuals to complete a Health Profile

A Health Profile is only effective if it is read and used to inform care planning and delivery. Respondents were therefore asked to indicate the frequency with which the Health Profile is used in practice by clinical staff to inform care delivery. Table 13 below details their responses:

In your experience how often do staff in your hospital access and use the Health Profile when a patient with a learning disability attends / is admitted?					
	Always	Often	Sometimes	Never	Unsure
Acute care senior nurses (n=4)	2 (50%)		1 (25%)		1 (25%)
Acute care nurses (n=49)	9 (18.4%	13 26.5%)	20 (40.8%0	4 (8.2%)	3 (6.1%)
Learning disability liaison nurses (n=7)		3 (42.9%)	4 (57.1%)		
Learning disability senior nurses (n=7)	1 (14.3%)	2 (28.6%)	1 (14.3%)		3 (42.9%)
Total (67)	**12 (17.9%)**	**18 (26.9%)**	**26 (38.8%)**	**4 (6%)**	**7 (10.4%)**

Table 13: Frequency of healthcare staff accessing and using the Health Profile

The learning disability liaison nurses were asked whether they were routinely informed when a patient with a learning disability is admitted / attends the acute care setting. Five (71.4%) indicated 'always' whilst 2 (28.6%) stated 'sometimes'. In relation to who provides this information they were asked to identify all key informants they have experienced. Four (57.1%) indicated the patient's family, 4 (57.1%) their paid carers, 6 (85.7%) the ward team and 5 (71.4%) the community learning disability team.

The acute care senior nurses and acute care nurses were asked whether acute care liaison nurses (where employed) and community learning disability teams are informed when a patient with a learning disability is admitted. Their responses are provided in Table 14 below:

		Always	Often	Sometimes	Never	Unsure
If there is a learning disability liaison nurse in your hospital how often are they informed when an individual with a learning disability is admitted to your clinical area?	Acute care senior nurses	3 (75%)				1 (25%)
	Acute care nurses	14 (28.6%	12 (24.5%)	10 (20.4%)	5 (10.2%)	8 (16.3%)
When an individual with a learning disability is admitted your hospital how often is the relevant Community Learning Disability Team informed of the admission?	Acute care senior nurses	1 (25%)	2 (50%)			1 (25%)
	Acute care nurses	9 (18.4%)	11 (22.4%)	12 (24.5%)	5 (10.2%)	12 (24.5%)

Table 14: Frequency of informing acute care liaison nurses and community learning disability teams of admissions

Facilitating and supporting communication (with both the individual patient and their family and carers) is a key role of acute care liaison nurses and so they were asked about the frequency with which they perform this role. Table 15 below details their responses:

	Always	Often	Sometimes	Never	Unsure
How often are you called upon to support effective communication with patients with a learning disability?	1 (14.3%)	2 (28.6%)	4 (57.1%)		
How often are you called upon to support effective communication with families and/ or carers?	1 (14.3%)	4 (57.1%)	2 (28.6%)		

Table 15: Frequency of acute care liaison nurses being asked to support communication with individuals and their families

Finally, in relation to the communication elements of the care bundle, all respondents were given the opportunity to provide free comments in relation to what they feel is working well and what they feel needs to be improved.

A few comments were made in relation to the need to provide more support in relation to communication such as training regarding communication and communication aids being made more widely available. Some problems with cross border working were noted as were delays with flagging and referral to the learning disability liaison nurses. The need for more liaison nurses and more learning disability champions was identified.

The importance of the Health Profile was commented on:

> *'Health Profile is very helpful So it is absolutely vital it is made more available as a regular practice for effective communication and person centred care planning'* (Respondent 5976)

However, others commented that it was not always presented by patients and or care staff.

Finally, some respondents noted that environmental factors such as the lack of a quiet area and availability of single rooms had a negative impact on care.

Learning disability acute care liaison nurses commented that the relationships they had developed with clinical staff had led to improved communication especially in relation to scheduled care where it was possible to pre plan prior to admissions to ensure reasonable adjustments were in place. The introduction of learning disability champions training was also perceived as beneficial in increasing awareness and skills at a ward / department level.

The learning disability liaison nurses did, however, also identify areas for improvement. These related to the need for increased learning disability awareness amongst healthcare staff and for families and carers to be more aware of the liaison service. One respondent suggested that there was a need for a shared, generic system between health boards to improve access to information.

In relation to the Health Profile one learning disability liaison nurse respondent indicated that there is a need to have systems in place to 'push' all staff to read the document. They highlighted the need for catering staff to also do this given their central role in nutrition and hydration. This respondent also noted, however, that often people with learning disabilities often attend hospital without a Health Profile or that the information included in the document is poor quality. A need to promote the importance of the document amongst support staff was therefore identified. One respondent indicated that patients have said that they prefer the old hospital passport to the Health Profile. Finally, the need to extend the liaison service was identified:

> *'the service needs to be extended to 7 days a week (currently we do not cover weekends or bank holidays) and for there to be more than one member of the team in each of the acute settings'* (Respondent 2138)

The learning disability senior nurses indicated that the involvement of both the community learning disability team and the liaison nurses is improving communication and supporting better identification of patients with a learning disability. However, they also indicated there was a need for improvement in flagging systems and the need for WCCIS implementation across all health boards to ensure more effective communication and transfer of information. Finally, along with the other stakeholder groups they stressed the need for an increase in the learning disability liaison nurse workforce.

5.1.4 Person-centred care

This section of the acute care bundle requires that a person-centred care plan is developed with the patient, their family/ carers and that this is reviewed and updated. It should also be communicated to, and shared with, the ward team and a named nurse should be identified with whom the patient and their family / carers can link with during their admission. Accordingly, the survey asked questions in relation to each of these areas. In relation to the development of the person-centred care plan the responses are detailed in Table 16 below:

How often is a person-centred care plan developed when a patient with learning disabilities is admitted?					
	Always	Often	Sometimes	Never	Unsure
Acute care senior nurses (n=4)		2 (50%)	1 (25%)		1 (25%)
Acute care nurses (n=49)	14 (28.6%)	15 (30.6%)	13 (26.5%)	3 (6.1%)	4 (8.2)
Learning disability liaison nurses (n=7)		2 (28.6%	5 (71.4%)		
Learning disability senior nurses (n=7)	1 (14.3%	1 (14.3%)	3 (42.9%)		2 (28.6%)
Total (n=67)	**15 (22.4%)**	**20 (29.9%)**	**22 (32.8%)**	**3 (4.5%)**	**7 (10.4%)**

Table 16: Frequency of developing person-centred care plans

In terms of who is involved in the development of such a plan, respondents were asked to identify all parties involved. Their responses are detailed in Table 17 below:

Who is usually involved in development of this plan?					
	Acute care senior nurses	Acute care nurses	Learning disability liaison nurses	Learning disability senior nurses	**Total**
The patient with a learning disability	2 (50%)	38 (80.9%)	7 (100%)	6 (85.7%)	**53 (79.1%)**
The family	2 (50%)	38 (80.9%)	7 (100%)	6 (85.7%)	**53 (79.1%)**
Their carers	2 (50%)	35 (74.5%)	6 (85.7%)	7 (100%)	**50 (74.6%)**
The learning disability liaison nurse	2 (50%)	29 (61.7%)	6 (85.7%)	7 (100%)	**51 (76.1%)**
The community learning disability team	2 (50%)	19 (40.4%)	5 (71.4%	6 (85.7%)	**32 (47.8%)**
The hospital based multi-disciplinary team	1 (25%)	21 (44.7%)	6 (85.7%)	6 (85.7%)	**34 (50.7%)**
Other	2 (50%)		1 (14.3%)		**3 (4.5%)**

Table 17: Frequency of stakeholder involvement in development of the person-centred plan

Reasonable adjustments are an important part of a person-centred care plan. Respondents were therefore asked how frequently these were noted in the plan (where appropriate). Their responses are provided in Table 18 below:

Where appropriate, are any reasonable adjustments required included in this plan?						
	Always	Often	Sometimes	Never	Unsure	Not applicable
Acute care senior nurses (n=4)	1 (25%)	2 (50%)				1 (25%)
Acute care nurses (n=49)	19 (38.8%)	13 (26.5%)	10 (20.4%)	2 (4.1%)	5 (10.2%)	
Learning disability liaison nurses (n=7)	3 (42.9%)	2 (28.6%)	2 (28.6%)			
Learning disability senior nurses (n=7)	1 (14.3%)	2 (28.6%)	1 (14.3%)		3 (42.9%)	
Total (67)	**24 (35.8%)**	**19 (28.4%)**	**13 (19.4%)**	**2 (3%)**	**8 (11.9%)**	**1 (1.5%)**

Table 18: Frequency of including reasonable adjustments in the person-centred care plan

The acute care staff were also asked whether, in their clinical area, resources were available to assist them in making reasonable adjustments (for example Easy Read information). Thirty-nine (79.6%) said they were, 3 (6.1%) said no, and 7 (14.3%) said they were unsure.

Respondents were asked whether the person-centred care plan is communicated effectively to all staff in the clinical area. Table 19 below details their responses:

Is the care plan communicated effectively to all the staff team in the relevant clinical area?					
	Always	Often	Sometimes	Never	Unsure
Acute care senior nurses (n=4)	2 (50%)	1 (25%)			1 (25%)
Acute care nurses (n=49)	15 (30.6%)	12 (24.5%)	13 (26.5%)	4 (8.2%	5 (10.2%)
Learning disability liaison nurses (n=7)	1 (14.3%	2 (28.6%)	2 (28.6)		2 (28.6%
Learning disability senior nurses (n=7)	1 (14.3%		3 (42.9%		3 (42.9%)
Total (n=67)	**19 (28.4%)**	**15 (22.4%)**	**18 (26.9%)**	**4 (6%)**	**11 (16.4%)**

Table 19: Frequency of communicating the person-centred care plan to all staff

The final question in this section asked respondents whether there is a named nurse to act as point of contact for the patient and their family / carers. Their responses are detailed in Table 20 below:

Is a named nurse identified as a key point of contact for the patient with a learning disability and their family/ carers during an admission?					
	Always	Often	Sometimes	Never	Unsure
Acute care senior nurses (n=4)	1 (25%)	1 (25%)	1 (25%)		1 (25%)
Acute care nurses (n=49)	11 (22.4%)	5 (10.2%)	15 (30.6%)	10 (20.4%)	8 (16.3%)
Learning disability liaison nurses (n=7)		1 (14.3%)	2 (28.6%)	2 (28.6%)	2 (28.6%)
Learning disability senior nurses (n=7)	1 (14.3%)	1 (14.3%)	2 (28.6%)		3 (42.9%)
Total (n=67)	**13 (19.4%)**	**8 (11.9%)**	**20 (29.9%)**	**12 (17.9%)**	**14 (20.9%)**

Table 20: Frequency with which a named nurse is identified

Respondents were given the opportunity to comment using free text concerning what they feel is currently working well in relation person centred care and what improvements they feel are needed. In relation to what is working well comments were made concerning early identification of patients with a learning disability and the Health Profile (although the latter was qualified by the phrase ‘when used’). Once again learning disability liaison nurses were viewed as having a positive impact both in terms of supporting direct patient care and in in relation to facilitating communication within the acute care setting and across settings. One response made specific reference to the value of them being present during doctors rounds to explain to patients what is being said. Some areas for improvement were identified with one respondent feeling that work in this area needs to be an MDT responsibility rather than just being nurse driven. The need for increased awareness training and for doctors to become learning disability champions were also suggested. Finally, two respondents pointed to the need for increased use of the Health Profile with one stating:

> *‘To ensure health profile always comes with a patient - it would be amazing if these were attached to a patient's digital record’* (Respondent 7649)

Some acute care nurses commented that care planning is working well and that all care is person centred. Key elements of this were attributed to collaborative development of plans, getting to know what is important for the individual with a learning disability, and MDT input. Close working with the learning disability liaison nurse was mentioned several times as having a positive impact. In relation to the need for improvement some felt that more MDT involvement is needed. Several respondents referred to the need for increased education and awareness training although one commented on current barriers to this:

> *‘We have very poor LD training awareness uptake with all Dr and consultants. Most of hospital staff are not released to attend LD awareness training. If they do attend, its in their own time’* (Respondent 7615)

The need for earlier identification of patients with a learning disability was felt to be needed to promote planning at the earliest possible stage. Finally, one respondent commented that they would welcome the opportunity to make improvements to the environment (for example quiet areas, low stimulus, music) to improve care delivery.

The learning disability liaison nurses commented that through their involvement they could ensure that the individual remains the focus of care planning and that reasonable adjustments are in place. One also commented that acute care staff are becoming more aware of how the development of appropriate plans assists them in their role. The Health Profile was also mentioned:

> *‘The increased use of the health profile/hospital passport has really helped with person centred care-planning. There has also been a huge improvement in the engagement across the board with wards, outpatient departments and surgical teams’* (Respondent 4623)

In terms of areas for improvement the learning disability liaison nurses echoed comments from other stakeholders in relation to the need for additional training and awareness amongst acute care staff. One respondent noted that there is still some reluctance amongst acute care staff to engage although the pressures on acute care staff were also acknowledged:

> *‘The staffing pressures of the wards mean that it is rarely possible to allocate a key point of contact. As liaison nurses we tend to rely on the ward sisters for our communications as they are most likely to be among the regular establishment of staff. In the absence of the*

> *sister, the wards are often run by agency staff which makes consistency in person-centred approaches very difficult to maintain.'* (Respondent 4623)

Another respondent noted that within their hospital a named nurse system is not in operation and that including this in the care bundle may give rise to unrealistic expectations.

Some learning disability senior nurses indicated that involvement of the learning disability liaison nurses and the community learning disability team was assisting with the delivery of person-centred care but one also commented that MDT involvement was limited to discharge planning and not a key element of person-centred planning. In relation to areas for improvement then workforce development, the need for a standard form on the Welsh National Care Record, and an improvement when patients are admitted to another health board area were noted. Finally, one respondent identified the need for acute care services to take responsibility for the care bundle:

> *'Ownership by the acute hospital setting rather than expectation of liaison nurse role.' (Respondent 0963)*

5.1.5 Effective review and discharge planning

The final section of the acute care bundle relates to review of care whilst an individual with a learning disability is in hospital and the planning that should occur prior to their discharge. Questions were asked about each of these areas.

The care bundle indicates that there should be a review of progress within seven days of admission. Respondents were asked whether this occurs in their clinical area / health board. The responses are set out in Table 21 below:

When patients with a learning disability are admitted to your hospital how often is there a review of patient progress within seven days of admission?					
	Always	Often	Sometimes	Never	Unsure
Acute care senior nurses (n=4)	3 (75%(				1 (25%)
Acute care nurses (n=49)	12 (24.5%)	11 (22.4%)	10 (20.4%)	4 (8.2%)	12 (24.5%)
Learning disability liaison nurses (n=7)	3 (42.9%)	1 (14.3%)	2 (28.6%)		1 (14.3%)
Learning disability senior nurses (n=7)	1 (14.3%)	3 (42.9%)	1 (14.3%)		2 (28.6%)
Total (n=67)	**19 (28.4%)**	**15 (22.4%)**	**13 (19.4%)**	**4 (6%)**	**16 (23.9%)**

Table 21: Frequency of patient progress review within seven days of admission

Respondents were also asked who is usually involved in these reviews (they could tick more than one option). Their responses are detailed in Table 22 below:

Who is usually involved in this review?					
	Acute care senior nurses	Acute care nurses	Learning disability liaison nurses	Learning disability senior nurses	**Total**
The patient with a learning disability	2 (50%)	6 (12.2%)	6 (85.7%)	7 (100%)	**21** **(31.3%)**
The family	2 (50%)	4 (8.2%)	6 (85.7%)	7 (100%)	**19** **(28.4%)**
Their carers	2 (50%)	1 (2%)	6 (85.7%)	6 (85.7%)	**15** **(22.4%)**
The learning disability liaison nurse	2 (50%)	4 (8.2%)	6 (85.7%)	7 (100%)	**19** **(28.4%)**
The community learning disability team	2 (50%)	5 (12.2%)	3 (42.9%)	6 (85.7%)	**16** **(23.9%)**
The hospital based multi-disciplinary team	2 (50%)	15 (30.6%)	6 (85.7%)	7 (100%)	**30** **(44.8%)**
Other	2 (50%)	3 (6.1%	1 (14.3%)	1 (14.3%)	**7** **(10.4%)**
Reviews not conducted		10 (20.4%)			**10** **(14.9%)**

Table 22: Frequency of stakeholder involvement in progress review

Respondents were also asked to indicate who usually initiates such review meetings. The responses provided are set out in Table 23 below:

In your experience who usually initiates such meetings?					
	Acute care senior nurses	Acute care nurses	Learning disability liaison nurses	Learning disability senior nurses	**Total**
The patient with a learning disability		2 (4.1%)			**2 (3%)**
The family		3 (6.1%)			**3 (4.5%)**
Their carers		2 (4.1%)			**2 (3%)**
The learning disability liaison nurse	3 (75%)	9 (18.4%)	6 (85.7%)	5 (71.4%)	**23 (34.3%)**
The community learning disability team		6 (12.2%)	2 (28.6%	3 (42.9%)	**11 (16.4%)**
The hospital based multi-disciplinary team	2 (50%)	26 (53.1%)	3 (42.9%)	2 (28.6%)	**33 (49.3%)**
Other	1 (25%)	6 (12.2%)			**7 (10.4%)**
Reviews not conducted		11 (22.4%)			**11 (16.4%)**

Table 23: Frequency with which different stakeholders initiate review meetings

Where a patient’s needs have changed between admission and discharge then the acute care bundle requires that an agreed discharge plan is put in place. Respondents were asked about their experience of this, and their responses are detailed in Table 24 below:

Where a patient’s needs have changed between admission and discharge is an agreed discharge plan put in place?					
	Always	Often	Sometimes	Never	Unsure
Acute care senior nurses (n=4)	2 (50%)	1 (25%)			1 (25%)
Acute care nurses (n=49)	12 (24.5%)	14 (28.6%)	11 (22.4%)	3 (6.1%)	9 (18.4%)
Learning disability liaison nurses (n=7)	2 (28.6%)	5 (71.4%)			
Learning disability senior nurses (n=7)	1 (14.3%	2 (28.6%)	3 (42.9%		1 (14.3%)
Total (n=67)	**17 (25.4%)**	**22 (32.8%)**	**14 (20.9%)**	**3 (4.5%)**	**11 (16.4%)**

Table 24: Frequency with which a discharge plan is put in place when a patient’s needs have changed since admission

As with the other sections of the survey, respondents were given the opportunity to provide free text comments about what they feel is working well and what needs to be improved in relation to review and discharge planning. In relation to what is working well then, once again, the input of the learning disability liaison nurses was noted as was the ‘informal’ reviews that they regularly undertake of patients with a learning disability to identify changes in health status and needs. Improvement was, however, noted as being required in terms of providing cover for the liaison nurses when they are on leave or off sick. Another respondent commented:

> *‘The processes are in place and we need to keep improving staff awareness/education around the requirements of the bundle’* (Respondent 3455)

From the perspective of acute care nurses then MDT involvement and good communication (with patients, family, other professionals) were frequently identified as working well. One respondent specifically referred to the beneficial input of the community learning disability team:

> *‘If a member of the CLDT is involved there appears to be a more robust and safe discharge plan with the appropriate professionals and carers/parents involved.’* (Respondent 8626)

Interestingly the same things that were viewed as working well by some were seen as areas needing improvement by others namely communication and MDT involvement. Some respondents commented on the need for increased involvement / availability of learning disability liaison nurses. Also, some felt that discharge processes are too lengthy:

> *'Things tend to take a long time! Due to the amount of people involved in their care, things tend to happen very slowly and sometimes discharges can be delayed quite severely once the patient is medically fit for discharge'* (Respondent 0072)

The learning disability liaison nurses reported that they felt their involvement in review and discharge planning was working well and that this was achieved through taking a proactive approach and developing effective relationships with colleagues. However, one respondent felt that discharge meetings should be mandated for patients with a learning disability and another that the responsibility for leading discharge planning should be more clearly identified. Finally, one respondent highlighted the difficulties that can be experienced when seeking to effect discharge and the detrimental effect this can have on the patient:

> *'Discharge planning can be hindered by expectations and requests of care providers which are sometimes unrealistic and can lead to patients becoming deconditioned through lengthy stays in hospital'* (Respondent 4623)

The same respondent also noted that underlying such situations is often a lack of an appropriate social care package and disagreements between agencies regarding responsibility for funding.

Finally, the learning disability senior nurses echoed some of the views of the other groups in terms of what is working well namely coordination by the learning disability liaison nurses, involvement of the community learning disability team and effective interprofessional relationships. In relation to areas needing improvement then the need for an increase in the workforce was identified as were difficulties that can arise when patients are admitted (and hence discharged) out of area. The issues relating to social care provision impacting on discharge were also highlighted:

> *'Quicker ways to enhance care provision if needed, social care provision lacking if person requires a different care package.'* (Respondent 0963)

Another respondent also noted that communication with social care and commissioners needed improvement.

5.2 Stage two – focus groups

The original intention had been to hold three focus groups – one with acute care nurses, one with acute liaison nurses, and one with Improvement Cymru staff. However, no acute care nurses contacted the lead researcher to indicate that they would be willing to participate in a focus group. In addition, it was difficult to arrange groups within the required timeframe due to the work commitments of participants. Therefore, four groups were held – two with liaison staff and two with Improvement Cymru staff. A total of 9 individuals participated.

The transcripts of the focus groups were thematically analysed. Four themes were deductive in that they reflect the elements of the acute care bundle (identification, communication, person centred care and review/discharge). The other three were inductive in that they emerged from the discussion of the survey results and provide insight into the operational issues that arise in relation to implementation of the care bundle. These were the role of the acute liaison nurse, the need for education and awareness raising, responsibility and accountability, and the future of the care bundle. Each of these themes is explored below.

5.2.1 Identification of patients with a learning disability

Having an effective system for identifying patients with a learning disability is fundamental to implementation of the care bundle: without it then the required interventions will not be actioned. When presented with the survey findings focus group participants queried how survey respondents had interpreted the term ‘flagging’ and discussion highlighted several potential ways in which this could be understood.

All groups identified the presence of WPAS in which a ‘purple dot’ is used to identify that an individual has a learning disability. However, it was noted that clinical staff may not know the significance of the purple dot and that, unless the cursor is hovered above it, it would not provide the information that the individual has a learning disability:

> *‘I think WPAS, it's a little purple dot up in the top right hand corner of the screen so you can effectively say yes we have got a flagging system but whether people know what that purple dot means and whether that means that any action is taken as a result of that is open to question I would say’* (FG1 P2)
>
> *‘If you hover over it will tell you, but if you if you weren't to know, it's relatively easy to miss, but it is with all the alerts in the top right, the right hand corner.’* (FG2 P2)

It was also suggested that the term ‘flagging’ can be open to interpretation and could mean ‘flagging’ on a system or contacting the acute liaison nurse to inform them of an admission:

> *‘It's an interchangeable term for a lot of things.’* (FG3 P1)

Indeed, in one health board, in addition to the WPAS, there is a patient contact identifier system in which acute liaison nurses are emailed to inform them of an individual with a learning disability attending ED / being admitted with additional emails being sent to notify of any changes in ward. This system was reported to lead to a 65% increase in individuals referred to the liaison nursing team and highlighted any overnight or weekend admissions that the team might otherwise have been unaware of (due to the service being Monday to Friday 9 – 5). This system is based on the primary care liaison team working with GP practices to ensure that they accurately record if an individual has a learning disability and that individuals have an annual health check. When an admission to acute care takes place the GP record automatically triggers an alert within acute care.

In another focus group, however, difficulties with GP records were noted. In particular the range of Read codes that may be used to denote that an individual has a learning disability which means that it:

> *‘..is quite difficult to be able to identify exactly how many people for example have been flagged within … the system.’* (FG4 P1)

The participant indicated that this concern has been raised at an All-Wales level.

Problems were identified when individuals with a learning disability are admitted to an acute care setting in a different health board and, when they need to be admitted to services in England, since ‘flagging’ systems do not always work across health board boundaries. This means that community teams, primary care and acute liaison nurses may not be aware of some admissions. Other concerns were also expressed about systems not communicating with each other meaning that ‘flagging’ information is not always transferred across settings:

> *‘the other thing is, is the link with the Welsh PAS in in terms of the flagging, how that links in with the clinical portal and if you're flagged in Welsh PAS, you're not automatically flagged for example on the clinical portal system.’* (FG4 P1)

In relation to the question regarding effectiveness of flagging systems participants queried how survey respondents were judging effectiveness:

> *‘I'm not aware of a system… a specific system to monitor how effective flagging was.’* (FG3 P1)

One measure of effectiveness might be whether the system identifies all those with a learning disability who attend an acute hospital. However, a recurring theme across groups was the concern that many people (particularly those with mild learning disabilities) may not be identified within the acute care system:

> *‘… we also know that there are lots of people with LD who go into hospital and nobody actually knows about because nobody's reported them.’* (FG1 P2)

> *‘…the only way I'd know if it's effective was if it highlighted that somebody's coming to the hospital…But then you wouldn't know how many you've missed, either to know, yeah*.’ (FG3 P3)

A failure to identify some individuals with a learning disability would then mean that the supports available within the acute care bundle would not be triggered with potentially negative consequences. To address this situation some participants noted that they would try to work with ward staff to identify individuals but that this could be dependent on the willingness of staff. It was suggested that any developments in this area need to fit with the systems that clinical staff are currently using:

> *‘I think, and being solutions focused, and so because it's, you know it needs to be whatever it needs to be mainstream to within the systems they're using.’* (FG3 P1)

Another measure of effectiveness of a flagging system might be the extent to which a flag triggers the various actions outlined in the care bundle. Participants in the focus groups were therefore also asked their thoughts regarding survey responses concerning notification of community learning disability teams regarding admissions to acute care. It was noted that, since the care bundle was published, the criteria for referral to community learning disability teams have changed meaning that only those with the most complex needs are now supported by such teams.

> *‘Because of the stronger criteria for acceptance into see CLDT, I think a lot of people don't meet the eligibility criteria for CLDT now.’* (FG1 P2)

> *‘If they're not open to the team, why (would) you get the team involved?’* (FG3 P1)

This means that fewer people admitted are likely to be known to the community learning disability team (CLDT) and that if support is required post admission, then a new referral would need to be instigated.

Participant FG1 P2 also questioned whether the existence of acute liaison nurses (which is greater now than when the care bundle was introduced) might mean that acute care staff are less likely to refer to CLDTs. Another participant also suggested that CLDTs may not be contacted:

> *'Team can be contacted, but I don't know how often they would be contacted because that feels like more work for an acute ward, for example, you know, so kind of trying to work out, but you know, have them on liaison.'* (FG4 P1)

This participant also noted that when there are gaps in liaison nurse cover (for example whilst awaiting a replacement post holder) acute care staff may be reluctant to contact the CLDT for support.

5.2.2 Effective communication with patients, carers, family members and clinicians

A key strategy to improve communication between people with a learning disability and health professionals is the Health Profile. Referred to in the acute care bundle as a hospital passport the Health Profile was introduced in 2020 to try and standardise documentation across Wales and hence to improve patient safety. It was suggested in one focus group, however, that the Health Profile is not being consistently used with some still using older formats:

> *'There's no consistency with the, with the documentation that we use, but we really, really don't mind. It's more the quality of the information that's within that document. We don't care if it's the providers own or if it's a profile, or if it if it's our old hospital traffic light documents, as long as they've got that hospital passport, it's just so, so important.'* (FG2 P2)

In this instance the provision of key information is viewed as being more important than consistent use of the Health Profile.

To ensure that as many people as possible have a Health Profile one participant referred to the efforts that CLDTs are putting into supporting their completion:

> *'…so everyone open to our services will have a health profile and we do lots of training with people who are not open to our services in the community as well and some of our nurses will take health profiles out and health and complete them so they are starting to get recognised more when people do bring them, they're really good, but lots of people don't bring them'* (FG2 P1)

As noted above and below participants suggested that people with learning disabilities do not always bring their Health Profile with them when they attend acute care hospitals:

> *'…it's you know we've got an issue with ownership then people taking ownership and carers taking ownership of the health profile - we can bang on the door of the healthcare staff as much as possible (but) unless people are bringing them in and the more people are bringing them in the more they'll see them'* (FG3 P1)

> *‘We know a lot of people have got them at home, but if in an emergency situation often these things are left behind and then it's a bit of an afterthought…which is a real shame, because often when it's most needed is right in the very beginning.’* (FG2 P2)

Some suggestions were proposed as to why this might be the case:

> *‘The fact that it's a document that you carry around in some ways it means that you don't always have it with you…I think you know you don't always go to Marks and Spencer's on Saturday and have your health profile ready just in case you have a seizure and get whisked off to A&E, you know’* (FG1 P2)

In FG 1 participants also noted that there are several apps now in existence / development which might be a more practical way for individuals with a learning disability to carry with them the key information included in the Health Profile.

Even where they have a Health Profile people with a learning disability may not feel able to offer this to a health professional. The importance of asking individuals with a learning disability if they have a Health Profile was therefore noted:

> *‘It's about asking that question sometimes, isn't it? Do you have a health profile? Whether they have it with them or not, so long as they've got one and somebody can bring it in for them.’* (FG1 P2)

The same participant suggested that requesting sight of the Health Profile needs to commence at the earliest possible stage in the acute care journey:

> *‘…it's something to do with how it's asked for and when it's asked for, because I think you know, in A and E is probably where we're asking people to identify whether they've got one or the ambulance crews, you know, and then it it, it's a bit, you know, I don't think the message has got through that people can insist that people read it before they do anything with them or to them.’* (FG1 P2)

One participant highlighted the steps taken within their health board to promote use of the Health Profile:

> *‘…we always raise awareness around the health profile within the Health board and make sure that people, you know, as part of our policy in terms of asking the person has a health profile with them and if they don't have one, then the nurses or the liaison nurses in particular will support that individual to develop that health profile while they're in hospital’* (FG4 P1)

The importance of the Health Profile within the acute care bundle was also commented on:

> *‘… through all of the bundle this is one of the, you know, the health profile is one of the most important steps.’* (FG3 P1)

In particular one participant noted its importance in detailing what is ‘baseline’ for an individual and hence when the individual is ‘off’ baseline:

> *‘… one of the keys for me is having that baseline information because unfortunately… we do have a lot of people work with a lot of misconceptions and stereotypes of our*

> *individuals where they think that somebody might be actually at their baseline when that's they're nowhere near their baseline at all… And that document is can make all the difference… it's even saved people's lives.'*(FG2 P2)

Nonetheless, there was also recognition that even where an individual does have a Health Profile it is not always used by the nursing staff to inform care:

> *'…we've had a concern raised in the past, for example, where a parent felt that despite them encouraging the staff to look at an individual's health profile… it was dismissed by nursing staff'* (FG4 P1)

The final element of the communication section of care bundle discussed in the focus groups was the provision of a named nurse to act as a point of contact for the patient and their family / carers. Participants in the focus groups were presented with the survey responses in relation to this area.

Some participants expressed surprise that the responses to this question were as positive as they were given current pressures on staff within acute care settings:

> *'I think they people try to get regular nurses, but with the best will in the world, you know, everywhere…It's so short at the moment'* (FG2 P2)
>
> *'we know that it's quite dire straits in in the hospitals at the moment'* (FG3 P1)

Some participants suggested that all patients (whether or not they have a learning disability) have an identified nurse allocated to them for each shift. However, some participants also queried how the term 'named nurse' was being interpreted in this context:

> *'Definitely a language issue in that.'* (FG3 P1)

It was questioned whether some respondents were interpreting the acute liaison nurse as being the 'named nurse':

> *'… I'm wondering whether when they're saying yes, yes, there's a named nurse involved… It's the acute liaison nurse and not necessarily somebody on the wards, which is what the intention of the care bundle was.'* (FG1 P2)

5.2.3 Person centred care

Participants in the focus groups were presented with survey findings in relation to person centred care planning (including who is involved) and reasonable adjustments.

The care bundle requires that, regardless of length of stay, a person-centred care plan is developed with the patient and their family / carers. A key point of discussion was what is understood by the term *'person centred care planning'* and whether this was being interpreted by some respondents in the survey as simply completing the admission documentation and assessment.

The point was also made in more than one focus group that all patients (whether or not they have a learning disability) should have a person-centred care plan:

> *‘I do wonder what they what their perspective is, … but person-centred care is not alien to, you know it's not unique to LD nursing, so you'd expect your general nurses to equally understand that.’* (FG1 P1)
>
> ‘*My one thought is all care plans should be person centred.’* (FG3 P1)

The question then arose as to whether this should be specifically highlighted as being needed for people with a learning disability. However, another participant noted that even though all patients should have a care plan the quality might be questionable:

> *‘I guess that there's not many people that feel that they've had a totally person centered care and treatment whilst they've been in hospital, so that that that's interesting in itself.’* (FG2 P2)

In seeking parity for people with a learning disability, therefore, it could lead to ‘levelling down’ in which they are treated as the same as all other patients and hence not receive care that is appropriate to their needs. It was recognised, therefore, that there might be a need for more in-depth planning if an individual with a learning disability has complex needs.

It was also recognised that often hospital care is planned according to predetermined pathways linked to specific conditions:

> *‘I think it's care pathways they follow rather than care plans within general wards and very often,*
> *be it right or wrong, I think you and I would get the same care.*’ (FG1 P2)
>
> *‘…pre populated care plans and that debate, I get it ,I get it cause you know there's some issues are the same isn't it you know some aspects are always the same regardless of who you are but they're not personalised’* (FG3 P2)

There appears, therefore, to be a potential tension between adhering to agreed condition specific pathways and ensuring the person-centred care that is essential for people with learning disabilities. One way of addressing this might be through the implementation of reasonable adjustments:

> *‘maybe what we should be emphasizing is the reasonable adjustments needed to go on to that care pathway.’* (FG1 P2)

The provision of reasonable adjustment to promote equal access to health care is not only mentioned in the acute care bundle but it is also a legal requirement under the Equality Act 2010. Focus group participants were presented with the survey findings regarding how often participants say they are used when planning and delivering care for patients with a learning disability.

Whilst welcoming that almost two thirds (64.4%) of respondents indicated that reasonable adjustments were always or often incorporated into care plans where appropriate, concern was expressed that the other third (35.8%) indicated that this was only sometimes/ never the case of that they were unsure:

> *‘Given that it's a legal duty first and foremost, and given that we know that failure to provide reasonable adjustments can often lead to very poor outcomes’* (FG1 P1)

Some questioned whether these responses reflect a lack of education or a lack of willingness to engage. It was also suggested that they might be reflective of a lack of understanding as to what reasonable adjustments are:

> *'Do you think it's a non-recognition of what reasonable adjustments actually are?* (FG1 P2)
>
> *'I think it tells us what I, you know, the battle we have on a daily basis in our day is that people don't understand reasonable adjustments'* (FG1 P1)

Even where training is provided is provided there may not be recognition that. In practice, they are implementing reasonable adjustments:

> *'…they're quite shocked that they actually do and they just don't realise it'* (FG3 P3)

Some specific areas where acute care staff may not realise that reasonable adjustments are being made were also identified:

> *'if you look at the responses to the health profile question and then you look at this, actually if those people have got health profile that is a reasonable adjustment for that individual'* (FG1 P2).

The rapid risk assessment was also noted as one means to identify what reasonable adjustments might be required:

> *'we have, we have our rapid risk assessment that identifies main areas where the hospital ward would require to make any reasonable adjustments.'* (FG2 P2)

Another participant in the same focus group felt that making such an assessment part of the care bundle might be beneficial:

> *'Wouldn't it be great to add … that rapid risk assessment as part of the care bundle for the Ward staff? I'm just thinking, selfishly for (health board). But for the ward staff to do on someone coming in to do that rapid risk assessment, so they're identified straight away, isn't it?'* (FG2 P1)

The acute liaison nurse was also mentioned as key to the implementation of reasonable adjustments:

> *'they would usually, you know, seek advice from the liaison nurse on adjustments…can often be down to the liaison nurses that those reasonable adjustments are put in place.'* (FG4 P1)

5.2.4 Effective review and discharge

The acute care bundle requires that a full discussion including the individual, their family / carers and the MDT is held within 7 days of admission to review the care of the individual and/ or to plan discharge. Discharge planning is particularly important when the patient's needs have changed since admission.

As with some of the other elements of the acute care bundle focus group participants queried how survey respondents were interpreting ‘review’ since this could potentially have several meanings:

> *‘Are they talking about a multidisciplinary review, or is it the review when the doctor does this round, you know, what do we mean by a review of that progress?’* (FG3 P1)
>
> *‘I do wonder what they think we mean by review, because those numbers are a lot lower than I would have expected.’* (FG1 P1)

Some participants suggested that if anyone (with or without a learning disability) is in hospital for seven days (the period specified within the care bundle) then they would be reviewed. Moreover, it was suggested that periods of in-patient treatment are now much shorter than they were and hence were someone in hospital for more than seven days then it is likely that their needs would be complex. The pressure on beds within acute care settings was viewed as driving this:

> *‘So I think obviously with all the pressure, you know with the pressure on beds…they're going to be reviewing somebody's care whether suppose, learning disability or not much sooner’* (FG4 P1)

Given that all patients would be reviewed within the first seven days of admission one participant queried whether survey respondents who indicated that such reviews seldom or never take place were perceiving it as an additional intervention:

> *‘But so I wonder whether this who to be perceived as a hindrance and adding an extra layer when they're doing it in a different way but not recognizing it.’* (FG3 P2)

Some participants suggested that the acute care liaison nurse might be viewed as the person who undertakes a review:

> *‘Some might argue that the review is something that happens with the ALN’* (FG1 P1)

Indeed, a participant (who is an acute liaison nurse) commented:

> *‘we (are) reviewing the person on a daily basis’* (FG2 P2)

However, they also went on to say that this would depend on the complexity of needs and that it would only occur Monday to Friday as the liaison service is not available over the weekend.

In terms of who should initiate such a review one participant commented:

> *‘It's reassuring in some ways that 50% or thereabouts of the hospital based teams feel that that's what their job they do’* (FG1 P1)

Nonetheless the same participant also noted that they had experienced some acute care teams believing that it was the responsibility of the acute liaison nurse to initiate a review and also to undertake all of the administration that might be required in terms of arranging and minuting any meetings.

Few survey respondents had indicated that reviews were initiated by the patient with a learning disability or their family / carers. It was suggested in the focus groups that:

> *‘I think it's that power thing, isn't it?...It's that you're there to have things done to you by us and we're the ones in control.’* (FG1 P2)

Patients, their families, and carers may therefore not feel empowered to request / initiate a review. Noting that the number of respondents indicating that the community learning disability team initiate a review was also low the same participant also queried whether this was due to fewer people with a learning disability now being supported by community learning disability teams:

> *'Because of the stronger criteria for acceptance into the CLDT, I think a lot of people don't meet the eligibility criteria for CLDT now.'* (FG1 P2)

It was felt that this situation might lead to those with mild/ moderate learning disabilities not being identified and provided with appropriate support despite needing such support in the context of acute healthcare.

A key milestone in terms of care reviewing is discharge planning and the care bundle requires that, when discharge planning is undertaken, then consideration should be given to whether the patient's needs have changed during admission. Since this may require a new package of support then all relevant people should be involved in such planning. Issues surrounding discharge planning led to much discussion within the focus groups.

It was recognised that, as noted above, the pressure on beds within acute care settings is placing increased pressure on staff to discharge patients. In some instances, this was felt to lead to discharge to inappropriate settings:

> *'Because sometimes the pressure on beds means that we acknowledge that this home isn't the best one for you…But it's the only bed available off you go.'* (FG1 P2)

This can lead to 'failed' discharges:

> *'…three failed discharges from an (out of area) hospital before I was alerted to them and asked can you help out and then we made the discharge safe, but this poor person had three failed discharges before anybody thought of contacting the learning disability team'* (FG2 P1)

It was noted that, within Wales, a considerable amount of work has been undertaken in relation to discharge planning since the acute care bundle was introduced. However, participants felt that the specific needs of people with a learning disability may not have been included in such work meaning that whilst there are specific procedures that are implemented with other groups (such as older people) this did not occur for people with a learning disability:

> *'It's almost like you're reinventing the wheel every time, whereas the elderly have got a process that they follow and the wards are very sure of that'* (FG1 P2)
>
> *'Why would they use anything different for someone with a learning disability?'* (FG3 P1)

It was recognised that, across Wales, data regarding delayed discharges does not, at present, enable people with learning disabilities to be specifically identified. Nonetheless, some examples of delayed discharge were given:

> '*there are people who end up staying in hospital much longer than then they need to do and (that) opens up a whole load of other risks to that individual.'* (FG4 P1)

> *'You know, we've just had someone, … fit for discharge, but no placement in the community for her to go to and it's really difficult for somebody with a learning disability to stay on this ward then isn't it, you know?'* (FG2 P1)

As the above quotes indicate, such delays can have a negative impact on individuals with a learning disability. Several barriers to timely discharge were identified and examples of delayed discharges were given including a change in need leading to the need to recommission packages of care and support and consequent challenges with agreeing funding for such packages:

> '*there's a whole recommissioning of care that delays your discharge'* (FG1 P1)

One participant suggested that if an individual is medically fit for discharge, then delays are not an issue with the care bundle but instead a matter for the community learning disability team:

> *'to me that's an important issue, but it should be taken away from the care bundle because the care bundle can't fix that.'* (FG3 P2)

However, a delay in discharge means that an individual remains in acute care and that their need for appropriate and person-centred care continues, which is part of the acute care bundle.

It was suggested that sometimes those who support people with learning disabilities can seek to delay discharge by mentioning additional health problems (not those that precipitated the attendance/ admission):

> *'often you will find our Community colleagues very eager to get discharge planning meetings even when there's no particular need to have one and that's normally because they want to bring up several other preexisting issues that were nothing unfortunately nothing related to the current admission but they are health related.'* (FG2 P2)

It was also suggested that discharges may be delayed because the acute care bundle is interpreted as meaning that a meeting has to take place prior to discharge when this may not always be required:

> *'often a discharge planning meeting can sometimes delay discharge if it you know if it's not needed.'* (FG2 P2)

Likewise, delays can be caused by the belief that a written plan is required when, instead, effective communication and coordination are what is needed:

> *'it doesn't mean it's always actually physical plan, and I think some people get hooked up on…well, actually we need this physical thing'* (FG3 P3)

5.2.5 The role of the Acute Liaison Nurse

Whilst not an element of the care bundle it was evident from the survey responses that the learning disability acute care liaison nurses are perceived as playing an integral role in its implementation. This was therefore reported to focus group participants and what emerged was a range of different approaches to the role, as well as different systems and structures around the role.

In terms of the nature of the role, in the context of implementation the care bundle, different positions along a continuum were taken by participants. At one extreme the role is viewed as being supportive of acute care staff to enable them to provide safe and effective care for people with a learning disability. For example, in relation to discharge, one participant commented:

> *'I wouldn't be the person running it as liaison nurse (my role is) to support the team to make sure they don't miss things…You're not the person to run it, … we gotta stop stepping on other people's toes '* (FG3 P3)

However, at the other extreme, mention was made of a lack of commitment from acute care staff leading to the liaison nurses 'doing' the care bundle:

> *'…we actually had really good numbers for our care bundles. But the reason what being is that we were we were completing them...So we don't use the care bundle anymore because we're doing it.'*(FG2 P2)

In this context 'doing' the care bundle involved activities such as taking the lead in explaining care plans, undertaking risk assessments, and undertaking daily reviews of care.

In terms of systems and structures relating to the acute liaison nurse role there was general support amongst participants for the view that there is a need to expand provision. In particular, there is a need for provision that extends beyond the current Monday – Friday 9 – 5. However, the view was also expressed that acute care liaison nurses should be employed by acute care services (rather than learning disability services) to enable better integration into such services:

> *'part of me says a lot of this could be sorted by having the liaison nurses employed by the hospitals'* (FG1 P2)

Another issue that was highlighted was the need for there to be effective systems of support in place for acute care liaison nurses and for the focus to be on developing a liaison service rather than on individual posts:

> *'… it is very, very stressful. If you don't have the right level of support or the right amount of time to be able to fulfil your duties, you're often by yourself…So you're having to, you know, you've got no one to bounce off, any ideas off, you know you're often having to battle with consultants or other senior clinicians around a variety of issues…so it's really important that you've got that type of support network.'* (FG2 P2)
>
> *'you know, really developing a liaison service rather than individual posts.'* (FG4 P1)

5.2.6 The need for education and awareness raising

Implementation of the care bundle depends on clinical staff being aware of its existence and its contents.

It was noted that, in some areas, the care bundle was not being used and that it was necessary to raise awareness amongst key staff:

> *‘first thing we did was find it and then refresh the ward managers of what they needed to do for people with a learning disability’* (FG2 P1)

In the survey an issue that was raised by some respondents was that bank and agency staff often appear to not be aware of the acute care bundle. In the focus groups it was noted that, in some instances, such staff might be used as additional staff to ‘special’ someone with a learning disability and that, in such instances, this lack of awareness is a particular problem:

> *‘And if that person (the agency staff) , specialing hasn't got any specialism, it's not a lot of use really, is it?’* (FG1 P2)

More broadly, current staffing issues in the context of acute care settings, mean that bank and agency staff are frequently used:

> *‘Yeah, you can train all the (Learning Disability) Champions you want on the ward, but when it comes to the weekend and the ward haven't got any of their regular staff, you're just left with agency, aren't you?* (FG2 P2)

There seemed to be a lack of clarity about whether bank and agency staff are able to access available training. However, it was also noted that where there was not a full complement of learning disability acute liaison nurses this could also impact on the amount of champion training that can be provided:

> *‘we've not had over the last probably 12 months the focus that we wanted on learning disability champion training’* (FG4 P1)

Some participants spoke of the importance of the Learning Disability Champion training in relation to raising awareness not only of the acute care bundle, but also in terms of how support can best be provided for people with learning disabilities. In the survey responses there was less mention of the Paul Ridd Mandatory Training Level 1 but focus group participants felt that this was a reflection of its more recent implementation.

5.2.6 Responsibility and accountability

The acute care bundle sets out what care and support should be provided when people with learning disabilities attend / are admitted to acute care facilities. However, it does not indicate who has responsibility for ensuring that the interventions it includes are implemented. The survey responses suggested that key interventions may not always occur and hence the issue of responsibility was explored in the focus groups. Challenges in relation to clarity of responsibility were identified at different levels.

For example, as discussed above in the section relating to the role of the acute liaison nurse, there seems to be variation between areas as to what is the responsibility of the acute liaison nurse and what is the responsibility of the ward based acute staff. In securing permissions for this review to be undertaken in health boards there also appeared to be a lack of clarity in relation to where, within an acute directorate, senior responsibility lies for implementation of the acute care bundle. In one focus group it was suggested that this has occurred over time and that in the early days of implementation there were individuals clearly identified:

> *'people have left or the senior nurses that were in charge within the general hospitals have moved on or changed post, then Covid hits and nothing kinda got relaunched post Covid'*. (FG1 P2)

It was also suggested that this lack of clarity regarding responsibility might be attributable to a perceived lack of ownership amongst acute care staff in relation to the acute care bundle:

> *'There should be more ownership of it because I don't know that we ever actually nailed it for the general side to own this pathway like they own the appendicitis pathway or the fibromyalgia pathway'* (FG1 P2)

Difficulties in identifying who should be responsible for actions were also identified as occurring for family members:

> *'…the family wasn't aware that the hospital should have done it'* (FG3 P2)

Some issues relating to responsibility were identified as occurring between acute settings and community learning disability teams:

> *'With community learning disability teams… I meet with them quite regularly, saying, you know what, we got concerns we don't know who's coming in.'* (FG4 P1)

Whilst it is important to identify key responsibilities for implementation of the acute care bundle, some participants felt that it was also important to clearly identify the location of accountability and that people/ organisations should be held accountable:

> *'…not just the clarification of responsibility, but then having some accountability for completing it as well.'* (FG2 P2)
>
> *'…there's that lack of accountability and responsibility'* (FG3 P2)
>
> *'It's and you know there needs to be some consequence if it needs to be part of what they have to do doesn't cause at the moment they don't have to do it and there's no consequence if they don't do it, there's nothing really we can do with there.'* (FG2 P1)

In one area it was mentioned that actions had been taken to try and increase accountability in relation to the acute care bundle:

> *'I think it's something that we can hold people to account and for really what, you know what we've tried to do within in (Health Board) is translate those standards into a policy.'* (FG4 P1)

5.2.7 The future of the care bundle

Participants were asked whether, given the findings of the survey and their experience, the care bundle should be continued as it currently is, modified, or discontinued. It was felt that there needs to be something in place to ensure that the care of people with learning disabilities in acute care settings in Wales is both safe and of a good quality:

> *'We need something… if it was discontinued and we didn't have anything, I think…people with a learning disability would be in a really tricky situation '* (FG2 P1)

However, interestingly no-one suggested that the acute care bundle should continue in its current form. Participants thus either argued for modification or discontinuation with several factors appearing to influence thinking here. It was acknowledged that since the acute care bundle was introduced much has changed in terms of terminology, policies, personnel, and systems. This means that some elements are now either ambiguous and/ or do not reflect current practice:

> *'I'm between modified and discontinued and when I say discontinued I think the way it is at the moment it was it was a moment in time 10 years ago and I think the whole face of healthcare has changed since then.'* (FG1 P2)

It was also acknowledged that the pressures on acute care settings at present mean that whatever is introduced should not be perceived as 'extra' work for staff:

> *'it's gotta be doable by the band five in A and E when they've got 65 other people sitting in the waiting room waiting to be seen'* (FG1 P2)

It was felt that it should be viewed as a means of supporting acute care staff to provide the best care possible for patients with a learning disability whilst not being perceived by such staff as additional work. An important element of achieving this was felt to be the need to map out current systems of care planning, review, and discharge within acute care and to make sure that what is advocated for people with a learning disability is reflected in these: people with a learning disability should be viewed as a group of people who require additional supports within existing systems of healthcare. To ensure that this would achieve the desired standards of care it would, however, require that there is a good level of understanding of reasonable adjustments.

It was also suggested that instead of reviewing the acute care bundle it would be better to discontinue it and to introduce a set of standards that need to be achieved by acute healthcare settings:

> *'it probably needs to be modified and to become more standards orientated rather than a pathway or checklist.'* (FG1 P1)
>
> *'We have been long advocating for … a set of standards for people to work towards'* (FG2 P2)

It was also stated that some work had already been undertaken on the development of such standards by acute liaison nurses.

One suggestion was that a system should be introduced through which wards and departments are accredited along the lines of the dementia friendly initiative:

> *'You know, wards went through that whole assessment process about how you would dementia friendly ward and if you are and you meet certain criteria used to get like a little stamp on you to say we're a dementia friendly ward…It, it's more about the standard that we're expecting rather than the pathway.'* (FG1 P1)

One potential advantage of introducing such standards is that they should be reportable and hence could promote greater accountability. However, it was also recognised that the development of standards alone would be insufficient, and that staff need to be supported in their implementation:

> *'I suppose setting standards cause then you got something to monitor or to audit, but will that help the staff to deliver?'* (FG3 P2)

Finally, it was noted that when reviewing the acute care bundle, it is important that it is viewed as part of a wider system or patient journey that is interdependent with other elements of healthcare for people with a learning disability:

> *'we've got focus on primary care, annual health checks being proactive and early intervention and all that and then how and that kind of links in with secondary care.'* (FG4 P1)

Such proactive work might reduce the need for attendance at acute care settings, but annual health checks (for example) can be key to ensuring that people with a learning disability are 'flagged' when attending acute care since they will record someone on the GP records as having a learning disability.

6. Discussion

This section will discuss the findings of both the survey and the focus groups in the context of policy, practice, and wider literature. First, the elements of the care bundle will be discussed, followed by the context in which it operates, and the factors that impact on its implementation, before the future of care bundle is explored.

6.1 The elements of the care bundle

The systematic review undertaken by McCormick et al (2020) concerning the experiences of people with learning disabilities accessing acute hospital services identified three key themes: communication, information sharing, and compassion and respect. Each of these elements are evident within the acute care bundle with its focus on identification, communication, person-centred care and review/ discharge planning and its emphasis on collaboration and coordination. It can thus be seen that the care bundle seems to reflect wider practice and the factors that are recognised as being important in enhancing access to acute healthcare for people with learning disabilities.

The results of the survey indicate, however, that whilst the care bundle provides the framework for promoting safe and effective acute healthcare for people with learning disabilities its elements are not always implemented and/ or effective. For example, whilst most respondents indicated that there are systems for identifying people with learning disabilities when they are admitted to acute care settings, 40% felt that such systems are either only partially effective or not effective. Only 18.4% of respondents reported that people with learning disabilities always or often bring their Health Profile with them when attending acute care, 59.2% that they always or often ask to see the Health Profile if a patient does not offer one, and only 44.8% reported that the Health Profile is always / often used to inform care.

Within both the survey and the focus groups some views were expressed that the elements of the care bundle (the development of a person-centred care plan, review of care, and planned discharge) are what would be considered appropriate practice for anyone admitted to acute hospital settings. Arising from this it was also queried as to why people with learning disabilities are not just included within systems such as discharge planning that are in place for other groups such as older people.

These observations give rise to the question as to whether there needs to be a separate policy (the care bundle) for people with learning disabilities. However, this question needs to be considered in the context of evidence that indicates that people with learning disabilities continue to experience premature and avoidable deaths (O'Leary et al, 2018). This point will be explored further below when the future of the care bundle is discussed. Here it is, nonetheless, appropriate to hypothesise that a special policy would not be required if people with a learning disability are appropriately identified when admitted to / attending acute healthcare settings and reasonable adjustments are consistently made to existing policies and practices to ensure their specific needs are met.

In the survey, whilst the majority (64.2%) reported that reasonable adjustments are made when appropriate this means that 35.8% indicated that such adjustments (a legal requirement) are only made sometimes/ never, or they are unsure. These results could suggest several things including a lack of awareness of the need to make reasonable adjustments, an unwillingness to make reasonable adjustments, or respondents not realising that they are currently making reasonable adjustments in their practice. These findings are of concern and reflect similar findings elsewhere (Moloney et al, 2023; McCormick et al, 2020; Heslop et al, 2018). Therefore, the findings suggest that relying on the current level of understanding and knowledge regarding reasonable adjustments alone would not be sufficient to ensure safe and effective healthcare.

The focus group discussions provided the opportunity for further discussion and exploration of these issues and some possible reasons for this gap between the policy (acute care bundle) and reported practice were proposed. First, it was felt that some of the terminology in the acute care bundle is open to differing interpretations (for example how is 'identification' of people with learning disabilities understood in practice?) and that some language might be dated. For example, the term 'named nurse' had a particular meaning at the time the care bundle was written but changes in practice now mean that this is not now understood in the same way and perhaps as not feasible within the current demands on acute healthcare staff.

The publication of the acute care bundle predates the launch of the Health Profile by several years and hence in the care bundle reference is made to the use of hospital passports. The Health Profile was introduced in Wales in 2020 to promote the use of a single, evidence-based communication tool that would be recognised by healthcare professionals across Wales. However, this current review of the care bundle reveals that there remains some variation across Wales with some health boards appearing to still use the old hospital passports / traffic light documents.

Despite this, across both the survey and the focus groups, there appeared to be consensus that where the Health Profile is used then it is helpful in promoting safe and effective care. This concurs with both the wider literature (McCormick et al, 2020) and the recent evaluation of the Health Profile in Wales (Northway et al, 2023). What is interesting, however, is that people with learning disabilities who participated in that evaluation reported that they are usually not asked by health professionals to show their Health Profile and, even where they present it to health staff, it is not used to inform their care (Northway et al, 2023). In contrast most respondents in this survey indicated that people with a learning disability do not bring their Health Profile when they attend acute care. This may just be a difference in perception but in the focus group it was suggested that people may not always remember to take a paper health Profile with them to hospital and that a digital version might be more helpful. This issue was also raised in the Health Profile Evaluation (Northway et al, 2023).

6.2 The context and factors impacting on implementation of the care bundle

As was noted in Section 2 of this report, many aspects of healthcare have changed since the introduction of the care bundle in 2014. These include changing information systems, policies, and pressures on acute care services. Results from the survey and discussions in focus groups revealed how these changes impact on the current implementation of the care bundle.

In relation to the identification of patients with a learning disability it was noted that several different systems exist. For example, there is the 'purple dot' on WPAS but this may not always be consistently applied and/ or its significance understood by health professionals. In some areas there are additional alert systems which appear to be working well but there are issues with cross health board and cross-country admissions where information may not always be transferable. It was also noted that, sometimes within one hospital, outpatient systems may not link with inpatient systems. It would thus appear that whilst there are systems in place that could/ should support the aims of the care bundle they are not always working effectively, and some gaps exist.

Another issue that arose in relation to the identification of patients with learning disabilities was a concern that people with mild and moderate learning disabilities may not be recognised when they are admitted to acute care settings and hence not receive additional support they might require during and after admission. This is recognised as a wider issue as Glover et al (2019) argue that the number of people with learning disabilities admitted to acute care settings is much higher than is officially recorded and that this is, in part, due to systems of identification within GP records not being complete. Indeed, in the focus groups the issue of the number of Read codes used by GPs was identified as problematic. However, another issue that was highlighted in the focus groups is that since the care bundle was introduced the criteria for referral to community learning disability teams have tightened and that individuals are usually only supported for shorter periods in relation to specific issues. This means that individuals with a learning disability may not be known to the local community learning disability team which, in turn, impacts on their identification within systems of acute healthcare. It also means that elements of the care bundle that require contact with the community learning disability team may not operate easily with individuals not being known to / open to the team and a new referral being needed.

This highlights a wider issue that became evident in the focus groups namely that the care bundle should not be viewed in isolation but instead as part of a wider ecosystem of care and support in which its effectiveness requires that the interdependence of the different elements is both recognised and supported. For example, it was noted in the focus groups that where the systems for identification of people with learning disabilities admitted to acute care were working well this was achieved by primary care liaison nurses working with GP practices to promote uptake of the annual health check and, in this process, ensuring that GP records correctly identify those with a learning disability. It was also recognised that discharge planning can be more effective when community learning disability teams are involved, and wider research indicates that community learning disability learning nurses can play a key role in supporting access to acute healthcare (Rees and Northway, 2022).

The need for care and support for people with learning disabilities in acute care settings to be included as part of wider systems at a different level was also raised in the focus groups. It was suggested that providing safe and effective care for people with learning disabilities should be as easy as possible for acute care staff and not viewed as imposing any additional burden on them. The latter point was viewed as particularly important in the context of current pressures on acute care staff. One way of achieving this was felt to be greater integration into existing systems (such as discharge planning) rather than appearing to require a separate (and different) care pathway for people with a learning disability. Heiftez and Lunsky (2018) writing about their experience of introducing a health communication tool in Canada, similarly concluded that fitting this into existing systems was important since staff were then more likely to use/ adopt it. However, this would require acute healthcare staff to have a good understanding of reasonable adjustments and their role in implementing them: as previously noted such a level of understanding does not appear currently to be present.

Across both the survey and the focus groups a key factor influencing implementation of the care bundle was the acute liaison nurse. Concerns were expressed regarding gaps in liaison nurse support overnight, at weekends, part time posts, and gaps when existing post holders leave. What was also apparent was that just as the level of provision varies between health boards, so does the role of the liaison nurse in relation to the care bundle. In some it is the primary care liaison nurses who promote its use within community hospitals, in others the role of acute liaison nurses is to prompt and support acute care colleagues to implement it, whilst elsewhere it was reported that acute liaison nurses ‘do’ the bundle to ensure that it happens.

It is beyond the remit of this report to review what level of acute liaison nursing provision is needed nor is it appropriate to propose what level of uniformity of provision is required across the health boards in Wales. However, it is important to note that the level and nature of provision does seem to influence implementation of the acute bundle and hence should be considered when exploring future developments. It is also relevant to note that the acute liaison role is viewed as improving the acute care experience for people with a learning disability (McCormick et al, 2020), it is recognised as being important to the delivery of safe healthcare (HSSIB, 2023), and that work is currently being undertaken in England to develop a competency framework and a ‘uniform approach’ for acute care liaison nurses (hanging Our Lives, 2023).

Whilst liaison nurses ‘doing’ the care bundle may ensure that important elements of care and support are not missed it does mean that this shifts responsibility from acute care staff to the liaison team (who are not there 24 hours a day). This issue of responsibility and accountability was a recurring theme throughout this project. In setting the project up it was difficult to locate a senior individual with responsibility for oversight of the care bundle in some health boards. This lack of clarity with regards to whose responsibility it is to ensure its implementation was then also visible at other levels. The care bundle itself specifies what should happen but not who has responsibility for doing what. The reasoning behind this approach is probably due to a desire to promote a culture in which its implementation is viewed as the responsibility of all healthcare professionals. Whilst this is a worthy goal it does, nonetheless, mean that it can be viewed as someone else’s responsibility and without clear lines of accountability its implementation cannot be fully monitored. This lack of responsibility and accountability was discussed in the focus groups and was viewed as an essential element to consider when determining the future direction.

6.3 The future of the care bundle

The overall remit of this evaluation was to review the use of the acute care bundle and to make recommendations for its future. Three options were proposed for consideration – continue, revise, or discontinue.

Whilst survey responses indicated that some elements of the care bundle are viewed as important and are implemented and valued, there are also some perceived issues both with both its contents and its implementation. It is perhaps not surprising, therefore, that no participants in the focus groups felt that it should continue in its present format. Most felt that there is a need for something that highlights how the health needs of people with learning disabilities can best be identified and met in acute care settings but that the care bundle either needs to be reviewed or discontinued and a set of standards introduced instead.

Whether a revised care bundle is developed or whether a set of standards is produced this process needs to take account of the points discussed above to ensure that it is fit for purpose in the context of current healthcare. Whatever is developed should be viewed as part of a wider ecosystem of healthcare, it should 'fit' with existing systems that currently operate within acute care, and there should be clear lines of responsibility and accountability. Linked to this latter point it would be helpful to consider undertaking a baseline assessment when a new policy/ approach is introduced and to establish a system for subsequent audit. It is also important to heed the words of Heifetz and Lunsky (2018) who argued that 'continued efforts' are needed to ensure that interventions introduced to improve healthcare for people with a learning disability are maintained. Introducing any new system would require awareness raising, education and support for implementation. Given the findings of this review it is also evident that further education regarding the need for reasonable adjustments is needed.

7. Conclusions and recommendations

Before drawing conclusions and making recommendations it is important to recognise the limitations of this review. First, given the number of nurses in Wales the overall number of respondents/ participants might be viewed as small. However, respondents / participants were obtained from all health boards in Wales, from a range of pay bands, and from a range of specialities. It must also be remembered that whilst the survey sought respondents' perceptions / experiences there was no direct observation of practice. The limitations of self-report must therefore be noted but the fact that the survey was anonymous hopefully promoted honest rather than socially acceptable responses. Finally, participants were self-selecting, and many had either undertaken learning disability champion training and/ or had undertaken the Paul Ridd Mandatory Training. They thus are likely to be those staff who have an interest in, and knowledge of, the needs of people with learning disabilities. Despite these limitations, however, several clear themes emerged which allow conclusions to be drawn and recommendations made.

From the results of the survey and the findings of the focus groups, it can be concluded that the elements of the care bundle appear to reflect good practice in relation to supporting people with learning disabilities in acute healthcare settings. However, implementation of this policy appears to be variable across health boards and across settings. Several factors seem to influence this including the introduction of acute and primary care liaison services, a lack of 'fit' with policies and systems introduced since the care bundle was published, and current pressures on acute care services. A further key issue is that a lack of clear lines of responsibility and accountability for its implementation means that variations and deviations may not be easily identifiable and therefore not addressed.

It is evident that the acute care bundle is only one element of a wider ecosystem of care that influences the healthcare experience of people with a learning disability. The various elements are interdependent and failings in one area impact on others. The care bundle should not, therefore, be viewed in isolation.

It can also be concluded that whilst the various elements of the care bundle might be viewed as what would be expected for anyone admitted to acute healthcare settings, the fact that they are not always delivered for people with a learning disability suggests that there may still be a lack of awareness, a lack of confidence and/ or a lack of knowledge and skills amongst some acute care staff in relation to identifying and meeting the needs of people with a learning disability. For there to be a reliance on expecting acute care staff to just adapt existing systems and processes there would be a need for there to be a good understanding of and confidence in making reasonable adjustments (including use of the Health Profile which is both a reasonable adjustment and contains information concerning other adjustments required). This study suggests that such understanding is not currently universally in place.

Overall, therefore, it can be concluded that the care bundle in its current format does not appear to be fully fit for purpose. However, some provision is required to ensure that the specific needs of people with a learning disability as presented in acute healthcare settings are recognised and appropriately addressed.

The recommendation from this review is thus that the acute care bundle should be reviewed and that the following should be addressed when undertaking this revision:

- The review should include acute care staff from the outset to promote ownership of the process and outcomes.
- The ecosystem of care should be mapped, and the interdependencies between the various elements be identified so that a revised policy can reflect these.
- The current policies operating in acute healthcare settings (for example relating to care planning and discharge) and current information systems (for example the Welsh Nursing Care Record) should be reviewed to identify where adjustments may be needed to ensure that the needs of people with learning disabilities are appropriately identified and addressed.
- The recommendations of the recent evaluation of the Health Profile (Northway et al, 2023) should be considered alongside this report to ensure effective coordination.
- Consideration should be given to whether the most appropriate way forward is to develop a revised care bundle or whether development of a set of key standards might be more effective.
- That, within the revised policy, there should be clearly identified lines of responsibility and accountability for implementation, that a baseline should be established, and regular audits undertaken.
- That there is a continued focus on awareness raising and education for acute healthcare staff and that this should include a clear focus on use of the Health Profile, the legal requirement to make reasonable adjustments, and strategies for achieving these.

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