

 **Children and
Adolescent Mental
Health Services
Review
And
Recommendation
September 2018**



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Foreword

We would particularly like to thank the parents and carers who were forthcoming with their views and more importantly their solutions. A solution based approach with everyone working together can only be a positive.

We would also like to thank RDASH for their support and funding contribution to the production of the report.

Joanna Saunders
Healthwatch Rotherham Chair

Tony Clabby
Healthwatch Rotherham CEO



Executive summary

Background

Healthwatch Rotherham represents and makes known the views of local people on health and social care services.

Healthwatch Rotherham has, since 2015, provided advocacy support service to Children and Young People (CYP) and families who are accessing, or about to access mental health services. The service aims to enable them to cope better with the challenges resulting from interaction with the various services and any emotional wellbeing or mental health issues.

In Rotherham, stakeholders have come together to produce and deliver the Rotherham CAMHS Transformation Plan.

In early 2015, the Department of Health published the national 'Future in Mind' report. This was structured around five key themes:-

- Promoting resilience, prevention and early intervention.
- Improving Access.
- Care for the most vulnerable.
- Accountability and transparency.
- Developing the workforce.

The report laid out the Government's plans for developing CAMHS services over the next five years to 2020 and it required all CCGs to develop a 'Local CAMHS Transformation Plan'.

The original plan was published in October 2015 and detailed how, at a local level, the Clinical Commissioning Group (CCG) would deliver key recommendations from the Future in Mind report. The Healthwatch Rotherham CAMHS report in May 2014 contributed to the Transformation Plan.

The Rotherham CAMHS transformation plan has had three updates now, with the most recent taking place in October 2017.

The aim of this review is to repeat the April 2014 Healthwatch Rotherham report so that comparisons can be made. It seeks to:-

- Obtain views on how local people believe the culture of CAMHS is affecting service delivery.
- Obtain views and ideas as to how things could be done better.

- To share the views of local people with the provider and commissioners of CAMHS.
- Ensure local people in Rotherham know about this activity.

To enable Healthwatch to achieve the above aims, four methodologies were used.

- A purpose designed survey.
- A public two day event gathering views on themed topics.
- A review of the Healthwatch Rotherham Database.
- Analysis of the Healthwatch Rotherham Advocacy Service for Children and Young People.

The first three methodologies were purposely designed to collect the views of the citizens of Rotherham and were triangulated to draw overall themes and ideas. This report has been produced to affect change within Rotherham's CAMHS. They were also used in the 2014 report. The final methodology was added as it allowed more direct personal interaction over a sustained period of time.

The findings from the methodologies were derived from thematic analysis using frequency of comments/ideas as an indicator of priority.

Results

In all of the scenarios presented apart from one, improvement has been made in terms of those strongly agreeing on the statements presented. Though most statements are still showing a net result of people disagreeing with the statements which involve interpersonal interaction between staff and families, and it is in these areas that issues exist.

The responses when broken down show, in the main, improvement for the mental health service pathway.

Those on the autism pathway have generally shown dissatisfaction with the service offered and received.

It is the strong number of respondents on the autism pathway that are affecting the net result of people disagreeing with the statements.

In terms of the free text it can be concluded that there is a high level of dissatisfaction with the autism service provided by CAMHS, reiterating the findings in the 2014 survey.

The attendees felt that parents were not part of CAMHS processes, but they want to be and feel they need to actively work together. They do not feel listened to or valued, their strengths and knowledge of their child are not acknowledged. When they are in the system then they generally feel the service works well for the family, but they have difficulties entering the service.

A difference exists between autism and mental health in terms of the experiences received. Generally, those on the autism pathway respond with negative experiences and those using mental health services respond, in the main, a lot more positively.

More positive comments were received this time than in the previous 2014 report.

Findings

The report has shown that a differences exist between the experiences of those on the mental health pathway and those on the autism pathway. The mental health pathway has shown improved results since the last report. The autism pathway has received a lot of negative responses and those negative responses have affected the overall results of the data collected.

Ideas and practical solutions

The results of each of the methodologies highlight the frustrations experienced by parents/carers, but practical solutions were offered by them. Families want to be empowered to work together to resolve their individual child and family problems.

Creation of an autism stand-alone service

- To enable those on the autism pathway to receive specialist support.
- Enable the needs and expectations of those on the autism pathway to be delivered and acted upon.

Child and Family Centred approach

- To engage with all practitioners who are involved with the young person, which could be SENCO, community groups etc.
- To use tools in place, i.e. The young person version of a WRAP (Wellness Recovery Action Plan).
- Involve parents and children in the process and make them feel it's a team effort of staff and family listening and working together.

Communication

- Make the initial assessment more age friendly, trying to move away from a clinical approach.
- Written communication and website to be more child friendly.
- Return phone calls within a set period of time.
- Move away from conversations of reading through a checklist approach and allow discussions that enable the questions to be answered and listen to the answers.

Appointments

- Should be young people focussed and adapt to individual situations, i.e. how would the young person prefer the appointment was conducted. Where possible a number of options should be presented.
- Provide clear and concise information of where parents can find more information and the services who are able to offer support.

Long term support

- Have volunteer “experts by experience” to give talks to families.
- Provide details of support services.

Contact with staff

- Be with the family though the journey and explain the journey with the parents.

The solutions put forward are based around empowering the family and CAMHS to work together in a timely manner to facilitate the outcome that all parties desire.

Recommendations

In light of the evidence and feedback collated by Healthwatch Rotherham to produce this review of Rotherham CAMHS (see the full report) then Healthwatch Rotherham offer the following suggestion

That Commissioners from both Rotherham Clinical Commissioning Group (RCCG) and Rotherham Metropolitan Borough Council (RMBC) take an integrated approach and urgently review existing Autism Services available and consider the commissioning of a standalone, integrated and focussed Autism Support Service (separate from CAMHS) for Rotherham.

This would be particularly timely as it would coincide with Rotherham Autism Partnership Board's development of an All Age Autism Strategy for Rotherham. Rotherham is not unique in facing the issues raised by having Autism included within the CAMHS service but here we have the opportunity for Rotherham to take an innovative, proactive lead in the national debate around Autism Services.

Tony Clabby
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The Current Context and our research findings

Background

Healthwatch Rotherham represents and makes known the views of local people on health and social care services. For Healthwatch to carry out its role, it undertakes engagement activities within the Rotherham Borough. Views, opinions and experiences of local people are trend analysed, these trends are then fed into the Healthwatch Rotherham Board.

In May 2014 Healthwatch Rotherham produced a report on Rotherham Children and Adolescent Mental Health Service (CAMHS).

Local Evidence

The Healthwatch Rotherham database holds a list of members who wish to have their views and opinions heard and/or want to be informed of changes in health and social care in Rotherham. The comments collected by Healthwatch Rotherham staff and volunteers have been collated since July 2013. The comments are from conversations with the public at events and drop-ins, including those visiting the Healthwatch office. These comments are from non-led conversations. In addition to the comments collected from the public, the database collates information from national surveys, Care Opinion, NHS Choices, social media and the local media. All comments collected are in relation to Rotherham services. A number of comments have been collected on the Rotherham CAMHS service.

Healthwatch Rotherham (HWR) since 2015 has provided an advocacy support service to Children and Young People (CYP) & families who are accessing, or are about to access, mental health services enabling them to cope better with the challenges resulting from interaction with the various services and any emotional wellbeing or mental health issues. HWR also facilitate feedback by CYP and their families to services, which ensures that these services are developed with real input from service users and their families. The service is free, independent and confidential.

Strategic relevance

In Rotherham, stakeholders have come together to produce and deliver the Rotherham CAMHS Transformation Plan. Rotherham NHS Clinical Commissioning Group (CCG) is responsible for commissioning a range of CAMHS services in Rotherham. Other organisations also commission CAMHS services, including; Rotherham Metropolitan Borough Council (Public Health and Children's services), NHS England and individual schools/colleges.

A large number of organisations provide CAMHS services across a range of levels. These include Rotherham Doncaster and South Humber Foundation Trust (RDaSH), The Rotherham Foundation Trust (TRFT), Rotherham & Barnsley MIND, Rotherham MAST, RMBC Early Help, Looked after and Adopted Children's services and Educational Psychology services, GPs, the Youth Offending Service, voluntary sector organisations such as Barnardos & the National Autistic Society, and various private sector Inpatient providers such as Alpha.

In early 2015, the Department of Health published the national 'Future in Mind' report. This was structured around five key themes:-

- Promoting resilience, prevention and early intervention.
- Improving Access.
- Care for the most vulnerable.
- Accountability and transparency.
- Developing the workforce.

The report laid out the Government's plans for developing CAMHS services over the next five years to 2020 and it required that all CCGs develop a 'Local CAMHS Transformation Plan'.

The original plan was published in October 2015 and detailed how, at a local level, the CCG would deliver key recommendations from the Future in Mind report. Healthwatch Rotherham's CAMHS report in May 2014 contributed to the Rotherham CAMHS Transformation Plan.

The transformation plan has had three updates now, with the most recent taking place in October 2017.

Decision making

Rotherham Doncaster and South Humber Foundation Trust approached Healthwatch Rotherham to enquire if a follow-up publication could be made to the April 2014 report. The Healthwatch Rotherham Board discussed the request and based on the evidence collected, agreed that a review of the report would be produced.



Methodology

The aims of this investigation are to replicate the methodologies of the April 2014 report so that comparisons can be made in order to illustrate areas of improvement.

- Seek views on how local people believe the culture of CAMHS is affecting service delivery.
- Obtain views and ideas as to how things could be done better.
- To share the views of local people with the provider and commissioners of CAMHS.
- Ensure local people in Rotherham know about this activity.

To enable Healthwatch to achieve the above aims, four methodologies were used.

- A purpose designed survey.
- A public two day event gathering views on themed topics.
- A review of the Healthwatch Rotherham Database.
- Analysis of the Healthwatch Rotherham Advocacy Service for Children and Young People.

The first three methodologies were purposely designed to collect the views of the citizens of Rotherham and were triangulated to draw overall themes and ideas. This report has been produced to affect change within Rotherham's CAMHS. They were also used in the 2014 report. The final methodology was added as it allowed more direct personal interaction over a sustained period of time.

The findings from the four methodologies were derived from thematic analysis using frequency of comment/ideas as an indicator of priority.

Survey

The results from the survey have been analysed. The 2014 survey opened on the 1st April 2014 closed on the 1st May 2014. The 2018 survey was opened on 31st January and closed on 28th February.

Participants were asked to indicate if they; strongly agree, agree, not sure, disagree or strongly disagree, with predetermined statements. The statements were formulated by the reference group in 2014, made up of six parents of children who

had/have contact with CAMHS. Each of the members described their family's journey. From these six experiences themes and 'I' statements were formed for the survey.

The statements used, refer to the following areas

- Child and Family centred approach
- Communication,
- Appointments
- Long term support,
- Contact with staff,

At the end of the survey people were asked to complete 'free text' spaces to give qualitative data. The free text section asked people to tell us any further comments they would like to make.

Public events

Two focus groups took place in 2014 and again in 2018.

2014	Springwell Gardens on the Monday 7 th April and Saturday 12 th April 2014
2018	Talbot Lane Centre on Tuesday 20 th February and Kimberworth Place on Monday 12 th March 2018 with 2 follow up focus groups at Kimberworth Place on 20 th August 2018

Open invitations to the event, were advertised publicly for families and children to attend who had experiences and had views of the RDaSH CAMHS over the last two years. Participants were invited via the survey sent out to people on the Healthwatch Rotherham database, social media and website. Healthwatch also contacted people who have used the Advocacy service. Contact was also made to local agencies who would be able to promote the event.

Attendees to the events were facilitated to enable them to raise their views based on the themes below.

- Child and Family centred approach
- Communication
- Appointments
- Long term support
- Contact with staff
- Complaints

The Healthwatch Database

The Healthwatch Rotherham database holds over 54,000 comments.

The comments collected by Healthwatch Rotherham staff and volunteers have been collated since July 2013. The comments are from conversations with the public at events and members of the public visiting the Healthwatch office in the town centre these comments are from non-led conversations.

In addition to the comments collected from the public, the database holds information from national surveys, patient opinion, and the local media. All comments collected are in relation to Rotherham services.

Healthwatch Advocacy Service for Children and Young People

Healthwatch Rotherham (HWR) since 2015 has provided an advocacy support service to Children and Young People (CYP) & families who are accessing, or about to access mental health services which enables them to cope better with the challenges resulting from interaction with the various services and any emotional wellbeing or mental health issues. HWR also facilitate feedback by CYP and their families to services, which ensures that these services are developed with real input from service users and their families. The service is free, independent and confidential.

Survey

In 2014 12 people completed the CAMHS Survey between the 1st April 2014 and 1st May 2014.

In 2018, 27 people completed the CAMHS Survey between 31st January and 28th February.

Statement 1:

I feel that people who have seen my child listen to me			
	2014	2018	Movement
Strongly Agree	0%	8%	↑
Agree	11%	12%	↑
Not Sure	11%	4%	↓
Disagree	33%	34%	↑
Strongly Disagree	45%	42%	↓

The 2018 responses broken down

I feel that people who have seen my child listen to me		
	Mental Health	Autism
Strongly Agree	30%	0%
Agree	40%	0%
Not Sure	0%	5%
Disagree	30%	35%
Strongly Disagree	0%	60%

The combined results show that the majority of people disagreed or strongly disagreed with this statement. The breaking down of the 2018 response shows that those on the autism pathway respond negatively to the statement whilst those using mental health services have had positive experiences.

Statement 2:

It was easy to talk to the people who have seen my child			
	2014	2018	Movement
Strongly Agree	0%	8%	↑
Agree	22%	12%	↓
Not Sure	22%	4%	↓
Disagree	33%	34%	↑
Strongly Disagree	23%	42%	↑

The 2018 responses broken down

It was easy to talk to the people who have seen my child		
	Mental Health	Autism
Strongly Agree	29%	0%
Agree	43%	5%
Not Sure	14%	11%
Disagree	14%	42%
Strongly Disagree	0%	42%

The results show that the majority of people either disagreed or strongly disagreed with the statement. The overall statement shows movement from not sure to disagree. The breakdown of the 2018 responses shows that the autism pathway is showing negative response to the statement.

Statement 3:

I was treated well by the people who have seen my child			
	2014	2018	Movement
Strongly Agree	0%	8%	↑
Agree	22%	15%	↓
Not Sure	22%	19%	↓
Disagree	33%	38%	↑
Strongly Disagree	23%	19%	

The 2018 responses broken down

I was treated well by the people who have seen my child		
	Mental Health	Autism
Strongly Agree	29%	0%
Agree	43%	6%
Not Sure	14%	17%
Disagree	14%	50%
Strongly Disagree	0%	27%

The combined results show that half of all people commenting on this statement either disagreed or strongly disagreed. The breakdown of the 2018 responses show those on the autism pathway disagree with the statement, whilst those using mental health services agree with the statement.

Statement 4:

My views and worries were taken seriously			
	2014	2018	Movement
Strongly Agree	0%	8%	↑
Agree	22%	8%	↓
Not Sure	0%	4%	↑
Disagree	44%	31%	↓
Strongly Disagree	34%	49%	↑

The 2018 responses broken down

My views and worries were taken seriously		
	Mental Health	Autism
Strongly Agree	30%	0%
Agree	30%	0%
Not Sure	0%	5%
Disagree	30%	30%
Strongly Disagree	10%	65%

The results show that half the people strongly disagreed with the statement, which is over double from the previous survey. The breakdown shows a strong difference between the two pathways regarding the statement.

Statement 5:

I feel the people at CAMHS know how to help with problemn facing my child			
	2014	2018	Movement
Strongly Agree	0%	4%	↑
Agree	0%	4%	↑
Not Sure	22%	12%	↓
Disagree	44%	18%	↓
Strongly Disagree	34%	62%	↑

The 2018 responses broken down

I feel the people at CAMHS know how to help with problemn facing my child		
	Mental Health	Autism
Strongly Agree	12%	0%
Agree	12%	0%
Not Sure	30%	6%
Disagree	12%	20%
Strongly Disagree	34%	74%

The results here show that the majority of the people disagreed with this statement. In the breakdown the two pathways show that they both disagree with the statement but the Autism pathway disagreement is much larger, with 74% strongly disagreeing.

Statement 6:

I have been given enough explanation about the help available from CAMHS			
	2014	2018	Movement
Strongly Agree	0%	4%	↑
Agree	11%	8%	↓
Not Sure	11%	4%	↓
Disagree	43%	15%	↓
Strongly Disagree	35%	69%	↑

The 2018 responses broken down

I have been given enough explanation about the help available from CAMHS		
	Mental Health	Autism
Strongly Agree	14%	0%
Agree	14%	3%
Not Sure	14%	0%
Disagree	44%	3%
Strongly Disagree	14%	94%

The results here show that over three quarters of the people either disagreed or disagreed strongly with this statement. The breakdown shows the big area of strong disagreement is within the autism service.

Statement 7:

I feel that the people who have seen my child are working together			
	2014	2018	Movement
Strongly Agree	0%	4%	↑
Agree	23%	0%	↓
Not Sure	11%	12%	↑
Disagree	17%	30%	↑
Strongly Disagree	49%	54%	↑

The 2018 responses broken down

I feel that the people who have seen my child are working together		
	Mental Health	Autism
Strongly Agree	14%	0%
Agree	0%	0%
Not Sure	43%	0%
Disagree	43%	26%
Strongly Disagree	0%	74%

This statement shows that half the people commenting on this statement strongly disagreed. A big change was those in agreement of the statement decreased. The breakdown of the 2018 responses shows that all on the autism pathway disagreed or strongly disagreed with the statement.

Statement 8:

The facilities at Kimberworth Place are comfortable			
	2014	2018	Movement
Strongly Agree	0%	12%	↑
Agree	78%	50%	↓
Not Sure	0%	15%	↑
Disagree	11%	8%	↓
Strongly Disagree	11%	15%	↑

The 2018 responses broken down

The facilities at Kimberworth Place are comfortable		
	Mental Health	Autism
Strongly Agree	43%	0%
Agree	43%	52%
Not Sure	0%	21%
Disagree	0%	11%
Strongly Disagree	14%	16%

This shows that a majority of people commenting on this statement were still in agreement.

Statement 9:

The appointment are usually at a convenient time			
	2014	2018	Movement
Strongly Agree	0%	11%	↑
Agree	33%	35%	↑
Not Sure	23%	27%	↑
Disagree	44%	23%	↓
Strongly Disagree	0%	4%	↑

The 2018 responses broken down

The appointment are usually at a convenient time		
	Mental Health	Autism
Strongly Agree	43%	0%
Agree	43%	32%
Not Sure	0%	37%
Disagree	14%	26%
Strongly Disagree	0%	5%

In this statement, just under half of the people commenting, agreed with the statement. The breakdown shows more negative response to the statement from those on the autism pathway.

Statement 10:

It is quite easy to get to the place where appointments are			
	2014	2018	Movement
Strongly Agree	20%	15%	↓
Agree	56%	54%	↓
Not Sure	0%	15%	↑
Disagree	24%	8%	↓
Strongly Disagree	0%	8%	↑

The 2018 responses broken down

It is quite easy to get to the place where appointments are		
	Mental Health	Autism
Strongly Agree	57%	0%
Agree	43%	61%
Not Sure	0%	17%
Disagree	0%	11%
Strongly Disagree	0%	11%

The majority agree with the statement. A big decrease in the number who had previously disagreed with the statement. Those on the mental health pathway agreed or strongly agreed with the statement.

Statement 11:

Overall, the help I have received is good			
	2014	2018	Movement
Strongly Agree	0%	4%	↑
Agree	0%	8%	↑
Not Sure	34%	4%	↓
Disagree	33%	27%	↓
Strongly Disagree	33%	57%	↑

The 2018 responses broken down

Overall, the help I have received is good		
	Mental Health	Autism
Strongly Agree	14%	0%
Agree	29%	0%
Not Sure	14%	0%
Disagree	29%	36%
Strongly Disagree	14%	64%

Overall a majority of people disagreed with this statement. The not sure response has changed significantly with more moving towards disagree. The autism pathway respondents in 2018 disagreed or strongly disagreed with the statement. However, in Mental Health 43% strongly agree or agree that overall the help they have received is good – a huge jump from 0%!

Statement 12

If a friend needed similar help, I would recommend the CAMHS Service			
	2014	2018	Movement
Strongly Agree	0%	4%	↑
Agree	0%	8%	↑
Not Sure	15%	7%	↓
Disagree	48%	12%	↓
Strongly Disagree	37%	69%	↑

The 2018 responses broken down

If a friend needed similar help, I would recommend the CAMHS Service		
	Mental Health	Autism
Strongly Agree	14%	0%
Agree	29%	0%
Not Sure	14%	0%
Disagree	29%	6%
Strongly Disagree	14%	94%

Overall the number of people strongly disagreeing with the statement has doubled. The 2018 figures show that 100% of the respondents on the autism pathway disagree or strongly disagree with the statement whereas 43% of mental health service users would recommend the CAMHS service.

Summary of the free text

The participants of the survey were asked 'any other comments you would like to make'. 15 people added free text comments.

"As my daughter is on the autism waiting list she hasn't got a diagnosis therefore I am doing my own research into supporting her. I have had help from a voluntary organisation but I do feel quite isolated as there is a lot of information and one size doesn't fit all. I worry that pre diagnosis I may be making the situation worse by guessing what her needs are. I wish that I had some support pre diagnosis or that the waiting list for the assessment was shorter."

"CAMHS put me off for life. It was a waste of time and only made me blame myself even more. I was told self-harming would only make my family worse and if I continue it is all my fault. It was shocking service and I ended up going through years of suffering because of the awful and not helpful service provided."

"I've had 3 referrals declined in the past 8 years and not much help and advise. My Son is now on the waiting list for a full ASD assessment which we were told it was a 3-6months waiting list which should have been Christmas time and still haven't received an appointment. I've rung on two occasions about my safeguarding and a danger to the public issue and all I'm told is my Son is number 37 on the list and nothing else can be done."

"Whatever you do don't phone as you could be waiting months for a call back. The lady who worked with my son did not listen at all to what we had told her and we

have been on a waiting list for nearly a year with no help off no one for my son who is crying out for help so why oh why is there no help from anyone.”

“The staff at CAMHS were very helpful in assessing my son, they opened my eyes up to the fact he had mental health issues, I didn't think he had, I was especially impressed with Jan Ridgeway as she helped me every step of the way in respect with getting my son into a special needs school. The whole process was made so much easier knowing that the professionals were on my side and on the other end of the telephone should I have needed them.”

“Rotherham CAMHS come to a conclusion when my child was 6 and despite numerous concerns being raised with them from professionals had tunnel vision and stuck to their original conclusion. This has led to my child not receiving the correct support for years. 7 years later she has a diagnosis and medication but has not received any sort of service despite her behaviour placing her at risk of harm. We have had good service very recently with a new worker but I am concerned it is too late for my child now.”

“The only bad thing 18 month ago we were given trial medication for our son, it has since been increased twice at his medication review, but we have never been given a diagnosis on what the medication has been issued for even after asking at every review.”

“We are shifted from pillar to post as no one is sure which team my son comes under. No one wants to take responsibility and keep passing the buck continually. Had you asked me this several years ago when he was under Dr Kerr I would have said the help and support was outstanding. It has definitely gone downhill for us since she left.”

“They haven't provided my son with medication reviews.”

“Was told my son didn't have ADHD and then I asked for a second opinion and he had in fact got it. “

“If school don't back you up then CAMHS don't want to know. “

“No consistency of staff.”

“Huge lack of communication.”

“Staff look down their nose at you or think they know your child more than the parents.”

“To date we haven't got through the process far enough all contact has been with one individual or phone. The individual has been helpful to a degree but is always a messenger to others. The phone contact has been incredibly disappointing. Individuals who appear not to know the subject matter (ASD in Girls in this instance), very dismissive, rarely return calls and clearly working

in unmanageable processes. I work elsewhere in the NHS and from what I have seen so far, process redesign, clearer team communication and increased use of IT would make a massive difference.”

“My son is autistic with anxiety issues and despite 2 referrals he has been turned down by CAMHS therefore I am dissatisfied by the service.”

“I feel CAMHS failed my daughter over the 9 years she was under them. “

“CAMHS have done nothing for my child or listened to my concerns. They are the complete opposite of a mental health service and I strongly feel they need investigating. I feel they have let my child down, my family down & many others.”

“More explanation on waiting lists. It’s too easy to blame parents and parenting courses are not always the answer.”

“Impossible to get an urgent appointment or to speak to a doctor when you have serious concerns about a child. They never ring back although they promise to.”

“I feel the concerns I have about my sons behaviour and social problems have not been listened to and no help or information given to me when he was discharged from their service. School also have concerns too.”

The comments collected indicate that people find the services difficult to access, are not listened to and feel the family needs or concerns are dismissed. This all leads to the families feeling unsupported. Discharge from services is inadequately planned leaving people unsure what is happening.

A clear difference exists between the experiences encountered between autism and the mental health services.

Summary

In all of the scenarios presented apart from one, improvement has been made in terms of those strongly agreeing on the statements presented. Though most statements are still showing a net result of people disagreeing with the statements which involve interpersonal interaction between staff and families and it is in these areas that issues exist.

The responses when broken down show, in the main, improvement for the mental health service pathway.

Those on the autism pathway have generally shown dissatisfaction with the service offered and received.

It is the strong number of respondents on the autism pathway that are affecting the net result of people disagreeing with the statements.

In terms of the free text it can be concluded that there is a high level of dissatisfaction with the autism service provided by CAMHS which was the same in the 2014 survey. A significant portion of responses at focus groups were related to autism and some of them were historical cases, i.e. pre 2014.

It would also be fair to say that young people's comments, generally, were less negative than those of their parents.

Public Events

The public events were held on 20th February, 12th March 2018 and on 20th August 2018.

In total 18 parents/carers and 4 current CAMHS service users attended providing 100 comments. The attendees were asked to comment on 5 topics.

- Child and Family centred approach
- Communication
- Appointments
- Long term support
- Contact with staff

Each attendee was asked to state their issues, suggestions and positive experiences based on these topics. The comments received have been summarised.

Child and Family Centred Approach

Issues

Discount parents views/experiences

Child expected to engage with staff not staff engage with child. If young person struggles this is very difficult.

No care plan or action plan given to young people or families.

Only looked at old reports which parent had evidence were incorrect and would not consider new ones.

No input into Education, Health and Care Plans (EHCP).

Part of the illness is ambivalence so be aware and try to engage.

Don't abuse your power, listen to parent.

For those who find the waiting room a daunting place there is no alternative for them. FOR EXAMPLE – child suffering from anxiety can't cope with noise and people find the waiting area a frightening place to be.

Nothing age appropriate in waiting room for older children.

No consideration given to the cost of travelling to CAMHS appointments + stress + anxiety caused to child travelling distances. For Example, two bus journeys to reach CAMHS appointment.

Positives

Service received by Mum and her Son stated “it was exceptional “and has changed not only her son’s life but hers too, staff fantastic.

Happy with waiting room area, felt it was age appropriate (5yr old).

Had to fight for CAMHS involvement, very stressful time, but as soon as CAMHS became involved everything changed – worker very good with child and consistent in their approach + been able to call CAMHS + change appointment, no problem.

Suggestions

- Involve parents and children at the heart of the process.
- Are policies/rules preventing better engagement with families and young people?
- Talk to young people to get suggestions of coping mechanisms they use to stop crisis developing.
- Take information from practitioners who spend more time with child, eg. SENCO completes forms but doesn't see child/young person often.
- Diagnosis leads to strategies to reduce anxiety which has a positive impact on mental health.
- WRAP Plans (Wellness Recovery Action Plan - use them, there is a young person version and a guide for parents.
- Need continuity around worker – for children to feel confident and gain trust to be able to talk about issues around family life.
- Offer a quiet room for those who are anxious and can't cope in a busy waiting area.
- Have age appropriate materials in waiting area.
- Offer appointments in alternative venues i.e. home, local library, look at telephone Skype appointments (this was a suggestion 4 years ago).

Communication

Issues

Don't appear to talk to each other or pass on messages.

Previously had a meeting with a member of CAMHS staff and drew up comments. Rang up once desperate, young person suicidal. Dismissive attitude 'where will he get his gun' - to commit suicide.

These phrases are not helpful in recognising young person's feelings.

Letters poor and badly written. Leaves open to challenge, mentions next steps but doesn't say how. Verbally told differently, flaws in decision making.

Do not return calls, receptionists say you will be called back but they don't

Young person going through CAMHS with no parents and no support. Worker didn't attend appointments on time, letters not the best way to communicate, young person told they would be communicated with by phone but workers never rang.

Not informed with regard to support services and entitlements.

Managers promised to sort issues out but this didn't happen – it was only by constant nagging that someone listened.

Afraid to give honest feedback due to fear of service being affected.

Lack of communication into how CAHMS process works.

Lack of information and communication into realistic expectations – keeping family /child informed as to what they can realistically expect.

Inappropriate comments made – child needed help with how to speak with peers appropriately he was told he would learn when he had been punched enough times – not acceptable.

Positives

Individuals found communications to be good, their child worker remained consistent, caring + child centred, phone calls returned.

Suggestions

- Initial assessment- ask young person about them, find out who they are. Currently too clinical, utilise approach of Early Help worker which is informal.
- Website should be designed with users in mind and user input.
- Improve communication, phone back when they say they will.
- I strongly suggest that CAMHS listen more instead of ticking boxes, and that communication is the thing that is fuelling parents and children's frustrations.

Appointments

Issues

ME and resulting health condition. Referral accepted. Assessment but heard nothing from it. Difficulties for young people in engaging with services, not able to open up and nearly discouraged.

Weight loss extreme, fought to be seen. On verge of being admitted, tried to pass on to crisis team but not old enough.

No after-hours service for emergency. Can't get appointment for months.

Families paying private to get the help they need, difficult to fund as expensive.

Waiting time in a system has a very negative impact on the child/young person. 'Why can't they help me?'

Referral process needs addressing –great difficulty getting CAHMS assessment.

Not signposting to services which could be of support to both child and family.

Don't assume parents know.

Feel that referrals need addressing. For Example: Who can refer? How can this be achieved?

Make it easier for getting an assessment.

Positives

There were no positives recorded for this topic

Suggestions

- Meet with parent and walk the walk with them.
- How much training do staff get on young people and conditions, as often the young person has to tell worker about their condition.
- If you don't know what you are talking about, don't pretend to.
- Adapt the system to fit young people rather than the other way round – for example, how would the young person prefer the appointment was conducted and let them know what their options are (if any).
- Health professionals to ensure parents receive knowledge about other services who are able to offer support.

Long term Support

Issues

ASD- Mental health difficulties attributed to autism, told don't do post diagnostic support. Offensive comment.

Transition does not work for young people, there is nothing to transition to. Support plan not acted on and young people unsupported.

Should autism come under Mental Health?

Parents get anxious and need reassurance and support. Skill practitioner-use them for training others to develop necessary skills in dealing with anxious children and parents.

Empathy training sessions/ empathy comes from shared experience.

Health Professionals to put themselves in child/parent's shoes.

Transitioning (how does this work?)

Not asking child what they want and taking notice of them.

Continuity of service not always possible, but where possible make sure this happens.

Feel that the parent has to chase for action on their child's situation.

Had problems getting CAHMS to deal with son's case once he was assessed by them.

Positives

The service has some very skilled practitioners.

Suggestions

- Make parents aware of other services, e.g. SENDIASS.
- Have a volunteer (expert by experience) to give talks on Life Skills Training should be available.

Contact with staff

Issues

Staff work part time/term time so gaps in provision

Don't get female presentation of autism

Parent blamed for child's issues- prescribed medication taken during pregnancy.

Why is a diagnosis important- No help out there, don't need a label.

Don't have training but act and say things as if they understand.

Other practitioners believe child has ASD, CAMHS not listening.

Very defensive if you bring up things that are not working.

Family therapist made parents feel patronised by some comments.

Decision made before you go through the door and look at information which supports their view. Ignore other evidence including private reports.

Information (eg, part of a social group due to having social communication difficulties) is ignored/discarded as part of assessment. If check lists don't show this it is not mentioned.

Assessment process isn't clear to parents, school and practitioners. In parents experience biased to text book view.

Practitioners view is that parent is talking for them which is misunderstood, parents are advocating for them.

It is recorded in notes that CAMHS believe that parents are seeking assessment to obtain DLA.

Positive

- **Psychologist working well with daughter. (Katie Gregson) provides a person centred approach. Appointments are set out for 6 months.**
- **More informed and supported through Healthwatch and Parents Forum. Met with Manager and CAMHS Practitioner.**
- **Some of advice over phone helped at times.**
- **I now have good support from CAMHS after a year of fighting.**
- **Young person in crisis- CAMHS paid for taxi to Kimberworth Place.**
- **Previous service manager moved things forward, listened and told me when assessment would be.**
- **Locality worker, great just not around enough.**

Suggestions

- **Meet with parent and walk the walk with them.**
- **How much training staff do you get on young people and conditions, as often the young person has to tell worker about their condition.**
- **If you don't know what you are talking about, don't pretend to.**

Summary

The attendees felt that parents were not part of CAMHS processes but they want to be and feel they need to actively work together. They do not feel listened to or valued, their strengths and knowledge of the child are not acknowledged. When they are in the system they generally feel the service works well for the family, but have difficulties entering the service.

A difference exists between autism and mental health and the experiences received. Generally, those on the autism pathway respond with negative experiences and those using mental health services, in the main, a lot more positively.

More positive comments were received this time than in the previous 2014 report.

Database

Since July 2013 Healthwatch Rotherham has received a number of comments regarding the Child and Adolescent Mental Health Services (CAMHS) in Rotherham. For the purpose of this report, comments collected since 2015 have been included to allow for more recent comments to be focussed on.

The comments received are from family members of the service users. Comments received come via telephone calls received, people visiting the Healthwatch Rotherham Shop or from outreach engagement events.

The comments received are grouped together around three main themes:

- Appointments
- Long term support
- Contact with staff

Appointments

No emergency appointment. Told I have to wait until December for an appointment. (July 2016)

Let us down. Attended an appointment at Kimberworth Camhs today with my grandson for 1pm to be told they had got the time wrong and had us down for 12 noon so he couldn't have his therapy we had waited over 2 weeks for. Yet again they let us down. (February 2016)

Eventually got an appointment to see the doctor. The doctor spent a lot of time with my granddaughter and I feel more positive now. (February 2016)

The School my grandson went to asked for an urgent referral into the service and 24 hours, the school and my daughter are waiting for a call back (February 2016).

Long term support

My son is now 12 and was first under CAMHS when he was 6-8 years old. It is unclear if a mainstream school can refer or if you must go through your GP. After filling in numerous forms and attending many meetings they finally did an autism

assessment, but it came back as traits only after most of the questions on the GARS2 and SCQ lifetime and current forms sounding just like him and ticking them accordingly. They did say he was too young for the test but ran it anyway.. He went through a period of a few months of improved (not normal) behaviour so they said they would put his case on dormant but if his behaviour deteriorated we were to get back in touch. A year or so down the line when we were struggling to cope we got back in touch to be told we had to start again with a new referral!! So we did. We completed more forms and attended more meetings, taking hours to complete forms which then got lost by the receptionist in making their way to the relevant person. The forms were in a sealed envelope with the person to whom it was intended clearly wrote on the front. Receptionist can't be bothered to pick up the phone, doctors can't be bothered to ring you back and I think the CAMHS key worker (or whatever they are called now) must be permanently on holiday. You are not allowed the phone number of your key worker as they do not want to be contacted. I managed to get hold of the persons email address but never hear anything back. My child was in the infants Aspire just next to CAMHS. Due to a change of routine he went into meltdown one day and we were called in to pick him up. He was swearing at staff from CAMHS as we were trying to get him into the car as he was climbing out of the window. CAMHS staff took some encouragement to come out and witness this behaviour for themselves. It was like we were asking them to do the impossible. Nothing came of them witnessing his behaviour. Anyway due to police involvement a few years ago he was allowed on risperidone, an anti-psychotic without a diagnosis. Recently due to increased blood fats and the fact he shouldn't have been on it in the first place he has been taken off his medication. We have completed GARS 3 forms and SCQ forms again and after their completion into the results of them and just what the scoring should be interpreted as. We believe he scores very highly but CAMHS do not. The only good thing that CAMHS have done for us is to provide us with a letter saying that my son struggles to queue at places such as theme parks. This letter is now out of date. Recently as CAMHS cannot diagnosis or will not pay for any more assessments my son has been discharged against our wishes and strong disagreement. Apparently they can only test for autism and closely related issues. We have made an appointment about 2 weeks ago for a GP appointment to try for a second opinion. We still have 2 weeks to go until that appointment, but it seems like the second opinion is through the same health body - is that allowed, surely not. At least my son is now in a suitable school, but this is of no help from CAMHS. (February 2018)

Absolutely heart breaking no help whatsoever. My family member begged to be put in hospital to get significant treatment in there. CAMHS response "what do you think they will do in a hospital!!!!!" Now his mental health got so bad he couldn't fight it any more they have turned their back on him to cover themselves well not on my watch. I will get justice if it kills me! (December 2017)

Really happy now with the support receiving from CAMHS. Please keep it up. (May 2017)

Really happy with the support received (May 2017)

Contact with Staff

Thanks to involvement from **** from CAMHS, young people receive the support they need. She is knowledgeable, reliable, tenacious and professional and does what she says she will do. (February 2018)

Poor diagnostic process. Contempt for parents. Badly written assessment report, unable to answer simple questions, attitude of Dr very unprofessional. (February 2018)

They have no interest in helping children unless your child presents as severe. They are beyond incompetent and do not listen to the parent or the child, they do not return calls or do a thorough assessment. Disgusting so called service to children in need of support (October 2017)

No response. Once again Kimberworth Camhs has failed us. I wrote 3 times before I got a reply to say someone would call me. No one has called me yet. It doesn't get any better. (November 2016)

No returned call. We rang CAMHS 3 weeks ago following a problem at my grandsons' school when we needed urgent advice and support. We were told his therapist would ring back. We are still waiting for that call (August 2016)

My time with CAMHS, has seen ups and downs with my condition, like many patients, however, this is more to do with myself and medications as oppose to anything else. My journey with them has been a long one, has seen a tier 4 admission, numerous medications and a number of workers. But I'm pleased to say it has definitely been a successful one. The team at CAMHS, for the most part, has been absolutely wonderful. Especially my CBT therapist and Peer Support Worker (PSW). I would definitely say that without them, I wouldn't have got better from the state I was in. Or if I did, it would have been a much longer and more difficult process. When I was at my worst, I was housebound and couldn't leave the house at all. This caused no end of problems for accessing treatment. Especially because at the time, there was no community intensive team like there is today. Despite this, my CBT worker still made the effort to come out to the home to see me. Shortly after which, I started seeing my PSW who at the start I couldn't even look at, let alone talk to. After several months, I started to be able to go out the house with the PSW. Eventually they set up a group with me and another patient who had similar difficulties. This really helped me combat my anxiety was mainly around socialising. During this process I felt fully supported and that my needs were most definitely accommodated. I honestly can't sing the praises enough of Rotherham CAMHS and the workers there which I met along the way. I don't have any real negative experiences of the service, other than that the process of recovery isn't quick enough, which it never is when feeling the way I did.

Since being discharged, I've been able to be involved in several areas of CAMHS, really opening my eyes as to just how patient orientated the service is under current management. (August 2018)

Summary

Obtaining an appointment and successful referral remains an issue. Issues raised around communication, with messages left by parents not getting acknowledged and acted upon. Once engaged in the service generally the service received is positive. It was commented on that when the CAMHS staff member remains consistent it helps build and maintain a positive relationship.

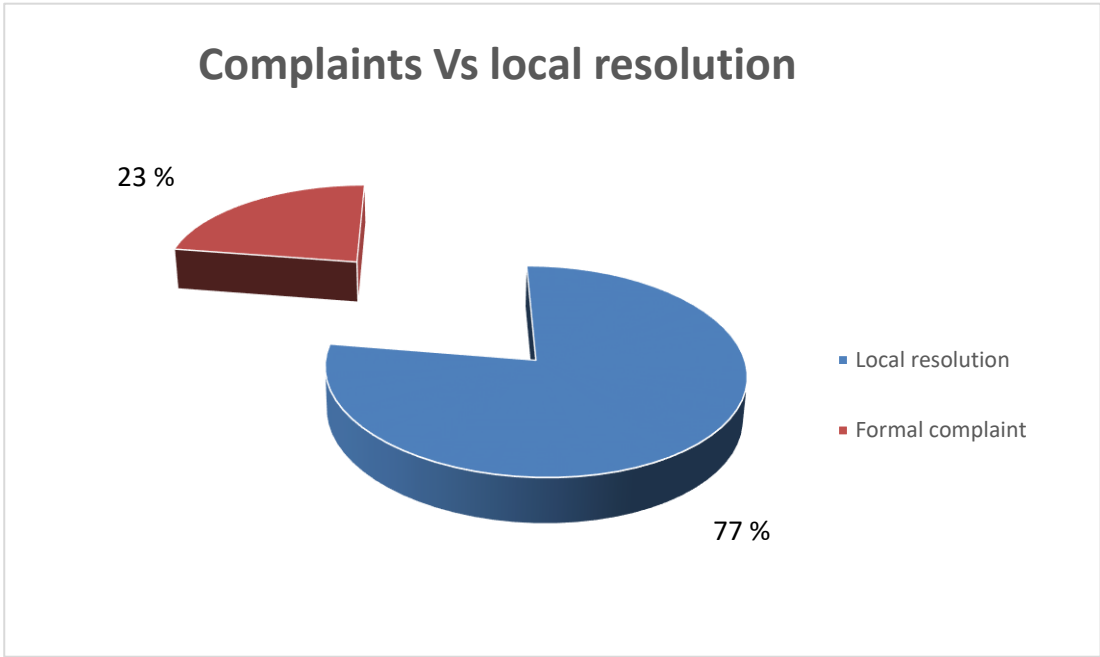
Healthwatch Advocacy Service for Children and Young People

The information below is up to the end of February 2018

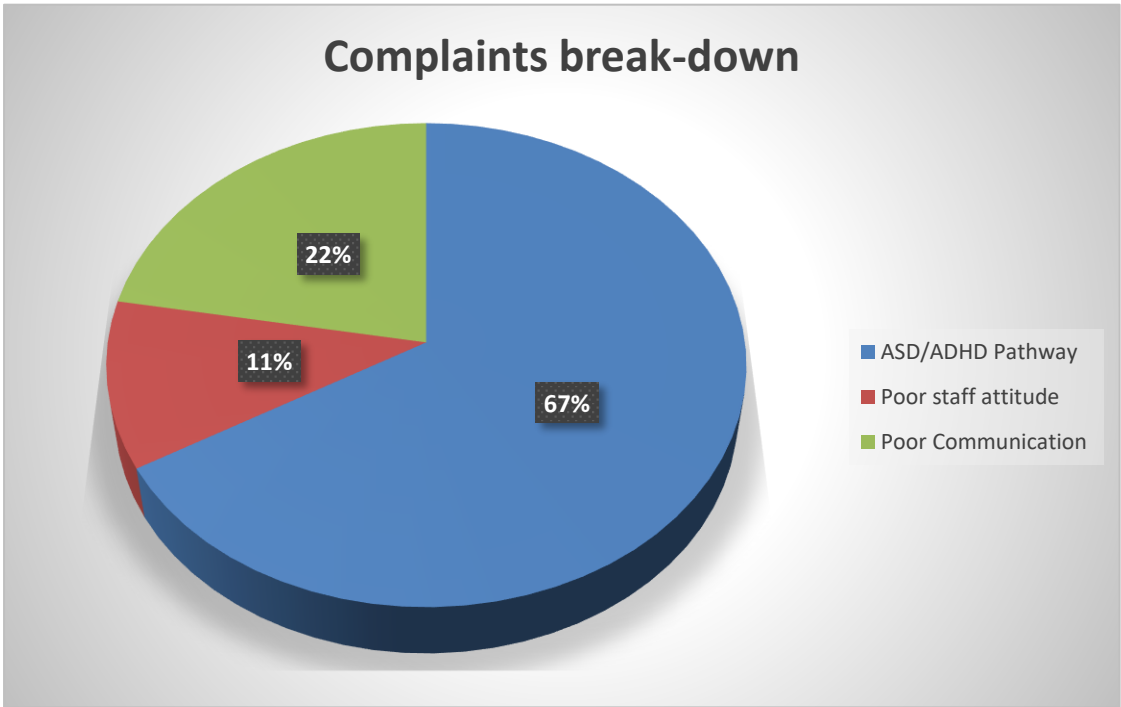
	Total to date
Number of Children, Young People and Families supported	39
Number of open cases	15
Number of cases closed	24
Feedback Survey Received	15
Feedback survey 4/5 or 5/5 of service given by Healthwatch	15
Feedback Survey 3/5, 2/5, 1/5 of service given by Healthwatch	0

Note for Feedback (1=Very poor, 5 = Excellent)

Demographic data	Total
Age:	
0-8	16
9-18	23
Ethnicity:	
White	36
Mixed/multiple ethnic groups	
Asian/Asian British	2
Black/African/Caribbean/Black British	1
Other ethnic group	
Child status	
Looked after Child (LAC)	0
Child in Need (CIN)	6
Child Protection (CP)	1



77% of all cases are resolved by local resolution.



67% of the cases are around the ASD pathway.

Case Study of Advocacy work

Who	Client/parent and carer come to HWR via word of mouth Seeking advocacy for their son/daughter
Why	RDASH Adult Mental Health services refuse referral from CAMHS to adult Mental Health Services No reason offered for refusing the referral No correspondence provided to the family Young Person (YP's) mental health deteriorating Transition stage, Mental Health Services, education. No alternative suggestions made
What happened / outcomes?	Achieved through advocacy at meetings, via emails and telephone – outcome. YP was accepted into adult services and CAMHS continued to support the YP until an suitability trained and appropriate worker could be found <ul style="list-style-type: none"> - Apology offered by RDASH - YP request a change of RDASH worker - Achieved through advocacy at meetings, via emails and telephone – outcome – change of worker agreed

This shows a working together approach has reduced the number of formal complaints. This is helping families to inform RDaSH quicker and in return for all to have a greater understanding. The other benefit to RDaSH is that it reduces the resources that go into a formal complaint process if issues can be resolved quickly informal and allows those issues to be dealt with in a timely manner to improve service delivery.



Findings

The findings of this report are drawn from the methodologies applied to investigate the current culture of RDaSH CAMHS. The main themes of comment were.

- Child and Family centred approach
- Communication,
- Appointments
- Long term support,
- Contact with staff,

In each of these themes a high level of dissatisfaction was still expressed in comparison with the previous report. All the methodologies highlighted that the themes from the previous report are still occurring though its clear that the majority of this is occurring in the autism pathway.

- Parents/carers do not feel listened to.
- Parents/cares feel blamed for the problems they and their child are experiencing.
- There is no clarity on what people can expect from CAMHS and what services they provide.
- Accessing the service in a timely manner.

Changes have occurred and the Healthwatch Advocacy service has helped enable a positive change of working together for local resolution.

The report has clearly shown that a difference exists between the experiences of those on the mental health pathway and those on the autism pathway. The mental health pathway has shown significantly improved results since the last report. The autism pathway however has had a lot of negative responses and those negative responses have adversely affected the overall results of the data collated.

Ideas and practical solutions

The results of each of the methodologies highlight the frustration but practical solutions were offered. A clear difference exists between those on the autism and mental health pathway. Families want to be empowered to work together to resolve their individual child and family problems.

Creation of an autism stand-alone service thus making mental health and autism separate

- To enable those on the autism pathway to receive specialist support.
- Enable the needs and expectations of those on the autism pathway to be delivered and acted upon.

Child and Family Centred approach

- To engage with all practitioners who are involved with the young person, which could be SENCO, community groups etc.
- To use tools in place, eg, The young person version of a WRAP (Wellness Recovery Action Plan).
- Involve parents and children in the process and make them feel it's a team effort of staff and family listening and working together.

Communication

- Make the initial assessment more age friendly, trying to move away from a clinical approach.
- Written communication and website to be more child friendly.
- Returning of phone calls within a set period of time.
- Move away from conversations of reading through a tick list approach and allow discussions that enable the questions to be answered and listen to the answers.

Appointments

- Should be young people focussed and adapt to the situations, i.e. how would the young person prefer the appointment was conducted giving where possible a number of options.
- Provide clear and concise information of where parents can find more information and who are able to offer support.

Long term support

- Have volunteer experts by experience to give talks to families.
- Provide details of support services.

Contact with staff

- Be with the family through the journey and explain the journey with the parents and the child.

The solutions put forward are based around empowering the family and CAMHS to work together in a timely manner to facilitate the outcome that all parties desire.

Recommendations

In light of the evidence and feedback collated by Healthwatch Rotherham to produce this review of Rotherham CAMHS (see the full report) then Healthwatch Rotherham offer the following suggestion

That Commissioners from both Rotherham Clinical Commissioning Group (RCCG) and Rotherham Metropolitan Borough Council (RMBC) take an integrated commissioning approach and urgently review existing Autism Services available and consider the commissioning of a standalone, integrated and focussed Autism Support Service (separate from CAMHS) for Rotherham.

This would be particularly timely as it would coincide with Rotherham Autism Partnership Board's development of an All Age Autism Strategy for Rotherham. Rotherham is not unique in facing the issues raised by having Autism included within the CAMHS service but here we have the opportunity for Rotherham to take an innovative, proactive lead in the national debate around Autism Services.

Tony Clabby
CEO Healthwatch Rotherham

Joanna Saunders
Chair Healthwatch Rotherham

healthwatch
Rotherham