



**Shaping The Local Offer:
YOUR VOICE**

**Parent/Carer Engagement Day – 18th May 2018
FOCUS GROUP 1/10: Early Years/Early Intervention**

Comments and quote from Parent/Carers below.

POSITIVES

- Staff at 1:1 level are good with the children
- Early years services opens up other areas of support if parents are aware of where to go.
- Some schools positive, but not all consistent
- Parents meeting other parents at social activities
- Portage support invaluable

ISSUES

- Private day nurseries not equipped to deal with SEN
- Provisions not met/ addition needs not identified
- Staff not involved with therapy sessions
- Lack of support without an EHCP.
- Poor experience visiting schools, schools does not understand/ accept disabilities, poor staff attitude
- Nursery staff inexperienced with SEND funding paperwork
- Progression not being made by SEND children in nurseries
- Lack of overall support
- Lack of 1:1 funding
- Problems around provision for children with medical needs/ conditions
- Drop in sessions not working
- Nurseries having to be 'hand fed' information
- Millwood short of specialist places
- Lack of specialist nursery provision
- Early intervention is not being made early enough some people waiting over 2 years
- Lack of joined up working with different trusts/ cross boarder issues
- Not all services are available to all parents/ some services are unknown of/ no consistency
- Parents of complex care children feel they are stuck in the house
- Worries around children whose families do not/ cannot fight for their rights
- Lack of transition support between school/ nursery settings
- No help/ advice in choosing a school
- Hard to judge a good SEND school/ parents have to visit many schools/ OFSTED rating means nothing

EFFECT ON FAMILIES & C&YP

- Families are not aware of services
- No consistency in the approach/ availability of services. Very unfair.
- Children are missing out
- Families experiencing a frightening time, trying to learn about their children and their condition.
- Very overwhelming and upsetting. Need help at this critical time.
- Parents are expected to feel 'lucky' if they have access to good provision
- Families are going through grieving process with no support for the child or family
- Families are becoming very isolated
- Siblings unsupported, easily become additional carers
- Parents/ carers depressed, stressed, poor mental and physical health
- Families feeling the financial strain/ unable to work
- Parents have no confidence in the health/ education system
- Parents do not know how to help their children meet their full potential
- Sensory needs are being ignored
- Parents struggling through the diagnosis process
- Missing out on available funds through benefits etc
- Lack of Blue Badges for children aged 0-5 is leaving our families isolated and depressed.

SUGGESTED IMPROVEMENTS

- Need more regulation on SEN in day nurseries
- Improvement in SENCO training/ knowledge of funding paperwork
- SENCO should be available/ no appointments needed
- Staff should be involved in therapy session
- Staff training on autism/ SEN/ How to recognise/ awareness of needs/ adjustments etc
- More 1:1 support available
- TAF meetings to make things work
- More specialist nursery provision must be available
- Transparency around the specialist provision placements at Millwood/ Hoyle
- EARLY INTERVENTION is key and must be treated as such rather than crisis management
- Better support for child and the parents/ family
- More support with transition nursery to school
- Assistance in choosing schools/ support during the process
- Learning disabilities support group would be helpful
- More access to health visitors for health intervention
- Sibling support groups
- More parental mental health support/ counselling
- Overhaul of Bury's blue badge application for 0-5.
- Highlight portage and reduce waiting times
- More equipment should be available
- After appointments there should be a contact that you can easily reach to refer to for advice
- Transparency about the referral/ access to portage team
- Sensory needs must be addressed early on
- More social opportunities available for girls
- More support needed pre/ during and post diagnosis
- More key workers required
- More specialised provisions in more schools like Hoyle
- Would like to see ASD specialists to help and support families

<ul style="list-style-type: none"> - Negative experiences when you come out of appointments alone, no support - Lack of health visitor referrals/ need proactive health visitors - Parent's mental health poor, they are drained, hard when parents have siblings - No sibling support - No support through/ during the diagnosis process - Portage is hit and miss, some love it, some never heard of it, some unhappy with waiting times - Not enough equipment available until nursery/ school - Cost of travelling from area to area, finding the best provision available. - Full time nursery support needed, but do not have enough hours funding - Lack of functional support - After school provision is lacking - No sensory needs assessment/ help available - Certain schools do not like to take children with disabilities - Girls lacking social interactions opportunities - Families feel unorganised with no idea where to turn to - Too much paperwork/ too many appointments/ whole process disjointed - Families unsure about benefits available/ grants/ DLA/ no consistency - Blue badge applications declines, advised autism is not a lifelong disability. 		<ul style="list-style-type: none"> - Help and advice on benefits/ short breaks/ and what's available to families - More resourced nursery provisions that are attached to good, inclusive community (non-religious schools) that start at age 2. - More specialist places at Millwood from age 0. - More advertisement and encouragement for private nursery staff to undergo specific training at Millwood. - More workshops from all services delivered at the BURY2GETHER centre, reducing the need for an appointment and reducing waiting lists. E.g. SALT, signing sessions, board maker sessions, Incontinence Team, Learning Disability Nurses could deliver Sleep Training, Portage play sessions, Ed Psych drop-in. - An overhaul of the post diagnostic service – have we asked parents if this is what they want? - Help for our parents who are waiting 2 years for a diagnosis or for those who will never receive a diagnosis.
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	YOUR VOICE	
<p>Parent/Carer Engagement Day – 18th May 2018 FOCUS GROUP 2/10: Social Opportunities</p> <p>Comments and quote from Parent/Carers below.</p>		<ul style="list-style-type: none"> - Social opportunities give the family a well needed break. - With a good PA the service is invaluable to families and children. - The child gains independence. - Opportunity for the child to be around their peers. - To do and take part in activities they maybe wouldn't have access to.
ISSUES	EFFECT ON FAMILIES & C&YP	SUGGESTED IMPROVEMENTS
<p>Overall majority of parents on the tables had never heard of short breaks/ PA's or respite.</p> <p>What is the criteria for a social assessment?</p> <ul style="list-style-type: none"> - Lack of information - How does a family apply, what do they ask for, what are they entitled to and who do they speak to? - One parent asked about the Social opportunities on her child's EHC plan and was told to leave it blank as her child did not matter at that time and it was something they would look at in the future. - Parents get more information of each other than they do off the Local Authority. - What is the point of a provider having a service when nobody knows about it? - Why spend all the money on a service when it is not advertised properly? - Why do you need a social worker? <p>Why do families have to be at CRISIS point before offered help?</p> <ul style="list-style-type: none"> - Why am I offered help when completely desperate and not earlier as early intervention does work and I if had the right social support in place we would not be in crisis now. - One family was told 'you are not at crisis point so we can't offer any help'. - One family was told they wouldn't meet the criteria even when the MASH team requested support for the family. <p>Carers Assessment</p> <ul style="list-style-type: none"> - Nobody knew what this was or had ever heard of it. 	<ul style="list-style-type: none"> - Further referral to other services due to mental health problems. - More money wasted on services to treat rather than prevent. - Family's health and child's health suffers. - Siblings are affected. - Child lacks confidence and self-esteem. - ASC children especially affected by lack of social opportunities and skills. - Child's anxiety levels are raised. - No opportunities to make friends like their peers. - It has a knock on effect and causes sleep problems and problems at school and other areas. - Not fair that our children cannot access what neurotypical children can. 	<ul style="list-style-type: none"> - Parents talked about having one individual professional (key worker) who represents and helps the family to navigate the system and support the family with setting the system up and helping get a PA. - The system needs to be family friendly and flexible to each family's needs and circumstances and work around the family. - For schools and professionals to be more informed and offer the service sooner rather than later. - For Social Opportunities information to be more available and easy to understand for families. - For more providers to offer specialist activities and groups in Bury. - For the system to be user friendly and easy to understand and navigate and for the local authority to offer help and guidance when necessary. - Waiting times for referrals and assessments to be cut and the system to be easier to access. - More social opportunities in schools. - Holiday clubs specifically aimed at SEND children in Bury (there is currently only 1 at Elms Bank School). - There needs to be more agencies offering skilled, experienced and trained PA's and more information available to prospective PA's, these should be included in the cost of your package if it is a requirement for the family.

<ul style="list-style-type: none"> - So important that the carers and also taken care off. - cost of carer stress if they are not supported <p>Referral/Assessment wait too long</p> <ul style="list-style-type: none"> - Referrals and assessments take too long – one family’s wait for hours was 2yrs after assessment. <p>Social care seems to be a battle</p> <ul style="list-style-type: none"> - It’s a battle to get what you are entitled to. - Any changes to a Social Care package felt like a budgeting decision (told it must go to panel) and was not worth the hassle. - Stick by the rules – if you miss a week you can’t get the hours back and not allowed to break the hours up, it must be used all at one session – no flexibility and not family friendly. <p>Not an easy system to navigate</p> <ul style="list-style-type: none"> - When offered social care package, I don’t know how to get a PA or get help. - There is no help for the family in setting the package up and maintaining it. - The system is overwhelming for families. - the carers are under extreme stress already and are scared of the responsibility of employing a PA and have no confidence in local agencies. <p>Children in mainstream are not given ANY information re social opportunities</p> <ul style="list-style-type: none"> - Mainstream children and families are not offered ANY help or information from school. - Schools should help more. - SENCOs should be ensuring families are aware of support available <p>Not enough Social Opportunities in Bury & lack of providers</p> <ul style="list-style-type: none"> - Parents must research their own social groups for their children - Not enough variety - Not enough sporting opportunities - Not enough specialist groups - No sibling groups. - One size does NOT fit all. 		<ul style="list-style-type: none"> - For the family to have peace of mind that their child is in the best hands and their needs are met. - For providers like Together Trust to have one to one communication with families for when things go wrong. - An overhaul of the Short Breaks system and budgets, looking at preferred models such as Manchester and Rochdale. More flexibility, more options. - Short Breaks provision for under 5’s (not currently available) - Published clarity on how to access short breaks. - Published clarity as to what Bury families can use budgets to pay for. - The immediate removal of Social Workers to access Short Breaks. - The immediate removal of costs to access Short Breaks such as ‘Action for Children’ who are currently charging families. - ‘Do you want a Social Care assessment and/or a Carers Assessment’ tick box included in all EHCP paperwork.
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<ul style="list-style-type: none">- One family has 3 hours per week but has only had 1 PA who works 3 hours every 2 weeks. That was 7 months ago and nothing has been done by the provider or the local authority. The provider is still getting paid by the local authority to provide 3 hours per week for this child. <p>Lack of PA's and agencies</p> <ul style="list-style-type: none">- One parent had 2 PA's and they have both left. Now she has the hours but does not know where to look for new PA's.- PA not suitable and lack experience or skills.- Parents having to be there child's PA and take them out for social activities because shortage of staff. <p>Gender provision for girls</p> <ul style="list-style-type: none">- Nothing offered for girls in school or out in community- Gaps in girl's provision for ASC <p>There are no holiday clubs for our children</p> <ul style="list-style-type: none">- Loads of mainstream clubs but none that are suitable for our kids- Lack of support and staff so nothing is offered- Absolutely nothing to cater for our children in the holidays- 6 week summer holidays can be exhausting for our families and children		
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**Shaping The Local Offer:
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POSITIVES

Parent/Carer Engagement Day – 18th May 2018
FOCUS GROUP 3/10: Specialist Provision

Comments and quote from Parent/Carers below.

- Parents spoke highly of Hoyle resourced provision- Huge improvements with verbal and social communication-
- 'My son was virtually non verbal when he joined but the early intervention has meant he is now coping brilliantly in the right mainstream school'
 - High quality teachers and teaching assistants in specialist provision-
 - 'It makes a huge difference to send my child somewhere that understands my child needs'

ISSUES

EFFECT ON FAMILIES & C&YP

SUGGESTED IMPROVEMENTS

Lots of parents shared concerns about mainstream schools having poorly trained teaching assistants and echoed similar concerns around Teaching staff who had broadly basic training on SEND-

- 'If they don't understand our children, it impacts our children negatively'
- 'Poor understanding of autism and processing difficulties mean they fall behind and anxiety increases'
- 'Poorly trained teaching assistants don't understand our children's sensory needs and behaviour then blame us as parents. They don't understand the impact on our family when our child comes home'
- 'Mainstream school feels unsafe, even the dinner ladies didn't understand my daughters needs'
- 'Mainstream schools don't seem to understand the concept of masking where as specialised schools were aware and adapt to those needs'
- Several parents shared concerns about lack of options for Girls in Bury-
- 'My daughter slipped through the net, primary school didn't want to know and then we had a daughter with mental health problems unable to cope in high school'

- Not feeling listened to/heard
- School staff / other children and young people not understanding SEND 'I should be able to go to a mainstream school' (quote from a young person)
- Children attending Schools that aren't in their local communities (social and mental health effects)

- An event for all parents of children with SEND where they can meet with each schools SENCo and gather views /info about what's on offer at each school
- Informative events to support school moves
 - An informative website which lists what each school has on offer to limit the risk of failed placements
 - Sharing skills of highly trained teaching assistants in Specialist placements with Mainstream schools
 - High quality training for all staff in mainstream schools to ensure that children are understood and have their needs met
 - Intervention much earlier for children who cannot have their needs met in Mainstream so that they are not left to suffer or out of Education
 - More specialist places in borough for 0-5 age children in Millwood or good, inclusive mainstream schools that have a resourced provision.
 - Resourced provisions specifically targeting girls in both Primary and Secondary to support girls' mental health and wellbeing.
 - A resourced provision specifically targeting 'high functioning' boys that has a focus on IT.
 - We are missing Resourced provisions in localities such as North Bury and Radcliffe.
 - Resourced Provisions should be more equipped to deal with Sensory Processing Disorder.

<ul style="list-style-type: none"> - 'My daughter was isolated and doesn't seem to fit anywhere. Its affected her confidence and she's isolated from the world' - 'Girls need to be given more help in Bury' - Poor communication between staff was mentioned frequently, for example- - 'My son wasn't receiving his sensory breaks. They were in his EHCP but the teacher said she hadn't been told by the SENDCo' - 'School don't communicate with SENDCo so no support for parents' - 'School asked me to write a person specification for my sons support. Great but took 2 years' - 'It was identified that my daughter needed exam support but it wasn't provided which had a huge effect on child and family' - Most parents agreed that they would prefer mainstream schools but their children are frequently 'failed' by their schools, then removed from school with no education until specialist placements can be found- - 'Not enough specialist placements for high functioning children who's needs cant be met in mainstream so my daughter went without an education' - 'More specialist places for complex needs' - 'Outstanding school- didn't mean that their SEND provision was outstanding' - 'I live on Bury/Bolton border but chose a Bolton school because i knew how poor Bury was' - 'Mental health isn't prioritised in Mainstream but is better monitored in Specialist Provision' - 'Verbal children have their ability over estimated in Mainstream' - An overwhelming amount of parents agreed that they felt their children were unwelcome in Mainstream 		<ul style="list-style-type: none"> - More community health services should be delivered from Resourced Provisions such as we have in Special Schools to reduce appointments for parents.
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schools. Some spoke of hostile teaching staff and SENDCos, also the inability to speak to SENDCOs for long enough to ensure that their children's needs are better understood-

- 'We felt pushed out'
- 'They had no patience for our son'
- 'The school refused any reasonable requests that would make my child's day more manageable'
- 'Schools see the parents and pupils as the problem and don't see that the schools approach needs to change'
- 'We was told we only had 20 minutes to discuss our sons needs and felt rushed out of the room, by the time we had left we hadn't been able to cover important issues'
- 'School not carrying out what they were supposed to do in relation to my child receiving his support. When i complained there was no route to appeal'
- Parents of children with SEND spoke about a lack of information and guidance in Bury regarding school selection and accessing school support-
- 'I feel like we don't receive enough support/information about selecting the right school for our children'
- 'Not enough support with decisions in changing schools, I didn't know who i was supposed to turn to'
- 'My son has just been diagnosed with a rare condition but the SENDCo said he doesn't fit into many boxes to receive support but i feel he does need support'
- 'We weren't motivated by performance tables when considering which school would be best for our child, we wanted to know which where the most inclusive schools but didn't know which way to turn'
- 'Not enough information on Bury council website about individual schools'
- 'It felt impossible to access information regarding SEND provision from primary, secondary and post 16'
- 'Parents require at least 2-3yrs to plan High School placements because we have no real guidance'
- There was a general feeling that there wasn't enough variety in specialist provision in Bury. Parents spoke about their children having to be in crisis and missing a

<p>large amount of education before being considered for specialist places-</p> <ul style="list-style-type: none"> - 'There isn't enough autism friendly Schools in Bury' - 'There is only one Enhanced provision primary school and High School with limited space which means my child has to travel for over 2 hours on a bus each day because there are no local schools which can offer what my child needs' - 'My daughter was bullied in High School because of her disability. School didn't act adequately which resulted in me removing her. We had to pay for a tutor and hoped for enhanced provision but there were no places - ' My child thrived at Hoyle resourced provision but then went to mainstream primary schools where there is a stark difference, they aren't as child centred or approachable - "There seems to be a lack of half way house' type placements for children who aren't quite mainstream' - 'My daughter went to Resourced provision pre school but then started at mainstream. it feels like the wrong place but its like I have to wait for her to fail first' - Parents shared the negative impact on school placement failures. Many shared similar feelings that its affected the whole family- - 'We need to get it right for our children because removing our child had a huge impact on our child and whole family' - 'My child lost what felt like his whole identity. We felt forced out and isolated" - 'My marriage has suffered and my other children too' - 'I had to give up my job which massively affected our family finances' 		
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**Shaping The Local Offer:
YOUR VOICE**

POSITIVES

- Feel listened to by some schools
- Person-centred meetings in school
- When schools are creative/outside the box thinking

Parent/Carer Engagement Day – 18th May 2018
FOCUS GROUP 4/10: Preparing for Adulthood

Comments and quote from Parent/Carers below.

ISSUES	EFFECT ON FAMILIES & C&YP	SUGGESTED IMPROVEMENTS
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- Lack of support in hospital visits and stays for years 16+ and carers
- No one knows what is available
- Don't know what to expect
- Too low a level of support
- What is available for 20+ adults?
- Limited funding for 1:1 support
- No progression plans for students leaving Bury College
- Year 10 is too late for planning the transition
- Late diagnosis – no support
- TA's need more SEN training
- If child has complex needs, left up to parents with no professionals involved
- No clear pathway for parents
- Lack of courses available at colleges
- Unsure what to do after college
- YP cannot access groups/ activities due to lack of 1:1 support/ PA hours
- Lack of help with independence
- Not knowing who to ask for help/ info
- There were a few cases of children and young people who have been 'completely missed' and this is not acceptable
- **Working Well/ Positive Points**
- Buddy's for children with autism is a fantastic services, but a little bit expensive
- **Effect on Young People and Families**
- Everything feels like a constant struggle
- Constant worry not knowing how things are going to go in the future

- Not feeling listened to/heard
- School staff / other children and young people not understanding SEND 'I should be able to go to a mainstream school' (quote from a young person)

- 3rd Sector**
- Available training for local companies/sports groups etc around how to support children and young people with SEND 'No-one should be left out' (quote from a young person).
- School**
- Start with engagement within the schools
 - Training/workshops for school staff and young people around SEND
 - Information shared in schools about what should be done to support children and young people with SEND.
- Health**
- Person centred meeting in other areas (not just schools)
 - Home visits rather than having to go to the hospital
- LA**
- Would like a 'one stop shop' of where we can get support from the LA
 - 'Autistic' friendly / SEND friendly events in Bury
 - A process whereby parents/carers, children/young people can be listened to
- Support for parents/carers**
- Links/support for parents/carers, including parent groups at schools
 - Parents/carers, children/young people need to be empowered/feel able to speak out
 - A range of different options for parents/carers, children/young people to engage with the LA
- Young people**
- Parents/carers, children/young people need to be empowered/feel able to speak out
 - A range of different options for parents/carers, children/young people to engage with the LA

<ul style="list-style-type: none"> - Suggested Improvements - <u>More communication with parents</u> - Explain the different pathways available for adulthood - Availability of basic courses for things such as handling finances, cooking, applying for a job etc. at school - Adult social workers meet with families earlier - Age 14-16 provision for children who find GCSE programmes difficult/ inaccessible - Ensure vocational options are maintained - Join services with social care - More connection with other services, not just LA - More training for mainstream schools on equality law and SEND - Step by step guide to adult services - Curriculum needs to be accessible for all and differentiated for SEND - Start transition to adulthood in year 9 - Run adult transition clinics – or if they are being run make sure people are aware of them - Improve provision in hospitals – e.g. make sure carers can accompany their children 		<ul style="list-style-type: none"> - Social groups available for children and young people with SEND – this could also be a way in which they feed into LA processes - Methods for children and young people to support other children and young people. - A children and young person steering group - Use of social media to support participation and engagement. - Would like an event for children and young people to discuss how they can engage with the LA. Would like this to include drawing and other methods of communication. Would like only a few adults to attend but for key stakeholders in the LA to come at the end.
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**Shaping The Local Offer:
YOUR VOICE**

POSITIVES

- We have some great staff that work in for HYM and HY.

**Parent/Carer Engagement Day – 18th May 2018
FOCUS GROUP 5/10: Mental Health**

Comments and quote from Parent/Carers below.

ISSUES

- Waiting times after referral has been made is too long. Parents unsure whether their child will be seen. Waiting times and pathways unclear and seem different for each family.
- Diagnosis too vague- not focused e.g. ASD and ADHD, PDA, PICA, SPD. The CDC needs to recognize more specific diagnosis' so our families can learn how to address different conditions and access the right support. PDA is not recognized in the two diagnostic manuals that the CDC and HYM use. This is an outdated view as other LA's do recognize PDA such as Rochdale and Oldham.
- Lack of communication with parents and young people, no timeframe is given like you get with EHCP.
- Not enough services for Autistic children pre & post diagnosis, i.e. help understanding my diagnosis either in groups or 1:1 if that's better for the child's needs.
- Parents feel they are not listened to during appointments and having to constantly repeat themselves.
- Parents feel their children have been failed by the current system.
- Any Intervention that is needed takes too long from referral to therapy.
- Needs to be more focus around helping children understand their feeling and their communication skills.
- First Point is not working as a post diagnostic service this needs to come from HYM,
- Needs to be earlier intervention, i.e. courses around challenging behavior, anxiety, sleep, social and communication skills and how and when to access the service.
- HYM should take over CDC, feels like we have to start again going from one service to another for the same reasons. One clear pathway for all children.

EFFECT ON FAMILIES & C&YP

- Bury families are at crisis point.
- Unspecific diagnoses are leading families to not get the correct support. This also can mean that Schools are not equipped to deal with pupils properly.
- Bury families feel completely helpless.

SUGGESTED IMPROVEMENTS

- 'One age' pathway for all needs.
- Offer support first, assess second then the benefits can be seen.
- Immediate support and advice available for parents through drop-ins.
- More trained staff in schools that are trained by HYM as a first point of contact- mental health champion in each locality.
- Other options for post diagnostic support.
- 'Early bird' training for under 5's.
- Combined CDC and HYM.
- Specific Parent/Carer counselling sessions and group counselling sessions.
- More signposting to HM for parent/carers.

<ul style="list-style-type: none"> - No communication between all the services involved in the child's care i.e. SALT & OT etc. After they have each carried out their assessments parents should be invited to a multidisciplinary meeting to discuss diagnosis, this shouldn't be done round a table of people that know very little about a child and parents should be able to correct any mistakes. - Teachers not trained enough in children's Mental Health, to pick up children at risk and to be directed to earlier intervention before getting to crisis point and needing a referral to HYM. HYM should offer this service to schools. - No sensory assessments available, especially if a child doesn't fit in the same box at home and school. - School believed more than parents, the coke effect should be recognized more. - Needs to be more information around what HYM can offer. - A redirect service, if HYM isn't the right service for that particular child. Parents shouldn't have to keep going back to the GP wasting more time getting the help they need. - No drop-in sessions for help around behavior. - Parenting courses are great for some children but there needs to be one that center around - children with SEND and the name changed. Many parents feel this means they are failing. - Parents need HELP as well! There should be someone for parents to speak to at the child's - initial assessment and that can offer information around where they can access support. - Anxiety needs to be targeted more in children. Peer pressure / school pressure, is much greater - than it was when parents were younger. - HYM will not accept referrals to see children with anxiety (as recommended by the consultant) if they have a diagnosis of ASD. There is no other service available for this. We have been told only option to pay privately. - During one appointment we were told there was no help available whilst awaiting diagnosis and that there was a whole waiting room full of people in the same situation 		
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**Shaping The Local Offer:
YOUR VOICE**

POSITIVES

Parent/Carer Engagement Day – 18th May 2018
FOCUS GROUP 6/10: CDC

Comments and quote from Parent/Carers below.

- Working well/positives**
- TAF meetings that can feed into CDC
 - Nursing staff that offer advice
 - Carol at the CDC keeps our families smiling.

ISSUES

EFFECT ON FAMILIES & C&YP

SUGGESTED IMPROVEMENTS

- Difference in pathways and accessibility for 8 and under and 9's
- No mental health support for under 8's
- 6-12 months wait for MDA
- No support available whilst waiting
- Cancelled appointments by hospital with no new date set or arranged for months later
- Lack of support
- Lack of transparency of processes
- Re-telling the story, doctors not reading the notes and having to spend appointment time updating them.
- Very upsetting retelling distressing events e.g. birth stories
- Concerns about discussing issues in front of children
- Feels like parents are blamed for behaviors told to attend parenting courses
- 'it's taken 3 years of repeated appointments to get a diagnosis
- 'Financial waste'
- 'loosing time'
- 'not listened too'
- Need a key worker service that acts as a key worker not a named person
- 'feel as though I need to go to my MP to get things moving'
- HYM should be needs led not age related
- More nursing support that actually supports families not just chaperones
- 'cdc is quite useless'
- Use appointment time wisely. Nurses to talk to parents and offer advice
- Signpost about other SEND services

- Stress and anxiety at waiting times
- Concerns that child's needs not met
- Unnecessary stress at retelling story
- Basic human rights not met if children can't be changed appropriately
- Parents hurting their back lifting children to change and weigh them
- Risk of medication being wrong if children can't be weighed and the dose is based on weight
- Child at risk when trying to park close to CDC or child at risk of escaping from inappropriate building
- Unspecific diagnoses are leading families to not get the correct support. This also can mean that Schools are not equipped to deal with pupils properly.

- Purpose built building with better parking.
- CDC moves into a community provision e.g. Millwood, BURY2GETHER Centre or the Children's Centre.
- Play facilities and sensory room/quiet space included.
- Viewing stations for children included.
- Better use or training of nursing staff
- Only tell your story once
- Well trained key worker
- Changing space facilities
- Weighing facilities
- Better links with other hospitals e.g. sharing notes
- Other services to be a part of CDC assessment e.g. community dentist and orthotics.
- Pediatric and other service monthly drop-in's/ workshops at the BURY2GETHER Centre.
- More specific diagnoses
- Access to help/workshops across the board for pre-diagnosis.

- Environment is poor, not accessible, poor parking, lack of toys, long wait, no changing space or appropriate scales and height charts
- Action plan of what is happening and when would be useful
- Community dentist needs to be included
- No post diagnostic service for under 8's
- No sensory service
- Not joined up
- Reliant on HV to refer
- Sue Hall is invaluable
- Diagnosis too vague- not focused e.g. ASD and ADHD, PDA, PICA, SPD. The CDC needs to recognize more specific diagnosis', so our families can learn how to address different conditions and access the right support. PDA is not recognized in the two diagnostic manuals that the CDC and HYM use. This is an outdated view as other LA's do recognize PDA such as Rochdale and Oldham.
- Staff texting during CDC assessment
- Staff seem disinterested
- Appointments are too short
- 1-3 hour waiting times
- Consultants inconsistent and don't always listen
- It feels like the 1st appointment at every appointment
- Look at Manchester model, ASD pathway, buzzers, screens to tell you when doctor is ready to see you that are displaced across the hospital enabling parents to go for a walk
- Parents not able to ask questions between appointments
- Terminology difficult to understand
- Some professionals not aware of multi-dis
- Parents told they are having multi dis then not happened
- TAF meetings are critical and work well. Medics need to be involved in this to answer questions
- Appointments cancelled by doctors
- Having to tell your story over and over
- Parents don't understand process and pathway
- Building is a huge barrier
- Loud busy waiting area
- Not appropriate environment for children with sensory needs
- Inaccurate findings in appointments

<ul style="list-style-type: none"> - CDC to go into nursery provision e.g. Millwood with assessment unit 'one stop shop' where parents can access all services. - No help given for dietary issues for children with ASD. Referred to dietician who had no experience of ASD and was unable to help. - During one appointment we were told there was no help available whilst awaiting diagnosis and that there was a whole waiting room full of people in the same situation. - Quotes from parents - Key worker system at CDC is pointless - Poor bedside manner - Access to CDC reliant on community service - CDC not communicating or visiting children in schools - No psychiatric support in CDC - Parents views ignored - Parents made to feel like a liar - Health care professionals not reading case before hand - Nurses not supportive or serving a purpose - Car parking poses a danger to some children 		
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**Shaping The Local Offer:
YOUR VOICE**

POSITIVES

Parent/Carer Engagement Day – 18th May 2018
FOCUS GROUP 7/10: Complex Care

Comments and quote from Parent/Carers below.

- Sue Hall- Health Visitor from Disability Team
- Physiotherapy Team are great and supportive
- OT team are great and supportive
- Vision and Hearing Team are great and supportive
- Community Nurse Team are reachable and care for their families

ISSUES

EFFECT ON FAMILIES & C&YP

SUGGESTED IMPROVEMENTS

- When ringing 111 having to answer questions based on a typical child
- No one to speak to in regards to epilepsy and having to go round in circles on 111 phone calls with suspected seizures
- Hospital passport not in action, one parent is told their child can skip AnE due to having passport but this has never happened
- Health is very separated from the other services/red tape
- Services not working together around each family
- Lack of general support via health/social care
- Lack of provision for complex children with significant health needs. One particular young boy now out of nursery setting due to closure with nowhere else to attend due to needs/short notice. Little support for this family during this time. Another family felt forced into mainstream with no other options for their medically complex child, nursery now struggling with such high demands of young boys needs
- Appointments coming in huge waves and sometimes overlapping
- No clear information of how your child's health needs will be met at school
- Parent/carers constantly chasing up services, appointments and NHS
- Parents asking for help and only being heard at crisis

- Child's needs not being met
- Exhausted parents
- Having to repeat story/diagnosis and journey constantly
- Scared parents feeling lost and unsure what to do
- Made to compromise meeting all their child's needs
- Feeling of being passed from pillar to post
- Stretched to try attend all appointments on time
- Losing out financially with travel expenses to appointments. Going to hospitals for things that could be in the community
- Child distressed travelling from appointment to appointment then too tired to work hard if its therapy especially if public transport
- Anxieties for the future as little communication around starting school and what help will be available during transition
- Spending too much time chasing
- Unsafe and undignified due to lack of equipment and changing places for disabled/those with continence needs
- Feeling their families needs are not important enough. Having to fight for basic right so as changing places is exhausting and leaves them feeling unworthy and accepted in their community
- Overwhelmed
- Unheard
- Confused

- Suggested improvements
- More provision for medically complex children
- Epilepsy nurses to work within the community before diagnosis and after
- Date to be shared across all services; health, social and education to create 1 bundle of care that meets the child's needs
- Joining some appointments/services to meet needs in one big appointment where appropriate. For example joining vision and physio, portage and speech, portage and vision
- Having 1 key support worker that works with the family from day 1 and coordinates services to ensure the family are accessing everything they need, when they need it and helping the family to not be overwhelmed, and supporting them through diagnosis. Here it would mean that the child was receiving what they needed when they needed it. For example one mum believes her child would have benefitted from physio every week rather than month, child now need spinal surgery.
- More Health Visitors from the Disability Team
- Appropriate changing places for children with continence needs
- Appropriate scales to weigh disabled children in clinic/hospitals/GPs for medicine reviews
- One community hub/one stop shop to discuss child's needs and do clinic that is accessible and SEND friendly
- Someone to contact within health to discuss concerns

<ul style="list-style-type: none"> - No great communication between professionals and parent/carers regarding what's best for the child - Children with disabilities and continence needs struggle to access community and medical places due to lack of accessibility and inclusion - Unrealistic appointment times - CDC: Long waiting times, cancelled appointments, long waits to be seen for urgent matters, unable to solve matters unless Dr Bose is in clinic, having to repeat story between the different consultants, unaccessible, lack of facilities, important matters forgotten (one mum speaks about her child's Advanced Care Plan and how it was done at home with community nurse then taken to clinic for it to be forgotten about and unfinished, mum wants it done and dusted as was emotional to do in first place, and worries if the worse was to happen, there would be no plan in place), multi disciplinary meetings should happen quickly and parents should be informed what they are - Awful experiences at diagnosis appointments where families don't feel their questions are valuable/being answered - Upsetting admissions for 16 year old girl and her mum as there was confusion as to whether to send her to adult ward or not, where there was no room for mum to stay with her, lack of facilities/equipment and little understanding from staff that young girl couldn't be left - Parents left to google diagnosis due to no clear discussion/information at appointment - Parents left wondering child's future after diagnosis/neurology appointments - Parents getting to crisis point then feeling overwhelmed and not always knowing what they need as they don't know what they are entitled to and struggle to accept help also as they have emotions around their child's health - No consistency between what families are receiving 	<ul style="list-style-type: none"> - Parent not respected and recognised as part of the team around their child, their child's voice 	<ul style="list-style-type: none"> - Communication and working together model for health professionals involved in child's care. Such as manchester and fairfield - Professionals to have empathy and compassion when speaking about the child, and understanding that the family need basic language to ensure understanding. They also need patience and maybe counselling - Families to meet with professionals to discuss what is available and for there to be equal opportunities for all families. - Clear understanding of what happens post 16/18/25 in cases of emergency - Clear understanding that even though a child reaches adulthood they still have needs and need a carer to be with them in emergency, especially those who require 24 hour care/nonverbal/no understanding - A service for post 16 in emergency who can be there at admission, an adult ward is not appropriate for medically complex young people - Each child should have a tailor made plan of care. One child may need physio weekly, whereas another monthly. There shouldn't be set slots, but individual plans - Separate ward/provision for children with disabilities/complex medical needs in hospitals
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<ul style="list-style-type: none">- Alarm bells only ring when safeguarding and mental health needs of the child are being compromised because of parent/carers not being able to mentally and emotionally support their child due to very poor/ lack of services being accessible and automatically shared with families- Poor understanding of different family dynamics. For example, children living with Grandparents or adopted children. Whoever the child is living with, they should be valued as the child's carer and addressed in the way the family request- Consultants who hold all the information are not sharing to all the significant professionals		
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**Shaping The Local Offer:
YOUR VOICE**

POSITIVES

Parent/Carer Engagement Day – 18th May 2018
FOCUS GROUP 8/10: School Support

Comments and quote from Parent/Carers below.

- SENDIASS provided us with great help. They are fantastic
- We had no problem with the EHCP process, everything ran smoothly
- I found getting the EHCP easy
- My school has been good at implementing the EHCP
- IASS service is knowledgeable and accessible

ISSUES

EFFECT ON FAMILIES & C&YP

SUGGESTED IMPROVEMENTS

- Lack of resources or inadequate resources**
- Our SENDCO is never available, she has other responsibilities within the school and has no time to see us
 - We had to fundraise and use charities to provide an essential software and computer for my child to be able to communicate.
 - Specialist seating was provided but it's bulky and can only be used at the back of the class. We need seating equipment for him to be included and able to participate to carpet time.
 - Schools don't have the resources
 - No consistency of support – my child has had 6 TA's
 - There is a lack of support in school
 - SENDCO doesn't have enough time
 - Attitude of "that'll do"
- Communication / information**
- No one tells you the options
 - The SEN team are not communicating with us effectively
 - Communication between school and parents is poor
 - SEN team told me that they failed me in handover from one school to another
 - There is a culture in our school that is dismissive, hostile and defensive towards the parental view. It's exhausting and there's no external support to help with this.
- Training**
- My ADHD child is labelled as Naughty
 - The teaching assistant in school has no knowledge of my child specific needs

- Constantly fighting the system**
- They always offer the lowest amount of support as possible, you need to fight to get what your child deserves
 - My child transitioned between schools. He has complex needs and it takes so long to train people. I had to do all the running between the 2 schools and my son has been out of education for 5 weeks
 - We seem to be constantly trying to convince people of the support he needs.
 - The parent's knowledge is often ignored, we have to prove everything. All the time
 - Too much pressure on parents to be proactive and contact / work with professionals
 - The system is too complicated and inaccessible to parents with difficulties themselves.
 - I feel passed around
 - Parents have to do all the chasing
 - Fighting to get support
 - Parents have to battle for EHCP and there is no support
 - It's me that has to do all the running, he's been out of school 5 weeks
 - Fobbed off
 - Lack of empathy
 - Have to justify EHCP by school having to prove they have spent £6k – disincentive for less determined or parents with less resolve
 - It's a battle
 - If you ask for help, it's more battling to get any.
- No inclusion**

- Training of school and staff**
- We need quality training embedded within school
 - We need to have a better differentiation of curriculum at school.
 - There should be a basic minimum standard of training for SSA's – higher than there is now. People who mean well but are untrained are not helpful.
 - Special Schools should deliver regular workshops for teachers and teaching staff. This should be encouraged and promoted to Early Years settings, Schools and parents.
 - Parents should be involved in the interview process for their child's 1-1.
 - More flexibility if your child's 1-1 isn't suitable.
- Proactivity**
- No early intervention, it seems that the child needs to be in extreme difficulties to get any support.
 - Need to work with children when needs are first identified
- More communication**
- School should inform parents of services available.
 - SENDCO to have a place where they can share ideas on how to deal with SEND children. SENDCO from specialist school and mainstream school together and share good practice
- Consistency**
- There needs to be a consistent approach between schools – a non-negotiable standard for all schools
- Education/curriculum**
- SEND children are compared to their peers, should be against their own potential

<ul style="list-style-type: none"> - He's got complex needs, it takes so long to train people, he's been out of school 5 months - There needs to be more education of teachers - Needs misunderstood – he CAN'T do things, not WON'T - School presume bad parenting - When an assessment is made school staff don't always have the knowledge to implement it – more training is needed <p>EHCP</p> <ul style="list-style-type: none"> - EHCP contains out of date information - Transfer from Statement has taken 18 months, ongoing - Parent has to find all information themselves about EHCP process - EHCP still not processed in time to start reception when the process has been started when he was 2 years old. - Transferring from EHCP to statement started last year in January, it's still not finished - Parents weren't involved in transfer from Statement to EHCP - Waiting too long for assessment, and no assessment means no support - We had to rewrite the lot (EHCP) - What are termly review meetings? - Don't recognise the child described in the EHCP - No respect for statutory process of annual review - Not child centred – funding decision prioritised school and not child <p>Eligibility</p> <ul style="list-style-type: none"> - My child is too academic for specialist support - There is no suitable nursery for my grandson with complex needs since his old nursery closed but we cannot access respite because he is not accessing the 15 hr free funding for nursery - You have to be in crisis to access support - I was bounced around different services – GP, school, SEN team etc - Told “don't even bother applying” (special school) <p>Provision</p> <ul style="list-style-type: none"> - School bus keeps being cancelled all the time, our families are in crisis as a result 	<ul style="list-style-type: none"> - A parent has been told to choose between integration or education “you can't have both” - My child feels isolated - Forgotten children - The child and family are second class citizens in the process <p>No education</p> <ul style="list-style-type: none"> - They're offered him a school in a shed.1 room with a light nothing else, that's not suitable - Out of school, under the radar. - No-one at school or LA seem to care my child has been without education for 6 months and I had to make official complaint to get bare minimum support <p>Mental health</p> <ul style="list-style-type: none"> - Lack of support leads to low self-esteem, which leads to mental health problems - School refusal due to poor provision and effects on mental health - Social, emotional and mental wellbeing is seen as less important than academic progress - Significant impact on child and my mental health <p>Loss of career</p> <ul style="list-style-type: none"> - I had to stop my career and take early retirement to take care of my grand children - Oh yeah, it's a career killer - I had to give up work to provide was is not there - I have given up my job due to a lack of support - My career is over - My career options are limited, not only because of the care needs of my child, but also because of the admin requirements of monitoring his education and fighting for his legal entitlements. It's a part time job in itself. <p>Family relationships</p> <ul style="list-style-type: none"> - We are suffering - Siblings suffer - High turnover of staff impacted on my child's behaviour adversely at home - I am worried to death - I feel isolated too 	<ul style="list-style-type: none"> - Parents suggested a social curriculum/alternative (less academic, more about SEMH) - Immediate, radical overhaul of the transport system and a guarantee that no bus will be cancelled in 18/19 due to 'no escort'.
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<ul style="list-style-type: none"> - No vocational courses, we had to go out of borough - If no EHCP, there don't seem to be any support - Mainstream is not set up for children like mine - No suitable placement - "Out of borough" is a false economy - No provision if SEND child is academically gifted - Some children need bespoke packages, not available - Children out of school due to unsuitable provision - Too many children per class in most mainstream schools - The PRU offers only a part time education - We want in borough placements - Have to home school (not through choice) - No provision in Bury for high functioning ASD girls - Clear failures at school / LA don't seem to care or follow up - Inadequate number of enhanced provision secondary places and no local primary enhanced provision places. No-one wants young children travelling a long way to primary school. <p>Inconsistency</p> <ul style="list-style-type: none"> - Support extremely unequal between one school and another – discrepancy of support - Implementation of EHCP good in some schools, not for others - The law is sound, implementation by schools is variable, and there is no monitoring of compliance with SEND COP - How can some local schools plead that meeting SEND COP requirements is not feasible due to budget constraints, when another down the road can provide well for SEND children? 	<ul style="list-style-type: none"> - I am THAT PARENT, I know I am. No-one wants to be. - School refusal to support or recognise need leads to extreme anxiety when at school and follows with meltdowns after school. <p>Financial hardship</p> <ul style="list-style-type: none"> - I had to use my retirement fund to provide my grandson with an education using private tutoring. The system is failing him - I had to fund counselling as it was not available to him and school cannot support him - I have lost income because my child was out of school - We have funded independent assessments and reports which has not been easy to find funds for, but necessary because they are comprehensive and of good quality, unlike those provided by LA/NHS - Families don't feel they are able to work due to the consistency of Bus cancellations. This is completely unacceptable. 	
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**Shaping The Local Offer:
YOUR VOICE**

POSITIVES

Parents were in agreement that the Local Offer could be a really valuable resource for parents at every stage of their SEND journey.

Parent/Carer Engagement Day – 18th May 2018
FOCUS GROUP 9/10: The Local Offer

Comments and quote from Parent/Carers below.

ISSUES

EFFECT ON FAMILIES & C&YP

SUGGESTED IMPROVEMENTS

Awareness of the local offer

- Many parents had not heard of the local offer
- Most who had heard of it were confused about what it is and what it offers
- Parents were not made aware of the local offer – found out themselves after searching
- The Gov. website only has one sentence about Local Offer. Does not explain it and no link.
- Term Local 'Offer' is confusing

Comments by parents who had accessed the site

- Name Bury Directory is confusing – does not explain what it is
- It is not SEND information specific
- It is difficult to navigate
- Contains out of date information
- Links do not work
- Buttons on categories do not work
- Information is inaccessible to those with a with learning difficulty/additional needs
- Categories too technical and not user friendly

- A complete lack of awareness of their entitlements
- Social isolation for families
- Preventing families from helping themselves

To increase awareness of Local Offer

- Professionals need to be educated about the Local Offer as many may not be aware
- Information sheet should be given to parents on diagnosis of a disability/condition
- Information sheet to be provided to parents by schools, CDC and other professionals.
- Information should be provided at face-to-face meetings.
- Leaflets re. the Local Offer website to be displayed and available at relevant organisations
- GP's to give information of website out to parents of children who may have SEND prior to any diagnosis

Improvements for website

- Hub not just a website – more an advice centre
- Needs to be clear, concise and well set out
- Information should be basic with option to read more
- To include range of media eg. Images, videos, written content.
- Site to be rebranded with name that reflects purpose eg. Bury Send Support/services, Bury SEND Hub
- Information to be updated regularly
- Ability to filter information by condition/age etc
- Categories eg. Services for people with ASD, Service for wheelchair users
- Feedback system so that users can easily report a problem with the site/information. eg. report a problem button

Suggested content for website

- Information on Educational entitlements and law. Links to organisations such as Sendiass

		<ul style="list-style-type: none">- Information and contact details for Child Development Centre- Information for parents on who to contact if concerned a child had SEND (clear pathway)- Contact for a central hub that is trained to direct parents to appropriate service- Links to DSA website- Information on Local Authority Policies- Information of organisations providing private diagnosis and if this is accepted by L.A- Clear information of entitlement to services and contact details eg. Physiotherapy, Occupational Therapy.- Details of Social opportunities, clubs- Information and contact details for Social Care, Personal Assistants- Information on travel eg airports, welfare seats.- Information for parents on self-care and wellbeing. eg quitting smoking. Obesity, stress, mindfulness etc.- Information on Healthy Young minds- Links for useful organisations eg Cerebra, Family Fund.- Safeguarding information- Information on legislation eg. Equality Act 2010, Children and Families Act 2014- Links for parents and professionals- Help with filling out forms
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**Shaping The Local Offer:
YOUR VOICE**

POSITIVES

- Feel listened to by some schools
- Person-centred meetings in school
- When schools are creative/outside the box thinking

Parent/Carer Engagement Day – 18th May 2018
FOCUS GROUP 10/10: Engagement with Children and Young People

Comments and quote from Parent/Carers below.

ISSUES

- Currently feel parents/carers are unable to engage with the LA
- Lack of communication across the LA
- Limited opportunities to express views
- Appointment times are not children/young people friendly
- Having to talk about your child/young person in front of them
- Having to talk mostly about what your child can't do
- Worries about social care – what their role is
- Issues around transport
- Don't know what's on / available
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EFFECT ON FAMILIES & C&YP

- Not feeling listened to/heard
- School staff / other children and young people not understanding SEND 'I should be able to go to a mainstream school' (quote from a young person)

SUGGESTED IMPROVEMENTS

- 3rd Sector**
- Available training for local companies/sports groups etc around how to support children and young people with SEND 'No-one should be left out' (quote from a young person).
- School**
- Start with engagement within the schools
 - Training/workshops for school staff and young people around SEND
 - Information shared in schools about what should be done to support children and young people with SEND.
- Health**
- Person centred meeting in other areas (not just schools)
 - Home visits rather than having to go to the hospital
- LA**
- Would like a 'one stop shop' of where we can get support from the LA
 - 'Autistic' friendly / SEND friendly events in Bury
 - A process whereby parents/carers, children/young people can be listened to
- Support for parents/carers**
- Links/support for parents/carers, including parent groups at schools
 - Parents/carers, children/young people need to be empowered/feel able to speak out
 - A range of different options for parents/carers, children/young people to engage with the LA
- Young people**
- Parents/carers, children/young people need to be empowered/feel able to speak out
 - A range of different options for parents/carers, children/young people to engage with the LA

		<ul style="list-style-type: none">- Social groups available for children and young people with SEND – this could also be a way in which they feed into LA processes- Methods for children and young people to support other children and young people.- A children and young person steering group- Use of social media to support participation and engagement.- Would like an event for children and young people to discuss how they can engage with the LA. Would like this to include drawing and other methods of communication. Would like only a few adults to attend but for key stakeholders in the LA to come at the end.
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