Review of Service Provided by Cumbria Partnership NHS Foundation Trust for Diagnosis and Management of Children with Autism
Dr Karen Horridge MB ChB (Honours) MSc MRCP FRCPCH
Consultant in Paediatric Disability, City Hospitals Sunderland NHS Foundation Trust
Sunderland UK
Tel: 0191 565 6256
Email: karen.horridge@nhs.net

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Contents
About the author ..................................................................................................................... 3
Purpose ................................................................................................................................... 6
Scope ..................................................................................................................................... 6
Expectations from this review ................................................................................................. 6
Stakeholders interviewed and written contributions reviewed 21-22 August 2016.................. 6
Executive Summary ............................................................................................................... 7
Findings ................................................................................................................................. 7
Recommendations ................................................................................................................ 7
Themes arising from interviews ............................................................................................. 8
What is going well .................................................................................................................. 8
What is not going well ............................................................................................................ 8
1. Restore the confidence of families across Cumbria in the interagency specialist social communication assessment pathway and services offered by CPFT to support them Error! Bookmark not defined. 11
2. Put in place training in autism awareness for all universal services that come into contact with children and young people across Cumbria ........................................................................... 12
3. Multi-agency competency building for all involved in the assessment, management and support of children and young people with autism spectrum conditions ................................................................. 13
4. Parent training in the promotion of social communication, management of behaviours that may be seen as challenging and promotion of resilience in children and families for all who would like it .................................................................................................................. 14
5. Refine the referral process to the Cumbria interagency social communication assessment pathway ........................................................................................................................................................................ 14
6. Standardise new patient assessment in community paediatric service ................................ 16
7. Individualise the assessment pathway based on individual needs ........................................ 19
8. Refine the assessment process for those who require review ............................................. 21
9. Robust care planning and support for families at the point of diagnosis, transparent care pathways for support when needed and robust arrangements for expert-to-expert peer support and continuous education for autism specialist team ....................................................... 22
10. Strengthen partnership working with primary care .......................................................... 24
11. Robust data collection at the point of care and robust planning for the needs of the local population in Cumbria .............................................................................................................. 25
12. Lifespan approach ........................................................................................................... 25
Conclusion ............................................................................................................................ 27
Acknowledgements ............................................................................................................. 27
Appendix I ............................................................................................................................ 29
Autism Spectrum Assessment Sheet ...................................................................................... 29
About the author

I have over 30 years of clinical experience in the NHS. I have trained and worked in a range of settings and services. I have been consultant in paediatric disability in Sunderland since 2001.

I have a busy clinical practice, providing healthcare for children and young people with a range of disabling conditions aged 0-19 years. I have particular interests in children and young people with cerebral palsy, epilepsies, complex disabilities, learning disabilities, autism conditions and palliative care needs. I also have expertise in teaching, training, population disability data and its use to inform clinical care, service planning and to underpin research. I am designated medical officer for disabled children and young people and those with special educational needs in Sunderland and south east County Durham.

I have been privileged to have led on the development of the competency based curriculum and successful bid for paediatric neurodisability to become a separate subspecialty of paediatrics, with Grid training programmes available since 2005. I have served as national training advisor and chair of the specialty training committee of the Royal College of Paediatrics and Child Health for neurodisability. I have chaired the British Academy of Childhood Disability since 2013. I am co-director of the MSc course in paediatric neurodisability based in Sheffield, a collaboration between Sheffield Children's Hospital and Sheffield Hallam University. I serve on the Children with Complex Needs Board of NHS England. I am an editorial board member of Mac Keith press. I have been the chair of the North of England Collaborative Cerebral Palsy Survey, until Public Health England took the decision not to continue to support it.

I was clinical lead for Disability Matters, www.disabilitymatters.org.uk

I am clinical coordinator for the paediatric neurodisability work programme of National Confidential Enquiry into Patient Outcome and Death (NCEPOD), which is using the cerebral palsy as exemplar disabling conditions and involves detailed anonymised case note reviews to assess aspects of clinical care.

Awards
Sunderland Carer's Centre ‘Caring for the Carers’ Award, 2007 (nominated by parent of patient)
Sunderland Echo ‘Hospital Doctor of the Year’ Award, 2009 (nominated by parent of patient)
Local level 9 clinical excellence award 2010, renewed 2016
Runner up, clinical governance award, City Hospitals Sunderland, 2011 and 2012
30 years service to the NHS, 2015
City Hospitals Sunderland Team of the year award for Paediatrics, 2015

Publications


Horridge KA. Attitudes Matter. Dev Med Child Neurol. 2015. 57(3)208


Horridge KA. A Child with Cerebral Palsy: what difference does it make for parents? Dev Med Child Neurol. 2015. DOI: 10.1111/dmcn.12721


Spencer A, Horridge K, Downs D. Empowering data collection at the point of care. *Arch Dis Child.* 2015;100(9):815-7


Horridge KA. Quantifying multifaceted needs captured at the point of care. Development of a Disabilities Terminology Set and Disabilities Complexity Scale. Plain English Summary June 2016

[http://www.scope.org.uk/Support/Professional/Medical/Complex-needs](http://www.scope.org.uk/Support/Professional/Medical/Complex-needs)

Purpose

- To evaluate the current service provision across Cumbria for children and young people with a suspected diagnosis of Autism Spectrum Disorder and to make recommendations for change that will improve the outcomes for those children and their families.
- The review will facilitate the implementation of an Autism Spectrum pathway that meets the requirements of NICE guidance, ensuring timely access to care, the earliest possible diagnoses and early access to intervention and support for those children with a positive diagnosis.

Scope

- Pre-school, School and Transition
- Multidisciplinary assessment
- Evidence based
- Training/Skills for Workforce
- Patient Journey and Experiences

Expectations from this review

- Advisory recommendations to CPFT with pragmatic solutions, taking into consideration that challenges posed by geography, finance and workforce are unlikely to change.
- If service transformation is indicated, recommendations will be included on goals, implementation and metric and how each success milestone will be measured.
- Identification of specific issues related to skills and access to training and how this could be resolved.
- Support for aspiration to be one of the best in the country in improving outcomes for children with ASD through evidence-based pathway.
- CPFT stakeholders: CCG, patient/carer groups and CQC to see CPFT as a champion in providing services for children with autism.

Stakeholders interviewed and written contributions reviewed

21-22 August 2016

- Parent carers
- Paediatricians
- Specialist speech and language therapists
- Specialist community learning disability nurses
- Specialist teachers (autism specialist teacher and a mainstream Special Educational Needs Coordinator)
- GP CCG commissioner countywide
- Clinical services managers for both paediatrics and CAMHS
- Integrated team manager
- Business support administrator
- Senior information analyst
Executive Summary
Findings

It was heartening to meet and hear from professionals across agencies who are committed to working together to improve the care pathway for children and young people with possible autism spectrum conditions across Cumbria. There are excellent working relationships across agencies to build upon. However, families have lost confidence in the care pathway, which takes too long to reach a conclusion, lacks transparency and is not consistent across the county. Clinics are not all delivered in premises that are child or family friendly and lack appropriate support and equipment. The autism assessment has become unwieldy and lacks strong clinical leadership. Families are waiting too long for feedback after professionals meet together, without parents present, to deliberate about the outcome of assessments. The workforce are not all robustly trained in disability issues. Austerity is challenging services across agencies, which are more stretched with less resources to draw upon.

Recommendations

1. Restore the confidence of families across Cumbria in the interagency specialist social communication assessment pathway and services offered by CPFT to support them
2. Put in place training in autism awareness for all universal services that come into contact with children and young people across Cumbria
3. Multi-agency competency building for all involved in the assessment, management and support of children and young people with autism spectrum conditions
4. Parent training in the promotion of social communication, management of behaviours that may be seen as challenging and promotion of resilience in children and families for all who would like it
5. Refine the referral process to the Cumbria interagency social communication assessment pathway
6. Standardise new patient assessment in community paediatric service
7. Individualise the assessment pathway based on individual needs
8. Refine the assessment process for those who require review
9. Robust care planning and support for families at the point of diagnosis, transparent care pathways for support when needed and robust arrangements for expert-to-expert peer support and continuous education for autism specialist team
10. Strengthen partnership working with primary care
11. Robust data collection and planning for the needs of the local Cumbrian population
12. Lifespan approach

I believe that if professionals across agencies work together with parent carer representatives and take account of the views of children and young people in delivering the above recommendations, then it should be possible to redesign an autism assessment care pathway that achieves the best possible outcomes for children, young people and their families across Cumbria.
Themes arising from interviews

What is going well

- Committed staff who are:
  - Enthusiastic
  - Able to reflect on their practice
  - Keen to work according to best evidence
  - Keen to improve
  - Willing to look at different ways of working to achieve better outcomes for children, young people and their families
- Excellent working relationships across agencies
- Senior management support at CPFT and willingness to explore all possible drivers and support for improvement
- Parent training courses highly valued by those who can access them
- Support from autism family support workers highly valued
- Active parent carer peer support, mostly works via social media

What is not going well

- Loss of families’ confidence in the service (parental report and complaints)
- Time taken to reach outcome of diagnostic process
  - Can be up to three years from referral to when families receive feedback
  - Those families who shout loudest get seen soonest; the most vulnerable families who are less good at advocating for themselves wait longest, despite often their children having the greatest needs. This includes families for whom English is not their first language.
  - In some areas, children not having the opportunity to be assessed and diagnosis considered until they are school-aged. This results in a flurry of activity for the school SENCo to make referrals and initiate school support and the Education, Health and Care planning process for a number of children at the same time who had not been referred for assessment from nurseries
  - Current measurement of ‘RTT’ is not ‘Referral to Treatment’ at all, rather it is ‘Referral to More Assessment”. If referral to treatment were really to be measured, this would need to be from point of referral to the point where an intervention or treatment is put in place for the child, young person and family.
- Lack of transparency for families about the diagnostic process (by parental report)
  - Some families don’t even realise their child is on the assessment pathway
  - No explanation for some families as to what ‘MAAT’ means (Multi-Agency Assessment team)
  - Lack of communication about expected timescales: who will be doing what, when and when to expect communication
  - Despite family input into development of leaflets for families about the process (e.g. health builders) these were never published. Families left feeling their input was a waste of time, their views are not heard or acted upon and ‘nothing ever changes for the better’
Secrecy around timing of MAAT – admin staff ‘not allowed’ to tell parents when the meeting about their child will be. This does not inspire parental confidence and leads to parents feeling that “provide the parents with as little information as possible’ seems to be one of the ‘service values’

**Variation in assessment process across the county**
- Variation in staffing with recruitment issues, reliance in locums of varying levels of experience and competence in autism assessments. This has led to some duplication of effort as substantive staff are repeating assessments where these have been deemed by them as inadequate.
- Variation in scrutiny of new referrals – some go straight to the Multi Agency Assessment Team pathway without being seen by a paediatrician first, others are seen by paediatrician then referred to the pathway.
- Variation in appointment length given for new patients – some paediatricians have one hour, others an hour and a half.
- Some telephone consultations, which can help in sharing information but mean that the child is not physically seen or examined which limits the overall assessment.
- Variation in appointment length for review patients – 30-45 minutes depending on clinician.
- Morning clinics not starting until 9:30am based on historic practices.
- Variation in ‘not brought to appointment’ rates – up to 19% not brought in some areas of the county.
- Clinics mostly limited to one to two new and two to four reviews per clinic. All of the above have significant impact on patient throughput which does not balance with the demand for the service.
- Variation in waiting times to be seen.
- Variation in time taken for letters and reports to be typed up – reported to be up to 4 months, which adds to the overall length of the diagnostic process.

**Variation in clinic facilities across the county**
- Not all clinic facilities are child-friendly in line with national recommendations.
- Not all clinics have appropriate, regularly calibrated weighing and measuring equipment for children and young people. Doctors having to carry their own equipment, including their bathroom scales to weigh older young people.
- No support available in clinics – often not even a receptionist, so families may wander around looking for where they are to be seen.
- No support in clinics for taking blood samples at the time of the appointment, although other arrangements seem to work for most, with appointments in other clinics and outreach by community children’s nurses.

**Large administrative burden in managing ‘the process’**
- The ‘process’ has become unwieldy and an end in itself. It needs a lot of maintenance.
- Admin teams are spending 2-3 days a week of their time overall in trying to manage ‘the process’, including taking calls from angry parents who are frustrated by the delays and poor communication about ‘the process’. Consequently, takes admin staff away from typing clinic letters.
- The dominance of the ‘process’ is detracting from what matters most, which it is clear from interviews and written contributions that all the professional involved really want, which is **improving outcomes for the children, young people and their families**.
• **Lack of robust clinical leadership in the autism assessment process**
  o Although many of the team saw the paediatrician as the lead in the decision-making about diagnosis, this was reported as ‘not robust’ and not always clear.
  o A number of professionals across agencies expressed frustration that despite there being ample evidence available to support a diagnosis, the diagnostic process was further delayed by waiting for additional reports because ‘the process’ demanded them, rather than because further evidence was needed in order to make a diagnosis.
  o The paediatricians do not always seem to be aware of what reports have come in from others and are therefore not setting the agenda about who needs review and when.
  o Paediatricians are asking for more administrative support, but the administrative support available is overly consumed by the current process, that is not working, leaving insufficient time for clinic letters to be typed and distributed. Paediatricians must take responsibility for management of their own caseloads and time, based on what is known about the needs in the local population, demands on the service and resource limitations that everyone is facing at all levels.
  o Despite having ample evidence to support a diagnosis, there is still **routinely** a Multi Agency Assessment Team meeting to discuss every child before feedback is given to families. These meetings are difficult to arrange as ‘the rules’ set in the Cumbrian pathway say they need to be quorate with a minimum number of professionals present in order to discuss and make a diagnosis. Sometimes the meetings are cancelled because they are not quorate or because key professionals cannot attend. Parents are ‘not allowed to know’ when these meetings are taking place about their child (parent report), although some do find out and can choose to attend the first part, but not all, of the meeting to share their views. Some meetings have been rearranged two or three times, further lengthening the diagnostic journey. There has been a drop of in engagement and attendance at the meetings from other agencies including learning disability nurse specialists and CAMHS due to pressures on their own core services and frustration at the process.

• **Long delays between MAAT discussion meeting and feedback for families** – up to 4-6 months in some cases, due to ‘pressure on paediatricians’ diaries’

• **Workforce not all robustly trained in disability issues**, including in recognition of ‘red flags’ of an autism condition, in autism assessment, management or how best to make reasonable adjustments to better support children, young people and their families. This was reported by many of those interviewed as being an issue across services and agencies: paediatrics, education, CAMHS etc.
  o Various ‘screening proformas’ in use based on personal practice, largely geared towards ADHD/ADD assessment rather than ASD assessment. Feedback from those interviewed is that the Connors questionnaires are scored and graphs drawn by the band 3 and 4 admin staff which is wholly inappropriate. These forms are burdensome for families and colleagues across agencies. It is not clear how their current use informs the commissioned assessment pathway for ADD/ADHD which is led by CAMHS. The “physical health referral form” makes space to specifically mention ‘switching off the television’ but with no mention of the breadth of issues that are commonly known to occur.
  o Practitioners not all comfortable in their own competence to adequately and holistically assess the needs of older young people, especially where there are significant emotional, behavioural and possible mental health issues.
• Practitioners not all comfortable in their own competence to differentiate disorders of attachment from autism conditions, especially where there are many risk factors for low resilience in families, poor socioeconomic circumstances etc.

• Resources increasingly stretched and more limited across agencies.
  o Austerity cuts across sectors affecting expert teams
  o Senior, knowledgeable practitioners retiring, replaced by newly qualified (cheaper) staff
  o Recruitment difficulties across sectors

• Increasing number of referrals coming in to the pathway, still all age groups including older young people approaching adulthood

• Increasing complexity of young children being assessed

• Despite best efforts at cooperative working across agencies, there is a perception by some practitioners that CAMHS workers are not all ‘autism aware’ and do not know how best to assess and manage issues arising in a child or young person with an autism condition. CAMHS are thus seen by some as not including children and young people with autism conditions equally or of actively excluding them by ‘bouncing’ referrals in to the service where autism is part of the formulation.

• A reverse perception from CAMHS professionals that the ASD assessment process led by paediatrics takes too long and that communication and planning across agencies is not always as good as it could or should be, with silo working and planning. For example, a plan being made by the paediatrician with a family without including the CAMHS worker who knows the family well.

• Little support for families along the assessment journey, unless a therapist or teacher involved and keeping the family updated (parent report)

• Little support for families on receipt of diagnosis, although parent and setting training courses highly valued for those who can access these (parent report)

• No organised support for children and young people themselves post-diagnosis, other than adjustments and support in schools

• Lack of autism awareness or support when children and young people with autism +/- LD need to access acute care

• No consistent, easily accessible, robust population data about numbers entering the autism assessment pathway, numbers diagnosed, numbers at various ages in the local population with a diagnosis of an autism condition who may need ongoing support through childhood and on to adulthood, nor data about the range and complexity of physical, emotional and mental health needs of this group

• Lack of robust, interagency strategic planning across the lifespan for people with autism conditions based on good data about identified needs
What CAN be done to achieve better outcomes for children and young people with social communication needs: Recommendations

1. Restore the confidence of families across Cumbria in the interagency specialist social communication assessment pathway and services offered by CPFT to support them. This will involve:
   - Demonstrating that services are person-centred and family focused
   - Actively listening to the views of children, young people and their families about the service
   - Redesigning the autism assessment pathway so that it provides timely, expert interagency assessment and support for families from the outset with transparent communication about the pathway and progress

How this can be delivered:
   - “Nothing about me without me” to be a cornerstone principle of service redesign
   - Listen to, hear and take on board the views of parents as expressed in the complaints to CPFT and in the evidence heard as part of this review
   - Give parent groups the opportunity to read and give feedback on this report so that their views are fully included in the redesign of the service
   - Ensure there are robust mechanisms in place for continuous feedback from families about their satisfaction (or not) with the service
   - Ensure that families’ involvement is embedded in strategic planning and design of services on an ongoing basis
   - Involve families in rebranding and relaunching the Cumbria interagency social communication assessment pathway
   - All letters and reports to be written directly to families in plain English, with all medical terms fully explained and copied with the family’s consent to professionals on a need-to-know basis. All letters to include clear outcomes as agreed with families and timed actions to achieve these – who will do what and by when

How can outcomes be measured:
   - Feedback from families about their involvement in pathway redesign, rebranding and relaunching
   - Family satisfaction regarding the autism assessment pathway in practice e.g. Friends and Family Test, locally designed feedback
   - Family feedback about how family-centred the autism assessment pathway is e.g. using a Process of Care measure such as the MPOC-20
     https://www.canchild.ca/en/shop/1-m poc-20
   - Family feedback about the reports they receive and quality of the written information that they are provided with
   - Regular clinical audit and service evaluation

2. Put in place training in autism awareness for all universal services that come into contact with children and young people across Cumbria
Target audience: GPs, Health Visitors, School Nurses, Nursery Nurses, General Paediatricians, Children’s ward nurses, Emergency department staff, walk-in centre staff, teachers, SENCos, youth workers, Youth Offending Team workers, Safeguarding teams, Police, voluntary sector, community and faith groups etc.

Content to include:
- Recognition of ‘red flags’ for autism conditions
- How to access timely expert assessment and advice
- How to begin to make proactive reasonable adjustments to reduce and minimise distress for the child, young person and family
- How to access support for families, from the point of identification of need (not having to wait for a diagnosis to be confirmed)

**How this can be delivered:**
- Consider setting up a bespoke learning pathway in Disability Matters for the workforce and voluntary groups in Cumbria (www.disabilitymatters.org.uk). This can be badged for Cumbria. This is available free of charge. For more information contact disabilitymatters@rcpch.ac.uk or contact karen.horridge@nhs.net
- Ensure there is accessible and widely available information about how to access expert assessment where a child or young person has red flags suggestive of a possible autism condition and what the assessment pathway involves. This must include transparently clear and easily accessible information in the Cumbria Local Offer, in materials available in nurseries, schools, local information services, libraries, drop in centres, GP surgeries etc. Families should be actively involved in the design of all new resources to ensure they are fit for purpose

**How can outcomes be measured:**
- Confidence in recognition of red flags for ASD before and after training (built in to the Disability Matters resources)
- Confidence in beginning to support a child where there are red flags suggestive of a possible autism condition (built in to the Disability Matters resources)
- Age trends over time at first presentation to autism assessment pathway (data should be available in Rio)
- Age trends over time at diagnosis of autism condition (data should be available in Rio)
- Family feedback about the timeliness of their concerns about their child being heard and acted upon by professionals in universal services
- Improved experience of families when children with social communication needs, require acute healthcare
- Regular clinical audit and service evaluation

3. Multi-agency competency building for all involved in the assessment, management and support of children and young people with autism spectrum conditions

Target audience: Paediatricians, CAMHS workers, therapists, specialist teachers, educational psychologists, SENCos, Nursery managers etc.
How this can be delivered
Blended learning to include distance learning modules and face-to-face training delivered locally in Cumbria covering the basics of autism assessment (for those less confident or competent) as well as a more thorough grounding in assessment and management, recognising the time and resource constraints and geographical challenges of delivering services across Cumbria.
Please contact karen.horridge@nhs.net if CPFT would like ideas about setting this up.

How can outcomes be measured:
- Confidence in assessment and management amongst professionals
- Improved positive feedback from families
- Reduced complaints from families
- Regular multi-agency clinical audit and service evaluation

4. Parent training in the promotion of social communication, management of behaviours that may be seen as challenging and promotion of resilience in children and families for all who would like it
The parent training that is available across Cumbria is valued by families but not everyone can access it. Some of the current training depends on having a confirmed diagnosis. If families recognise that their child is following a different developmental journey to what was expected, the family want to know what they can do in practical terms to promote their child’s development in a positive way.
I recommend that practitioners across services and agencies, in partnership with families, further develop the range of parent training courses available across Cumbria, ensuring there is flexibility in delivery to allow access for parents who work. This would address families immediate need for support and practical advice about how best to promote their child’s development, social communication, resilience and how best to manage behaviours that challenge and promote positive behaviours.
Different short courses could target different needs.

How this can be delivered
- Local experts need to come together with parents to design courses, based on local needs
- Courses should be offered to groups of parents in localities. This has the added benefit of bringing families together and encouraging ongoing peer support

How can outcomes be measured:
- Outcomes should be set by the group who develop the local training programmes so that they are meaningful for the local communities who will be using them
- One outcome should be improved, meaningful ‘Referral to Treatment’ indicators (RTT). Parent training is an intervention or ‘treatment’, so the ‘RTT’ clock can legitimately stop once this has started. This should be a driver to getting parent training in place as soon as possible. This should be of significant benefit for many families, including those who are waiting for outcomes from the current multi-agency assessment team pathway.

5. Refine the referral process to the Cumbria interagency social communication assessment pathway
All referrals to the community paediatricians for any reason, including if the child is ‘looked after’, should be accompanied by a generic paediatric information gathering tool, such as the
family-completed Background Information Sheet appropriate for the age of the child or young person, or local tools that cover the same breadth of issues. Consent should be sought at the outset from the family for appropriate sharing of the background information that they provide with members of the assessing team, which will save them having to repeat the same information many times.

Pre-School Background Information Sheet:
http://www.bacdis.org.uk/policy/documents/PreSchoolBIS.pdf

School Age Background Information Sheet
http://www.bacdis.org.uk/policy/documents/SchoolAgeBIS.pdf

Use of such tools ensures that a breadth of vision is maintained throughout the initial assessment with the community paediatrician, without too early a focus on symptoms of ADHD which seems to be the case at the moment with use of the Connor’s and CADDRA questionnaires. The background information sheets include space not only for the referrers concerns, but also for those of parents or carers, which may be different. The sheets have prompts for detailed medical, developmental and family history, a detailed review of current functioning and prompts for physical examination.

These background information sheets are intended for completion by families, who can be supported by the referrer if need be. Family feedback is that completing the background information in advance gives them the chance to think about what the issues are that worry them most and to gather information from other family members or staff and nursery or school if need be. Many families find it easier to write some things down than to speak about them in a consultation and experience is that the written information is very much richer than could be achieved in a consultation alone.

Having a completed background information sheet at the time of referral allows the assessment to be better tailored to individual needs. Involvement of the referrer, for example the health visitor, GP, school nurse, teacher etc. in supporting the family to complete the background information sheet should highlight any issues that can start being addressed by the referrer, such as sleep or behavioural issues or the need for additional support or parent training courses.

Families are more likely to keep appointments if they understand what is to be covered – using the background information sheets helps with this, in the experience of those services that use them.

School teams should be clearly advised that if they are making referrals to paediatricians, in addition to the family completed background information sheet, a nursery or school report, including any reports from specialist teachers or educational psychologists should also be sent, to ensure that the paediatrician has the best possible information at the outset upon which to base their assessment.

All referrals and completed background information sheets should be reviewed by a community paediatrician. Where there is sufficient information in the completed background information sheet to indicate that there are red flags for a possible diagnosis of autism, of emotional, behavioural or mental health conditions, these referrals should all be discussed at the outset with the CAMHS team, to decide who is best placed to lead the assessment and to participate in the assessment. NICE guidance encourages consideration of all aspects of physical and mental
health by appropriate experts. Families get fed up of telling their stories endlessly to different professionals. Working together across Paediatrics and CAMHS from the outset will reduce silo working and should provide a more seamless service for families that better addresses their needs. Clear role definition will be very important to avoid duplication, with excellent communication between all involved.

**How can this be delivered**

- The background information sheets are available via the links above and can be used or adapted without charge.
- There need to be discussions locally across paediatrics and CAMHS about how best to jointly triage referrals to ensure the most efficient and effective assessment pathways for each child, based on their needs evident in the referral information and completed background information sheet. NICE guidance is clear that ALL children and young people where there are red flags for an autism spectrum condition require assessment, examination and if need be investigation with a paediatrician. This is happening at the moment, but what is not happening as consistently is the expert assessment by the CAMHS team regarding the issues that they have greater expertise to assess, such as possible issues around attachment, anxiety, mood, depression or other red flags for mental health issues. Joint working across paediatrics and CAMHS from the outset, with clear role definition and excellent communication between professionals and with families should deliver more thorough assessment and lead to better outcomes for children, young people and their families.

**How can outcomes be measured:**

- Improved time to diagnosis/diagnoses
- Improved accuracy of specific diagnosis/diagnoses
- Improved patient and family experience of assessment
- Regular clinical audit and service evaluation

6. **Standardise new patient assessment in community paediatric service**


This must be addressed across Cumbria as currently paediatricians are being expected to work in adult clinic spaces, often with not even a receptionist to greet families leave alone support to weigh and measure children and young people, take blood samples etc.

There must be suitable equipment available to weight and measure children and young people that is regularly calibrated. It is not safe or good practice for doctors to be expected to bring their own weighing and measuring equipment, which is likely to go out of correct calibration by being moved around.

All clinics, regardless of setting, should be supported to the same standard as would be expected in a hospital-based clinic setting. Support staff should be available to greet families, to weigh and measure the children and young people and to take blood samples on the day as needed. Health care assistants can be train to fulfil these duties. This would provide a higher quality of service, improved family experience and shorten the patient journey. If clinics are
properly supported, the paediatricians can use their time more efficiently and effectively to carry out their clinical duties, rather than having to use their valuable and expensive time doing clinic support tasks. Community paediatricians are highly skilled and must be valued and supported at the same level as would be expected in a hospital setting.

There must be standards that are implemented about timeliness of clinical letters being typed and sent out. Current waits for typing are unacceptable and are adding significantly to the length of the patient journey. Redesign of the interagency specialist social communication assessment pathway should lead to a reduction in administrative burden, which should free up administrative time to type and send out letters in a timely way. The same standards for timeliness of clinic letters should be applied to community paediatric letters as to hospital outpatient letters. To have different standards is to undervalue community paediatricians and to treat them and their patients as less important, which I am sure is not the intention. Administration reviews in other organisations have determined that the longer the wait for letters to be typed, the more the burden for administrative staff by way of telephone queries, requests for case notes etc. and the greater the storage problem for the large backlog of case notes where letters are waiting to be typed up. Clearing clinic letters on the day where possible or at least within a few days reduces the burden overall for administrative staff and improves job satisfaction.

If clinics are more appropriately supported, then the paediatricians will be able to work more efficiently. There should be a consistent time slot for new patients across all paediatricians. I would suggest 45 minutes consistently for a new patient, which is the time allowed for most new patients across the north of England in similar services. This will only be achievable with the right clinic support in place, as I can quite understand how extra time is needed to sort out greeting, weighing, measuring etc.

Consultations based on a completed background information sheet are more efficient, as areas of no concern can be covered quickly, leaving time to explore those areas where there are concerns in greater detail.

**Assessment and investigation should follow best practice guidance, for example:**


If all new patient assessments are based on use of the background information sheets, then standard clinic letter templates can be designed that use the same headings. This makes dictation quicker, typing quicker and helps those who read the reports to navigate and find the specific information relevant for them. These letters should be addressed to families and copied to the GP and all those who need to know, with parental consent. I would discourage clinicians from using their valuable and expensive medical time in typing up their own reports as there is clear evidence of the need for clinicians to be using as much of their time as is possible to see patients.

I would encourage all letters to start with a list of ‘active concerns’, then any possible, probable or confirmed diagnoses. There should be a list of **outcomes** that have been agreed with the family and of **actions** agreed to achieve these outcomes. There should be clear timescales for all outcomes and actions, so that there is transparency for families and all involved about what to expect and when.
This is in tune with the philosophy of the Children and Families Act 2014 and accompanying code of practice to ‘do once and share’. Sharing the latest letter across the team will make it clear as to exactly what has been discussed and agreed with the family. This practice also helps the paediatrician to reflect carefully on what it is that their input is aiming to achieve and what needs to be done to achieve this. If the paediatrician is struggling to think of any outcomes or actions that they need to deliver on, then it is likely that the child or young person can safely be discharged to universal services.

For examples of outcomes and actions for Education, Health and Care planning that relate to a range of conditions, including autism spectrum conditions, please see the following freely available resources:

Explanatory Glossary for Paediatric Terminologies with guidance for considering person-centred outcomes and actions for Education, Health and Care planning (PDF)

Explanatory Glossary for Paediatric Terminologies with guidance for considering person-centred outcomes and actions for Education, Health and Care planning (fully searchable eBook)
http://www.bacdis.org.uk/policy/ExplanatoryGlossaryofTerms.epub

If red flags for ADD or ADHD are identified by the paediatrician, then a prompt referral should be made electronically to CAMHS as per the commissioned care pathway that complies with NICE guidance. Paediatricians should focus on the general paediatric and broader disability aspects of assessment, including assessment for possible autism spectrum conditions, recognising that some children and young people will need assessments with both paediatric and CAMHS teams to most accurately define and address their needs. It was very concerning to see evidence of ADHD being diagnosed in the paediatric service without clear evidence of appropriate clinical supervision and outside of the agreed local pathway. This is to be strongly discouraged. Much stronger links with CAMHS should be developed.

Where a report is not already available from nursery or school at the time of paediatric assessment, this should be promptly requested. If there are red flags for an autism condition, there should be a specific request for information from nursery or school about the child’s play, social communication with adults and other children, motor mannerisms, learning and any red flags for ASD as per the locally agreed diagnostic criteria (DSM V or ICD-10). The paediatrician’s report should be shared, with the family’s consent, with the SENCo to ensure all are aware of the assessment process and can contribute in a timely way.

Where a child is considered by the paediatrician to have a possible or probable autism condition, a referral should be made to the speech and language therapist, unless the child is already known to the service and a timely assessment and report sought. Whilst it is recognised that speech and language therapy services are under pressure and have their own resource issues, the same Referral to Treatment target (RTT) rules should be applied, to ensure that the overall assessment can be completed in a timely way. Again, the paediatrician should share their report with the speech and language therapist.

The above should apply regardless of age. At present, some pre-school children in some localities are brought in to Child Development Centres for assessment. This is more for the convenience of the therapists to facilitate appointments, based on the evidence of those interviewed. Bringing together a group of young children all with social communication difficulties in order to assess their social communication and interaction is not ideal, as the group is unlikely to include children who can initiate social interactions with them in a typical way. These children need good models for language and learning to spark off, in order
to see them at their best in social settings. The therapists admit that better quality information is gained by observing a child in their usual social setting. More emphasis should be put on facilitating this, recognising the travel needed, trying to combine assessments wherever possible to make best use of professional time. For example, if several children in the same nursery need assessments, ensuring that observations are on the same day.

**How can this be delivered**
- Urgent review of all clinic facilities and upgrading to ensure they are child and young person friendly and welcoming
- Urgent provision in all clinic facilities of appropriate equipment to weigh and measure children and young people, including accessible equipment for the disabled
- Urgent provision in all paediatric clinics, regardless of location, of appropriate support staff to greet families, weigh and measure children and young people, take any necessary blood samples on the day etc.
- Urgent implementation of standards for timeliness of clinic letter typing and distribution
- Refresh training if need be on the assessment and investigation of the child who is following a different developmental journey. Please contact karen.horridge@nhs.net if further advice or support required on this
- Use of the freely available resources discussed above
- Careful planning of assessments to make best use of professionals time, keeping the focus always on the best interests of the child or young person and achieving the highest quality information about their needs

**How can outcomes be measured:**
- Improved family experience of the clinical environment
- Improved efficiency of investigations
- Improved experience for the community paediatricians, who should have more time to do the jobs that need a doctor to do them
- Reduced wait for letters to be typed
- Improved feedback from referrers on quality and timeliness of assessment and outcome
- Reduced complaints from families
- Improved positive feedback from families
- Regular clinical audit and service evaluation

7. **Individualise the assessment pathway based on individual needs**
A strength of the current multiagency assessment pathway is the robustness of interagency working. This needs to be maintained, as NICE guidance is very clear that assessment of children and young people with social communication difficulties must take account of information gathered over time and across settings. However, it is possible to refine the current process so as to maintain robust interagency input, but with a much more efficient pathway that leads to more timely diagnostic decisions.

For those children where it is clear to the paediatrician that a diagnosis if autism is probable from the history, referral information and their own observations, additional information from the observations of the speech and language therapist in a social setting and from the teacher or SENCo should be sought.

Assessment by an educational psychologist should be based on individual needs, informed by the view of expert colleagues in Education. There should not be insistence on a report from
an educational psychologist or autism specialist teacher before a diagnosis of an autism condition can be made. The authors of the NICE guidance would be dismayed if they thought that diagnoses were being delayed due to overly rigid interpretation of NICE guidance. The guidance is guidance. Pragmatism and practicality must prevail, keeping the best interests of the child and family as paramount at all times. Families MUST be kept fully informed about their child or young person’s assessment journey, what to expect when and who to contact if new concerns arise along the way.

As already discussed, for some children and young people, autism assessment should be led by CAMHS rather than paediatrics, although a detailed paediatric assessment is still required as part of the assessment process. This is to identify any medical issues that may be amenable to treatment of surveillance and to identify any conditions that may have implications for families.

Whoever is leading the autism assessment – the paediatrician or CAMHS worker – must ensure that reports from other members of the assessment team are received in a timely way. The lead practitioner for the autism assessment must assess the information in the reports from other agencies as well as their own assessment and decide if there is sufficient evidence to meet the criteria for a diagnosis of an autism condition (or not). If need be, a template to gather evidence for and against each item on the DSM V diagnostic criteria can be circulated by secure email to all involved in the individual’s assessment team. This will provide robust documented evidence to support or refute the diagnosis.

A template for gathering such evidence is attached as Appendix 1.

Email discussion can occur if need be between professionals, or a telephone conference can be arranged. This should include the referrer and the child’s teacher or SENCo where possible. Including teachers/SENCos will improve their confidence and competence in recognition of red flags for autism conditions and hopefully over time will strengthen working relationships across services and sectors.

It may occasionally, in the most complex of cases, be necessary for the assessing team to meet face to face to discuss further. The views of families MUST be taken into account in such meetings and they should be kept fully informed of when such meetings take place and be invited to attend for as much of the meeting as they wish to. Wherever possible, these meetings should be integrated into early support, school support or education, health and care planning meetings. This will ensure that they are person-centred and family focused.

The outcome of the assessment should be shared with the family as soon as practically possible, by a means agreed in advance with the family. Some families are happy for information to be shared by telephone if they have been well supported along the assessment journey. The outcome must be shared within a month at most but sooner if at all possible.

Where there is disagreement between professionals about the diagnostic decision, especially if the family disagree with the outcome of the assessment, a further expert opinion should be sought promptly from the regional neurodevelopmental disorders service in Newcastle. This should not be seen as a failure of the system, rather an honest recognition that sometimes it is very difficult to make a diagnosis. Working together with the regional service to review the most challenging cases will, over time, improve the competence and confidence of the local service.

How can outcomes be measured:
• Trends in time from referral to diagnosis
• Family satisfaction
• Reduction in professionals time in meetings, allow for more direct contact time
• Measures of process of care e.g. https://www.canchild.ca/en/shop/1-mpoc-20
• Regular clinical audit and service evaluation

8. Refine the assessment process for those who require review
The Trust has had a drive to improve referral to treatment targets (RTT). What is actually being measured at the moment is referral to assessment, rather than to treatment. Introduction of parent training courses that are not dependent on diagnosis should help put this right. Transfer between electronic record systems seems to have left a lot of patients in need of review in limbo. This needs to be addressed.
There are almost 400 children who have been referred to the autism assessment pathway (MAAT) but have not completed for various reasons from the evidence presented for this review.
There needs to be a concerted effort, with additional resources, to address the needs of this group.

How can this be delivered:
• Each case needs local review of all available case notes and reports by an experienced paediatrician to determine:
  • Whether assessment on the Cumbria interagency social communication assessment pathway is still appropriate (or not)
  • Whether more information is needed to reach a diagnostic decision.

May need:
  o To call parents to discuss
  o To call SENCo to discuss or request further reports
  o Up to date report from speech and language therapist
  o To circulate the evidence template (see Appendix 1) based on the DSM V diagnostic criteria to gather more up to date evidence from involved professionals to inform the diagnostic formulation
  o Email discussion (secure) between involved professionals in the light of information in completed evidence template
  o Peer review with senior and experienced consultant colleagues, including if necessary discussion with the regional neurodevelopmental disorders team
• Where possible, the lead paediatrician should then make a diagnostic decision and arrange appropriate and timely communication with the family
• Extra clinics will need to be commissioned to manage these patients as there are so many of them
  o This needs to be considered separately from redesign of the new pathway for new referrals coming in

I strongly recommend use of the Health, Functioning and Wellbeing ‘traffic light’ tool for all review appointments with the community paediatricians. This is designed to be completed in the waiting room on the day of the appointment. The tool helps celebrate what is going well, to prevent the clinic appointment being a long list of all that the child cannot do or finds challenging. There is then a section that encourages families to troubleshoot for themselves about what might best help them to improve the participation and quality of life
of the child or young person. There is then space for questions and concerns. On the reverse side is a list of the health conditions, functional areas and issues that might arise, based on evidence and designed together with families and the multidisciplinary team, so that each family can indicate, traffic light fashion, as to whether there are serious, some or no concerns in a particular area. This brings focus to the consultation and ensures that the issues that matter most to the family that day are fully addressed.


The duration of review appointments should also be consistent across all paediatricians. 30 minutes should be ample and is in line with most other services across northern England.

**How can outcomes be measured:**

- Reduction in pending review caseload
- Improved family satisfaction overall
- Improved family satisfaction with clinic letters that reflect and address their concerns

9. **Robust care planning and support for families at the point of diagnosis, transparent care pathways for support when needed and robust arrangements for expert-to-expert peer support and continuous education for autism specialist team**

It is good news that the specialist learning disability nursing team is expanding and they are to extend their remit to supporting children with a diagnosis of an autism condition who do not have a learning disability, up to the age of 11 years, as well as all of those with autism conditions in addition to a learning disability. There are already plans to further develop the existing parent training programmes. Thought should be given to also inviting professionals working across settings to share in the training, to continue to improve competence and confidence in best practice in supporting children and young people with autism conditions.

There does need to be clear, interagency care planning when an autism condition is diagnosed. If the pathway is working well, families should already have been offered generic parent training and have had the chance to meet with other parents for peer support. Care planning should take place within the framework of the Children and Families Act 2014 and code of practice and be part of early support, school support and/or education, health and care planning, depending on the level of needs for the individual child or young person. This should ensure that all care planning is person-centred and family focused and includes the views of the child, young person and their family as well as all members of their own interagency, multidisciplinary team in setting individualised outcomes that matter to them and the actions that are needed to achieve these.

There needs to be attention also to specific support for children and young people post-diagnosis.

Autism affects at least 1% of the population. It is not possible for paediatric services or specialist support services in education to directly follow up every child and young person with an autism condition indefinitely. However, the interagency autism specialist team across Cumbria should know who and where all children and young people with autism conditions are and keep an up to date database for overall service planning.
Most children and young people with autism conditions are healthy and do not require medical treatments.

All children and young people with autism conditions require their needs to be understood and proactively addressed by all who work or volunteer with them in universal services. If the competence and confidence of universal services in recognition of autism conditions and in making proactive reasonable adjustments are improved, then the majority of children and young people with autism conditions should be safely managed by universal services.

There needs to be sufficient capacity in specialist services, including community paediatrics, CAMHS, specialist autism teaching service, specialist speech and language therapy, learning disability nursing and educational psychology, to be able to respond promptly when new concerns are identified by families or by universal services that indicate that review and further expert opinions are needed from the specialist team.

If members of the interagency autism specialist team meet regularly together for peer support, mutual problem-solving, case discussions and ongoing professional development, there should be a robust mechanism in place to decide which member of the specialist team is best placed to re-assess a child or young person, depending on the nature of the new issue that has arisen. This should be much more efficient and effective than current arrangements for MAAT meetings and should build on existing strengths in interagency working. This should also allow for more robust strategic planning and a population overview of services for people with autism conditions.

How can this be delivered
- Ongoing development of training courses for families and professionals, including specifically where there is a confirmed diagnosis of an autism condition
- Development of specific courses or groups to support children and young people post-diagnosis, or safe support via social media if this is more practical given the constraints of geography
- Development of a formal Cumbria-wide, interagency autism specialist team (education, health, social care, voluntary sector, parent carer input) to support children, young people and families post-diagnosis and to provide support and training for universal services
- Clear care pathways with easy access from universal services for timely expert advice from autism specialist services when needed
- I strongly recommend contacting the Sunderland Autism Outreach Team for ideas: [http://www.sunderlandaot.co.uk/index.php](http://www.sunderlandaot.co.uk/index.php)

If you explore the site, you will see the range of parent and young people courses and supports available as well as training and support for schools and settings. I am sure that the team would offer mentorship if that would be helpful. Please let me know if you would like me to facilitate this at all.

If a Cumbria-wide specialist autism team were to be formally developed across agencies that meets regularly, shares and develops best practice and has rapid-fire discussions to troubleshoot where there are specific issues for children and young people, outcomes are likely to soon improve. Working together is smarter than in silos, costs no more and delivers better outcomes.

How can outcomes be measured:
- The local interagency team need to set the outcomes that they want to achieve.
Course success can be measured by feedback from participants
Family feedback can be sought about ongoing team support systems
Regular clinical audit and service evaluation

10. Strengthen partnership working with primary care
GPs have their own pressures at this time, but it is clear from those interviewed that children and young people are seen as a priority group and there is willingness to improve partnership working between GPs and paediatricians.
GPs are looking to work in locality clusters for populations of 30-50,000. They are keen to have a children’s champion for each cluster. This should improve working relationships and build confidence and competence.

It is not known what the uptake of the enhanced service for people with a learning disability is across Cumbria, which includes an annual health check for everyone with a learning disability from 14 years of age onwards. Although this will only apply for those with autism conditions who also have a learning disability, this group is known to be especially vulnerable and to have the worst outcome opportunities and mortality rates. Often at transition to adult services, healthcare defaults to the GP. Having a framework for assessment of needs on a regular basis is very helpful and should help to improve outcomes over time.
And [https://www.england.nhs.uk/learningdisabilities/improving-health/](https://www.england.nhs.uk/learningdisabilities/improving-health/)

**How can this be delivered**
- Follow up discussions locally with the CCG lead for children and young people to ensure that children’s champions are appointed for each GP cluster, which could be a community paediatrician.
- GPs to be invited to participate in Disability Matters training, including the module designed specifically for GPs that is part of the RCGP e-learning resource. See [http://elearning.rcgp.org.uk/course/info.php?id=171](http://elearning.rcgp.org.uk/course/info.php?id=171)
- GPs to be actively encouraged to flag all children and young people with a learning disability on their electronic records and to offer an annual health check for all with a learning disability from 14 years of age onwards, also the annual influenza vaccination.

**How can outcomes be measured:**
- Named children’s champion in place for each GP cluster
- Improved quality of referrals from GPs
- Uptake of Disability Matters training by GPs
- Feedback from completion of Disability Matters training by GPs
- Trends in numbers of GP annual health checks for people with learning disabilities, including from 14 years of age
- Trends in uptake of influenza vaccinations for young people with a learning disability from 14 years of age
11. Robust data collection at the point of care and robust planning for the needs of the local population in Cumbria

The trust may or may not be aware that they are mandated to report data collected at the point of care to NHS Digital (formerly the Health and Social Care Information Centre) through the Children and Young People’s Health Services Dataset (CYPHS). This is helpful as it gives a clear picture of the needs in the local population and better informs the Joint Strategic Needs Assessment locally and plans to better support children and young people. For more information please see:


Data from the CHIMAT Child Health Profile for Cumbria
evidences that in 2012 there were 105,900 children and young people aged between 0 and 19 years living in Cumbria. Autism conditions are known to affect at least 1% of the population. There are thus likely to be at least 1059 children and young people with autism conditions living in Cumbria. There were 25,300 children aged 0-4 years living in Cumbria in 2012. Of these, at least 253 will have autism conditions. Therefore the Cumbria interagency social communication assessment pathway needs to have the capacity to assess at least 316 pre-school children (assuming ~80% of those assessed on the pathway receive a diagnosis). There then needs to be additional capacity for assessment of school-aged children. The fact that so many much older young people continue to be referred for assessment is evidence of a past history of under-diagnosis. The current service should strive to identify children with autism conditions at as young an age as possible, as early intervention is known to be of benefit. It is not surprising that the current pathway is grinding to its knees, as demand is far outstripping the capacity of the assessment pathway to cope with the numbers. Keeping a population overview is absolutely essential if everyone in the local population is to have equal opportunities to achieve the best outcomes. The local pathway design MUST take account of the numbers of children and young people who are likely to need assessment and must be practical and deliverable. The current pathway is clearly unsustainable. It is highly unlikely that additional paediatricians will be found to increase capacity as there are national crises in recruitment, especially to community paediatric posts at this time.

12. Lifespan approach

Paediatric services are struggling to cope with the demand for autism assessments and support and are creaking with the backlog history of under-diagnosis in children and young people. These issues will be magnified many times in services for adults. If the total population of Cumbria is 521,756, we know that there are at least 5218 people living with autism spectrum conditions in Cumbria. Of these, ~1060 are children and young people.
There are ~4158 adults living with autism conditions in Cumbria, of which many will be as yet undiagnosed. Vulnerable groups include those with a learning disability and those in the criminal justice system, including those in prisons. There needs to be a clear plan across the lifespan in Cumbria to ensure that there are safe and sustainable systems in place for the accurate recognition of red flags for autism conditions in adults across universal services, competency-building in how to make proactive reasonable adjustments to best support people who may have autism conditions and clear care pathways for timely expert assessment and support.

**How can this be delivered**
- Interagency collaboration will be required to assess what is in place at present and what needs to be developed to better identify and support adults with autism conditions across Cumbria

**How can outcomes be measured:**
- Trends in numbers of adults known to have autism conditions in Cumbria
- Confidence of those delivering universal services in the recognition of red flags for autism conditions, in how to make proactive reasonable adjustments and how to access timely expert assessment and support
- Feedback from people with autism conditions and their families about the services they receive
Conclusion

It has been a privilege to lead this review. There is much good practice in Cumbria to build upon and a genuine commitment across agencies to improve outcomes for children and young people. I believe that many of the recommendations in this report can be delivered without the need for additional resources, by changing working practices and pathways. Some recommendations will need new resources, such as making all clinic environments child friendly and ensuring that paediatricians have appropriate clinic and administrative support in place no matter where the clinics are delivered. I believe these changes to be essential to improve outcomes for children and young people and to improve the experience of families and of the professionals who are working hard to deliver quality services.

This report should be made available to local stakeholders, including parents. A governance group across agencies should be set up to oversee the recommended changes in practice with representation from commissioners, providers and parent carers. A timeline for implementation should be agreed. A positive media campaign would help to launch the newly designed pathway and demonstrate to families that their feedback has been fully taken on board. This should begin to restore their confidence that services in Cumbria aspire to deliver the very best outcomes that matter to children, young people and their families.

Acknowledgements

I would like to thank all stakeholders who contributed to this review process for their time, openness and genuine willingness to improve services offered for children, young people and families across Cumbria.

1. Raj Verma  
   Associate Medical Director/ Consultant community Paediatrician  
   CPFT Children and Families Care Group

2. Kerrie Bumbie  
   Education  
   Cumbria County council

3. Gill Ireland  
   Clinical Service Manager  
   CPFT Children and Families Care Group

4. Jane Walker  
   Business Support Administrator,  
   CPFT Children and Families Care Group

5. Dr Ben Hamida  
   Consultant Community Paediatrician  
   CPFT Children and Families Care Group

6. Dr Astagi  
   Consultant Community Paediatrician  
   CPFT Children and Families Care Group

7. Dr Edgell  
   Community Paediatrician  
   CPFT Children and Families Care Group

8. Dr Su Ching Tan  
   Consultant Community Paediatrician  
   CPFT Children and Families Care Group

9. Jill Neame  
   Specialist speech and language therapist  
   CPFT Children and Families Care Group

10. Chris Smith  
    Senior Community Learning Disability Nurse for Children, Children’s Community Team  
    CPFT Children and Families Care Group

11. Kath McBride  
    Integrated Team Manager  
    CPFT Children and Families Care Group

12. Rachel James  
    Specialist speech and language therapist  
    CPFT Children and Families Care Group

13. Amanda Boardman  
    county lead GP children and safeguarding,  
    Clinical Commissioning Group
14. Jackie Bell  Parent  National Autistic Society (Furness Branch)
15. Jo Wilcox  Specialist Community Learning Disability Nurse  CPFT Children and Families Care Group
16. Caroline Pollard  CCC Professional Lead, SEND Teaching Support, Autism Spectrum Team  Cumbria County Council
17. Claire Bennett  Parent
18. Helen Johnstone  Clinical Service Manager CAMHS  CPFT Children and Families Care Group
19. Deidre Boys  Consultant Community Paediatrician  CPFT Children and Families Care Group
20. Stephen Cade  Consultant Community Paediatrician  CPFT Children and Families Care Group
21. Glenys Marriot  Parent
22. Barbara Garrick, Business support for Admin support
23. Vikki Templeman, Business support Manager
Appendix 1

Autism Spectrum Assessment Sheet

Name of observer: ___________________________
Role: __________________________
Setting: __________________________
Date/s of observation: __________________________

Please include evidence both FOR and AGAINST each item with as much detail as possible, including specific examples.

REMEMBER it is the QUALITY of social interaction and social communication that matters. Are the following deficits in social communication and social interaction persistent over time and across settings and contexts?

A. Persistent deficits in social communication and social interaction across multiple contexts, currently or by history in the following:

- 1. Deficits in social-emotional reciprocity
   This means persistent difficulties over time and across settings in taking turns in social interchange with other people.
   For example:
   - Persistently unusual way of socially approaching other people.
     This might include:
     o Not acknowledging others at all even when they make an approach
     o Getting up very close and ‘in their face’ or otherwise being ‘overly friendly’ without any insight into this not being the thing to do, especially if the other person is not known to them
     o Touching, tapping, sniffing, licking others in an unusual way
     o Any other approach to another person that is persistently unusual
   - Failure of back-and-forth conversation.
     This might include:
     o Dominating a conversation on one topic oblivious to the other person trying to join in
     o Speaking over the other person
     o Not responding to questions but echoing back what has just been said by the other person
     o Saying the same thing over and again despite what the other person is saying
   - Reduced sharing of interests, emotions or affect (feelings).
     This might include:
     o Not pointing things out to others or not bringing to show things in order to share interest in something with someone else
     o Not showing concern if others are hurt or upset, or responding inappropriately, including laughing or showing other emotions that are out of keeping with the situation
     o Seeming to be oblivious to the feelings and emotions of others
     o Not seeking comfort when hurt or upset
• Failure to initiate or respond to social interactions.
  This might include:
  o Seeming to ignore other people even when they are trying to communicate or interact
  o Not asking for help when in obvious difficulty
  o Not greeting other people or interacting in a setting where this would usually be expected

PLEASE GIVE SPECIFIC EXAMPLES AS EVIDENCE FOR OR AGAINST THE ABOVE
2. **Deficits in nonverbal communicative behaviours used for social interaction**
   
   This means persistent difficulties over time and across settings in nonverbal communicative behaviours used for social interaction.
   
   For example:
   
   - Poorly integrated verbal and nonverbal communication. This is where a person is saying something but their facial expression and/or body language is not in keeping with the content or tone of what is being said.
   
   - Unusual use of eye contact. This is not all-or-nothing. It is the *quality* of eye contact and how it is used compared to how it would be usually expected to be used in the social situation and context that matters.
   
   - Unusual body language for the social situation and context.
   
   - Deficits in understanding or using gestures.
   
   - Total lack of facial expressions and nonverbal communication.

**PLEASE GIVE SPECIFIC EXAMPLES AS EVIDENCE FOR OR AGAINST THE ABOVE**
3. **Deficits in developing, maintaining and understanding relationships**
   This means persistent difficulties over time and across settings. For example:
   - Difficulties adjusting behaviour to suit various social contexts
   - Difficulties in sharing imaginative play
   - Difficulties in making friends
   - Absence of interest in peers

   PLEASE GIVE SPECIFIC EXAMPLES AS EVIDENCE FOR OR AGAINST THE ABOVE
B. Restricted, repetitive patterns of behaviour, interests, or activities as manifested by AT LEAST TWO of the following, currently or by history:

1. Stereotyped or repetitive motor mannerisms, use of objects, or speech
   For example:
   - Simple motor stereotypies (patterns of movements)
   - Lining toys up
   - Flipping objects
   - Echolalia (echoing back what the other person has just said)
   - Idiosyncratic phrases e.g. repeating a set phrase out of context
   - Any other examples

PLEASE GIVE SPECIFIC EXAMPLES AS EVIDENCE FOR OR AGAINST THE ABOVE
2. **Insistence on sameness, inflexible adherence to routines, or ritualised patterns of verbal or nonverbal behaviour**

For example:

- Extreme distress at small changes
- Difficulties with transitions (moving on from one place, activity or pattern or routines to another)
- Rigid thinking patterns
- Greeting rituals
- Need to take the same route to a place
- Need to eat the same food every day
- Any other examples

PLEASE GIVE SPECIFIC EXAMPLES AS EVIDENCE FOR OR AGAINST THE ABOVE
3. Highly restricted, fixated interests that are abnormal in intensity or focus
   For example:
   - Strong attachment to or preoccupation with unusual objects
   - Excessively circumscribed or perseverative interests (does the same thing endlessly)
   - Other examples

PLEASE GIVE SPECIFIC EXAMPLES AS EVIDENCE FOR OR AGAINST THE ABOVE
4. Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment
   For example:
   • Apparent indifference to pain and/or temperature
   • Adverse response to specific sounds or textures
   • Excessive smelling or touching of objects
   • Visual fascination with lights or movement
   • Other examples

PLEASE GIVE SPECIFIC EXAMPLES AS EVIDENCE FOR OR AGAINST THE ABOVE
C. Symptoms must be present in the early developmental period, but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life.

PLEASE GIVE SPECIFIC EVIDENCE FOR OR AGAINST THE ABOVE
D. Symptoms cause clinically significant impairment in social, occupational or other important areas of current functioning

PLEASE GIVE SPECIFIC EVIDENCE FOR OR AGAINST THE ABOVE
E. These disturbances are not better explained by intellectual disability (learning disability) or early developmental impairment. Autism spectrum conditions can co-occur with intellectual disability (learning disability). To make a diagnosis of an autism spectrum condition in a person with an intellectual disability, their social communication should be below that expected for their general developmental level.

PLEASE GIVE SPECIFIC EVIDENCE FOR OR AGAINST THE ABOVE