



**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 Report**

Executive Summary

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Contributors:

Wendy Simpson, Public Health, Playfield Institute, NHS Fife

Carolyn Brown, Educational Psychology, Fife Council

Zoe Claisse, Paediatrics, NHS Fife

Emma George, Playfield Institute, NHS Fife

Ruth Metcalfe, Clinical Psychology, NHS Fife

Julia Neufeind, Playfield Institute, NHS Fife

Nara Nisbet, Speech & Language Therapy, NHS Fife

Lorna Watson, Consultant in Public Health, NHS Fife

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

In conclusion, 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. 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 the full 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.

Recommendations

In the light of the conclusions of this pilot, the authors have agreed on the following main recommendations for service planning:

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

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