Bolton Multiagency Autism Pathway

Review date: July 2019

Contents

Version

V1.2	08.06.17	Original document draft
V1.3	06.07.18	Update of guidance following approval of pathway
V1.4	11.07.18	Additional amendments following multi-disciplinary group meeting
V1.5	19.07.18	Amendments to layout and addition of contents page

Diagnosis of Autism Pathway

Introduction

The purpose of this pathway is to describe expected practice in relation to children and young people and their families who may have Autism (Appendix 1 & 2). It is recognised that early identification supports better outcomes for children and young people with a diagnosis of Autism. The pathway focuses particularly on the importance of joint working among professionals when Autism is suspected. All relevant agencies in Bolton, which employ professionals involved in making a diagnosis of Autism, have agreed that this pathway will be followed in line with clinical need.

A large number of professionals in different agencies work with children who have been identified with Autism, which may involve specialist intervention. The Autism pathway is designed to help families and professionals know where to go for additional help for the child. It also makes the process as clear and timely as possible, ensuring that the child and family receive the appropriate input at the right time. Most importantly, the pathway should allow children, young people and their parents/carers to understand how the various services will work together, with the aim of obtaining the best outcome as soon as possible.

Assessment

The Diagnosis of Autism Pathway will involve new ways of working with creative and positive thinking and practice. It should limit duplication, potential confusion and the hurdles families often face and, offer the opportunity for early support (even in the absence of confirmed diagnosis, such as Autism). A guiding principle of this work is that whenever possible, a child’s presenting needs should be met from within universal services (such as Education), since in reality, this is where they will spend much of their time. However, in some cases a child and family may require an additional, more specialist level of intervention such as from the Integrated Community Paediatric Service and Child and Adolescent Mental Health Services (CAMHS) or to inform or enhance how the child will continue to be managed in the universal setting (such as Education). This involves a graduated approach in which more specialist services may be incrementally added to the universal services on the basis of individual need, but without in any way replacing them.

The Importance of Parents/Carers

Parents/Carers are essential partners in the assessment process. They are also an invaluable source of information. While we recognise that practitioners may have a range of hypotheses, especially in the early stages of investigation, it is considered good practice that parents/carers be included in and aware of these hypotheses. It is important that such information is coordinated amongst the professionals involved with the family to avoid mixed, or confusing, messages. Precisely how this information should be shared with parents/carers is a matter for professional judgement.

Working towards a diagnosis of Autism

This section should be read in conjunction with the ***Pathway for the Diagnosis of Autism in Children and Young people < 19 years***

(Embedded below and in Appendix 3)

Final PDF Version
Assessment of Autisn

Stage 1: Initial concerns re. social communication skills are made and information is gathered

I. A parent/carer or other professional raises concerns about a child/young person's social communication skills with Health Care/Education Professional

II.
   a. GP or other Health Care Professional e.g. School Nurse assesses concerns, gathers information and review
   b. Education professionals follow the Assess, Plan, Do, Review cycle as per SEND Code of Practice[1]

III. Parents and carers are referred to the Bolton Parent Carer Consortium for support and signposting.

Telephone: 07715 201798
Email: enquiries@bpcc.org.uk
Website: http://www.bpcc.org.uk

IV. If concerns still exist, after a review of the information gathered and/or interventions and strategies that have been implemented, consent must be gained to share information with other professionals within Education and Health

V. Children and young people exit the diagnostic pathway if their needs can be met by advice/interventions of explained by other causes or factors/ An early referral for medical assessment to be made to the relevant service(s) if necessary

Referral for medical or CAMHS assessment:

Community Paediatrics	**CAMHS**
- Pre-School and Primary school age - If concerns about child's development - There are concurrent medical issues such as possible seizures or regression	-Secondary School age or older -Suspected associated mental health problems e.g. ADHD / Attachment / Behaviour

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[1] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf

Stage 2: Information Gathering and Educational Observations

I. Using Early Help processes, Health Care / Education Professional shares concerns with other agencies including Health Visitor (if appropriate age), Nursery/School setting.

   a. GPs or other Health Care Professionals will complete the GP sharing information form (Appendix 4) or produce a letter which contains all the required information on the form and send to the child/young person's Special Educational Needs Coordinator (SENCO) or Health Visitor

   b. For School age children and young people who are not in an education setting, the health professional should gather as much information as possible and contact the Elective Home Education Officer for advice.

Referral to SENCO by GP or other Health Care Professionals

- **The Integrated Working (IW) Team will be able to inform which School a child goes to.**
- **Telephone: 01204 331392**
- **Email: boltonISA@bolton.gov.uk**
- **GP/Health Care Professional to send GP Sharing Information Form* securely to the School to initiate Early Help Action Plan**

***Please ensure GP Sharing Form content is covered if sending a GP letter to SENCO instead.**

II. An Education Professional or Health Visitor must be identified as a **Lead Professional** to support the child/young person and their parent(s)/carer(s) through the assessment process. Once identified, the parents/carers and other professionals involved in supporting the child/young person should be informed (preferably in writing) by the Lead Professional. The Lead Professional should support the family in involving the child/young person in the process

III. An Early Help Action Plan identifies interventions and strategies for School and Parents/Carers. If relevant, this should include meeting any wider needs the family may have. The School/Setting should refer to Assessment and Intervention Strategy in the SENCO Handbook.

IV. An Early Help Review of assessments, interventions and strategies is undertaken (for a minimum of one term). As per SEND Code of Practice, the setting must refer to outside specialist support service(s) for further assessment including but not limited to Ladywood Outreach, Behaviour Support and Education Psychology. Contact and referral details can be found on Bolton's SEND Local Offer website[2]

   a. If following the review, concerns are reduced and improved outcomes for the child/young person and their family are noted (or difficulties are explained by

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[2] http://www.localdirectory.bolton.gov.uk/send.aspx

other cause or factors), continue to review and close when best outcomes are achieved.

b. If concerns still exist following the review, Early Help Review is updated to identify outstanding concerns, including success (or not) of any interventions and strategies which were implemented.

For children and young people who cope without significant difficulty in education setting however the health professional seeing thinks that a diagnosis of autism assessment is necessary, the health professional should gather as much information as possible and contact Bolton Social Communication Integrated Panel (BSCIP) via boh-tr.icpsreferrals@nhs.net for advice.

Stage 3: Multi-agency assessment

I. Lead Professional to refer to Bolton Social Communication and Interaction Panel (BSCIP) with parental consent via Early Help with all information collated in Stage 2. Referral information to be securely emailed to the Integrated Community Paediatric Service (ICPS) on boh-tr.icpsreferrals@nhs.net

II. Further information on Early Help processes including access to resources can be found on:

http://boltonsafeguardingchildren.org.uk/working-with-children-and-young-people/early-help-and-working-together/

III. BSCIP triages request and arranges further assessments as needed (including either Children and Adolescent Mental Health Services (CAMHS) or Community Paediatrics)

IV. Additional specialist assessments are completed and returned in a timely manner

V. BSCIP meets on a monthly basis to consider all the information about the child/young person. Other professionals working with the child/young person will be invited to the panel if required. The BSCIP membership is compliant with NICE Guidelines.

VI. Autism Diagnostic Observation Schedule (ADOS) assessment to be completed if required

   a. Part of the assessment should include considering other conditions that can occur alongside Autism e.g. Attention Deficit Hyperactivity Disorder, Sensory issues etc. If found, these conditions should be managed as usual
   b. The use of the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) diagnostic criteria has been agreed to be used in Bolton as a common tool used within the assessment.

Stage 4: Outcome of Assessment

Autism Identified

I. Once the professionals involved in the assessment are satisfied that any uncertainties have been resolved, and a diagnosis of Autism is identified, this should be confirmed in a face to face meeting with the parents/carers. Information about available support and agencies should be given to the parents/carers at this meeting. The identification of an Autism diagnosis should then be confirmed in writing to the parents/carers and all professionals.

II. There should be a discussion with the family about how and when to share the outcomes of the process with the child/young person, taking into account their age, developmental level and parental wishes.

III. Families should be given the contact details of the local National Autistic society phone number and web details to obtain up to date information on local resources/ help and to receive the LNAS Link magazine.

IV. Follow up with relevant professionals should be arranged within 6 weeks

V. A care plan is prepared and implemented by relevant agencies integrated with education plans as appropriate

Autism Excluded

I. Where more time is required for assessment (such as for a child to develop, or for an intervention to be evaluated), then parents/carers should be informed verbally (and in writing) of what the next steps are and when the circumstances will be reviewed.

II. Where parents/carers or a young person disagrees with the outcome, it is important to try to resolve the disagreement amicably. This may involve identifying and clarifying the nature of the disagreement, consulting with colleagues and advising parents/carers of the possible next steps. An external second opinion may need to be sought

Dealing with disagreements

I. Where there is uncertainty or disagreement within the group of professionals involved with the child as to the outcome, then the practitioners should seek a joint assessment or external second opinion.

II. When parents/carers or a young person disagrees with the outcome, it is important to try to resolve the disagreement amicably. This may involve identifying and clarifying the nature of the disagreement, consulting with colleagues.

III. If the disagreement is not resolved and an external second opinion is requested by the parents/carer, they should be directed to contact Bolton Clinical Commissioning Group.

Appendix 1: What is an Autism Spectrum Disorder?

The term “Autism Spectrum Disorder” is used to describe a range of conditions, which share certain core features. However, the picture is unique to each individual, depending on factors such as gender, age, ability and personality style and may vary in degree and expression.

All children with an Autism Spectrum Disorder have difficulties in the following three areas, known as the “Triad of Impairments.”

a. Difficulty with social understanding and relationships with adults and children
b. Difficulty with social communication and language
c. Difficulty with social imagination (i.e. difficulties with flexibility of thought and behaviour)

In addition, their sensory perception and processing is often different from other children (Bogdashina, 2003). They can be hypo or hyper sensitive and can have difficulty selecting out what is relevant, thus being overwhelmed or confused by sensory information.

(For more details on the Triad of Impairments, please see Appendix 2)

Difficulties in these areas must be present before the age of 36 months for a diagnosis to be made (ICD-10, WHO, 1992), although such difficulties can be missed in the early years so that the diagnosis often occurs at a much later age, particularly in the more able group. While all children may show some or all of these difficulties at some time or another, where they are continuing, occur in more than one setting and/or are at a level unusual for the child’s age, the matter should be investigated.

How many people have an Autism Spectrum Disorder?
Diagnosis is based on observation and history taking and there is no definitive test for ASD. The Medical Research Council review of Autism research (see overleaf) states that there is likely to be about 60 per 10,000 children with an ASD under the age of 8 years. This rate is likely to increase with age, as more children are identified. More boys are diagnosed as having an ASD (overall ratio 4:1) than girls, particularly in the more able group.

What causes an Autism Spectrum Disorder?
There is evidence from twin studies and studies of family members that genetic factors are involved in ASD, probably with the involvement of several genes. Several environmental factors and possible triggers are also being researched.

Are children with Autism Spectrum Disorders more likely to have other problems?
As traditional methods of learning require good communication skills, then all children with an ASD will need staff to be aware of learning styles for children with ASD. About 70% of children with Autism also have additional learning difficulties and will be delayed in their development. About 30% of children with Autism and all of those with Asperger Syndrome will be of average or above average intellectual ability and can do very well academically. However, their good academic skills may mask their difficulties in social and emotional understanding, problem-solving and independent living skills. Children with ASD are more likely to have epilepsy, hearing difficulties, visual problems, sensory problems, motor problems, difficulties sleeping and dietary problems.

Some medical conditions are also commonly associated with Autism Spectrum Disorders. These include conditions such as Fragile X syndrome, Rett Syndrome, Down Syndrome and Tuberous Sclerosis.

Can children with Autism Spectrum Disorder be helped?
It is generally accepted that ASD is a lifelong condition and that education is the most effective

intervention (NIASA, 2003). With appropriate support and interventions, children can develop strategies to help address the difficulties they have in social understanding, interaction and communication, so that with time, their ASD might be less apparent and disabling.

References

Medical Research Council (2001) Review of autism research: epidemiology and causes, London: Medical Research Council

National Initiative for Autism: Screening and Assessment (2003) National Autism Plan for Children, London: National Autistic Society

Appendix 2: The Triad of Impairments

As noted in Appendix 1, all children with Autism Spectrum Disorders have the following characteristics, described as the “Triad of Impairments.” These are:

a. Difficulty with social understanding and relationships with adults and children
b. Difficulty with social communication and language
c. Difficulty with social imagination (i.e. difficulties with flexibility of thought and behaviour)

In addition, their sensory perception and processing is often different from other children (Bogdashina, 2003). They can be hypo or hyper sensitive and can have difficulty selecting out what is relevant, thus being overwhelmed or confused by sensory information.

The following notes elaborate on these three areas. Children with an ASD can be very different from one another so not all the features described will be seen in all children or to the same degree (both within and between genders).

a) Difficulty with social understanding and relationships with children and adults

Four different social subgroups have been identified in the autism spectrum (Wing, 1996). Children can change over time in terms of which group best describes them.

i) The aloof group
Children in this group are not people focused. They may behave as if other people do not exist. They may avoid physical contact from others (including hugs), unless this is initiated by them. They may walk past others without acknowledging their presence. They may use another’s hand to carry out tasks (e.g. open a fridge door), without looking at the person.
This group is often described as being “in a world of their own.” Claire Sainsbury (2003), a very able woman with ASD says, “We are in your world, but we are just attending to different parts of it.”

If children take part in rough and tumble play, social contact may appear “typical” and appropriate, but the child will often return immediately to his or her “own world” once the game is over.

ii) The passive group
This group will accept social approaches from others but may not initiate social contact with children or their parents/carers. Like the aloof group, they may avoid people and make very few demands on their parents/carers. They are often termed prematurely independent or as babies may be described as ‘too good’.

iii) The ‘active but odd’ group
Children in this group often make social approaches to others, most often with adults, but this often feels one-sided. The manner in which they make contact can be unusual and inappropriate (e.g. touching others; hitting others; interrupting loudly with a question about their special interest). Physical contact can be over-enthusiastic and they may cause pain to others but not realise this – as they may have difficulties in interpreting and /or expressing pain. They may therefore be termed rude, selfish and aggressive, when this is not their intention at all. They fail to understand and appreciate others’ needs and emotional feelings.

This group may be misdiagnosed as their active social approaches can mask their lack of understanding of how and why to interact socially.

iv) The over-formal, stilted group

This may be seen in those who are most able and who have a good level of spoken language. They may be excessively polite and formal in their behaviour and try hard to stick rigidly to the rules of social interaction. They have difficulty understanding these rules and have difficulty in understanding that these rules change with the social context.

b) Difficulty with verbal and non-verbal communication and language

All children and adults with Autism Spectrum Disorders have difficulties in understanding the purpose of communication and in how to communicate effectively. They often only communicate with others for a very limited range of functions (usually requests for objects or activities) and do not communicate for the simple pleasure of sharing ideas and observations with others. They may have problems in processing the spoken language of others and take language literally and so be confused with phrases such as 'Paint the child next to you' or with metaphor and jokes. Apart from children with Asperger Syndrome, all other children on the autism spectrum are delayed in developing spoken language by the age of 3 years and some of those children will need alternative forms of communication to speech. Children with good spoken language can have problems with holding conversations with difficulties with social timing, intonation, body language and in changing the focus from their interest to that of the listener.

c) Difficulties in flexibility of thought and behaviour

Children without ASD are usually able to adapt if situations change and can predict what they might do instead – often recalling similar, past experiences. This enables them to problem solve, to make choices and to engage with different social partners. In ASD, children find it very hard to work out what to do when their usual routine or activity is interrupted or cannot be followed and this can cause great distress. It is very helpful if they are given visual reminders or suggestions of what they might do. They may not appreciate that toys represent the real object nor that they can pretend to be someone else in a game – and so find other ways to explore a toy car or train (e.g. spinning the wheels). Their play therefore often looks unconventional and they may need support in broadening out the range of play activities.

Once they have developed a particular routine (e.g. route to school) or way of doing an activity (drinking from a bottle), some children with ASD prefer to stick to this routine – as they know it works and they can succeed. Suggesting an alternative can be very anxiety-provoking as they cannot then predict what might happen instead. Change therefore has to be gradually introduced and planned to reduce anxiety and panic.

Strengths and special interests

Not all children with ASD will have an area of exceptional talent or skill. However, it is very important for ALL children that their strengths, special interests and skills are assessed, recorded and made a part of their programme of support. Children with ASD are not as motivated by the usual social rewards, and so their special interests can act as incentives for working on less desirable activities or difficult areas.

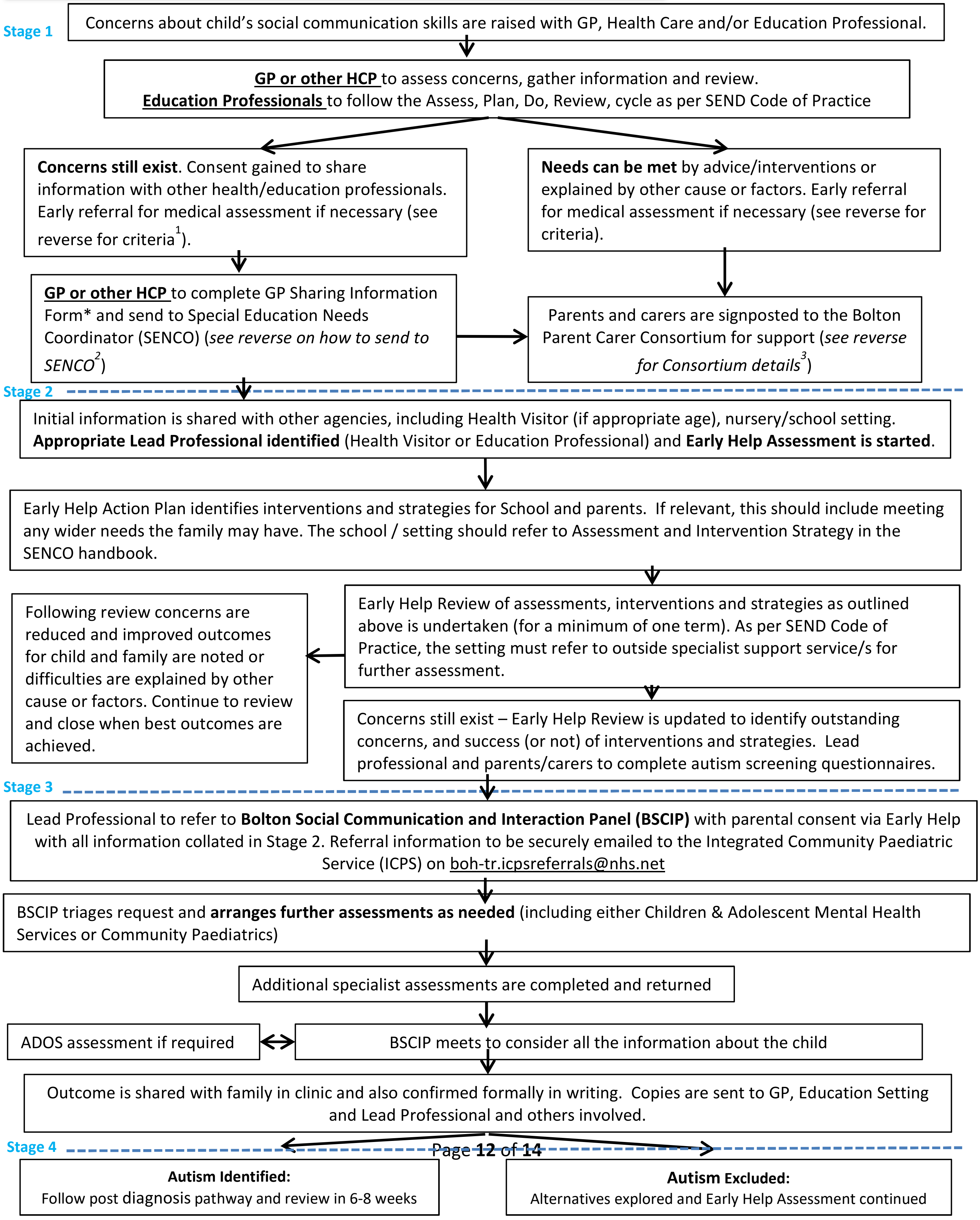
It is worth noting that some able adults with ASD are keen to see ASD as Autism Spectrum Difference and not Autism Spectrum Disorder, as they maintain their way of being is a valid and successful way of being – and that they are only disabled when they are misunderstood and upset by others who do not know them and do not understand ASD.

Wing, L (1996)
The autistic spectrum: a guide for Parents and professionals London: Constable

Appendix 3: Bolton's Pathway for the Diagnosis of Autism in Children and Young People <19

Pathway for the Diagnosis of Autism in Children and Young People <19 years

NHS
Bolton Clinical Commissioning Group



Stage 1

Concerns about child's social communication skills are raised with GP, Health Care and/or Education Professional.

GP or other HCP to assess concerns, gather information and review.
Education Professionals to follow the Assess, Plan, Do, Review, cycle as per SEND Code of Practice

Concerns still exist. Consent gained to share information with other health/education professionals. Early referral for medical assessment if necessary (see reverse for criteria[1]).

Needs can be met by advice/interventions or explained by other cause or factors. Early referral for medical assessment if necessary (see reverse for criteria).

GP or other HCP to complete GP Sharing Information Form* and send to Special Education Needs Coordinator (SENCO) (*see reverse on how to send to SENCO*[2])

Parents and carers are signposted to the Bolton Parent Carer Consortium for support (*see reverse for Consortium details*[3])

Stage 2

Initial information is shared with other agencies, including Health Visitor (if appropriate age), nursery/school setting. **Appropriate Lead Professional identified** (Health Visitor or Education Professional) and **Early Help Assessment is started**.

Early Help Action Plan identifies interventions and strategies for School and parents. If relevant, this should include meeting any wider needs the family may have. The school / setting should refer to Assessment and Intervention Strategy in the SENCO handbook.

Early Help Review of assessments, interventions and strategies as outlined above is undertaken (for a minimum of one term). As per SEND Code of Practice, the setting must refer to outside specialist support service/s for further assessment.

Following review concerns are reduced and improved outcomes for child and family are noted or difficulties are explained by other cause or factors. Continue to review and close when best outcomes are achieved.

Concerns still exist – Early Help Review is updated to identify outstanding concerns, and success (or not) of interventions and strategies. Lead professional and parents/carers to complete autism screening questionnaires.

Stage 3

Lead Professional to refer to **Bolton Social Communication and Interaction Panel (BSCIP)** with parental consent via Early Help with all information collated in Stage 2. Referral information to be securely emailed to the Integrated Community Paediatric Service (ICPS) on boh-tr.icpsreferrals@nhs.net

BSCIP triages request and **arranges further assessments as needed** (including either Children & Adolescent Mental Health Services or Community Paediatrics)

Additional specialist assessments are completed and returned

ADOS assessment if required

BSCIP meets to consider all the information about the child

Outcome is shared with family in clinic and also confirmed formally in writing. Copies are sent to GP, Education Setting and Lead Professional and others involved.

Stage 4

Autism Identified:
Follow post diagnosis pathway and review in 6-8 weeks

Autism Excluded:
Alternatives explored and Early Help Assessment continued

Appendix 4: GP Sharing Information Form

GP Sharing Information Form for Assessment of Autism

F.A.O SENCO LEAD:	***(insert school name)***
School secure email	***(insert school secure email)***

The Integrated Working (IW) Team will be able to inform which school a child goes to. (Telephone: 01204 331392 / Email: boltonISA@bolton.gov.uk).

1. GP Details

GP Practice:		Telephone Number:	
Address:		Email Address:	

2. Children and Family Details

Children(s) Name:		Gender:	
Date of Birth:		Primary Language:	
Ethnicity:		Other languages spoken:	
Primary Address:		Telephone/mobile:	

3. *Free text re any concerns prompting this sharing of GP information*

4. Childs Health

4.1. Any known medical problems on records?

4.2. Any developmental concerns from own assessment or records?

4.3. Any previous involvement with speech language or paediatrics re communication concerns?

4.4. Any other specialist inputs/ hospital appointments?

4.5. Any regular medications or allergies?

4.6. Any FH of any significant conditions known?

5. Family Details

Name:	
Relationship to child:	
Address (if different to above):	
Telephone (if different to above):	
Do parents have any special requirements such as disability, language/communication difficulties, mental health issues? If so, explain clearly	
Any social concerns e.g. housing/ finances?	
Any previous/ current SG issues/ concerns with any child linked to the home?	
Any concerns regarding siblings from medical notes/ family?	
Any other adults known to be living in the home?	
Any concerns over health seeking behaviours of family?	

6. Action required by SENCO

SENCO to commence Early Help Action Plan to identify intervention and strategies for the school and parent as per The Bolton Assessment of Autism Pathway.

7. The Bolton Parent Carer Consortium

Parents and carers are signposted to the Bolton Parent Carer Consortium for support.
Telephone: 07715 201798 / **Email:** enquiries@bpcc.org.uk / **Website:** http://www.bpcc.org.uk

Enter 'X' to say information leaflet re The Bolton Parent Carer Consortium given: ☐

8. Consent

I understand and agree with the information recorded on this form. I understand and agree that it will be stored and used for the purpose of providing services. I have had the reasons for information sharing explained to me and I understand those reasons.

	Name	**Date**
Young person (if old enough);		
or Parer;		
or Carer		
Practitioner		