



Leeds Clinical Commissioning  
Groups Partnership

# Parenting Support: Mental Health & Autism

Engagement dates: January – May 2018

## Assessment of Equality Impact and Engagement Report

Version 1.

Author: Voluntary Action Leeds – Leeds Voices Team



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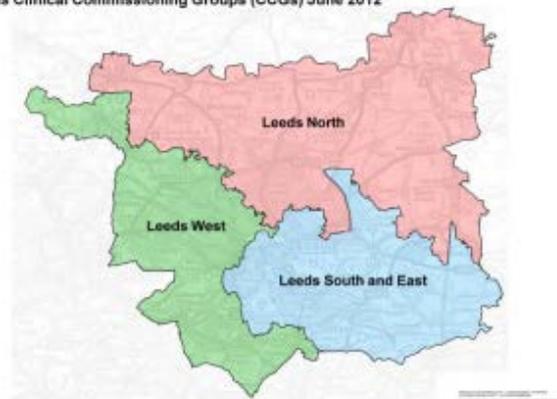
# 1. Background information

The NHS Leeds CCG partnership The CCG partnership covers the three NHS bodies in Leeds responsible for planning and funding (commissioning) the majority of health services for people in Leeds. The partnership is made up of the three Leeds CCGs; NHS Leeds North CCG, NHS Leeds South and East CCG and NHS Leeds West CCG.

The CCG partnership commissions a range of services for adults and children including planned care, urgent care, NHS continuing care, mental health and learning disability services and community health services.

From 1 April 2016 the CCG partnership began co-commissioning GP primary care services with NHS England. We do not commission other primary care services such as dental care, pharmacy or optometry (opticians) which is done by NHS England through their local area team more commonly referred to as NHS England (West Yorkshire). NHS England also has the responsibility for commissioning specialised services such as kidney care.

Leeds Clinical Commissioning Groups (CCGs) June 2012



Leeds is an area of great contrasts, including a densely populated, inner city area with associated challenges of poverty and deprivation, as well as a more affluent city centre, suburban and rural areas with villages and market towns.

The most recent census (2011) indicates that Leeds has a population of 751,500 people living in 320,600 households, representing a 5% growth since the previous census of 2001. Leeds has a relatively young and dynamic population and is an increasingly diverse city with over 140 ethnic groups including Black, Asian and other ethnic-minority populations representing almost 19% of the total population compared to 11% in 2001. There are currently 105 GP practices in Leeds.

Involving people and the public in developing and evaluating health services is essential if we want to have excellent services that meet local people's needs. It is our responsibility, and one that we take very seriously, to ensure that our local communities have the opportunity to be fully engaged in the decisions we take.

## b. Engagement support

Voluntary Action Leeds delivers the 'Leeds Voices' project to undertake public and community consultations on behalf of NHS Leeds Clinical Commissioning Groups (CCGs). There are three distinct elements to this project:

- Our Engaging Voices network of third sector organisations, we provide opportunities for seldom heard communities and vulnerable groups to get involved in consultation and engagement activities.
- Our Working Voices project offers opportunities for businesses to enable their employees to be involved in CCG engagement activities, by allowing working people to volunteer their time to be involved in consultations within the workplace.
- Our volunteer Leeds Health Ambassadors directly engage with the public and patients at a range of venues, public events and activities across the city.

## About the Engagement

Commissioners have been involving children and young people over the last 2 years on developing the mental health website MindMate. MindMate has been a crucial tool to provide children and young people with the information they need. However, it has been recognised that the support offer for parents and carers of children/young people experiencing mental ill health could be improved. This engagement sought to collect information from parents and carers in order to inform the ongoing development of the offer.

In addition the engagement incorporated the views of parents and carers of children and young people diagnosed or pre-diagnosed with autism, recognising the gaps in knowledge around the support needs of this group. This work builds upon a previous engagement project – Crisis Engagement Young People.

The broad aim of the engagement was to find out from parents/carers of children and young people experiencing mental ill or autism what support they need, and in what form they would like to receive it.

Objectives for the engagement were to gain insight into:

- Parents/carers of children/young people experiences of caring for children/young people diagnosed with mental ill health or autism
- The support needs of parents/carers of children/young people experiencing mental ill health or autism prior to crisis point
- The support needs of parents/carers of children/young people experiencing mental ill health or autism during a crisis situation
- Parents/carers views on how the current support offer could be improved

The groups prioritised within the engagement were:

- Parents/carers supporting children and young people between the ages of 3 and 18 from marginalised communities
- Parents/carers supporting children and young people with mental ill health
- Parents/carers supporting children and young people with autism

## 2. How did we engage the public?

Prior to delivery of the project, an engagement plan was developed by the Leeds Voices team to maximise opportunities to achieve the set engagement objectives and reach pre-identified priority groups.

Using the asset-based engagement model, our network of 70+ Engaging Voices partner organisations were notified of the engagement via e-bulletin. Partner organisations working with people from priority groups were identified and targeted with additional communications.

A mixed methods approach to data collection was adopted within the consultation, providing reach and depth of enquiry.

A brief questionnaire was created for both the mental health and the autism component of the engagement, to collect quantitative data from the broadest possible sample and offering indications of trends. Copies of the questionnaire were delivered to partner organisations together with brief instructions on how they should be administered.

Questionnaires were followed up with a series of focus groups and interviews conducted within partner organisations identified as working closely with priority groups. These focus groups offered a source of more in-depth and insightful information.

### 3. Analysis and reporting

When the data had been collected, questionnaire data was inputted into an online survey tool, survey monkey. Descriptive analysis was conducted to provide summaries.

Recordings/notes from focus groups and interviews were critically reviewed and summarised initially by the group facilitator and then by another member of the team. Thematic analysis was performed on summary data to identify crosscutting themes and to reveal unique areas of insight. Quotations representing these points were identified to aid reporting.

A pragmatic approach to reporting was adopted, separating the unique questionnaire data and in most cases pooling the qualitative data from the focus groups and interviews, reporting overarching themes and outliers and extracting any relevant condition specific insight. This approach was taken due to the presence of parents/carers of children/young people with dual or multiple diagnoses of mental ill health, autism and other conditions within focus groups and interview cohorts, and the emergence of clear crosscutting themes between the two elements of the engagement.

Within this report, data from the mental health specific questionnaire is reported on a blue background, data from the autism specific questionnaire reported on a green background and qualitative data reported in the body of report.

### 4. Who responded?

In total 129 people consented to be involved in the engagement. 10 people completed the mental health specific questionnaire, 80 people completed the autism specific questionnaire. A full breakdown of questionnaire monitoring data for the mental health specific questionnaire can be found in [Appendices A and B](#)

Of the 10 people answering the question 80.0% (n=8) supported one child/young person, 10.0% (n=1) supported two and 10.0% (n=1) stated that they supported three children/young people.

The age range of those children/young people supported was relatively evenly distributed across the years 4-18 (see Appendix A). The age range for diagnosis or first signs of mental health issues was 3-17 years old.

Of the ten people answering the question within the mental health questionnaire, the most commonly picked descriptors of the mental health issues faced by their child/young persons were “feeling different” chosen by 90.0% (n=9) of respondents; “Feeling really stressed or worried”, chosen by 80.0% (n=8) of respondents and “Feeling very low or extremely sad”, chosen by 70.0% (n=7) respondents. For a full breakdown of responses, see Table 1.

**Table 1: Mental health issues faced by children/young people**

Descriptor	Frequency (n=)	Percentage of those responding (%)
Feeling like hurting themselves	3	30.0
Feeling really stressed or worried	8	80.0

Feeling very low or extremely sad	7	70.0
Self image	3	30.0
Feeling angry	4	40.0
Dealing with bereavement	1	10.0
Feeling different	9	90.0
Bullying	2	20.0
Drugs or alcohol	1	10.0
Looking after somebody	1	10.0
Having a long term disability that impacts on their mental health	5	50.0
<b>Number answering the question</b>		10

Of the 80 people answering the question 77.5% (n=62) supported one child/young person, 20.0% (n=16) supported two and 2.5% (n=2) stated that they supported three children/young people.

The age range of those supported was relatively evenly distributed across the years 3-18. One person stated that they supported a person with autism aged 23 another two stated that they supported a person aged 25.

Of those answering the question (n=78), 47.4% (n=37) stated that the child/young person they support showed signs of autism or was diagnosed at age 3, 14.1% (n=11) stated that they showed signs of autism or were diagnosed at age 4. 33.3% (n=26) stated that they showed signs of autism or were diagnosed between the age of 5 and 10. 15.4% (n=12) reported that the child/young person they supported was diagnosed over the age of 10.

## Focus Groups and Interviews

A total of 39 people consented for their interview/focus group data to be included in the analysis. This group consisted of participants from:

- A local kinship carers support group
- Three groups supporting families of children with Autism Spectrum Conditions (LS13, LS16, LS25)
- A Community Centre (LS12)
- A family support charity

A full breakdown of participants' characteristics can be found in [Appendix C](#).

## 5. What did people tell us?

Across the engagement, there was a broad recognition of the diversity within the categories of mental ill health and autism. Whilst there were common traits referenced in regard each of these categories, parents and carers of children and young people also identified experiences of care, crisis and support which cut across the categories. The following section provides a structured summary of the views provided.

## Manifestations of crisis

Interviewees and focus group participants were asked to define, what they understood by the term 'crisis' within the context of their experiences. Within the context of a child/young person's autism these manifestations included:

- Meltdowns
- Aggression
- Violent and challenging behaviours (VCB)
- Suicidal acts
- Deterioration of mental health
- Removal from, or absconding from school and the home

*"We just had to lock ourselves away in the bedroom to prevent him injuring us"*

Within the context of a child/young person's mental ill health these manifestations included:

- Being upset
- Feeling depressed
- Feeling anxious
- Presenting eating disorders
- Self-harming
- Being unwilling/unable to talk
- Presenting abusive and threatening behaviours

*"She does not want to talk about it; if I try she gets anxious and self harms. If I try to get her to eat she gets really upset and tells me to stop going on at her."*

Whilst each individual participant reported differing interpretations of the term 'crisis' drawing on their own experiences of caring for a child or young person experiencing mental ill health or autism, some common themes emerged in these definitions.

Participants used terms such as 'breaking point', talked about struggling to cope, loss of control, a need to act quickly and an absence of support in describing the term crisis.

*"To me it means almost breaking point, people need to act quickly before it goes severely wrong, there is a lack of support around that area"*

*"Crisis to me is when, a child would get to a certain point... and you've tried everything, well what do I do now...where do I go, who do I speak to, where can I get help from."*

Of the 73 people answering the question in the autism questionnaire, 83.6% (n=61) stated that they could see a crisis building up. 26.6% (n=21) stated that crises built up slowly, 34.2% (n=27) selected other with many of these stating it varied, or was both slowly and suddenly.

## Impact on parents/carers

Whilst crisis, was commonly reported in terms of the experience of the child or young person, participants also provided insight into how crises and broader care provision was experienced from the parents/carers perspective. In describing these experiences participants used terms such as exhaustion, stress, anxiety,

guilt, as well as expressing confusion and a fear of being labelled as 'not coping' (see picture 1). One participant also referenced the financial impact on the family.

*"I have to physically buy [bed kyliies] myself, they're not cheap"*

Some parents and carers articulated a connection between their experiences of caring for a child/young person with mental health or autism and their own mental health and wellbeing.

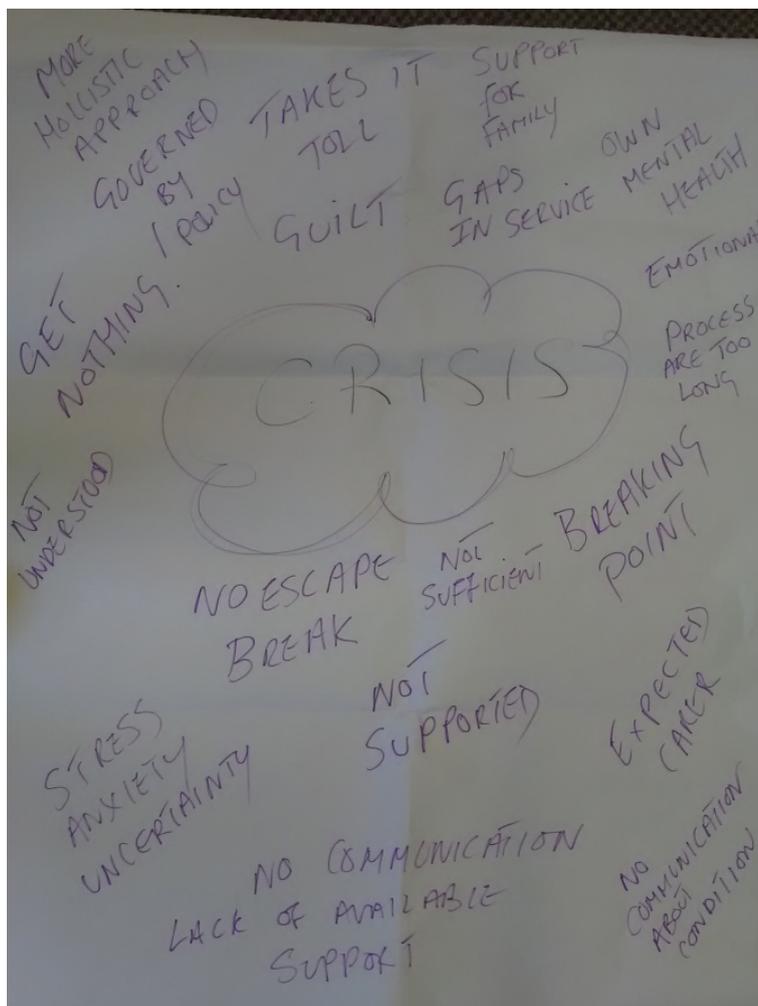
*"It winds you down to the ground, you know not sleeping. I was at points when I literally didn't want to get out of bed, but I've got nobody else around me to help me"*

*"You are so worn down by the system half the time you end up just getting on with it yourself and getting through the day. All you can hope is that as a parent you keep going until someone listens to what you have to say about your child's support needs."*

*"I think as a parent/carer of a child with mental health issues you never escape it and you never have a break, but because of the lack of support in the NHS you're expected to be the person that's caring and treating them and trying to help that young person but you're not supported in any way... and as a parent there is so much emotional attachment as well so there is a lot of things you're going through yourself too."*

*"The strain on our family has been immense. Being academically able, artistically talented, popular and socially confident nobody understood how she really felt about things and her extreme behaviour at home was dismissed."*

**Picture 1: The impact of crisis on parents and carers**



## Triggers of crisis and circumstances affecting mental well being

Data from the questionnaires, focus groups and interviews presented a wide array of triggers of crisis and circumstances reported to be affecting children and young people’s mental wellbeing.

Parents/carers completing the mental health specific questionnaire were asked the question ‘Are there specific circumstances that are currently affecting the mental well being of your children/young people?’ Of the ten people answering the question, 60.0% (n=6) cited “issues with school”; “child development issues” and “aggression in the home” were each cited by 50% (n=5) of respondents; “family breakdown”, “issues with sleep” were cited by 40.0% (n=4) of respondents. Other circumstances cited were, “eating”, “sensory issues”, negative labelling, “exam stress”, side-effects to medication and Autism Spectrum Disorder (ASD).

A total of 79 parents/carers completing the autism specific questionnaire answered the question ‘Please tell us about any particular triggers that you have experienced that have caused your children/young people to go into crisis’. The most commonly chosen triggers were “sensory overload”, chosen by 86.1% (n=68); “changes to routine”, chosen by 82.3% (n=65); “issues with school or any setting that they attend”, chosen by 78.5% (n=62); “issues with sleep”, chosen by 72.2% of respondents (n=57) and “lack of awareness of their condition, from people supporting them”, chosen by 69.6% (n=57) (see table 2 for a full breakdown).

**Table 2: Triggers of crisis for parents/carers of children/young people with autism**

Triggers of Crisis	Frequency (n=)	Percentage of those responding (%)
Changes in routine	65	82.3
Issues with school or any settings that they attend	62	78.5
Lack of awareness of their condition, from people supporting them (youth workers etc.)	55	69.6
Sensory overload (e.g. language/lighting/noise/decorations)	68	86.1
Isolation due to lack of friendships	40	50.6
Bullying	35	44.30
Health problems (including depression etc.)	34	43.0
Puberty	28	35.4
Life changes (family breakdown/bereavement etc.)	23	29.1
Issues with sleep	57	72.2
Other( please give details)	11	13.9
<b>Number answering the question</b>	<b>79</b>	

Data from interviews and focus groups provided further insight into the triggers, with parents referencing similar issues to those documented within the questionnaire but also others, such as ‘not understanding how to share’ and ‘toilet incidents’ (see picture 2). Some participants talked about the fragile interactions, indicating a fear of pending crisis.

*‘[It] can be like treading on egg shells’*  
[Paraphrase]

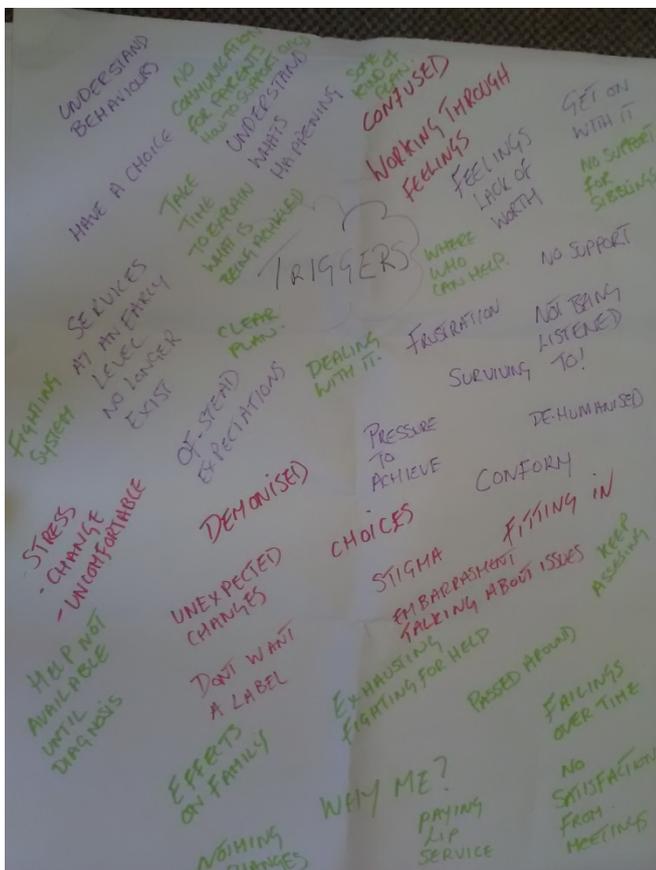
Some of the triggers cited by participants were framed within the context of the child or young person struggling with the demands of mainstream society, or social practices; this theme was particularly strong within the context of a child/ young person with autism. Here participants referenced issues such as change, imposed demands, loss of control, cleanliness and hygiene and not understanding what is expected of them as

potential triggers of crisis. Other triggers of crisis referenced, such as new, stressful or uncomfortable situations were also seen as challenging for the general population, but it was acknowledged that these situations could provide greater difficulties for some children/young people with autism or mental ill health.

*[You] can see her going into meltdown, triggers include, changes to routine, cleanliness, she only wears certain things, people going near her food. She struggled going to school, had strong support network at primary school but at upper school it fell apart.'*  
 [Paraphrased]

*"When you're already trying to fit in a society that doesn't understand you, change is so much bigger, than it would be for us."*

**Picture 2: Triggers of crisis**



Schooling was identified by a number parents/carers as a key source of 'triggers', with parents citing issues around school transitions, social pressures within the school environment, imposed demands and standardised ways of communicating and learning. For one parent/carer of a child/ young person with autism, the transition between primary and secondary schools was identified as a trigger; another participant suggested that the school system was not enabled to meet some of the needs of pupils who present diverse characteristics.

*"My eldest had a breakdown on transition to high school. [They] struggled with making friendships and spent most of the time in bed."*

*"The school system doesn't allow for that sort of variation, the pressure in schools to perform, to do certain things by a certain age, these kids don't fit into that."*

Stigma and bullying also emerged as theme with participants caring for children/young people with autism and mental ill health. Parents and carers talked about bullying triggering crisis situations but also fear of bullying and being negatively labelled as preventing open discussion and help seeking.

*“The big thing for her is, she’s embarrassed and the stigma, that’s a really big thing for her, at the moment she doesn’t want to talk about it, she doesn’t want to deal with it.”*

Within one of the focus groups a lack of support emerged as a key stimulus for crisis. One group participant indicated that the lack of choices and feeling as though they were not being listened to lead to the child/young person feeling frustrated and depressed. For another participant, deficits in support were highlighted as a key trigger for mental health crisis. The quote below illustrates how this lack of support was seen as compounding the child/young people’s mental ill health.

*“One of the triggers with my daughter, is the fact that she can’t get support, so she does feel as though she’s not worthy and she’s obviously not losing enough weight... When you’re suffering with mental health issues, if you haven’t got that support network around you or somebody to listen to you then you quickly do slip into crisis.”*

## Support and management of crisis situations

Participants highlighted a number of support needs for both children/young people experiencing autism or mental ill health and also those caring for them. These included:

- Emotional support for children/young people and families
- Respite for parents/carers
- Support with system navigation
- Clear communication from service providers
- Rapid access to crisis support

Those completing the mental health specific questionnaire were asked ‘What kind of support do you currently access to help you to offer support to your children/young people experiencing mental health issues?’. Of the ten people answering the question on the mental health specific questionnaire, 60% (n=6) stated that they accessed online information to help support the children and young people under their care. 50% (n=5) stated that they accessed “Face to face” support from teachers, GPs or other health professionals. 40% (n=4) accessed “informal support from family and friends” and 30% (n=3) accessed advice from support groups or networks. 20.0% (n=2) stated that they did not currently access support (see Table 3 for full distribution).

Respondents to the mental health questionnaire cited a number of resources, tools and strategies which they felt worked well, these included support from professionals, family members and others who had experienced similar issues.

**Table 3: Support currently accessed by parents/carers of children/young people with mental health issues**

Support currently accessed	Frequency (n=)	Percentage of those responding (%)
Information leaflets	2	20.0
On line information	6	60.0
Telephone advice/support	1	10.0
Advice from support group/network	3	30.0
Training	1	10.0
Informal support from family and friends	4	40.0
Face to face (teacher/GP/ other health professionals)	5	50.0

Support through school	2	20.0
Child and Adolescent Mental Health Services	2	20.0
Did not access any support.	2	20.0
<b>Number answering the question</b>	<b>10</b>	

Those who completed the autism specific questionnaire were asked what support they accessed leading up to the crisis, in total 79 people answered this question. The most commonly reported support was “Advice from autism support group/network”, chosen by 57.0% of respondents (n=45). “Informal support from family and friends” was chosen by 50.6% of respondents (n=40); “Online information” was chosen by 36.7% of respondents (n=29); “Face to Face (teacher/GP/other health professionals) was chosen by 36% of respondents (n=29); “Child and Adolescent Mental Health Services”, were chosen by 35.4% of respondents (n=28) (see Table 4 for full distribution).

**Table 4: Support accessed by parents/carers of children/young people with autism in the lead up to crisis**

Support Accessed	Frequency (n=)	Percentage of those responding (%)
Information leaflets	6	7.6
On line information	29	36.7
Telephone advice/support	10	12.7
Advice from autism support group/network	45	57.0
Training	15	19.0
Informal support from family and friends	40	50.6
Face to face (teacher/GP/ other health professionals)	29	36.7
Support through school	26	32.9
Child and Adolescent Mental Health Services	28	35.4
Did not access any support.	17	21.5
<b>Number answering the question</b>	<b>79</b>	

Those completing the autism specific questionnaire were asked if they felt like they ‘left the situation feeling like they would be better prepared if it happened again’, following accessing support. Of those answering the question (n=75), 49.3% (n=37) felt like they would be better prepared if it happened again.

Providing further insight participants in focus groups and interviews talked about a perceived deficit of support available to them, this deficit was emphasised in terms of general support prior to a crisis occurring. Parents/carers talked about this deficit leading to feelings of frustration, anxiety, isolation and loss of confidence.

*“I can’t explain to you how much you lack confidence when you go through a crisis... Your confidence is continually eroded, because nobody is saying we will support you.”*

Some participants recognised that support was available, through Child and Adolescent Mental Health Services (CAMHS), schools, social workers and the police when families entered crisis situations, however this support was sometimes deemed to be ineffective or inappropriate and not joined up. As the second quote illustrates, this lacking in support could negatively impact on the wellbeing of parents and carers.

*‘[We] tried to get him to go to the doctor but he refused, we have no support. The only people we have talked to are police and school and neither were helpful.’*  
[paraphrased]

*“[Our] previous school often rang when she had a meltdown. Sometimes this left us feeling hopeless.”*

Some participants highlighted the positive support offered by community based support groups, referencing the benefits of knowledgeable and dynamic support that some groups could offer. One person also suggested that community groups could offer valuable support in terms of providing bespoke support, for example through a personal assistant, or facilitating engagement with mainstream services. The support of family and friends was also valued. One focus group highlighted the additional support needs of kinship carers.

*“The only advice given was join a support group! Joining the support group has been beneficial, however autistic children should be provided with a support worker who could be available within a timely manner, without having to wait months for a CAMHS appointment!”*

## **Barriers to accessing support**

Participants highlighted a number of perceived deficits in the support available to their child, these included:

- A general lack of awareness of the diverse care needs of children and young people with autism/mental ill health amongst professionals
- Difficulties in finding and engaging support services
- A lack of capacity within relevant services
- Complex and prolonged assessment processes
- Restrictive eligibility criteria for services
- A lack of joined up working between support services

The perceived lacking in awareness of children and young peoples needs, combined with restrictive diagnostic processes and a general lack of support was identified by one parent as having a negative impact on the mental health of children and young people.

*“There is an overall lack of understanding and an overall focus to push autistic children into neurotically situations (schools) where they struggle to cope. This is at the extreme detriment to their mental health and the real crisis occurs from unmet mental health [needs] that have been developed as a result of lengthy diagnostic processes and no actual support.”*

Schools were seen by a number of participants as providing barriers to accessing services for the children/young people. One participant indicated that there was a discontinuity of service as a result of support being offered through the school when a child is of school age.

*“The Head and pastoral teams in the primary school were not trained well enough to see red flags for more serious mental health issues - they accepted that she had anxiety without making referrals; they did not support my application to CAMHS and said “she is fine in school”; they told the school nurse “possible attention seeking”.*

*“A lot of things stopped when [my child] turned five, , we used to have speech therapists come in, every week or every two weeks, physio... occupational therapists, we used to have all of those until turned five, school aged, that’s it it’s all done through school.”*

A number of participants across the engagement presented negative experiences in attempting to access support through CAMHS. As the quotations below illustrate, participants reported barriers including eligibility criteria, lengthy assessments and ineffective communication.

*“The high threshold of a child in crisis by CAMHS who only prioritise if a child is self harming at severe levels. They have an accepting attitude when a child is deteriorating. When I attempted to give information to CAMHS in-between parent meetings of 6-8 weeks apart, I was told most firmly and quite rudely this was not appropriate.”*

*“The waiting times for CAMHS Leeds autism assessments are appalling and there is no help for co-existing mental health conditions apart from CBT offered. CBT does not fit well with autistic people.”*

## **Service Improvements**

Participants offered a number of suggestions for improvements to services which they felt may help avoid crisis in future or better support for them when in the midst of a crisis. Suggested improvements included:

- Greater awareness of the diverse needs of children with mental health and autism across services
- Greater awareness of diversity within mental health and autistic spectrum conditions
- Improved access to existing services such as CAMHS
- Improved communication between parents/carers and services
- Clearer care pathways and improved adherence to care within agreed health and care plans
- Improved communication between services
- Greater continuity of care

Participants also highlighted a number of gaps in current provision. These included:

- A need for more localised service provision
- A need for emergency support e.g. access to sedation
- Access to 24 hour specialist helpline
- Access to alternative therapies

There was a clear theme amongst focus group participants and interviewees around a need to improve support before crisis. As the quotes below indicate participants highlighted a need for support to be made available in the early stages of a diagnosis. Participants also talked about, this perceived lack of preventative support producing additional problems further down the line

*“There’s nothing to know what help’s out there, so you’re suddenly put in this position where you discover your child is autistic or there is mental health [issues] and you’re in a state of stress and anxiety and uncertainty”*

*“I see it as short sighted that the support isn’t put in place, creating further problems that is costing more and more money to deal with... again with my daughter I’m just waiting for the next crisis.”*

A number of parents and carers highlighted the need for a more empathic and supportive approach to parents, in which they are treated as advocates for the children.

*“She would get taken off into a room and I had been told it was confidential... she wouldn’t communicate with me... I’m taking her home to care for her for two weeks, but nobody is saying ‘this is how you care for her for two weeks’... it was confidential”*

There was discussion around the need for a more accessible, dynamic, understanding and joined up support service, tailored to the needs of families. A number of participants highlighted the value of a 24 hour helpline, which would enable families to access emergency advice and support. Mechanisms to enable families to access peer support was also seen as valuable

*“Face to face support from professionals [is needed] or...a CAMHS passport to access quick short consultation before child gets too stressed”*

*“[It would be], nice to have somebody to ring and get immediate support, no services that provide emergency care and everything is on a waiting list, all takes too long, needs to be a 24 hr helpline.”*

*“Every time [my child’s] paediatrician changed, we had to go through all the information again, that is annoying... they need to share information”*

*“Finding local families to talk with in person whose child had also experienced a breakdown. Finding local parent support groups to attend. Finding online support groups to share information and get support. It is shocking how many families are in the same position.”*

One interviewee suggested a need for more appropriate, accessible information, citing an example of support received from a health visitor who had created a portfolio of information and service contacts for parents and carers.

*“[The specialist health visitor] had a folder, and it had all information on all services within Leeds and surrounding areas of people that you could contact, for all different ranges of things... I feel that all parents with children with additional needs should have one.”*

There was also an acknowledgement that broader support should be offered, taking into account the health and wellbeing needs of the whole family, this included recognition to improve respite care for parents and carers.

*“If they want the child supporting, they need to think about how to support the family as well, that’s really key and I don’t think that’s out there really.”*

*“[We need] proper support, respite, activities for my children to attend that don’t cost as we only have support from school”*

## **6. What are the key findings from the feedback?**

A number of key findings emerged across the two components of the engagement, these can be summarised as follows:

- Participants highlighted diversity within the labels of mental health and autism, but also talked about common experiences of caring for children and young people with mental health and autism.
- The term ‘crisis’ was defined in a variety of different ways, referencing the experiences of both the child/young person and wider family. In regard to parents and carers common themes emerged including ‘struggling to cope’, ‘loss of control’, ‘a need to act quickly’ and an ‘absence of support’.
- Triggers of crisis cited by participants in the engagement were varied. Parents and carers commonly talked about new and stressful situations triggering crises, but also suggested insufficient or inadequate support could inform the development of crises.
- The engagement highlighted a deficit of support available to parents, carers and families in general. Participants emphasised the lack of early and routine support available, which may prevent crises occurring.
- Participants talked about a need to improve access to and quality of existing services and broader support. Child and Adolescent Mental Health Services and support through schools were highlighted as requiring particular improvement.

## 7. Recommendations

Following the engagement the CCG are asked to receive the report and consider the following recommendations arising from the key findings:

Finding	Recommendations
There are common experiences of caring for children and young people with mental health and autism	Explore opportunities for learning, sharing of good practice and joined up working between new and existing services.
'Crisis' was defined in a variety of different ways, drawing on experiences of both the child/young person and wider family.	Conduct further investigations and continue to engage parents and carers from diverse communities in dialogue around the meaning and impact of 'crisis', for all family members and carers of children and young people with mental ill health and autism.
Triggers of crisis were varied. Parents and carers talked about new and stressful situations triggering crises, but also suggested insufficient or inadequate support could have a negative impact.	Conduct further investigations and continue to engage parents and carers from diverse communities in dialogue around the triggers of crises for all family members and carers of children and young people with mental ill health and autism.
The engagement highlighted a perceived deficit of support available to parents, carers and families in general. Participants emphasised the lack of early and routine support available which may prevent crises occurring.	Further work needs to be conducted to identify key gaps in support provision, with a focus on crisis prevention. Particular consideration should be given to support available to marginalised groups.
Participants talked about a need to improve access to and quality of existing services and broader support. Child and Adolescent Mental Health Services and support through schools were highlighted as requiring particular improvement.	Additional work should be conducted to help improve access to and improve the experience of children and young people experiencing mental ill health or autism engaging with CAMHS.  Additional work is required to ensure appropriate support is provided by schools as part of a joined up offer of care to families with children and young people experiencing mental ill health or autism.

Additionally, and as part of the continuing development of the asset-based Leeds Voices programme, it's important that the CCG inform VAL of the outcome of this work in order to feedback to partner organisations and participants.

## 8. Reflections

In leading on this engagement the Leeds Voices team noted a number of points in interpreting the findings presented in this report:

- In engaging in dialogue with a diverse group of parents and carers, with a multitude of experiences around complex issues, the Leeds Voices team experienced challenges in differentiating the voices of parents and carers. Whilst the report provides value in highlighting a number of common issues pertinent to parents and carers of children and young people experiencing mental ill health or autism, the more nuanced issues relevant to each may have been masked for example parents/carers of children/young people pre and post diagnosis and the additional needs of kinship carers.
- The response rate for the mental health specific questionnaire was lower than for the autism specific questionnaire. The Leeds Voices team attribute this to the broad nature of the term 'mental health' and a relative lack of parent/carer focussed/led provision from Engaging Voices partners around child/young peoples mental health, compared to autism.
- Findings from the engagement must be interpreted as part of a broader dialogue with health care professionals, stakeholders and families. Evidence around 'what works' in supporting parents and carers of children and young people presenting mental ill health and autism and other diagnoses, from diverse communities should be reviewed and used to inform future developments.

## Appendix A – Equality monitoring for mental health questionnaire respondents

### Gender identity

88.9% (n=8) of the 9 respondents answering the question were women, 11.1% (n=1) were male. No participants answering the question (n=8) reported having a gender identity different to what was assumed at birth.

### Age of respondents

Of those answering the question (n=9), 22.2% (n=2) were in the 26-35 age bracket; 33.3% (n=3) were in the 36-45 age bracket, 22.2% (n=2) were in the 46-55 age bracket 22.2% (n=2) were in the 56-65 age bracket.

### Ethnic Background

88.9% (n=8) of those providing information on their ethnic background (n=9) stated that they were 'White British', the remaining 11.1% (n=1).

### Area of residency<sup>1</sup>

Of the 9 people who provided the information, LS6 and LS25 the most commonly reported area of residency with 22.2% of responses (n=2).

Postcode area	Frequency (n=1)	Percentage of those responding (%)
LS6	2	22.2
LS12	1	11.1
LS15	1	11.1
LS17	1	11.1
LS19	1	11.1
LS25	2	22.2
LS26	1	11.1
<b>Total</b>	<b>9</b>	<b>100</b>

### Disability Status

Of those who responded to the question (n=9), 22.2% (n=2) identified as being disabled people. The two respondents stated that they had a mental health condition.

### Sexual Orientation

All 9 (100%) of the people answering the question stated that they were heterosexual/straight.

### Pregnancy and Maternity

None of those answering the question (n=9), stated that they were currently pregnant and nobody had given birth in the past 26 weeks.

### Religion or Belief

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<sup>1</sup> Index of multiple deprivation data for Leeds can be found [here](#)

Of the 9 people who answered the question 55.6% (n=5) stated that they were Christian, 33.3% (n=3) stated that they had no religion and 11.1% (n=1) stated that they were Muslim.

### **Relationship Status**

Of those responding (n=8), 37.5% (n=3) stated that they were in a marriage/civil partnership; 37.5% (n=3) stated that they lived with a partner, 12.5% (n=1) stated that they were widowed and 12.5% (n=1) stated that they were divorced.

### **Caring responsibilities**

66.7% (n=6) of the 9 people answering the question stated that they were a carer.

## Appendix B – Equality monitoring for autism questionnaire respondents

### Gender identity

94.7% (n=71) of the 75 respondents answering the question were women, 4.0% (n=3) were male and 1.2% (n=1) preferred not to say. 5.3% (n=4) of the 75 respondents answering the question stated that their gender identity was different to the sex they were assigned at birth, 1.3% (n=1) preferred not to say.

### Age of respondents

Of those answering the question (n=77), 2.6% (n=2) were under 16, 13.0% (n=10) were in the 26-35 age bracket; 46.8% (n=36) were in the 36-45 age bracket, 31.2% (n=24) were in the 46-55 age bracket 3.9% (n=3) were in the 56-65 age bracket and 2.6 (n=2) preferred not to say.

### Ethnic Background

79.2% percent of those providing information on their ethnic background (n=77) stated that they were 'White British'.

Ethnic Background	Frequency (n=)	Percentage of those responding (%)
White British	61	79.2
White Irish	1	1.3
Mixed White & Black Caribbean	1	1.3
Asian/Asian British Pakistani	2	2.6
Chinese	1	1.3
Prefer not to say	4	5.2
Other	7	9.1
<b>Total</b>	<b>77</b>	

### Area of residency<sup>2</sup>

Of the 71 people who provided the information, LS25 was the most commonly reported area of residency with 12.7% (n=9).

Postcode area	Frequency (n=)	Percentage of those responding (%)
LS4	1	1.4
LS5	3	4.2
LS6	1	1.4
LS7	4	5.6
LS8	2	2.8
LS9	1	1.4
LS10	5	7.0
LS12	6	8.5
LS13	2	2.8
LS14	3	4.2
LS15	4	5.6
LS16	4	5.6
LS17	1	1.4
LS18	1	1.4
LS19	3	4.2
LS20	1	1.4
LS21	1	1.4
LS22	1	1.4

<sup>2</sup> Index of multiple deprivation data for Leeds can be found [here](#)

LS23	2	2.8
LS25	9	12.7
LS26	5	7.0
LS27	4	5.6
LS28	5	7.0
WF3	2	2.8
<b>Total</b>	<b>71</b>	

### **Disability Status**

Of those who responded to the question (n=75), 9.3% (n=7) identified as being disabled people. Respondents stated disabilities were: mental health condition (n=6), long standing illness (n=3), physical impairment (n=3), prefer not to say (n=6).

### **Sexual Orientation**

Eighty-seven percent (n=67) of those answering the question (n=77) identified as hetero-sexual/straight 6.5% (n=5) identified as bisexual. 5.2% (n=4) preferred not to say and 1.3% (n=1) preferred not to say.

### **Pregnancy and Maternity**

None of those answering the question (n=67), stated that they were currently pregnant and nobody had given birth in the past 26 weeks.

### **Religion or Belief**

Of the 77 people who answered the question 45.5% (n=35) stated that they were Christian, 40.3% (n=31) stated that they had no religion; 1.3% (n=1) stated that they were Muslim; 1.3% (n=1) stated that they were Jewish; 6.5% (n=5) preferred not to say and 5.2 (n=4) identified as other.

### **Relationship Status**

Of those responding (n=77), 61.0% (n=47) stated that they were married or in a civil partnership; 11.7% (n=9) stated that they lived with a partner, 10.4% (n=8) stated that they were single; 15.6% (n=12) stated that they were divorced; 1.3% (n=1) preferred not to say

### **Caring responsibilities**

84.2% (n=64) of the 76 people answering the question stated that they were a carer.

## Appendix C – Equality monitoring for focus groups and interview participants

### Gender identity

94.9% (n=37) of the 39 respondents answering the question were women, 5.1% (n=2) were male. 5.1% (n=2) of the 39 respondents answering the question stated that their gender identity was different to the sex they were assigned at birth, 2.6% (n=1) preferred not to say.

### Age of respondents

Of those answering the question (n=39), 5.1% (n=2) were in the 26-35 age bracket; 35.9% (n=14) were in the 36-45 age bracket, 46.2% (n=18) were in the 46-55 age bracket 10.3% (n=4) were in the 56-65 age bracket and 2.6 (n=1) were in the 76-85 age bracket.

### Ethnic Background

89.7% (n=35) of those providing information on their ethnic background stated that they were 'White British'.

Ethnic Background	Frequency (n=)	Percentage of those responding (%)
White British	35	89.7
White Irish	1	2.6
Mixed White & Asian	2	5.1
Other	1	2.6
<b>Total</b>	<b>39</b>	

### Area of residency<sup>3</sup>

Of the 35 people who provided the information, LS10 was the most commonly reported area of residency with 17.1% (n=6) respondents stating this as their area of residency.

Postcode area	Frequency (n=)	Percentage of those responding (%)
LS7	1	2.9
LS9	2	5.7
LS10	6	17.1
LS11	2	5.7
LS12	3	8.6
LS15	1	2.9
LS16	3	8.6
LS17	1	2.9
LS18	1	2.9
LS19	1	2.9
LS22	1	2.9
LS23	1	2.9
LS25	5	14.3
LS26	2	5.7
LS27	3	8.6
LS28	2	5.7
<b>Total</b>	<b>35</b>	

<sup>3</sup> Index of multiple deprivation data for Leeds can be found [here](#)

### **Disability Status**

Of those who responded to the question (n=37), 16.2% (n=6) identified as being disabled people, 73.0% (n=27) selected no disability, 10.8% (n=4) preferred not to say. Respondents stated disabilities were: Long standing illness (n=3) physical impairment (n=2), mental health condition (n=4), visual impairment (n=1), 2 people preferred not to say.

### **Sexual Orientation**

89.2% (n=33) of those answering the question (n=37) identified as hetero-sexual/straight; 5.4% (n=2) identified as a Lesbian/Gay Woman; 2.7% (n=1) identified as bisexual. 2.7% (n=1) preferred not to say.

### **Pregnancy and Maternity**

None of those answering the question (n=38) declared that they were currently pregnant, 5.3% (n=2) preferred not to say. None of those answering the question (n=36) declared that they had given birth in the past 26 weeks, 8.3% (n=3) preferred not to say.

### **Religion or Belief**

Of the 38 people who answered the question 63.2% (n=24) stated that they were Christian, 36.8% (n=14) stated that they had no religion.

### **Relationship Status**

Of those responding (n=38), 44.7% (n=17) stated that they were married or in a civil partnership; 13.2% (n=5) stated that they lived with a partner, 18.4% (n=7) stated that they were single; 5.3% (n=2) stated that they were widowed 15.8% (n=6) stated that they were divorced; 2.6% (n=1) preferred not to say

### **Caring responsibilities**

76.3% (n=29) of the 38 people answering the question stated that they were a carer.

