



The Keyhole Early Intervention Project
in Autistic Spectrum Disorder

Research Project

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The Keyhole Early Intervention Project in Autistic Spectrum Disorders

Final Report

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Authors

Roy McConkey, Elaine McGreevy, Heather Crawford and Arlene Cassidy

Further copies of this report are available from:

PAPA, Knockbracken Healthcare Park, Saintfield Road, Belfast BT8 8BH

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Executive Summary

A growing number of children are being diagnosed with Autistic Spectrum Disorders¹ (ASD). In many instances this is apparent before two years of age. Yet families often receive little advice or assistance until their child is much older.

The Keyhole project aimed to design, develop and implement an holistic approach to interventions with families who had preschool children aged between two and four years. This included a home-based teaching service; training courses for staff in mainstream playgroups and preschools, and support groups for parents.

The goal was to develop approaches of proven effectiveness that could be adopted by statutory and non-statutory services in Northern Ireland and elsewhere. New teaching resources for use with children, families and preschool personnel have been produced.

The project was funded by the Department of Health, Social Services and Public Safety (NI) through a grant to PAPA (the NI Autism charity). Down Lisburn HSS Trust, South & East Belfast HSS Trust, Belfast Education and Library Board, South Eastern Education and Library Board, Barnardos and the Northern Ireland Preschool Playgroups Association were the main service partners. The University of Ulster facilitated the evaluation of the project.

This report describes the work undertaken by the project and summarises the main findings. Key recommendations for future action are identified.

Section 1: Background to the project

From literature reviews and consultations with a range of professionals throughout Northern Ireland, it was concluded that:

- Autism can be diagnosed in children from 18 months onwards.
- Families need practical guidance on how best to help their child following a diagnosis.
- They value home-based support provided by a professional with expertise in autism.
- Specific approaches have been found to be effective; in particular those that promote communication, social interaction, independence and socially acceptable behaviours.
- Multi-disciplinary and multi-agency working is required to meet the needs of these children and families.
- Early intervention services are not readily available throughout Northern Ireland.

Section 2: The Keyhole Project

Four principles guided the work of the project. It was participative and parent-centred; it worked through partnerships and aimed to produce practical outcomes. It had four main aims.

1. To identify the needs of preschool children and their parents.
2. To develop and evaluate a home-based intervention programme for preschool children

¹ Throughout the report, the term autism is used interchangeably with Autistic Spectrum Disorders.

3. To enhancing provision for children with autism in preschool provision through the training of staff.
4. To explore the value of small groups in supporting Parents

The project undertook the following studies:

- Family interviews:** University personnel completed home-based interviews with 72 families with a child under five years of age who had a diagnosis of autism.
- Home Visiting Service:** Twenty-four families were offered a home-based intervention programme consisting of 15-18 sessions – each lasting up to two hours - over a period of six to nine months. In all twenty families completed all the sessions.
- Evaluation of the Intervention:** The impact of the intervention on the children and parents was assessed through measures taken pre- and post the intervention along with comparison to a contrast group of 12 children and families who did not have the intervention.
- Survey of preschools:** A survey of 56 staff working in 38 preschools of various types in the Greater Belfast area was undertaken to identify their experiences of having a child with autism in the group, the supports they have received or would like to have and their reactions to the future enrolment of children with autism.
- Training of Preschool Personnel:** A five session, 12.5-hour training course was developed and delivered in association with NIPPA. The course was presented to four groups of preschool personnel in Belfast and Newtownards. In all, 64 persons participated.
- Survey of PAPA Branch members:** In all 68 members drawn from 13 PAPA Branches throughout N. Ireland gave their views through self-completed questionnaires on the ways the Association has helped them and the ways in which they feel they could be better supported.
- Parent Support groups:** Two groups, consisting of 15 mothers met on four occasions with an experienced facilitator. The reactions of the families to the groups were obtained through verbal and written feedback.
- Development of Training Resources:** A guide has been prepared to assist personnel offering home-based interventions along with booklets that can be used with parents and children. A training pack has been prepared for use with preschool personnel. This consists of PowerPoint slides, video illustrations, tutor notes and detailed outlines of each training session.

Section 3: The needs of children and families

The survey undertaken with 72 families who had a child less than five years of age found:

- Boys greatly outnumber girls in a ratio 9 to 1. Families come from all sections of the community.
- Preschool children with a diagnosis of autism show a wide variation in their development; some function close to their age peers whereas others have marked delays.

- The most commonly reported problems by parents are their child's language delay, relating to other people, play, unusual behaviours and adapting to change. Most parents feel they lack the skills to deal with these problems.
- These problems were usually evident by the time the children were two years of age.
- Although families see a range of professionals they feel improvements are needed to education, health and social services.
- The children attend a range of preschool facilities and most take part in normal family activities outside of the home.

Section 4: Impact of home-based interventions

The evaluation of the intervention found that:

- All the families felt they had learnt new things from the intervention and they were broadly satisfied with it. Nearly all would recommend it to other parents.
- After the intervention parent's reported fewer problems with their child and an increase in the number of problems that were now "getting better". This was particularly so with problems in language and play.
- The children made greater progress on the communication and socialization domains of the Vineland Scale with no significant change in motor or daily living skills. Hence the effects of the programme were specific to the domains targeted.
- Independent assessors of the children rated significant improvements across various psycho-educational domains.
- Parents appear to be more aware of their child's difficulties as a result of the intervention.
- This evaluation did not address the issue as to whether or not the approach used in this intervention is more effective than other approaches such as Applied Behaviour Analysis (ABA) derived from Lovaas and Smith (1989).

Section 5: Preschools

The following conclusions were drawn from the survey of preschool facilities and staff along with the evaluation of the training course.

- Although the staff and preschool facilities in this study were probably biased towards enrolling children with ASD, nearly all reported having few training opportunities and most felt inadequately skilled to meet the particular needs of these children.
- Staff in preschools encounter broadly the same range of problems as do parents, and they find behaviour and communication difficulties the hardest to cope with.
- A specially developed, ten hour training course was well received by the participants who three months later had implemented much of the advice given on the course.
- Course participants appeared more willing to enrol children with ASD in their groups although a minority did express some reservations.
- A resource pack for tutors has been prepared so that similar courses can be delivered elsewhere in the future.

Section 6: Parent Support Groups

Information gathered suggested that:

- Parents who have children with ASD value the opportunity to meet with and to learn from other parents. This is truer for mothers than for fathers.
- A range of approaches are possible but the value of a small group of parents coming together to focus on a particular issue with a knowledgeable facilitator is the most common.
- Group work seems to provide mothers with encouragement, emotional support and information.
- Nonetheless the number of mothers availing of invitations to join groups is low which may reflect changes in parental working patterns and the difficulty in finding a suitable time and venue that is convenient.

Section 7: Recommendations

This section is aimed primarily at service commissioners and providers in education, health and social services. Underpinning all our specific recommendations is an over-arching one, namely an integration of the preschool services provided to families by HSS Trusts and Education & Library Boards.

Although present administrative arrangements in Northern Ireland do not facilitate this aspiration, integration is necessary to avoid unnecessary duplication, to harness the scarce expertise that is presently available and to provide some element of continuity and co-ordination to families. In particular we recommend:

- The joint provision of multi-disciplinary assessment teams.
- The joint provision of home-based early intervention programmes.
- The joint support of preschool facilities and personnel.
- The joint provision of training to community health, social service and educational personnel.

In all 22 specific recommendations are noted. These are intended to produce the following outcomes.

- The severity of a child's disabilities will be ameliorated through early identification and intervention. Thus the thrust of these recommendations is towards preventative action.
- Families will feel more supported and better able to cope with their child. Fewer demands may be placed on high-cost, out-of-home provision.
- The knowledge and skills of staff in both mainstream and specialist services will be increased and they will provide a higher quality of service in line with parental aspirations.
- Services will be more child and family-focussed with present administrative systems reformed to be 'fit-for-purpose'.

Future service developments should be monitored and evaluated against these outcomes.

Section 1: Background to the project

Introducing the Keyhole Project

In Northern Ireland, increasing numbers of preschool children are being identified as having an Autistic Spectrum Disorder (ASD). Families often feel helpless as to how best to help their child. International experience suggests that positive changes are possible with early intensive education that involves the parents and provides direct teaching of essential skills with the child.

The Keyhole project aimed to design, develop and implement an holistic approach to interventions with families who had preschool children aged between two and four years. This included a home-based teaching service; training courses for staff in mainstream playgroups and preschools, and support groups for parents.

The goal was to develop approaches of proven effectiveness that could be adopted by statutory and non-statutory services in Northern Ireland and elsewhere. New teaching resources for use with children, families and preschool personnel have been produced.

The project was funded by the Department of Health, Social Services and Public Safety (NI) through a grant to PAPA (the NI Autism charity). Down Lisburn HSS Trust, South & East Belfast HSS Trust, Belfast Education and Library Board, South Eastern Education and Library Board, Barnardos and the Northern Ireland Preschool Playgroups Association were the main service partners. The University of Ulster facilitated the evaluation of the project.

This report describes the work undertaken by the project and summarises the main findings. Key recommendations for future action are identified.

Finally, the name Keyhole was chosen as often these children and families see the world as through a keyhole; in a room apart from society. Hopefully the project has discovered some keys to opening the door.

What is autism?

"Autism is a complex developmental disorder that essentially affects the way a person communicates and relates to people". It is often evident by two years of age but it affects children in varying degrees of severity. The term Autistic Spectrum Disorders is used to reflect this variation.

Children with ASD share three common impairments. They have difficulty interacting socially and appropriately with other people; they have problems both with understanding and in using language to communicate and their capacity to think imaginatively is impaired.

Their intellectual abilities also differ markedly. Some will have severe learning difficulties whereas others function in the average or above average range. The latter tend to be referred to as Asperger's Syndrome.

Children with ASD may look like other children but many behave inappropriately for their age.

They can experience a range of additional difficulties in everyday life such as limited attention span, anger or aggression when things go wrong, poor organisational skills,

sleep irregularities and clumsiness due to poor motor control. They engage in repetitive play activities and obsessional routines.

Autism appears to be a life-long condition although there are claims that 'recovery' or cures are possible for certain individuals. Recent advances strongly suggest that the condition is remediable and improvements are possible.

The numbers of children being diagnosed as having an autistic spectrum disorder is increasing in the United Kingdom (Loynes, 2001).

What causes autism?

The short answer is we don't know for sure. Autism appears to have a strong genetic component that affects the development of the brain although the sites of the relevant genes have not been identified. It can occur in association with other conditions such as maternal rubella, anoxia and encephalitis.

Debate continues over links with MMR vaccinations although this has been discounted by authoritative sources in the United Kingdom and United States.

Former theories of parenting styles causing the disorder have been discounted.

It is not possible to identify those families most at risk of having a child with autism. However it is much more common among boys than girls.

What can be done to help?

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

Among the important dimensions to educational provision are:

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

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.

What approaches are effective?

Various teaching and treatment approaches have been developed to address the needs of children with autistic spectrum disorders. Definitive evidence is lacking that any one approach is consistently better than another. Rather the conclusion reached by reviewers is that "the most effective programs for students with autism are those that incorporate a variety of best practices" (Heflin and Simpson, 1998).

Among the elements which Dawson and Osterling (1997) identified as being common to effective intervention programmes were:

- A focus on specific skills that the child needs to learn.
- A structured environment which includes strategies for generalisation of learning.
- Predictability and routine to help the child transfer from one activity to another.
- A functional approach to analysing and dealing with behaviours.
- Family involvement is central to the overall programme.

In addition the following strategies have been shown to be beneficial (Department of Education NI, 2002).

- 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. 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).

No one professional presently has the necessary expertise to diagnose and plan intervention programmes for this diverse group of children. Hence multi-disciplinary teams of professionals are involved consisting of specialist doctors, psychologists, speech and language therapists and educationalists. In addition other disciplines such as Occupational Therapy, Physiotherapy and Social Work may be involved. It is not easy to achieve consistent, high quality working across disciplines and agencies.

What helps families of pre-schoolers?

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 (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.

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 interventions 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.

What's been happening in Northern Ireland for these families?

In recent years a number of significant developments have occurred.

The formation of PAPA: Formed in 1990, PAPA is the N. Ireland Autism Charity primarily for parents of people with autistic spectrum disorders. It has 13 branches and four support groups throughout the North of Ireland and in Donegal. PAPA has developed its role from the provision of advice, information and support to that of a significant provider of specialist training and an effective lobbyist for quality service provision.

Provision of diagnostic services: A review has been undertaken of existing diagnostic services in Northern Ireland; examples of good practice were noted and recommendations made for their development (Moore et al, 1998). This review underlined the need for early diagnosis.

Intervention approaches: Various agencies – mostly non-statutory - have responded to parents' needs by developing a range of training courses and workshops, organising parent support groups, providing specialist preschool facilities and organising intensive programmes for individual families.

Task Group on Autism: The Minister of Education set up this wide-ranging review of services in Northern Ireland and it reported in 2002. Extensive recommendations are made as to how improvements could be made to current provision. Particular emphasis is placed on "developing multi-disciplinary agreement and protocols on good practice in assessment, diagnosis and early/prompt intervention services" (p.109).

Even so, many Northern Irish parents and professionals feel that much remains to be done if these children and families are to receive the help they need.

Conclusions

- Autism can be diagnosed in children from 18 months onwards.
- Families need practical guidance on how best to help their child following a diagnosis.
- They value home-based support provided by a professional with expertise in autism.
- Specific approaches have been found to be effective in particular those that promote communication, social interaction, independence and socially acceptable behaviours.

- Multi-disciplinary and multi-agency working is required to meet the needs of these children and families.
- Early intervention services are not readily available throughout Northern Ireland.

Section 2: The Keyhole Project

Four principles guided the work of the project.

Participative: The project needed to draw on the experiences and expertise of a wide range of professionals from various disciplines throughout Northern Ireland working in both non-statutory and statutory services including health, social services and education. This was achieved by having a Reference Group with 13 members from throughout Northern Ireland as well as an inter-disciplinary, inter-agency Project Steering Group of 14 persons (see Appendix 1).

Parent-centred: The project needed to listen to Northern Irish parents and to attend to their needs and concerns. This was achieved through information obtained from the PAPA Branch network and by undertaking individual interviews with over 70 parents who had preschool children with a diagnosis of autism. Moreover their reactions to new initiatives were sought.

Partnerships: The project had to work in partnership with existing agencies in order to achieve its goals. In particular staff from Down Lisburn HSS Trust and South & East Belfast HSS Trust were instrumental in identifying the children and families and in devising the home-based interventions. The Northern Ireland Preschool Playgroups Association (NIPPA) had a mutual interest in developing suitable training courses. The University of Ulster assisted with information gathering and provided independent evaluations of the project's work.

Practical Outcomes: The project would yield tangible outcomes in the form of teaching resources that could be used with parents, children and preschool staff along with tested methods for informing the development of early intervention initiatives by agencies in Northern Ireland and elsewhere.

Defining early intervention

A starting point was to review the components of early intervention. This was done through the Reference and Steering Groups set up for the project and through an analysis of parent responses in interviews and groups.

Five main themes featured in their thinking.

1. Important features of Early Intervention Services

- It is available from an early age – from when the child is two years old
- It merges assessment and intervention.
- The service needs to be flexible so that it can accord with parent and child needs.
- Individual Family plans are drawn up with realistic objectives. Records are kept and the plans are regularly reviewed.
- All the people in the child's world are involved so that they know the features of the condition and appropriate responses.
- There is clear and consistent communication among everyone – between and among professionals and with parents
- It enables the child to be socially included in family and community life.
- It takes a holistic approach to the child and does not focus only on the child's problems/disabilities.

2. Promoting the Child's Development

- Teaching is done in realistic and varied settings
- The child is given the tools for coping in their world, notably providing predictability, warning of change; use of visual referents and providing augmentative means of communicating in addition to language.
- The child is assisted with learning to wait; share; turn-taking; feeding, washing, dressing, toileting and sleeping.
- The child needs the ability to attend, to imitate others, comprehend and use language, play appropriately with toys and interact socially with others.
- Child needs to be helped to cope with unpredictability.
- The child is taught socially acceptable behaviours so that they can survive in the real world.
- Play, songs and music, and creativity – such as art and modelling – should be encouraged as this assists with the child's emotional development; integrates their skills, encourages socialisation and lets children experience feelings and name them.
- Children are encouraged to interpret other people's feelings and emotions.
- The child's participation in group experiences with the family and peers is encouraged

3. Family focus

- Accessible and relevant information is provided to parents about services and sources of support; with particular respect to statutory entitlements to education and financial benefits.
- Supportive relationships are nurtured among parents, siblings, grandparents and other family members.
- Advice is provided on establishing family routines that will assist the child, for example around bedtime.
- Practical support is available to give parents a break from their caring role, such as child-minding, crèches etc.
- Parental counselling is available to help them cope with stresses; feelings of guilt and blame, and to work towards acceptance and productive coping strategies.
- Opportunities are provided for parents to meet with other parents.

4. Training

- Education about autism is made available to all the people in the child's world – parents, playgroup personnel, teachers - particularly about assessing the child's developmental level; practical advice for helping the child and the support and advice they could access in their locality.
- Parents (and others) need to be given an understanding as to how the child's mind works.
- Parents are taught to observe and reflect on the child behaviours and their own.
- Behaviour management approaches are taught to parents and professionals.

5. Improving systems

- There needs to be better professional awareness of autism in all service sectors.
- Services should identify these children at an earlier age than they do at present.
- Improved systems are needed for assessing and determining children and family needs.
- There must be improved co-ordination among services particularly health and education.

Project Aims

A three-year project with limited funding had to be selective in the work undertaken. Further consultations with the partners identified four main themes each with its own set of objectives.

1. The needs of preschool children and their parents

It is only in recent years that preschool children are being diagnosed as having an autistic spectrum disorder. Hence few studies have been undertaken with this population. Our objectives are listed below along with the main reasons for choosing them.

- 1.1 *To obtain a representative sample of families who had a child under five years with a confirmed diagnosis of autism.*
- 1.2 *To gather information on both the characteristics of the child and of the family.*
- 1.3 *To obtain insights as to the form of help that parents would value in the preschool years.*

A representative sample would help to define the range of difficulties that preschool children may experience even though they share a common diagnostic label of autistic spectrum disorders.

Rarely has the impact on families of preschool children has been assessed and yet this has to be a major concern especially with home-based early intervention programmes.

Information was also needed on the help and support that families were currently receiving and their views on the type of additional assistance they would find beneficial. Any intervention would then be guided by family need.

2. Home-based intervention programmes for preschool children

Four objectives were identified.

- 2.1 *To design and evaluate an intervention programme for two and three-year olds which aimed to enhance and improve parent-child interaction through a combination of visual communication, structured teaching environments and positive routines.*

The programme drew on various intervention approaches that have been used with older children with autism. These included TEACCH (Mesibov, 1997); Picture Exchange Systems (Bondy and Frost, 1994) and Hanen Early Communication (Tannock, Girolametto and Siegel, 1992) along with behavioural management techniques as needed derived from applied behaviour analysis.

The emphasis in the Keyhole Project was not to develop a new approach to intervention but rather to explore an approach that deliberately uses a range of techniques according to the child's needs.

2.2 To deliver the programme through a time-limited series of home visits by a professional worker with expertise in speech and language therapy and autistic spectrum disorders.

Although the value of home-based interventions is well attested in the literature among children with intellectual disabilities (Guralnick, 1997) this approach has not been widely used at least in these islands with families who have children with autism.

Home-based support is also the preference of parents and one that offers access to the wider family – fathers, siblings and other relatives.

This pilot service would help identify the resources needed to support this form of service and the interfaces required, especially for onward referral.

2.3 To identify methods which service personnel could use to monitor the impact of early interventions.

A major criticism of past interventions is the lack of attention paid to systematically measuring the impact of interventions on children and families. This should enable adaptations to be made to programmes to better meet the child's needs.

A range of measures and approaches are available but there is little consensus as to which would be particularly helpful to busy service personnel.

2.4 To produce teaching resources that can be used by professionals and parents with children.

There is a dearth of commercially available teaching resources for this age group of children. The provision of these should make it easier for parents and professionals to implement early intervention programmes.

3. Enhancing provision for children with autism in preschool settings

A crucial issue, is what happens after the home visiting service ends? Although the child and family may receive ongoing help from individual professionals such as therapists, the main provision is likely to be in education and particularly preschool facilities in the first instance, such as playgroups, nursery schools and day care centres. Certainly it is an aspiration of parents that their child will be able to avail of the same opportunities as their peers. However this raises issues about the capacity of preschool facilities to meet the needs of these children. To date little information is available internationally on this topic.

The project adopted three objectives in this area.

3.1 To identify the training needs of personnel and the supports available to a range of preschools.

3.2 To develop and evaluate a short training programme of around 10 hours duration aimed at preschool personnel.

3.3 To produce a pack of training materials along with identified supports that could be used by trainers of preschool personnel throughout Northern Ireland.

4. Supporting Parents

The third chosen theme focussed on the needs of parents; particularly the need for information and emotional support. Local and international experience suggests that some parents value the opportunity to meet with other parents. However it is not clear the particular benefits that parents obtain from support groups or how these might best be provided. Hence two objectives were chosen.

4.1 To identify the benefits that parents derive from attending PAPA Branch meetings and how these might better meet their needs.

4.2 To explore the value to parents of small groups meeting for a limited number of sessions with an experienced professional as facilitator.

Inevitably this left at least two important gaps that we acknowledge but hopefully these will be addressed in the future (see recommendations).

- We were unable to follow the preschoolers beyond the preschool years and to examine the interface of home-visiting and/or preschool provisions with schooling in either mainstream or special schools.
- We were unable to examine how these initiatives could be developed beyond the demonstration projects that were set up as part of this initiative.

Project Work

The project undertook the following tasks.

Family Interviews

University personnel completed home-based interviews with 72 families with a child under five years of age who had a diagnosis of autism. These interviews obtained information on the child's and family's characteristics; the particular concerns and difficulties they encounter; the services they avail of and their perceptions of the help they require. This forms one of the largest samples of families with preschool children in the international literature.

Home Visiting Service

Twenty-four families were offered a home-based intervention programme consisting of 18 sessions – each lasting up to two hours - over a period of six to nine months. In all twenty families completed all the sessions. The programme was undertaken by a full-time project worker, Elaine McGreevy who was seconded from the Speech and Language Service of Down Lisburn HSS Trust.

Evaluation of the Intervention

The impact of the intervention on the children and parents was assessed through on-going monitoring of the children by the home therapist and by reviews undertaken at the half-way point.

The children were assessed by experienced personnel in autism prior to the intervention and these assessments were repeated after the intervention ended by personnel who had not been involved with the programme.

University staff visited the families at home three months after the intervention finished to obtain in confidence their view on the programme and the parent's perceptions of the child's progress.

A contrast group of 12 children and families were recruited once the intervention phase of the project was completed. These families would have been eligible for the home-based programme had it continued. The progress of the children was assessed in the same way as for those families who had received the programme. Comparisons between the two groups would help to determine the impact of the intervention.

Training of Preschool Personnel

A five session, 12.5 -hour training course was developed by Heather Crawford, Kate Doherty and Barbara Crozier, and delivered in association with NIPPA. The course was presented to four groups of preschool personnel in Belfast and Newtownards. In all, 64 persons participated. This included 7 persons who had been identified by NIPPA as potential tutors of the course in the future.

Self-completed questionnaires were used to assess participants' reactions during the course. University staff contacted participants three months after the course ended to obtain their views on the course and the impact it had on their practice.

Survey of preschools

A survey of 56 staff working in 38 preschools of various types in the Greater Belfast area was undertaken to identify their experiences of having a child with autism in the group, the supports they have received or would like to have and their reactions to the future enrolment of children with autism.

Survey of PAPA Branch members

In all 68 members drawn from 13 PAPA Branches throughout N. Ireland gave their views through self-completed questionnaires on the ways the Association has helped them and the ways in which they feel they could be better supported.

Parent Support groups

Two groups, each consisting of 5-6 parents met on four occasions with an experienced facilitator – Pamela Seeds – from Barnardo's Carrigfoyle Project. The reactions of the families to the groups were obtained through verbal and written feedback.

Development of Training Resources

A guide has been prepared to assist personnel offering home-based interventions along with booklets that can be used with parents and children.

A training pack has been prepared for use with preschool personnel. This consists of Powerpoint slides, video illustrations, tutor notes and detailed outlines of each training session.

Summary

In summary then,

- The project had four strands – survey of family needs, home-based intervention, training of preschool personnel and supporting families through parent groups.

- It worked in partnership with statutory and non-statutory agencies.
- The views of parents with preschool children was central to the project's work.
- The emphasis was on practical outcomes that would facilitate the development and implementation of early intervention initiatives throughout Northern Ireland.

Section 3: The needs of children and families.

The information in this section is taken from the survey of 72 families who represent around 75% of all families with preschool children in the two HSS Trusts at the time the survey was undertaken. However many more came from one Trust because they had a specialist assessment clinic to which children could be referred at an early age.

The children

Of the 72 children with a diagnosis of autistic spectrum disorder, 90% (N=65) were boys and 10% (N=7) were girls.

The mean age of the children was three years; 31% (N=22) were aged two years; 38% (N=28) three years and 31% (N=22) four years of age.

Just over one in five children (22.2%: N=16) had a brother or sister with similar problems. However for 25 children (35%) a member of the extended family had similar problems.

Typically there were two children in the family home (43%: N=30) but the range was from one to six. The child with ASD tended to be the youngest in the family (56%: N=40) with 19% (N=14) in the middle and 13% (N=9) were the oldest children in the family. Nine children (12.5%) were only children.

Fourteen of the 72 children (19%) had a visual or hearing impairment while a further nine children (13%) were reported to have epilepsy.

Parents reported that their children had various problems, compared to other children of the same age. Those reported by a majority of parents are shown in Table 1.

Table 1: The number and percentage of children with reported problems

<i>Behaviour</i>	<i>Problem</i>	<i>Was a problem but now getting better</i>	<i>Not a problem</i>
Problems with language	60 (83.3%)	11 (15.3%)	1 (1.4%)
Relating to other people	56 (77.8%)	12 (16.7%)	4 (5.6%)
Problems with play	50 (69.4%)	14 (19.4%)	8 (11.1%)
Unusual interest in toys/objects	45 (62.5%)	8 (11.1%)	19 (26.4%)
Adaptation to change	43 (59.7%)	12 (16.7%)	17 (23.6%)

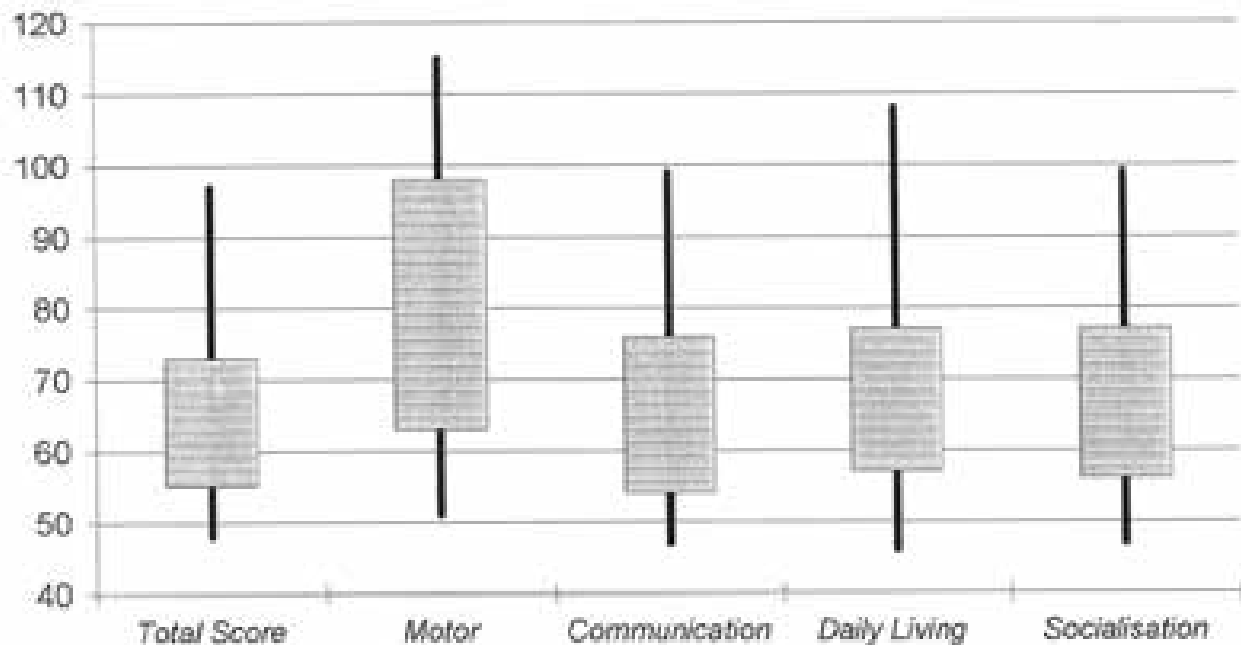
These problems are the classic symptoms of autism. Only a small proportion of parents reported that the problems were 'getting better'. Overall, parents reported a mean of 6 problems (range 1 to 11).

Although the great majority of parents (82%: N=59) report agreement within the family on how to deal with these problems, only 26% (N=19) of parents felt they had the skills for adequately addressing these problems. This is particularly so with parents of younger children.

The problems that parents found most difficult to deal with were: the child's behaviour (N=30 parents mentioned this: 42%); communicating with the child (N=29: 41%); temper tantrums (N=17: 24%) and speech and language difficulties (N=14: 20%).

The Vineland Adaptive Behaviour Scales were used to obtain a picture of the child's overall development based on parental reports. This is done in terms of a standard score in which the average child scores 100 for his/her age. As well as giving an overall or total score, sub-scores are available for the domains of motor development, communication, daily living skills and socialisation. Figure 1 shows the average scores (the shaded area which is defined as one standard deviation on either side of the mean) along with the highest and lowest scores for the sample of children (this data was missing for one child).

Figure 1: The average, maximum and minimum scores on the Vineland Scales (N=71)



The Figures shows:

- A wide range of scores in all domains suggesting that some children are functioning close to their non-disabled age peers whereas others show marked developmental delays.
- Children's development of motor skills is better than in the other three domains were their average scores are significantly lower.
- Most children with ASD show developmental delays in communication, daily living skills and socialisation.

The families

Of the 72 children, 62 (86%) lived in two parent families and 10 (14%) lived in one parent families,

Nearly two-thirds of the parents (64%: N=46) were aged between 30 and 39 years with 19 (26%) aged under 30 and 7 (9%) aged 40 and over.

In 81% of families (N=58) there is a wage-earner but in 14 (19%) there was not.

Ten parents (14%) left school at 15; a further 31 (44%) after O Levels/GCSEs; 10 (14%) took A Levels and 20 (28%) completed higher education.

In all 53 (74%) owned their own house; 16 (22%) were in rented accommodation and 3 (4%) lived with their own parents.

In terms of ethnicity, all but one (N=71: 96%) of the families were white.

Early Signs of a Problem

Nearly one-third of families (31.9%: N=23) had identified a problem before the child was one year old; a further 35% (N=25) of families by the time the child was 18 months old and another 22.2% (N=16) by two years of age. In only eight children (11%) was the child aged over two years. Hence nine out of ten families would benefit from advice and support before the child is two years of age.

The main indicators that alerted the parents to a problem were delayed speech (N=45: 63%); the child's unusual behaviours (N=33: 46%); lack of interaction (N=30: 42%) and suspicion of hearing difficulties (N=26: 36%).

In the majority of cases (54%: N=39) it was the mother who first spotted the problem; although in eight instances (11%) both parents noticed it; in two cases (3%) it was the father and two (3%) the granny. However in 21 families (29%) it was a person outside the family who suggested to the parents there might be a problem; most commonly a health visitor (N=14: 19%) followed by speech and language therapist (N=3: 4%), community medical officer (N=2: 3%) and a preschool teacher (N=2: 3%).

Even so, in a sizeable proportion of families (N=24: 34%) there were disagreements as to whether or not there was a problem.

Health visitors were the professionals from whom most families sought advice and help (N=55: 76%) followed by GPs (N=28: 39%). Only a minority of parents reported seeking advice from their families (N=24: 34%) but very few did this with their friends (N=5: 7%).

Impact on families

Parents were asked to describe the impact the child with ASD had for them as parents. Only two mothers (3%) felt that it made no real difference to them – *'I don't know any different so I just get on with it'*. The remainder reported one of more deleterious effects. These are summarised in Table 2.

Table 2: The number and percentage of parents reporting effects on families (NB Parents could report more than one type of impact).

<i>Impact</i>	<i>N</i>	<i>%</i>
Social Limitations in family and community	25	35%
Continual stress, strain, lack of sleep	19	26%
Other children in family miss out, treated differently	17	24%
Constant supervision and having to plan ahead	17	24%
Worry about the future	13	18%
Embarrassment, hurt, devastated	9	13%
Financial worries – may have to give up job	8	11%
Need to have a positive outlook	8	11%

This data suggests that parents need extra support to cope with the demands that the child may place on them and their families.

Services and Support Received

The families reported having contact with a range of professionals in the past 12 months. These are listed in Table 3 along with the parent's rating as to whether or not the contact was helpful to them. The most common were speech and language therapists, health visitors and doctors.

**Table 3: The percentage of parents who had contact in past 12 months
With different professionals**

Professional	No contact	Found it Helpful	Found it unhelpful
Speech & Language Therapist	6.9%	80.6%	9.7%
Health Visitor	20.8%	63.9%	12.5%
Clinic/Hospital Doctor*	29.6%	53.3%	14.1%
Social Worker	36.1%	47.2%	13.9%
GP	45.8%	40.3%	11.1%
Home teacher	51.4%	43.1%	2.8%
Educational Psychologist+	56.9%	31.9%	8.3%

* A lower percentage of 3 years-olds had contact than two and four year olds.

+ Contact was very much greater with four-year olds.

Overall parents reported having contact with an average of five professionals in the past year (range 0 to 9). However in many instances these contacts were limited to one consultation.

Comments about unhelpfulness tended to reflect a lack of follow-up by the professional, pessimistic attitude to the child, lack of knowledge about autism and insufficient contact.

Those parents who reported having more problems with their child did not receive any more help than those reporting fewer problems.

The most commonly mentioned improvements to services were more speech and language therapy (N=14 parents mentioned this: 21%); more support groups for parents (N=11: 17%); more specialised places in preschools and schools (N=9: 14%) having a follow-up pack after diagnosis (N=8: 12%) and having access to up-to-date information (N=7: 12%).

At the time of the survey, 32 children were attending a preschool facility with 7 children having previously attended a similar facility (54% in all); 10 (14%) went to Mother and Toddler groups and 18 (25%) attended a special preschool or school. Twelve children (17%) did not attend any preschool facility.

In terms of informal support, 65% (N=47) of families reported receiving extra support from extended family members, 28% (N=20) received support from friends, 13% (N=9) received support from neighbours and 6 % (N=4) received support from a church group. However one third of families (N=24) had no source of informal support.

Social Inclusion

The majority of children were reported to get on very well (41% N=24) or well (42% N=25) with their other siblings; however 10 (17%) did not.

Over three-quarters (78% N=56) could be left with a child-minder; mostly family members although 20 (28%) were left with non-family members.

In all 58 children (81%) were able to be taken on outings to shops; 53 (74%) could be taken on visits to other people's homes and 50 parents (69%) reported they enjoyed family outings with the child. Only five children (7%) were unable to do any of these activities and a further nine (13%) one of them. These tended to be children whose parents reported having more problems. Hence at this age nearly all the children were able to join in the usual family activities.

Parents were also asked about future school enrolment. The majority (N=49: 68%) hoped for mainstream schooling, making mention of the need to have learning support assistants available. By contrast 15 parents (21%) opted for special schools, noting that their child won't be able to cope with mainstream schools and a further 5 (7%) talked in term of a special unit linked to a local school. (Only three parents were unsure).

Conclusions

- Boys greatly outnumber girls in a ratio 9 to 1. Families come from all sections of the community.
- Preschool children with a diagnosis of autism show a wide variation in their development; some function close to their age peers whereas others have marked delays.
- The most commonly reported problems by parents are the child's language delay, relating to other people, play, unusual behaviours and adapting to change. Most parents feel they lack the skills to deal with these problems.
- These problems were usually evident by the time the children were two years of age.
- Nearly all parents report deleterious impacts on them and family life of living with a child who has ASD.
- Although families see a range of professionals they feel improvements are needed to education, health and social services.
- The children attend a range of preschool facilities and most take part in normal families activities outside of the home.
- Most parents hope that their child will attend the local mainstream school.

Section 4: Impact of home-based interventions

Families in two HSS Trusts whose child met the selection criteria for the project were consecutively offered the home intervention service. This was done as they were identified as having an autistic spectrum disorder over a 12-month period.

All the families accepted initially however four families opted out of the project: two at the beginning of the project because they were unable to commit fully to the programme of visits and 2 mid-way through the project. One family withdrew because their child was not making progress. The other family opted out because the majority of their child's behaviour problems had resolved after the child had been prescribed Ritalin.

Selection criteria

The criteria for inclusion in the early intervention were:

- The child must not be older than 4 years old but preferably younger.
- Child must have a confirmed diagnosis of Autism with assessments providing evidence to support the diagnosis.
- The child must live in the geographical area covered by Down Lisburn Trust or South and East Belfast Trust.
- The child must not be attending any other pre-school service such as nursery school during the first 5 months of intervention.
- Parents have agreed to participate in the project.

Home Visiting Programme

The home visiting programme was split into 3 stages.

Stage I: Assessment and Information Stage

A maximum of four visits were made at weekly intervals to get to know the parents and the child; to gather information and carry out any further assessments. During these visits, the diagnosis was discussed, parents' questions answered and further information was supplied about autism. At the end of this period, therapy goals were devised specific to each individual child's needs and strengths as well as the needs and priorities of the parents/family.

Stage II: Intensive Therapy Stage

This phase lasted for around 12-14 visits. There were a number of common features across all children.

- TEACCH Methods were introduced at session 1 to develop attention and play skills and to calm and organise the child's behaviour.
- Parents were given training during the early sessions on:
 - Their interaction style with the child.
 - Minimal speech input
 - Modelling language suitable to child's ability level
 - Providing opportunities for the child to communicate and interact (see Guide).

- Methods based on Picture Exchange Communication Systems (PECS) were introduced at session 3 to develop expressive communication skills. Vocabulary was developed and extended as per each child's progress. PECS was discontinued as the child developed functional verbal requesting or if the child was unable to use this strategy (see Guide).
- Visual communication strategies (based on TEACCH and ICON to ICAN methods) were introduced between sessions 2 – 6 to facilitate the child's understanding and in some cases to help manage the child's behaviour:
- Difficulties with sleeping, dressing, eating, behaviour outside the home and toilet training were addressed at the parents' request, typically between sessions 4 and 12.
- Children with developing expressive language and who had acquired the necessary language comprehension skills received a speech and language development programme using the Derbyshire Language Scheme (Masidlover, 1985)
- At the final session of the intensive therapy stage, the child's progress was reviewed and arrangements were made to visit the child's nursery school or playgroup to provide advice to educational staff and support the child to settle into the pre-school establishment.

Stage III: Carry Over Stage

Families received between one to four follow up visits on a monthly basis. Here the aims were:

- To provide ongoing support and advice.
- To encourage parents to continue specific aspects of the therapy programme.
- To further extend specific aspects of programme according to the child's progress.
- To facilitate parents in problem solving and managing the child's behaviour.
- To support parents in making decisions regarding school placement.
- To provide ongoing support to nursery schools and pre-school settings at parent or teacher's request.

Further details of the content of the home visiting programme and the methods used in it are given in the Guide.

Ten children received approximately 18 home visits over an 11-month period. Visits in the latter 4-6 months of this period were less frequent (usually monthly).

Seven children received approximately 15 home visits over a 9-month period. Visits in the latter 2-3 months of this period were less frequent (usually monthly).

Three children received approximately 15 home visits over a 6-month period with one follow up visit following discharge from the project.

This variation was due to time constraints on the project worker and the length of time funding was available for the project.

Children and families

Mothers were most often the primary care giver for the child and 18 were responsible for carrying out the programme with just two fathers (10%) taking a key role in implementing their child's programme.

The parents were mainly aged 30-39 years (N=15: 75%) with three under 30 years (15%) and 2 over 40 years (10%). In all 12 (60%) had left school at 15 years or with O Levels while 8 had completed either A Levels (10%) or taken higher education (30%). In five families (20%) there was no wage earner. Fourteen families (70%) owned their own homes and the remainder were in rented accommodation.

Of the 20 children, 17 were boys and 3 girls with ages between 24 and 43 months. In 3 families (15%) there were reported to be other children with similar problems.

Evaluating change

The impact of the intervention was judged in a number of ways.

1. Parents' opinions of the intervention programme.
2. Comparison of the children before and after the intervention from parental reports.
3. Changes in the children as assessed by independent assessors.

As well as the 20 children who completed the intervention programme, a contrast group of 12 families were also recruited after the programme ended. Their progress over an equivalent time period was ascertained through interviews six months apart when they had received the usual services available through the HSS trust.

1. Parents' Opinions

An independent researcher from the University visited the family at home and talked to them in confidence about their reactions to the home visiting programme. This was done for 19 of the 20 families (95%) who completed the intervention and one of the four families who dropped out. Two families were not contactable despite repeated efforts.

All 19 parents who completed the programme would recommend it to other families. All felt they had learnt new things to do with their child. All were satisfied with the home visitor's knowledge and skills, the way she went about her work, the notes she left after the visit and the time of day when she visited.

A minority were dissatisfied with other features of the programme: 1 parent (5%) felt s/he could have been told more about autism; 1 parent did not think the onward referral was appropriate; 2 parents (11%) would have liked the visits to be longer; 3 parents (16%) wanted more visits and 5 (26%) did not like the video camera being used.

Overall, 17 parents (90%) thought that the family had benefited from the visits and 16 (84%) that their attitude to the child had changed as a result of them.

The parent who had opted out felt that the family had not benefited and she expressed dissatisfaction with all aspects of home visiting programme. Nevertheless she did feel that she had been told new things; that she had learnt new skills in working with the child and that her attitude to the child had changed.

2. Changes in the children and parents

In this section we compare the children before the programme and three months after its completion. This information was obtained from parental reports given either to the home therapist at the start of the programme or to a university researcher. However all the post-interventions were done by the university researcher.

Perceived difficulties

Parents identified from a listing of 11 problems those which were difficulties for the child and those that had been difficulties but were now getting better (see earlier). After the programme parents noted significantly fewer problems overall – a mean of 6.1 (range 0-11) before and 2.6 (range 0-5) afterwards ($t=4.71$; $p<0.001$). By contrast there was a marked increase in the number of problems reported to be getting better – a mean of 0.7 (range 0-5) before and 2.7 (0-6) afterwards ($t=4.78$; $p<0.001$).

Table 4 summarises the number of parents reporting each type of problem before and after the intervention. The greatest improvements were reported in language and play on which the intervention had focussed.

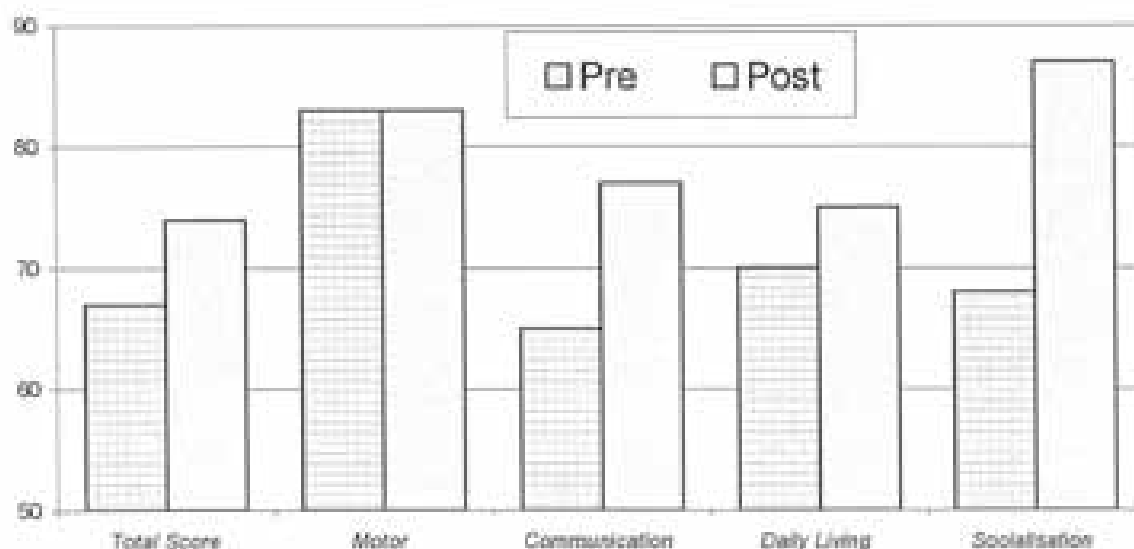
Table 4: The number and percentage of children with reported problems

<i>Behaviour</i>	<i>Problem Before</i>	<i>Problem After</i>
Problems with language	19 (95%)	3 (15%)
Relating to other people	19 (95%)	8 (30%)
Problems with play	18 (90%)	2 (10%)
Unusual interest in toys/objects	11 (55%)	5 (25%)
Adaptation to change	11 (55%)	6 (30%)

Vineland Scale

Figure 2 gives the mean standard scores for the 19 children before and after the intervention.

Figure 2: Means standard scores on the Vineland Scale (N=19)



However only the differences in the Communication and Socialisation domains were statistically significant ($t=3.58$ $p<0.005$ and $t=3.80$ $p<0.001$ respectively). This suggests that the intervention had a specific impact on the child's development rather than a result from overall developmental progress, which would have been the case if improvements had been found on all four domains.

Parental Stress and Resources

Parents were asked to complete a questionnaire that was designed to assess the stresses they experienced in parenting a child with special needs (Friedrichs et al, 1986). This consists of two main factors and a higher score is indicative of greater stress.

On the scale measuring Family and Child Problems, there were no differences before and after with the mean scores being 8.1 (SD 5.2) before and 8.9 (SD 5.2) afterwards. However there was a significant increase in the scores on the Pessimism scale from 5.2 (SD 2.9) before to 7.0 (SD 3.0) afterwards ($t=2.2$ $p<0.05$). This suggests that parents had become more aware of their child's difficulties.

Changes in PEP-R Scores

All the children were assessed by independent assessors before and after the intervention on the Psycho-Educational Profile - Revised (PEP-R) (Schopler et al, 1990). This is a developmental assessment devised to assess the learning style, strengths and deficits in children with Autism or related development disorders with a view to planning educational goals. It is most appropriately used with children aged from 6 months old to 7 years old. The PEP-R provides developmental levels for Imitation, Perception, Fine Motor, Gross Motor, Eye-Hand integration, Cognitive Performance and Cognitive Verbal Skills.

Figure 3. Mean Developmental ages in months on PEP-R Before and After intervention

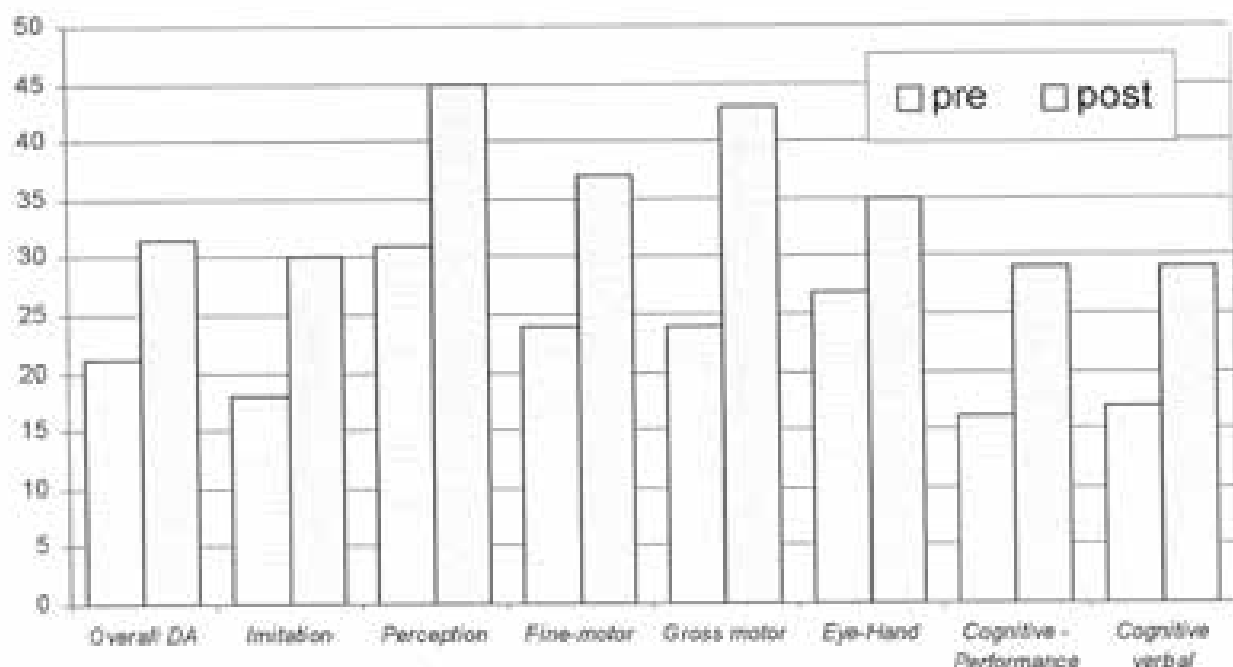


Figure 3 gives the mean developmental ages in months of the 20 children who took part in the project. (However three children were not testable on this test prior to the intervention but they were afterwards).

All the differences on each subscale were statistically significant ($p < 0.005$). Overall the children's developmental gains in months were an average of 0.9. Thus there was independent verification of the children progressing in areas that are problematic for children with ASD.

Conclusions

- All the families felt they had learnt new things from the intervention and they were broadly satisfied with it. Nearly all would recommend it to other parents.
- After the intervention the parents reported fewer problems with their child and an increase in the number of problems that were now "getting better". This was particularly so with problems in language and play.
- The children made greater progress on the communication and socialization domains of the Vineland Scale with no significant change in motor or daily living skills. The effects of the programme were specific to the domains targeted.
- Independent assessors of the children rated significant improvements across various psycho-educational domains.
- Parents appear to be more aware of their child's difficulties as a result of the intervention.
- This evaluation did not address the issue as to whether or not the approach used in this intervention is more effective than other approaches such as Applied Behaviour Analysis (ABA) derived from Lovaas' model.

Section 5: Preschools

The government aspires to provide some form of preschool education to all children aged four years upwards. This is equally applicable to children with ASD and most parents are eager for their child to attend a local facility. But how willing and able are local preschools to take these children? What training and support might staff in such facilities require?

The project's work in this area consisted of a survey of staff working in a range of preschool facilities in the greater Belfast area and the evaluation of a specially designed training course for preschool personnel on autism. To date no similar course has been produced in these islands and possibly elsewhere.

Survey of preschools

This survey consisted of staff who had been involved in the new training course. Hence they may form a sample of people who are predisposed to enrolling children with ASD in their facilities and may not be typical of staff in all preschools. Even so their experiences and needs will give some indication of the issues that require to be addressed in this area.

Preschools

In all, 56 staff working in 38 preschools of various types in the Greater Belfast area returned self-completed questionnaires. The groups consisted of community-run playgroups, crèches and day nurseries, special needs nurseries and Irish medium playgroups. On average there was around 24-30 children in the groups per session but the range was from 7 to 62 children.

The staff were mostly playgroup assistants or nursery nurses (N=26) playgroup leaders/managers (N=16) or supervisors (N=11). The median number of years they had worked with children was 8 years (range 2 to 30 years) and they had worked in their present group for a median of 3 years (range 1 month to 22 years).

Only a minority – 7 persons (13%) reported having a relative with autism.

Table 5 shows the amount of experience they felt they had with different groups of children. Less than a third of staff had experience of dealing with children who had ASD whereas over two-thirds had some experience of language and communication difficulties and behaviour problems.

Table 5: The number and percentage of preschool staff with experience of different children

<i>Children with.</i>	<i>A lot</i>	<i>Some</i>	<i>Limited/ None</i>
Language and communication problems	18 (32%)	22 (39%)	16 (29%)
Behaviour problems	14 (25%)	29 (52%)	13 (23%)
Autism	2 (4%)	14 (25%)	40 (71%)

Nearly all (N=53: 95%) felt it was their role to support children with autism in their playgroup. However only 20 staff (36%) currently had a child with ASD in their group although 29 (52%) had had such a child in the past five years. Just over one-third of staff (N=21:38%) felt they had the skills required to carry out specific activities for children with autism in their group.

Characteristics of the children attending

Staff were asked to give details of a child with autism presently attending their group and if there was more than one, to give information on the child who had been attending longest and those who had most recently enrolled. Information was given for 25 children in 20 preschools.

There were 20 (80%) boys and five girls (20%) with a median age of 38 months (range 24 to 72 months). The median length of time they had attended the group was 6 months (range 2 to 24 months). Nine children (35%) had a brother or sister attending the group.

Table 6 gives the number of children perceived to have problems in comparison to their peers. This is broadly similar to those reported by parents (see Table 1).

Table 6: The number of children with problems (N=25)

<i>Problems</i>	<i>N</i>	<i>%</i>
Problems with play	22	88%
Problems with language	21	84%
Difficulty in imitating	19	76%
Difficulty in relating to people	17	68%
Unusual interest in toys or objects	17	68%
Adaptation to change	18	72%
Unusual posture	14	56%
Unusual reaction to pleasant situations	17	68%
Unusual response to something new	13	52%

However the two most difficult problems were managing the child's behaviours (such as temper tantrums, moods) that 8 staff mentioned and problems with language and communication, which were mentioned by 6 staff.

Support for staff

For the 38 facilities, information was obtained on the advice and support they had received in the past 12 months to help support children with special needs in the group. Table 7 summarises the numbers of groups who received support and whether or not they found it to be helpful or unhelpful.

Table 7: The people from whom participants received advice or support

<i>Persons</i>	<i>Yes & helpful N (%)</i>	<i>Yes & not helpful N (%)</i>
Child's parents	25 (88%)	7 (18%)
Speech and Language Therapist	19 (50%)	2 (5%)
Social worker	11 (30%)	3 (8%)
Psychologist	8 (21%)	1 (3%)
Visiting teacher/ advisor	8 (21%)	0
Health visitor	6 (16%)	3 (8%)
School doctor/ specialist	4 (11%)	0
Committee Members	2 (5%)	0
Peripatetic teacher	2 (5%)	0

Although parents were the most commonly cited source of information and advice this was also the most likely to be seen as unhelpful by the preschool facility.

Speech and Language therapists were the professionals with whom they had most frequent contact and reflects the priority of these services in the areas in which the groups were located.

Rather surprisingly the access to educational advice from teachers and advisers was limited.

In all eight groups (21%) received no advice or support from any professional with 13 (34%) having help from one professional, 7 (18%) from two professionals and 8 (21%) from three or more.

Training needs of staff

The 56 staff were asked about the training they had received in ASD. Only 9 persons (16%) described it as adequate; 26 (46%) thought it was inadequate and 21 (38%) reported having none at all. Table 8 summarises the areas in which they would value having training.

Table 8: The number of staff wanting training in different aspects of autism (N=49)
(NB Staff could mention more than one area. Some staff were unsure.)

<i>Area</i>	<i>Number</i>
Techniques and Strategies for assisting children with autism	14
More background to autism – a knowledge / understanding autism	13
Support for parents/children	8
Understanding and dealing with behaviour	8
Communicating with parents – Giving information to parents	6
Activities/ teaching aids/ room layout	6
Identifying children with autism	5
Language/Communication of child	5
Interacting with other children	3
All areas/aspects	9

As the table shows, staff were keen to know what they could do for children with ASD in their groups and wanted to have a fuller understanding of this condition. They also were keen to know how best to support parents and to pass information on to them.

In sum then, a sizeable number of preschools have the experience of taking children with ASD and staff do receive advice and support from a range of professionals. It is likely that this self-selected sample of staff and facilities is biased towards those more favourably disposed to enrolling such children but even so a majority of staff feel they have had inadequate or no training and they report a lack of knowledge and skills to help these children.

Training for preschool personnel

In association with the Northern Ireland Preschool Playgroups Association (NIPPA), a five session training course was developed to meet the training needs of staff working in a range of preschool facilities.

The course was developed and tutored initially by a teacher, a pre-school autism specialist and a speech and language therapist who had a great deal of experience

in dealing with pre-school children with autistic spectrum disorders and in working with playgroups and nursery school staff. Subsequently the courses were presented by NIPPA tutors who had taken the course as participants alongside an autism specialist.

Course aims and objectives

The course aimed to enhance participant's knowledge about autism and of the intervention strategies that are effective in assisting young children to communicate and interact with others.

The specific objectives were:

- To explore how autism manifests in the pre-school child and what difficulties the child may have in the playgroup situation.
- To identify strategies for effectively interacting with children with autism.
- To address the basic principles of behaviour management in the playgroup.
- To develop the participants' skills including children with autism in the activities of the playgroup.

Course content

The training course consisted of five sessions, each approximately two to two and a half hours in length. The course content is described in detail in the Tutor's Guide but briefly five themes were covered.

Theme 1: "Characteristics of Autism" This focused on an explanation of autism – its features and prevalence. Video material was used that had been recorded in clinic and playgroup settings. This contrasted the development of preschoolers with and without autism and showed progress in children over the years.

Theme 2: "Structured Teaching" The second session demonstrated how autism manifests in pre-school children using case histories. The difficulties that a child would have in a playgroup were discussed, along with ideas of how to deal with them.

The emphasis was on identifying and meeting the need of the individual child in the playgroup. The four elements of structured teaching were introduced in session 2 and developed in session 3, namely, work systems, routines, visual clarity and physical structure.

Theme 3: "Communication" The fourth session focused on the stages of communication development in both children with autism and children without autism. Effective communication strategies were discussed; concentrating mostly on visual communication strategies. Emphasis was placed on supporting language with objects and other visual supports such as books, menus and choice boards.

Theme 5: "Bringing it all Together" The involvement in the playgroup of parents and speech therapists was discussed and other sources of support were identified such as the peripatetic autism provision in certain Education and Library Boards. The importance of interagency support and communication was stressed along with how to introduce a child to the playgroup, and the ongoing support that should be given to staff. This session was successful in awareness raising and in giving a parental perspective.

Teaching methods

The main teaching methods were talks and presentations using handouts and Power Point overheads, video examples and group activities. The training facility also had a room set out as a dedicated playgroup. This was used to demonstrate how the room can be organised for individual work and to provide examples of visual communication and play equipment suited to preschoolers with autism.

Course Participants

The course was taken by four groups of participants; who were recruited through the Northern Ireland Preschool Playgroup Association (NIPPA). The course publicity made clear that preference would be given to personnel who had children with autistic spectrum disorders in their groups or who anticipated taking such children in the future. Participants paid reduced fees, as subvention was available through training grants to NIPPA.

A total of 62 self-selected participants attended the training courses that were held in the evenings over five consecutive weeks. Nearly half of the participants (N=30; 48%) were playgroup leaders or supervisors and a further 25 (40%) worked as assistants. The remaining seven persons (12%) consisted of trainers and advisers. A range of various facilities was represented including community-based groups; day nurseries and crèches, special needs groups, Irish medium groups, state nursery and a private playgroup.

The median length of time people had been working in playgroups or nursery was ten years (range 2 to 30 years) and the median length of time spent in their present post was two years (range 1 month to 22 years).

Of the participants, eight (13%) were aged less than 30 years; 17 (28%) were aged 30-39 years; 24 (40%) were 40 –49 years and 11 (18%) were 50 –59 years of age (two persons did not disclose their age). In all 32 (52%) had attended higher education; 20 (32%) had at least O levels and seven (11%) had left school at 15 years (three people omitted this information).

Overall 82% of participants attended all sessions and the remainder (18%) attended four sessions.

Evaluation of the course

The course participants were asked to complete a "Pre-Course Questionnaire" at the start of session 1. At the end of each of the five training sessions, the participants completed a "Session Evaluation Form" which recorded their reactions to the content and teaching methods used. Names were not requested on any of these forms or on the pre-course form.

A "Follow-up Questionnaire" was posted to each participant approximately three months after each course had ended. The time gap was to avoid any 'halo effects' arising from the course attendance. Participants could chose to answer the questionnaire via a telephone interview with a researcher or by completing it themselves and posting it back.

Session Evaluations

Nearly all participants rated the length of the sessions as 'just right' (95% - 100% across the five sessions) and most felt that the input had made them more knowledgeable about the subject (87% - 100%). Ratings of the helpfulness of the

sessions ranged from (88% to 97%) but the percentages were lower about doing something differently in their own playgroup. These were highest for sessions 3 and 4 (82% and 80% respectively) than for sessions 1 and 2 (both 67%), which were more knowledge based. Very few participants noted something they had not enjoyed about the sessions (0%-3%). One person commented: *In the groups some people do not get involved; they keep to themselves and talk among themselves about things not related to the activity.*

In sum, the training sessions were very well received by the participants.

Three-month follow-up

This questionnaire enquired about the aspects of the course that participants had found most helpful; whether or not their attitudes towards children with autism had changed; if they adopted any of the practical suggestions made on the course and their willingness to enrol children with autism in the future. Responses were obtained from 62 (98%) of the 63 participants.

Helpfulness: The most common comments about helpfulness of the course related to practical advice they had been given about activities for the children, work programmes, use of schedules and visual aids (32 people mentioned: 52%). In all 15 people (24%) mentioned having a better insight into autism and seeing things from the child's perspective and 13 people (22%) noted the characteristics of autism.

Among the other features they had found helpful were the personal accounts of others of having children with autism in their groups (5 persons: 8%); working with parents (4 persons: 7%) and finding professional support (2 persons: 3%).

Attitudes to autism Participants were asked if their attitudes and perceptions of the children with autism had changed since taking the course, if at all. All but six participants (90%) stated that they had. In all 34 (57%) reported having a greater understanding of autism; 20 (33%) noted more awareness of strategies for working with these children and 11 (18%) felt more confident in working with these children.

Adaptations in the playgroup: The participants were also asked if they had adapted the activities of the playgroup or changed their approach to children with autism since taking the course. All of those who presently had a child with autism in their group reported doing so and the responses are given in Table 9.

Table 9: The number of participants reporting adaptations in their approach to children with autism after the course (N=48)

<i>Adaptations of activities/ changes of approaches</i>	<i>N</i>	<i>%*</i>
Introducing clear routines to group by using structured teaching approach (setting up schedules, making activities, physical structure)	25	52%
Assisting children with visual structure	7	15%
I have adapted my communication by simplifying my language	6	13%
1:1 work time	5	11%
Increased observation of children	3	6%
Daily notebook for mother	2	4%
Try to involve children in all activities	1	2%
Heightened awareness of the child's likes and dislikes	1	2%
Focus on the child's concentration	1	2%

* participants could give more than one response.

The use of the structured teaching approach was by far the most commonly stated change of approach mentioned by participants followed by the use of visual structures and simplifying their use of language.

Future enrolment of children with autism In all 37 (67%) of the 55 participants currently working in playgroups reported that they would definitely be willing to have children with autism in their playgroup in the future while 17 (31%) would be willing to consider this if asked (one person did not reply to this question). The reasons for these responses are given in Table 10.

Table 10: The reasons given by participants for enrolling children with autism in their playgroups.

<i>Reasons for definitely being willing to enrol the children</i>	<i>N =37</i>	<i>%</i>
Autistic children should be integrated into mainstream and not excluded/ they have same rights/ benefits mainstream children	18	49%
I am more knowledgeable about/ confident with autistic children now	9	24%
It is satisfying/ challenging to watch children develop	6	16%
The children in our playgroup have been turned away elsewhere	4	11%
Need playgroup for support to parents.	4	11%
I am very eager to help any children	1	3%
I am more aware of the support network through the contacts because of the course	1	3%
It's a learning experience for staff to have children with autism in the playgroup	1	3%
<i>Reasons given for being willing to consider enrolment</i>	<i>N=17</i>	<i>%</i>
Depends on number of staff / if enough for 1:1 attention could they cope	5	29%
Characteristics of the child; need to consider severity of autism	3	18%
Need additional staff/ financial support and advice from professionals	2	12%
Our group should be open to all children	2	12%
I am more confident in dealing with these children	2	12%
I feel I need more experience in working with children with autism	1	6%
It would depend on other special needs children in the group at the same time	1	6%
Would depend on staff training being available	1	6%
I would take child for trial period	1	6%

* participants could give more than one response.

The most commonly given reasons for definitely accepting the children were the wish to include them in ordinary playgroups as it is their right to attend followed by participants feeling better able to cope with these children. Their reservations about taking a child into the group centred on the extra staff that may be needed and the supports available to them.

In sum, the course was well received by the participants, it increased their knowledge and understanding of ASD but more significantly most staff reported implementing the teaching approaches and strategies taught on the course into their groups and they were more willing to accept children with ASD into their groups in the future.

Conclusions

- Although the staff and preschool facilities in this study were likely biased towards having children with ASD, nearly all reported having few training opportunities and most felt inadequately skilled to meet the particular needs of these children.
- Staff in preschools encounter broadly the same range of problems as do parents and they find behaviour and communication difficulties the hardest to cope with.
- A specially developed ten-hour training course was well received by the participants who three months later had implemented much of the advice given on the course.
- Course participants appeared more willing to enrol children with ASD in their groups although a minority did express some reservations.
- A resource pack for tutors has been prepared so that similar courses can be delivered elsewhere in the future.

Section 6: Parent Support Groups

Information in this section comes from three sources. First the study involving 72 parents with preschool children; a survey of members of PAPA branches throughout Northern Ireland and the results of support groups held for parents.

Parents of preschool children

Of the 72 parents interviewed, 30 (42%) reported having contact with other parents who had children similar to their own. In the main this came about through contact with organisations such as PAPA (N=14) or taking part in training courses (N=7). Only a few parents made contacts through mutual friends (N=6).

The main benefits that parents reported were: getting information (N=12); feeling you are not alone (N=8); sharing experiences with others (N=9) and emotional support (N=6).

Of those 42 parents who did not have contact with other families, 28 (67%) expressed a wish to do so; 12 (29%) did not want to and 2 (5%) were unsure.

Survey of PAPA Branches

A self-completion questionnaire was sent to all 13 PAPA branches and replies were received from 72 persons in all. Although this represents around 15-20% of PAPA memberships it is reflective of an estimated 50% of people who attend branch meetings at least once a year.

The mean age of the children represented in the survey was 8.5 years (range 2 to 22 years).

The mean length of time that people had been involved with their Branch was 1 year 9 months (range 1 month to 7 years).

Table 11 shows the percentage of parents who strongly agreed with each of the statements (NB. These were presented on a five-point scale from strongly disagree to strongly agree).

The same broad pattern of responses held for all parents with the exception of two items. Parents of younger children appreciate meeting professionals working in the field of autism and also gaining from the advice and information from other parents, more so than do the parents of older children.

When asked what they found most helpful about the Branch, the most common replies were the support from other parents (N=26: 36%); overall support in coping with autism (N=22: 31%) and information received (N=16: 22%).

Parents mentioned few things that they would like to see changed or done differently. These included having better structured meetings with more speakers involved; more opportunities for parents to discuss issues and greater effort to welcome new members. Parents expressed a wish to be more involved in training professionals and in raising awareness about autism locally. More support from central office was noted particularly for the Chairpersons of Branches. Others mentioned specific topics they would like to see covered including early intervention, services for older persons, sibling support, claiming benefits and creating 'baby-sitting' circles.

Some noted the poor attendances at meetings.

Table 11: The number and percentages of parents strongly agreeing with statements

<i>Item</i>	<i>Parents with children under 8 years</i>	<i>All Parents strongly agree</i>
I gain support from other parents	21: 66%	38: 60%
An opportunity to discuss issues of interest	20: 63%	37: 59%
I can listen to guest speakers	20: 63%	37: 58%
I gain advice and information from others*	23: 72%	36: 57%
I hear about forthcoming PAPA events	16: 50%	33: 51%
My family can attend outing/events	17: 53%	30: 46%
Be part of a group lobbying for local services	14: 44%	29: 45%
I feel less isolated	16: 50%	26: 41%
I meet professionals working in autism*	15: 47%	22: 35%
I provide support to other parents	12: 38%	20: 33%
A night for myself	10: 33%	20: 33%

P<0.10

Parent Groups

Staff linked with Barnardo's Carrigfoyle Project facilitated two support groups for parents who had preschool children with autism. Each group met on four occasions for around 90 minutes. In all 15 mothers took part.

The aims of the groups were:

- To give parents an opportunity to meet others facing similar issues in relation to their child's diagnosis of autistic spectrum disorders;
- To enable parents to fill in the gaps in their knowledge and understanding of this condition.

The ethos of the groups could be summarised as follows:

- Parents are a resource for one another in terms of managing the pressures and challenges presented by children who have autistic spectrum disorder and in sharing their experiences.
- The sessions were not intended to provide answers but rather they were an opportunity for discussion and for exploration of feelings.
- Parents need access to information that is meaningful to them.

The families were identified by the two HSS Trusts linked with the Keyhole Project or else they had already been referred to Barnardo's. Each family was personally contacted to explain the aims and content of the proposed support groups. This was vital in overcoming the apprehension that some parents may feel about joining with a group of 'strangers'.

A crèche was provided for the children and siblings. This was necessary to allow parents to focus on their issues without being distracted if the children were also present. Transport was also provided if needed.

The first session had as its theme how parents became aware of the child's difficulties. This provoked much discussion about the reactions of professionals and how the giving of a diagnosis could be better handled.

Session 2 focussed on how family and friends react to the child with ASD and the pressures mothers felt in daily life. Although most mothers felt supported by family and friends they also recounted instances of denial, anger, spoiling and overindulgence, fear and apprehension, and the critical attitudes of others to them. The differences between mothers and fathers reactions were also discussed. Mothers felt that being able to cry about their child's diagnosis was a positive emotional release which men cannot easily avail of. On the other hand, mothers identified their partner's employment as being an opportunity for them to switch off by having time-out and that this enabled them to cope with the emotional impact of the child's problems.

The third session dealt with the main features of autism and what it meant for each child. Many commented on the need for better liaison among professionals and for them to see the child in his/her natural environment if they are to get a fuller picture of the child. They were frustrated by the lack of therapy resources. The need to have a person 'speaking up' for you was one favoured solution.

In session four the various therapies and approaches to ASD were outlined with a particular emphasis on the points to consider when choosing an intervention. Discussion centred around the feelings of guilt or unease if they decided not to pursue an approach recommended to them; the financial implications of embarking on certain approaches and maintaining a balance between being a mother and being a therapist.

Parent reactions

Reaction of participants to the group sessions was obtained through self-completed questionnaires at the final session and then again three months after the groups ended.

All respondents felt that they had been given enough information about the groups before they started and that the group size was about right. However a minority felt that each session was too short although the others felt it was 'just right'. All felt it had been helpful to hear of others' experiences and that they would recommend the groups to other parents because through them they had gained information, encouragement and support. One mother valued *"being able to talk and laugh about the children with people who have been through the same experiences as you."*

They all reported discussing the session content with their partners and that fathers were interested in having a similar group for men. Indeed a follow-up session for fathers was subsequently held but only three men turned up. They felt that less-frequent meetings – perhaps once a term – would suffice.

Conclusions

- Parents who have children with ASD value the opportunity to meet with and to learn from other parents. This is truer for mothers than for fathers.
- A range of approaches are possible but the value of a small group of parents coming together to focus on a particular issue with a knowledgeable facilitator is the most common.

- Group work seems to provide mothers with encouragement, emotional support and information.
- Nonetheless the number of mothers availing of invitations to join groups is low which may reflect changes in parental working patterns and the difficulty in finding a suitable time and venue that is convenient.

Section 7: Recommendations

This section is aimed primarily at service commissioners and providers in education, health and social services.

Even so we envisage that the main responsibility for these children will remain with their parents as they are uniquely placed to respond to the individual needs of their son or daughter.

Yet they do need support and encouragement as they sometimes struggle to cope with the extra demands and stress such children can cause to their families. In this respect it is not just the statutory services who have a role to play but also self-help and voluntary organisations, alongside the wider community.

These recommendations echo those in previous reports such as the Task Group on Autism (Department of Education, 2002) and the Report by the Foundation of People with Learning Disabilities (2003). This is not surprising but we have rooted them in the evidence gathered as part of the Keyhole Project.

Underpinning all our specific recommendations is an over-arching one, namely an integration of the preschool services provided to families by HSS Trusts and Education and Library Boards.

Integrating health, social services and education

Although present administrative arrangements in Northern Ireland do not facilitate this aspiration, it is necessary to avoid unnecessary duplication, to harness the scarce expertise that is presently available and to provide some element of continuity and co-ordination to families. In particular we recommend:

- The joint provision of multi-disciplinary assessment teams.
- The joint provision of home-based early intervention programmes.
- The joint support of preschool facilities and personnel.
- The joint provision of training to community health, social service and educational personnel.

We appreciate that joint working is happening to some degree in certain areas within Northern Ireland and these initiatives may serve as a model for elsewhere.

Given this context, there are four themes that require attention.

1. Early referral

The majority of families were aware of the child's difficulties by two years of age. We recommend:

- Health visitors, GPs and preschool personnel should encourage early referral to specialist assessment teams. These persons should be better informed about ASD and the services available locally.
- Each HSS Trust should have a multi-disciplinary team able to assess and diagnose Autistic Spectrum Disorders. At a minimum this should consist of a doctor, speech and language therapist and psychologist.
- Parents should be involved in the assessment process with information gathered in the child's home as well as in clinics.

- Parents should be given a written report on the main findings and the opportunity to talk through this with a named member of the team. This report should identify clear suggestions for parents about home-based activities and routines they should follow.
- Each family with a confirmed diagnosis should be assigned a named worker from the team whom they can contact for further information and advice.
- The parents should be given the name of local support groups such as PAPA and/or the names of other parents in their locality who are willing to talk to 'newly diagnosed' parents.
- PAPA should have an information leaflet about their activities for assessment teams to give to parents and they should continue to train at least two parents in each Trust area who are willing to be contacted by new families.

2. Home-based intervention

Children with ASD benefit from specific teaching strategies and management approaches. These can be effective from an early age. We recommend:

- A home-based intervention service is provided in each HSS Trust and offered to all families with a child who has ASD. This service should be part of the assessment and diagnostic service.
- The home visitor needs to have expertise in ASD and be competent in a range of therapeutic approaches, notably TEACCH and Applied Behavioural Analysis. Persons could be drawn from a range of disciplines but experience in Northern Ireland and elsewhere suggest that the three most likely are speech and language therapy, psychology and special education.
- There should be regular opportunities for members of the assessment and intervention teams to be trained and updated in various therapeutic approaches. A budget should be allocated for this.
- The form and content of the home-based programme will depend on the child and family needs and this in turn will determine the number of posts required. As a start we recommend one post is required per 100,000 of the population.
- The home visitor would be the named person for the family and they would co-ordinate the inputs and advice from other disciplines such as Speech and Language Therapy and O.T. Equally they could refer the child for specialist help as required.

3. Preschool Provision

All children with ASD have the right to a preschool placement if the parent's wish it. In order for this to happen and for the placement to be beneficial we recommend that:

- The home therapists should support the child's move into preschool facilities such as playgroups, day care or nursery schools. Time needs to be given in their caseload for this function.
- Training courses are provided regularly for preschool personnel who enrol or who are considering enrolling a child with ASD. The local assessment team allied with NIPPA should have the responsibility for this.

- Preschool facilities should have a named person from the assessment team whom they can contact with any queries. This is in addition to the home therapist whose function may end once a particular child has settled in the group.
- The child's progress should be reviewed each term with the parents and members of the assessment team involved with the family. Individual plans should be drawn up so that there is consistency in approaches used at home and in the preschool. These should help to inform the drawing up of statements of special educational needs.
- Certain children with more complex needs may benefit from having a learning support assistant allocated to the preschool facility for a time-limited period. A pool of such personnel could be linked to the assessment and early intervention team.

4. Training of community personnel

The social inclusion of children with ASD is dependent of the attitudes, knowledge and skills of staff working in mainstream services. Hence we recommend that:

- Health visitors receive training in ASD with particular reference to early signs and available services.
- Learning support staff in nursery and primary schools receive basic training in assisting children with ASD to learn and to manage their behaviours.
- Teachers in nursery and primary schools receive training in ASD as part of their initial teacher training and through regular in-service courses.
- Similarly health and social service personnel such as therapists and social workers should have the option of taking a module on autism as part of their initial training.
- Domiciliary social services workers who go to the family home to provide support to certain parents should also have access to basic training linked to NVQs.

These initiatives would build upon the introductory CD-Rom and video training packages recently produced by the Department of Education (NI).

Outcomes

Finally these recommendations are intended to produce the following outcomes.

- The severity of a child's disabilities will be ameliorated through early identification and intervention. Thus the thrust of these recommendations is towards preventative action.
- Families will feel more supported and better able to cope with their child. Fewer demands may be placed on high-cost, out-of-home provision.
- The knowledge and skills of staff in both mainstream and specialist services will be increased and they will provide a higher quality of service in line with parental aspirations.
- Services will be more child and family-focussed with present administrative systems reformed to be 'fit-for-purpose'.

Future service developments should be monitored and evaluated against these outcomes.

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Appendix One: Memberships of Groups

Project Co-ordinating Group

Arlene Cassidy, PAPA

Heather Crawford, Speech and Language Therapist, Down Lisburn HSS Trust

Roy McConkey, University of Ulster

Elaine McGreevy, Project Domiciliary Therapist, seconded from Down Lisburn HSS Trust

Project Steering Group

Gillian Boyd, Head teacher, Glenveagh School, Belfast

Barbara Crozier, Service Co ordinator, Forward Steps, Barnardos

Kate Doherty, Specialist teacher, South-East Education and Library Board

Judith Liddell, Speech and Language Therapist, South and East Belfast HSS Trust

Sonya Longridge, NI Preschool Playgroups Association

Marion McAroe, Children's Services, South and East Belfast HSS Trust

Mary McDaid, Clinical Psychologist, Down Lisburn Trust

Katherine O'Flaherty, Educational Psychologist, Belfast Education and Library Board

Sally Anne O'Rourke, Speech and Language Therapist, South and East Belfast HSS Trust

Margaret Stanfield, Senior Community Medical Officer, Down Lisburn HSS Trust

Ruth Twyble, Social Worker, South and East Belfast HSS Trust

Reference Group

May Anderson, Project Leader, Barnardos

Maria van den Berg, Medical Practitioner, Camphill Communities, Northern Ireland.

Brian Campbell, Educational Psychologist, Western Education and Library Board

Vivienne Dale, Associate Specialist in Community Paediatrics, Foyle HSS

Gloria Duigan, Consultant Clinical Psychologist, Homefirst HSS Trust (now Craigavon Banbridge HSS Trust)

Mina Hollinger, Senior Community Medical Officer, Newry and Mourne HSS Trust

John Hunter, HMI, Department of Education (Northern Ireland).

Paula Jordan, Southern Education and Library Board

Marjorie Keenan, Director of Learning Disability Programme, Foyle HSS

Irene Knox, Southeastern Education and Library Board

Gillian Montgomery, Speech and Language Therapist, Homefirst HSS Trust

Lorraine Scott, Specialist Teacher, NEELB/SELB

Lesley Scott, Project Leader, Sense