

Integration Index – Joined-Up Care

Experiences of People with Learning Disabilities and/or their Carers of Hospital Discharge

April 2021



Introduction

What is Healthwatch?

Healthwatch Cheshire, consisting of Healthwatch Cheshire East and Healthwatch Cheshire West, is an independent consumer champion for health and care across Cheshire East and Cheshire West and Chester, forming part of the national network of local Healthwatch across England. Our role is to make sure that those who run health and care services understand and act on what really matters to local people.

Healthwatch Cheshire East and Healthwatch Cheshire West undertake continuous engagement activities with the public to hear about concerns and compliments regarding health and care services. The information we gather is then analysed so that we can identify and act upon trends and common themes by presenting our findings to decision makers in order to improve the services people use. We also share people's views locally with Healthwatch England who strive to ensure that the government put people at the heart of care nationally.

Background – Integration Index

Healthwatch Cheshire have been asked by Healthwatch England and NHS England to create a methodology to be used as part of the development of the Integration Index. The Integration Index will measure how well services are providing joined-up care. Healthwatch Cheshire will develop a methodology using a project to understand whether there are currently good outcomes and a consistent approach to providing services for people with learning disabilities who have had an admission to hospital within the last three years and their unpaid/family carers. To do this, we have been talking to people to find out their experience of how well services are working alongside each other, and linking with our four local health trusts (Cheshire and Wirral Partnership, Countess of Chester Hospital Trust, Mid-Cheshire Hospitals NHS Foundation Trust, and East Cheshire Trust), and two Local Authorities (Cheshire East Council and Cheshire West and Chester Council). In this report, we compare what people have told us about their experience to the policies of the health and care system, which outline the experience people should expect. This will help to obtain key information from people to inform the health and care system in measuring how well services are providing joined-up care; a key element of the Integration Index. The project took place during the period of December 2020 up until April 2021.

Project Rationale

- People receiving care should be supported by joined-up care providers working in partnership, responding together as one to meet all the needs of an individual.
- To ensure that people receive support that meets all of their needs, it is important that health services such as GP Practices and hospitals work well together with local social care services and factors that impact the wider determinants of health, including employment, housing, transport and education, amongst others.
- The health and care system has been exploring and developing partnerships to provide care in this way for some time, and important changes have been made already. But to know if these are working, they need to hear from people about their experiences of care.
- The 'Integration Index' is split into two parts which are being tested over the next few months:

- The National part: A regular survey of people using the NHS which will ask the same questions in every area of the country. People will be asked whether they think services are working well together or not. This will help areas see how well they are doing compared to other parts of the country.
- The Local part: A number of methods for local areas to gather more detailed views from people that are relevant to that town, city or county. This will help the NHS, local authorities, and their local partners to understand where there is good practice, and why things might not be working well and then work with local people to fix things. This Healthwatch project is one of these methods.

What is this project for?

- Healthwatch England are gathering the experiences of particular groups of people in different parts of the country of how services are working alongside each other. This will assist in the development of the Integration Index, which will measure how well services are providing joined-up care and help the health and care system understand why something is or isn't working.
- This method is currently being tested in five parts of the country by local Healthwatch, with five groups of people who have lots of interactions with NHS services, care support and other public or charity services. The five groups are:
 - Children and young people with mental health support needs who are becoming adults.
 - People with diabetes who are of South Asian origin.
 - People with learning disabilities who have recently been in hospital.
 - Black men with a number of health needs including a recent experience of cancer.
 - Women with a number of health needs including a recent experience of a heart condition.
- The intention is that this piece of work can then provide a method of engaging with various different groups to find out their experiences of joined-up services in the future.

Why people with learning disabilities?

- Healthwatch Cheshire have been asked by Healthwatch England to seek the experiences of people with learning disabilities who have had an admission to hospital within the last three years and their unpaid/family carers.
- This group has been chosen because they are a priority in the NHS Long Term Plan.
- They are a group who use a broad range of services including health, social care, supported living/housing, education, transport, and more.
- This will also provide insight from carers.

Why this approach?

- Asking people about their stories and experiences means that service providers and commissioners can look at what is and isn't working from the perspective of the individual, and can also explore why.
- This approach will enable health and care providers to focus in-depth on groups who may have particular additional needs or are at increased risk of health inequalities.

Overview of Findings

Below is a summary of the findings of this project, both regarding the positives and negatives of using the methodology described later in the report, and of people's experiences from the interviews we held. For the purposes of this report, in presenting the findings we will refer to the four local health trusts as Trust A, B, C, and D; and will refer to participants as Interviewee 1, 2, 3, 4 and 5.

Methodology

- In all, the methodology worked well, and enabled 10 people with learning disabilities and/or their carers across four local health trusts to share their experiences and get their voices heard in this instance through semi-structured one-to-one interviews.
- Conversations with key staff members within the health and care organisations allowed us to gain an understanding of the process of what happens when somebody with a learning disability is admitted to, and discharged from hospital.
- Key staff members within the health and care organisations were also able to put us in touch with prospective participants and the interviews were then able to be arranged very quickly.
- Difficulty attempting to get in touch with the appropriate people in some organisations was experienced due to the short timescale for the project and people taking annual leave within the health and care system to use up their entitlement before the end of year.
- We were not provided with adequate documentation from health and care partners that showed specific policies relating to adults with learning disabilities, despite contact being made to ask for this.
- Completing the project during the COVID-19 pandemic also provided difficulty, with members of the Healthwatch team redeployed to help with the vaccination rollout this period, and many staff in health and care organisations redeployed as part of the response.
- The format of semi-structured one-to-one interviews with our participants worked well because they provided us with a flavour of people's experiences and allowed us to consider the impact on each individual and their own particular journey.
- Using a prompt sheet of questions for participants to consider prior to the interview helped interviews to run efficiently.
- In the majority of interviews, the individual was supported by a carer or an advocate, who had an in-depth knowledge of the person we were discussing, what was important to that person and the level of their need. In one case, the conversations were solely with a carer.

Methodology

Objective

The overall objective is for Healthwatch England to develop a qualitative research methodology for local health and care systems to help them assess how well they are doing at providing joined up care.

This will be used alongside the National Integration Index, and other tools being developed by other partners for the Local Integration Index (e.g. citizen panels).

Why is this needed?

The qualitative approach is an important addition as it will enable systems to ask not just what is and isn't working but it also provides an opportunity to explore why.

It will enable systems to focus in-depth on groups who may have particular additional needs or are at increased risk of health inequalities.

By its very nature, this qualitative method will also unearth comments, questions and ideas for local systems which would simply not emerge from systems themselves because it will approach the delivery of care solely from the user's perspective.

This is an overview of the methodology undertaken, with more information on particular steps included in the body of the report.

Preliminary work

- Healthwatch England reviewed the data they hold nationally on people with learning disabilities' experiences of joined up services, as well as NHS England policies on learning disabilities and integration. A summary of this can be found on page 7 of this report.
- Healthwatch Cheshire reviewed information we already have on the experiences of people with learning disabilities and hospital discharge. We contacted local groups and organisations, local NHS Trusts, CCG and Councils to find out what current policies there are relating to this area. This includes supporting data such as the Joint Strategic Needs Assessments for both local authorities, annual health check targets, hospital admissions and discharge, and delayed transfers of care. This allowed us to build a picture of what people with learning disabilities should expect from services. A summary of this can be found on page 12.

Developing our approach

- As we have focused on finding out the experiences of people with learning disabilities who have had a recent admission to hospital in both Cheshire East and Cheshire West and Chester, we needed to find people who fit this profile using Healthwatch contacts within Cheshire CCG and Local Trusts.
- Cheshire CCG and Local Trusts then approached people identified to establish if they would like to be involved and share their experience with us.
- We determined the best method to be used when discussing people's experiences of using health and social care services, such as their GP Practice, hospital appointments, supported living, etc. This was on a one-to-one basis, which in the current climate had to take place virtually. This helped us to explore how well health, care, community support, housing, and education services are working together to provide a joined-up experience.

- Other local Healthwatch are doing similar pieces of work with different groups of people, and so our approach was discussed and compared with them.

Finding out people's views

- We spoke to 5 people in Cheshire East and 5 people in Cheshire West and Chester, in the form of one-to-one conversations, to further understand their experiences of being discharged from hospital, and how they think things could improve.
- Key questions were developed to structure the sessions.
- Some one-to-one interviews required conversations to be recorded to transcribe, and permission was sought for this. Once the transcription was agreed with the individual, the recording was destroyed.
- Consideration was given at each stage to ensure that any information is clear and understood by all participants.

Follow-up

- This report as a whole will be shared with Healthwatch England. Findings and potential areas for development will be shared with Integrated Care Partnership Boards, the Learning Disability Partnership Board, NHS Cheshire CCG, local Hospital Trusts, Cheshire East Council and Cheshire West and Chester Council. They can then provide feedback on what people have told us, and how they intend to use this information, which we will share with participants.
- As per Healthwatch England's recommendation, we will follow-up a year later with our focus group members to compare whether or not their experiences have changed, and with local Trusts and Local Authorities to establish what actions were taken.

What experience should people expect based on national guidance?

The below is written by Healthwatch England and details, based upon national policies and guidance, the experience that somebody with a learning disability leaving hospital should expect. Following this, we have produced what somebody should expect locally in Cheshire.

What kind of care should this health and care experience profile be able to expect?

When adults are moving between hospital and social care settings¹, they must have existing care plans shared with the admitting team, a named discharge coordinator, and their family or carers involved in discharge planning if they are providing support after leaving hospital. Furthermore, a hospital-based multidisciplinary team must be identified as soon as the person is admitted to hospital, including housing specialist, social worker, doctor, pharmacist and specialists in the person's conditions.²

Service Standards³ for people with profound and multiple learning disabilities state that people should have a Hospital Passport with staff skilled at liaising with the hospital/Learning Disabilities Acute Liaison Nurse to ensure quality of health provision. There must be effective communication and support with all relevant professionals throughout the admission period and pre-discharge planning so that the person is ready for discharge and any change in need can be met, including sharing information about a person's wellbeing.

For people who have learning disabilities and mental health issues⁴, they should be supported by a designated leadership team consisting of healthcare professionals, educational staff, social care practitioners, and health and local authority commissioners. This team will ensure that care is person-centred and integrated within a care programme by:

- involving people in the care pathway
- sharing information across services, with patient and carer
- coordinating transition between services within and across different care pathways to maintain consistency of care.

¹ NICE (2016) [Transition between inpatient hospital settings and community or care home settings for adults with social care needs \[QS136\]](#)

² NICE (2015) [Transition between inpatient hospital settings and community or care home settings for adults with social care needs \[NG27\]](#)

³ PMLD Link (2017) [Supporting people with profound and multiple learning disabilities: core and essential service standards](#)

⁴ NICE (2016) [Mental health problems in people with learning disabilities: prevention, assessment and management \[NG54\]](#)

Furthermore, people with learning disabilities being admitted to mental health inpatient settings, should be offered an opportunity to visit the inpatient unit before their planned admission. It should be ensured that there be ongoing communication and involvement of the inpatient team, carers, and relevant teams in the community such as learning disability teams, community mental health teams and housing support teams about admission, treatment and discharge.⁵

NICE Quality Standards⁶ for people growing older with learning disabilities and NICE guidance⁷ for older people with social care needs and multiple conditions state that people should:

- be involved in developing plans for their care and future
- have a named lead practitioner and that they should review needs regularly, recognising that people with existing conditions may not take in information when they receive a new diagnosis
- have an annual health check, used to update their health action plan⁸
- meet hospital staff before any planned hospital admission to agree arrangements that make the stay easier for them
- have community-based multidisciplinary support to recognise the progressive nature of many conditions.

NHS England's national plan⁹ and service model¹⁰ to transform care for people with learning disabilities, has aimed to reduce the number of people needing to go into hospital for their care by building community capacity. This will be achieved by:

- accessing support based on individual need with an understanding of both historic and current contributory factors
- providing care and support to improve quality of life
- using integrated specialist multidisciplinary and multi-agency teams working in partnership with the person and those who provide day-to-day support
- intensive 24/7 access to specialist health and social care support in the community.

In particular, a carer of an adult with learning disabilities is entitled to an individual assessment of their needs in line with the Care Act 2014, including personal budgets for

⁵ NICE (2016) [Transition between inpatient mental health settings and community or care home settings \[NG53\]](#)

⁶ NICE (2019) [Learning disability: care and support of people growing older \[QS187\]](#)

⁷ NICE (2015) [Older people with social care needs and multiple long-term conditions \[NG22\]](#)

⁸ Public Health England (2016) [Annual health checks and people with learning disabilities](#)

⁹ NHS England (2015) [Building the right support: a national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition](#)

¹⁰ NHS England (2015) [Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition: service model for commissioners of health and social care services](#)

themselves and for the person they care for.¹¹ Health and social care practitioners should work in partnership with carers and treat them as a valued member of the care team around the person being cared for. Practitioners involved in transferring people to and from hospital should seek to identify carers and refer them to appropriate services.¹² A carer must be involved in care planning, especially when assessed eligible needs are being met by a carer. This means that the local authority must record the carer's willingness to provide care and the extent of this in the plan of the person and the carer, in order to respond effectively to changes in circumstances (e.g. breakdown in the caring relationship). Where the carer also has eligible needs, the local authority should consider combining the plans of the adult requiring care and the carer to establish if the carer requires an independent advocate.¹³

What does the evidence tell us about experiences of integrated care for this health and care experience profile?

There is a lack of data looking at people with learning disabilities' experiences of health and social care, particularly when they are admitted to hospital. It's difficult to identify sub-groups of people with learning disabilities from general national satisfaction surveys as they are too small. Additionally, routinely collected satisfaction information is rarely administered nationally in accessible formats for people with learning disabilities, highlighting a gap in data collection for this group.¹⁴

In 2013, The National Institute of Health Research conducted a study to identify factors affecting the safety of people with learning disabilities in NHS hospitals.¹⁵ They found that there was:

- a lack of effective flagging systems to identify patients with learning disabilities with limited detail in assessment records¹⁶
- a lack of staff understanding of learning disability issues
- insufficient carer involvement and staff misunderstanding of the carer role
- and the absence of clear lines of responsibility and accountability for the care of patients with learning disabilities.

¹¹ NICE (2015) [Older people with social care needs and multiple long-term conditions \[NG22\]](#)

¹² NICE (2020) [Supporting adult carers \[NG150\]](#)

¹³ Department of Health & Social Care (2020) [Statutory guidance: care and support statutory guidance](#)

¹⁴ Nuffield Trust (2016) [Where to find care quality data on learning disability](#)

¹⁵ National Institute for Health Research (2013) [Identifying the factors affecting the implementation of strategies to promote a safer environment for patients with learning disabilities in NHS hospitals: a mixed-methods study](#)

¹⁶ Public Health England (2018) [Learning disabilities and CQC inspection reports](#)

The 2019 annual report of The Learning Disabilities Mortality Review (LeDeR) Programme¹⁷, found that the majority of problems with organisational systems and processes related to poor coordination of care and information sharing within and across different agencies, out of date social care assessments, and a lack of specialist learning disability services. Concerns also related to unsafe discharges from hospital and a lack of communication with families or paid carers.

In 2020, Healthwatch England investigated people's experiences of leaving hospital during the pandemic.¹⁸ It was found that people with learning disabilities had difficulties communicating with hospital staff, making it hard to understand the information relating to their discharge. Family carers also reported feeling disconnected from their loved ones and unable to advocate, which increased their worries and anxieties. Community staff supporting people with learning disabilities highlighted that there is a critical gap in the assessment of people with learning disabilities after they leave hospital, with very little consideration given to the environment a patient is returning to and what support is available.

In 2019, Healthwatch carried out research with thousands of people from across England living with a range of conditions, including learning disabilities.¹⁹ This work focused on understanding how people felt the NHS could better support their health and wellbeing. Some of the key findings included:

- People with learning disabilities felt that there was disparity in the levels of support in place for them compared to support offered for people with other conditions such as cancer and heart disease.
- People with learning disabilities and autism reported that referrals were often slow and there was limited support after diagnosis, particularly in relation to healthy living advice and support services (e.g. cooking classes).

"There is very little support out there. People often expect that we are on various lists or in systems, but we aren't as my son does not need regular health care support...We need more of an integrated support from health and social care. My son's health needs are few at the moment, but we need to monitor his weight and activity levels to keep him healthy and I am not confident this would happen if it wasn't by us. It needs to be a whole family approach. I am the main carer so if I am ill, I cannot support him. If he can't be in his normal routines, like taking him to regular activities then his anxiety levels rise, and his behaviour deteriorates. This behaviour (and the guilt I feel for causing it) has a negative impact on my own mental health. I may need quick access to a GP to sort myself out first." - Shared with Healthwatch England

¹⁷ University of Bristol (2019) [Annual report 2019: the learning disabilities mortality review \(LeDeR\) programme](#)

¹⁸ Healthwatch England (2020) [590 people's stories of leaving hospital during COVID-19](#)

¹⁹ Healthwatch England (2020) [What people want from the next ten years of the NHS](#)

through our engagement with people across the country about the
NHS Long Term Plan

- People were frustrated by the fact that they had to repeat themselves to different professionals involved in their care and they wanted information sharing between services to be simpler, so they could focus on getting the support they need.
-

“[There needs to be] much more joined up thinking. I have a looked after child with a learning disability. She has seen numerous professionals, no-one has taken an overview of her care and looked at the bigger picture as to what is going on with her... Different specialisms: paediatrician, CAMHS, speech therapy, enuresis, occupational health, physio, plastic surgeons... Why can't you see one professional, tell them your child's issues and then they do all onward referrals?” - Shared with Healthwatch England through our engagement with people across the country about the NHS Long Term Plan

Healthwatch England published a briefing in 2018, bringing together 5,447 carers' experience from across England.²⁰ It found that people faced difficulties accessing support from their local council and often support is only available when they reach crisis point. Accessing reliable information and advice about local services was challenging, despite Council's duty to provide it. Many carers are not aware that they are entitled to assessments for support. In fact, however, for those who do get an assessment, it can have a positive impact on their health and wellbeing.

²⁰ Healthwatch England (2018) [What's it like to be a carer?](#)

What experience should people expect based on local guidance?

What we did

Healthwatch Cheshire spoke to our contacts at Cheshire East Council, Cheshire West and Chester Council, NHS Cheshire CCG, Countess of Chester NHS Foundation Trust, Mid Cheshire Hospitals NHS Foundation Trust, East Cheshire NHS Trust, and Cheshire and Wirral Partnership NHS Foundation Trust (CWP). From this, we were then put in touch with a number of relevant people who have involvement in the experiences of people with a learning disability when accessing a local hospital provision. These included:

- Mental Health and Learning Disability Service Lead; the Senior Commissioner for Learning Disabilities, and the Locality Manager for Learning Disabilities at Cheshire East Council.
- Manager of the Learning Disabilities Team; and the Participation and Engagement Practitioner for Learning Disabilities at Trust D.
- Safeguarding and Complex Care Lead at Trust C.

We held video call conversations with each of these people, and were also put in touch with the Integrated Discharge Team at Trust C, and the Social Work team and Health Facilitators at Trust D, who play a key role in guiding people with learning disabilities through hospital. From these conversations, we were able to gain a clearer understanding of the process of what happens when somebody with a learning disability is admitted to, and discharged from hospital. It was also agreed that we would be sent any documentation held by the Local Authorities, CCG and Trusts regarding this.

From the range of requests that were sent out, Healthwatch Cheshire received the following documentation:

- Cheshire East Council Joint Strategic Needs Assessment (JSNA)
- Cheshire West and Chester Council JSNA
- Countess of Chester Hospital NHS Foundation Trust Elective Care Access Policy (January 2014, updated May 2016, new proposed draft July 2020)
- East Cheshire NHS Trust Patient Access Policy (September 2020)
- East Cheshire NHS Trust Hospital Passport
- Mid Cheshire Hospitals NHS Foundation Trust Joint Discharge Policy & Process (December 2013)
- Mid Cheshire Hospitals NHS Foundation Trust Patient Access Policy (April 2018)
- Mid Cheshire Hospitals NHS Foundation Trust Major Incident Plan (Version 9.3).

We found difficulty attempting to get in touch with the appropriate people due to the short timescale for the project. The timing of the project also fell at the time of year when people were taking annual leave within the health and care system to use up their entitlement before the end of the holiday year. We were not provided with adequate documentation from health and care partners that showed specific policies relating to adults with learning disabilities, despite us making contact to ask for this. The above documentation that we did receive holds very limited information on policies relating to people with learning disabilities.

Healthwatch Cheshire would like to thank those staff from our local authorities, CCG and Trusts who helped and assisted with our requests, and who were very happy to arrange video calls with us and provide us with the information we needed extremely quickly and efficiently.

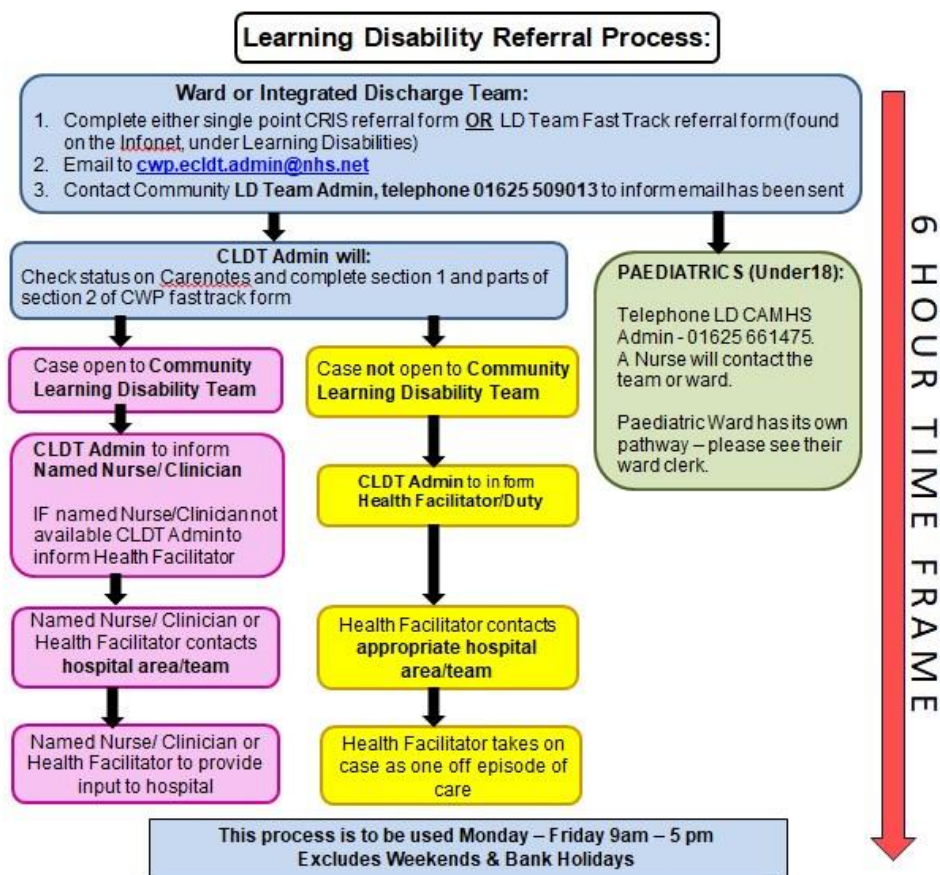
The below details the experience that somebody with a learning disability leaving hospital should expect, based upon the information provided to us from the conversations and documents outlined above.

In relation to people with learning disabilities from both Cheshire West and Chester and Cheshire East, an Equality Impact Assessment from the Mid Cheshire Hospital Joint Discharge Policy and Process document states:

“Disabled patients, including LD, could need specialist equipment for discharge or different discharge personnel. There is a need for an individual assessment prior to discharge. The communication needs should be considered throughout.”

Cheshire East

We spoke to the health facilitators who work in partnership with Macclesfield Hospital over online video call. They provided us with a general process of how an adult with learning disabilities is discharged. As part of this, they shared with us their flow chart of this process. This flow chart is based on the policies used at Macclesfield Hospital:



Cheshire West and Chester

We spoke with the acting Head of Safeguarding and Complex Care from Trust C. They provided us with a brief outline of what takes place during a discharge for adults with learning disabilities.

It was explained to us that the Complex Care team is notified of the upcoming discharge for the adult with learning disabilities. They are then to meet with the individual and the discharge team to see if there are any adjustments that are needed to the patient's care plan. We were told that not every patient with a learning disability will need a discharge plan if there has been no change to patient care.

We were told that Trust C were in the process of making changes to their discharge policies. Healthwatch Cheshire asked if we could be sent the current policies which should represent the current experience of adults with learning disabilities leaving hospital. We have not received this information prior to the completion of this report.

What people told us

What we did

With help and assistance from health partners and local authorities, we were introduced to five people from Cheshire East and five people from Cheshire West and Chester who have a learning disability and an experience of hospital discharge within the last three years and/or their carers. All confirmed that they were happy to hold one-to-one conversations with us over telephone and video call.

Ideally these interviews would be conducted in person, but due to the social distancing restrictions in response to the COVID-19 pandemic we decided to use video and telephone calls. One-to-one interviews work better than a focus group in this instance, particularly for people with learning disabilities and in the context of a video or telephone call. Each conversation is unique and conducting semi-structured interviews on a one-to-one basis can provide us with a flavour of people's experiences and consider the impact on each individual and their own particular journey. These interviews took place during March 2021.

To provide structure to our conversations and to get people thinking about what it was we wanted to ask, we used the questions below as a prompt sheet for participants to consider prior to the interview. The questions for the semi-structured interviews were developed from knowledge previously known to Healthwatch Cheshire from working alongside people with learning disabilities and their families/or carers, and from the conversations and documentation provided to us by the health professionals.

Experiences of people leaving hospital

Hospital care

- Do you have a health passport?
- How was it for you when you were leaving hospital?
- Has anyone helped you when you were coming out of hospital?

Social care

- Did the hospital social worker come to talk to you prior to leaving hospital?
- How did the social worker help you?

Community support

- Did anyone from your doctor's surgery call you after you came home?
- Have you had any support from the community to help you settle back into your home?

	Tick box
Occupational therapy	
Social worker	
Physio	
Local GP	
Community Nurses	
Podiatry	
Food and nutrition support	
Other	

- Is there anything else you want to tell us?

Overview - What did people tell us about their experiences?

- Alert system - Trust B has implemented an Alert system that supports those people with a learning disability to access dignified healthcare. Reports appear to indicate that this is working well.²¹
- Health Facilitator - the Health Facilitator, employed by CWP, is based within Macclesfield Hospital and appears to be well integrated within the hospital, providing a single point of contact for staff and carers.
- The Learning Disability Awareness Training of all members of staff at Trust B was felt to be good practice and clearly demonstrates importance of providing dignity and respect to all patients.
- From what we were told by participants, a Dignity Matron/Nurse at Trust A and Trust C is in place however they do not appear to be as well integrated.
- Participants reported issues at all three hospitals with discharge concerning medications and other medical needs, however there was evidence of organisation, recognition and learning within Trust B.
- A number of interviewees told us of rushed and chaotic discharges from Trust A and Trust C - often at inappropriate times of the day.
- We were told of some nursing staff at Trust A and Trust C who displayed a lack of understanding of the patient and their needs and did not communicate with their carers and professionals concerned in their care plan.

²¹ The Alert system that has been put in place by the Patient Experience Manager is working very well and this supports the Health Facilitator in early identification of those patients who may require support and/or reasonable adjustments. It has also identified safeguarding concerns so that appropriate investigation and action can take place.

Interview summaries

Below are summaries of the experiences people shared with us during semi-structured one-to-one interviews, together with how this relates to what people should expect when being discharged from hospital based upon the policies described above. Whilst not verbatim, these use language and terminology as used by participants.

Cheshire East

All of the participants below used hospital services at Trust B.

Interviewee 1

- 70-year-old female with lifelong learning disability.
- Has ongoing kidney function problems, recently bereaved from husband of 40 years (Husband died of COVID-19).

Lady attended hospital late last year for a routine appointment due to her kidney treatment, following which she had a COVID-19 test and this came back positive. This required her to be admitted to hospital. This was not a good experience as her husband of 40 years had recently died from COVID-19 and the lady's grief was still very raw.

Following her admittance, she was re-housed to the Crewe area just prior to Christmas - this was not in line with her wishes and it was quickly realised that the placement did not suit her when she began to refuse food and drink, resulting in a real concern for her health and a weekend hospital trip to Trust B A&E and admission to hospital due to hydration concerns, thus exasperating her kidney problems.

Hospital staff wanted her to stay but she was fearful due to recent experience and left hospital of her own volition.

The alert system had notified the Health Facilitator who brought it to the attention of the Community Learning Disability Team (CLDT). One of the team has known and supported the lady for a number of years and went to visit her to understand her concerns, gain her trust, and to help address her health needs. At this time, she was quite unwell, both physically and mentally.

Initially there was some reluctance to allow some 'reasonable adjustments' within the hospital, however the staff from the CLDT and the Health Facilitator at the hospital were able to overcome these. This resulted in her having a day admission for a drip for a number of hours to ensure that she was properly hydrated, and also to have a carer with her as is her statutory right. The clinicians were happy with this and it addressed the immediate health concern.

The CLDT also recognised her current placement was not suitable to support her ongoing health and that it had been done at a time, i.e. Christmas, which has historically been a difficult time for the lady. They initiated a move to supported living whilst a more permanent move is being planned (a bungalow with a garden in the Macclesfield area so she can visit her husband's grave).

CLDT have stated that had they been involved in the decision to move the lady to Crewe they would not have supported this and believe that this contributed to a decline in her

mental health resulting in the A&E attendance. This has since been captured and presented at the Trust D Board as a case study.

What kind of care should this person be able to expect?

Do they have a health passport? YES

Did an 'alert' system identify that the patient has a learning disability? YES, it was the Health Facilitator that notified the CLDT of the ongoing concern.

Were reasonable adjustments made during hospital stay? YES, the CLDT were able to advocate on her behalf and, using the trust she had with them, enabled her to have a day procedure accompanied by a support worker.

Do they have a named discharge coordinator? YES

Are their families and carers involved in the planning of their discharge and provided with support after leaving hospital? YES, support with CLDT and Social worker to secure new accommodation. CLDT working to provide some ongoing mental health support.

Was there a coordination consideration of the environment a patient was discharged/returning too?

NO - Not on the initial hospital stay where the patient had contracted COVID-19, the decision by Social Workers was to move her to an unfamiliar environment. However, since the CLDT team became involved she is now in temporary supported living with plans to move to a permanent bungalow in an area more familiar to her.

Do they have an annual health check? YES

Interviewee 2

- 60-year-old male living in supported accommodation since his mum died.

Prior to the COVID-19 pandemic he was busy 5 days a week, and particularly enjoyed gardening clubs. However, with the onset of the pandemic and the need to shield, he quickly became very isolated and low to the extent he stopped eating and also refused his medication. This led to a hospital admission at Trust B.

The Alert system 'kicked in' immediately and ensured that he was supported. The Health Facilitator and the nurses on the wards were described as amazing and he was looked after very well. They were particularly relieved that despite being in hospital a long time he was put on a side ward and this prevented him from getting COVID-19. The nurses quickly adapted their way of working with him to get him to have his medication which he is always reluctant to take.

Prior to his discharge there was a planning meeting, which included his family, to manage his physical and mental health. He has stated he did not want to come back to his old home and associates it with feeling unwell and unhappy. Therefore, the decision was made to move him temporarily to a small setting with other residents. He was purposely given the room overlooking the garden and has begun to do some gardening which has had a massive impact on his mental health. The long-term plan is for him to move into a mews adjacent to his current setting.

He has his own social worker so had no involvement with the hospital social worker.

The discharge plan included the following professionals and all has worked to plan and he is in a much better place health-wise.

- Social worker
- Occupational Therapist
- Physio
- Community Nurses
- Food and Nutrition has trained and supported staff at the home.

What kind of care should this person be able to expect?

Do they have a health passport? YES

Did an 'alert' system identify that the patient has a learning disability? YES, the patient was very poorly both physically and mentally, it was recognised immediately that a bespoke approach was needed and continuous support in hospital.

Were reasonable adjustments made during hospital stay? YES, they were provided with a side room as due to his condition he was at an increased risk should he contract COVID-19; it could be catastrophic. Staff had to adjust their way of treatment particularly concerning medication which he was reluctant to take.

Do they have a named discharge coordinator? YES, the Health Facilitator.

Are their families and carers involved in the planning of their discharge and provided with support after leaving hospital? YES, there was a planning meeting prior to discharge which included his family and carers to best manage his physical and mental health. The views of the patient were forefront - which included a change of accommodation

to a setting which provide them with a 'fresh start' and also supported his hobbies and interest. He is currently residing in a new home where he has access to better outside space and heavily involved in the gardening. This along with additional therapy is having a great impact on his mental health which is also promoting his physical health.

Was there a coordination consideration of the environment a patient was discharged/returning too? YES, the patient was adamant that they did not wish to return to their old flat as they associated it with unhappy memories - therefore the use of temporary supported accommodation was agreed. He has since been able to be more involved in the planning of his permanent home.

Do they have an annual health check? YES

Interviewee

- Lady in her mid-50s. Resides in supported accommodation with a couple of other ladies.

She had no major issues - had the occasional fall (possibly one a year). However, it became apparent that over a relatively short period of time she had had 9 falls, 5 of which had resulted in A&E attendance to treat injuries to either knee or head. In the main these tended to happen at weekends.

Each time she went to hospital the focus was on her fall - there was never any follow-up discharge information or indeed link up with her own GP. Due to the alert system, the Health Facilitator became aware of the repeat visits and identified a safeguarding concern.

There was a growing concern with the home staff and her family and a 'best interest' meeting was held with the GP. There was a slight concern that she may have suffered a minor stroke. However, it was acknowledged by all involved that the lady did not tolerate procedures even minor ones such as blood tests and an ECG. It was decided that they would start with the least invasive procedure such as a medicines review. During this review, it was established that a particular medicine had been administered over 5 years to treat urine incontinence. A rare side effect of this drug was to cause imbalance. By removing this medicine an immediate benefit was noticed.

As a further process to support the lady's wellbeing, the physiotherapy team was involved and some falls prevention strategies were put in place. Podiatry have provided support shoes. All of these interventions are helping the lady maintain a level of independence.

The home itself conducted an internal review of their process which has resulted in a more streamlined and central process of recording accidents and with a greater overview to identify patterns and repeat incidents.

What kind of care should this person be able to expect?

Do they have a health passport? YES

Did an 'alert' system identify that the patient has a learning disability? YES - It also identified a pattern which then triggered a 'safeguarding concern'

Were reasonable adjustments made during hospital stay? YES, the patient was able to have round the clock carers with them throughout their stay in hospital.

Do they have a named discharge coordinator? YES

Are their families and carers involved in the planning of their discharge and provided with support after leaving hospital? YES, there was a 'Best Interest' meeting held with the hospital, carers, family and patient's GP to discuss their treatment plan - which involved using the least invasive means. Community Health Teams such as podiatry and physiotherapy have provided additional support.

Was there a coordination consideration of the environment a patient was discharged/returning too? YES, the safeguarding concern was not regarding the care of the patient and the medicine review had immediate benefits to their balance. Further processes were put in place internally at the supported accommodation to identify patterns at a much earlier stage.

Do they have an annual health check? YES

Interviewee

- Lady in her mid-50s living in supported accommodation. Has communication difficulties.

Staff noticed that all of a sudden, she was presenting as slightly unwell, nothing obvious in itself however she was “grabbing at staff and seemed quite disturbed”. A phone call to NHS 111 advised to go to hospital where she was diagnosed with a twisted bowel and required an emergency operation.

The hospital alert system kicked in immediately upon her admittance and the Health Facilitator was on hand to coordinate support, both in the hospital and on discharge.

The procedure was to repair the bowel as opposed to a full removal requiring a colostomy. The ongoing treatment is such that she will require daily enemas for life. Whilst in hospital this was performed by the nursing staff. However, reasonable adjustments were made and this allowed 2 members of care staff to go in every day to support her generally and at night 1 member of care staff was present, thus providing people familiar to the lady.

When it came to discussing the discharge plan for this lady, the Health Facilitator and the lady's GP were involved, bringing in district nurses for the daily enema. Going forward, training was provided so the care staff at the lady's home could complete this task under the guidance initially of the district nurses. This has helped the lady recover well and it is included as part of her morning routine so she can enjoy the rest of the day.

Dieticians are involved in supporting the nutrition of this lady and in the management of her condition.

Her GP has always been on hand to provide advice to the staff regarding her ongoing care following this procedure.

Upon discharge she was required to isolate on returning to the care environment. There is however a dedicated building for this and the lady took this in her stride and decided that she was on her holiday.

What kind of care should this person be able to expect?

Do they have a health passport? YES

Did an 'alert' system identify that the patient has a learning disability? YES

Were reasonable adjustments made during hospital stay? Yes, carers from the patient's supported living accommodation were allowed to be present 24 hours a day to provide ongoing comfort and support.

Do they have a named discharge coordinator? YES, Health Facilitator

Are their families and carers involved in the planning of their discharge and provided with support after leaving hospital? YES, it was acknowledged that the patient would require daily treatment for the remainder of her life. This was completed by district nurses. Training was arranged to allow her carers to complete these tasks thus allowing it to become part of her daily morning routine as opposed to waiting for the nurses to arrive. Her GP was happy with this arrangement.

Was there a coordination consideration of the environment a patient was discharged/returning to? YES, due to COVID-19 the patient had to isolate in another setting prior to return to her own home. This was managed by turning it into a 'holiday'. The patient thoroughly embraced and enjoyed this approach.

Do they have an annual health check? YES.

Interviewee 5

- Female in her 70s
- Lived in supported accommodation since 2006.

The lady had been admitted due to aspiration pneumonia, following which there was a pre-discharge meeting coordinated by the Health Facilitator to discuss ongoing treatment. Consideration was given to SALT guidance, pressure relief mattress to reduce the risk of pressure sores and ongoing medication.

However immediately following the discharge it became apparent that there was no SALT information or medication guidance provided to carers. Telephone guidance post discharge was conflicting and within 24 hours care staff reported concerns regarding aspiration occurring. The lady was readmitted to hospital for further treatment.

At the following pre discharge meeting it was agreed that a more coordinated approach was required and the SALT team provided training to the lady's support team in order to understand and follow the guidance. This was very well received and has prevented further repeats of aspiration to date.

The Health Facilitator also provided support staff some guidance regarding pressure sore management and tissue viability.

They also ensured that the patient accessed some ongoing Physio and Occupational Therapy and have conducted a review in order to provide some equipment which will provide greater comfort, i.e. shower chair.

Organisational learning was taken on board by Trust B in order to better inform the discharge process for patients with a learning disability.

What kind of care should this person be able to expect?

Do they have a health passport? YES

Did an 'alert' system identify that the patient has a learning disability? YES

Were reasonable adjustments made during hospital stay? YES - The patient was always permitted visitors.

Do they have a named discharge coordinator? YES - Health Facilitator

Are their families and carers involved in the planning of their discharge and provided with support after leaving hospital? Somewhat - A Discharge planning meeting was held, however upon discharge, the SALT and medication advice was missing. The patient was re-admitted within a day. The second discharge was much smoother and SALT provided training to the patient's support worker.

Was there a coordination consideration of the environment a patient was discharged/returning too? YES, Physiotherapy and OT have been involved via the patient's social worker.

Do they have an annual health check? YES.

Cheshire West and Chester

All participants are residents of Cheshire West and Chester. Some used hospital services at Trust C and others accessed hospital services in Cheshire East at Trust A.

Interviewee 1

- Female who resides in over 55's supported living due to her learning disability.

This lady spoke to Healthwatch on her own during a one-to-one interview without a carer. Whilst she was able to explain what had happened, there were some questions she was unable to answer.

"In October I fell over and hurt my head and broke my arm. When I went to hospital [Trust C] they found out I had pneumonia. So, I had to stay in hospital, they were very kind. I then came home to my flat, the carers have helped me have my shower, make my tea with me. They take me shopping and are very nice to me. I was glad to be home as a lot of my friends are there and we can go into the garden or go for walks."

She explained that a lady helped her when she was leaving hospital and made sure that she saw her GP. Furthermore, she said that she feels well supported at home by carers.

What kind of care should this person be able to expect?

Do they have a health passport? Doesn't know.

Did an 'alert' system identify that the patient has a learning disability? Doesn't know.

Were reasonable adjustments made during hospital stay? Doesn't know.

Do they have a named discharge coordinator? Possibly a lady called X

Are their families and carers involved in the planning of their discharge and provided with support after leaving hospital? Carers on return to supported accommodation.

Was there a coordination consideration of the environment a patient was discharged/returning too? Doesn't know.

Do they have an annual health check? Yes - "My doctor is very kind to me"

Interviewee 2

- Female in her 50s with Down Syndrome. Lives in supported living and has a volunteering job. When COVID-19 happened, it all came to a “shuddering halt”.

In the past year the lady caught COVID-19 and required admission to Trust C. She didn't have any understanding of what was happening and was resisting all treatment, e.g. pulling out tubes, would not wear a mask. Thus, she was sedated in order for them to treat her.

Unfortunately, her health deteriorated and she needed to be moved to an out of area hospital for a tracheostomy where she stayed for 4 weeks.

The treatment and care were described as “brilliant”.

- It appeared obvious that they had read her care plan.
- Took a lot of time to explain what had happened to her and they acknowledged how frightening it was for her.
- They provided distraction tools such as blue tack and ‘fiddle muffs’.
- Treatment was paced to her needs, e.g. very slow at weaning off the sedation following the operation.
- Hospital had excellent communication with parent and community social care team. Kept a detailed diary.

She was then transferred back to the Trust C Intensive Care Unit and eventually the Recovery Ward where it “went a little awry”. There was not such a joined communication system here; they would speak to her parent (elderly) and not inform the CLDT/Social Care who were actually responsible for the management of her Care Plan and could ensure that carers could go into the hospital to support her. This eventually happened and had a massive positive effect for the lady.

When it came to discharge, this was described as “a mess”. The nursing staff told her on a Friday afternoon that she was going home and even started packing her things in front of her - it was very rushed and no care plan was in place to accommodate her needs upon release from hospital.

The CLDT only found out about her discharge by chance when one of the support carers at the hospital told them. The team had to say no to the discharge as it was unsafe (her home needed things such as grab rails, shower equipment and bed sensors). The District Nursing Team were informed to help with the wound management of the tracheostomy. Physio was needed due to having been bed bound for weeks to help build up her strength.

As expected, the lady was very distressed as she wasn't going home. Her parent was also upset as they had to be made aware of any decisions before they were acted upon.

The CLDT were able to act quickly to put things in place for the following week which was a mammoth task; however, the following was achieved:

- Bed sensors
- Grab rails
- Safety measure for her shower
- Physio
- District nursing team for wound dressing and daily injections.

Overall, the interviewee told us that as Trust C knew she was going into supported accommodation, the whole discharge was extremely rushed and they appeared not to have

an understanding of the role of the carers and that they are not nurses. There was a feeling that there was very little understanding from nursing staff regarding the lady's needs suggesting that no-one actually read her care plan or hospital passport.

On a positive note, they felt that the Complex Care Needs Nurse at Eastway Inpatient Unit did her utmost to try and support the lady during her stay by ensuring she had access to letters, cards, message and video calls with friends and family.

She spoke very highly of the care, support and communication at the out of area hospital.

What kind of care should this person be able to expect?

Do they have a health passport? YES

Did an 'alert' system identify that the patient has a learning disability? YES - Went into hospital with a Care Plan

Were reasonable adjustments made during hospital stay? Eventually, when on the Recovery Ward a carer was provided round the clock.

Do they have a named discharge coordinator? NO

Are their families and carers involved in the planning of their discharge and provided with support after leaving hospital? NO not initially - CLDT team had to stop a rushed discharge whilst things were put in place to ensure the safety of the patient.

Was there a coordination consideration of the environment a patient was discharged/returning too? No - as above.

Do they have an annual health check? Yes - the GP has been having phone consultations and her annual health check is being brought forward following this episode.

Interviewee

- Interviewee was the parent of a male in his mid-40s with complex needs residing in supported living
- Experience of admission to Trust A due to gastric problems
- Since son moved into supported living they do not feel as informed about his medical needs as previously.

What kind of care should this person be able to expect?

Do they have a health passport? YES - But parent doesn't believe that it is read as there are always issues concerning his medication, which wouldn't happen if they read the passport as it clearly states within it.

Did an 'alert' system identify that the patient has a learning disability? YES - he usually goes in with support staff.

Were reasonable adjustments made during hospital stay? YES - Support staff have stayed with him, however due to funding this is only during the day which given he is in 24-hour supported accommodation did not feel right to the parent.

Do they have a named discharge coordinator? YES - Dignity Nurse - However doesn't feel that a lot of the other hospital staff understand the differing needs of those with a learning disability.

Are their families and carers involved in the planning of their discharge and provided with support after leaving hospital? "As he now resides in supported living - as his parent I am not told anything by the hospital unless I ask."

Was there a coordination consideration of the environment a patient was discharged/returning too? Thinks it is very rushed, sometimes in the middle of the night which is very disorientating for him.

Do they have an annual health check? YES

Interviewee

Male in supported living with one-to-one care from 8am-10pm.

He was a patient in Trust A following a fall out of bed and breaking his leg (pre- pandemic). Then a further stay following gastro problems (during pandemic). He has complex needs.

Admission Pre-COVID-19 Pandemic

Should have gone for Rehab to help him walk again but no-one would take him stating “he didn’t meet the criteria”. They believe it was because he has a learning disability and so was sent back to supported living. It took him a long time to settle and now he uses a wheelchair.

Admission during COVID-19 Pandemic

Following a recent stay in Trust A there was no discharge meeting; the hospital sent him home in the middle of the night via ambulance without any warning. This was disruptive to both the patient and the other residents of the home.

When he was discharged there was no MARS sheet or any instructions. There are no medical staff at the supported living. The following morning his GP was contacted and they were unaware of the discharge.

The male requires regular blood tests which are done by the District Nurses however they were not done during the pandemic. He was not tested for COVID-19 upon discharge, despite returning to a multi-occupancy accommodation.

Now in supported living it is really difficult to get the aftercare, even Occupational Therapy.

“I feel there is no dignity in the discharge of a lot of adults with a Learning Disability.”

What kind of care should this person be able to expect?

Do they have a health passport? YES

Did an ‘alert’ system identify that the patient has a learning disability? Doesn’t believe the alert system has been in place during COVID-19, however carers go to hospital with him.

Were reasonable adjustments made during hospital stay? Carers stay during day time.

Do they have a named discharge coordinator? NO - There is a Dignity Nurse - but that seems to be more for in the hospital.

Are their families and carers involved in the planning of their discharge and provided with support after leaving hospital? No, usually discharged without warning.

Was there a coordination consideration of the environment a patient was discharged/returning too? No - it is assumed that as the discharge is to supported living that the staff are nursing however there are no medical staff.

Do they have an annual health check? YES

Interviewee

- Male in supported living with a Learning Disability

Man had burn injuries to his groin following dropping a hot drink. He was taken via ambulance to Trust C. Despite being triaged, he sat in his wheelchair in the main waiting room for 6 hours, with burns to his penis and testicles, with no pain relief. He was clearly in a lot of pain. Supported Living staff were with him but there was plainly no alert system despite him clearly having a Learning Disability.

After he was seen, he was transferred to the Specialist Burns Unit at an out of area hospital. They were very good with him there and he got very good treatment. His aftercare with his GP and district nurses was much better.

What kind of care should this person be able to expect?

Do they have a health passport? YES

Did an 'alert' system identify that the patient has a learning disability? NO

Were reasonable adjustments made during hospital stay? Once at an out of area hospital.

Do they have a named discharge coordinator? Don't know

Are their families and carers involved in the planning of their discharge and provided with support after leaving hospital? VIVO

Was there a coordination consideration of the environment a patient was discharged/returning too? YES

Do they have an annual health check? YES

Summary - What did people tell us about their experiences?

The residents of Cheshire are served by three main hospitals, namely:

- Macclesfield Hospital - mainly Cheshire East residents.
- Leighton Hospital - located in Cheshire East but serves both Cheshire East and Cheshire West and Chester residents.
- Countess of Chester Hospital - mainly Cheshire West and Chester residents.

It is important to recognise this distinction as there appears to be a difference in experience of the interviewees, dependent on the hospital they attended.

Cheshire East

Those people who had experience of Trust B spoke extremely positively about the Health Facilitator, she was described as “*amazing*” and “*brilliant*” and “*if there’s a problem, she will get it sorted - she’s excellent*”. From our research it is felt that the Health Facilitator, who is part of Trust D and based in the hospital, is well-embedded and demonstrates good evidence of integration.

People felt that the Alert system that has been put in place by the Patient Experience Manager is working very well and this supports the Health Facilitator in early identification of those patients who may require support and/or reasonable adjustments. It has also identified safeguarding concerns so that appropriate investigation and action can take place (see Cheshire East Interviewee 3).

We were able to talk to the Health Facilitator at length about her role, she was able to explain how she has developed it further by completing fortnightly Ward visits to introduce herself to staff and explain her role. This has promoted good relationships and nursing teams will contact her for advice regularly.

Furthermore, we were told that both she and the Patient Experience Manager have ensured that all staff receive training in supporting the needs of those people with a learning disability; these include Porters, Security Staff, Cleaners and Volunteers in addition to Nursing staff. This ensures that people are treated with dignity and respect as soon as they enter the hospital to the moment they leave and beyond.

Our findings showed that in the majority of cases a Discharge Plan is in place prior to discharge, it is recognised however that on occasion things have been missed despite having been agreed. In all of the cases we discussed, the carer identified the problem (e.g. Cheshire East Interviewee 5) and the Health Facilitator was informed and this was actioned. Furthermore, each case is escalated for organisational learning.

Cheshire West and Chester

The experience of those people we spoke to living in Cheshire West and Chester who used both Trust A and Trust C whilst similar to each other, is somewhat different.

None of our interviewees were aware of an ‘Alert’ system which identifies a patient has a learning disability when in hospital, although it would be apparent as all the people we discussed had carers with them when they arrived.

Some individuals were aware of ‘a person who can assist whilst they are in hospital’, but could not mention them by name, some described a ‘Dignity Matron’ and stated “*they do their best - but they are just one person and they cover everyone - not just people with LD*”. Unfortunately, we were unable to speak to this staff member, and they were only mentioned when talking to the interviewees rather than by the staff we had spoken to at the organisations.

When we asked people about Hospital Passports, we were told on each occasion that the patient has one and they always went with them to hospital. However, people were not confident that they were being either read or acted upon.

The discharge process across these two hospitals was described to us as “*rushed and chaotic*”. The professional carers from Supported Living establishments all stated that there is an assumption that a person returning to Supported Living will get nursing care. Therefore, they are sent home without a thought of wound management, medication management, physiotherapy, Occupational Therapy or Speech and Language Therapy (See Cheshire West Interviewees 2 and 4). We were told by staff at the Trust C that they are beginning a review of their discharge process and now have a Learning Disability Working Group.

The most powerful thing we were told during the interviews was when we asked one lady:

“*XXX can you tell me what is important to you about your care?*”

She replied “*To be listened to.*”

Conclusion

Commissioned by Healthwatch England, this project aimed to devise and test out a methodology to help measure and people's experiences of the integration of health and care services. The methodology was outlined by Healthwatch England, including the particular cohort of people that we were to focus on; the number of participants to be included in information gathering; and the timeframe for delivery. Overall, the methodology detailed earlier in this report worked well, enabling people with learning disabilities and/or their carers to share their experiences and get their voices heard.

Healthwatch Cheshire would like to thank all people who shared their experiences. This has been invaluable for us to better understand the issues faced by people with learning disabilities and whether, and to what extent, services are working together. We would also like to thank those staff from our local authorities, CCG and Trusts who offered their help and assistance with our requests.

Completing the project during the COVID-19 pandemic provided difficulty, particularly as delivery of this project coincided with the rollout of the vaccination programme. This meant that members of the Healthwatch team needed to change focus to assist with the communications and support for the programme locally. Furthermore, it resulted in many staff in health and care organisations either being redeployed as part of the response, or not being able to see this work as a priority.

Healthwatch Cheshire holds existing local insight into the experiences provided to us by people with learning disabilities, their families and/or carers, and support groups. We are also active members of both local authorities' Learning Disability Partnership Board. However, in approaching local systems to collate current policies which set out what people with learning disabilities should be able to expect from services, we found that whilst we were able to hold conversations with some relevant staff, we generally found difficulty attempting to get in touch with the appropriate people in most of the organisations. We were signposted to various places and people but there did not seem to be one contact who held all of the required information. It should be noted that those who did respond were happy to arrange conversations over video call. We were also put in touch with the Integrated Discharge Team at the Trust C, and the Social Work team and Health Facilitators at Trust D, who play a key role in supporting people with learning disabilities through hospital. From these conversations, we were able to gain a clearer understanding of the process of what happens when somebody with a learning disability is admitted to, and discharged from individual local hospitals. With respect to how the system works as a whole, we found limited evidence of awareness of how policies interacted with those of other organisations within the health and care system, and services that influence the wider determinants of health.

Within the scope of this project, we were not provided with adequate documentation from some of the health and care partners showing policies specifically relating to adults with learning disabilities. The short timescale for the project and people taking annual leave within the health and care system to use up their entitlement before the end of the holiday year compounded this issue as it gave limited opportunity to hold follow-up conversations. The documentation we did receive was varied in quality, fragmented, difficult to navigate, and holds very limited information on policies specifically relating to people with learning disabilities, despite making contact to ask for this. This all demonstrates the difficulty in readily accessing current policies and action plans that allowed us to comment on

integration. A future recommendation would be to ensure longer timescales for the project to allow for contact with the most appropriate people from other organisations and to allow more opportunity to receive and review the appropriate policies and documentation. Now that they are meeting again, a further recommendation would be to present findings from this report to the Learning Disability Partnership Boards and Integrated Care Partnerships, to gain a multi-agency perspective on the perceived lack of integration highlighted in our findings. Our recommendation would be that this methodology should be applied to the relevant overarching organisations for each of the patient cohorts. This will be useful in our follow-up work to determine how recommendations have been acted upon.

In order to recruit participants to establish what and whether key changes are needed to improve their experiences of integration, we used established links into support groups and peer support groups for people with learning disabilities and/or their families and carers; contacted individuals who had made us aware of recent experiences of hospital discharge either directly or through our Feedback Centre; and spoke with health and care support professionals. At all stages we ensured that we received consent from those taking part. Where participants were identified by professionals, interviews were then able to be arranged very quickly. As a future recommendation, consideration is needed to ensure that there are a wide range of participants involved, so as to avoid selection bias.

The format of semi-structured one-to-one interviews with our participants worked well as they provided us with a flavour of peoples' experiences. Open-ended questions allowed us to consider the impact on each individual and their own particular journey, and included the question 'Is there anything else you wanted to tell us?'. We were unable to conduct these interviews in person due to the social distancing restrictions in response to the COVID-19 pandemic, and so we decided to use video and telephone calls. One-to-one interviews proved a better approach than a focus group in this instance, particularly for people with learning disabilities and in the context of a video or telephone call. Using a prompt sheet of questions for participants to consider prior to the interview provided structure to our conversations and got people thinking about what it was we wanted to ask, helping interviews to run efficiently. The questions for the semi-structured interviews were developed from knowledge previously known to Healthwatch Cheshire from working alongside people with learning disabilities and their families/or carers, and from the conversations and documentation provided to us by the health professionals. At the time of production, many learning disability and carers groups were not meeting due to COVID-19 restrictions. A recommendation for the future would be to embed co-production to a greater extent in determining that the process used is appropriate for the client group.

This report will now be submitted to Healthwatch England, and findings to individual providers. Recommendations will be submitted to the relevant local overarching organisations/boards to ensure improvements to health and care integration for people with learning disabilities in Cheshire.