

# **Autism Spectrum Disorder (ASD): Improving Community Services *Recommendations Report from the ASD Special Interest Group***



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## ***Recommendations Report from the ASD Special Interest Group***

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## **Abbreviations / Glossary of Terms**

SCN	Strategic Clinical Network
CMSCN	Cheshire and Merseyside Strategic Clinical Network
ASD	Autistic Spectrum Disorder
Pathway	A referral, assessment and diagnostic pathway
SIG	Special Interest Group
CCG	Clinical Commissioning Groups
CYP	Children and young people
NICE	National Institute for Clinical and Health Excellence
GP	General Practitioner

## Foreword by Janine Arnott

Coming to terms with the possibility that your child may have an ASD can be a worrying and confusing time. The assessment process leading up to a diagnosis can feel daunting and overwhelming and receiving a diagnosis can be heart breaking. Every family has a different experience but all families will need support. For some families, receiving a diagnosis can be a relief as they begin to understand the reasons for their child's often complex and confusing pattern of development and behaviour. With the right support, parents can then begin to move forward and work with practitioners to find the best support for their child.

Multi-disciplinary assessments and early interventions are essential to support children and their families. In 2011 the National Institute for Clinical Excellence (NICE) issued guidelines for the timely and appropriate assessment of children with a suspected ASD. However, many families still report struggling to access services. Following a priority setting meeting in 2013, the Cheshire and Merseyside Strategic Clinical Network adopted improving access to services for children with a suspected ASD as work stream.

The Autistic Spectrum Disorder Special Interest Group had a remit to review and make recommendations to improve access to service for children with a suspected ASD and their families. Over the last 2 years we have worked with families, practitioners, clinicians and service providers and commissioners. Our work suggests that families, service providers and commissioners are sometimes struggling to meet the needs of children with ASD within current guidelines and resources and that there is still room for improvement they delivery of local services for these children and their families.

Time and resources restraints mean we haven't got answers to all the questions raised during our dialogue with families and community services but we believe we have started an important conversation about the needs of children with ASD and their families. We hope that conversation will continue and that our tentative findings will go some way to improving services for families in the future.

**Janine Arnott**

**Chair: ASD Special Interest Group**

**Cheshire and Merseyside Strategic Clinical Network**

## Foreword by Tim McDougall

I wish to thank Janine Arnott and the members of the Special Interest Group for their hard work in producing this important report. They highlight some challenging and complex issues that require a coordinated strategic response from health and local authority commissioners, service providers and parents and carers. This resonates with [Future in Mind](#) which identifies commissioning services for children and young people with autistic spectrum disorders as complex, bureaucratic and difficult to navigate for families and professionals alike.

The Special Interest Group highlight the problems of waiting times from referral to assessment. For some it can be years rather than months and this is not good enough for children and young people and their families who may already be struggling to get help. One important recommendation is that commissioners should set standards for access, assessment and treatment in partnership with all stakeholders.

*Future in Mind* reminds us of the importance of carefully planned and supported transitions for children and young people with autism spectrum disorders. This report shows that there is still work to do to get this right across Cheshire and Merseyside. This was highlighted as a strategic challenge for partners in [Real People, Real Lives](#) which was the report of our pilot project on transition with Liverpool John Moores University earlier this year.

Finally, it is essential that we invest in the workforce required to improve outcomes for children and young people and their families with autistic spectrum disorders. This requires partnerships with education and training institutions so that practitioners are adequately trained and supported.

**Tim McDougall**

**Children's and Young Peoples Clinical Lead:  
Cheshire and Merseyside Strategic Clinical Networks**

## Executive Summary and Key Recommendations

In 2011, the National Institute for Health and Care Excellence (NICE) published guidelines for the recognition, referral and diagnosis of children and young people on the autistic spectrum<sup>1</sup>. NICE recommended that each local area establish co-ordinated multi-disciplinary and multi-agency referral, assessment and diagnostic pathways (hereafter referred to as the “pathway”) for children with a suspected ASD.

In February 2014, the Cheshire and Merseyside Strategic Clinical Network (CMSCN) established an Autistic Spectrum Disorder (ASD) Special Interest Group (SIG) to review community services for children with ASD and their families in the Cheshire and Merseyside region. The aim of the SIG was to:

1. Identify and map current multi-agency pathways from diagnosis to transition for Children and Young People (CYP) with Autistic Spectrum Disorder (ASD)
2. Review existing Parent Support Programmes for CYP aged 11-15 years with ASD
3. Develop a process to allow measurement of CYP and family experience

The SIGs programme of work was originally intended to run until March 2016. However, ongoing changes to national service improvement policy and the adaptation of Strategic Clinical Network (SCN) priorities meant the SIGs work programme was condensed to one year with an aim to complete by March 2015. As a result, work on aims 2 and 3 were “paused” with acknowledgement and scope for wider stakeholders to explore these issues further.

## Key Findings

- There was considerable variation in the availability and quality of referral pathways within the Cheshire and Merseyside region and it was difficult to establish to what extent some referral pathways were meeting NICE guideline recommendations.
- Parents reported poor access to services and frustration and confusion with the referral pathway.
- With a few exceptions, the voluntary sector was largely disengaged from the process. Those that gave a reason for not engaging with the process cited a feeling of repeated broken policy promises and raised expectations that were not subsequently met.
- There was variable but significant pressure on resources and some areas were unable to meet parent expectations or to meet the NICE recommendation.
- There was considerable expertise in ASD and a passion across all voluntary, health, education and social care agencies to improve services for children with ASD and their families.

## **Key Outcomes**

- A standard blueprint referral pathway template that maps onto NICE guidelines recommendation.
- A parent and carer information leaflet which can be used at point of referral.
- An initial assessment of parent's priorities during the referral pathway with the aim of informing the development of a tool for measuring parents' experience.

## **Key Recommendations**

- Clinical Commissioning Groups (CCGs) to refer to NICE guidance and ensure that there is a suitable ASD pathway in place for referral, assessment and diagnosis of children with a suspected ASD in their area.
- CCGs to consider workforce and training needs review, to ensure there is sufficient experience and expertise to meet NICE guidelines.
- CCGs that are due to review or renew their ASD pathway or are developing new process, give consideration to using the blueprint pathway template.
- CCGs to tailor the blueprint pathway template to local needs following a detailed analysis of current local services and gaps.
- CCGs to give consideration to the results of the parent survey when developing their pathway and when developing tools to measure parent experience.
- CCGs to consider developing and expanding on patient and public involvement (PPI) within their catchment area where possible, taking into account families under pressure may need additional support to engage in PPI processes.
- CCGs to consider using the parent information leaflet to provide preliminary information and signposting to support for parents at the point of referral.

## 1. Background

An autistic spectrum disorder (ASD) is a life-long condition that is characterised by impairments in social interaction, social communication and restricted and repetitive behaviour<sup>2</sup>. A person with an ASD may also display hyper- or hypo-sensory sensitivity and challenging behaviour due to their poor understanding of their environment. ASD also carries an increased risk of co-morbidities such as epilepsy and learning disabilities.

The diagnostic criteria and perceived causes of autism have historically been complex and at times controversial. In 1943, Leo Kanner first described a group of 11 children who displayed echolalia, repetitive behaviour, a dear of change, and unusual pattern of social interaction and communication and an apparent lack of empathy<sup>3</sup>. Kanner used the term *early infantile autism* to describe this group of children. In 1944, Hans Asperger described a group of 4 highly verbal and intelligent children with a similar profile to that described by Kanner. This group of children were later referred to as having Asperger's syndrome or '*high functioning autism*'<sup>4</sup>.

Studies by Lorna Wing *et al* during the 1960's and 1970's reassessed these early diagnostic criteria and found many children displayed some similar but not all features to those described Kanner and Asperger's. Their work found variation in how children in this group presented but also that they all shared the same qualitative abnormalities in 3 keys areas; that of social interaction, social communication and social imagination. This became known as the triad of impairments<sup>5</sup>.

Following the work by Wing *et al*, autism was viewed as a disorder occurring on a continuum. Various terminologies have been used to capture that continuum such as *autistic continuum disorder*, *under the umbrella of autism* and *autistic tendencies*. More recently, the key policy documents in the United Kingdom and national charities have adopted the term *Autistic Spectrum Disorder (ASD)* to describe this group of children and this is the term that will be used in this document.

ASDs effects approximately 1 in 100 children<sup>6</sup> and, together with their families, the National Autistic Society estimates that up to 2.8 million people in the UK are touched by ASD in some way<sup>7</sup>. All children with ASD share similar characteristics but each child will be affected by their condition in different ways. There is no cure for ASD but early interventions and sympathetic environments can help support children with an ASD to reach their full potential.

## **2. Key National Policies and Reports**

### **2.1 Education Act (1996) and the Special Educational Needs Code of Practice (2001)**

The Education Act (1996) through the Special Educational Needs (SEN) Code of Practice made provision for the educational assessment of children with suspected special educational needs and for the issuing of a Statement of Education Needs to make provision to meet any special educational needs identified through that assessment. The Act included provision for parents to appeal to an independent tribunal against decisions made by the local education authority regarding the assessment and provision for their child.

### **2.2 All Party Parliamentary Working Group on Autism (APPWGA) (2000)**

All Party Working Groups are non-statutory cross party parliamentary working groups who share a common interest. The APPWGA was established 2000. The group's aim was to raise awareness of issues affecting people with autism and Asperger syndrome, their families and carers; to raise Parliamentary awareness of autism; to campaign for changes to government policy to benefit people with autism and Asperger syndrome and improve diagnosis or, support for, people with autism and Asperger syndrome.

### **2.3 Medical Research Council (MRC) Review of Autism Research: Epidemiology and Causes (2001)**

In 2011, the MRC published its findings from a review of autism prompted by ongoing public debates about the link between the Measles, Mumps and Rubella (MMR) vaccine and a new variant of autism with an associated bowel disorder. The review found no evidence to support such a link but it did affirm the notion of autism as occurring on a continuum and the term autistic spectrum disorder (ASD) in line with DSM-IV and ICD-10 criteria. The report also highlighted paucity of research into the cause and epidemiology of ASD; the complexity and variations in the assessment and diagnosis of ASD and an awareness of the prevalence of children and adults in the population.

### **2.4 National Autism Plan for Children (2003)**

The National Autism Care Plan for Children (2003) was a joint venture between the Autistic Society and the Royal College of Paediatrics and Child Health with the backing of the All Party Parliamentary Group on Autism. The aim of the working group was to develop and plan for the identification, assessment, diagnosis and access to early interventions for pre-school and primary school aged children with autistic spectrum disorders. The plan recommended multi-agency and multi-disciplinary co-ordinated assessment teams for children with a suspected ASD, early interventions; the provision of key workers and care plans, appropriate training for professionals and the strategic planning and coordination of services.

### **2.5 NICE Guidelines (CG128) Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum (2011)**

The National Institute for Clinical Excellence (NICE) issued guidelines in 2011 on the assessment and diagnosis of children with a suspected ASD. The aim of the guidelines was to improve the recognition, referral and diagnosis, and the experience of children, young people and those who care for them. Key recommendations were that the development of local autism multi-agency strategy groups with appointed leads. In addition, A multidisciplinary group (the autism team) should be set up and include relevant clinicians and practitioners to conduct child assessments through a single co-ordinated point of referral. Parents should plan an important role in that assessment and the findings of assessments should be communicated to parents and, with parental consent, to appropriate clinicians and practitioners. The Guidelines are due for review in June 2016.

## **2.6 Children and Families Act (2014) and the Special Educational Needs and Disabilities (SEND) Code of Practice (2014)**

SEND replaces the SEN Code of Practice (2001) and increases the upper age of children and young people covered by the Code of Practice from 19 to 25 years; provides for multiagency seamless assessment and provision for children and young people with complex needs; provides guidance on the publication of Local Offers to support families and provides guidance on additional support and provision and support for children and young people with SEN and disabilities in education, work and in the community with a greater emphasis on supporting transition between children and adult services.

### **3. The Autistic Spectrum Disorder Special Interest Group**

The Autistic Spectrum Disorder Special Interest Group (ASD SIG) first met in March 2014, following a priority setting meeting with key stakeholders from Cheshire and Merseyside in which concerns were raised about families' access to assessment, diagnostic and support services. The ASD SIG was formed as one of eight task and finish working groups within the Cheshire and Merseyside Maternity, Children and Young People Strategic Clinical Network. Terms of Reference for the ASD SIG can be found in Appendix 1.

The ASD SIG was chaired by Dr Janine Arnott and consisted of a broad spectrum of representatives from the ASD community including clinicians, practitioners (health, social care and education), representatives from the voluntary sector and parents. Membership of the group can be found in Appendix 2.

The SIG met seven times between March 2015 and June 2015. After that time the ASD SIG continued to meet virtually via email until the SIG ceased to operate in July 2015. This final report has been reviewed and commented on by the members of the ASD SIG.

The deliverables of the ASD SIG were developed and agreed by the members of the ASD SIG during their first meeting held in March 2014. The deliverables were:

1. To identify and map current multi-agency pathways from diagnosis to transition for Children and Young People (CYP) with Autistic Spectrum Disorder (ASD).
2. To review existing Parent Support Programmes for CYP aged 11-15 years with ASD.
3. To develop a process to allow measurement of CYP and family experience.

## 4. Deliverables

This section of the report describes the 3 key deliverables undertaken by the ASD SIG along with key outcomes and recommendations.

**Deliverable 1: Identify and map current multi-agency pathways from diagnosis to transition for Children and Young People (CYP) with Autistic Spectrum Disorder (ASD)**

### ***Method***

The ASD SIG contacted all CCGs in Cheshire and Merseyside and requested copies of their ASD referral, assessment and diagnostic pathway (pathway). Six CCGs provided us with copies of their pathway. We compared the pathways to identify core similarities and differences.

### ***Results***

#### ***Gap analysis***

Our initial mapping of the six submitted CCG pathways showed that although diagnostic tools were fairly consistent there was considerably variation across CCGs as to the availability and content of the pathways and this raised some concerns. These concerns were:

- Not all CCGs provided a pathway, making it difficult to determine whether those CCGs who did not provide a pathway had developed one in line with NICE guidelines
- No pathways identified a clear clinical lead, as recommended by NICE guidelines
- None of the pathways include how they communicated a diagnosis of ASD to the child, only to parents
- There was general confusion around flow of certain CCGs pathways and concerns about whether the pathways met NICE recommendations
- A key concern was the lack of clarity about who could and should make an initial referral and whether parents could self-refer to the pathway
- Some pathways lacked sufficient detail to establish whether they were meeting NICE recommendations

#### ***Consultation with working group***

Consultations with members of the SIG working group identified a number of further significant concerns about the implementation of pathways. These included:

- Significant waiting lists in some areas both in terms of the length of time families waited and in terms of the numbers of children on the waiting list.

- Insufficient funding to respond to demand for assessments.
- Lack of appropriately trained clinicians and practitioners.
- Insufficient educational and social support and services for children following a diagnosis of ASD.

*In the face of continuous funding cuts autism needs more funding, more diagnosing practitioners, less waiting times. Everything. The Economic Cost of Autism is staggering and at least 1/3 of that cost would be reduced by early intervention and continual targeting of social communication difficulties” (Non-statutory practitioner).*

### **Response**

In response to the findings described above, the ASD SIG developed a blueprint pathway template to support CCGs in developing, reviewing or refining their own pathways. This pathway can be found overleaf and in Appendix 3. The pathway template was developed using gap analysis and the expert members of the SIG input to develop a standard model ASD pathway that could be adapted to meet local needs.

The model pathway is intended to be used as a ‘blueprint’ template rather than a prescriptive model and was intended to be accompanied by a simple set of guidelines to support CCGs in adapting the template to local service structure while meeting NICE recommendations. Although the template is intended to be generic and easily adapted for local use it does include 3 specific elements that the ASD SIG deemed to be crucial to the successful flow and delivery of the service:

- Information and support for parents made available from point of referral
- Safe and legitimate exits from the pathway with full explanation and next steps
- Appropriate Multi-Disciplinary Team to carry out the assessment.

The pathway template aims to address these three areas of elements in addition to responding to the gap analysis of existing pathways.

# A blueprint pathway template to support CCGs in developing, reviewing or refining their local pathways



## **Deliverable 2: Review existing Parent Support Programmes for CYP aged 11-15 years with ASD**

### **Method**

The ASD SIG conducted an internet search of all local support groups in the area to map available support for parents through the voluntary sector and contacted all known local support groups and invited them to attend a focus group with the aim of mapping local support for families, engaging with the voluntary sector and providing a forum for the voluntary sector to feed into the overall work of the ASD SIG. The ASD SIG consulted with parents and representatives from the voluntary sector who were members of ASD SIG to attempt to map statutory support for families of children and young people with ASD.

### **Results**

- We found that both voluntary sector and statutory sector support for families was diverse and complex. Although some ASD specific support existed, other support was integrated into generic services making it difficult to map the ASD specific support available to families.
- We identified a number of ASD specific groups across the Cheshire and Merseyside. None of which wished to engage in consultation. Groups who gave a reason for not engaging in a consultation cited a history of what they perceived to be wasted opportunities to improve services and unmet expectations.
- Parents felt confused and uninformed about referral and assessment processes and support services and felt unsupported.
- More understanding of how desperate parents can be (Non statutory practitioner).

*“A suitable ASD Pathway needed to be implemented and services need to be commissioned at a sufficient level to meet the needs of the ever-increasing number of children presenting for assessment and diagnosis. Children often cannot access correct support without diagnosis, and too many are left suffering, labelled as 'naughty' and misunderstood” (Parent).*

### **Response**

Within the time and resources available to us we were unable to map services in any more detail or provide a wider consultation with families. As the key finding to emerge from conversations with parents and the voluntary sector highlighted considerable confusion and frustration with the pathway, the ASD SIG decided to develop an information leaflet to support parents shortly before and during the referral and assessment process and there was wide support for this from the SIG (Appendix 4).

The leaflet was developed with the aim of guiding parents through the process, myth and jargon busting, explaining who may be involved in their child's assessments, support parents to fully engage in the child's assessment, and signposting parents to further support.

A key question of terminology remains unresolved. The leaflet currently uses the term '*social and communication disorder*' as it was felt that to use the term ASD before a child had been referred and assessed could be pre-emptive and unnecessarily distressing for parents. However, there is an acknowledgement that this needs further consultation.

The leaflet has not been piloted or evaluated at this time. However, if adopted, the leaflet could be made available in hard copy and electronically and could be hosted on central website such as the CCG or local authority. This would enable both parents and clinicians and practitioners to access the leaflet.

**Deliverable 3:            Develop a process to allow measurement of CYP and family experience**

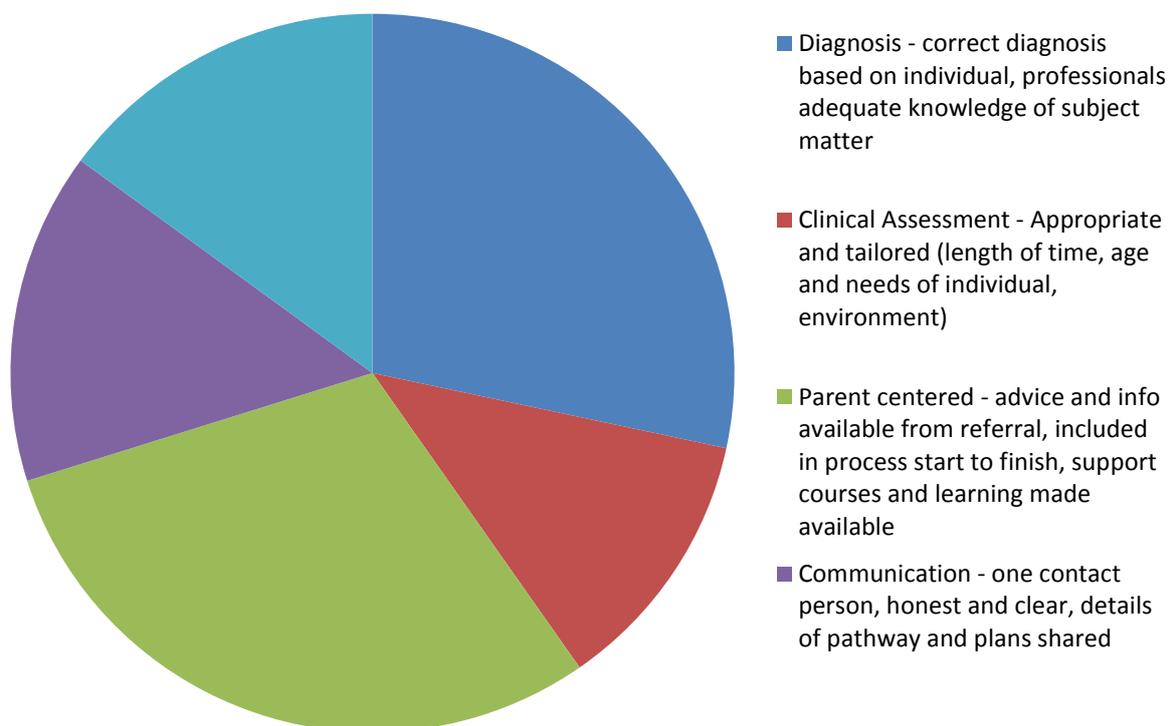
The ASD SIG reviewed existing tools for measuring patient and parent satisfaction but didn't find any tools suitable for measuring parents' experiences through a referral and assessment pathway. Therefore we agreed to develop a tool to measure parents' experience. Before doing this we needed to establish what was important to parents so we could be sure that any tool we developed was measuring what mattered to parents as well as what mattered to policy makers and commissioners.

***Method***

In order to establish parents' priorities during the pathway we adapted a method used in hospitals to identify patients' priorities. We developed a tool called '*What matters to me*'. This was a one page survey that asked parents to list up to 5 things that mattered to them most during the pathway (Appendix 5). We then asked four special schools to distribute the surveys to parents of children with a diagnosis of ASD. This way we could be confident that the parents receiving the survey had been through a referral, assessment and diagnostic process.

We received 15 responses from parents and we grouped these into 5 key recurring themes shown in the pie chart over the page.

## Survey Results July 2015



**Diagnosis** was the largest recurring response with the majority of parents stating simply, *“I wanted to know what was wrong with my child and how I could help”*. Under the theme of diagnosis, also fell the importance of correct diagnosis for the *individual*, and this could only be achieved by the health professionals involved in the pathway having adequate knowledge of the diversity of ASD patients and the correct procedures to follow.

One parent described the difficulty in attaining a referral as the child did not exhibit specific indicators that this particular professional associated with a ‘typical’ ASD case. The results show the need to not just ensure there is an adequate Multi-Disciplinary Team to undertake a sufficient assessment but the importance of the correct training and knowledge of every member of staff associated with the ASD pathway.

The second largest theme was **Parent centred**. The benefit of including a parent in the diagnosis and assessment process is invaluable not only for the parents but for the professionals to have a full and rounded picture of the child’s symptoms and case.

The further themes of **Communication**, **Length of time** and **Clinical Assessment** can all be addressed and resolved by ensuring a suitable local pathway is in place and the blueprint pathway template developed here should help support local CCGs deliver that service.

*“...the average waiting time from initial referral to diagnosis is 4 years. This is totally unacceptable”* (Parent)

*“[waiting time is] 15 months” (Practitioner)*

*[Waiting time is] 3 years (non-statutory practitioner)*

Time and resource constraints meant we were unable to develop the tool for measuring parents experience any further. However, we did demonstrate that it is feasible to use the method we adopted here to establish parents priorities during the pathway and consideration should be given to extending this method of consultation to inform the development of a tool for measuring parents’ experience of the ASD pathway. See Appendix 6 for full survey responses.

### ***Additional Key Questions Arising During the Review***

The exercise highlighted a number of key issues that require further exploration. These were:

1. *What is the role of an ASD specific service versus a neurodevelopment pathway?*

There was considerable discussion around the utility of ASD specific referral and assessment provision rather than a more general neurodevelopment pathway for a number of reasons. Firstly, an ASD specific referral and assessment pathway could be pre-emptive and that this risks excluding children who displayed atypical ASD features. Parents raised concerns about informal ‘filtering’ of referrals in that a child may only be referred for assessment once a community or educational practitioners feel a diagnosis of ASD is likely. Secondly, there was concern that an ASD specific pathway could focus assessments too narrowly, missing alternative or additional diagnosis or disorders. Thirdly, there were questions about which aspects of an assessment within an ASD pathway were unique to ASD or were relevant to broader neurodevelopment assessments and whether ASD specific pathways were the best use of scarce resources.

There was a general consensus that, while children with ASD may require some dedicated referral, assessment and therapeutic and educational provision, there was a need to explore new ways of meeting increased demand for services and whether this demand could best be provided within a general neurodevelopment pathway.

*“Changes in practice and roles – Ensure the best use of practitioner time and look at new roles to support families which can take some time off the specialist practitioners”*  
(Practitioner)

2. *Who should be assessing children?*

NICE provide guidelines on the composition of assessment teams. However, our review found wide variation on who lead, co-ordinated, and conducting ASD assessments. The pathway ‘blueprint’ offered here goes some way to addressing that gap. However, parents and practitioners reported concern about access to clinicians and practitioners with experience and expertise in assessing children with a suspected ASD at every level.

*“...many CAMHS practitioners seem to have no understanding of Autism whatsoever, and Community Paediatricians are leaving in droves and not being replaced “ (Parent)*

*“Not enough trained practitioners – Lack of specialist staff including Community Paeds...” (Practitioner)*

*“Local authorities are NOT meeting national guidelines as recommended in The Autism Act. Autism needs more funding, more diagnosing practitioners” (non-statutory practitioner).*

It was not possible to conduct a workforce and training needs review however the SIG feels this would be a helpful for ensuring children have timely access to appropriate assessment provision.

3. *What terminology should be used prior to a diagnosis?*

As mentioned above, it was felt that the use of the term ASD during the initial referral and assessment process could be pre-emptive. This also became an issue when developing information and signposting support for parents during the early stages of assessment. There is a recognised need for more support for families prior to and during an ASD assessment and the SIG responded to this unmet need by developing an information leaflet for parents. The SIG was keen to ensure that the leaflet was relevant to the specific needs of parents around this time while avoiding pre-emptive language such as ASD. This raised important issues about terminology that remain unresolved.

4. *How can service provision be simplified and streamlined?*

A final observation during the review process was the complexity of statutory and voluntary sector service provision. In many areas, ASD specific service provision was so complex it was impossible to map services or identify who was providing specific services. Simplifying service commissioning, named local leads and improved signposting could help resolve this issue.

*“Joint working and commissioning across health and education to support CYP with ND conditions including with social care when required. Models to be developed which ensure co-presenting issues are supported which does not involve numerous referrals to different organisations e.g. have 1 single point of access” (Practitioner)*

## 5 Summary

The review of ASD assessment, referral and diagnostic pathways and community services across the Cheshire and Merseyside Strategic Clinical Network provided an opportunity for clinicians, practitioners, parents and the voluntary sector to come together and review an important community service. The results of the review were mixed. The complexity of service commissioning and provision along with review 'fatigue' amongst the voluntary sector and parents meant we were unable to map services and engage with non-statutory services and service users as hoped. Where we were able to map service provision through a gap analysis of pathways and through consultation with SIG group members, we found wide variation in service provision, frustration with the complexity of service provision and concern about waiting lists, unmet needs, increasing demand on services and resources that can't be met within existing funding and a perceived lack of expertise within the community assessment teams.

On a more positive note, we found numerous examples of good practice alongside an energy and optimism to improve community services for children with ASD. There was a sense that progress had been made during the review in terms of identifying unmet need and placing these on the local commission agenda and, in its broadest sense this was the overall aim of the SIG. The review also produced 3 key outputs; a blueprint pathway, an information leaflet for parents and a feasibility study to inform the development of a tool to measure parent's experiences of the pathway. The review also raised 4 key unexpected questions relating to the utility of an ASD specific pathway, the use of ASD language prior to and during an assessment and the complexity of statutory and non-statutory service commissioning and provision.

The ASD SIG has highlighted significant unmet family need and pressure on local ASD services. The ASD SIG has provided key recommendations in response to these findings. The SIG has also provided the groundwork for further research and review of services. Evaluating and integrating the 3 key outputs from the ASD SIG will be an important short term 'next step' in providing tangible improvements for parents at ground level. In the medium term, addressing the 4 key unexpected questions provides further opportunity to develop more streamlined and responsive services for children with a suspected ASD and their families. Finding ways to engage more effectively with parents and the voluntary sector will be crucial in ensuring the success of any further development work.

## 6 Testimonies

*“It’s been a privilege to chair the ASD SIG and to work with such a diverse group of people who are all passionate about improving services for children with an ASD and their families. I’m confident that the good work started here will continue and will lead to genuine improvements for children and their families”.*

**(Dr Janine Arnott, Chair ASD SIG, Research Fellow, UCLan and the CNRU at Alder Hey Children’s Hospital)**

*“The referral and diagnosis process for both children and parents can be a scary, confusing and frustrating time. I hope that the work of this group will make the process more straightforward and patient/carer focussed so that children and families can gain the specialist support they need as quickly as possible.”*

**(Liz Thornber, Trust & Corporate Fundraiser, Autism Initiatives)**

*“My experience of working with the group in preparing this report has given me the opportunity to share first-hand experience of supporting families affected by autism and the difficulties they often face on the journey to a clearer understanding of their child’s support needs. It is my hope that this report helps to address the difficulties that families and professionals often face in reaching a clear diagnosis and understanding of a child’s and family’s needs. Further I hope that this report adds to the understanding of how we can all best support each other to achieve positive, empowering results for all those on this journey”*

**(Steve Vasey Manager Children and Family Services Wirral Autistic Society)**

*“Thank you for all of your hard work around this important subject. I’m sure that young people and their families will find the information leaflet useful and reassuring”*

**(Yvette McKearn, Warrington Clinical Commissioning Group)**

## 7 References

1. National Institute of Health and Care Excellence (2013) *Recognition, referral and diagnosis of children and young people on the autistic spectrum* NICE Clinical Guidance 128. [Online] Available from: <https://www.nice.org.uk/guidance/cg128>
2. Medical Research Council. (2001). *MRC review of autism research: Epidemiology and causes*. London. Medical Research Council
3. Kanner, L. (1943) Autistic disturbances of effective contact. *Nervous child*. Vol.2, pp. 217–50 Le Couteur, A. (2003). *National autism plan for children*. National initiative for autism: Screening and assessment. Available at: [http://iier.isciii.es/autismo/pdf/aut\\_napc.pdf](http://iier.isciii.es/autismo/pdf/aut_napc.pdf) (Accessed August 2015)
4. Asperger, H. (1944). "Die "autistischen psychopathen" im kindesalter". *Archiv für psychiatrie und nervenkrankheiten* Vol.117, pp.132–135.
5. Wing L. et al (1993). The definition and prevalence of autism; *European child and adolescent psychiatry*. Vol.2, Iss. 2, pp.61-74
6. The Education Act. (1996) (C 56 Vol. 1 Pt. IV) London. The Stationary Office  
Wallace, S et al (2012). *1 in 100*. Autistica. Available at <https://www.autistica.org.uk/wp-content/uploads/2014/10/One-in-a-Hundred-Autisticas-Report.pdf> (Accessed September 2015)
7. National Autistic Society (2015). [Online] Available from: <http://www.autism.org.uk/>

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# Appendix 1

## Terms of Reference

## Maternity, Children and Young People Strategic Clinical Network

### Autistic Spectrum Disorder Special Interest Group

### Terms of Reference

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#### 1. PURPOSE

- 1.1. The purpose of the Maternity, Children and Young People Strategic Clinical Network (MC&YP SCN) is to provide a model through which professionals, organisations and service users collaborate across organisational boundaries to deliver programmes which result in improved health and wellbeing outcomes and improved quality of patient care. The expertise and leadership of the MC&YP SCN enables it to be an advisory body, making recommendations in support of safe, sustainable high quality and cost effective care.
- 1.2. The organisational structure for the strategic clinical network provides for the establishment of SCN subgroups. For the MC&YP SCN, these subgroups will be known as **Special Interest Groups**.
- 1.3. The Special Interest Groups (SIGs) will each be charged with tackling a specific priority within the Maternity, Children and Young People's SCN. There should be representation from commissioners and providers who have knowledge and interest in the issue under consideration, and where possible, representation from patients/carers/members of the public.

#### 2. ACCOUNTABILITY

- 2.1. The MC&YP SCN Special Interest Groups are accountable to the MC&YP Steering Group. Further detail of the groups and reporting arrangements can be found in **Appendix A**.

#### 3. MEMBERSHIP

- 3.1. Minimum core membership for each MC&YP Special Interest Group should consist of:

- Chair
- Quality Improvement Lead for Maternity, Children and Young People
- Patient/Carer/Public representative(s)
- CCG representatives
- Provider representatives
- Voluntary/charity representatives

Other stakeholders may be co-opted to join a special interest group as and required. A template for member details of each special interest group is available in **Appendix B**.

#### 4. CORE ACTIVITIES

- To clarify the group's purpose
- To agree group membership
- To identify a wider reference group for consultation and comment
- To determine and prioritise the tasks required

- To draw up a timetable and milestones/Key performance indicators
- To monitor progress against the timeline and be accountable for result

## **5. FREQUENCY OF MEETINGS**

5.1. To be determined by each Special Interest Group

## **6. QUORUM**

6.1. No business shall be transacted at a meeting unless at least 50% of members and the Chair or their nominated deputy are present, and the Chair is satisfied that the members present represent a sufficiently broad view to arrive at a decision.

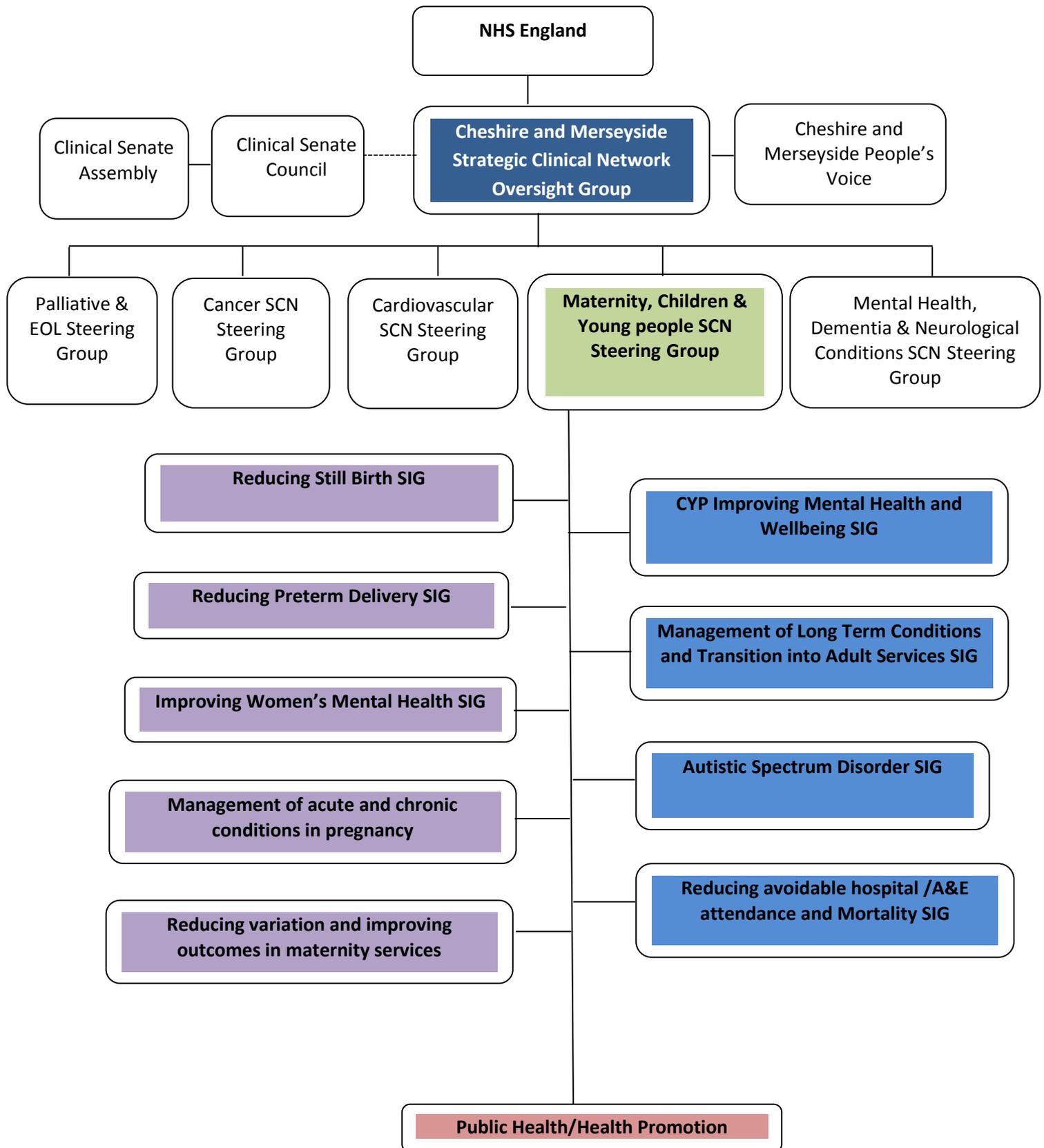
## **7. REVIEW**

7.1. The Terms of Reference and Membership of the MC&YP SCN Special Interest groups Group will be reviewed on a yearly basis.

**DATE AGREED: 19\_03\_14**

**DATE FOR REVIEW: March 2015**

**Appendix A: MC&YP SCN Reporting Structure including Special Interest Groups**



## APPENDIX B: Membership for the Maternity, Children and Young People Special Interest Group

<b>Name of SIG: Improving Paediatric Community Services</b>		
<b>Member Name</b>	<b>Job Title</b>	<b>Organisation</b>
Janine Arnott (CHAIR)	Research Fellow	UCLAN/Alder Hey
Gail Whitehead	Consultant Paediatrician & Clinical Lead	East Cheshire NHS Trust
Katy Coxhead	Service Redesign Manager	Wirral CCG
Angela Price	Professional Development Lead for Health Visiting	Wirral Community Trust
Norma Currie	Commissioning Manager	Wirral CCG
Vicky Harris	Senior Face 2 Face Coordinator	Scope/Alder Hey
Marie Fairbrother	Named Nurse Safeguarding Children	Bridgewater Community Healthcare Trust
Jane Uglow	Locality Development Manager-Lead for Children	Sefton CCG/Southport and Formby CCG
Elaine Huntingdon		Liverpool JMU
Charlotte Fazackerley	Public Sector Partnership Manager	North of England, The Prince's Trust
Barry Holland	Independent Psychologist specialising in autism/aspergers	
Katie Hinds	Principal Educational Psychologist	Liverpool Council
Janet Roberts	ADHD Specialist Nurse	Mid Cheshire Hospital Trust
Wendy Henshaw	Head of Medical Needs Educational Support	Sandfield Park School
Amy Irwin	Young Advisor	Sefton Young Advisors
Kieran Maher	Young Advisor	Sefton Young Advisors
Julie Karmy		Halton CCG
Carla Lydiate	Parent	
Julie Pendleton	Parent	
Donna Kelly	Parent	
Ursula Boulton	Assistant Headteacher	Abbots Lea School
Jane Carolan		Wirral Centre for Autism
Lesley Bayliss		Eastern Cheshire CCG
Helen Traynor	Hospital Play Specialist	Alder Hey Children's Hospital
Jo Garner		CHAPS – Cheshire Autism Practical Support
Karen Burton		
Lisa Nolan	Commissioning Manager	Liverpool CCG
Paul Dagnall		Children & Young People's Services, Liverpool Council
Rita Omar	Clinical Lead/Service Manager for Children's SLT. SLT	Liverpool Community Health Trust

	Consultant ASD Pathway.	
Andrew Curran	Consultant Neurologist (with an interest in ASD)	Alder Hey Children's Hospital
Jan Lee	Outreach Manager, Central Area Support Team	Knowsley Council
Annette Edmonson	Parent	Sefton Parent Carer Group
Jill O'Neil	Integrated Commissioning Manager	Knowsley Council
Sarah Cobbe	Advisory Teacher for ASD	Knowsley Council
Steve Vasey	Manager Children & Family Services	Wirral Autistic Society
Sarah O'Connell		

# Appendix 2

## Membership

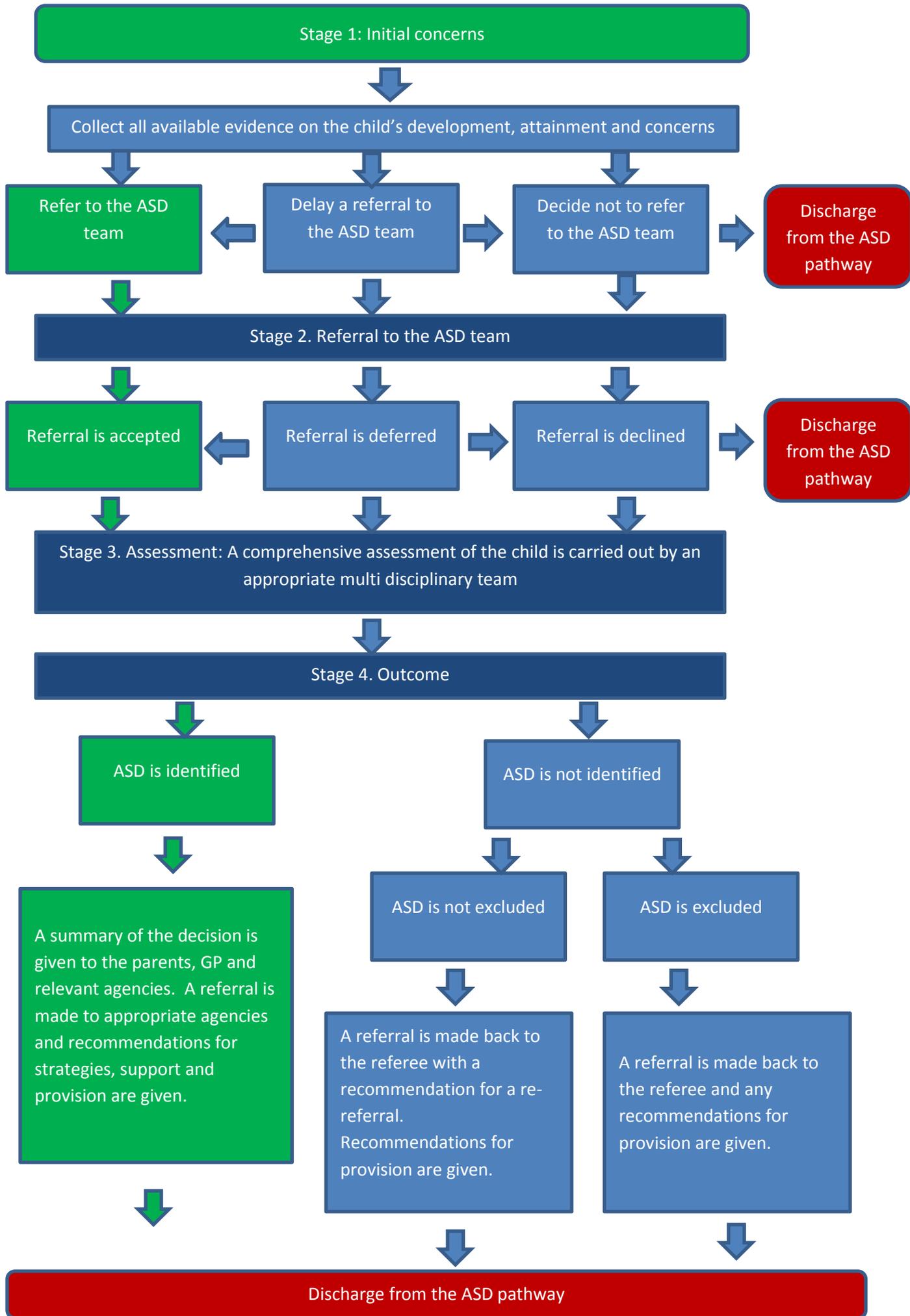
**Maternity, Children and Young People Strategic Clinical Network**  
**Autistic Spectrum Disorder Special Interest Group**  
**Membership**

Name	Job Title	Organisation
*Elaine Huntingdon	Researcher	Liverpool JMU
*Charlotte Fazackerley	Public sector Partnership Manager	North of England, The Prince's Trust
*Dympna Edwards	Assistant Director Public Health	St Helens MBC
Aline Delmotte	School Nurse	CWP
Angela Price	Professional Development Lead for Health Visiting	Wirral Community Trust
Caroline Baines	Public Health Programme Manager	NHS England (Cheshire, Warrington & Wirral Area Team)
Craig Gradden	Medical Director	Liverpool Community Health
Jacqueline McKenna	Researcher	Edge Hill University
Jane Banks		Liverpool Community Health Trust
Karen Garside	Safeguarding	Halton CCG
Gail Whitehead	Consultant Paediatrician & Clinical Lead	East Cheshire NHS Trust
Jayne Wood	Head of Childrens Services 5-19 yrs	Liverpool Community Health
Marie Fairbrother	Named Nurse Safeguarding Children	Bridgewater Community Healthcare Trust
Nicola Mullin	Consultant in Sexual and Reproductive Health	Countess of Chester NHS Trust
Norma Currie	Commissioning Manager	Wirral CCG
Rachael Gosling	Consultant in Public Health	Liverpool Community Health NHS Trust
Richard Brown	Divisional Manager, Womens, Childrens & Clinical Support Services Division	Warrington & Halton Hospitals NHS FT
Sam Nellist	Parent Carer Team Manager	Sefton carers Centre
Sian Barker	Children's Head of Early Years	Liverpool Community Health NHS Trust
Sheila Daulby	Divisional Manager, Children's Services	Liverpool Community Health NHS Trust
Stef Woof	Deputy Manager & Communications	Warrington Voluntary Action
Suzanne Payne	Headteacher	Crossens Nursery School
Valerie Clare	Associate Director of Midwifery and Nursing	Wirral University Teaching Hospital NHS Foundation Trust
Vicky Harris	Senior Face 2 Face Coordinator	Scope/Alder Hey

# Appendix 3

## Blueprint

# A blueprint pathway template to support CCGs in developing, reviewing or refining their local pathways



# Appendix 4

## Parent Leaflet

## The Cheshire and Merseyside Social and Communication Disorder Referral Pathway



○ **What is the purpose of this leaflet?**

This leaflet explains about the Cheshire and Merseyside Social and Communication Disorder referral pathway.

○ **What is a social and communication disorder?**

A social and communication disorder (SCD) is defined by long term difficulties with verbal (spoken) and non-verbal (such as pointing and eye contact) communication. Children and young people with a SCD may also experience difficulties with social relationships, such as making friends, or taking turns or following rules when playing.

○ **What is the social and communication disorder referral pathway?**

The SCD pathway coordinates the referral and assessment of children and young people who are showing signs of a SCD.

○ **Why have I been given this leaflet?**

You have been given this leaflet because you or a healthcare Practitioner feels it would be helpful for your child to be assessed on the pathway.

○ **What happens now?**

You should be given the name of a person who is responsible for coordinating your child's referral and assessment. That person will gather all the necessary information about your child from relevant health care practitioners and from your child's school or nursery. The referral coordinator will then decide whether to refer your child to the assessment team for a full assessment. The reason for any decision will be explained to you.

○ **What happens during an assessment?**

A number of healthcare professionals will be involved in assessing your child and they will all work together to assess your child's development. The 'who's who' box below describes some of the people who may be involved in your child's assessment. Your child may not see all these people; the team who assess your child will depend on your child's individual needs. You and your child may see some health care practitioners separately for assessments or together as a multi- disciplinary team; this will also depend on your child's individual assessment needs.

### Questions you may like to ask

Who will be involved in assessing my child?

Will I be able to meet with the healthcare professionals?

Will I see any reports written about my child?

Who is coordinating my child's assessment?

How long will the assessment take?

How will I be informed of the outcome of the assessment?

### How can I help with my child's assessment?

Keep a diary of your child's development and behaviour

Make a list of things your child has learnt to do or can do really well.

Make a list of things you are concerned about

○ **Does my child have to wait until the end of the assessment to receive any help?**

No. If your child needs support, such as speech and language therapy, they can get that help even while on the pathway and before an assessment is completed. You can also find information about early advice and support from your Local Offer Council

Website. You can find links to Local Offer websites at the end of this leaflet in the 'Advice and Support' section.

○ **Do I have any input into the child's assessment?**

Yes! Parents should play an essential role in the referral and assessment process and the multi-disciplinary team of healthcare and education practitioners will want to hear about any concerns you have about your child's development and especially about your child's strengths. It is important that you feel involved in your child's assessment. The box to the right gives you some ideas about how you can help your child's assessment.

○ **What happens next?**

Once the assessment has been completed someone will explain the results to you. Sometimes it isn't possible to make a clear diagnosis and this can be frustrating but you can talk to someone about what this means for you and your child. If your child is diagnosed with a social and communication disorder it is important that you understand what this means for you and your child. Someone will explain the diagnosis to you and give you the opportunity to ask questions and talk about what this means for your child.

### **Local information and support**

Every council is required to publish a directory of what local support is available for children and young people with special educational needs and / or disabilities (SEND), called the Local Offer. You can find this by typing into a search engine e.g. Liverpool Council Local Offer. Or if you are reading this online please see the links below

Liverpool Council – <http://fsd.liverpool.gov.uk/kb5/liverpool/fsd/localoffer.page>

Knowsley Council - <https://www.knowsleyinfo.co.uk/>

Sefton Council - <http://www.seftondirectory.com/kb5/sefton/directory/localoffer.page?localofferchannel=>

St Helens Council - <http://www.sthelens.gov.uk/what-we-do/schools-and-education/sen-the-local-offer/>

Halton Council - <http://localoffer.haltonchildrenstrust.co.uk/>

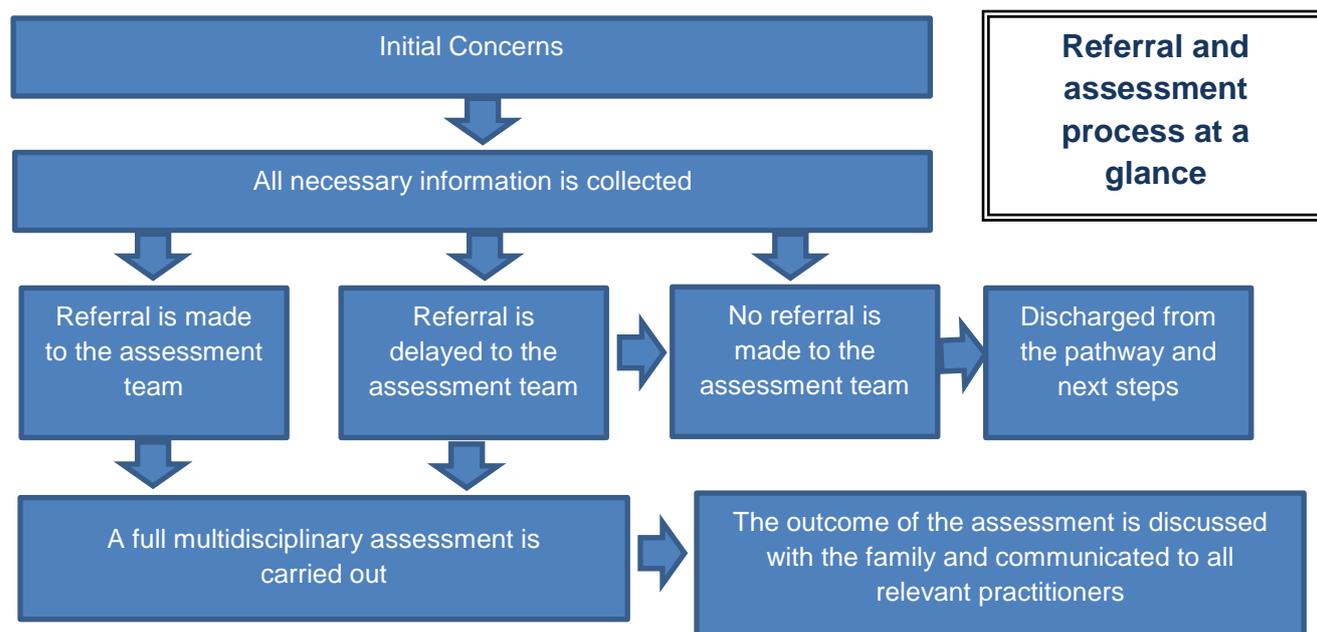
Wirral Council - <http://localofferwirral.org/>

Cheshire East Council - <https://ice.cheshireeast.gov.uk/>

Warrington Council - <http://warrington.fsd.org.uk/kb5/warrington/fsd/localoffer.page>

West Cheshire Council -

<http://www.westcheshirelocaloffer.co.uk/kb5/cheshirewestandchester/directory/home.page>



#### Practitioners who may help assess your child.....

**Psychologist:** Psychologists study people’s behaviour - how they think, act, react and interact.

**Psychiatrist:** A psychiatrist is a qualified medical doctor, who has taken further training and specialised in the treatment of mental health problems.

**Speech and Language Therapist:** Speech and language therapists work with children and adults who have speech and communication difficulties.

**Paediatrician (community):** A paediatrician is a doctor who has specialised in children’s medicine. Paediatricians can also refer children to a particular specialist when needed. Community paediatricians are senior doctors who provide services to children in their local community.

**Neurologist:** A neurologist specialises in the diagnosis, treatment and management of nervous system disorders. These are known as neurological conditions.

**General Practitioner:** General Practitioners are family doctors who deal with people’s day-to-day medical care. They can refer patients to clinics, hospitals and specialists.

**Health Visitor:** Health visitors are nurses who also have training and experience in child health. They can help families receive the local services they need.

**SENCO:** A SENCO is the teacher at a school whose job it is to make sure the school knows about any children at the school who have special educational needs and to help them get the support they need.

**Social worker:** A social worker knows what financial benefits and services there are to support a child and their family or an adult wherever they are living

CAMHS: Child and Adolescent Mental Health Service. A multidisciplinary team providing care for children and adolescents with mental health issues, including emotional and behavioural issues.

# Appendix 5

## What Matters to Me

# What matters to me

## The social and communication disorder referral pathway

Strategic Clinical Networks (SCNs) bring together service users, providers and commissioners who work together to improve the quality of local and regional healthcare services.

The Cheshire and Merseyside SCN want to develop a survey to measure parent's experiences of their child's assessment for a possible social and communication disorder (SCD). Before we do this, we need to know what matters most to parents during their child's assessment so we know we are measuring the right things.

As the parent of a child with a SCD we would really like to hear about your experiences.

Thinking back to when your child was assessed for a possible SCD, please tell us up to five things that were important to you. For example, you may want to comment on the length of time the assessment took or whether you felt involved in the assessment.

The five things that mattered to me the most were.....



1
2
3
4
5

**Thank you for taking part. Your views really matter to us**

**Please return the survey to school in the envelope provided**

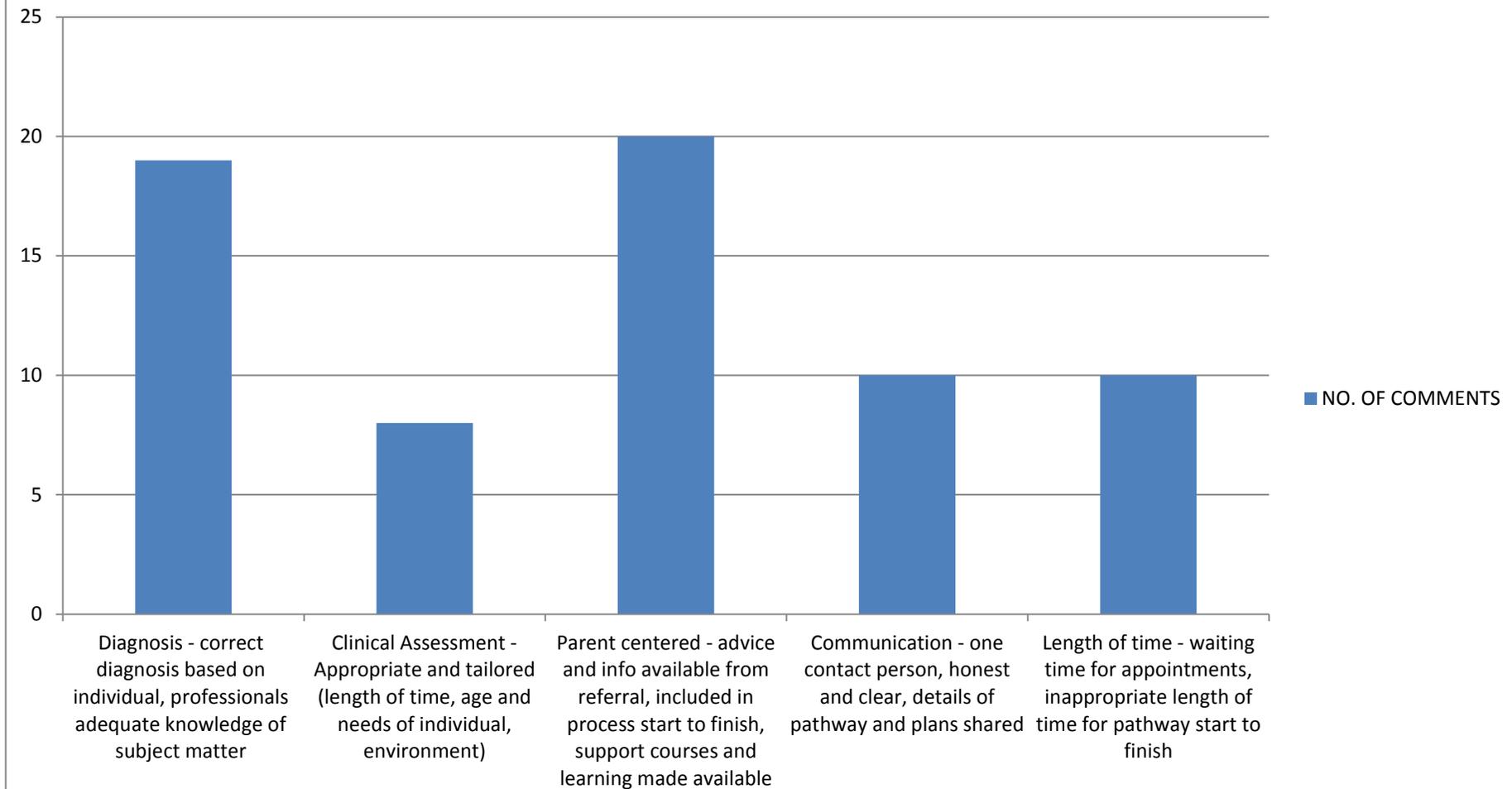
For more information please contact Janine Arnott at [Jarnott@uclan.ac.uk](mailto:Jarnott@uclan.ac.uk) or Quality Improvement Lead, Cheshire & Mersey Strategic Clinical Network & Senate. Te: 01138254647 | 07814228940 | [gemma.ingham@nhs.net](mailto:gemma.ingham@nhs.net)

**This information is available in other languages and formats on request**

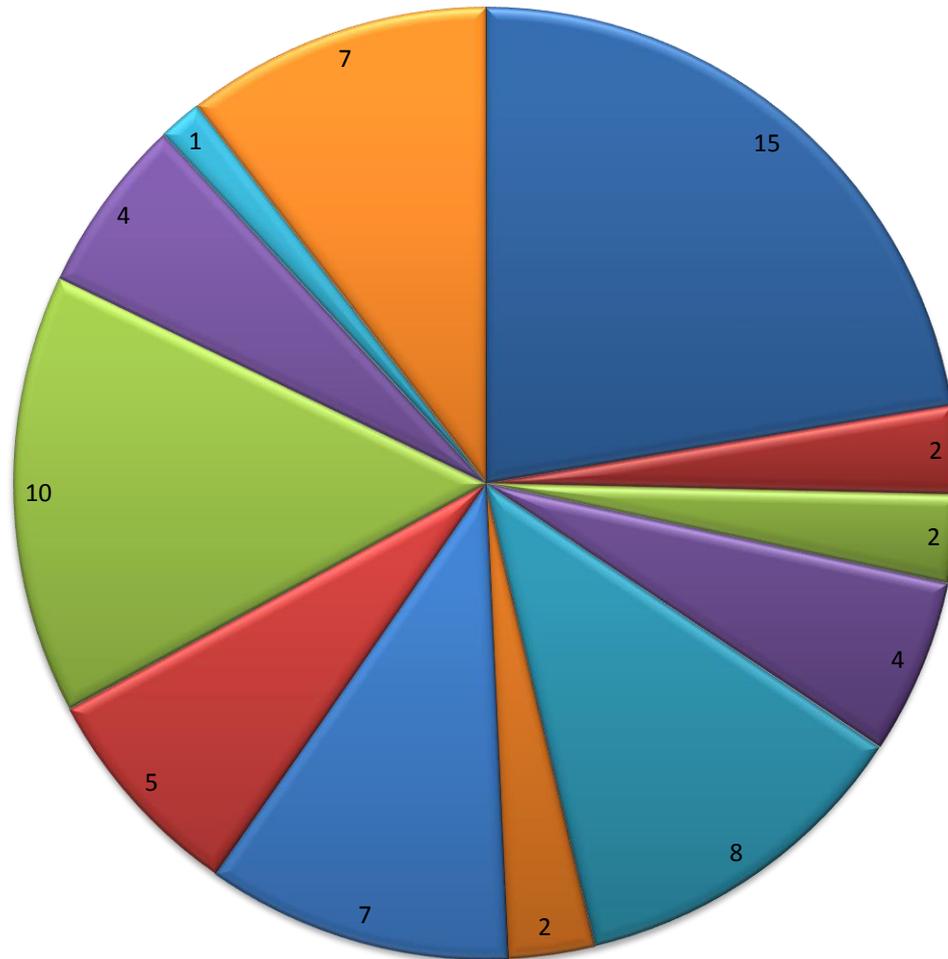
# Appendix 6

## Survey Responses

## ASD Parent Survey Results July 2015

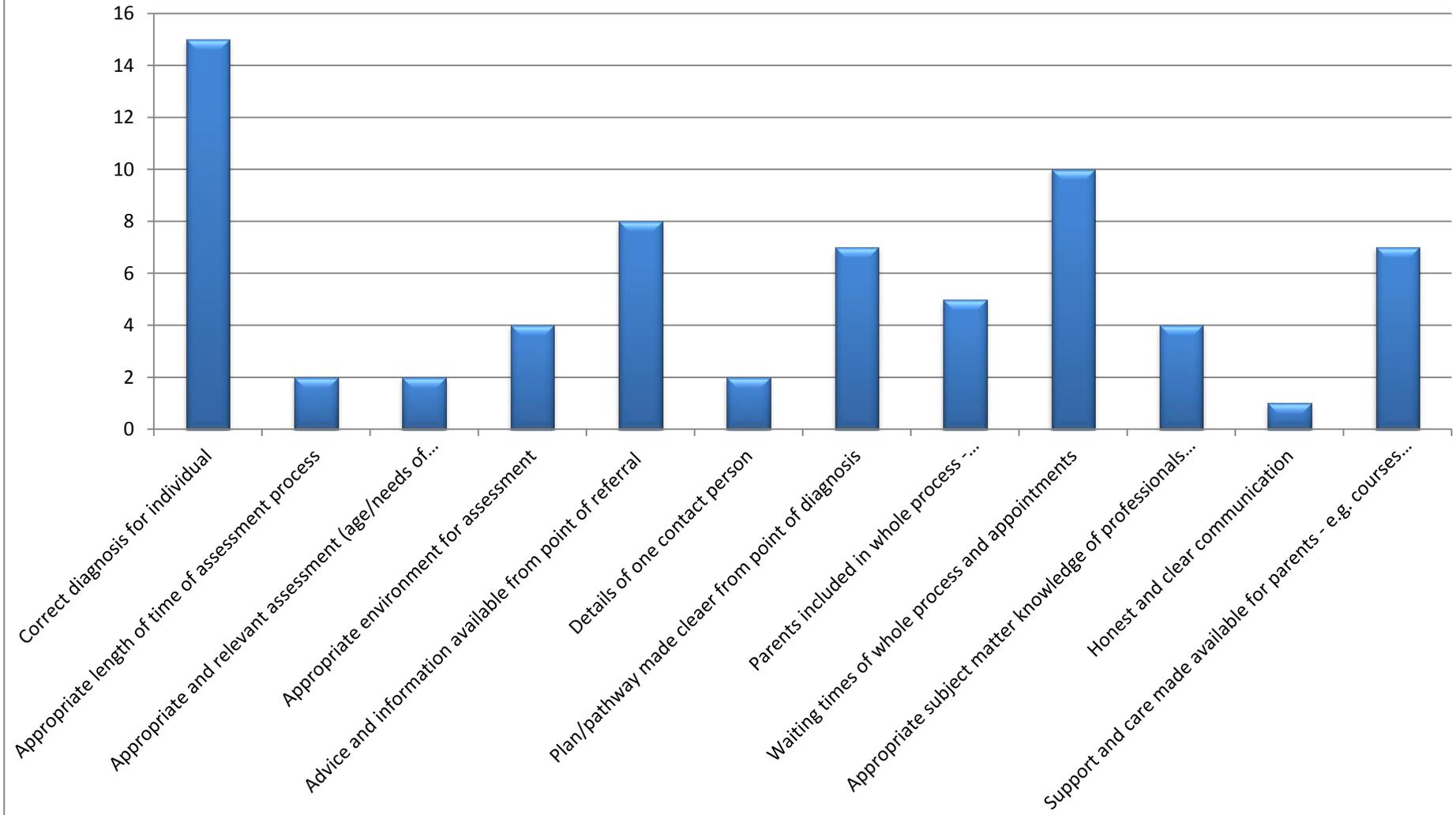


## NO. OF COMMENTS



- Correct diagnosis for individual
- Appropriate length of time of assessment process
- Appropriate and relevant assessment (age/needs of individual patient)
- Appropriate environment for assessment
- Advice and information available from point of referral
- Details of one contact person
- Plan/pathway made clearer from point of diagnosis
- Parents included in whole process - assessment/diagnosis/recommendations etc
- Waiting times of whole process and appointments
- Appropriate subject matter knowledge of professionals dealing with child's case
- Honest and clear communication
- Support and care made available for parents - e.g. courses and learning

## NO. OF COMMENTS



**Produced by:  
Cheshire and Merseyside  
Strategic Clinical Networks  
December 2015**