

# West Yorkshire & Harrogate Health and Care Partnership

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Mental Health and Learning Disabilities  
engagement and consultation mapping

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March 2019

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# Section 1: Introduction to the report

## 1. Purpose of the report

The purpose of this report is to present the findings from mental health (MH) and learning disabilities (LD) engagement and consultation activity which has taken place from April 2014 to March 2019, across West Yorkshire and Harrogate Health and Care Partnership (WY & H HCP).

It updates the previous report that covered the period April 2014 – Oct 2017 and covered MH only. The report captures intelligence collected from engagement and consultation activities and will support commissioners to:

- Provide information on work which has already taken place or is underway to avoid duplication
- Highlight any gaps in activity across West Yorkshire and Harrogate by each of the service areas
- Understand some of the emerging views gathered from local people across West Yorkshire and Harrogate
- Ensure that any future plans have a baseline of engagement intelligence to support the work

In addition, the report can be a working document which is added to as projects progress. The intelligence collected will ensure we meet our legal requirements and ensure we:

- Consider the views of patients and the public as part of service redesign; and
- Ensure the feedback is considered in the development of any future options to change the way a current service is provided or delivered
- Highlight patient and public priorities and ensure these priorities are in line with current thinking and ensure commissioners can consider all public views

## 2. Background

The leadership and staff of health and care organisations in West Yorkshire and Harrogate, in their role as part of Health and Wellbeing Boards, have existing plans to deliver ambitious improvements to health and social care services for people in Bradford, Airedale, Wharfedale, Craven, Calderdale, Harrogate, Kirklees, Leeds and Wakefield.

These plans, alongside our West Yorkshire and Harrogate priorities, make up our West Yorkshire and Harrogate Health and Care Partnership draft plan. This work, managed in partnership, allows us to work together on good practice and shared solutions.

We will work together locally and at a regional level, to make sure that mental health and learning disability conditions are treated the same as physical health issues. Local mental health and learning disability services will be integrated with physical health and care services. This will ensure we care and treat the 'whole' person tailoring care to the person's

need; supporting people with long-term conditions to cope with anxiety or depression, and ensuring people only go to hospital when absolutely necessary.

We are developing services across the region to reduce difference in the quality of care people receive in order to improve their wellbeing and make services more effective and efficient for the future.

Since the previous report, the West Yorkshire Mental Health Services Collaborative has been established to ensure that decisions across the region are made together around a shared programme of work. The new committee will help ensure that decisions are made together and in a streamlined way around a shared programme of work. It will also see that collective ambitions are achieved, for e.g. eliminating out of area placements for young people, and delivering the region's five-year suicide prevention strategy, launched in November 2017.

To support this work the West Yorkshire and Harrogate Health and Care Partnership Mental Health work streams originally requested that a mapping document be produced focusing on the following 4 areas:

- Acute mental health care
- Autistic Spectrum Condition (ASC) and Attention Deficit Hyperactivity Disorder (ADHD) services (all age)
- Child and Adolescent Mental Health services
- Eating disorders

For the refreshed 2019 report, new areas for mental health have emerged and, as stated previously learning disabilities has been added as a priority for the partnership.

## **2019 Update**

### **Mental health**

New emerging themes which have been added in this report are:

- Primary care;
- Community care;
- Rehabilitation and recovery;
- Older people's services transformation;
- Mental health needs assessment/ emotional wellbeing;
- Special educational needs and/ or disabilities;
- Children's emotional health and wellbeing

### **Suicide prevention**

Suicide prevention is a key priority for the Partnership. We have developed a zero suicide approach which has been signed up to by health providers, local authorities, police and voluntary organisations across West Yorkshire and Harrogate. The approach is led by a suicide prevention strategy where every suicide is seen as preventable with a culture of collaboration and partnership working across all organisations, promoting a coordinated and shared approach to suicide prevention and self-harm.

Work around this agenda includes developing relationships and membership of the Suicide Prevention Advisory Network (SPAN) and the Federation of NHS Trusts (FONT), providing an invaluable link to the Public Health Community of Interest. Along with a valuable piece of engagement work has also taken place to enhance links to experts by experience and to improve suicide bereavement services across WYHCP.

Work continues to embed the suicide prevention strategy and the zero suicide approach, which will include further stakeholder engagement and working with local people to develop action plans and activity.

During the development of the report, it was identified that there was a body of engagement work taking place around suicide prevention, although specific themes from this engagement could not, at the time of writing, be identified. This is an area that would benefit from further investigation in future reports.

### **Learning disabilities**

For learning disabilities, emerging themes are:

- Access to learning disability services;
- Assessment and treatment units;
- Health inequalities;
- Improving access to primary care;
- Social isolation;
- Transforming care for children and young people.

### **General**

Work is also taking place nationally and locally around 'Transforming Care' for people with learning disabilities, autism or both who display behaviour that challenges, including people with a mental health condition, to get the best possible care.

Listening to, and learning from, people's experience is an important part of our work. In February 2019, NHS England and [Pathways Associates](#) published a document called [Beyond The High Fence](#), which was co-produced with people with a learning disability and autistic people who are, or have been, in hospital.

This piece of work was led by Gavin Harding MBE, a learning disability adviser for NHS England, who has personal experience of being in hospital himself. It is written for specialist commissioners, clinical commissioning groups, local authorities and anyone working in the criminal justice system. People share their lived experience and offer their views on what more needs to happen to improve quality of care and support people to make a successful return to their communities.

A copy of the full updated 'Mental health engagement and consultation mapping' report can be accessed <https://www.wyhpartnership.co.uk/engagement-and-consultation>

## Assessment and treatment units

Locally, learning disabilities colleagues have been working with NHS England's 'Experts on Tour' team. The three ATU providers and some of our community services who support people with learning disabilities and complex mental health and/or behaviour that challenges met with the team at the beginning of February. The team of experts acted as a 'critical friend' and helped shape current and future thinking about quality assurance models, how to increase carer engagement and co-production. Colleagues also reflected on the need to make sure there is good communication across the wider health and social care system in relation to the recognised interdependencies that ATU provision has on community services.

Work is taking place in 2019 to look at the way care is provided across the 3 ATUs and how as a region we make the best collective use of our services. Engagement activity has taken place in February 2019 but findings of this work are not yet available. The engagement process has aimed to seek the views of service users, carers, families, staff and key stakeholders who have experience of ATUs across West Yorkshire to further inform the next stage of the work. The next stage will be to look at how to reconfigure ATU provision in the region to ensure maximum benefit for both service users and the system.

## 3. Process

The documents in this report were sourced via requests to the West Yorkshire and Harrogate Health and Care Partnership work stream leads, engagement leads across CCGs, Healthwatch and providers, and a review of documents held on websites of all key organisations.

Each document was reviewed, and the key themes and details were written up in to an evidence summary. The majority of the work that was sent had already been thematically analysed, and in those cases, the themes were copied. Some of the engagement and consultation reports that were reviewed had also been analysed to establish if there was any variation in the views expressed by people from protected groups. Any specific themes raised by protected groups are also included within this document.

After summarising all of the documents, the key themes from those documents were reviewed and a list of the key themes for each of the workstreams was created. Consideration was given to how many pieces of work that theme had been mentioned in, how many people had taken part in the engagement activity that mentioned the theme, and how much discussion there had been around that theme by the people who had been involved in that engagement.

## 4. Use of existing data

For this updated report, a review has taken place of all relevant engagement and consultation that has taken place between March 2018 and March 2019. This work builds on the previous mapping exercises that have taken place and all the original data from previous reports is also contained within this report.

The original mapping consisted of **105** documents, and additional **26** documents were analysed for this updated report. Some were produced by the Clinical Commissioning

Groups (CCGs), others came from Healthwatch, providers, voluntary and community Sector (VCS) and Local Authorities. See Appendix A for a full list of the documents reviewed, those analysed for this report are highlighted in **green**.

## 5. Our responsibilities, including legal requirements

Engaging people is not just about fulfilling a statutory duty or ticking boxes, it is about understanding and valuing the benefits of listening to patients and the public in the commissioning process.

By involving local people we want to give them a say in how services are planned, commissioned, delivered and reviewed. We recognise it is important who we involve through engagement activity. Individuals and groups play different roles and there needs to be engagement opportunities for both.

A West Yorkshire and Harrogate Communications and Engagement Strategy underpins the principles by which the engagement and consultation will operate, and highlights the commitment to good practice in delivery. Engaging people who use health and social care services, and other stakeholders in planning services is vital to ensure services meet the needs of local communities. It is also a legal requirement that patients and the public are not only consulted about any proposed changes to services, but have been actively involved in developing the proposals.

### Legal requirements

There are a number of requirements that must be met when discussions are being made about the development of services, particularly if any of these will impact on the way these services can be accessed by patients. Such requirements include the Health and Social Care Act 2012 and the NHS Constitution.

[Health and Social Care Act 2012](#), sets out the Government's long-term plans for the future of the NHS. It is built on the key principles of the NHS - a comprehensive service, available to all, free at the point of use, based on need, not ability to pay. It sets out how the NHS will:

- put patients at the heart of everything it does, 'no decision about me, without me'
- focus on improving those things that really matter to patients
- empower and liberate clinicians to innovate, with the freedom to focus on improving healthcare services

It makes provision for CCGs to establish appropriate collaborative arrangements with other CCGs, local authorities and other partners, and it also places a specific duty on CCGs to ensure that health services are provided in a way which promotes the NHS Constitution - and to promote awareness of the NHS Constitution.

Specifically, CCGs must involve and consult patients and the public:

- in their planning of commissioning arrangements

- in the development and consideration of proposals for changes in the commissioning arrangements, where the implementation of the proposals would have an impact on the manner in which the services are delivered to the individuals or the range of health services available to them, and
- in decisions affecting the operation of the commissioning arrangements where the implementation of the decisions would (if made) have such an impact

The Act also updates Section 244 of the consolidated NHS Act 2006 which requires NHS organisations to consult relevant Overview and Scrutiny Committees on any proposals for a substantial development of the health service in the area of the local authority, or a substantial variation in the provision of services.

The duties to involve and consult were reinforced by the [NHS Constitution](#) which stated: 'You have the right to be involved directly or through representatives, in the planning of healthcare services, the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services'.

[The Equality Act 2010](#) unifies and extends previous equality legislation. Nine characteristics are protected by the Act, age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, sex and sexual orientation. Section 149 of the Equality Act 2010 states that all public authorities must have due regard to the need to a) eliminate discrimination, harassment and victimisation, b) advance 'Equality of Opportunity', and c) foster good relations. To help support organisations to meet these duties a set of principles have been detailed in case law. These are called the Brown Principles;

- The organisation must be aware of their duty.
- Due regard is fulfilled before and at the time any change is considered as well as at the time a decision is taken. Due regard involves a conscious approach and state of mind.
- The duty cannot be satisfied by justifying a decision after it has been taken.
- The duty must be exercised in substance, with rigour and with an open mind in such a way that it influences the final decision.
- The duty is a non-delegable one.
- The duty is a continuing one.

[An Equality Impact Assessment \(EQIA\)](#) will need to be undertaken on any proposals for changes to services that are developed through the programme, in order to understand any potential impact on protected groups and ensure equality of opportunity. Engagement must span all protected groups and other groups, and care should be taken to ensure that seldom-heard interests are engaged with and supported to participate, where necessary.

#### [Secretary of State's key tests](#)

Any service change proposals are expected to comply with the Department of Health's four tests for service change. These are:

- 1) Strong public and patient engagement;
- 2) Consistency with current and prospective need for patient choice;
- 3) A clear clinical evidence base; and
- 4) Support from proposals from clinical commissioners

For significant service changes, NHS England operates an assurance process whereby they provide support and guidance to commissioners so that they can demonstrate compliance with the four tests and other best practice checks. The assurance process concludes with an assurance checkpoint at which time NHS England provides a recommendation regarding whether the tests have been met.

## **6. West Yorkshire and Harrogate mental health and learning disabilities engagement and consultation activity at a glance**

In order to deliver work in these areas in West Yorkshire and Harrogate it is essential that partnership networks work together to understand the view of local populations.

Where there are gaps in this information we can progress to have further conversations based on what we already know. This means that any future service provision uses what we already have, prevents duplication of existing conversations and ultimately has the public at the centre of everything we do. In addition, work done regionally should not confuse the public who may have given their views at a local level. The communications supporting any further engagement and consultation activity needs to be managed with this mapping in mind.

The tables below sets out the conversations already hosted across West Yorkshire and Harrogate, the topics of those conversations and where further plans may benefit from local intelligence. For the purpose of the mapping we wanted to know;

- Any engagement completed between April 2014 and March 2019 that would provide intelligence.
- Any formal consultation which has ensured a service is in the process of being changed based on the engagement activity.

Each of the areas are then looked at in more depth drawing on the information from each local area, and where appropriate identifying any specific themes that have emerged for protected groups. This is based on what we already know but may not be exhaustive.

Any new intelligence that has been discovered regarding engagement and consultation work since the previous report is highlighted in the table below in **green text**.

## West Yorkshire and Harrogate 'Mental health' engagement and consultation activity at a glance

(E= Engagement, C = Consultation, PE = Patient Experience)

	Acute mental health care	ASC/ADHD services*	Child and adolescent mental health services	Eating disorders	Primary care	Community care	Rehab and recovery	Older people's services	Perinatal mental health	Mental health needs assessment/emotional wellbeing	Special educational needs and/or disability	Children's emotional health and wellbeing	Suicide prevention	
Airedale, Wharfedale and Craven	F	F	F	F PE				F					F	Support for ASC, Transformation of older adults services
Bradford City	E	E F	E	E PE				F					F	
Bradford District	E	E E	E	E PE				F					F	
Calderdale	E PE E	E PE	E	E PE				E	E				E	Enter and view – inpatient wards, older people/ dementia and frailty services, Transformation of older adults services, Perinatal mental health services
Greater Huddersfield	E PE	E PE	E E	E PE			E	E					E	CAMHS transformation; Rehab and recovery;

	Acute mental health care	ASC/ ADHD services*	Child and adolescent mental health services	Eating disorders	Primary care	Community care	Rehab and recovery	Older people's services	Perinatal mental health	Mental health needs assessment/emotional wellbeing	Special educational needs and/or disability	Children's emotional health and wellbeing	Suicide prevention	
														Transformation of older adults services
Harrogate and Rural District	E	E	E	E PE				E					E	Transformation of older adults services
Leeds	E	E	E E	E PE	E	E		E					E	Mental health in pregnancy; Primary mental health care for adults; Support needs of carers/parents of young people with mental health needs; Young people and mental health crisis; Transformation of older adults services, Community mental health services redesign

	Acute mental health care	ASC/ ADHD services*	Child and adolescent mental health services	Eating disorders	Primary care	Community care	Rehab and recovery	Older people's services	Perinatal mental health	Mental health needs assessment/emotional wellbeing	Special educational needs and/or disability	Children's emotional health and wellbeing	Suicide prevention		
North Kirklees	PE PE	PE PE PE	PE PE	PE PE	PE	PE	PE	PE	PE	PE	PE	PE	PE	CAMHS transformation; Children's emotional health and wellbeing; Future in mind transformation plan,(2018 refresh); Specialist autism service; Sahaara women's emotional wellbeing; Emotional wellbeing; Rehab and recovery; Transformation of older adults services, Perinatal mental health services, Public mental health and wellbeing needs	

	Acute mental health care	ASC/ ADHD services*	Child and adolescent mental health services	Eating disorders	Primary care	Community care	Rehab and recovery	Older people's services	Perinatal mental health	Mental health needs assessment/emotional wellbeing	Special educational needs and/or disability	Children's emotional health and wellbeing	Suicide prevention	
														assessment
Wakefield	E PE	E PE E	E	E PE				E					E	Young people; Parents and carers experiences of autistic spectrum disorders; Transformation of older adults services

\*ASC / ADHD – all evidence submitted just related to ASC

Eating disorders – all evidence submitted for eating disorders was in relation to services provided in Leeds. However, as some of those services are provided to people across West Yorkshire and Harrogate all the areas have been ticked.

**Table 2: West Yorkshire and Harrogate ‘Learning disabilities’ engagement and consultation activity at a glance** (E= Engagement, C = Consultation, PE = Patient Experience)

	Improving access to primary care	Access to learning disability services	Transforming care for children and young people	Health inequalities	Social exclusion	Key areas covered
Airedale, Wharfedale and Craven				E		Inclusive involvement of people with LD
Bradford City				E		Inclusive involvement of people with LD
Bradford District				E		Inclusive involvement of people with LD
Calderdale				E		Inclusive involvement of people with LD
Greater Huddersfield				E		Inclusive involvement of people with LD
Harrogate and Rural District			E	E		Inclusive involvement of people with LD; Transforming care for children and young people
Leeds	E			E	E	Inclusive involvement of people with LD; the Togetherness Project (reducing social isolation); Improving access to primary care
North Kirklees		E		E		Inclusive involvement of people with LD; Access to LD services for South Asian people
Wakefield				E		Inclusive involvement of people with LD

## **Section 2: Findings from engagement April 2014 – March 2019**

### **1. Mental Health - main themes and findings**

The main themes and findings for each of the following areas are:

#### **a. Acute mental health care**

Acute mental health care services provide assessment and treatment for adults aged 18+ with acute, or a 'crisis' episode during their mental illness. This may mean a person needs care as an inpatient in hospital for a period of time or intensive support through a home treatment team in the community.

There was limited engagement or consultation on specific service areas within acute mental health care, the evidence reviewed tended to relate to the development of mental health strategies.

The main themes raised across all the documents reviewed in relation to acute mental health care were:

#### **Awareness of mental health**

- It was felt that due to a lack of understanding of mental health issues and the services available this has resulted in some patients not being able to access the most appropriate care.
- People spoke about the importance of early education about health and wellbeing, working in close partnership with schools, colleges and employers, housing and primary care.
- They highlighted the need for primary care providers not to allow diagnosis of mental illness to overshadow other conditions, and also to understand the impact of long term physical conditions on a person's mental health.

#### **Alternatives to inpatient/hospital care**

- People want to feel supported right from the start, so if they have to wait for specific treatment they need to know how long they will have to wait, and they need access to support while they are waiting.
- Want more outreach services, based where people already access services. These should be accessible evening and weekends. Mental health problems can often be worse at night-time and weekends. Having a 'safe' place for service users to meet with a member of staff for 1:1 assessment.
- Improved in-reach services that promote early supported discharge, and better outreach / preventative work using creative approaches, such as Creative Minds and Recovery Colleges.

- Some people want to use technology to empower themselves, but don't want us to assume that this will suit everyone. The level at which people are comfortable with technology should form part of the assessment.
- To be provided with help at home to stay safe.
- Improvements people want to see/ be considered are provision of more support for families and carers to be involved.

## **Crisis intervention**

- Many causes of crisis are non-medical, including issues around housing, benefits and a range of social issues. It was felt that these crises can only be resolved and prevented by addressing non-medical causes in a joined-up way.
- There is a need to provide ongoing support for people, and to do more to help people to stay well. There was a feeling that people should be able to access more services earlier to help prevent a crisis occurring.
- People felt that crisis services were difficult to access and were only interested in those that were 'severe'. They felt that staff needed to recognise that even though someone may not meet the official guidelines for crisis intervention, they still need a rapid response, which will likely prevent an actual crisis from developing.
- People felt that crisis care was not of a high enough standard, they cited a lack of 136 suites and not always being treated by the most appropriate service.
- Some felt that A&E was not the place to be treated during a crisis, unless life-saving treatment was needed. There is a need for an alternative resource for people to be seen in a safe, friendly and compassionate centre especially for people in a crisis.
- It was also recognised that there is a need for services to cater for those with dual-diagnosis. There were instances where people had felt that nurses in A&E had treated them unfavourably because of their alcohol problems, and as a result did not receive the mental health treatment they needed.
- People reported difficulties in being able to access the most appropriate transport, at times this has seen patients in crisis being transported in police cars rather than by ambulance.
- Particular concerns were raised about the disparity between the ease of access to physical and mental health treatment in a crisis.

## **Inpatient / hospital care**

- People want services to be close to home and feel that out of area placements should be limited. There should be purpose built bed bases for services users with long term complex mental health needs who would not be able to live on their own within their own homes or in the community.
- Discharge from detention and/or PICU (psychiatric intensive care unit) should be made easier and quicker.
- It should be easier to make quick re-referrals when necessary;
- People using hospital care reported poor staffing levels and frequent use of 'bank' staff;

- It was identified that there needs to be clearer mechanisms for patients providing feedback available – more inventive mechanisms could be used e.g. post-it notes, graffiti boards

### **Involvement in decisions**

- In their interaction with mental health professionals, some service users and carers felt they had faced a greater level of stigma and assumption about their mental health.
- People want to be listened to and seen quickly by the same person
- People want to be talked to as an adult, with honest conversations that focus on their potential, not their illness.
- They want to be fully informed of the treatment options available to them, the possible side effects of their medication, and be supported in making decisions about their care.
- They want to feel that they are in charge of their care plan, not the service, and that their whole life is taken into account when creating the plan.

### **Co-ordination of care**

- There is a need to improve co-ordination of care between agencies, so patients receive the best care in a seamless way.
- There is a need to have more co-ordinated, flexible and responsive services to support people once they are discharged. GP's are sometimes not informed when their most vulnerable patients have been discharged from hospital, leaving those patients without the support and follow - up they need.

## **b. Autistic Spectrum Condition (ASC) and Attention Deficit Hyperactivity Disorder (ADHD) services (all age)**

Autism is a spectrum condition. All autistic people share certain difficulties, but being autistic will affect them in different ways. Some autistic people also have learning disabilities, mental health issues or other conditions, meaning people need different levels of support.

Attention deficit hyperactivity disorder (ADHD) is a group of behavioural symptoms that include inattentiveness, hyperactivity and impulsiveness.

All areas have developed an Autism Strategy for their area using feedback from patients, their families, and healthcare professionals, and undertaken engagement to understand experience of autism services. There was no evidence that engagement around ADHD had taken place, and as such the following themes relate just to ASC. The main themes raised across all the documents reviewed in relation to ASC were:

### **Awareness of condition**

- Schools, GP's, job centres, universities and the police need to have a better understanding of the needs of children, young people and adults with autism. There is

a need for knowledgeable teachers, staff and employers within all settings so that they understand how it can affect people, and the reasonable accommodations that should be made to help them

- There was significant variation in the level of knowledge and understanding of ASC in schools and nurseries. Some schools and nurseries have been supportive and understanding but many others have left parents feeling dismissed, ignored and unsure of the next step to take in getting a diagnosis or support.
- Some adults with autism, parents and carers felt that doctors did not listen to them when they said they or their child was experiencing problems and felt dismissed by GPs when trying to get a referral for diagnosis. And that some GPs did not appear to have a clear understanding of how the referral process works.;
- Children and young people (CYP) wanted to not be seen as a label – “diagnosis is complex and we are much more than our diagnosis” CYP feel that their strengths and aspirations as well as their personal conditions need to be understood, including understanding how these will impact on them during their time in mainstream and further education;
- CYP feel that mainstream providers need to improve their awareness and working practice with young people with special educational needs.

### **Assessments/ Waiting for a diagnosis**

- Long, sometimes extended, waiting times for an assessment appointment or specific services are a frustration for adults with autism, families and carers. In some cases an assessment appointment took years, rather than the few months recommended by NICE quality standards for autism, to be given.
- The long waiting times that people experience sometimes can lead to difficulties with their studies and employment, as universities and businesses are unlikely to make reasonable adjustments without a clinical diagnosis. This can result in people failing courses, losing jobs, and getting into debt. It can also impact on their health and wellbeing if they are left to struggle with the effects of ASC without any support.
- A lack of a single point of contact for patients, families and carers from the outset was seen as the biggest difficulty. This resulted in inconsistent services, breakdown in communications between the service and patients, families and carers and between the service and other providers in the intended pathway, and ultimately delays in service provision from initial assessment through to the transition of diagnosed children / adults through the ASC service pathway.
- A lack of clear pathways in general was noted as were disparities, i.e. where experience was dependent on who is assessing the adult or child with suspected ASC.
- Parents and carers reflected on a ‘pillar-to-post’ experience where they were referred to and from different contact points, e.g. GPs, schools, CAMHS or VCS groups.
- Some parents self-diagnose their children, leading to missed opportunities for access to services or missed diagnosed comorbidity condition.
- Some people find the whole process of seeking a referral via the NHS too daunting or are put off by the long waiting lists before having an assessment. In some of these cases they can pay for a private clinical assessment which is a much quicker process.

- Parents and carers felt that the option of home visits for assessments would help staff understand the family and the patient better;
- Parents and carers felt that services for assessments should be based (geographically) together;
- Parents and carers felt that processes need to be better explained to them, particularly at times of transition e.g. changes in waiting lists

## **Diagnosis**

- When people did get an appointment, the environment in waiting rooms for health and care services could be stressful. More work needs to be done to make waiting rooms autism friendly.
- People reported some level of satisfaction that the overall service is good once people suspected of having autism are finally seen for an assessment. Examples of good practice occurred when assessments were delivered across multi-disciplinary teams and in conjunction with school services.
- In some cases, assessment did not necessarily result in a diagnosis. This left people in an uncertain situation – no diagnosis, but person demonstrating symptoms and families / carers having to follow this up again.
- There needs to be better identification and assessment for girls with autism and support needs to reflect the gender differences.
- Letters and reports that are produced following diagnosis need to be understandable for parent and carers. A lay person's summary was felt to be a useful way to do this.

## **Support pre and post diagnosis**

- There is often a lack of support for those waiting for assessment or diagnosis but also post diagnosis. There is a need for professionals to ensure that children, young people, adults and their families have the necessary information about local services to access the support they require.
- Whilst some support does exist, in some areas this is often for a narrow age group or is geared towards people with learning disabilities or mental health conditions, which excludes people with ASC alone.
- Education and health need to work better together post diagnosis to ensure that information is shared and influences future support. Support within education is inconsistent and on occasions has been withdrawn.
- Due to limited support, people are forced to use support not designed for autistic people, or is insufficient to meet their needs.
- Support offered is short-term or inconsistent, and people can find the help they are getting is reduced after a while.
- CYP would like small group sessions with other young people of a similar age
- CYP would like someone that they trust and are confident to talk to and to access help and advice without feeling judged.
- CYP would like supportive advocates and workers that understand their needs, skills and support them to be heard when important discussions are taking place.

- CYP would like professionals that are reliable, trusting, and who value and take them seriously without dismissing their views.
- Parents and carers felt that more regular reviews by a paediatrician would have been useful rather than being reviewed by support staff e.g. communication nurse.
- Parents and carers felt that there was not enough access to support services such as SALT and OT following diagnosis.
- Parents and carers felt that there was a lack of support for parents, carers and patients both whilst patients were on a waiting list and also following a diagnosis.

## **Support for parent / carers**

- Parents and carers require good information pre and post diagnosis about services and resources available. They would like a single point of support during crisis and would benefit from additional training to learn strategies in relation to behaviour management.
- Support for parents and carers should continue throughout the child or person with autism's life, to ensure they retain good emotional and mental health and plan for the future
- Better information, guidance and support is needed for parents, carers and individuals with autism for children moving from primary to secondary school; for those leaving school for FE/HE/employment; and how to help young people prepare for the transition to adult services.
- Parents want schools and other professionals to acknowledge parents' expertise in relation to their child's needs.
- CYP felt that Improvements in families understanding of ASD/ ADHD so they are able to assist them and deal with transformations and change;
- Parents and carers felt that they did not know where to go for support as they were having trouble navigating the system

## **Transitions**

- CYP feel that there needs to be more investment in experiences of transitions e.g. school to college or college to work;
- Parents and carers highlighted lack of continuity between child and adult services being problematic as periods of major change can be difficult for patients with additional needs;
- Parents and carers felt that their role as 'main carer' changed through transition from children's to adult's services and they were no longer included in assessments, contact with services or asked to remain silent. They found they were unprepared for this and it was distressing.

## **Joined up approaches**

- CYP feel that there needs to be better communication between health, education, the young person and the family to ensure a shared understanding of needs and, strategies to support the young people meet their potential.

- Colleges, schools, health professionals and wider services need to ensure they work together to provide timely support for young people to prepare and help them through times of change.

## **Education and employment**

- CYP would like employers to have a better understanding of the benefits of employing young people with special educational needs and disabilities including ASD, Asperger's, personality disorders and ADHD.
- CYP would like to see improvements in careers advice and guidance to assist young people to move from further education and training into employment and ongoing support should be available and accessible for young people in employment and volunteering.
- CYP would like meaningful support during work, education, training or employment and to be valued in their own right.
- CYP would like to be able to stay on and further their knowledge within further education.
- CYP would like appropriate and timely support with finding and staying in employment.

## **Mental health**

- Cumulative impact of all issues raised can have a devastating effect on the mental health of autistic people and their families.
- More knowledge/ recognition is required among professionals of increased risk of mental health issues in this group and more support to manage these.

## **Adults with autism**

In addition to the themes raised above, specific themes were raised for adults, these were:

- Communication with adults needing referral and diagnosis wasn't always suited to their needs. And difficulties in transition from children's services to adult services.
- People want an improved diagnostic pathway with shorter waiting times and the option of out of area diagnosis.
- In some areas it was reported that there is a lack of post diagnostic clinical support and appropriate mental health care for adults with ASC. People want better post diagnostic support to help with managing the effects of ASC including communication issues, hypersensitivity, difficulties with social situations, and day to day problems with planning and organising.
- Support groups were acknowledged to be helpful for some adults with ASC, but they are few in number and not accessible for everyone. Want a wider range of managed ASC friendly support and social groups in accessible venues to suit the needs and interests of more people.
- A lack of support for carers of adults with ASC, with the majority not having had a Carers Assessment to ascertain their needs. Want more support for and awareness of the needs of people caring for adults with ASC.

- Adults with ASC sometimes struggle to negotiate many of the services and procedures that are part of everyday life, and without access to ASC trained support and social workers they can end up with difficulties managing their finances, housing, and relationships, as well as struggling with basic day to day issues like eating, sleeping and cleaning. Want assistance from ASC trained social workers, mental health workers, PAs, support workers and advocates, to provide consistent support to help people live normal lives.
- People were worried about employment prospects for people with ASC, because of a lack of understanding amongst employers. And adults with autism don't always feel that they have access to facilities and activities in their local community, or opportunities to learn new skills and qualifications.
- Want housing services which are able to support people with autism. And to be able to access welfare benefits advice and be provided with advice and information for those who are not in receipt of social care support.
- Want criminal justice services which are able to communicate well with people with autism.
- It was suggested that Clinical Commissioning Group Boards, in general practice, at the council and other providers of health and care services have learning disability and autism champions.
- Because services do not understand communication needs, autistic people often struggle to understand the info provided to them, or to engage effectively with healthcare professionals.

### **Empathy and compassion**

- Parents and carers felt that more empathy and compassion could be displayed towards both parent and child throughout the services;

### **c. Child and Adolescent Mental Health services (CAMHS)**

CAMHS is used as a term for all services that work with children and young people who have difficulties with their emotional or behavioural wellbeing.

A significant amount of engagement / consultation has taken place across West Yorkshire and Harrogate in response to the recommendations in the NHS England report published in March 2015, *Future in Mind: Promoting, protecting and improving our children and young people's mental health and wellbeing*. Following the development of the local plans, further engagement has taken place to support the implementation and monitoring of those plans.

The main themes raised across all the documents reviewed in relation to CAMHS were:

#### **Accessing services**

- Young people, parents and professionals rated highly the quality of services offered by CAMHS for those children and young people that 'got through the door' but felt that some of the most vulnerable children and young people were 'slipping through the net'.

- Parents often feel that the whole system is difficult to navigate, and there is a lack of communication in relation to the “right” entry point. Therefore when they are trying to get help for their child they spend a lot of time ringing different agencies (a feeling of having to fight their way into services and tell their story over and over again before professionals will believe that their child is ill) and are told different things. When parents do eventually find the correct referral mechanism for example, their G.P or school, referrals are made but access to support takes too long and communication back to referrals and parents is poor. Therefore a strong message from parents was the need for a single point of access and a system without tiers.
- A recurring theme was that they felt something could have been done earlier and if it had been they would have been in a better place much sooner.
- Suggested that the referral criteria for provision of the CAMHS service for young people needs to be clarified for General Practice, consultants, schools etc to avoid inappropriate referrals and help create an understanding of the services provided. There was concern amongst some professionals about the threshold for referral to CAMHS being too high, and that only referrals for children and young people with the most serious issues were being accepted.
- Parents and young people said that having different ways to self-refer was important. Being able to complete an online form and make a phone call were the most popular options for young people and parents respectively. Drop-in was also popular amongst young people, with the idea of support available to make a self-referral.
- Many children and young people felt that they wait too long for the right support, particularly within specialist CAMHS. They mention the lack of support and communication from services during their wait, and the detrimental impact of the wait on their mental health and family relationships.
- Where there are long waiting times for particular services, young people and their families should be offered support. The self-help needs of children and young people on the waiting list need to be considered separately from those of the parents/carers of these young people as they appear to want different things with most children and young people wanting self-help groups/materials and most parents/carers wanting supportive telephone calls or a helpline
- Provide better and more accessible information about existing NHS and non-NHS services that can help support young people with emotional difficulties and their families.
- Most CYP go to family and friends for support initially so accurate and relevant information and advice needs to be easily available for everyone.
- The support CYP value most is having someone to talk to if they are struggling, or being able to talk to other people who have experienced the same issues.

## Assessments

- Assessments need to be more in depth and done in partnership with a worker/ individual that knows the young person.
- Young people feel services should not support their physical health conditions without taking into account their emotional and mental health needs and similarly not deal with

their emotional and mental health needs without taking into account their physical long term health condition.

- Young people want to know what they can expect from a service and be able to make choices about the kind of therapist they see. Be offered a range of treatment options, not just medication or counselling, they'd like to try other therapies including music, art, drama and equine therapy.
- Young people want to share in decision making and be kept informed. They want systems where they are not left guessing what is happening and what professionals are thinking e.g. feedback from workers, visible care plans and true participation.
- Both the setting and the staff are important to ensure that young people feel comfortable enough to talk about their feelings. This should be taken into account when planning services.
- If a child or young person is deemed not appropriate for support by the CAMHS team, there is little if anything else to offer in its place.;
- People stated that communication between services was often disjointed

## **Support in schools**

- There is increasing feedback from young people feeling under pressure to succeed academically. Teachers raised concerns and recognise the immense pressure put on students from school plus the pressure students put on themselves which leads to anxiety, not sleeping or eating and emotional breakdowns in school and some pupils are being monitored by teachers to make sure they don't 'crumble'
- Young people age 10/11 are wanting someone to talk to at school about their problems or advise in the build up towards transition to increase their confidence and lower anxiety for when they go to 'big school'
- Many young people expressed concerns about the lack of support available in their school. Schools do not typically have enough of the right people to help, and that they should be more understanding and do more to promote mental health.
- Suggested that need to have named members of staff who are approachable and who respond quickly to student concerns; ensure all students know what support is available in school, especially those new to the school or in Year 7; make sure that time is given to deal with emotional wellbeing issues promptly and in a non-judgemental way; focus on resilience, prevention and early intervention.
- The development of peer mentoring and support groups in school is seen as valuable by some children and young people, particularly where the support is provided by young people who have themselves encountered and been helped to manage their own emotional or mental health difficulties. However, they did add that it could be unhelpful too when people advised the wrong things.
- The two forms of support provided by schools that children and young people find the most helpful – lessons about mental health run by an outside organisation and on-line counselling for pupils – are rarely provided. Online counselling is popular as it alleviates concerns about confidentiality.
- Similarly, forms of support considered to be helpful by parents namely information on the school intranet, evening sessions for parents looking after their child's mental

health, lessons about mental health for pupils, and signposting to access support, are not provided by schools very often.

## Ongoing support

- Services should be easy to access both in terms of physical location and in terms of process. Many young people feel that a drop-in offers this accessible and timely support. Drop-ins should be in youth cafes, colleges, local community and youth centres.
- Children and young people suggest they need better education about mental health, such as feelings, emotions and reactions to environments and events so that they have a better awareness of how their mental health might be affected as they grow up. Encouraging open dialogue about mental health will help children and young people to feel more confident in approaching an adult or peers about their problem.
- A common theme that emerged from young people is that if a person can manage a difficult experience without adult intervention, it is better for them. Helping children and young people to develop coping strategies in advance of any difficult situations was a clear suggestion from young people. Providing young people with the knowledge of what support is on offer and where to seek it.
- Using SMS texting for appointments, when young people have to ring and opt in to make appointment this can sometimes be difficult when they have anxiety issues.
- Support should be more flexible, offered outside school's teaching time, in a variety of ways and should not interrupt their education
- One size does not fit all, use a range of approaches: outreach, group work, peer support, one to one, creative, active, talking therapy, drop in – co-design these approaches with the children and young people.

## Crisis

Have other routes young people can take to get into the crisis care service. Crisis Care is not accessible for some young people as ringing and talking to someone on the phone is inaccessible. Need an email and text service so young people find it easier to approach them.

- Minimal assessments and least restrictive access criteria
- There was a preference for crisis support where assessments are kept to a minimum. People described wanting to make contact with someone to offload or to have someone around to help them feel safe, reassured or contained.
- Access criteria is set so that people might use it when something was bubbling rather than feeling like a full-blown crisis.
- Informal rather than clinical setting
- Choice of support e.g. online and face to face
- Human, caring, welcoming response

## Transition

- The transition to adult services was an issue for some young people. They highlighted a need for an improved transition process as people move from young people's to adult mental health services. It was suggested that the age when young people transition to

adult services should be increased to 21 or even 25, and should be based on what is appropriate for the young person.

- It needs to be recognised that transition sometimes takes longer for 'specific' young people, for example those who are Deaf, from African communities, or looked after children who find it even more difficult without support to navigate services. The system needs to be responsive to the individual's transition to adulthood. As young people hit different stages of adulthood and become independent their resilience varies and changes over time.
- Accessing CAMHS at 17yrs old can be difficult as young people feel they are 'fobbed off' until they are 18 to go to adult services, this impacts on their mental health (having to wait and things get worse).

### **Patient confidentiality**

Young person's right for confidentiality as oppose to parents right for their information. Be very clear on the age a young person can keep their information private from their parent. It should not be down to the worker's personal judgment but clearly defined and described in very clear policies that leave no doubt to the young person, professional or parent what we mean by confidentiality and how it will be followed.

### **Support for parents / carers**

- Parents told us they need some support in their own right when managing their children's conditions or behaviours. This is important because parents feel their own health and social circumstances can suffer due to their caring role, and ultimately impacts on them and the wider health and social care system. Parents have suggested that programmes such as mindfulness training would be helpful, as well as taking whole family approaches to care including care planning for the whole family.
- Parents told us that given the right support that they want to be part of the solution for helping their children. Therefore if a CAMHS system gave them more support and training in how to manage certain behaviours and difficulties that they could manage certain aspects of their children's behaviour without need one to one support from services.

## **d. Eating disorders**

Eating disorders are characterised by an abnormal attitude towards food that causes someone to change their eating habits and behaviour. Eating disorders include a range of conditions that can affect someone physically, psychologically and socially.

The evidence submitted was from the Yorkshire Centre for Eating Disorders, and the Leeds Children and Young People's Eating Disorder Service. The main themes raised were:

## Inpatient experience

- Most people stated that their experience of the inpatient stay had been positive. It appeared that service users found the experience challenging but they were pleased that they had completed the programme.
- All people using the service stated that their dignity, privacy, independence, confidentiality and human rights were respected during their stay.
- The boundaries of the programme provided a safe environment for most people and helped them to explore factors (behaviours, emotions and thoughts) that had triggered and maintained their eating disorders.
- The positive aspects of their experience were support from staff and peers, attending groups, one to one sessions, regular meals, information on the effects of eating disorders, multidisciplinary team meetings and nutritional rehabilitation.
- The less positive experiences were: lack of consistency in particular at meal times (in particular around portion size), lack of staff at times and the peer group when they discussed weight and diet. Some felt isolated because of being the only person on a specific programme e.g. symptom interruption or being the only male on the unit.
- Most people found one to one sessions and group programmes helpful.
- Service users found the team members who explained topics, listened and provided rationale for boundaries were most supportive because it facilitated engagement.
- People that had previously been an inpatient felt that their subsequent experiences of inpatient services were better because the programmes were individualised.
- There were some comments around food, as some felt that there was a lack of variety, not getting what they ordered, and the food being lukewarm.
- Suggestion to increase the range of therapies available, such as art, music, and drama
- To establish a buddy system to help people settle in. And have ex patients come to talk to patients in risk reduction.
- Would like regular involvement with community teams during their stay, including 1.1 whilst on the ward.

## Children and young people

- Mostly happy with the staff that they saw, they felt they were listened to and treated well. And that the clinicians they saw were knowledgeable, supportive and person centered.
- Being referred into the service can sometimes be difficult as there appears to be a lack of awareness amongst some GPs and schools. Once they had been referred they felt that it was quick and that there was flexibility to be re-referred when necessary.
- In preparation for their first appointment children and young people want to know who they will be seeing, what to expect at the appointment and to be provided with leaflets / information on the service.
- Texts, e-mails, letters and phone calls were the method that most people said they would like to be offered appointments, with texts being the most mentioned method.
- They wanted to be given options about when they were seen, most felt that after school was the best time for them to be seen, and many worried about missing out on their education.

- They would prefer appointments at home or at existing CAMHS bases. It is important that the rooms have a homely feel (including cushions and pictures), are light and bright (including air conditioning), and have suitable child friendly facilities (including toys).
- They felt that appointments for therapy were offered regularly, that there was continuity in the service, they liked that they were offered therapy over a long period of time and they found being offered family based treatment (FBT) through COS (CAMHS outreach service) the most useful. Although handover between COS and community service was sometimes inadequate. And there was at times a lack of joined up working between community eating disorder service, COS and inpatient teams.
- There was also sometimes a lack of support at weekends when this can be the most fraught time.

### **Support for families / carers**

- It was highlighted that there is a need for ongoing support for families / carers. This could be provided through a monthly support group where they could receive practical advice, share their experiences, and ask questions. They would prefer it if this was clinician led. In addition to the support group they would like to be able to access support through a range of options, such as online, drop-in sessions, newsletter, telephone, and social media.
- For those families / carers whose family member had been admitted as an inpatient, they wanted to be provided with more information prior to their admission, so they knew what to expect. And once they had been admitted to be kept up to date on their progress, and to be given the opportunity to discuss treatment options available.
- When a family member is on home leave or discharged from hospital, families / carers would like to be offered help and support.

### **e. Primary care**

People in Leeds had mixed views about existing services, with 43% satisfied or very satisfied with the service they received, and 33% dissatisfied or very dissatisfied. People identified a number of key areas that need to improve:

- Information – some people wanted more information about general mental health, mental health services available in Leeds and how to access services.
- Access – most people told us that they needed to be seen much more quickly. They also told us that the referral process and criteria were unclear and confusing. Some communities told us that more could be done to create inclusive services.
- Quality – while many people were happy with the service they received, others told us that services needed to be more consistent; patient centred and have more trained and experienced staff.

## **f. Community care**

### **Awareness of mental health**

- Need for a cultural shift in attitude to mental health. Not feeling comfortable accessing mental health support was a major barrier to getting help – this was linked to concerns around stigma and discrimination.
- Lots of people told us that the nature of mental health problems means that it can take a long time for people to realise that they need help. Respondents told us that a general lack of awareness around mental health, and of the support available, means that people often seek support only when they are approaching crisis.
- Lots of people told us about how messages in the media have affected them when accessing mental health support. This was in both a positive and a negative way
- It was highlighted that work to raise awareness of mental health support in BAME communities would be beneficial.

### **Access to information / self-care**

- People told us that there needs to be more awareness, information and education about what PCMHS are available in Leeds. They also told us that there needs to be more information on how to access the service and what the service can provide;
- Many people were not sure about what would help them to self-care but they did state that talking, being listened to, having help at work and not being isolated would all help;
- Many people were not aware of what mental wellbeing support was available in their area although most were able to name some form of support.

### **Access to services**

- Most people told us that they needed to be seen much more quickly. They want early intervention and quick access to therapy services
- They also told us that the referral process and criteria were unclear and confusing. Some communities told us that more could be done to create inclusive services.
- Within community services there should be somewhere that offers 24/7 access to service users who need it. This should be a 'safe' place where service users can meet with a member of staff 1:1.
- Community services need to be close to people's homes.
- A mental health 'hub' (where one is not already available) should provide signposting and support.
- More joined up pathways with the voluntary/ community sector and more investment to extend their range of service provision;
- Some people asked wanted to see specific services to support those affected by sexual violence;
- People felt that community services need to be available every day of the week and that people in crisis are seen quickly;

- Where mental health professionals were embedded within other services, this was seen as working well as it meant issues could be dealt with as part of the overall patient journey, rather than having to refer to a separate service;
- People felt that services needed to be more integrated and person focussed rather than single issue centred.

## **Waiting times for services**

- The majority of people who responded to the survey raised concerns about the length of time it took to access the service. This experience was shared by patients, members of the public, providers and referrers. This was the strongest theme from the engagement and reoccurred throughout the survey.
- People also expressed concerns about how long waiting times to access the service can increase anxiety, push people to find other ways of coping with the problem which can be harmful and also, can have an impact on family members, especially children.

## **Contact/ support whilst on waiting lists**

- Many people told us that a lack of contact while they were waiting to start an intervention exacerbated their condition and reduced their trust and confidence in the service. Patients, the public and professionals told us that they often did not get feedback from the service about the status of the referral or when the patient might be seen. Many people also raised concerns at the lack of support during these periods.

## **Quality of service**

- While many people were happy with the service they received, others told us that services needed to be more consistent; patient centred and have more trained and experienced staff.
- People wanted more availability of 1 to 1 support and 'drop-in' services.
- People wanted consistency of staff within services and were concerned about workforce capacity to deliver any changes suggested;
- People would like a 'tiered' system that they can move through as appropriate.
- Services need to be culturally appropriate for the demographic of people that access/ may need to access services;
- People felt that communications around appointments and clinics could be better

## **Changes to services**

- People engaged with around service changes were interested to hear how proposed plans will be evaluated longer-term;
- People engaged with around service changes were concerned that the main motivation for planned change was to introduce efficiencies rather than improve services.

## Home-based treatment

- There were mixed views expressed about home based treatment services with some people expressing concerns about loneliness and preferred the idea of attending a “therapeutic day service” whilst others welcoming support at home.

## Rehabilitation and recovery

### Accommodation

- People needing rehabilitation/ recovery want accommodation that is flexible, safe, local and comfortable with 24-hour access;
- People wanted facilities which were person-centred with adapted facilities to meet physical disabilities and conditions;

### Staffing

- People highlighted that staff working in these areas need to be highly qualified but also need to be compassionate, caring, understanding, empathetic, patient and a good listener.

### Quality of service

People wanted a service that:

- Offers a range of facilities and therapies;
- Culturally sensitive;
- Welcomes family and friends;
- Has space for activities to help with life skills;
- Be able to signpost to support service

## g. Older people’s services

### General satisfaction with services

- Older people have lots of praise for services, confidence in the services and highlight the dedication of staff. Patients generally feel that they have been referred to the right place and seen by the right person.

### Waiting times

- Older people wanted shorter waiting times

### Dedicated older people’s service

- Older people like the idea of a dedicated service for them and feel that this happens at the moment anyway.

### Continuity of care

- Older people really valued seeing the same person throughout their care.

### Communication/ partnership between services

- Older people felt that there needs to be better understanding/ communication between the GP practice and specialist services, particularly focussing on GP care in relation to carer support.

- Older people felt there needs to be better communication about when follow-up appointments are and that these need to be more regular.
- Older people felt that care being provided closer to their home and within one team was a good thing but highlighted that there needs to be good links between MH service providers and local healthcare providers.

## Logistics

- Older people would prefer not to have early morning appointments as often they are travelling on the bus.
- Older people have concerns that any changes in services will result in them having to travel further/ elsewhere for appointments.
- Better parking facilities need to be made available at Fieldhead for older people using memory services.

## Memory assessments

- Older people were supportive of the idea of having a local, more co-ordinated and holistic approach to memory assessments.
- Some people were already attending support groups which they said were more beneficial because of their informal nature, an opportunity for “getting to know others” and the flexibility to attend as and when they felt like it.

## Intensive home support

- Older people strongly support imperative to find alternatives to hospital bed admissions.
- Older people were supportive of the approach to provide people with increasing needs e.g. memory needs with a more intensive, short term package of care from an intensive home support team.
- Some concerns expressed about resources required for this kind of service.

## Other

- Older people were concerned about the impact of any service changes on loneliness and social isolation.

## Information

- Older people would like name badges with bigger fonts.
- Older people dislike use of technology (text messages and automated phone calls).
- Older people felt that they were provided with good quality information but maybe too much of it all at once and would like the opportunity to ask more questions after diagnosis.
- Older people would like more support around the time of diagnosis especially in the clinic session when receiving a diagnosis;
- Older people are in support of the idea of having separate functional and dementia wards but there was a more mixed response as to whether this should be done by having a central, specialised unit. Concerns expressed over increased travel time that may result from this.

## **h. Perinatal mental health services**

South West Yorkshire Mental Health Trust have engaged across their service area with staff and patients regarding the launch of a new perinatal mental health service. Key findings were:

- Staff really appreciated the events which raised awareness of the service and referral process of perinatal pathway
- Staff were really pleased that a contact number for discussing concerns was available
- Staff were really glad that this service was available to help support them in their work and the mums they work with and expressed how much the service was needed;
- Staff felt that partnership work is key to the service being a success;
- Staff identified that the service needs to be culturally sensitive and in particular raised concerns around access and appropriateness for South Asian communities and people with experience of substance misuse/ alcohol issues;
- List of partners missing from local network map i.e. school hubs + colleges, 3rd sector, Housing, Health visitors etc.
- Staff would like to see a perinatal networking group to support this work
- Staff highlighted the impact of the lack of mother and baby groups in the area due to the closure of Sure Start and Children's Centres;
- It was highlighted through the engagement that there needs to be a shift in attitude with regard to referral to the Perinatal Mental Health Service e.g. traditionally thresholds for secondary care services are quite high but this is not the case with this service e.g. they will accept referrals for women who are 'well' but may have a family history of mental illness;

## **i. Specific themes raised by protected groups**

Some of the engagement and consultation that has taken place has been analysed to establish if there are any variations in the views expressed by people from protected groups. The key themes raised by protected groups were:

### **Ethnic groups**

- Cultural beliefs about mental health, particularly Romany Gypsy and Traveller Communities /African communities/other Black and Minority Ethnic communities (BAME), can mean that some people will not access mental health services.
- There is a need to raise awareness of mental health problems and available support across all communities. This should include greater visibility of services in the community.
- Use a variety of media to publicise services including community radio networks.
- Some people reported a lack of cultural sensitivity where workers were not from the same background as children and young people, leading to social/cultural misunderstandings and disengagement.
- Recruit staff who are more representative of the local population and communities and recognise and value the extra strengths they bring to services.
- Increase access to independent interpreters and provide more services in people's first language.

- Some concerns over accessibility to Perinatal Mental Health Services for the South Asian Population.

## Religion

- Due to the stigma around mental health, it was recommended to have a 'community hub' which could sign post either to GPs or to Mental Health Trust or to an Imam or faith/spiritual Healer.
- Access to support and advice from fully skilled and trained multi faith pastoral care team was acknowledged as an area that was currently underutilised.

## Disability

### Long term conditions

- Support for mental health should be built in to the patient pathways for long-term conditions, so that it is routinely offered to people rather than leaving patients and carers to seek out support for themselves.
- When addressing the mental health needs of patients with long-term conditions, professionals should take a holistic approach and recognise the benefit of social activity and peer support alongside talking therapies and medication.

### Learning disabilities

- When communications are poor, people with learning disabilities feel they are not listened to and not understood – their views are not taken into account and changes in care are being made 'to them'.
- There needs to be raised awareness at all levels of learning disability and autism.
- Advocacy availability for all vulnerable people needs improving.

## Carers

- A great many people highlighted that carers are an under-valued resource.
- People feel it takes far too long for carers to be formally recognised, and that there is insufficient support for them (including occasional respite).
- Carers themselves wanted better links with GPs, pointing out that they are often better placed to communicate with, and on behalf of, their loved ones.
- Carers said that they would like their details on the care record of the person that they care for, so they can be contacted in case of emergency. They said that they often attend appointments with the person that they care for, be it for their physical or mental health.
- Carers should have a role in assessing the safety and quality of services offered to their loved ones.
- A first admission for carers can be very difficult and extra time should be allowed to acknowledge this. Carers have also asked for extra support when people are discharged as they can feel isolated and alone.
- Carers acknowledge the importance of Community Psychiatric Nurses (CPNs), but feel that they do not know the person they care for as well as family members and friends, who can spot tell-tale signs, yet it is CPNs who have all the authority to access

additional support. Carers feel that their vital role is being ignored, especially as they are often the people left to deal with the aftermath of any significant difficulties.

## **Lesbian Gay Bisexual Transgender (LGBT)**

- LGBT young people reported that they need to talk to someone, some are told 'it's a phase' this affects their mental health and confidence. Some young people are experiencing poor mental health as a result of living a secret (not told parents so live in fear of them / peers finding out).
- Transgender young people are desperate to talk or get information about where to go for advice.
- Support groups specifically for young LGBT people provide a safe environment to be themselves that isn't school, college or related extracurricular activities but with other people in similar situations. Enables young people to understand more about what it means to be LGBT; assists in the 'coming out' process, not just in telling friends/family members, but coming to terms with being LGBT themselves; builds confidence in being themselves again after traumatic events; and learn more about the LGBT community, information you aren't taught at school.

## **Substance Misuse and Alcohol Misuse**

- Some concerns over accessibility to Perinatal Mental Health Services for this population.

## **2. Learning disabilities main themes and findings**

### **a. improving access to primary care**

#### **General**

- Patients are generally happy with the service
- Patients want to receive reminders of their appointments in accessible formats
- Patients want it to be easier to make appointments at times that suit their needs
- Information from clinicians was not always clearly explained
- Surgeries running late made patients anxious and stressed
- Wheelchair access into waiting rooms can be a problem
- GPs and staff should have more awareness of the needs of people with learning disabilities
- Some people felt that they were not being listened to
- A number of patients felt that GPs and staff didn't speak to them, but spoke to their carers instead.
- A small number of patients felt that they would be more comfortable in their appointments if they were shown around the surgery.
- A few patients told us that sometimes due to their more complex needs home visits are sometimes more appropriate

## Breast screening

- A female carer who herself is a professional said she was embarrassed to even ask at reception, as to where she need to go for the session as the person at reception was a male.
- Checking one-self or the person with a learning disability is not something they have considered, so the question of how important it is to self-examine did not arise. Another said, they would have difficulty trying to explain to the person with LD why they would want to check their breasts or explain to them why the individual themselves should self-breast examine because of limited understanding and shyness/embarrassment for both parties.
- All were in agreement that more work needs to be done to raise awareness around self-breast examination for people with learning disabilities, especially those from minority groups is very important.

## b. Health inequalities

- About their bad experiences of accessing healthcare, people with LD noted feelings of being upset, frustrated and helpless.
- About their good experience of going to the doctor or hospital, they showed feelings of respect, confidence and happiness.
- Redesign how the NHS communicates with people with learning disabilities;
- People with learning disabilities to help NHS understand how to reach the 'hard to reach';
- Challenge how the NHS prescribes to people with learning disabilities;
- Make letters and documents in easy read;
- Help with transport to appointments and make waiting times be less anxious;
- Set up links to communities and listen to their points of view.
- Employment for people with learning disabilities is very important. They need proper contracts and salaries.

## c. Social isolation

- Participants with LD do not describe themselves as being socially isolated or lonely when they are in a session specifically put on for this purpose;
- People with a LD who are socially isolated and/ or lonely often struggle to break the cycle and take themselves out of their comfort zones.
- It is difficult to engage with people with a LD who are socially isolated.
- People have a lot of preconceptions and think that we only do arts and crafts. Someone who works in another office at Hillside saw our poster and presumed the project was for elderly people.
- It's hard to explain to people with LD what we do/ what support is available on a poster, and get across that we create a friendly, fun and inclusive environment.

## **d. Specific themes raised by protected groups**

### **Ethnic groups**

#### **Taking part**

- e.** The most common activities people with an LD were involved in were volunteering, respite care, attending day centres and learning English.

#### **Support to live in the community**

- f.** Nearly half of the respondents felt that they did receive support to live in the community as opposed to just over half not feeling this way. This can lead to people feeling socially excluded and could be linked with finding accessing information difficult.

#### **Where to live, choice of home and meeting needs**

- g.** Over half of the respondents felt that they did have a choice of where they live and just over a quarter felt they did not. Just over a half of the respondents felt that their home met their needs, whereas over a quarter felt that their needs weren't met at home.

#### **Accessing services**

- h.** When asking respondents how easy it was to access services, over a quarter felt that it was neither easy nor difficult. However when adding the number of responses from those people who found it very difficult and difficult respectively, this made up half of all the responses, indicating a disparity and highlighting that barriers exist for South Asian carers and people with learning disabilities.

#### **Services and activities**

- i.** Healthwatch Kirklees asked respondents what services they would find helpful, or what activities they would like to participate in.
- j.** The main theme that emerged from all the comments we gathered above related to activities (almost half); the most popular being the desire to improve health and wellbeing. Other responses included:
  - a. the desire for more social groups;
  - b. groups that were more culturally appropriate/sensitive;
  - c. activities within the community;
  - d. creative activities
  - e. educational sessions and short courses

#### **Funding**

- We also asked people completing the questionnaire if there was anything else they would like to tell Healthwatch Kirklees. The subject emerging here, that was not explicitly mentioned previously, were frustrations with lack of funding or a perceived lack of help from the local council or government.

## Carers

### Accessing help and support

- k.** People have not had assessments or don't feel that they are always conducted satisfactorily, either because assessments are made over the telephone or that outcomes are unhelpful to the individual or family
- l.** Some people are living in homes that are felt to be currently unsuitable or unsafe
- m.** Some families don't have an assigned social worker at all, whereas others have been told by their social worker that they are demanding or fussy because they are perceived to be asking for too much help.
- n.** Some people have never received support of any kind to help cope or care for their loved one with a learning disability
- o.** Lack of support and help at some schools, where bullying can also be an additional issue that needs to be tackled
- p.** Citizens Advice Bureau are unable to help carers with unresolved issues relating to receiving support for their loved ones
- q.** Authorities being unaware of people with learning disabilities conditions and situations

### Mental health

- r.** Almost all of the accounts that carers and some people with learning disabilities have provided to Masoom Care, describe people taking anti-depressants in order to tackle poor mental health caused by loss of identity, stress, anxiety and/or isolation. People feel that their requests for help are ignored and have lost hope or motivation, having to "take one day at a time" in order to cope.

### Poor nutrition

- s.** Vulnerable people who live alone can be very dependent on relatives and the goodwill of neighbours for their food. Accounts by Masoom Care, describe individuals who depend on consuming unhealthy snack foods such as chocolates, crisps and sugary beverages, until relatives visit their homes to provide them with meals, or friends and neighbours dropping in with donations of food.

### Poor general health

- t.** Carers and people with learning disabilities can experience poor health in general – accounts include people who constantly feel ill, tired or are unable to sleep.

### Hygiene and dignity

- u.** The importance of maintaining hygiene can cause carers to feel stressed and isolated but also challenge the cared-for person's dignity if they have to be helped by someone from the opposite sex+. One parent does not feel able to leave their loved one alone at all in fear of this impacting on the cared-for person's personal hygiene – the reasons for this were unclear, however research in this area shows that there is a need to prioritise cultural and religious needs of all service users including having same-sex carers when it comes to intimate personal care tasks

## Pressure

- V.** Mostly female but also male, experience great pressures on their time. They can care for more than one person with a learning disability at a time, but also have large families (sometimes up to six young children) to also look after, often for long periods on their own as their loved ones are working.

## Impact on the cared-for and other family members

- W.** Help with care is much appreciated, but is felt to be insufficient. For example, one child with high-spectrum autism only receives up to six hours respite care per month with a parent who also has other children to care for. This has proven to be very challenging and results with arguments in the home and the autistic child becoming bored, angry, frustrated and then lashing out or running out of the house. Other stories describe pressures in the home that have resulted in the break-up of the families, with male or female partners leaving as they feel unable

## Education

- X.** Family members don't always know how to improve the home environment for the person with the learning disability, e.g. having regular routines or creating a quieter area in the home for children with autism. This is also an issue that has been brought up in a conversation with staff working in Ravensthorpe Community Centre.

## Language

- y.** A barrier for some carers is their lack of English skills, which makes navigating the care system even more difficult and raises the importance of helping people to learn English in genuinely accessible and inventive ways that take carer pressures into account, such as time.

## Appendix A – Documents reviewed

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