



**Evaluating the Feasibility and Acceptability of a
New Model of Autism Spectrum Disorder (ASD)
Assessment and Diagnosis by a
Multi-Agency Community Based Team**

The WASP Project (West-fife Autism Spectrum Pilot)

Evaluation Full Report

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Thanks to you all,
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Introduction

National guidelines stress the importance of early diagnosis of Autism Spectrum Disorder (ASD) and intervention by multi-agency services to help children maximize their potential. At present in Fife there are three specialist ASD assessment teams that receive the majority of referrals. Waiting lists are approximately 18 months for this service and ASD diagnosis rates are 49%. This pilot was set up to investigate the feasibility and acceptability of assessing children in their school and community by local workers. The aim of this approach was to promote earlier identification of ASD; to reduce the number of children being referred unnecessarily to the specialist ASD assessment service and to provide seamless links to support in the child's school and community.

The study asked whether the local teams were able to make decisions about ASD diagnosis and whether their decisions were in line with specialists' views; how long the process took; what factors influence the decision-making process; whether the process was feasible and whether the model was acceptable to the parents and workers involved.

Method

Workers were required to attend a planning meeting, then to carry out assessments of the child and finally attend a decision meeting where, as a group, they came to a decision about whether the child definitely had ASD, did not have ASD or needed to be referred for further assessment. Specialist observers were present to validate the decision. Interviews and focus groups were carried out by a researcher to assess the views of parents and workers.

Results

17 children took part in the study from 11 primary schools in West Fife. Six were identified with ASD, three as not ASD and eight were referred for further assessment. 16/17 decisions were validated by the specialist observers. Excluding the case not validated, younger children under 8 were more likely to be given a diagnostic decision than those 8 or over ($p < 0.05$). Those without co-morbidity were more likely to be given a diagnosis of ASD than to be referred for further assessment ($p < 0.05$). The average length of time taken for the process was 18 weeks. In general, the model was found acceptable to parents and workers. They particularly appreciated the natural environment for the assessments and the wide range of information gathered from different sources. However, they found the process difficult, in particular setting up the meetings. Workers also felt they needed more information about how to carry out meetings, to make assessments and compile reports.

Conclusions

The results show that this approach has the potential to significantly increase early diagnosis of ASD in Fife, reduce demand for specialist assessment, and to provide better links to interventions. It is recommended that the model should be rolled out, but, to improve the process, there should be detailed consideration of administration requirements, information-provision, communication and training.

Background

Autism Spectrum Disorder (ASD) has been the subject of considerable political and media attention in recent years. Reviews of the most recent, rigorous studies have estimated that the overall population prevalence of ASD in children is approximately 70.3 per 10,000 (PHIS, 2001, MRC, 2001). This translates to an estimation of 7,714 children under 19 with ASD in Scotland (PHIS, 2001), and approximately 550 children under 19 in Fife.

National guidelines stress the importance of early diagnosis and intervention by multi-agency services to help children maximize their potential. (PHIS, 2001; NAP-C, 2003). On the basis of these guidelines, a Fife Multi-agency Autism Spectrum Disorder (ASD) steering group, chaired by health services, developed a Joint Care Pathway for Assessment and Diagnosis of ASD.

In line with Stage 3 of the Care Pathway, the service in Fife was developed by increasing the number of ASD specialist teams from one to three teams. These teams are known as FAST (Fife Autistic Spectrum Teams). Most children with suspected ASD in Fife are referred, automatically, to one of the three FAST teams which means that there are very long waiting times for a FAST assessment (approx 18 months). Only 49% of the children referred to FAST are diagnosed with ASD (Roberts, 2008).

The steering group agreed that there was a need to develop Stage 2 of the care pathway to support Multi-agency, local community teams to be able to carry out assessments to help them make decisions about which children definitely did not have ASD so that they would not be referred to FAST unnecessarily. It was also recognized by the steering group that some children presented with very obvious signs of ASD and it was hypothesized that it would be possible for the multi-agency community teams to diagnose these children without the need to refer to FAST. However, it was recognized that there would also be cases (due to complexity or subtlety) where the community teams would not have the experience to diagnose ASD with confidence. These cases would need to be referred to FAST for assessment by more experienced professionals and with the use of specific ASD assessment tools (e.g. ADOS, ADI). In summary, we wanted to know whether multi-agency community teams would: be able to make diagnoses of less complex ASD cases; be able to decide confidently when a child definitely did *not* have ASD; and know when they should refer to FAST.

A previous study investigating the views of parents of children with autism in Fife found that parents thought waiting times for assessment should be reduced. They also reported that the best places for assessment of their children would be in the home and school, not in a clinic. Moreover they thought that schools should have more involvement in the process and more training in ASD (Simpson & Hyland, 2003).

The Pilot Model

The pilot involved the school-based, local teams of professionals in West Fife. These teams consisted of the core team of educational professionals already working with the child, with additional support (if not already involved with the child) from the local clinical psychologist, speech and language therapist and the school paediatrician. They carried out a range of assessments in the child's environment (home, school and local clinic), with reference to the ICD-10 criteria to reach their conclusion. Together, these teams made decisions about ASD diagnosis or non-diagnosis for a child or the need to refer on to FAST.

The aim of this proposed model was, primarily, to reduce the number of cases being referred directly to FAST: including those cases which are definitely not ASD and those which are very straightforward ASD cases. This model was proposed to have a number of further benefits: greater knowledge of ASD amongst local health and education professionals; earlier identification of ASD; and more seamless links to support and intervention packages in the school and community setting.

This pilot model is in line with the recent SIGN guidelines for the assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders. These guidelines state that professionals involved should collaborate with relevant multi-agency colleagues to achieve diagnostic consensus. It also states that they should have a low threshold of referral to more specialized colleagues in cases of diagnostic disagreement or subtle presentation. It also recommends the use of the ICD-10 diagnostic criteria for ASD which helps to increase the reliability of the diagnostic process (SIGN, 2007).

Clinical governance of the pilot was dealt with via the NHS. The multi-agency team was requested to adhere to an agreed protocol and took joint responsibility for the diagnosis. Final clinical responsibility lay with the area

consultant paediatrician whose role it was to verify, support and ultimately take responsibility for the team processes, assessments and decisions.

Research Questions

The WASP (West-five Autism Spectrum Pilot) project aimed to assess the feasibility and acceptability of this proposed model for school aged children. The specific research questions we asked were:

1. To explore whether the pilot teams could reach decisions about diagnosis of non-ASD and ASD cases and whether they could reach decisions about which children should be referred to FAST for further assessment.
2. To explore whether decisions made by the pilot teams were in line with FAST specialists' decisions.
3. To explore whether there are any factors which influence the decision-making process by the pilot team, e.g. age of child, sex, presence of co-morbidity, presence of learning disability, etc.
4. To assess the feasibility of the model in terms of administration requirements and time taken from initial referral to final decision by the team.
5. To measure the acceptability of the proposed model in terms of parents' satisfaction, pilot team's views and FAST specialists' views
6. To determine any requirements of the pilot teams for further training.

Study design

This study used qualitative methods to determine acceptability and feasibility of the pilot model and quantitative methods to examine characteristics associated with particular outcomes. Qualitative methods used were participant observation of the team meetings to explore the decision-making process and semi-structured interview and focus group techniques to explore views of parents and professionals. Ethical approval was provided by the Fife and Forth Valley Research Ethics Committee for the conduct of this study. Quantitative analysis was carried out using SPSS version.

Recruitment

1. Potential participants were identified from the waiting list of the West Fife FAST team.
2. The families of all potential participants were informed in detail about the pilot with a participant information sheet and asked for their consent to take part. It was made clear that the pilot involved a different assessment / diagnostic process which was being evaluated. They were informed that they may have the benefit of a quicker assessment and diagnosis as a result of taking part. They were assured that if there were any doubt about the diagnosis, they would be offered a more detailed assessment. They were also informed that they could choose to opt for a more detailed assessment if they preferred. If they were required or chose to be seen by the FAST team, they would retain their original place on the waiting list. We aimed to recruit around 20 participants from, ideally, 3 - 4 schools.
3. The GPs, of families who chose to take part in the study, were informed.

Pilot teams

The pilot teams were planned to consist of a number of workers as defined in our local ASD care pathway under Stage 2: Developmental Assessment, which is in line with guidance from the PHIS (2001) and NAP-C (2003) reports, including:

- School representatives (e.g. head teacher, class teacher, learning support teacher)
- Educational psychologist
- Child clinical psychologist
- Speech and Language Therapist
- School Doctor

They were asked to carry out a range of assessments relevant to their professional background (see Procedure 5). They were asked to refer to the ICD-10 diagnostic criteria for the triad of impairments of ASD to help them reach a decision about diagnosis.

Procedure

1. Guidance and recommendations regarding team constitution was sent out to the relevant schools.
2. A member of the pilot team spoke to the parents by phone for an initial discussion of the process involved.
3. A team meeting (Meeting 1) was held by the school for the purpose of planning and sharing information already available and identifying tasks to be carried out by all the professionals involved.
4. Team members conducted their assessments of the child within a timescale agreed by the planning meeting.
5. Assessment included all components of specialist assessment as documented in the SIGN guidelines for ASD (SIGN 2007), i.e. a history-taking element, a clinical observation/assessment element and the obtaining of wider contextual and functional information. Specifically, in this project, assessment included documentation of parents and referrers' concerns; developmental and family history-taking; assessment/exclusion of co-morbid conditions including medical examination; assessment of child and family psychological health/wellbeing; contextual information (e.g. pupil learning plans, integrated support plans and coordinated support plans); standardised assessments at home and school or at a clinic, agreed by the team, including the school based observation schedule; screening test for ASD

(SCQ questionnaire); assessment of speech and language and communication skills.

6. Two representatives from FAST observed the child briefly in the school environment.
7. A team meeting (Meeting 2) was planned and held by the school to discuss the results of the assessments. Two representatives from FAST were present as observers and advisers. The multi-agency group's opinion on a diagnosis of ASD was noted at this stage, i.e. definitely ASD, definitely not ASD, unsure. The FAST members then provided their view on the decision reached by the team.
8. FAST representatives not only provided validation of diagnosis but were able to provide on-site training /confidence building of pilot team when required.
9. Parents were then informed of the decision, either: a) ASD diagnosis b) not ASD, with possible referral for further assessment, or c) referral to FAST for further assessment.
10. The decision making process was observed by one of the researchers, who acted as a participant observer. A standardized observation form was completed by a researcher for each of the 2nd meetings.
11. Assessment reports were gathered from all the relevant professionals. A multi-agency report was compiled including the decision reached. This was sent out to parents following Meeting 2.
12. Approximately one month following Meeting 2, face-to-face, semi-structured interviews were carried out with the parents in a place convenient for them, to assess their views of the assessment process and the diagnosis.
13. Focus groups, telephone interviews and face-to-face interviews were carried out by the researcher with as many representatives of the pilot teams as possible, to determine their views of the process and their confidence in making a diagnosis.
14. Focus groups were carried out by the researcher with the FAST observers to determine their views of the decision-making process and outcomes.
15. Tape recordings from interviews and focus groups were transcribed by a secretary and analysed, along with the notes from telephone interviews

and written notes from some professionals, by two researchers using grounded theory to generate common themes. These themes are reported in the sections below, summarizing both the parents' and staff views under each theme.

Participants

20 children were selected from the FAST waiting list for West Fife. One parent declined to participate at this stage, leaving 19. Another child was then added from the waiting list to make the numbers up to 20. One participant moved away from the area and two left the project during the process; one because they had received an ADHD diagnosis and didn't want to go further with ASD assessment, the other because the parent no longer wanted an ASD assessment. This left 17 participants, from 11 schools, in the project. The average age of participants was 7.6 years (range 5 - 11 years). There were 15 boys and 2 girls.

Parents of all 17 children involved in the pilot were interviewed. 16 had face to face interviews in their own homes or in their child's school. One had a telephone interview.

Of the 11 schools involved in the pilot, 9 representatives were interviewed. Two schools did not respond to requests for an interview with a representative. They were interviewed either by telephone, or face to face in the school.

One Focus Group was held with the 3 of the educational psychologists plus a manager who was representing feedback from another 2 educational psychologists. Written feedback was received from 1 educational psychologist.

One Focus Group was held with 3 of the clinical psychologists. One face to face interview and one telephone interview were carried out with another two clinical psychologists. Written feedback was received from one further representative.

Two Focus Groups were carried out with Speech and Language Therapists, one with two, and the other with three representatives from the pilot. Written feedback was received from one further representative.

One focus group was carried out with 2 paediatricians. A further two paediatricians who were not able to attend the focus group were asked for written feedback on their views but this wasn't received.

Two Focus Groups were held with FAST observers, one with 4 representatives and one with 5 representatives. An interview was held with one further representative from FAST.

Decisions made by WASP teams

As shown in table 1, the WASP teams made the decisions to diagnose six children with ASD. They decided that three children should be given no diagnosis of ASD. They decided to refer eight children to FAST for further assessment. In only one case (child 1 in Table 1), the FAST specialist observer opinion differed from that of the WASP team. The WASP teams were able to reach decisions that were in line with FAST specialists in 16 / 17 cases (94%). Of these 16 accurate decisions, eight (50%) were able to be given a diagnosis or no diagnosis of ASD.

Effect of child's attributes on decision made

Age of child

Diagnoses were reached in 6/8 cases in the <8 group and in 2/8 cases in those aged 8 or over. The case for which there was disagreement was excluded from this analysis. The mean age of children given a diagnosis of ASD or not ASD was 6.9 years (n=8) compared to those who were referred to FAST, mean=8.6, (n=8). This difference was found to be significant ($t=2.44$, $df=14$, $p<.05$),

Sex of child

There were only two girls in the sample and 15 boys so it is not possible to draw any conclusions about the effect of sex on decision made. Both girls received a referral to FAST, but this may have been due to their age (9 years and 11 years), not their sex.

Presence of co-morbidity

As shown in Table 1, there were a number of children in the sample for whom there was another diagnosis, e.g. ADHD, dyspraxia; or concerns about other diagnoses, e.g. Tourettes; or other recognised difficulties, e.g. language

difficulties, anxiety. There was a significant association between co-morbidity and decision made. Most of the children with a co-morbid condition were referred to FAST and most of those without co-morbidity were diagnosed with ASD (*chi-square* = 5.9, *df*=1, *p*<.05). Those who were given a decision of not ASD were excluded from this analyses.

Presence of learning disability

Although it was considered that learning disability may have been a factor in the decision-making process, none of the children in the study group were found to have a learning disability so this factor could not be considered.

Table 1: Decisions made by WASP teams¹

Child	Age	Decision	FAST opinion	Co-morbid conditions or other concerns?	ICD-10 used?	Notes
1	6 yr	ASD	FAST	Yes	No	Parents chose not to go to FAST, but then decided at a later date to go ahead with FAST
2	6 yr	ASD	ASD	No	Yes	
3	6 yr	ASD	ASD	No	Yes	
4	7 yr	ASD	ASD	No	Yes	
5	5 yr	ASD	ASD	Yes	No	parents decided to go ahead with FAST anyway
6	8 yr	ASD	ASD	No	Yes	parents decided to go ahead with FAST anyway
7	6 yr	Not ASD	Not ASD	Yes	Yes	
8	7 yr	Not ASD	Not ASD	No	No	
9	10 yr	Not ASD	Not ASD	Yes	Yes	
10	9 yr	FAST	FAST	Yes	No	
11	7 yr	FAST	FAST	Yes	No	
12	7 yr	FAST	FAST	Yes	No	
13	9 yr	FAST	FAST	Not known	Not known	Parents decided not to go to FAST
14	9 yr	FAST	FAST	Yes	No	
15	8 yr	FAST	FAST	No	Yes	
16	9 yr	FAST	FAST	Yes	No	
17	11 yr	FAST	FAST	Yes	Yes	

Observation of 2nd School Meeting

A researcher was present at the majority (14/17) of the 2nd school meetings to observe and record aspects of the decision making process and to explore factors which may have affected that decision. Some information from another two of the meetings was gained from school minutes. The main findings from this observation are as follows:

¹ Grouped according to outcome

Who was involved in making the decision?

As shown in Table 2, most of the pilot team members suggested to attend the decision-making meeting attended each meeting. There was a good attendance from education staff who were on site. Some meetings were difficult if one professional was unable to attend, as a decision had to be delayed until a report was received and agreement given by the missing pilot team member. For the majority of the observed meetings, (n=14), the headteacher chaired the meeting (n=11). Other meetings were chaired by the depute headteacher (n=2), or the educational psychologist (n=1).

Table 2: Pilot team members' attendance at decision-making meeting

Main pilot team participants*	Present at how many meetings? **
Head teachers	14
Class teachers	10
Special needs teachers	13
Educational psychologists	16
Speech and Language Therapists	14
Clinical Psychologists	14
Paediatricians	15
FAST rep 1	16
FAST rep 2	13

* **Other participants at some meetings were:** Depute headteachers (present at 2 meetings), School secretary (present at 1 meeting), Occupational therapist (present at 1 meeting), Parents (present at 1 meeting)

** Data only available for 16 of the 17 meetings

Was ICD-10 used in the meeting?

As shown in Table 1, in 8 of 16 (50%) of the school meetings for which there are data, the ICD-10 was used. In the other 8 meetings (50%) it was not used. Looking at the data separately for those cases where the ICD-10 was used and not used, there was found to be a significant association between use of the ICD-10 and decision made. Those who used the ICD-10 were more likely to make a decision about ASD or not ASD than those who didn't use the ICD-10 (Chi-square = 4.0, df= 1, p<.05). However, small numbers

mean that this result should be considered with caution. There were no significant associations between use of the ICD-10 and group's confidence.

Was the pilot group confident about their decision?

In the researcher's view, 6 of the 14 (43%) pilot groups observed found it very easy to make the decision and 5 (36%) found it fairly easy. Only one group found it very difficult to make the decision. This was due to concerns about co-morbidity. In this case, an ASD diagnosis was given, but the parents decided to go to FAST anyway for further information. Also, the researcher observed that 7 of the 14 (50%) groups appeared confident in making the decision and 5 (36%) were fairly confident. For the remaining two groups, data were missing.

Did anyone have the final say?

In two of the 14 meetings observed, the researcher reported that the paediatrician had the final say, but in all other meetings it was observed as a group decision.

Who told the parents?

There was a variety of different ways of telling the parents. Some parents were invited into the meeting to meet the whole team: at some meetings they were given the result of the decision and had a short discussion; at other meetings they were given summarised reports by all team members. Other parents were informed by one or more of the pilot team after the meeting, usually involving one member of the school staff and at least one health professional.

Was support discussed? What kind of support?

In 13 of the 16 meetings for which there were data, there was some discussion about ongoing support. This included the support plan in school, Early Bird Plus, mental health services, Occupational Therapy assessment, the ASD information pack and ASIST consultation.

Time taken for process

For the 17 children involved in the study, the average length of time taken from referral letter being sent to the school until the 2nd school meeting was 18 weeks, ranging from 14 to 26 weeks.

Feedback from participants on the process

Planning of meetings

Parents' Views

Parents reported that waiting lists for FAST are very long, so they felt that the WASP process was better from the time point of view (i.e. 6 months is better than 18 months).

'I found it [WASP] really good, I know it is an 18 month waiting list for the FAST team, it is a very long time you know if your child has difficulties, it is a long time to wait' [parent of child 9]

However, most parents still felt the WASP process took too long for assessments and meetings to get organised.

Staff Views

The School representatives felt that it was a lot of work for them to set up the meetings and a very frustrating experience. They were unsure if they should be responsible for setting up and hosting the meetings. They mentioned that they would need a lot more guidance and support (including financial support) if they were to do this in the long term. However, a number of head teachers mentioned that they would be happy to host the meeting if someone else set the meeting up.

The Clinical Psychologists and SALTs commented on the schools' difficulty in organising the school meetings.

School meetings

Parents' Views

Many parents felt that the 1st planning meeting was unorganised. Two parents said that the professionals did not appear to know what to do and there was a perceived lack of leadership:

'The first meeting as I say was a complete farce, as no one knew what was going on' [Parent of child 16]

They said that someone needed to be there who understood the process. One parent commented that they felt the school meetings should not be led by the school staff. A couple of parents commented that there was no point in the paediatrician being at the 2nd meeting when they hadn't seen the child.

Staff Views

Some of the school representatives felt unsure about chairing the meetings and were not sure whether this should be their responsibility. Others were happy to chair as they were used to chairing multi-professional groups. One headteacher reported that she had chaired five meetings for WASP and had found that it got easier over time because the process became much clearer and she had worked out her own way of making the process effective.

Educational Psychologists felt that the 1st school meeting was useful for information gathering. They thought it could be used as part of the assessment process.

Clinical Psychologists felt that the chair should be an ASD expert, and not someone from the school.

FAST members commented on the great variability of the school meetings, depending on the different schools, different professionals and different cases involved. They felt that the meetings rely on a strong chair person to guide them.

The SALTs also felt that there were organisational problems around the chairing of the meetings. Some of them felt that the meetings were disorganised and that they weren't sure what was supposed to happen.

Clinical psychologists reported that they were unsure how much information they could share at the school meetings, particularly about sensitive information, such as child abuse, maternal depression, traumatic births, etc. They felt that because this was in a school and not a health setting, this information would not be appropriate and they had concerns about confidentiality.

Paediatricians commented that some schools didn't always get the timing right for the second meeting and when to bring the parents in. Some of the meetings took a lot longer than expected, and so parents were kept waiting. They felt there was pressure to make a decision because the parents were waiting.

Assessment process

Parents' Views

Most of the parents were satisfied with the assessment process:

They valued the views of a range of professionals;

It was encouraging that it was all these people who were deciding what was apparent for [child]. [Parent of child 2]

They felt it was good to have the assessments in a range of natural environments;

Coming in to observe him in the classroom and playground was good... You can see how he is with his peers and how he behaves. [Parent of child 9]

And they did not feel the process was disruptive for their child.

He didn't know anything about it [Parent of child 11]

However, some parents felt that not all assessments were necessary and they felt repetitive. Also some parents felt unsure about what had happened during the assessment process, because it had happened at school and they were not involved.

Two parents reported that they found it hard to remember details of when their child was little. One of these parents suggested that the history-taking form should be sent out in advance to give them time to ask other family members for help in remembering details.

Two parents reported that it was very difficult to get a paediatric assessment done.

One parent said they felt like their child was a '*guinea pig*' [parent of child 13] because of all the assessments they had to go through. However, it was not clear whether this was just related to feelings about assessments as part of the WASP process or whether the parent was referring to other assessments that had happened over the years since recognition of the child's difficulties.

One parent felt '*disillusioned with the whole process*' [parent of child 7].

Staff Views

Educational psychologists felt that the process varied widely in different schools due to different personnel - they felt there needed to be more guidance to all professionals on what was expected of them in the assessment process.

Clinical psychologists also felt that they needed more guidelines on what assessments to do. They were particularly concerned about duplicate assessments by different staff.

A paediatrician had often seen the child early in the system (before the WASP process). Paediatricians in the WASP team reported that they found it difficult to know what should be done on top of that initial assessment.

Paediatricians also commented that the parents of the children in the study may have been a biased group as the children had been on the waiting list for FAST. In many cases, the parents had read up on autism, and therefore may have been able to give more detailed histories during the assessment process.

Decision process

Parents' Views

Some parents were unclear about how the decision had been reached.

One parent felt that it wasn't a good thing to focus on their child's problems.

In many ways it is more helpful to think he hasn't got a problem.
[parent of child 13]

Staff Views

Clinical psychologists felt that the decision making process was very varied, depending on the school, the chair, and the individual professionals present. They commented that they thought it was unhelpful that the individual professionals had given their conclusion at the end of their individual reports. They felt that the reports should just contain what they had observed, and that the decision should then be made by the group. They also raised concerns that there was group pressure, especially the pressure to make a diagnosis.

Likewise, the Paediatricians reported that they felt the pressure to make a decision, even in cases where there was co-morbidity. They found it difficult to go to parents and say that they still hadn't reached a diagnosis (even though parents were aware that this might happen). They also commented that the order for reporting assessment results at the 2nd meeting had an effect on the amount of information given by some professionals. Less input was given if the professional was later in the order for reporting back, because often they would just agree with what had been said before. They commented about one situation where they felt that the group was looking to them (paediatrician) to make a final decision. In other meetings they felt it was definitely a joint decision.

The SALTs reported that the teams worked well together in coming to a decision. They also pointed out that using the ICD-10 was useful for structuring the decision making at the second meeting.

FAST members reported that they thought the discussions at the 2nd meetings were very productive.

Confidence of staff

In general, educational psychologists felt that the team, as a whole, were able and confident in making the decision. They commented that

schools see ASD as a medical diagnosis and have not been part of the process until now, so it is a very new process for schools.

The School representatives reported feeling confident about the decisions that were reached.

The SALTs reported that they felt confident in making the decisions only as part of a group, and would not feel individually confident in assessing ASD.

Presence of parents in decision making process

Parents' Views

Most of the parents reported that they felt they should be involved in the 2nd school meeting (i.e. decision making process) to hear the reports and contribute their views.

Would have been good to go in at the very start of the discussion, I was keen to get notes from each person, you kind of feel you have missed out...[Parent of child 9].

But some parents did not mind and one said they would not have wanted to be in the 2nd meeting.

I was glad I wasn't at the meeting for the whole time, wouldn't have been nice to hear the whole conversation - I was glad I only came in at the end. [Parent of child 12]

Staff Views

School representatives felt that the parents should perhaps be more involved in the 2nd school meeting.

Educational psychologists felt that not involving the parent in the discussion about diagnosis was uncomfortable and thought the parent should be more of a partner in the decision-making process

Clinical psychologists were unsure if the parents should be involved in the 2nd meeting. Some felt very strongly that the parents should not be part of this. However, others acknowledged that this was a sensitive issue and that perhaps the parents should be given a choice.

Paediatricians felt that when parents were there, frank discussion was held back. However, they believed that the parents would have liked to have heard everyone's opinion.

The SALTs suggested that parents' presence at the 2nd meeting should be flexible.

Communication of decision

Parents' Views

Some parents did not like having to wait outside during the 2nd meeting for the result to be given. Many of them felt that, if they were not to be present in the 2nd meeting, the result should be communicated to them by one or two people.

Staff Views

Paediatricians put forward the idea that one professional could go and visit the parents at home after the meeting to give feedback. They felt this would be better for the parent as they would not have to come into a situation where the group have been talking about their child. However they acknowledged that it may be difficult for one person to represent everyone's views.

The SALTs wondered who should tell the parents about the decision made, and felt that this should be flexible, depending on whom the parents knew well and how able the professionals were to represent everyone's views.

Reports

Parents' Views

Parents thought it would be helpful to receive all reports prior to the 2nd meeting in order to review them and bring up their own points - some were expecting this and were disappointed not to have received them. Most parents were frustrated that they had still not received the reports when interviewed for the evaluation which was generally one month following the 2nd meeting.

Staff Views

Educational psychologists felt that the reports should all have been received in advance and summarised briefly at the meeting

Clinical psychologists raised concerns about the reports, how they were handled and when they were given to the parents. They felt there needed to be greater consistency in managing the reports.

SALTs reported being somewhat unsure about the guidelines for writing reports.

FAST members were very impressed with the quality of the reports that the professionals wrote for the 2nd meetings

Parents' expectations and acceptability of outcome

Parents generally wanted an answer from the WASP process - a yes or no, or 'closure' as defined by one parent. A couple of parents reported that they didn't expect the diagnosis on that day.

The majority of parents received the outcome they expected. Those parents who received ASD or not ASD were generally pleased to have a conclusion, but some commented that it didn't change their child.

At least I know now and you can get on with your life. It doesn't change him - he is a great wee boy, he is lovely. [Parent of child 4]

We can close the book on Aspergers [Parent of child 9]

Some parents of children referred to FAST were uncertain about what would happen at FAST and were concerned about what was wrong if no diagnosis were to be given at FAST. Some parents were disappointed if their child was referred to FAST, but they understood why.

'Disappointed, but I do understand - maybe because he is a complex case - if he was straightforward then he maybe would have got the diagnosis.' [parent of child 16]

Some parents reported confidence in the group's decision. However, one parent reported a lack of confidence in the decision made and wanted a 2nd opinion so decided to go to FAST.

One parent said they wanted to know what was wrong, so a 'not ASD' result wasn't helpful.

I was left thinking, what now? He was not diagnosed with Aspergers so I am pretty much back to square one again, I don't know what to do now. [Parent of child 8]

One parent commented that they felt a label was not helpful for their child and so they decided not to go ahead with their FAST referral.

It [label] would knock his self-confidence [parent of child 13]

Staff views on diagnoses & FAST referrals

Educational psychologists felt frustrated about certain cases going to FAST when most people agreed on the diagnosis and only one person disagreed. They felt that parents would be frustrated about this as they thought the parents believed the WASP process would be conclusive.

FAST members stated that it is crucial that professionals are clear that the WASP process should only be about ASD and not about making other diagnoses. If there is any co-morbidity, a referral to FAST should be made. They also felt that the parent's expectations need to be addressed. They had observed that parents seemed disappointed when they were still referred to FAST following the WASP meetings. They felt it needed to be made explicit to parents that this could happen.

Support

Some parents commented that they had received lots of helpful information due to the WASP process.

Some parents mentioned the benefits of getting a diagnosis for receiving the support they need.

It opens more doors, we can go on the list for EarlyBird plus having the diagnosis opens a few doors - you don't seem to get into anything without diagnosis - it is like an invisible barrier. [parent of child 3]

Some parents were uncertain about how to manage their child's behaviour and reported that they were not getting answers because they didn't have a diagnosis.

Until they have the concrete answer....no one has come and said this is what you can do in the meantime [parent of child 15]

Others commented that support was already in place in the school so the diagnosis made little difference.

Those parents who had received some support, e.g. Early Bird, interventions at school, etc. were generally positive about it.

Views on the model and continuation of the approach

Parents' Views

Most parents commented that the model was a good idea and should continue. However, two parents commented that they thought it was good, but they didn't know how the FAST model differed. One parent who knew about FAST said that they thought FAST was easier because it was all in the one place at the one time.

Most parents of those children referred to FAST commented that the WASP process was worthwhile as it provided useful information for FAST.

Most parents felt that the school was an ideal place for the ASD assessment process because of:

"being community based, environments that children are used to".
[parent of child 3]

However one parent commented that school was not best placed for this process and neutral ground would be more acceptable.

Most parents were positive that the pilot team knew the child well and took time to make assessments. Moreover, some parents felt it was helpful to have a group of professionals all providing '*an all round picture*' [parent of child 15].

Some parents were impressed with the process and one expressed their appreciation of having been part of it:

“The WASP project is great, filling in forms, observing him, I was really impressed with it. It was really thorough...good assessment was done for him, I thought it was really good” [parent of child 9]

Some parents felt the process had helped to give them an answer and to understand their child better.

We are getting somewhere now, never known she has been on the borderline (of ASD) - we thought she is just playing up, you know. [parent of child 10]

Some parents felt the process had provided them and the school with lots of useful information and some parents felt it helped improve communication with the school.

Staff Views

School representatives commented that they had learned a lot from the process, enjoyed working with the different professionals and appreciated “being heard”. They also thought that the process was good for speeding ASD assessment up.

Educational psychologists liked the WASP model due to the assessment being in context - i.e. in the school and home. They also commented that they felt it was a good assessment model due to its collaborative, comprehensive assessment process.

FAST representatives felt that this was a comprehensive way to bring information together, and that the information was very useful for FAST (if the child was referred to them). They also felt that this way of assessment would be very useful in reducing FAST waiting times.

In general, the School representatives felt that this multi-agency approach was a very good way of assessing children with possible ASD, although one said she would not want to be asked to take part if the model were to be rolled out.

Educational psychologists commented that they felt excited that education was so involved in this innovative approach.

Clinical psychologists felt that the multi-agency process in WASP was interesting and helpful, and was, in principle, the best way to assess a child. They thought that the WASP process should continue, and that a tier 2 assessment was very important.

The Speech and Language Therapists had mixed opinions about the WASP process; with some finding it very positive overall but others had negative views.

Some commented that the WASP process was not proper multi-agency work, in that the professionals all worked separately. However, others felt that it was a good example of multi-agency work. Most of them felt that the WASP process should be implemented. However, one felt that it was only a good idea in theory, but that it didn't work out in practise. Furthermore, this SALT also felt that ASD was too big a topic to be diagnosed by non-ASD specialists.

The FAST representatives felt that the WASP process should be implemented.

Training suggested by participants

All staff stated that there should training in the spectrum of ASD symptoms and using the ICD-10. Paediatricians commented that professionals had different interpretations of what the ICD-10 statements were saying. The school representatives had some queries around how to interpret it.

Clinical psychologists raised the issue of training needed for the person breaking the decision to the parents.

SALTs felt that they would personally benefit from seeing what happens at a FAST clinic.

Improvements suggested by participants

- The first meeting could just be between the parent and one professional who would explain the whole process. (*parent*)

- The developmental history form should be sent to parents in advance to give them plenty of time to think about it and consult with family. (*parent*).
- Parents should be given a clearer idea about the entire process - it should be more 'parent friendly'. (*parent*)
- There should be one main point of contact for parents. (*parent*)
- There should be more observation of the child and less questioning of the parents. (*parent*)
- Someone should come out to the house to give the result. (*parent and paediatricians*)
- Parents should be informed about how the decision was reached. (*parent*).
- There should be training for professionals on how to give the result. (*parent and clinical psychologists*)
- In future the process needs to be clarified. (*all*)
- Someone other than the schools should set up the meetings. (*School representatives*).
- There should be more guidance to all professionals on what is expected in the assessment process. (*all staff*)
- Clearer guidelines must be given as to when a child should be referred to FAST (e.g. co-morbidity). (*FAST representatives*)
- In future, a project worker should be in place to monitor and organise the process. (*FAST representatives*)

Discussion

This pilot aimed to assess the feasibility and acceptability of a new model of ASD assessment in the community.

Results showed that the multi-agency community teams could reach decisions about diagnosis of ASD and non-ASD for many straightforward cases particularly in the younger age group. They could also usually reach decisions about which children should be referred to FAST for further assessment.

Out of 17 cases, there was only one case where the FAST representative disagreed with the decision made by the community team. For 16 out of 17 cases, the FAST representatives agreed with the team's decision. In this one case where there was disagreement, the child had a diagnosed, co-morbid condition which would normally mean onward referral to FAST unless there were few obvious symptoms of ASD. This co-morbidity was the reason why the FAST representative disagreed with the pilot team. The pilot team in this case had obviously not been made aware, adequately, of the protocol for cases with co-morbidity. Thus to ensure appropriate decisions by community teams in future, this protocol would have to be made very clear. Use of ICD-10 was also significantly associated with making a diagnosis. This was supposed to be undertaken in every case, but was actually used in only 8 cases.

This study investigated factors which influenced the decision-making process. The results show that the community teams were able to make definite diagnostic decisions in 75% of cases in the younger age-group, i.e. under eight years of age, compared to 25% of cases in the older age-group. Consideration should therefore be given to targeting this community model for children in the younger primary school years. This would result in the greatest reduction of referrals to FAST. Also it was found that co-morbidity had an influence on the decision made. Most of the children with a co-morbid condition were referred to FAST and most of those without co-morbidity were diagnosed with ASD. This is in line with the study hypothesis that the community teams would be able to make diagnoses of less complex ASD cases, but that more complex cases would have to be referred to FAST for more detailed assessment. Consideration should therefore be given to screening cases for co-morbidity before referral to the community team, as those with a co-morbid condition could perhaps be

fast-tracked to FAST. However, the quality and comprehensiveness of the pilot assessments are of additional value by allowing the FAST team to operate efficiently with relevant information immediately available, therefore it can be argued that all cases should be assessed by the second tier. Neither sex nor learning disability could be investigated in this study as possible factors influencing decisions because of very low numbers of girls and no cases of learning disability. It is likely that those children with a significant learning disability would be diagnosed before primary school age which may be a reason there were no cases in this study sample.

In terms of feasibility of the model, the average length of time for the whole process was 18 weeks which is considerably shorter than the 18 month wait for FAST and it complies with the SIGN guidelines which state that the assessment is necessarily a lengthy process. Administration of school meetings was not easy and caused a lot of frustration for all concerned, particularly school staff who were expected to coordinate the two school meetings. Detailed feedback from all groups concerned has been fundamental in helping to consider recommendations for further roll-out of the model. However, for the majority of the 2nd school meetings, all the relevant professionals attended and provided a report which is testament to the persistence of the school staff despite the frustration and hard work involved. Variability was observed and reported between all meetings, depending on the staff involved. Most participants observed the need for clearer guidelines for all concerned to help ensure a consistent approach.

In terms of the overall model's acceptability, the process and outcomes appeared to be generally acceptable to parents, pilot team members and FAST specialists. There were numerous concerns and frustrations about the process and some concerns about the outcomes, but most of these were to do with the shortage of information about the process and the model. The perceived benefits of the model agreed by the majority of participants (staff and parents) were: the shorter waiting times and opportunity for earlier diagnosis; the natural environment for most of the assessment process (i.e. home and school and local staff); the lack of disruption to the child; the large range of assessments provided; the multi-agency group decision process; the opportunities for all concerned (all staff and parents) for listening to each other and learning from each other, leading to increased knowledge about ASD amongst frontline staff; the ability for useful, contextual information to be gathered by this team which can be

sent to FAST if referral to FAST; and the improved links to support and intervention for the child and family.

This study aimed to determine any requirements for further training of community staff. Results indicated that multi-agency staff would require training on the purpose and benefits of the model; details of assessments that would be required by their particular service; how to manage the decision process; the purpose and use of the ICD-10; and how to communicate the outcome of the assessment/diagnosis process. A training strategy would be required to lead this process to ensure that all staff in the various services received the minimum necessary training required.

Conclusions and implications

In summary, this pilot suggests that it is feasible to set up multi-agency community teams, based in schools, which are able to diagnose straightforward ASD cases and non ASD cases and which are also able to make decisions about when to refer to the specialist service, FAST. Although it was a relatively small pilot group, the results indicated that referrals to FAST for school aged children may be able to be cut by 50% if this model is rolled out, with 75% of younger children and 25% of older children being given a definitive decision. This would have a significant impact on waiting lists, which are currently unacceptably long. There is also a view that tier 2 assessments should be undertaken prior to FAST assessment in all cases. The majority of workers and parents involved were able to appreciate the benefits of this model of working in terms of earlier diagnosis, a more natural assessment environment and improved links to support. However, in practice there were many frustrations relating to dissemination of information about the model and the process. Future development of this model requires careful consideration of the views of participants expressed in this report, the improvements they suggested and the staff training requirements outlined. In particular there is a clear need for dedicated administration support and a high quality, detailed information manual for parents and staff. Moreover, a plan for ongoing monitoring of the service would need to be created including audit of outcomes and validation of the decision-making process.

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Recommendations

1. A roll-out sub-group should be set up to oversee the roll-out aims, materials and process.
2. A current study of clinicians' time for taking part in this pilot will inform the roll-out plan. We would envisage the requirement for some re-configuration of health services and possibly the need for additional resources within some of the health service teams. There should be no need for additional resources for the education service.
3. A plan for ongoing monitoring of the service; audit of outcomes and validation of the decision-making process will need to be created. We would envisage some ongoing involvement of FAST in this process.
4. A manual should be compiled including:
 - a. Clear guidelines for all staff about the step-by-step process for the two school meetings, the assessment process and the compiling of reports.
 - b. Clear guidelines for staff about the actual decision process, including how to use the ICD-10. In particular, there is a need to reassure staff that there is no pressure to make a diagnosis, indeed that their threshold for referral to FAST should be low. Also that the diagnosis is for ASD only - the team should not be making other diagnoses as part of this specific process.
 - c. A clear explanation for parents of the entire assessment / decision process and the care pathway, (i.e. that this is stage 2 of the process and that only more obvious cases can be diagnosed or ruled out at this stage, but that it is an important part of the process of contextual information-gathering for FAST). This could also include guidelines for parents on how to explain the process and the condition (if diagnosed) to their child.

- d. All necessary printable paperwork, e.g. standardised letters to parents and GPs, meeting agendas, screening tools, history-taking forms, etc.
5. Standard agendas should be created for both school meetings to ensure consistency of approach. The agenda for the 1st meeting should consist of: sharing current information; addressing parental concerns; planning joint assessments; and asking parents how they want to be involved in the decision-making process. The agenda for the 2nd meeting should include: presentation of assessment reports; use of ICD-10; decision-making; discussion of ongoing treatment/care plan, whatever the outcome; and informing the parents of the result if they have chosen not to attend the meeting.
6. Parents should not be present at the second meeting. However they should be clearly informed of the process of making a decision. To be informed following the meeting, they should be seen by the headteacher (or other school representative) and a clinician (preferably one who already knows the family). Training should be provided for these professionals to ensure effective and appropriate communication with parents about the outcome of the assessment/diagnosis process.
7. A protocol for the presentation of the final report should be developed. Reports should be sent to all professionals involved and the parents in advance of the 2nd school meeting.
8. The multi-agency teams will take joint responsibility for the diagnoses and will be required to adhere to the agreed protocol. Assuming the protocol is adhered to, final clinical responsibility will lie with the area consultant paediatrician whose role it will be to verify, support and ultimately take responsibility for the team processes, assessments and decisions.

9. We would recommend that a permanent senior administrator post should be created. We would envisage that this post would be jointly funded by health and the council and would report to the joint ASD steering group. This post would act as general project manager for the roll-out, with the following main tasks:
 - a. managing a central referral system including FAST referrals
 - b. maintaining a database of all children in this system across Fife
 - c. taking responsibility for setting up all school meetings
 - d. planning an on-going training programme for staff
 - e. organising the distribution of all necessary documentation - letters, manuals, assessment reports, final reports to parents and staff
 - f. acting as a central contact point for all staff and parents involved
 - g. planning the ongoing monitoring/audit process