

<i>item:</i>	7
<i>report:</i>	CYP09/07

# EVALUATION OF MULTI-AGENCY AUTISM SERVICES

## By UHI Millennium Institute

### Summary

This report introduces further summary findings papers from the UHI Millennium Institute evaluation of integrated children's services, with regard to multi-agency services for children on the autistic spectrum. It also updates the Committee with plans for an international conference to launch the research.

### 1 Background

1.1 In August 2003, the Joint Committee confirmed the commission of a three-year evaluation of integrated children's services in Highland, through UHI Millennium Institute by Dr Morag MacNeil and Dr Bob Stradling.

1.2 The evaluation is now concluding, and has involved research into the effectiveness of:

- the roll-out of the Integrated Community School Approach
- youth justice services
- multi-agency autism services
- the Gypsy/Traveller Health & Wellbeing Initiative
- action to address Anti-social Behaviour.

1.3 In addition to periodic reporting during the fact finding stages, the Joint Committee has agreed that the findings from each element of the evaluation will be subject to five stages of analysis and reporting:

1. discussion with immediate stakeholders
2. presentation to the Evaluation Reference group
3. presentation of summary findings to the Joint Committee
4. publication of findings
5. publication of academic papers in relation to the research.

### 2 International Conference

2.1 Some considerable time ago, the Joint Committee considered the best means for disseminating the findings of this research, and took the view that a major event would be an appropriate central vehicle.

2.2 Agreement has now been reached with Children in Scotland and the Scottish Executive, to hold an international conference in Highland on 5<sup>th</sup> and 6<sup>th</sup> September.

- 2.3 This Conference would link the developments in integrated children's services in Highland with the implementation of 'getting it Right for Every Child', and would also provide a platform for learning about similar developments across the UK, Ireland and Norway.
- 2.4 The conference will present real and innovative practice developments within the context of policy and legislative change. It will use the most extensive research ever undertaken into integrated children's services to examine what is working well and what barriers we continue to face. By introducing a perspective from outwith the UK and Ireland, and also involving professionals from Norway, it will also allow us to step outwith the box of our traditional concepts, to:
- showcase the research undertaken in Highland by the UHI Millennium Institute;
  - explore the reform agendas, to look at what is working well, what is still challenging and what lessons are being learnt;
  - draw on international experiences, policy and practice from Norway and Ireland;
  - examine further innovative approaches to change in practice.

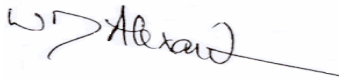
### **3 Multi-agency autism services**

- 3.1 Further to the investment in multi-agency autism services, a central part of the research undertaken by UHI has been about the impact of this initiative.
- 3.2 The researchers conclude that:
- Overall much progress has been made in a comparatively short time.
  - Most of the professionals and parents who participated in the evaluation identified aspects of the initiative which they felt were particularly successful and needed to be continued.
  - Most of the structures, pathways and procedures are now in place to enhance multi-agency working. It is important to ensure that these are utilized by all concerned in the ways for which they were intended.
  - Priority needs to be given to ensuring that professionals in all of the relevant services and agencies adopt a holistic view of the needs of the child rather than compartmentalise those needs into the concerns of specific services.
- 3.3 The attached summary findings from the study have already been shared with the key staff and parent/carers who participated in the fieldwork. The full report will be also be made available to them, and to Committee members.
- 3.4 The findings will be used to inform further service developments.

## **Recommendation**

The Joint Committee is asked to:

- endorse the proposals to hold an international conference in Highland in September;
- consider and comment on this evaluation of multi-agency autism services.

A handwritten signature in black ink, appearing to read "Bill Alexander", with a long horizontal line extending to the right.

**Bill Alexander**

Head of Service (Children, Young People & Families)



# **Integrating services for families with children on the Autistic Spectrum: An evaluation of the Highland Initiative**

**Robert Stradling, Alison Clark and Morag MacNeil<sup>(1)</sup>**

## **BACKGROUND**

The last fifteen years has seen a considerable growth in the prevalence of Autistic Spectrum Disorders (ASD) across the United Kingdom. Research undertaken in the early 1990s indicated that prevalence rates amongst young people were around five in every 10,000. By 2001 these estimates stood at either 60 in every 10,000 or 90 in every 10,000 depending on the source<sup>(2)</sup>. More recent studies suggest that the current prevalence rate may be even higher now<sup>(3)</sup>.

This increase in the number of children and young people diagnosed with Autistic Spectrum Disorders has emerged at a time when Children's Services in Scotland have been undergoing profound changes. A Scottish Executive strategic action plan, *For Scotland's Children*, (4) had set the direction for further development in 2001. The main aim was to improve services and outcomes for children and young people through core services, specialist services and other agencies working together more effectively.

At around this time the Public Health Institute for Scotland also published a needs assessment report on Autistic Spectrum Disorders<sup>(5)</sup>. This highlighted that provision of services for children, young people and adults with ASD was patchy across Scotland, often dependant upon local resources and geographical factors and insufficient to meet current or projected needs. It also highlighted the long delays leading to diagnosis across Scotland and the inadequate support for families and individuals once an assessment and diagnosis had been carried out.

Following the publication of the PHIS report, a multi-agency review of autism services was undertaken within Highland<sup>(6)</sup>. The resulting report highlighted several deficiencies in service

provision within Highland at that time, drawing particular attention to:

- delayed diagnosis and assessments;
- the lack of standardised diagnostic criteria;
- limited awareness amongst professionals of ASD.

Following this Review a multi-agency autism budget was created and a specific initiative was implemented to address the deficiencies identified by the Review:

- An ASD Co-ordinator, supported by a multi-disciplinary, multi-agency Project Management Board, was appointed to develop inter-agency services for children and young people with ASD and to take the lead in coordinating the development of an Integrated Pathway for children with ASD.
- Several additional posts were created, including a clinical psychologist, dietician, speech and language therapist, occupational therapist, and family support workers.
- The Autism Outreach Education Service introduced some operational changes to enable their staff to train teachers to work with ASD children.
- A community paediatrician, with support from other members of the Project Management Board, undertook to develop an assessment pro forma to help standardise the assessment and diagnosis process.
- A series of training programmes were funded for parents and professionals across the area.

## **THE EVALUATION**

It was within the above context that the authors of this Report were asked by Highland Council and NHS Highland to evaluate the effectiveness of the processes and procedures that have been introduced in Highland to provide a more integrated service to families and children on the autistic spectrum.

### The Aims of the Evaluation were to:

- establish whether the steps taken to standardise assessment and diagnosis were impacting on practice at the local level;
- find out if parents felt that access to information and support for themselves and their children before during and after diagnosis was improving;
- establish whether capacity to provide support at the local level was improving;
- evaluate the extent to which the provision of support was more integrated;
- elicit parents' and carers' views on the training provided.

The evaluation began in the summer of 2004 and continued for approximately eighteen months. During that period the following methods were employed:

- Interviews with a wide range of professionals working with ASD children and/or their families.
- Interviews with the Autism Services Coordinator, Project Management Group and service managers about the development and implementation of the new policy and procedures.
- Interviews with a small sample of parents and carers about their experiences and views on the effectiveness of the services provided.
- Focused group discussions with members of three Parent Support Groups about their experiences and the issues and difficulties they have encountered.

## **FINDINGS**

This is a summary of the main findings which emerged from the evaluation. It is intended that the full report, once it has been presented to Highland Council's Joint Committee for Children and Young People, will be made available on the Council web site.

The findings focus mainly on the key elements of the Initiative which were implemented or developed specifically in response to the Autism Review conducted in 2001-02.

## **Identification and Referral for Assessment**

There appears to be an emerging consensus amongst specialists working in the field of ASD that early detection is essential in order to enhance the likelihood of early, appropriate and consistent interventions that can improve the quality of life and prospects of many of the diagnosed children. Early identification in this context is not just or always related to the age of the child; it can also mean that detection and appropriate referral happens as soon as possible after the specific needs are first manifested.

The importance of early identification was recognised by all those professionals we interviewed who worked directly with children with Autism Spectrum Disorders. Most of the parents we interviewed or who took part in focus group discussions also emphasised the importance of early identification, observing that they had usually recognized that something was wrong when their child was between 15 months and four years old. For most of them it was a relief that someone else also recognised that their child was displaying language difficulties and/or social interaction or other behavioural difficulties. It was also a relief that this recognition by a health visitor, GP, nursery teacher or other professional triggered a formal referral process.

While most of the parents we talked to seemed reasonably satisfied with the speed with which professionals responded when they felt that a particular child was experiencing difficulties a minority expressed some dismay at the lack of action when they had voiced their concerns. Two specific situations were identified. The first was where the child's problems tended to be behavioural and were mainly manifested at home rather than in the school. The second was where the school believed that the child's learning needs or behavioural problems could be contained within the mainstream class without additional support.

In each of these cases the parental concern was that the potential referrers were not looking at their child in a holistic way. The professionals' concern was solely with the child at school and how best to manage his or her needs within that setting.

### **The period between referral and assessment.**

Each parent was asked about waiting times between the referral and the assessment and diagnosis. We obtained fairly detailed information about 25 children. It should be remembered, however, that this only represents 5 per cent of the total of school-aged children on the spectrum in Highland (currently estimated at 450), but, as yet, response times and waiting times are not being systematically monitored.

The average waiting time from initial referral to diagnosis for this sample was 13 months but the range varied from less than one month to 18 months. Just over half of these children were diagnosed before 2003, the others were diagnosed in 2003 or later. The waiting time for the group diagnosed earlier was only slightly longer than those diagnosed more recently.

Since 2004 the waiting times appear to have been reduced in some parts of Highland. Staff at the Central Communication Clinic in Inverness estimate that the average waiting time between referral and diagnosis is now six months. This is a significant improvement. However, it is our impression that information about waiting times is not yet being systematically monitored across the whole of Highland.

Some of the parents were convinced that the route through to diagnosis tended to vary depending upon the geographical area and the professionals involved. There was a widely-held perception amongst some of those living in the more remote areas of Highland that the time between expressing concern about their child and getting a referral and the time between the referral and the diagnosis were longer than they would have been had they lived near Inverness or Caithness. In practice this was sometimes the case but not always and, indeed, some of the parents living in the Inverness and Caithness areas also complained about delays and long waiting lists. Our impression, based on the experiences of the 29 parents who were interviewed or participated in focus group discussions, was that the variations in referral time and waiting for a diagnosis were just as likely to be the result of more random factors relating to staff turnover, sickness or a particular professional's case load.

There also appeared to be considerable variation across Highland in terms of the extent to which parents were kept informed about the process during the period between the referral and the first assessment. Some reported that they felt well informed and consulted during the process but this seemed to depend quite heavily upon the referring individual and also their own prior knowledge of the process. The parents of children diagnosed before 2002 were the ones most likely to report that they went to the meeting with the community paediatrician totally unprepared for what would happen, how long it would take, or what would be asked.

Most of these parents said that at this point they had had a lot of questions about the diagnostic process but did not know where or from whom to obtain the answers. Most turned to the Internet and found it helpful but it did not necessarily prepare them for the assessment.

It is clear that this situation has improved over the last three years. Parents are now more likely to report that a professional had explained the referral and assessment process to them before the first assessment.

It was not just the assessment process that concerned the parents. Some of them with children at nursery or primary school also reported that during this interim period between referral and assessment they had thought that nothing was being provided in terms of support and provision for their child until the diagnosis was completed. In practice some additional school-based support had usually been put in place but they were not necessarily informed about it or consulted. This is clearly a time when parental anxiety tends to be high and they need more than reassurance that something will be done, they also need information about what is being put in place in the interim as well as what will happen once the assessment process begins.

### **Enhancing and standardising the assessment and diagnosis process**

To help structure the assessment and diagnosis process and provide a standardised record of the outcomes a consultant community paediatrician based at the Central Communication Clinic in

Inverness, with support from other members of the Management Group, developed a General Assessment Form, An ASD-specific Assessment Form and a follow-up checklist.

These forms were based on best practice and the ASD-specific Form drew substantially on the highly regarded work of Filipek, Accardo and their colleagues<sup>(7)</sup> as well as on the considerable experience of the team at the Central Communication Clinic. In addition to providing space to record the observations of the paediatrician and others undertaking the general and specific assessments the Forms also made provision for recording information collected by other professionals, including those working in audiology, communication, educational psychology, GPs, health visitors, school nurses, et al. Finally, in addition to specifying the actions to be taken, the Forms also identified the key worker assigned to the child and family and provided space to record any other issues of relevance, including the general health of the child, other learning needs, housing, benefit entitlements, etc. The team also developed a parent questionnaire to be sent out in advance of the assessments to help parents/carers to gather the kinds of evidence that specialists would need in order to make the assessment.

These new forms were piloted by volunteers in Highland during 2004 and amended in the light of the feedback received. It was intended that the revised version should be introduced across Highland from 2005 onwards. However, the response proved mixed. Some community paediatricians used them as intended, others preferred to continue writing a case history in the usual way and some only used it as a referral form to the Central Communication Clinic rather than as an assessment and diagnostic tool.

The standardised assessment forms have now been abandoned. However, the case for standardized diagnostic criteria, which was highlighted in the Highland Autism Review in 2002, has not diminished. The problem here lay more with the implementation strategy which was adopted than with the tools themselves. Some of the specialist staff who had not been involved in the development of the forms did not have a

strong sense of ownership of this development and seemed to misunderstand its purpose.

Some of the parents also felt that a standardized post-diagnosis, follow-up procedure needed to be adopted. Almost all of the parents indicated that the community paediatrician had initiated a regular follow-up appointment with the child, either on a six-monthly or annual basis. However, follow-up meetings with parents in order to go through the diagnostic report in detail was not yet standard practice, although most of the parents whose children had been recently diagnosed reported that this had happened.

### **The Integrated Pathway**

Another important outcome of the Initiative has been the Integrated Pathway for children with ASDs and their families. This is designed to guide professionals and families through the whole process from early recognition of a concern, through referral to appropriate professionals, then the assessments and diagnosis, followed by planning to determine an integrated package of support for the child and family which will then be monitored with follow-up meetings with child and family.

The Integrated Pathway also plots assessment and support routes for children with multiple and complex needs which include ASDs and for children diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) or Developmental Coordination Disorder (DCD).

In addition to serving as a guide through the system for professionals and parents alike the Pathway also serves to ensure more integrated and coordinated multi-agency provision for each child with ASD and his or her family. This is a critically important outcome for the Initiative and should do much to ensure a more integrated and more effective multi-disciplinary and multi-agency provision of services to the families of children with ASD in Highland.

Some of the tasks specified in the Integrated Pathway should address concerns expressed to the evaluators by some of the parents and carers.

For example:

- That the referrer at stage 1 on the pathway triggers the information gathering process for the Integrated Assessment;
- That a multi-disciplinary core team will be put together at this stage specifically to meet the child's individual assessment needs;
- That a member of that core team will prepare the family for the assessment process as well as begin the information gathering process;
- That plans to provide support for the family can be operationalised before a definitive diagnosis has been made;
- That parents/carers are provided with an information pack on completion of the ASD specific assessments.

In our view the Integrated Pathway for Families with Children on the Autistic Spectrum offers an excellent model that should be transferable to families and children with a wide range of learning needs and disorders. It emerged towards the end of the evaluation and so we were not in a position to establish how it was actually being used in practice. We would strongly recommend, therefore, that some kind of internal review or self-evaluation process is initiated to ascertain if it is influencing professional practice across the services and agencies involved. In particular we would recommend that self-evaluation focuses on four areas of the process:

- Is the Pathway helping to break down the barriers between the different disciplines involved in the referral, assessment, diagnosis and support processes?
- Will the Integrated Pathway ensure that the various parallel pathways which may have existed up to this point for specific children now merge into a single integrated post-diagnosis pathway?
- Will the Integrated Pathway ensure that the parents' information needs are adequately provided for?
- Are the target response times in the Integrated Pathway realistic?

### **Multi-Agency Working**

Much progress has been made in Highland in the development of multi-agency working for families and children with ASD. By early 2006 there appeared to be a number of issues that remained several operational issues which still needed to be resolved. associated with multi-agency working with children with ASDs that still needed to be resolved. However, we suspect that most of them are teething troubles, given that the changes were introduced in about two years and had only been in operation for just over a year.

First, the use of family key workers seemed to be variable across Highland. The family key worker, and the support workers who regularly work with them, has an important mediating and coordinating role to play which could also ensure that the action plan for each child and family is implemented in a holistic way. However, although they were all line managed by senior social workers they did not all have the same job description. Also, some parents expressed concern that family key workers in certain areas were insufficiently integrated into the planning and review process for families and children with ASD.

Second, specialist services were not always perceived by parents and locally-based professionals as being effectively integrated with local services, particularly if they were based in Inverness and 'parachuted in' to different localities for a day or two before moving on or returning to the centre.

Third, some parents also observed that they were getting conflicting advice from different professionals and different services.

Finally, another issue which was proving problematic in some instances was the absence of effective mechanisms for obtaining parental consent to release non-confidential (and confidential) information to other key workers.

### **Managing Transitions**

A lot of progress has been made in helping ASD children and their families to cope with transitions from nursery to primary and from primary to secondary. But, most of the parents were very concerned about how their children were going to cope with transition from secondary school to

further education and training or work and from children's services to adult services. This concern was also shared by some professionals.

### Raising Awareness

Awareness of ASD has undoubtedly increased in recent years amongst frontline professionals and a number of parents highlighted some extremely positive examples of good practice, with schools, in particular, accessing specialist advice and implementing various strategies and innovative practices to address the needs of children with ASD.

The feedback we received from professionals about the awareness raising programme was very positive. There was a widely-held view that within many schools there now existed a higher level of expertise within Support for Learning teams for meeting the educational needs of children on the autistic spectrum. In addition, it was also widely felt that schools now had the capacity to draw effectively on other services and professionals, including the Autism Outreach Education Service, SALT, SSA, etc.

There was widespread support amongst the professionals and parents/carers whom we talked to for the view that awareness-raising now needed to be expanded within core services to include more professionals who only occasionally came into contact with the families of children with ASD. The in-service days run by the Autism Outreach Education team now include sessions for all school staff including janitors, catering, playground supervision, etc. as well as more specialist training for learning support and other teaching staff. This is a model that could be adopted in other services.

It was also widely recognized that something needed to be done to raise the awareness of health professionals who only occasionally came into contact with autistic children and teenagers. This included primary and secondary care nurses; dentists, opticians, etc. The main issue here was to raise awareness about how best to respond to children with social communication problems and behavioural disorders who needed general medical attention. A similar process is needed in other services such as housing,

leisure, the benefits agency, and staff working in sports and recreation centres.

### **Enhancing capacity of services**

A number of developments have occurred which should help to enhance capacity:

- The change of emphasis in the work of the Autism Outreach Education Service from working primarily with children to training school-based staff.
- Educational Psychologists are extending their brief to also provide a consultancy service and give support to teachers as well as assess children.
- The EarlyBird, EarlyBird Plus and HELP training programmes for parents have played an important role in enhancing the capacity of parents and carers to manage the child's needs within the family.
- The introduction of a range of integrated posts, such as family key workers, family liaison officers and children's service workers has also enhanced the potential for capacity building.

However, it is clear that there are still barriers which inhibit access to some specialist services in the more remote areas of Highland. This particularly applies to the availability of those services which are vital in providing parents with support and practical coping strategies after diagnosis. Some parents living in rural areas without cars were not always able to take up opportunities for home-based and residential respite care, training courses or networking with other parents and carers who have children on the autistic spectrum.

### **POTENTIAL AREAS FOR DEVELOPMENT**

All nursery and early years' teachers should have access to a user-friendly checklist, equivalent to the CHAT checklist used by health professionals with toddlers. This would help them to decide whether or not to refer a particular child to a specialist (in education or health) for further assessment.

All nursery and early years' staff also need access to appropriate contact numbers that can be passed on to parents or carers when they raise concerns

about their child's behaviour at home, even if these behavioural problems are not persistently manifested in the classroom.

The standardised assessment and diagnosis forms and checklist should be re-launched to coincide with the Highland Pathfinder phase of *Getting It Right For Every Child*. However this will require a more inclusive implementation strategy than the one used previously.

More thought needs to be given to how these assessment records and reports can best contribute to the post-diagnostic planning process for each child.

The Integrated Pathway for ASDs is a potential model for developing pathways for other disorders and learning needs.

It is essential that useful monitoring data are collected systematically on both processes (e.g. waiting times, sharing of information, contacts with parents and children, etc) and outcomes. With respect to outcomes it is essential that the child and young person's progress through the support and planning pathways is monitored from early years to adulthood to ensure that effective support is provided at each transitional stage.

The assignment of a key worker to each family whose primary role is to coordinate provision of services to the family is critically important. However, key workers need a clear and common job description with regard to working with families, regardless of which service they are drawn from. It is also important that parents have some say in who acts as their key worker since autism is a lifelong condition and the relationship between families and key workers is likely to be long-term.

Coordination would be enhanced and overlap and duplication reduced if a password-controlled integrated electronic database was developed which could be accessed by all professionals working with autistic children and their families. We acknowledge that there are issues here concerning confidentiality. We are not proposing a database that makes available detailed information about the child's medical condition or

the family's personal circumstances. But a lot of professionals who we talked to expressed frustration about not knowing who has seen the child or the family, when, why or what actions were taken. We are therefore suggesting that what is needed is a database on to which all professionals involved could import this kind of information following a school or home-based visit or a contact with another professional. This would facilitate integrated working. It is acknowledged that one of the objectives of GIRFEC is to develop an electronic record for all children, and it is further recognised that this record is likely to contain far more information about the child than we are suggesting here. However, the GIRFEC-generated electronic record may not be available for use for at least another two years and it is by no means clear how assessments and records of children with complex needs and disorders will be integrated into it. In the interim there is a need for a simpler kind of record to enhance coordination of support for children with specific needs and this could be a useful vanguard for that.

There also needs to be a unified consent form for parents and carers where a key worker (or other professional) explains the potential benefits of releasing specific bits of information to other professionals and the limitations placed on the circulation and use of that information. The parent or carer can then decide whether or not to give consent to each specific release.

For many parents the issue of consistent access to services is vital to the development of their child. Staffing pressures on certain core services such as Speech and Language Therapy and Occupational/Physiotherapy have considerably impacted upon the level of service and support that many families have received. The issue of capacity building is crucial here and needs to be embedded into the planning of all services which work with autistic children and their families (and with other children with complex additional needs).

## CONCLUSIONS

Overall much progress has been made in a comparatively short time. Evaluations of other similar initiatives would suggest that it can take four to five years for changes on this scale to be embedded in the practices of all of the professionals drawn from a variety of different agencies who are working with children and families.

Most of the professionals and parents who participated in the evaluation identified aspects of the initiative which they felt were particularly successful and needed to be continued beyond the lifetime of the initiative:

- The HELP!, EarlyBird and EarlyBird Plus training for parents and carers;
- The Newsletters and other steps taken by the Initiative to improve communications between services and parents;
- The awareness raising and multi-agency training for frontline staff;
- The introduction of new posts to enhance integrated working between services;
- The developing network of parent support groups;
- The variety of local initiatives, such as the Saturday Social Skills Club in Easter Ross.

Also, most of the structures, pathways and procedures are now in place to enhance multi-agency working. It is important to ensure that these are utilized by all concerned in the ways for which they were intended.

In our view priority needs to be given to ensuring that professionals in all of the relevant services and agencies adopt a holistic view of the needs of the child rather than compartmentalize those needs into the concerns of specific services, i.e.: the child as 'patient', 'pupil', 'family member', etc. for some this will entail a shift in perspective, expectations and assumptions. There was clear evidence of this happening in Highland but the extent of integrated thinking (as opposed to integrated structures and procedures) is variable. That is only to be expected given the relatively short time since these changes were introduced but it is probably the development that now needs further impetus.

## NOTES

(1) Drs Stradling and MacNeil are based at Edinburgh University and also the UHI Millennium Institute. Alison Clark works for Highland Council.

(2) The lower prevalence ratio is taken from the Public Health Institute for Scotland Report on autistic spectrum disorders published in 2001. The higher estimated prevalence ratio is used by the National Autistic Society.

(3) G. Baird et al (2006) *Prevalence of disorders on the autistic spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project, Lancet 2006 , 368, 210-215*

(4) Scottish Executive (2001) *For Scotland's Children*, Edinburgh.

(5) PHIS (February 2002), *Autistic Spectrum Disorders – Needs Assessment Report*, Edinburgh, NHS Scotland.

(6) Baines, J., Dickinson, P. & Cambell, M.; (2002) *Multi-Agency Review of services for Children with Autism Spectrum Disorders*, Highland Council, Inverness.

(7) Filipek, P.A., Accardo, P.J., Baranek, G., Cook, E.H., and Dawson, G. (1999), The Screening and diagnosis of autistic spectrum disorders', *Journal of Autism and Developmental Disorders*, vol.29, pp.439-484.