



**Evaluation Report on the
Western Area Support Project (WASP)
on early intervention with families
who have a child with Autistic
Spectrum Disorders (ASD)**

**Roy McConkey, Maria Truesdale-Kennedy
and Victoria Milligan**

*Institute of Nursing Research,
University of Ulster*

December, 2006

Contents

Executive Summary

Rationale for the Project

Western Area Support Project (WASP)

Phase 2 evaluation

Section 1. Information on children and families

- A. Children seen at clinics or waiting to be seen.
Parental reactions to the clinics.
- B. Children and families seen by the early intervention therapist.
Reactions of mothers to this service.
- C. Children placed in early years facilities.
Experiences of early years personnel
Rascals summer scheme

Section 2. Training for parents and professionals

- 1. ACCESS workshops for parents
- 2. Keyhole Early Intervention
- 3. Rainbow Boxes.

Discussion

References and Further Reading

Appendix 1: Members of Project Steering Group
and Terms of Reference

Appendix 2: Project Outcomes mapped against targets

Acknowledgements

We are very grateful for the help and assistance provided by Florence Trotter, Michelle Keenan and Dr Vivien Dale, and for the advice given by the Steering group. Roy McConkey's post at the University of Ulster is jointly funded by the EHSSB.

Executive Summary

The WASP Project is funded by the Children Fund and aims to develop a holistic approach to interventions with families in the Western Board¹ area of Northern Ireland. This is the first attempt in Northern Ireland to develop a Board-wide approach to the provision of specific ASD services for these families and children.

International experience suggests that positive changes are possible with early identification followed by consistent intervention that involves the parents and provides direct teaching of essential skills with the child.

The evaluation of the WASP project would garner the learning from this new initiative and assess the implications for the future development of these services and similar ones in Northern Ireland and elsewhere.

The stated aim of the Project is:

“To assist in ensuring the early diagnosis and assessment of children with ASD and to facilitate children’s access to early interventions and informed pre-school education resulting in the minimisation of ASD effects and the development of full pre-school potential in the WHSSB area.”

In achieving this aim, the project aimed to implement the three main elements of the Keyhole approach to early intervention developed by PAPA and its partner agencies in Northern Ireland and to work closely with PAPA branches in the Board’s area. Hence the project had the following dimensions.

- A core Home Visiting service – this is a series of visits to the child’s home which empowers parents in the knowledge of Autistic Spectrum Disorders and practical strategies needed to work with their child. Latterly a new PAPA project – Connecting with Autism - has developed a ‘Rainbow Box’ of playthings and educational equipment specially selected for use by families at home with preschoolers with ASD.
- Parent Training – ACCESS Workshops give advice on local services, Autism and parent support.
- Professional Training – This included a specially designed 12 ½ hour course for pre-school playgroups is delivered through a NIPPA/Barnardo’s/PAPA partnership as well as awareness training for early childhood professionals.
- Early years education – children with ASD are placed in a range of early years provision and supported by a range of professionals from education and from health and social services.
- PAPA Branches meet regularly in Derry and Omagh, as well as Dungannon and mid-Ulster.

The first phase of the evaluation focussed on documenting the learning experiences of the various stake-holders (parents, professionals and service commissioners) and their perceptions of further developments that are desirable and feasible. The numbers involved and the methods were detailed in an Interim Evaluation report presented in September 2005. Among the themes identified from experiences of the first 18 months were:

- The need for improved assessment and diagnostic services
- Earlier referral of children with suspected ASD

¹ The word Board is taken to mean both WHSSB and WELB unless otherwise stated.

-
- Improved follow-up to diagnosis
 - Increased Speech and Language Therapy services
 - The provision of guidance and information for families
 - Awareness raising and training of community staff
 - The contribution of Early Childhood Education
 - Multi-agency Planning
 - The Role of AutismNI (formerly PAPA) in further service development
 - The lack of resources available to statutory agencies.

The second phase of the evaluation focussed on obtaining more detail on the outcomes from the service developments undertaken in 2005/06. This included:

- Information on children with suspected ASD seen at assessment and diagnostic clinics or who were waiting to be seen.
- The view of parents who had attended these clinics or who were waiting to be seen.
- Feedback from parents who had attended ACCESS parent workshops.
- Details of families who had participated in the home-based intervention service.
- Reactions of staff who had attended Keyhole Training and workshops on Rainbow Boxes.
- Views of staff in early years facilities who had taken a child with ASD during the year 2005/06.

A review was undertaken of the original aims of the Project in light of the information gathered. A series of pertinent questions are posed to the Steering Group to draw out the learning from work done to date. These will lead to a number of recommendations that the two Boards may wish to consider in their future planning. These may include:

- Appropriateness of referrals of children to the specialist clinic in Foyle and how these assessments can be expedited and made more useful to families.
- The urgent implementation of multi-disciplinary assessments in Sperrin Lakeland.
- A database of all children presenting with ASD in the Board area should be maintained and reports sent regularly to service managers.
- The closer integration of education and HSS services to preschool children with HSS and implementation of an overall management structure for these services.
- The provision of a 'named person' with expertise in ASD to families as soon as a problem is suspected leading to one common family plan across all services.
- A review of the role and function of early intervention therapists; their reporting relationships, case load and additional responsibilities.
- Supplementation of the Speech and Language therapy service and their role in early identification, intervention, parent and staff training.
- Ongoing liaison with AutismNI to organise parental support and advocacy groups throughout the Western Board area.

-
- A regular training programme is provided for staff in early years facilities that extends the basic training provided to date, for example in specific interventions for children with ASD.
 - A costed action plan with detailed operational proposals would greatly assist in obtaining funding for these endeavours although some could be met through the better targeting and coordination of existing monies.

The WASP project illustrates the diversity of challenges that have to be faced in establishing appropriate services to a growing number of children with particular needs. Too often this has been left to the dedication and good will of a small number of professionals who have tried to do their best with limited influence and resources at their disposal. The Project has made all the clearer the job that needs to be done and an excellent learning foundation has been laid for future developments.

Rationale for the Project

The WASP Project is funded by the Children Fund and aims to develop a holistic approach to interventions with families in the Western Board² area of Northern Ireland. This is the first attempt in Northern Ireland to develop a Board-wide approach to the provision of specific ASD services for these families and children.

However in Northern Ireland PAPA (now known as Autism NI) has been instrumental in developing the Keyhole Early Intervention Project, primarily with Down Lisburn Trust and parts of this approach have been further developed in the SHSSB area. Evaluation reports on both these initiatives are available (McConkey, McGreevy, Crawford and Cassidy, 2003; McConkey and Truesdale, 2004).

In addition PAPA is currently engaged in another early years project that makes available learning materials to families (Rainbow Boxes). An evaluation report on the first phase of this project is also now available (McConkey, Truesdale-Kennedy and Poulton, 2005).

This development work in the Western Board has been fully informed by, and has extended the insights of international researchers and practice. It also pre-dated a study commissioned by the Department of Education on the assessment of the need and early support intervention for children (aged 2 to 4 years) with ASD in Northern Ireland (McConkey, Kelly and Cassidy, 2006). The WASP project broadly follows and indeed acted in part as a model for the recommendations emerging from this study.

International experience

International experience suggests that positive changes are possible with early identification followed by consistent intervention that involves the parents and provides direct teaching of essential skills with the child.

According to Jordan (1997), "*Education remains the one treatment approach with the best track record for dealing with the difficulties associated with autism*".

Among the important dimensions to educational provision she notes are:

1. Recognising and identifying the child's problems from an early age – 18 months onwards.
2. Developing an individual education plan to address the child's particular difficulties and needs
3. Training families on teaching programmes they can use with their child at home.
4. Supporting families with the extra stresses they experience.
5. Encouraging the social inclusion of the child in family and community life such as preschool facilities.

Although the need for teaching and treatments to commence for an early age is well recognised, experience of doing this remains limited. Nonetheless there are some important indications of what parents value, namely (Christie and Chandler, 2002).

- *Integrating diagnostic and support services*: Providing a diagnostic service is only a first step. Parents value an ongoing support service that will help them to address the specific needs of their child in a practical way.

² The word Board is taken to mean both WHSSB and WELB unless otherwise stated.

- *Home support:* Parental preference is for professional assistance to be given in the home. This provides a secure and familiar environment for the child and for the parents as well as being a natural context in which teaching takes place. Weekly visits are preferred.
- *Flexibility of approach:* Parents value having a clearly defined, autism specific approach yet one that is sufficiently adaptable to children's needs and family circumstances over time.
- *Communication:* Difficulties in communicating with the child are often a particular concern to parents. They value practical guidance on how to develop the child's understanding and use of language in communication.
- *Inclusion:* Families are keen for their child to have the same opportunities as their other children, notably in accessing preschool facilities.

For some families, the child with autism is not their only or main concern. They may well have to deal with other problems of both a short and long-term nature. Early intervention programmes need to be sensitive to this and in some instances may need to provide the information and support to deal with these other concerns if no other help is easily available.

Developments in Northern Ireland

The Task Group on Autism convened by the Department of Education NI, (2002) noted that the following strategies had been shown to be beneficial in working with preschool children with autism.

- One-to-one planning and work with the child.
- An emphasis on promoting communication
- An emphasis on a visual approach
- Developing the child's skills for independence.

These teaching approaches need to be done skilfully, by competent teachers and with a degree of consistency across teachers and settings. Although some would argue for daily intensive teaching sessions lasting upwards of four hours, this can place major strains on parents. Recent research suggests that the number of treatment hours does not appear to correlate with outcomes (Gabriels, 2001) and that there has been some over-estimation of the minimum number of hours required per week (Luiselli et al, 2000). Moreover teaching programmes need to adapt to family lifestyles and routines rather than the other way round, if stress in families is to be reduced (Jones, 2000).

Latterly increased interest has centred on the use of structured play in home-based interventions (Boucher and Wolfberg, 2003). Play activities can more easily engage the whole family; fathers, siblings and grandparents as well as mothers. They are more ecologically valid in that they can be adjusted to the culture and circumstances of the family. Activities can be chosen to match the child's developmental level and interests and hence increase the child's intrinsic motivation to join in rather than relying on extrinsic reinforcement. They provide a link into the play activities that children will experience in playgroups and preschools.

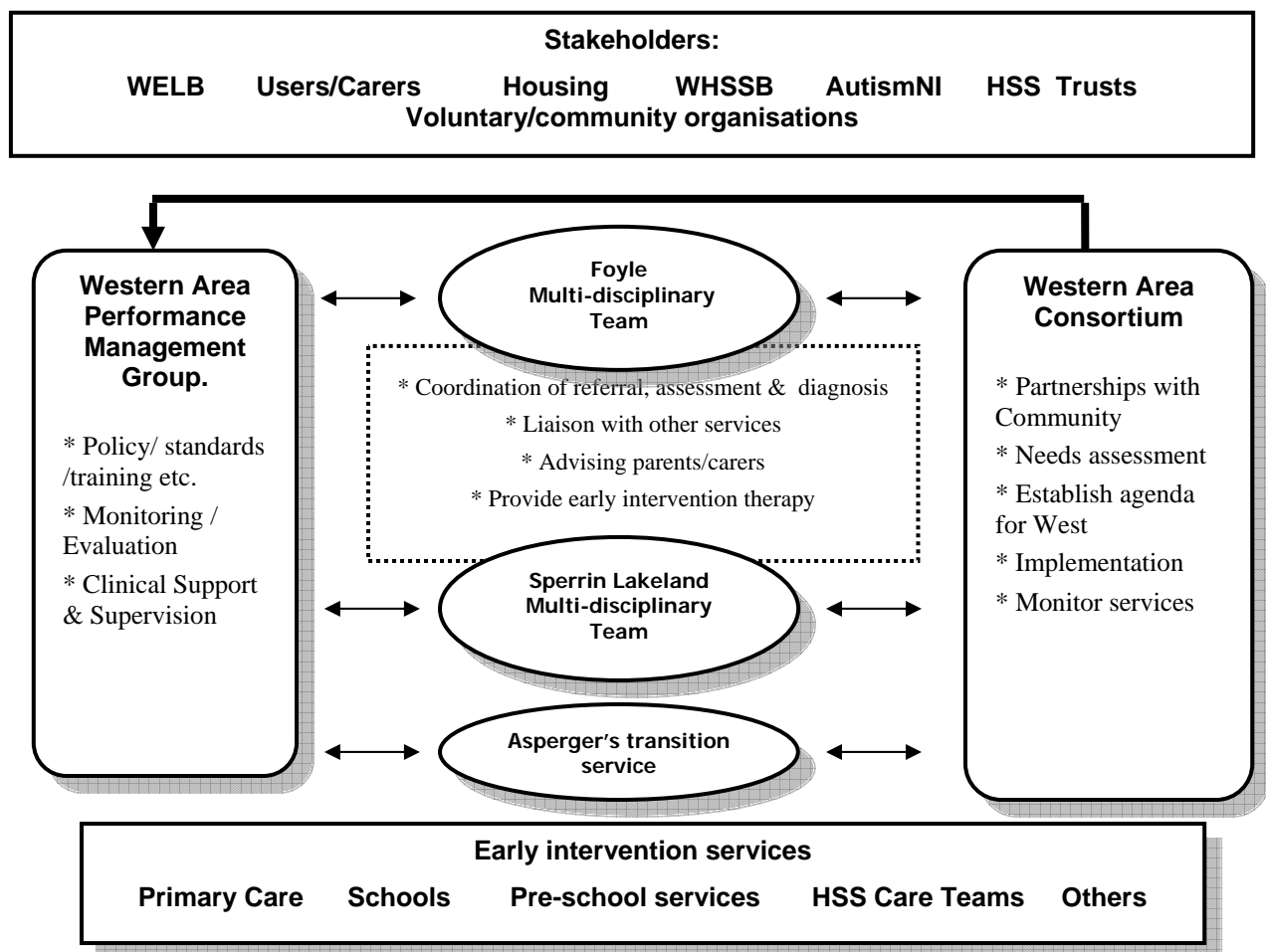
In many countries - Northern Ireland included - Health, Education and Social Services have been slow to implement these elements of good practice. In part this is due to a lack of financial resources but more crucial has been a lack of necessary expertise among service staff and effective inter-agency and inter-disciplinary working.

Nonetheless there is an increased commitment to improving service provision from Health and Social Services (as per the paper on autism prepared by the four HSS Boards in 2004) and the Task Group set up by the Department of Education (NI).

Furthermore the Department of Education commissioned a study to examine the needs of children aged two to four years (McConkey, Kelly and Cassidy, 2006). The overriding priority identified was to create structures and systems that will encourage partnership working across all the sectors (education, health and social services, and the voluntary/community sectors) while strengthening local initiatives to respond to particular needs and service developments. It was recommended that multi-agency Task Groups on ASD provision be established in the seven new super-council areas or in the interim on existing Education and Library Boards.

The Western Board Context

From 2002 onwards, the WHSSB and WELB along with other partners had developed an early intervention pathway in response to the needs of children with ASD and their families. The main features are summarised in the Figure below.



The bid to the Children Fund was to help facilitate the implementation of this model particularly for children under school age. The evaluation of W.A.S.P. project provides an opportunity to investigate the requisites to the development of an inter-agency, Board-wide service in an area that historically has had little provision for this emerging client group. It would garner the learning from this new initiative and assess the implications for the future development of these services and similar ones in Northern Ireland and elsewhere.

Western Area Support Project (WASP)

The stated aim of the WASP Project is:

“To assist in ensuring the early diagnosis and assessment of children with ASD and to facilitate children’s access to early interventions and informed pre-school education resulting in the minimisation of ASD effects and the development of full pre-school potential in the WHSSB area”

In achieving this aim, the project implemented the three main elements of the Keyhole approach to early intervention developed by Autism NI and its partner agencies in Northern Ireland and to work closely with Autism NI branches in the Board’s area. Hence the project had the following dimensions.

- A home-based, early intervention service based on the Keyhole programme developed by Autism NI which empowers parents in the knowledge of Autistic Spectrum Disorders and practical strategies needed to work with their child. Latterly a new Autism NI project – Connecting with Autism - has developed a ‘Rainbow Box’ of playthings and educational equipment specially selected for use by families at home with preschoolers with ASD.
- Parent Training – ACCESS Workshops give advice on local services, Autism and parent support.
- Early Years Training – two training courses have been developed by Autism NI for personnel working in early years facilities (nurseries and playgroups); one deals with the Keyhole approach and the second on the Rainbow Boxes (see above)
- Autism NI Branches meet regularly in Derry and Omagh and also in neighbouring towns such as Dungannon and in mid-Ulster.

A steering group was established for the Project consisting of WHSSB Board, HSS Trust and WELB representatives alongside Autism NI personnel (see Appendix 1 for membership and terms of reference). The Group felt that it was important to include in the evaluation the wider services available in the Western Board area so as to obtain a complete picture of provision. These were:

- Within Foyle Trust, a specialist Assessment Clinic has been established with Dr Vivien Dale and Dr Porter, community paediatricians working alongside educational psychologists to jointly diagnose preschool children in a multi-professional setting involving Speech and Language Therapists, OTs, social worker and the WASP early intervention therapist. Dr Michael Curran from learning disability services also links with this clinic.
- A similar team is developing in Sperrin Lakeland Trust where a fulltime administrator has been appointed, a social worker has been allotted two sessions per month and a health visitor, speech & language therapist and an occupational therapist have been allocated one session per month. In addition Dr Dale from Foyle Trust provides sessional input.
- Children with ASD are also attending early years facilities such as playgroups and nursery schools. Education and Library Board personnel along with HSS professionals and the Early Intervention Therapist provided to support to the staff.

Project objectives

A number of specific objectives were set for the WASP project along with performance targets as outlined in the project application. The objectives were:

Objective 1: *The Early Intervention (EI) Therapist (ASD) would work with WHSSB in managing and promoting a multi-agency, multi-disciplinary ASD assessment/diagnostic service*

Objective 2: *To provide advice & support for families engaged in assessment & diagnostic process*

Objective 3: *To provide practical, individually tailored, home based "early intervention" training for parents of children with ASD*

Objective 4: *To provide a practical training programme on the needs of children with ASD to Early Years practitioners*

Objective 5: *To provide awareness training for professionals across all agencies*

Objective 6: *To involve new families from the Western area in the wider advice & support network*

Although the project was scheduled to commence in 2003, there were delays in appointing personnel. A full-time Early Intervention Therapist was appointed in March 2004. Arlene Cassidy undertook the role of Project Training and Development Officer on a part-time basis until an appointment was made in September 2005 on a one-third time basis. The administrative officer, funded by Sperrin Lakeland Trust, took up her post in May 2005. The three year funding for the project was due to end in December 2006 but the DHSSPS has agreed to further funding so that the work of the early intervention therapist could continue and a second one appointed.

The work of the project will be described in the context of the results obtained during the evaluation.

The Evaluation of the Project

The evaluation was conducted in two phases.

Phase 1: Review of service developments.

The project became fully operational in March 2004 and in the first 12-15 months a range of service initiatives commenced as described later. The first phase of the evaluation therefore focussed on documenting the learning experiences of the various stake-holders and their perceptions of further developments that are desirable and feasible.

Specially developed, self-completion questionnaires (with an option of a telephone interview for families) were used with a freepost reply envelope enclosed. The questionnaires were developed from those used previously in the evaluation of the other ASD projects in Northern Ireland and members of the Project Steering Group commented on them prior to their distribution (copies of questionnaires are available on request). All respondents were assured of the confidentiality of their replies and they were not asked to give their name. Families were further assured that their decision to participate or not would have no affect on the services they received.

All questionnaires were distributed through the project office so that no names and addresses of stakeholders were divulged to the evaluators. However the evaluators directly contacted the service managers and facilitated the focus groups. Again assurances of confidentiality were given to these participants.

The following groups were involved in this interim evaluation:

- Families who have participated in home-based projects with WASP and in Access Parent Workshops (around 25+), and also members known to PAPA branches with

children aged under 9. This group included families with children under 6 years of age who had been diagnosed as having ASD in the Board area (30 questionnaires were distributed with 17 returned: 57% response rate).

- Selection of staff working in preschools, nursery schools and first classes of primary schools throughout the Board area and relevant staff in WELB (e.g. educational psychologists, special advisers). (212 questionnaires were distributed with 73 returned – 34% response). However due to an oversight some people were sent two different questionnaires hence some people may have returned more than one questionnaire).
- Participants and tutors in NIPPA training course held under WASP Project (22 persons in all with 7 returned: 32% response). Evaluation questionnaires (N=89) completed by participants in the training course for the Western Area Childcare Partnership and Early Years Forums were also made available for the evaluation.
- Community paediatricians, Health Visitors, AHP staff in two HSS Trusts (185 questionnaires were distributed and 41 returned: 22% response).
- Senior managers in WHSSB Board, HSS Trusts and WELB with responsibility for service planning (of the 8 persons identified, information was obtained from 7: 87% response).

In addition two Focus Groups were held for all interested persons in Derry and Irvinestown. Letters of invitation were sent with the questionnaires but only small numbers of people attended (6 in Derry and 4 in Irvinestown).

The variable response rate across these groups is not unexpected and in some instances exceeded expectations. It may reflect the lack of contact that certain groups – such as health and social service staff – have with preschool children with ASD. Nonetheless responses were obtained from all the different professions and disciplines.

However more responses were obtained from people in Sperrin Lakeland areas than in Foyle. This may be because the project has had a greater profile in that Trust area.

Phase 2: Impact of the Project

This phase commenced in September 2005 and was completed in December 2006. The aim was to assess the impact of targeted service developments undertaken by the Project. To that end information was gathered on:

- Children with suspected ASD seen at assessment and diagnostic clinics over a two year period in Foyle and Sperrin Lakeland or who were waiting to be seen. Details were provided by community paediatricians on 119 children.
- The views of nine parents who had attended these clinics or who were waiting to be seen.
- Details of 15 families who had participated in the home-based intervention service; ten of whom had completed a series of home visits by the early intervention therapist.
- The views of 11 families who had been involved in the home-based intervention service.
- Views of 10 staff in early years facilities who had taken a child with ASD during the year 2005/06.
- Feedback from 24 parents who had attended four ACESS parent workshops.

- Reactions of 63 staff who had attended Keyhole Training and 78 staff who attended workshops on Rainbow Boxes.

Summary of Phase 1 findings

Full details of the information gathered in Phase 1 is contained in the Interim Evaluation Report submitted in September 2005. The main conclusions that emerged from the analyses are summarised below and the possible recommendations for addressing them were discussed with the Steering Group as part of the process in developing the main priorities for the WASP Project in its final year and planning for the continuation of its work.

Among the themes identified from experiences of the first 18 months were:

- The need for improved assessment and diagnostic services in the Western Area
- Earlier referral of children with suspected ASD; most were over 4 years of age when diagnosed.
- Improved follow-up to diagnosis is frequently commented on by professionals but does not happen. Moreover clarity is needed on the different roles and potential overlaps among the home-based early intervention service; the ASD social worker (both provided by HPSS) and the home-based teaching service of WELB.
- Increased Speech and Language Therapy services. This is a common need and yet existing services were under-resourced.
- The provision of guidance and information for families. The lack of this is a recurring complaint.
- Awareness raising and training of community staff
- The contribution of Early Childhood Education could be further developed.
- Multi-agency planning and working is required but systems for doing this are under-developed.
- The Role of AutismNI (formerly PAPA) in further service development should be explored.
- The lack of financial resources available to statutory agencies is noted.

Phase 2

The remainder of this report summarises the findings from information gathered during the second phase of the evaluation. This is presented in two main sections.

1. Children seen at clinics; home-based interventions and early years educational settings.
2. Training provided for parents and early years professionals.

Section 1. Information on children and families

This information is in three parts.

- D. Children seen at clinics or waiting to be seen. This also includes parental reactions to the clinics.
- E. Children and families seen by the early intervention therapist. Reactions of mothers to this service.
- F. Children placed in early years facilities.

A. Assessment and diagnostic clinics

The community paediatricians in the two HSS Trusts in WHSSB area were asked to supply information on the following children known to them:

- Children who have been assessed and diagnosed as having ASD in the period 1 October 2004 to 30th September 2005 (i.e last 12 months) and who were under 6 years of age (i.e. their date of birth is on or after 2 October 1998). This was repeated for a second 12 month period: October 2005 to September 2006).
- Children on the waiting list for assessment on 1st October 2005 and whose date of birth is on or after 2 October 1999 (i.e. they are under 6 years of age). This was also repeated for children on waiting list on 1st October 2006.

Returns

The Table below shows the number of returns made in the two years from the two Trusts.

Table 1: The numbers and percentages of children returned from the two HSS Trusts over the two years (N=119)

Number of children	Foyle HSS Trust	Sperrin-Lakeland
2004/05 Confirmed diagnosis	14 (54% of all children in WHSSB)	12 (46% of all children in WHSSB)
2004/05 Not ASD	0	1
2004/05 Wait Listed	39	1
<i>Totals seen 2004/05</i>	<i>53 (79% of all children)</i>	<i>14 (23% of all children)</i>
2005/06 Confirmed diagnosis	13* (76% of all children)	4 (17%)
2005/06 Not ASD	1	0
2005/06 Further assessment	5	0
2005/06 Wait Listed	29	0
<i>Totals 2005/06</i>	<i>48 (92% of all children)</i>	<i>4 (8% of all children)</i>

** includes a child with confirmed diagnosis in 2005 who was seen again in 2006*

More information was provided for children in Foyle Trust in both years but noticeably so in 2005/06. As yet there is no specialist assessment service available in Sperrin Lakeland, and this may account for the difference in numbers reported between the two Trusts; especially for those on waiting lists.

Children on waiting list

(NB This data is available mainly for Foyle HSS Trust.) There were 10 fewer children on the waiting list at October 2006 (26% fewer) than at October 2005. Comparisons can be made between the characteristics of the children on the waiting list as at October 2005 and at October 2006. These are shown in Table 2.

Table 2: Comparisons of the characteristics of children under 6 years of age on the waiting list for assessment and diagnosis.

Characteristics	2005 (N=39)	2006 (N=29)
Male/female ratio	31:8 (79% male)	25:4 (86% male)
Mean age at referral	3.7 years (1.8 to 5.4 yrs)	3.7 years (2.7 to 5.7 yrs)
Aged under 4 at referral	21 (57%)	19 (68%)
Aged 4 plus at referral	16 (43%)	9 (32%)
Length of time of waiting list	9 mths (3 weeks to 2 yrs 5 mths.)	5 mths (1 week to 1 year)

There was a significant drop in the length of time children had been on the waiting list from an average of 9 months at October 2005 to an average of 5 months at October 2006. However the other characteristics of the children remained similar although there tended to be more children under 4 years referred.

In 2004/05 the majority of referrals of children on the waiting list came from community paediatricians (N=24:62%) followed educational psychologists (N=12: 36%) with one child referred by a SENSO in nursery school. The pattern was different in 2005/06 with children being referred by speech and language therapists (N=4: 14%) and health visitors (N=2: 7%) as well as community paediatricians (N=11: 38%) and educational psychologists (N=12: 41%). Although the numbers are small, children on average were younger when referred by a health visitor (mean 2.77 years: range 2.7 to 2.9 years) and oldest from educational psychologist (4.2 years: range 3.1 to 5.7 years).

An analysis of the 39 children on the waiting list at October 2005 showed by the following October 2006, only 10 had been reported as having a confirmed diagnosis of ASD. Of the remaining 29 children, 14 may not have been reported on as they were over six years of age at the census date but this leaves 15 children under six on 1 October 2006 who apparently did not have ASD when they were assessed or else they remain on the waiting list for assessment and their data should have been added to 2006 dataset. However the data on these 30 children requires to be validated by the community paediatricians.

Children seen at assessment and diagnostic clinic

This section compares the characteristics of children under 6 years of age who were seen at the assessment clinic during the two years; 27 in 2005 and 22 in 2006. (NB The child with a confirmed diagnosis who was seen for a second time in 2006 is excluded from these analyses). In all five fewer children were assessed but this is most noticeable in Sperrin Lakeland (4 compared to 13 in 2004/05). [However a full return may have been made as yet by this trust]. In Foyle Trust the number assessed rose slightly from 14 to 18. Moreover the proportion of children assessed compared to those referred increased in this trust from 26% in 2005 to 38% in 2006.

Table 3 provides details of the characteristics of the children for the two year groups as well as for the combined sample. Of particular note, children who were assessed had

been referred at a significantly younger age compared to those on the waiting list; on average they are 12 months younger and nearly all are under four years of age. However the average length of time they spend on the waiting list is 16 months and this rose significantly from 2005 to 2006 from 13 to 18 months which means that only one third of children were assessed by their fourth birthday.

Table 3: Comparisons of the characteristics of children aged under 6 years assessed at clinics

Characteristics	2005 (N=27)	2006 (N=22)	Total (N=49)
Male/female ratio (Gender missing for one person in 2006)	23:4 (85% male)	15:6 (71% male)	38:10 (79% male)
Mean age* at referral	2.8 years (1.3 to 4.3 yrs)	2.9 years (1.4 to 5.5 yrs)	2.8 years (1.3 to 5.5 yrs)
Aged under 4 at referral	21 (84%)	18 (83%)	39 (83%)
Aged 4 plus at referral	4 (16%)	4 (18%)	8 (17%)
Mean age at diagnosis	3.9 years (2.2 to 6.4 yrs)	4.4 years (2.9 to 6.4 yrs)	4.2 years (2.2 to 6.4 years)
Aged under 4 at diagnosis	15 (58%)	6 (27%)	21 (44%)
Aged 4 plus at diagnosis	11 (42%)	16 (73%)	27 (56%)
Length of time of waiting list	13 mths (0 to 3 yrs.)	18 mths. (6 mths to 3 yrs)	16 mths (0 to 3 yrs)

** age data is missing for two children*

There were four times more boys than girls (N=11;19%). In ten families (20%) there was one other child with ASD.

The referrals of children who were assessed came mainly from community paediatricians (N=19: 43%); health visitors (N=13: 30%); educational psychologists (N=4; 9%); SLTs (N=4: 9%) and GPs (N=4: 9%). However the latter personnel may have instigated the original referral to a community paediatrician. Children referred by Health Visitors and GPs were significantly younger (2.4 years) than those referred by educational psychologists (4.5 years).

Diagnosed children

The information in this section relates to children given a confirmed diagnosis of ASD: 26 in 2004/05 and 16 in 2005/06 (42 in all). This represents 35% of all children referred to the clinics over the two-year period and 85% of those assessed at the clinics.

Of the 42 children, 32 (76% were male). Their average age at referral was 2.9 years (range 1.4 to 5.5 years). They had waited an average of 1.3 years for a diagnosis (range one week to three years) and their mean age at diagnosis was 4.1 years (range 2.2 to 6.4 years).

Note: Given that the ages of children when referred ranged over a five year period, a prevalence rate can be calculated for ASD against the Board population of children aged 1 to 6 years – around 21,000 at the last Census. This gives an overall prevalence of 20 children per 10,000 which is close to the figure of 22 per 10,000 reported by Chakrabarti and Fombonne (2005) for children with autism based on prevalence studies in Staffordshire England. However in this study a further prevalence rate of 59 per 10,000 was reported for children with other pervasive developmental disorders. If this figure was applied to the population of the Board, a further 118 children aged 1 to 6 years might be thought to have an ASD.

The diagnosis was made by the community assessment team (N=28: 70%) or by the community paediatrician (N=12: 30%). The former was much more common in Foyle.

Seventeen of children (40%) were reported to have an associated learning disability. Thirteen children (37%) attended mainstream schools; 14 (40%) special schools; 7 (20%) preschools and one had a home teacher (2%) (NB This information was not available 7 children).

Informant were asked to rate the child's difficulties compared to their age peers on a four point scale: 1 was no real problems, 2 some problems, 3 marked problems and 4 severe problems. Table 4 summarises the median scores and ranges.

Table 4: The mean and range scores on child indicators

Rating	Personal Care*	Gross-motor*	Communication*	Socialisation*	Imagination*	Stereo Typed*	Disruptive Behaviours*
Mean scores	2.6	1.5	3.1	2.9	2.8	2.3	2.4
Range	1-4	1-2	2-4	2-4	1-4	1-4	1-3

As the table shows, the children's difficulties were most marked in communication, socialisation and imagination, and least noticeable in gross-motor. The range of scores was smallest on this dimension but greatest in terms of stereotyped behaviours, personal care and imagination. Children with an associated learning difficulty scores significantly higher on only dimension – that of communication.

Families

In all 30 children were reported to live with both parents and 9 with one parent (this information as not provided for 3 children. Fifteen families were known to own their own home and two did not but this information was not recorded for 25 families.

Informants rated the mother or father (if he is the primary carer) in relation to other parents on a three-point scale; 1- *Good/No problem*, 2- *OK/some problems* and 3 *Poor/Marked problems*. Table 5 summarises the mean and range scores.

Table 5: The mean and range scores on parental indicators

Rating	Self-esteem	Health	Stress	Anxiety	Concerned	Confidence	Coping
Mean	1.5	1.2	2.1	2.0	2.2	1.9	1.9
Range	1-3	1-2	1-3	1-3	1-3	1-3	1-3

As the table shows, ratings were highest for concern, stress and anxiety and lower for health and self-esteem. Single parents were rated higher on anxiety.

Information from postcodes will be used to provide an indication of social deprivation of the district where the family live.

Services

A variety of services were made available to children who had a confirmed diagnosis of ASD. Of the 39 children for information was supplied, 3 (7%) had no follow on services although referrals were made. Two children had one service; 20 had two services; 6 had three and 8 had four services.

The services received by children were as follows

Early Intervention therapist	22
Social Worker (ASD)	16
Speech and Language Therapy	10
OT	10
WELB Advisory service	9
Educational support in school	9
Learning Disability Team	8
Private therapy, ABA	2

The combinations of services varied across children and families. For example, the services received in addition to the Early Intervention service were as follows:

Early Intervention and Social worker	12
Early Intervention and Learning Disability Team	7
Early Intervention and ASD advisory service	6
Early Intervention and Speech & Language Therapy	4
Early Intervention and OT	4

However some families will be in receipt of services prior to their child being diagnosed but this could not be reported on by the community paediatricians until they had seen the family.

Parental reactions to clinics

In September 2006, the community paediatricians in the two Trusts wrote to all parents with children aged five years and under who had been seen at their ASD assessment clinic, or who are on the waiting list to be seen there. If parents were interested in taking part in a telephone interview with University staff, a number was provided for them to ring.

Ten parents responded, out of an estimated 50 letters sent out, although one has since proved uncontactable and one was not aware that the child had been referred to the clinic. All eight informants were from the Foyle area; four who had been seen at the clinic and four who had not been seen. The results from this small sample need to be treated with some caution.

The ages of the children at the time of interview were from 48 to 70 months. However five of the nine parents were aware of their child's difficulties from before two years of age and three before three years.

The four families whose children had been seen at the clinic were asked the following questions and their response are noted:

In what ways did the clinic help you?

3. *They didn't help me at all.*
5. *It didn't help at all, they told me everything I already knew about him.*
6. *It didn't help me at all, they didn't tell me anything that I didn't already know.*
9. *They drafted a report on N, sent him for a second assessment, they didn't really help at all.*

Are there any improvements you would like to see to the clinic?

3. *More support and information about autism, we were completely left in the dark and more information about what is available.*
5. *It seemed to be more about the professional and what they knew about my son, it was not family orientated at all.*
6. *The waiting time reduced.*
9. *No*

What happened after the assessment was done?

3. *Nothing I had one visit from a pre-school teacher.*
5. *They told me that they were going to send out an autism specialist to the house to help with potty training but we haven't heard anything else.*
6. *We are being sent to another educational psychologist to get N statemented.*
9. *He was referred to a local diagnostic unit school for children with SLD.*

Those mothers waiting to be seen at the clinic were asked the following questions (three had been waiting for one year and one had been referred in the past 4 weeks).

While waiting have you been given any information or assistance?

1. *The educational psychologist has been giving us advice and guidance.*
2. *N was given a one to one assistant while he repeats Primary one. Most of the information that we have received has been through a family friend who works with children with special needs, not from any services.*
4. *None*
8. *None*

Have you been given any reasons for your child's difficulties?

1. *They say that it could be a speech and language developmental delay but there is also suspected autism but I don't want to label him just yet.*
2. *No, I suspect autism because N had a traumatic birth and he had to be operated on straight after.*
4. *The teacher has suggested that N has autistic traits e.g. flopping, tensing and stimming. He also has no control of his temper.*
8. *Speech and language delay maybe Aspergers.*

What are you expecting to happen at the special clinic?

1. *I don't know, I just know that he will be assessed but I don't know what the outcome will be.*
2. *I am hoping for a diagnosis of Aspergers but after that I don't really know.*
4. *Help and advice anything at all.*
8. *I am expecting to find out what is wrong with N.*

All mothers were asked about the services they have received thus far. Four had received no services and the five who had received services commented as follows:

1. *Educational psychology offered home pre-schooling for 1 hour a week but we only had 2 months of this in May and June. We have had speech and language in block sessions.*
2. *We have had a referral to speech and language therapy but nothing really at all, also the use of a classroom assistant.*
3. *Speech and language therapy and occupational therapy but this is only once every three months.*
5. *Speech therapy but I am pleading for that.*

9. *Initially we got speech and language therapy but very little. None from then on.*

In what ways have they helped you?

1. *Pointers on what way to work with N, a visual timetable and use of language.*
2. *The classroom assistant has been a big help because now I don't have to run back and forward to school every day and now I might be able to go back to work. He is really settled in school.*
3. *Speech and language therapy has been no benefit at all and the occupational therapy was better but there wasn't enough.*
5. *Speech and Language Therapy is not improving N because he can't hear properly so he doesn't understand what is being said.*
9. *No help*

The difficulties that mothers find most difficult to deal with at present were:

1. *The lack of speech.*
2. *Communication and running away, it limits everything that you can do.*
3. *Behaviour*
4. *Behaviour and temper tantrums, the temper tantrums are becoming more regular.*
5. *Lack of hearing and understanding.*
6. *Temper tantrums can last up to 2 hours.*
7. *Speech and behaviour*
8. *Lack of speech*
9. *Behaviour, speech difficulties, sleep pattern.*

Only one two mothers reported using special treatments. One who used ABA noted:

It has given me direction and structure and how to deal with and help the children. Also understanding N's problems more. Able to teach N basic skills and how to manage N. ABA is not the proven choice of some professionals but you are not given any other help so there was nothing else for me to do.

Another mother used PECS. She noted:

It has helped communication and they use it in school.

Mothers were also asked about the help and advice they would like to have had when they first suspected their child had a difficulty.

1. *Just something to speed everything up it is just far too long a waiting list.*
2. *Anything at all, I did feel that the child psychologist was very helpful and that I could phone her at any time.*
3. *More support, what is involved with a diagnosis and what is out there for help. There is no advice at all.*
4. *We would have liked earlier help, they just kept saying it was due to his size because he is very big and that he was just a toddler. I always knew that there was something wrong other than that he just became more aggressive.*
5. *More advice on autism and how to work with children with hearing problems.*
6. *I got plenty of help and advice from the health visitor.*
7. *More speech and language therapy, he hasn't had any yet. They didn't give him a block (session); they told me that there were other people worse off.*
8. *I was totally shocked when we were told that there was a problem. Now we are just having to wait for someone to diagnose N, it is just too long a wait.*
9. *(Nobody told me) I did all the research myself*

The services that mothers would like to see available in the future were:

1. *More support from services for him and me and especially for the school so they know how to work with him. Also more speech and language therapy.*
2. *Language needs improvement and we need help with behaviour. I really don't know what N is entitled to.*
3. *More workshops, parent groups and more speech and language therapy and occupational therapy.*
4. *Someone for advice and help – a group to attend or other organisations that focuses on these specific types of problems.*
5. *Something to help with his hearing and how to change things in the house to help hearing.*
6. *Someone to talk to, a contact person, to advise on any problems that arise. Also respite.*
7. *More speech and language therapists and more blocks of speech and language therapy.*
8. *Somewhere to go to talk to other mothers or people who could offer help and advice*
9. *Something for over the summer, N loves routine and 9 weeks over the summer is a very long time.*

Conclusions

A number of issues emerge from the information gathered relating to the assessment clinics. The Project Steering group might wish to comment on:

- Are there comparable procedures in place in the two Trusts and if not, why is this?
- Are there too many children being referred who are not given a diagnosis of ASD? If so, this will prolong the waiting times for everyone.
- What is role of the diagnostic clinic in relation to service provision? For example when the child and family are already receiving assistance from Speech and Language therapy and educational services prior to assessments at the clinic?
- Why do some parents (e.g. the four who responded to the telephone interview) not find the clinics helpful to them?
- How soon are support services provided to families after diagnosis?

B. Children and families seen by early intervention therapist.

The early intervention therapist provided information on 15 children (2 siblings) and 14 families with whom she had worked over the two year period - October 2004 to October 2006). This is 36% of those with a confirmed diagnosis of ASD reported earlier. But of the 15, only four, possibly five were reported in the clinic samples; all of whom were from Foyle Trust.

However five families were seen on four or fewer occasions and hence 10 could be considered to have received the Keyhole early intervention programme (24% of those with confirmed diagnosis).

Of the 15 children, six (40%) were resident in the Foyle area and 9 (60%) in Sperrin Lakeland. (However as noted earlier, 26 (62%) of the 42 children with a confirmed diagnosis lived in Foyle area.)

The mean age of the children when referred was 3.8 years (range 2.6 to 5.6 years). The mean age when early intervention commenced was 4.6 years (range 2.6 to 6.1 years). The average waiting time was 9 months (range 1 week to 17 months).

Each family received an average of 7 visits to the family home (range 1 visit to 14 visits); a total of 102 visits plus phone calls. (If each visit is counted as a working day to allow for travel and preparation time; this equates to 22% of the therapist's time over the two years; i.e. approximately 460 working days in total).

For nine families, the mother was present while in six, fathers were also present but in 13 families, it was mothers who carried out most of the activities.

The therapist rated the children on a number of characteristics using the four point scale as described earlier(1 – no problems to 4 – severe problems). Table 6 gives the mean scores before and after the intervention. On two measures there were significant improvements ($p < 0.05$) – social isolation and imagination. The differences on the other ratings did not change significantly.

Table 6: The mean and SD scores on child indicators before and after early intervention

Rating	Personal Care	Gross-motor	Communication	Social isolation	Imagination	Stereo Typed	Disruptive Behaviours
<i>Before</i>	2.43 (1.1)	1.29 (0.6)	2.79 (0.98)	2.57 (1.02)	2.36 (0.93)	1.93 (0.48)	1.93 (0.73)
<i>After</i>	2.29 (1.1)	1.14 (0.36)	2.57 (0.76)	2.14 (0.77)	2.07 (0.73)	1.86 (0.36)	1.71 (0.77)

Similar ratings were made of carer's characteristics using a three point scale as noted earlier (1 - no problems to 3 – marked problems/difficulties). Table 7 presents the mean ratings for the 15 carers. On only one indicator was there a significant improvement noted, that of coping, although ratings for anxiety and concern tended to fall also ($p < 0.05$).

Table 7: The mean and SD ratings on parental indicators before and after intervention

Rating	Self-esteem	Health	Stress	Anxiety	Concerned	Confidence	Coping
<i>Before</i>	1.67 (0.62)	1.47 (0.64)	2.27 (0.59)	2.40 (0.51)	2.53 (0.52)	1.87 (0.52)	2.00 (0.66)
<i>After</i>	1.40 (0.51)	1.33 (0.49)	2.07 (0.49)	2.07 (0.59)	2.20 (0.56)	1.73 (0.46)	1.60 (0.51)

The therapist commented mostly on the help provided to the family, especially knowledge of ASD and why the child behaves the way he/she does. Advice was given on strategies and structure that parents could use, including turn-taking, visual communication, setting boundaries and moving to new activities.

Perceived changes in mothers were described mostly in terms of increased understanding, confidence and a sense of achievement.

After the intervention the therapist recommended further support was needed as follows:

Speech and language therapy	5
Occupational therapy	4
Child care	3
Behaviour support	2
Educational support	2

Reactions of parents who received early intervention

To date, 11 of the 15 families have agreed to be interviewed by telephone about their experiences of home-based early intervention. This includes all five families who had been visited on one to three occasions and six who reported having six to ten visits. Only one family reported using any specialist treatment programmes and that was Greenspan.

The questions asked of mothers and their responses are summarised below:

In what ways, if any, do you feel she helped N (the child)? (NB Five families noted that she had either not seen the child or else had focussed her attention on the parent(s)).

1. *Explaining how to do things with him, keeping him on task, developing concentration, his time on task improved and also language improved.*
3. *She knew when to engage N and when not to, developed concentration and the length of time on task.*
5. *Definitely helped fine motor skills and holding a pencil, also in recognising other family members through project.*
6. *More so by helping me this helped N*
7. *She worked one to one with him and developed concentration, helped with his behaviour and sitting in one place for a period of time.*
11. *Picture schedule made things a lot easier to understand.*

In what ways, if any, did she help you personally?

1. *Somebody for advice and information, support to turn to at any time if there is a problem. She was just like a family friend.*
2. *Visual aids for N and someone there if I needed her help or to contact her.*
3. *Helped to understand N better and understand difficulties better, became more aware of sensory issues.*
4. *Tips on how to work with N and just someone to talk to; to offer advice and help. Florence was so lovely and very helpful.*
5. *She was a good listener, offered support and advice and we were able to phone her for advice or any problems that occurred. Florence is a pleasure to work with.*
6. *She was someone to talk to and to talk problems through with, also provided support.*
7. *Support, someone to provide information, reduced the feeling of isolation. Also she helped to build confidence.*

8. *Listened, offering support, explaining behaviours and how to relieve them.*
9. *Someone to turn to that offered help and advice or just anything that we needed her to do. She gave us emotional support and encouragement. Florence has just been wonderful.*
10. *She didn't really do anything, it wasn't a consistent service. We asked her to help with speech and language therapist because she is a speech and language therapist and she said no it was out of her remit. If this is the case the boundaries are much too strict.*
11. *It is not about me – but she was someone to ask for help and advice.*

All mothers reported that they had been given information about ASD with leaflets, booklets and telephone numbers provided. Moreover ten of the 11 mothers reported that they had been told about new things to do with their child and seven felt their attitude had changed and another mother that her approach to the child had changed.

1. *It has just changed the way we work with N but not our attitude. It has changed the way that we approach him and talk to him.*
3. *Yes – we think about things more, have taken a step back and look at the broader picture.*
4. *Yes – I think before I speak now.*
5. *Yes – I don't give up on N as easily as what I used to, we are more positive.*
6. *Yes – I am more understanding*
7. *Yes – I know now that he can do certain things, I am stricter with him now that I know that he can do them.*
8. *Yes – she provided us with hope that this is not the end and we have realised that we can work with N and we are now more positive.*
9. *Yes – We are much more relaxed with N and we don't give up as easily we try that wee bit further with him now.*

Several mothers noted impacts on the wider family:

2. *Her older sister knows that N is unaware of what she is doing.*
5. *N is able to work with his older brother now, and his older brother understands him and his ways a lot better now.*
6. *All the information was passed onto husband (father), now understands more about N's condition.*
7. *His father was in denial, helped him to accept it more, and gave him general knowledge and awareness.*

All parents would recommend the service to other families and gave a variety of responses when asked to name the best thing about having the home visits.

1. *Before this there had been nobody or no help, it was nice to know that someone was out there trying to do something for those children who have autism.*
2. *It helped to give ideas on things to do with N, a chart of controlling her voice level which has been really useful for school and in the classroom.*
3. *It provided more structure.*
4. *Someone to talk to who can relate to what I am experiencing.*
5. *Not having to leave the house to make it to appointments.*
6. *I didn't feel isolated anymore because there was someone for me to talk to.*
7. *Knowing that my child can do more than what I thought, kept us motivated and provided structure.*
8. *Someone to be there to point out the key things that you need to know.*
9. *Someone to talk to.*

10. *It was inconsistent and didn't address our issues it was too basic. She is very knowledgeable person but it was useless for us.*

11. *Knowing that she has a wealth of experience and advice.*

The problems that mother continue to experience were:

1. *If he gets very excited his voice gets very high and it is very hard to get him down from that state.*

2. *Temper tantrums, it is her way or no way.*

4. *Temper tantrums*

5. *Aggressiveness to younger brother, he is scratching and hitting him.*

7. *Speech*

8. *Difficulty with pushing and hitting younger sibling.*

10. *Lack of communication, understanding of language and no sense of danger.*

Mothers were also asked to comment on their child's schooling which nearly all seemed pleased with:

1. *Delighted, it is very positive for him, he has a classroom assistant for 4 hours a day, this allows him to be more independent but she is there if he needs her.*

2. *Over the moon as it was her nursery teacher who discovered that N had a problem and the school can cater for her there.*

3. *It was the only school for her really, we didn't have a choice.*

4. *The school is very helpful; they are working closely with her.*

5. *So far things have been good; N has a classroom assistant 25 hours a week. The school is very good and understanding and we have a lot of input from the autism advisory service.*

6. *Very satisfied it is the perfect environment for N*

7. *Excellent the special needs coordinator is so helpful.*

9. *Yes – he has a one to one assistant and the school know him so well they know all his triggers.*

10. *It is a good school although we are providing the classroom assistant and without her I don't think that he could cope.*

11. *100% - it caters for his needs and his teacher knows him really well.*

The ways they felt educational, health or social services could be of benefit were:

1. *Money for parents to attend course because they are very expensive.*

2. *Something to help with the temper tantrums and controlling behaviour.*

3. *A befriender service*

4. *More contact with family and special needs groups.*

7. *Better communication with parents and better communication among professionals.*

8. *Yes – we haven't had any contact or advice from them so anything would be helpful.*

10. *More openness to change and thinking outside of the box- More multidisciplinary working.*

Conclusions

A number of issues emerge from the information gathered relating to the home-based early intervention service. The Project Steering group might wish to comment on:

- The number of families who received/required the service in the two year period.
- The primary purpose of the service, e.g. from the mother's perspective it appears to have been information giving and emotional support.

-
- The number of sessions that families require. Those who received a small number of visits still seemed to benefit.
 - How does the role of home-based early intervention fit with other services families receive, notably home teaching service and ASD social worker?
 - The need for parental support on behaviour management.
 - The high level of satisfaction that parents seem to have for the school placement.

C. Children placed in early years facilities.

Information was gathered from two sources. First from personnel in early year facilities – mainly nurseries and playgroups – about their experiences of having a child with ASD in their unit. Second, from parents and staff who had been involved with a week-long summer scheme for children with ASD in the Rascals preschool facility.

Experiences of early years personnel

A postal questionnaire was distributed in June 2006 to over 90 early year facilities throughout the Western Area and also to teachers working in the educational support service. This requested details on the number of children with ASD they had working with in the previous academic year and their reactions to this experience. Replies were received from 13 early facilities who had no children with AD enrolled, from 10 early year facilities who had had one or more children enrolled and from two educational support staff. This is an estimated response rate of around 25% which is usual for postal questionnaires.

Children's characteristics

Information was provided on 16 children; 12 boys (75%) and 4 girls (25%) whose average age was 4.4 years with range from 3.4 years to 5.4 years. Three-quarters had a confirmed diagnosis of ASD and four were suspected of having ASD. Half (50%) were reported to have a sibling with ASD. Half attended for five sessions per week; 7 (44%) for two sessions and one child (6%) for four sessions.

Staff were asked to rate the children on five indicators in the same way as had been done by the early intervention therapist and the community paediatricians. (The mean scores of the latter two raters are given as a comparison but these are for different groups of children).

Table 8: The mean and SD scores on child indicators

Ratings by	Communi- cation	Social isation	Imagin- ation	Stereo Typed	Disruptive Behaviours
Early years personnel	3.3 (1-4)	3.3 (2-4)	3.1 (1-4)	2.5 (1-4)	1.9 (1-4)
Early Intervention at end	2.6 (2-4)	2.1 (1-4)	2.1 (1-4)	1.9 (1-2)	1.7 (1-3)
Community Paediatrician	3.1 (2-4)	2.9 (2-4)	2.8 (1-4)	2.3 (1-4)	2.4 (1-3)

As the table shows, the early years staff tended to rate the children as having marked problems on communication and socialisation but less so in terms of stereotyped or disruptive behaviours, although the range of scores were wide. On the whole their ratings tended to be higher than those given by the paediatricians and the early intervention therapists for the groups of children they had rated. This suggests that the children in the early years facilities had marked problems.

Staff reactions

All ten respondents were able to name at least one benefit to having the children in their unit. This included an increase in their knowledge and confidence; other children accepting differences and giving parents a break. However all but one felt they had faced certain problems:

1. *Lack of training re structured teaching activities (practical strategies)*
2. *No relevant ASD training or previous experience in the setting*
3. *Tantrums and how to deal with them without upsetting others*
4. *Ensuring proper/appropriate support to enhance learning and not take staff from others*
5. *Very hard work initially, getting to understand each other, working out the best way to help*
6. *Child needed a bit more attention from an adult*
7. *Obsessive Compulsive behaviour. Lack of social skills, lack of another person to provide child with help*
8. *Child had no language, no attention span*
9. *Interaction with peers. Problem behaviour cause disruption.*

The following adjustments were reported:

1. *Adapted planning and activities to meet individual needs*
2. *Tried to provide structured approach to free play and 1:1 support*
3. *Applied for funding for additional member of staff and were successful*
4. *Daily programme had to adhere to strict routine or explain few days in advance if there was to be change*
5. *In progress-display/labelling*
6. *1:1 initially, lots of time spent with her but social skills improved gradually*
8. *No adjustments as such: just explanation of social skills had to be reinforced. Encouraging move to other activities.*
10. *Staffing increased. Each child has 1:1 help. Gradually phased in activities which upset children initially. Withdrew child for small group activities*

Only one staff reported difficulties with other children's reactions due to the child with ASD hitting them and taking their things. Five reported other children mixed "really well". Likewise two reported that other parents had been initially wary but this had dissipated with explanations.

Six of the ten staff reported having no prior training; two had attended keyhole training and one awareness training on ASD. A further staff member had gone to the child's home for a "small amount of ABA training" and the ABA supervisor had come to the preschool. Nine staff felt they would benefit from a range of training.

1. *Training on appropriate resources and strategies to use in classroom*
2. *More practical support/activities*
3. *Training on ABA. Talks/training by experienced worker*
4. *ABA training and a support worker*
5. *All staff go to Autism Awareness course. Help from parents, carers and other professionals working with ASD*
6. *Refresher training. Contact person for advice*
7. *Contact with someone other than Ed Psychologist who could confirm suspected tendencies are correctly identified. How to deal with parents and child*

8. *Specific training on ASD*
9. *More of any training available for ASD*

All staff would be willing to take another child with ASD although two did mention the need for extra support to be available. A respondent from a private nursery felt it was unfair that support assistants were not available in these settings although they were provided in the statutory and voluntary facilities.

Rascals summer scheme

Feedback was obtained from families whose child attended a week-long summer scheme provided by the Rascals Playgroup in Ballinmallard in August 2005. This was provided only for children with ASD and consisted of a programme of indoor and outdoor activities. Children aged 3-5 years attended in the mornings and those aged 5-8 years in the afternoon.

In all XX children attended the scheme and seven mothers agreed to be interviewed at home about their experience of the scheme and four staff completed written questionnaires. Their children ranged in age from 3 to 10 years.

This table summarises what mothers thought was best about the summer scheme.

Best things	Number
Knowing the benefits for the child e.g. stimulation in an appropriate environment; socialisation	4
Having time/respite to myself	3
Breaks up the holidays for the child	1
Peer play	1
Meeting other parents in the same situation	1
Needed service	1
Childs siblings were able to attend too	1

Examples were asked of what the child had learnt and these were often specific to his or her needs:

What child learnt	Number
To relate to others/social skills	3
Do not know due to lack of speech	1
Try new things	1
Turn taking	1
Work with others	1
Learning to sit at break	1
Adapt to a new environment	1
Adjust to visual schedule	1
Independence	1
Imaginative play	1
Help child understand own condition	1

Staff concurred with many of these outcomes, mentioning: turn-taking, following a structured routine; adjusting to new surroundings/people; having fun and trying new things. They also noted

Mothers felt they had personally benefited from the scheme:

How scheme helped you	Number
Time to myself to do normal day to day activities e.g. go shopping	4
Satisfied that child was in a service tailored to their needs	2
Time to spend with other children	2

Invaluable for the whole family (if my child wanted to go)	1
Other children also enjoyed the mainstream scheme	1
Meet other parents with similar problems	1

All staff felt they had coped very well (N=2); it was enjoyable/fun (2) they were comfortable and relaxed and felt they had plenty of support. One person did mention being nervous/anxious at the beginning. An induction night had been organised for staff prior to the scheme and some staff had attended training courses organised by AutismNI. However three staff had previous experience of working with children who had ASD.

Five parents mentioned improvements they would like to see in schemes of this sort were: better organisation beforehand; longer hours; longer duration; having sessions with similar ability children and advice session for parents.

A question about parents' views of children with ASD attending ordinary playgroups and schools elicited mixed feelings. Four parents felt it would be fine provided the appropriate support and resources were provided such as awareness and understanding; visual structures and classroom assistants. Another felt the child should have the chance to do normal things.

Others mentioned a range of reservations: I don't think the understanding is there; lack of funding; mainstream schools are not designed to cope with the needs of ASD children; school staff are not trained and have little awareness of ASD; lack of support in mainstream schools; more support and awareness is needed and concerns were expressed about the other children's reactions. The four staff were more positive about the children's involvement in mainstream provision although two did mention the need for support and time for one-to-one working.

The improvements parents would like to see in services more generally were: waiting lists for therapies too long; support for setting up early intervention programme; interventions other than ABA; development of pre-school services; having specialists e.g. sensory integration, OT, SLT; more information on clubs and events for child; advice centre and having local services.

Conclusions

A number of issues emerge from the information gathered relating to early years facilities. The Project Steering group might wish to comment on:

- Systems for recording the number of children attending preschool provision in WHSSB. (The number is likely to be greater than 16 reported here. For example, in the next section there is evidence reported that 18 facilities had children with ASD attending compared to the 10 noted here).
- The positive experience of staff working in this sector in coping with children who have ASD and their willingness to continue to take children.
- The apparent lack of training and preparation that the staff reported they had received.
- More training on practical strategies for use in groups and classrooms.
- Sparse mention of contact with any of the professional staff involved with these children and families.

2. Training for parents and professionals

As part of the WASP project, training was provided to parents through ACCESS workshops and for professionals through two-day courses on Keyhole Early Intervention and the Rainbow Boxes. Each of these training initiatives will be described in turn.

A. ACCESS Workshops

These workshops have been developed by AutismNI to give parents basic information about ASD and advice on local service provision. It is also a chance for parents to share their experiences and concerns. The workshop usually take place over four sessions although the number and length of sessions can be adjusted to meet parental needs.

Four workshops have been held throughout the Western area in the past 24 months. In total these have been attended by XX parents. However the take-up rate among families varied. In Foyle, parents of 17 children were invited to participate in a three day workshop (held one day a week at weekly intervals during October 2005. In all 6 families (35%) took up the invitation and ten parents registered (4 couples and 2 mothers). Three parents attended all days; 2 parents attended two days sessions and 5 parents attended one day (60% attendance overall). **Does this uptake and attendances reflect other workshops?**

Feedback sheets were completed by 24 families in all, although the extended feedback pro forma was only used with 8 respondents. These came mostly from mothers with only two from fathers. One family who attended were preparing to foster a 10 year old with ASD.

Parents felt very positive about the workshops and had many complementary things to say about the tutors (Sue and Florence).

The benefits to the parents were seen to be:

- Talking to other parents (16 mentions)
- Understanding better autism and information about it (8 mentions)
- Practical ideas and tips (7 mentions).
- Knowing the help that is available (4 mentions)

Example comments were:

7. Meeting other parents who are in the same situation to myself and my family. Contacts given v useful. Lots of positive ideas/thoughts given which helped me see beyond my son's autism.

13. Helped me feel not alone and talking with others made me feel there was light at the end of the tunnel. Learning how to come to terms with autism and all the therapy that is available

18. It covered all the important areas that I needed answered. Every week I took away something new and practical steps that I could apply to my child at home. Nice to share with people who understand exactly where you are coming from

22. It was all better than what I'd expected. Practical advice tips were the most needed, personally speaking. I found it an enlightenment to find other mothers going through the same everyday things regarding ASD

Eight parents mentioned that their attitudes to their child had changed. Example comments were:

1. I didn't realise that loud noises i.e. door bells can actually hurt my son

3. *A much better understanding of how an ASD child thinks and acts or reacts in normal situations and how literal he will interpret what he hears.*

4. *I know now that he can lead a normal adult life*

7. *I've come to the top of a hill (I feel) and at last can begin to peek over the edge! I can see my little boy now, not just his autism. Have found a deeper understanding of his "condition" for want of a better word*

Seven respondents from eight asked, felt that a similar course for grandparents would be beneficial. One commented:

4. *Would be great for grandparents. Would help alleviate some of their fears/worries*

Respondents had few suggestions for improvements. One parent mentioned that there was a lot of information to take in however others mentioned the need for further training e.g. in 'sensory and speech therapy'; Makaton and Signing, Schedules and boardmaker systems and others requested "top-up sessions" and any training that was available.

B. Training for staff in early years education

A two-day training course was provided in the Keyhole approach to early intervention. In addition to providing an introduction to autism, the course introduced participants to structured learning, visual communication, etc.

Feedback questionnaires were returned from 63 participants in the Keyhole workshops. They came from 37 different facilities and services throughout the Western area as the Table shows.

Early years services	Number of services
Playgroups	23
Child-care centres	4
Primary schools	2
Nursery schools	2
Family centres	2
Sure start	1
After school club	1
Travellers support	1
Women's activity	1
Home	1
Preschool service	1

Participants mostly worked as playgroup/preschool assistants and leaders, crèche, childcare and classroom assistants although a few held co-ordinator or teaching position.

However 12 facilities (31%) had at least one child with a confirmed diagnosis presently enrolled and a further six had a total of 15 children with a suspected ASD. In all 11 (28%) had previously had a child with ASD in their facility but 10 (26%) never had a child with ASD enrolled.

The aspects of the course that participants found helpful were:

- Practical strategies for use with children/in groups (30 mentions)
- Knowledge and understanding of ASD and signs if it (17 mentions)

- Course well delivered – especially input from a parent (17 mentions)
- Generally informative and well delivered (8 mentions)
- Increased confidence (2 mentions).

Example comments were:

The insight on how autistic children learn visually, how they feel and how they need routine. It was really easy to follow all the issues (26)

Finding out about all of the structured activities and getting ideas about how to make them and the session info in general. Facilitators were both brilliant and had good knowledge of autism. Useful, real life examples (29)

Helping with schedules for children. Ideas for different jigs for child to carry out. Excellent course and excellent tutor. Great to hear from Angela, hearing a parent's point of view (36)

I really enjoyed the course but when you don't have autism in the playgroup, it takes longer to learn about and understand. The course was v informative with good handouts (52)

How to break tasks down into small clear tasks and use pictures. I enjoyed the course and the practical activities made things clearer and understand the child's needs and from their perspective(61)

Only two improvements were noted by two participants: they found it a lot to take in a short space of time and would have liked more practical work. .

All participants felt they were knowledgeable about autism. Example comments were:

I had very little knowledge of autism before starting this course. I now would feel very confident working along with a child with autism. The course has given me so much information and understanding of autism. Overall the course was very good (23).

I have gained valuable information about how to recognise the signs of autism in a child and how to present activities in the playgroup which help a child to cope with routines and activities (34)

I am now more knowledgeable on the whole autism spectrum, signs to look out for and how to deal with it in my setting (37)

Built up my knowledge a lot in all areas, symptoms, strategies, parent/home links. (59)

Their attitudes and perceptions of children with ASD also changed. Some participants commented:

My perceptions have changed since taking the course, seeing ways in which they can be helped to be integrated in pre-schools; helping them to learn alongside other children (1)

It made me more sensitive and aware of individual needs with a child with autism and how to adapt my approach to best suit the needs of the individual child (13)

I now realise that autistic children need a lot of understanding from adults on their condition and they need a lot of support to help them adjust to the pre-school setting (34)

I will now be able to understand how they are feeling a lot more than before the course (37)

Among the ideas they reported putting into practice were:

Learning all children to work from right to left helps and more pictures with words helps them to learn better (26)

Structured task activities put in place and introduced use of daily schedules and work systems (33)

Making jig toys, instructions, speaking clear but not long sentences, showing what I want child to do, being firm but fair (42)

Lots of ideas using everyday objects with your activities and making things easy to understand (56)

A majority of participants expressed a wish for further training. Example comments included:

I would like further training and advice on all issues related to autism as I learned a great deal on autism but I would like to increase my knowledge. This course has given me a hunger for more info (61)

More training on individual plans (writing up) for children in preschool and sharing of info with parents. Dealing with temper tantrums, expecting these children to be part of a large group and cope with situations (group storytime) outside play, obsessions, interaction with other children etc (33)

Would love to have practical placement in a relevant setting (49)

Behaviour modification strategies for 4-5 year olds who have not previously received early intervention of any kind (63)

Willingness to take children in the future.

Of the 63 participants, none expressed an unwillingness to take a child within ASD into their facility in the future. In all 48 (76%) stated they would be definitely willing to consider this and 15 (24%) they would consider it if asked. Among the reasons they gave were:

Now have more knowledge and understanding of ASD, also how to deal with it and how to help them learn through Jig Activities and schedules (8)

As I m confident in working with a child with autism whereas before I didn't know how to deal with it (14)

A child with autism has as much right to be included in our setting. We are an equal opportunities organisation, also our staff that attended the training with myself, feel more confident and able dealing with autism (18)

Every child needs a chance and help no matter who they are and it learns other children to understand everyone is different but it is OK if you are (42)

I feel it probably would be a challenge for me and my setting but with perseverance and good planning, I would be able to cope (46)

I would like to work with a child with autism as I never have and to use what I have learned here and seeing it work for that child. Also it would be v good for all the staff in my setting (56)

When asked under what circumstances they may have to refuse a place to a child, the most commonly mentioned reason was staffing issues. Examples included:

If there wasn't appropriate adult/child ratio or properly trained staff to deal with it. Time spent in group may have to be reduced (8)

I would hope not to refuse a place but maybe due to a lack of funds for a one-to-one assistant (13)

Adult and child ratio in the setting. I honestly think an autistic child needs a 1:1 assistant to be able to benefit their full potential (20)

If child needs 1:1 support constantly and we did not have enough support in setting (37)

Lack of money for wages to pay for another member of staff for 1:1 with a child with autism (38)

Other reasons related to the number of other children with special needs in the group and the child being a danger to others. For example:

Only if there were too many children with autism looking for a place. Lack of resources. Under staffed (32)

If they were a danger to themselves or other children and if not being able to share your time with other children because so much time spent with ASD child (42)

Staffing problems, depending on how many special needs children we had at one time (43)

If I didn't have previous knowledge about what to expect and what to look out for (25)

However seven participants stated there were no circumstances that would prevent them taking a child with ASD.

A child with autism would not be refused our group. We have set our policy to provide spaces for children with additional needs (18)

Would try to accommodate all children. Maybe by moving to different sessions or take on staff (21)

I would not refuse any child with autism into playschool (22)

C. Rainbow Boxes

Autism NI as part of another project had developed the concept of a Rainbow Box containing a range of toys, teaching aids and information booklets specifically designed for use with families who had a preschool child with ASD or suspected of having ASD. The WHSSB purchased 100 Boxes for distribution in their area and three training courses were held in the WHSSB area (one in Derry and two in Omagh) to introduce early years practitioners to the Boxes and train them in their use. The job roles of the 87 participants are summarised in Table 9.

Table 9: Number of people attending training in WHSSB (N=87)

Professional background/work role	Number
Playgroups/ preschools	19
Family Centres/women's groups	8
Creche/Day centres	5
Sure Start	5
Nursery school (Irish speaking)	2
Travellers support	3
Health visitors	14
School Nurse	3
CPN	4
Speech and Language Therapy	10
OT	4
Behaviour Therapy services	3

Social worker	3
Child Guidance/educational psychology	3
Not given	1

The training attracted participants from a wider range of agencies with nearly half (N=42: 48%) from early years services; 21 (24%) from health visiting and nursing; and 26% from support services such as the therapies.

Self-completed evaluation questionnaires were returned by 46 participants from courses in WHSSB area. Of these, 18 persons (39%) presently had contact with a child who had ASD. Others may have had contact in the past and may do so again in the future.

Participants spoke highly of the training and the tutor; her enthusiasm and skill in communicating. The features they liked in particular were:

- Practical examples given
- Better understanding and insight to ASD
- Communication strategies
- Visual communication
- Strategies for working with families
- Ideas for activities
- Group discussions
- Hearing other people's experiences

Few suggestions for improvements were given:

- Interruptions from a course member
- Would have liked to have the Box to take away.
- Knew the content on Day 1 from previous courses.

However a few participants expressed concerns about how the Box might be used by people who had little grounding in ASD and suggested that links need to be made with local professionals who had this expertise. Likewise some participants were cautious about using the Kits with parents whose child did not have a confirmed diagnosis.

Follow-up

At the end of September a questionnaire was sent to all the services who had purchased a box requesting information on its use. Of the 88 forms distributed 23 have been returned to date (25%) and of these 11 respondents (12%) had used the Box and 12 (13%) had not. (These returns are from all of Northern Ireland.) Among the reasons given for the latter, were that the playgroup did not have a child with ASD enrolled at present; the social worker was too busy with other demands on her case-load; no access to the Box; had missed the training so do not use the Box, and the Box could only be used with a child who had a statement of Special Educational Needs (for ASD presumably) and there were no such children at present.

Although it is difficult to interpret non responses to the follow-up questionnaire, it seems likely that many Kits are still waiting to be used. This suggests that the uptake of a new resource may not happen immediately. However the delay could also indicate a reluctance among certain professionals to utilise a resource designated for children with ASD unless there is a confirmed diagnosis present.

Conclusions

Participants in all the training initiatives rate them very highly and have few suggestions for improvements. The tutors are praised for their delivery and friendliness. Most people are also eager to have further training. However a number of issues emerge from the information gathered on these training initiatives. The Project Steering group might wish to comment on:

- The number of families who do not accept the invitation to join an Access workshop (possible as many as 66% in some areas).
- The involvement of fathers (few appear to attend the workshops).
- The majority of the early years personnel who attended the training do not presently have children with ASD in their groups. Will they remember what they have learnt if a child comes in future years?
- The apparent low uptake of use of the Rainbow Boxes (@12% of attenders) even when they are given free to the participants in courses

Discussion

It is clear from the information gathered that the project has brought significant benefits to the children, families and early years personnel involved with it. Equally there is a learning to be gained from examining the methods used and the service systems in which the project worked. In this section, the aims and proposed outcomes of the project will be reviewed so as to draw out lessons for future planning. These will also have wider applicability beyond the West.

The primary aim of the WASP project (see page 8) contained four main strands and these will be examined in turn.

“To assist in ensuring the early diagnosis of assessment of children with ASD”

The project funding proposal estimated that 100 plus children would be assessed per annum. It is not clear if this referred specifically to children with a suspected ASD but if so, the numbers of these children who were seen at clinics in 2005 and 2006 were respectively 67 and 52.

However the main outcome was to achieve earlier diagnosis and a reduction in waiting times for assessment. For children still on the clinic waiting list, there was a significant drop in the waiting times for assessments in 2006 compared the previous year and there was a tendency for more children to be referred. However for those children who were given a diagnosis the actual length of time children were on the waiting list rose and fewer received a diagnosis by their fourth birthday in the third year of the project. The reasons may be intertwined and could include too many unnecessary referrals; insufficient sessions to clear a backlog and scheduled clinics possibly not taking place due to the unavailability of personnel. In addition the numbers of children are much greater in Foyle than in Sperrin Lakeland where a comparable clinic service has yet to be established two years after the project started.

In future years, the Boards should consider the particular role and function of the specialist assessment clinics. In particular, are all children who have a suspected ASD seen at the clinic or it is only those children whom community personnel find difficulty in diagnosing through the Child Development Clinics (CDC)? The latter option may mean further training in ASD being available to personnel working in these clinics. Indeed the numbers of children with a confirmed diagnosis is within the predicted range predicted from recently published prevalence rates in England and on a yearly basis would amount to around eight children with autism throughout the WHSSB area; although a further 24 might have an ASD.

“Autism NI will provide advice and support services for parents and carers engaged in the assessment process”

The ACCESS workshops provided by Autism NI were well received by the parents (from 24 families) who attended them. Although most families had been invited not all accepted the invitation but the reasons for this are not known. Certainly in rural areas it can be difficult to recruit a viable groups whose needs are comparable. However it is not clear if parents who were waiting for assessment received an invitation to these workshops.

It is also not known how many of the parents joined local branches of AutismNI; although the target of 50 new families had been set and one new self help group of parents would be established.

“To facilitate children’s access to early interventions”

The project had proposed that 25 children/families would be provided with early intervention training through a home visiting programme. In two years, 15 families had contact with the early intervention therapist of whom 10 received more than four visits. Of the 15, only five appeared to have had a specialist assessment and by contrast 17 of the child seen at the Foyle clinics who were recommended for early intervention appeared not to have been seen. The reasons for this discrepancy need to be examined closely by the Boards if these two services are to become more closely aligned.

In general this service was very well received because of the information and emotional support provided to mothers. However the mean age of the children when the service began was 4.6 years which is very much higher than the mean age of the children for whom the Keyhole programme was devised (2.8 years). Consequently most of the children were already in some form of early years education and possibly in receipt of other HSS services.

This suggests that the early intervention therapist may not have been used most effectively and the role and function of this service should be critically reviewed. The potential overlap with related professionals already in post within the Board area - home-teaching service of the WELB and the social worker for ASD in Foyle – needs particular attention.

“To facilitate children’s access to ... informed preschool education”

The project proposal aimed to involve 60 plus teaching staff in training courses; a target that has been exceeded through two different courses that have been provided in the area. However the bulk of attenders have come from voluntary and private nurseries and playgroups rather than nursery and primary schools. The willingness of early years personnel to enrol children with ASD is to be commended and parents welcomed this service.

Form the data gathered it is clear that in any one year, only a minority of early years facilities will have a child with ASD enrolled. This raises issues around targeting training resources and the provision of suitable courses on demand. Also there has been a disappointing uptake in the use of Rainbow Boxes.

“resulting in the minimisation of ASD effects”.

The primary outcome from these various interventions was to produce a minimisation the effects of ASD. The resources did not permit for this to be evaluated in any comprehensive manner but from the limited data to hand, it appears not to have happened within the context of the home-based early intervention service or for those attending early years facilities. Indeed this may have been a mistaken aim as it can prove difficult to effect pronounced and sustained changes in the developmental competences of these children. This is more likely to result when specific goals are set for individual children and a tailored programme followed with them. Future interventions – both from therapists and educationalists - should be subject to closer evaluation of developmental gains so as to improve the evidence-base underpinning their efficacy.

Future planning

In summary then, the Steering group should consider the following issues and identify possible action steps for taking them forward.

-
- Appropriateness of referrals of children to the specialist clinic in Foyle and how these assessments can be expedited and made more useful to families.
 - The urgent implementation of multi-disciplinary assessments in Sperrin Lakeland.
 - A database of all children presenting with ASD in the Board area should be maintained and reports sent regularly to service managers.
 - The closer integration of education and HSS services to preschool children with HSS and implementation of an overall management structure for these services.
 - The provision of a 'named person' with expertise in ASD to families as soon as a problem is suspected leading to one common family plan across all services.
 - A review of the role and function of early intervention therapists; their reporting relationships, case load and additional responsibilities.
 - Supplementation of the Speech and Language therapy service and their role in early identification, intervention, parent and staff training.
 - Ongoing liaison with AutismNI to organise parental support and advocacy groups throughout the Western Board area.
 - A regular training programme is provided for staff in early years facilities that extends the basic training provided to date, for example in specific interventions for children with ASD.
 - A costed action plan with detailed operational proposals would greatly assist in obtaining funding for these endeavours although some could be met through the better targeting and coordination of existing monies.

The WASP project illustrates the diversity of challenges that have to be faced in establishing appropriate services to a growing number of children with particular needs. Too often this has been left to the dedication and good will of a small number of professionals who have tried to do their best with limited influence and resources at their disposal. The Project has made all the clearer the job that needs to be done and an excellent learning foundation has been laid for future developments.

References and further reading

- Boucher, J. and Wolfberg, P. (2003) Editorial of special issue on play and Autism. *Autism*, 7, 339-346.
- Chakrabarti, S. and Fombonne, E., (2005). Pervasive developmental disorders in preschool children: Confirmation of high prevalence. *American Journal of Psychiatry*, 162, 1133-1141.
- Christie, P (1998) Assessment and Service Provision for Children with Autism. *Tizard Learning Disability Review*, 3:3, 7-15.
- Christie, P. and Chandler, S. (2002) A diagnostic and intervention package for young children with autism: what are the critical components? *Good Autism Practice*, 3, 2- 13.
- Dawson, G. and Osterling, J. (1997) Early intervention in Autism. In M.Guralnick (ed.) *The effectiveness of early intervention*. Baltimore, MD: Brookes.
- Department of Education (NI) (2002) *The education of children and young people with autistic spectrum disorders: Report of the Task Group on Autism*, Belfast: DENI
- Frazer, C.H. & Levine, K (1995) Parent Perceptions of the Diagnostic Evaluation for their Child with Autism or Pervasive Developmental Disorder (PDD). *The Journal of Behavioural Paediatrics*, 16, 305-314
- Frith, U. & Soares, I. (1993) Research into Earliest Detectable Signs of Autism: What the Parents Say. *Communication*, 27, 3, 17-18.
- Gabriels, R.L. et al (2001) Predictors of treatment outcome in young children with autism: a retrospective study. *Autism*, 5.
- Howlin, P and Moore (1997) Diagnosis in Autism – A Survey of over 1200 Patients in the UK, *Autism*, 1, 135-162.
- Jones, G. (2002) Editorial on Autism Early Intervention. *A special supplement to the Good Autism Practice Journal*. Kidderminster: British Institute of Learning Disabilities.
- Jordan, R. (1997) *Education of children and young people with Autism*. Paris: UNESCO
- Leathard, A. (1994) *Going Inter-professional. Working together for health and welfare*. Routledge. London.
- Loynes, F. (2001) *The rising challenge: a survey of local education authorities on educational provision for pupils with autistic spectrum disorders*. London: National Autistic Society.
- Luiselli, J., Cannon, B. and Sisson, R. (2000) Home-based behavioural intervention for young children with autism/pervasive developmental disorder. *Autism*, 4, 426-438.
- McConkey, R., McGreevy, E., Crawford, H. and Cassidy, A. (2003) *The Keyhole Project Early Intervention Project in Autistic Spectrum Disorders*. Belfast: PAPA
- McConkey, R. and Truesdale, M. (2004) *An evaluation of new autism services in SHSSB area*. Armagh, SHSSB.
- McConkey, R., Truesdale-Kennedy, M. and Poulton, B. (2005) *An interim report on the evaluation of the Connecting with Autism Project*. Belfast, PAPA.
- Moore, K., McConkey, R., Sines, D. and Cassidy, A. (1999) Improving diagnostic and assessment services for autistic spectrum disorders. *Early Child Development and Care*, 154, 1-11.
- National Autistic Society (2003). *National Autism Plan for Children*. London: NAS.
- Stallard, P. and Lenton, S (1992) 'How Satisfied are Parents of Pre-School Children who have Special Needs with the Services they have Received? A Consumer Survey', *Child: Care, Health and Development*, 18, 197- 205.

Appendix 1

Membership of the Project Steering Group

Arlene Cassidy, PAPA
Clare McGartland, WHSSB
Vivien Dale, Foyle HSS Trust
Florence Trotter, WASP Project
Kieran Downey, Sperrin Lakeland HSS Trust
Siobhan McIntyre, WHSSB
Sara Groogan, Foyle HSS Trust
Sally Parker, Western ELB.

Terms of Reference

Within the context of an holistic approach to interventions with families who have pre-school children aged between two and five years, to oversee the implementation of a home based service, training courses for staff in mainstream preschools/playgroups and nursery schools, as well as support groups and training for parents.

- Identify appropriate referral agents and agree protocols
- To oversee the implementation of the Keyhole Home-based Intervention Programme for pre-school children
- Enhance provision for children with Autism in pre-school provision through the training of staff [Keyhole pre-school training (NIPPA/PAPA/Barnardo's)]
- Facilitate the delivery of Keyhole Parent Discussion Workshops [ACCESS Workshops]
- Integrate all elements and work clearly with assessment and diagnostic core teams in Foyle and Sperrin and Lakeland Health and Social Services Trusts
- To monitor the development of the Project and receive verbal and written reports from postholder at each Steering Group meeting.

Facilitate the integration of the ASD Early Intervention Service (WASP) into the WH&SSB/WELB area wide network.

Support the delivery of a model of the best practice through an evaluation process designed and delivered by the University of Ulster (Prof. Roy McConkey, School of Health Sciences).

Promote a multi agency, multi disciplinary ASD assessment, diagnostic and early intervention service ethos, utilising PAPA's role in relation to parent support and parent/professional partnerships.

Facilitate and nurture a defined, integrated service role (post project) for relevant voluntary organisations.

Appendix 2: Project Outcomes

NB The information in this Appendix has been prepared and submitted by project staff.

Year 1: 2004/05 Measurable Targets/Outcomes

Target	Proposed Outcome	• Outcome
1. Establishment of WHSSB/PAPA protocol and plan for the diagnosis, assessment and treatment of children with ASD (Output).	Protocol established pre project commencement (Project commencement: April 2003).	<ul style="list-style-type: none"> • Draft protocols agreed pre-project. • Protocol implementation delayed due to WH&SSB difficulties in establishing diagnostic service i.e. referral base.
2. Appointment of two PAPA staff members – WASP Project Training and Development Officer (PDO); and WASP Project Family Liaison Worker – Early Intervention (FLW). (Output).	Interviews pre project commencement – post holders take office April 2003).	<ul style="list-style-type: none"> • Recruitment difficulties necessitated budget and project start date renegotiation with Children’s Fund. • Early Intervention Therapist appointed March 2004.
3. Diagnosis and assessment of children with ASD and PAPA advice and support service for parents and carers engaged in assessment process (Output).	100+ children assessed per annum.	<ul style="list-style-type: none"> • Diagnosis/assessment service is a statutory responsibility: delayed due to service development difficulties within WH&SSB. • 16 parents/carers have taken part in ACCESS workshops. • 4 parents have taken part in Jojingles sessions • 40 parents in awareness training. • 20 parents telephone enquiries • 23 parents visual strategies training
4. Provision by PAPA FLW of practical, individually tailored, early intervention training delivered in the homes of parents of children with ASD (Output).	25 children/families to be provided with early intervention training (Home visiting programme).	<ul style="list-style-type: none"> • 9 families in home intervention programmes • 4 families continuing into next years.
5. Provision of training programmes facilitated by PDO on the needs of children with ASD to nursery and playgroup staff (Output).	6 x 2 day courses involving 60+ teaching staff Ongoing telephone/personal advice/support to 15+ teaching staff	<ul style="list-style-type: none"> • 2 courses organised. • 46 persons trained for Childcare Partnership Training: • 170 staff trained in Autism awareness. • 20 staff visual strategies training • 30 telephone support/visual advice. • 22 Health Visitors awareness training
6. Involvement of families/carers in wider PAPA facilitated advice and support network (Output).	Involve 50 new families Establish one new local PAPA self help group Recruit one new parent/carer from the Western area to the PAPA management committee	<ul style="list-style-type: none"> • Diagnosis/assessment service is a statutory responsibility: delayed due to service development difficulties within WH&SSB • 16 parents/carers have taken part in ACCESS workshops • Some of the parents from ACCESS workshops are now active in the three existing Branches in the WH&SSB. The effect has been a definite strengthening of existing network of parent support in the West. • Target not achieved for PAPA Management Committee • 4 parents have joined PAPA Regional Lobby Committee • 6 parents have joined PAPA Regional Parent Mentoring Group.

<p>7. Anticipated higher levels of diagnosis of ASD amongst children (Outcome).</p>	<p>300% rise in the diagnosis of ASD (as per estimate in Dept of Education Task Force report).</p>	<ul style="list-style-type: none"> • Local difficulties as previously stated have to be overcome • Regional rise in prevalence rates have kept waiting lists to 2+ years • Comment on children diagnosed (see section 3 above).
<p>8. Children with ASD will be better enabled to develop to their full potential (Outcome).</p>	<p>Monitoring and evaluation results show 25 children enabled to varying extents through early intervention programme.</p>	<ul style="list-style-type: none"> • Evaluation by UU underway • Target achieved through parent empowerment (ACCESS) and home visiting programme (ref to section 3 and 4 above).
<p>9. Families/carers will become more knowledgeable re ASD and reporting ability to cope better with ASD children (Outcome).</p>	<p>Monitoring and evaluation results show 100+ parents/carers reporting increased ASD knowledge/coping skills.</p>	<ul style="list-style-type: none"> • Evaluation by UU underway • Target achieved through parent empowerment (ACCESS) and home visiting programme and involvement in Branch network (ref to section 3, 4 and 6 above).
<p>10. Pre-school teachers will report more confidence in dealing with ASD needs (Outcome).</p>	<p>Monitoring and evaluation results show increased ASD knowledge/teaching skills amongst 60 teachers.</p>	<ul style="list-style-type: none"> • Evaluation by UU underway • Target achieved through training and ongoing liaison • Ballinamallard playgroup WELB joint protocol with pre-school teachers. • 10 teachers awareness training • 2 playgroups given intensive ASD training

Year 2: 2005/06**Measurable Targets/Outcomes: as at July 2005**

Target	Proposed Outcome	Outcome
1. Establishment of WHSSB/PAPA protocol and plan for the diagnosis, assessment and treatment of children with ASD (Output).	Ongoing evaluation, assessment and review of protocol arrangements.	
2. Appointment of two PAPA staff members – WASP Project Training and Development Officer (PDO); and WASP Project Family Liaison Worker – Early Intervention (FLW). (Output).		
3. Diagnosis and assessment of children with ASD and PAPA advice and support service for parents and carers engaged in assessment process (Output).	100+ children assessed per annum.	10 parents (ACCESS Omagh Spring 06) 20 parents to be targeted (ACCESS Foyle/Fermanagh Autumn 05)
4. Provision by PAPA FLW of practical, individually tailored, early intervention training delivered in the homes of parents of children with ASD (Output).	25 children/families to be provided with early intervention training.	6 Foyle 2 SL NB Have tried to visit two new families – unable to meet with EI Therapist
5. Provision of training programmes facilitated by PDO on the needs of children with ASD to nursery and playgroup staff (Output).	<ul style="list-style-type: none"> 6 x 2 day courses involving 60+ teaching staff Ongoing telephone/personal advice/support to 15+ teaching staff 	25 professionals to be trained (Omagh Sep 05/Oct 05) 25 professionals to be trained (Derry Autumn 05)
6. Involvement of families/carers in wider PAPA facilitated advice and support network (Output).	<ul style="list-style-type: none"> Maintain 50 new families in support network Service new local PAPA self help group 	
7. Anticipated higher levels of diagnosis of ASD amongst children (Outcome).	Rise in diagnosis maintained	
8. Children with ASD will be better enabled to develop to their full potential (Outcome).	Monitoring and evaluation results show 25 children enabled to varying extents through early intervention programme.	
9. Families/carers will become more knowledgeable re ASD and reporting ability to cope better with ASD children (Outcome).	Monitoring and evaluation results show 100+ parents/carers reporting increased ASD knowledge/coping skills.	
10. Pre-school teachers will report more confidence in dealing with ASD needs (Outcome).	Monitoring and evaluation results show increased ASD knowledge/teaching skills amongst 60 teachers.	

Year 3 data could be included here