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An Autism Spectrum Disorders Forum: A Model for the Effective Use of Multidisciplinary Assessment and Intervention Planning with Limited Clinical Resources

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Abstract

Increasing numbers of young people are coming forward for assessment of autism spectrum disorders (ASD). Staff from pediatrics and child health services need to work together closely with Local Authority staff and child and adolescent mental health services (CAMHS). This paper describes the functioning of an ASD Forum, which allows for careful use of resources whilst providing comprehensive assessment and intervention planning services in an integrated way.

Keywords: Autism spectrum disorder; ASD; Mental health; Children and young people; Intervention planning

Background

There has been a large increase in the diagnosis of autism spectrum disorders (ASD) over the last 50 years [1], from 0.01% of people in the Western world receiving an ASD diagnosis in the 1960s to almost 1% in recent years [2]. This increase is in part related to the broadening of awareness and criteria [3], increased training of diagnosticians [2] and more people receiving diagnosis of high functioning autism and Asperger syndrome [4]. An increase in diagnostic labels being used to access educational support services [5] may also be encouraging parents to seek assessment. Despite this very clearly defined steady increase in need for assessment and intervention, commissioners have been relatively slow to commission new services. This may be related to government focus on new commissioning of other worthy causes (including early psychosis treatment, services for looked after children, youth offending services, drugs and alcohol services, carers and young carers), and more recently provision of universal cognitive behavioural therapy, parenting support and outcome monitoring [6]. Without new commissioning many localities have struggled to keep pace with increasing referrals and adult services have not been available for those in transition [7]. Some localities have received funding to develop diagnostic services encouraged by the National Institute for Health and Care Excellence (NICE) guidelines [8]. There have been several papers describing how services are organised for the assessment and diagnosis and intervention planning [9,10] of ASD, and other papers suggesting waiting lists and difficulties in delivering services to this growing group of children and young people [11]. Others have examined innovative ways of delivering care more cheaply, such as using visual media technologies for assessment and interventions [12].

In 1995 we opened a new ASD service by moving resources within our own services. This service initially began with two aims in mind. Several multidisciplinary professionals were being asked to see children with an ASD diagnosis leading to multiple assessments by different professionals, and some children were receiving different diagnostic labels from different services. We sought to unify around one diagnostic system by agreeing a nomenclature and an assessment system (the World Health Organization) and care pathway. We also brought clinicians together from child health services, child mental

health services, community pediatrics, and the Local Authority to avoid duplication and create a more streamlined system. In practice we achieved a third aim which was a far more efficient mechanism for organizing and coordinating interventions [13]. An initial trial of a clinic with real time multidisciplinary assessments proved unsuccessful because it proved to be too expensive (with multiple professionals seeing very small numbers of children in a clinic simultaneously), and unable to cope with the volume of referrals.

We then moved to a system that came to be called the Autism Spectrum Disorders Forum ("The ASD Forum"). The principle of this is that the multidisciplinary, multiagency group of professionals meets monthly for an afternoon to discuss children newly referred and with recently completed assessments where at least two professionals know the child. Assessments are arranged flexibly by individual professionals or pairs of professionals in between meetings with reports shared at the forum. The full assessment process is described in the York Strategy for children and young people with autism [14]. Any professional is able to bring a child for discussion at the first meeting by booking that child (with parental permission) into a centrally held diary in the Child Development Centre. The child is discussed using a systematic appraisal of the research diagnostic criteria for ASD across home, school, and clinic using a grid projected at the meeting. The meeting systematically considers the 12 main symptoms or behavior areas in the World Health Organization research diagnostic criteria, and each of these is considered across different settings or assessments (such as the parent interview, the play based assessment and the school observations).

Usually, at least two professionals have had contact with the child and information is shared about findings in different settings and contexts. Parental reports are always corroborated in at least one other

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setting (e.g. nursery school). Professionals known to the child and family are invited to add valuable information and may send reports (Figure 1).

At this point there will be some children for whom a diagnosis (or absence of a diagnosis) is very clear. This leads to discussion regarding a care plan with involvement from multidisciplinary professionals present or with agreed referrals to other professionals for service provision. If a diagnosis is not clear, a series of additional assessments are requested. This may be a speech and language assessment, hearing evaluation, occupational therapy assessment, physiotherapy or psychology assessment, or it may be a paediatric or social work assessment. If not already completed it may also be a specific Autism Diagnostic Inventory assessment (ADI-R), a specialist semi-structured interview with the parent [15], or an Autism Diagnostic Observation Schedule (ADOS-2) which is a play, activity, and interaction based assessment with the child or young person with five modules broadly arranged around language and cognitive ability [16]. These assessments are arranged with the family and a deadline set for re-discussion at the forum (usually two months). The family is provided with a designated keyworker (usually the initial referrer) who attends the ASD Forum and meets the family regularly and keeps them up to date. Families discuss drafts of reports to be presented at the Forum for comments and to enable them to check the accuracy of information presented. The ASD Forum is made up of sessional time from the following disciplines:

- Consultant child psychiatrists
- Consultant clinical psychologists
- Consultant paediatricians
- Speech and language therapists
- Educational psychologists
- Occupational therapists
- Child mental health nurses
- Social workers
- Autism specialist teachers
- Trainees of any of the above

A survey of the ten years between 2005-2015 is presented to explore throughput and activity.

Autism Spectrum Disorders Forum Survey 2005-2015

In total, the ASD Forum covers a catchment total population of 285,000. Currently, over a ten year period the ASD Forum has assessed and discussed 596 children and young people. 104 (19%) 0-18 year olds received a diagnosis of autism, 28 (5%) received a diagnosis of atypical autism and 173 (32%) received a diagnosis of Asperger syndrome. It is

not possible to equate this to a prevalence figure as we have no routine screening in place and many children with possible ASD may not have come to the attention of services. Children moving into the area who have been diagnosed elsewhere are discussed at the ASD Forum but some families do not come forward because their children/young people are doing well in mainstream schools and do not require help or already have the support they require (Table 1).

Of those children discussed, 542 were new referrals to the ASD Forum and 54 (10%) were repeat discussions. Table 1 shows that the number of new referrals to the ASD Forum over the ten year period has doubled from 38 to over 80, with an average of around seven children now discussed at each monthly ASD Forum meeting.

The mean age of first referrals was 8 years, 6 months (range 2 years, 1 month to 18 years, 3 months), with 81% being male (n=483). Waiting time data collected during 2005-2011 were analysed, which showed a mean waiting time of 4.15 months (range: 0-58 months) from first concern to referral and referral to forum diagnostic discussion.

Table 2 describes the number of diagnoses by year and diagnostic category. The majority of those who received a diagnosis were given a diagnosis of Asperger syndrome (n=172) followed by those with a diagnosis of autism (n=116) with the less common diagnoses of atypical autism (n=31) or ASD (n=14). The percentage of those receiving a diagnosis has risen from 42.42% to 68.5% over the 10 year span. This may be due to a variety of factors. A screening questionnaire was introduced in 2007 when the referral rate was growing. This allowed children to be redirected to other services if it was clear that ASD was very unlikely. Also, detailed discussions at the forum meant that the professionals attending the forum increased their understanding about the diagnostic criteria for ASD and hence they gathered relevant information which helped them to refer to the ASD Forum more selectively.

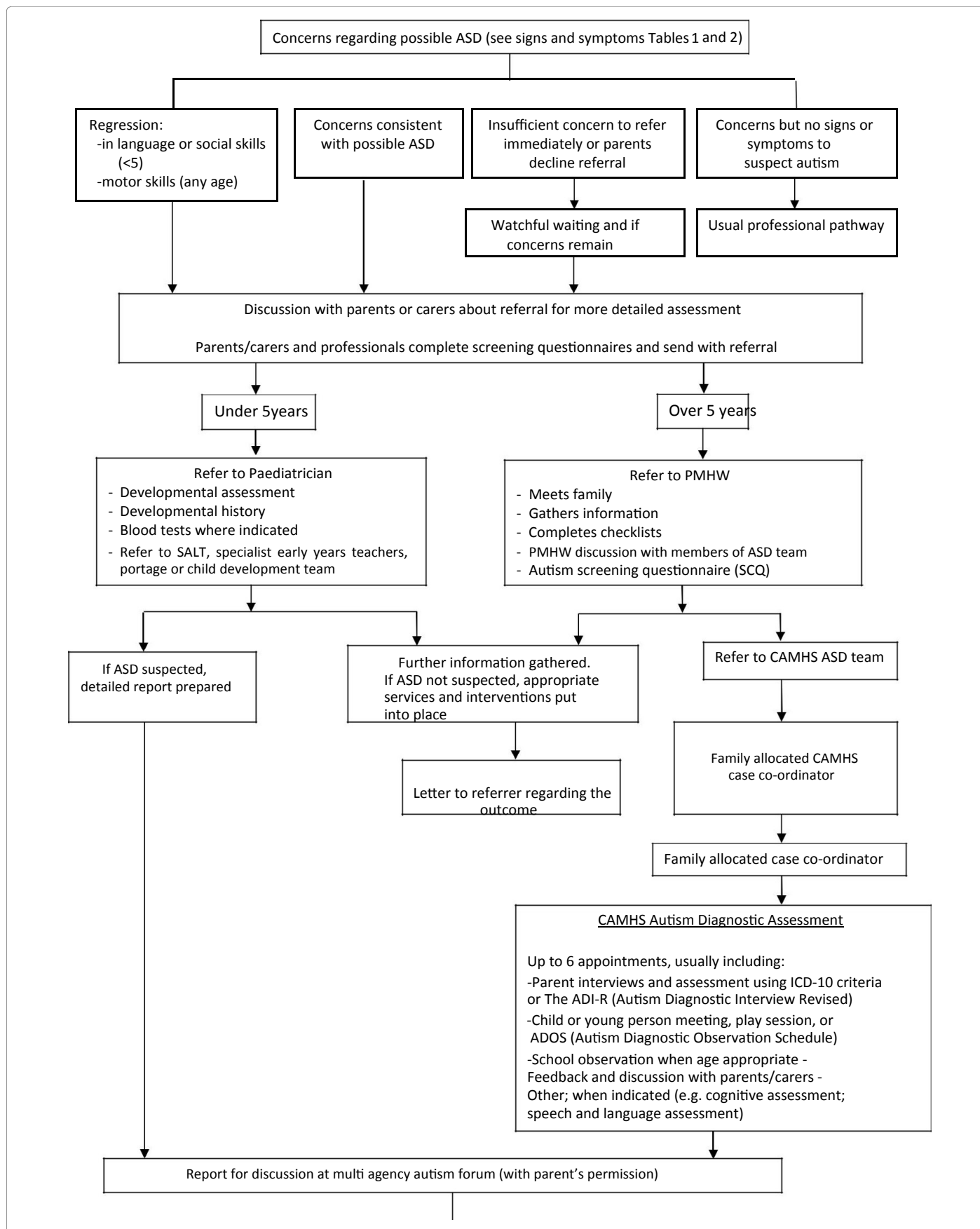
Intervention Planning

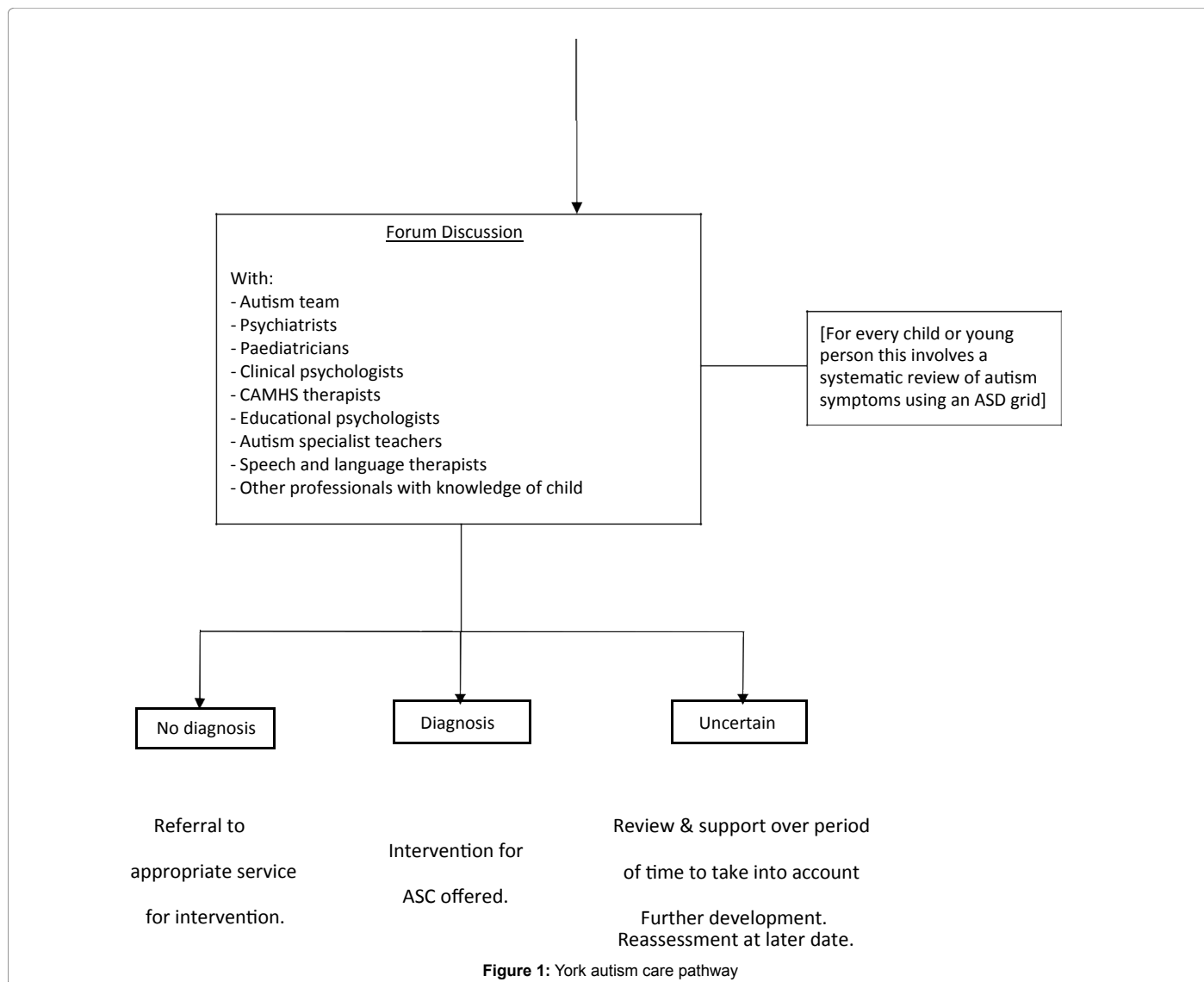
For those who do not receive a diagnosis

Around one third of children discussed at the ASD Forum did not receive an ASD diagnosis. The vast majority had other child mental health problems. The ASD Forum team has an agreement that support should be available for children and families if required regardless of a diagnosis. Children requiring further services were referred accordingly into other care pathways for further assessment and intervention for attachment disorders, language impairment, dyslexia, dyspraxia/motor coordination difficulties, conduct disorder/oppositional

	Numbers Discussed at the Forum												Total	New Referrals	Mean Per Month
	March	April	May	June	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb			
2005-2006	7	0	11	0	6	0	5	0	6	0	9	0	44	38	3.7
2006-2007	9	0	4	0	5	0	3	0	5	0	5	0	31	24	2.6
2007-2008	5	0	8	5	4	8	5	6	9	4	6	4	64	53	5.3
2008-2009	5	5	0	5	3	1	3	0	3	4	3	4	36	23	3
2009-2010	6	6	3	4	7	3	4	5	4	6	5	5	58	43	4.8
2010-2011	6	6	8	6	5	0	7	6	0	6	5	5	60	59	5
2011-2012	6	4	6	7	5	6	6	6	5	7	7	3	68	>40	5.7
2012-2013	6	6	6	5	6	8	7	8	5	9	5	6	77	80	6.4
2013-2014	8	7	7	6	7	0	7	6	8	4	7	8	75	89	6.3
2014-2015	7	7	8	8	6	9	5	8	9	9	7	0	83	>80	6.9
Total													596	542	

Table 1: Autism spectrum disorders forum numbers.





	Diagnosis agreed at the Forum						Total	% no diagnosis	% with diagnosis
	No diagnosis	Asperger syndrome	Autism	Atypical Autism	ASC				
2005–2006	19	6	7	1	0	33	57.58%	42.42%	
2006–2007	16	8	8	3	0	35	45.71%	54.29%	
2007–2008	27	17	11	5	0	60	45.00%	55.00%	
2008–2009	20	13	5	1	0	39	51.28%	48.72%	
2009–2010	29	11	11	2	2	55	52.73%	47.27%	
2010–2011	19	20	12	6	1	58	32.76%	67.24%	
2011–2012	25	19	16	5	0	65	38.46%	61.54%	
2012–2013	29	28	16	3	1	77	37.66%	62.34%	
2013–2014	24	21	19	1	6	71	33.80%	66.20%	
2014–2015	22	29	11	4	4	70	31.43%	68.57%	
Total	230	172	116	31	14	563	40.85%	59.15%	

Table 2: Diagnoses agreed at forum by year.

defiant disorder, attention deficit hyperactivity disorder, anxiety or depressive disorder, or to child safeguarding services. Children were referred initially because there was developmental concern about them

expressed by parents and/or teachers that was shared in part by at least one professional. A small number of assessments were to rule out a diagnosis of autism so that their teachers and parents could move on

and consider alternative explanations for the young person's difficulty and support them accordingly. In some cases additional support was sought from the assessing professionals (e.g. pediatricians, CAMHS, speech and language therapy, education support services). Sometimes there was an agreement from professionals to monitor the young person's progress carefully over a period of a year with interventions in place and a view to re-considering further assessment if required.

For those receiving a diagnosis

A number of available interventions have developed over the years and there are some universal offerings to any diagnosed child and their family. These are described in more detail by the City of York Council [14] and include the following:

Parents and carers groups:

Early bird: In the early years parents of the Forum preschool children with autism attended the Early bird programme [17], but this was replaced by ASCEND (Autism Spectrum Conditions – Enhancing Nurture and Development).

Ascend: EarlyBird has been superseded by the parent programme ASCEND [13], developed locally and evaluated positively with both quantitative and qualitative measures showing positive outcomes for the young person and parent/carers [18]. Three programmes run per year and parents come to groups for autism or Asperger syndrome separately. All parents of children diagnosed on the autism spectrum are offered a place on the course, whether preschool or school-aged. Over the seven years surveyed 81% (n=125/154) of parents of children with a new diagnosis attended ASCEND and 6% attended Early bird.

Parents/carers support group: A monthly drop-in service for parents and carers is led by specialist teachers for autism. All parents are welcome to attend this session to access information through leaflets and books, to meet other parents and to discuss any concerns informally with a specialist teacher. A different venue is chosen each year so that parents across the city may access the group more easily.

Group members support each other and highlight the needs of children, young people and their families. This is to develop the skills, knowledge and confidence of families and professionals to improve the lives of children and young people. There are two local groups, one for parents of children with ASD and the other of children with learning disabilities.

Siblings groups: Siblings have been offered groups for support as well as a chance to meet others children in similar situations. The groups are designed around various fun activities and trips out. A separate Young Carers project also offer support for groups and individual carers.

Carer support and respite

Some families benefit from respite in the form of Sharing Care, where another family supports activities or has the child to stay for activities, meals, overnight stays, weekends or holidays. This gives the child safe and positive experiences outside the home, and gives the parents/carers space and time to spend together, with other siblings or recharging their batteries.

Short breaks

Short breaks are provided for many children and young people with autism. A short break allows a disabled child or young person to have an enjoyable break away from their parent/carer and also gives

their parent/carer a break from their caring responsibilities. They can be for a few hours or longer, including overnight. This can be around a specialist activity with trained supporters (e.g. climbing, trampolining, skiing, and horse-riding). This might include the young person being supported to attend youth clubs.

Information

Information is shared with families and children and young people in a variety of forms; web-based, booklets, newsletters (both paper and online versions), and information given by practitioners. This includes information about sports, short breaks, events, the local parent/carer group, updates from specialist autism teachers, the National Autistic Society, and the charity Ambitious about Autism. The specialist teacher for autism regularly updates parents on an email list regarding relevant activities and events.

Education

Autism specialist teachers: Any child diagnosed with an ASD is referred to the specialist teaching service. The ASD Forum crosses the boundary between two Local Authorities (LAs) and both have floating specialist teachers (two in each LA) who assess children and advise schools and parents on school management and support, and individual education plans.

The York Autism Support team also has two specialist teaching assistants who may go into schools to deliver interventions with children and young people, as recommended by a specialist teacher.

Termly autism training is delivered for teachers and teaching assistants (TAs), plus bespoke training for individual schools as requested. The specialist TAs currently run a half-termly meeting for TAs supporting children with autism in the LA. These are of a practical nature and are very well received. They also co-deliver the ASCEND programme with colleagues from CAMHS and this joint working is felt to be very effective, and highly valued by parents.

Specialist teachers are involved in supporting schools to write My Support Plans and Education Health Care Plans at coordinated assessment meetings. The team work with children at nursery through to those attending college and university, as requested by the educational establishments.

Educational psychology involvement: The educational psychologist is also notified of any new diagnoses and in discussion with the autism specialist teachers will advise on issues such as:

- School provision (in discussion with the LA and in line with the local autism strategy)
- The need for support through SEN support
- My Support Plan (MSP)
- Requests for an Education Health and Care (EHC) Plan under the Children and families Act (2014) or the Special Educational Needs and Disability (SEND) Code of Practice (2015)

Classroom and home strategies: Most of the professionals involved have a good knowledge of a range of strategies used in ASDs and may jointly or individually advise on these strategies including the following:

Picture exchange communication system (PECS): PECS [19] is a system used to help children learn to communicate, to initiate communication and to interact with those around them enabling them to make their needs become known.

Visual timetables and visual calendars: Many children benefit

from the use of visual calendars and timetables to present visual information about the sequence of events.

Classroom strategies in autism units are organised using some principles of best practice from the Treatment and Education of Autistic and Communication Handicapped Children (TEACCH) [20] and other models. This includes clear structure and routine, provision of simple language, use of a range of visual strategies, and reduced classroom clutter.

“Now/Next” and “First/Then” strategies: Positive parenting and teaching is a central part of all interventions supported by all professionals. For example, children may benefit from visual prompts to enable them to transition from one activity to another. Well liked activities can be regularly paired with activities that enhance learning and may also help to motivate children to participate in activities with a clear expectation of future liked activities.

Desensitisation: Desensitisation is useful for helping young people to experience new things and cope with some fears. It works by breaking down the feared situation into very small steps so that children gradually learn to tolerate a small amount of anxiety at a time and do something that they have not been able to do before that is a positive experience for them. It gives them the confidence to move on in small steps until they are able to cope with the situation. It can be used in many different ways, including separation anxiety, fear of animals, and loud noises.

Making sure everyone is working together: Sometimes parents, teachers, grandparents and the child themselves have different views about the child’s needs and have different goals. Discussing this openly with the child’s future in mind can help to bring everyone together to think about how they can agree on goals and ways in which they can support each other and the child.

Traffic Lights: This is a system used in behaviour management for helping children to see their progress visually [13].

Social stories™: Children and young people with ASD and Asperger syndrome have problems understanding the social world. This is related in part to theory of mind delays (mind blindness) where they may have difficulty guessing how other people think or feel. They also find it hard to understand what to do and say in social situations. Carol Gray started writing Social Stories™ [21], as a way of helping children to gain social information, to make sense of specific situations and to help to fill the gaps in their understanding.

Referral for more specialist interventions

Due to the familiarity between the professionals in the ASD Forum, there is a free flow of inter-team referrals depending on the family needs. For complex situations, teams work together in a ‘team around the child’ model [22]. Such interventions may include:

- Paediatric assessments and treatments
- Specialist dental provision

Psychological therapies, including cognitive behaviour therapy [23] for those able to engage, behaviour management interventions and, specialist parenting intervention support [13,24]

Psychopharmacology [25,26] for:

- Serious compulsions that impact on daily living
- Serious sleep disorders not amenable to parenting and behaviour management support

- Serious catatonic symptoms related to ASD
- Other mental illnesses such as psychosis, serious anxiety or depression
- Occupational therapy advice including:
 - Helpful adaptations in the home
 - Management of the sensory environment at school or at home (for example to reduce over stimulation or to promote calm during periods of high stress)
- Speech and language therapy assessment and intervention advice to schools and home
- Social work support from the children’s health and disability team
- Children or young people attended a social skills group or a confidence building group
- Music therapy (received either privately or subsidised by a local charity)

Discussion

Having tried a variety of other models we have found this to be the best to utilise the limited resources of the various teams. It makes use of the various different skills of the professionals available. It also prevents duplication of work. It allows professional opinions to be integrated whilst recognising the very different work patterns of professionals involved. It is compliant with NICE guidelines [8].

In practice the child health teams tend to take new referrals for children aged 0-5 years old in the first instance, and the child and adolescent mental health service (CAMHS) usually assesses those over 5 years. However, there is considerable flexibility in this given the wide variety of presentations of children with many being referred initially to education services, speech and language therapy services, child development preschool groups and other services. There were fewer than expected referrals under age 5. One possible reason for this is changes in universal screening by general practitioner health visitors over time. In times when screening was reduced children coming forward for assessment were flagged up in multiple ways, but not systematically. This may be reflected in the late mean age of first diagnosis. Improved monitoring is now in place and good early detection processes are to be commended.

It is essential that that these children have access to early years support (e.g. Portage) and speech and language therapy who can offer advice, support and sign-posting to other services.

The added benefits include the development of trusting working relationships which has moved us a very long way from the wary professional relationships of the first six months those many years ago. Disciplines respect each other and see themselves as part of a jigsaw of services that provides a ‘team around the child’ to meet families various needs.

The ASD Forum has also led to the development of a range of tools for screening that staff have access to. This includes a ‘parent/carer questionnaire’ and a ‘professional’s questionnaire’, developed by the first two co-authors that seek to elicit good quality information about a child’s behaviour beyond standard ASD screening questionnaires. Crucially, they elicit examples of behaviours in all domains and can be used both as in depth screening tool but also as a mechanism for gathering very useful assessment information in a variety of different settings for the child.

Our findings show strengths and weaknesses of the system. The fact that 82% parents have attended the local parent training course

is very encouraging. This is despite this service currently not being commissioned by the Clinical Commissioning Group, and is testament to clinicians' dedication.

We have continued to use the ICD-10 [27] system rather than the DSM-5 [28] (or the previous DSM-4 [29] after assessment of strengths and weaknesses. One main criticism of the DSM from families and clinicians is the use of nomenclature, with many being reluctant to use what they perceived to be the unhelpful term 'pervasive developmental disorders not otherwise specified' in the DSM-4 in comparison to 'atypical autism' in the ICD-10. With more recent updates in nomenclature there is also feedback that "ASD mild, moderate or severe" in the DSM-5 [28] is unhelpful since it is usually very difficult to define what these mean in relation to another child given the diversity of symptom severity in a range of domains. It also removes the term Asperger syndrome which many (including the young people themselves) have found useful.

Conclusion

Having tried a range of different models, including multidisciplinary team clinics that assess children in a full team assessment, we have found this to be by far the best mechanism for using resources effectively and seeing the increasing number of children not placed on a waiting list waiting to be assessed. Family satisfaction is also high. We commend this model to commissioners as a mechanism for achieving high quality robust multidisciplinary assessment in a resource efficient way that not only reaches conclusions quickly for families but also allows holistic intervention planning. We also believe that this would be a helpful model for newly developing adult services.

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