



# **Connecting with Autism**

*Final Report on the Evaluation of the  
Keyhole® Rainbow Resource Kit*

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

*Institute of Nursing Research,  
University of Ulster*

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## Executive Summary

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 identification followed by consistent intervention that involves the parents and provides direct teaching of essential skills with the child.

Latterly increased interest has centred on the use of structured play in home-based interventions. However it is not known the extent to which play activities per se can assist the child with ASD and the family or whether more structured approaches are required either to facilitate the child's spontaneous play or to assist the child's learning when spontaneous play does not happen.

The overall aim of the Connecting with Autism Project is *"to help families minimise the effects of autism and to ensure the educational and social development of children with Autism to their full early years potential"*. The main means for doing was the development and evaluation of a Keyhole® Rainbow Resource Kits<sup>1</sup> that would enable *"parents to support their child through play"*. Families would have the support of a professional worker with experience of ASD in using the Kit.

### Phase 1: Development of Keyhole® Rainbow Resource Kits

In Phase 1, the Kit was devised and assembled. It contained a range of toys, teaching aids and information booklets. These were introduced to families by one of three 'Connecting with Autism' practitioners either employed by, or linked with AutismNI. All had particular expertise in Autistic Spectrum Disorders.

The key-workers visited the family home on at least five occasions. During the first visit, information was gathered on the child and the family. Parents were guided on the choice of activities and how they might introduce them to the child. Subsequent visits were made to check on progress and this also provided opportunities for mothers to have their questions answered about autism, in general, and the impact it had on the family. They were also asked to keep a diary record of their use of activities from the Kit.

On the final visit, information was collected on the mother's reactions. Three months later, a researcher from the University of Ulster visited the family at home to hear at first-hand their reactions to the Project and to repeat some of the information gathered at the outset of the project so that pre- and post-comparisons could be made.

### Participants

All the children who took part in the study were under five years of age; male and with a confirmed diagnosis of ASD. Most, but not all, showed the classic signs of ASD especially with regard to play, language and relating to people.

Most families had recognised the child's problems by two years of age and health visitors were the professionals they were most likely to approach. Nearly all children had been seen by speech and language therapists in the previous 12 months. The majority of children were attending preschools or schools.

This sample may not fully represent the target population for the Project, however the findings do suggest that Health Visitors and Speech & Language Therapists could be key introducers of the Kits to families; including those families awaiting a diagnosis.

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<sup>1</sup> For convenience this will be referred to as **the Kit** throughout the Report.

## Reactions and results

Nearly all mothers found the Kits helpful to their child, to them personally, and to some extent to the wider family. The regular home visits by the project workers were also welcomed.

Families identified ways in which the Kits might be improved as well as on the types of continuing support they would like to have available to them.

Mothers confirmed to the University researchers, the benefits of the Kit to families and children and the key role played by the project workers. Many appeared to be still using some the materials although there were things they no longer used. Most would have liked to have had the Kit when their child was younger. A range of different services were named by families as needed in the future although only small numbers of mothers (no more than 3) named particular services. Most of the children were attending some form of community preschool facility by the end of the project.

Parents reported various ways in which the Kit had helped their child although there were no significant improvements in the children's development as measured by standardised scales. However there was evidence that parents rated themselves as significantly less stressed.

### Phase 2: Dissemination of the Keyhole® Rainbow Resource Kits.

In Phase 2, over 170 professionals attended a two-day training course in the use of the Kit which was double the number in the project proposal. The course also covered the promotion of early intervention to assist the children's development and the family's adaptation. By December 2006, a total of 170 kits had been sold within Northern Ireland at a subsidised rate and as part of the training provided.

The aim initially was for 150 families to directly benefit from the use of the Kit distributed through trained personnel from a range of setting including health visitors, therapists and staff in early years playgroups and nursery schools. However it took much longer than expected for the Kits to be produced and for them to be used with families. It is likely that greater numbers of families will have access to them during 2007 and beyond. Informal feedback suggests that this happening.

The evaluation activities undertaken in this phase focussed on reactions to the training courses and the impact on families of using the kits.

This involved:

- Two focus groups held with 21 participants drawn from two training courses.
- Feedback questionnaires from 46 participants in the training courses.
- An analysis of the purchasers of the Kits.
- Interviews on two occasions with 17 families recruited through professionals who used the Kits with families. This gave mother's initial impressions of the Kits and their use of them with follow-up data some six months after they had been introduced to the Kits. Standardised scales were used at both time points so that changes in children and on parental characteristics such as stress and health, could be monitored.
- Feedback from 11 professional on the Kits and on their use by families. This was initially obtained from self-completion questionnaires supplemented by telephone interviews.

Parents and professionals generally found the Kit to be a valuable resource for information and ideas for promoting the child's development. A number of suggestions were made for improvements. Two main points for further debate were noted. Should the Kits be deliberately targeted at families who have not received a diagnosis of ASD but who may be waiting for an assessment because of parental concerns? Second, do the kits need to be introduced to parents by a professional who is skilled in ASD?

### **Conclusions and recommendations**

From results to hand, the following conclusions and recommendations can be drawn.

- There is a need to support families who have a preschool child with ASD and many parents and professionals feel the Kit contribute greatly to this.
- Many parents would like to have had the materials available to them when their child was younger and they suspected there was a problem.
- There is value in making the Kit available as soon as parents feel a concern about their child without a confirmed diagnosis being made. This may mean some re-labelling of the materials to broaden their suitability.
- A wide range of services and personnel have attended training courses and obtained the Kit. This is likely to continue and mechanisms need to be found for responding to this demand.
- Ongoing promotion of the Kits and training of personnel in its use needs to happen. Autism NI is well placed to do this, possibly on a self-financing basis. They intend to build this into their training plan for the coming year (2007-2008) at a minimum. However it is possible that staff working in ASD services who have been trained by Autism NI and who have used the Kits could fulfil this function for other staff in their locality – notably health visitors; crèche and early years educators.
- The Kit contains a valued range of resources to cover the diversity of children's needs within the autism spectrum. More guidance may be needed in selecting the level of activities that are appropriate to the child; hence the recommendation that families have access to an experienced professional to guide them.
- Professional staff felt that parents needed their support in order to use the Kit most effectively but some parents felt they could have used the Kit without support, although they valued the contribution of professionals in helping them.
- The most consistent evidence of improvement in the children was in terms of their socialisation and relating to other people as assessed by parental reports and ratings on standardised scales. There was less impact on other features of ASD such as language and stereotyped behaviours. This is not surprising given the diffuse nature of the intervention and the variation in the usage of the materials by parents as well the differences in the child's characteristics. This suggests that the Kit need to be used alongside other interventions directed to the individual child's needs.
- The Kit seemed to make a positive contribution in meeting parents' need for information and reassurance of appropriate actions they may take. In particular maternal stress arising from dysfunctional parent-child interactions was significantly reduced. The Kit also appeared to trigger greater involvement of different family members with the child. Further research could usefully assess the wider impact on families.
- Also there may be value in developing a more advanced version of the Kit, for example introducing basic literacy and numeracy skills to children with ASD.

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- Information about the project needs to be published nationally and internationally. A start has been made through a presentation at the World Congress on Autism (Cape Town) October 2006. AutismNI is also part of a European trans-national project on autism. Contacts have also been made with Autism Cymru and the Scottish Society for Autism to extend the project to these countries and with Autism Initiatives in Liverpool. In early 2007, the Kit will be introduced to services in Dublin and New York State.

## Rationale for the Project

In Northern Ireland, increasing numbers of preschool children are being identified as having an Autistic Spectrum Disorder (ASD) (see Appendix 1). A review undertaken for the Department of Education cites estimates of 6 per 1,000 children having ASD but notes widespread variation across Northern in the numbers of preschool children identified (McConkey, Kelly and Cassidy, 2006). A recent study in England reports even higher rates among 9-10 year olds of 11.6 per 1,000 (Baird et al, 2006).

Families often feel helpless as to how best to help their child (Carpenter, 2005). International experience suggests that positive changes are possible with early identification followed by consistent intervention that involves the parents and provides direct teaching of essential skills with the child. According to Jordan (1997), "*Education remains the one treatment approach with the best track record for dealing with the difficulties associated with autism*".

Among the important dimensions to educational provision noted 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 and there is a dearth of help available to families (McConachie and Robinson, 2006). 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.

A review of the literature on early identification and intervention of ASD in preschool children has identified a number of key recommendations which are summarised in Appendix 2. Often these stress the need for intensive, structured interventions provided by ASD specialists. However there are some important indications of what parents value, namely (Christie and Chandler, 2002).

- *Integrating diagnostic and support services:* Providing a diagnostic service is only a first step. Parents value an ongoing support service that will help them to address the specific needs of their child in a practical way.
- *Home support:* Parental preference is for professional assistance to be given in the home. This provides a secure and familiar environment for the child and for the parents as well as being a natural context in which teaching takes place. Weekly visits are preferred.
- *Flexibility of approach:* Parents value having a clearly defined, autism specific approach yet one that is sufficiently adaptable to children's needs and family circumstances over time.
- *Communication:* Difficulties in communicating with the child are often a particular concern to parents. They value practical guidance on how to develop the child's understanding and use of language in communication.

- *Inclusion:* Families are keen for their child to have the same opportunities as their other children, notably in accessing preschool facilities.

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

Latterly increased interest has centred on the use of structured play in home-based interventions (Boucher and Wolfberg, 2003). Play activities can more easily engage the whole family; fathers, siblings and grandparents as well as mothers. They are more ecologically valid in that they can be adjusted to the culture and circumstances of the family. Activities can be chosen to match the child's developmental level and interests and hence increase the child's intrinsic motivation to join in rather than relying on extrinsic reinforcement. They provide a link into the play activities that children will experience in playgroups and preschools. The value of enriched play environments is well attested for children with a range of developmental problems and disadvantaged backgrounds (Yawkey and Pellegrini, 1984).

However it is not known the extent to which play activities per se can assist the child with ASD and the family or whether more structured approaches are required either to facilitate the child's spontaneous play or to assist the child's learning when spontaneous play does not happen.

In USA. Division TEACCH had developed a resource kit of materials that families would find of use in implementing visual communication strategies with their child at home. This concept was adapted and extended by AutismNI: the Northern Ireland Autism Charity to include additional toys and play aids along with information booklets for parents. These materials would be targeted initially at families with preschool children who had recently received or were awaiting a diagnosis of ASD. The aim was to make the Resource Kit available throughout Northern Ireland.

## Connecting with Autism Project

Since 1999, Autism NI had developed a range of initiatives around early intervention under the Keyhole® programme. This included the development of home-based interventions; a training course aimed at personnel in early years education (in conjunction with NI Preschool Playgroups Association) and ACCESS workshops specifically for parents after their child is diagnosed with ASD. The fourth part of the Keyhole® 'jigsaw' would be the development of the resource Kit.

AutismNI obtained funding from a range of agencies; Community Fund (now the Big Lottery Fund); Esmée Fairbairn Foundation and the Tudor Trust. This enabled a full-time Development Officer to be appointed.

The three broad aims of the Project were:

- *"To help families and parents of children with Autistic Spectrum Disorder minimise the potentially devastating effects of autism on their child's development;*
- *To ensure the educational and social development of children with autism to their full preschool potential;*
- *To disseminate learning from the project to health professionals working with children with autism in order to promote further long-term positive change in the care and development of such children".*

The target groups for the project would be drawn from throughout Northern Ireland and included:

- Preschool children (aged up to 5 years) with suspected or confirmed diagnosis of ASD;
- Parents and carers of children with ASD;
- Health care professionals and early childhood educators who work with children with ASD.

The potential areas for development that the Kits would address were:

- Play skills
- Communication skills
- Social skills
- Self-help skills
- Coping with changes in routine
- Everyday family life will be less stressful.
- Parent skills enhanced.

The project was conceived in two stages.

*Phase 1:* This included the development of the Kit and Information Booklets designed specifically to assist preschool children with ASD and their families. This was done using the expertise of parents and professionals. A careful appraisal was undertaken of the rationale for the inclusion of all components using personal experience or evidence from literature on ASD. The initial version was then evaluated intensively with 15 families whose child had a confirmed diagnosis of ASD and who were recruited through existing services in which early intervention programmes were not yet established. Initially the children would not be attending any pre-school facility.

*Phase 2:* In the phase it was proposed that up to 150 Kits would be distributed through existing personnel in health and early childhood education to families throughout Northern Ireland who had a preschool children with suspected or confirmed diagnosis of ASD. Upwards of 80 personnel would be trained in the optimal use of the Kit based on experiences gained in Phase 1. A more detailed evaluation would be undertaken with a further 20 families who had been introduced to the Kit by a local professional.

Over the three years, the Project undertook work and achieved other outcomes that had not been originally foreseen in the funding application.

- The talents of the Project Co-ordinator (Sue MacLeod) as a trainer increased the demand for her services throughout Northern Ireland in organising additional awareness raising courses for parents, siblings and grandparents and contributing to professional training courses in early years and health visiting.
- The production of the Kits could not be done economically by a commercial company and hence was undertaken by project staff. This proved very time-consuming.
- The training courses stimulated personnel in early years facilities – playgroups, preschool and nursery schools – to use the Kit in their work with children and for their own personal development. In addition, staff worked with parents in these settings and not through home visits as had been originally envisaged.

## **Keyhole® Rainbow Resource Kits**

A panel of practitioners was recruited by AutismNI to advise on the contents of the Kits based on their experience. In addition a group of parents gave their perspective and in particular they assembled a Parent-to-Parent guide that was included in the Kit.

Each Kit contained the following items:

### ***Starter kit***

- 1 A Starter for Life booklet
- 1 Top 12 tips on ASD – pin board poster
- 1 Diary booklet
- 1 Parent-to-Parent Booklet
- 1 Structured activity (posting game)
- 1 Structured activity (matching game)
- 1 Distracter\* (Tangle toy and card explaining use)
- 1 Coloured play mat (with card explaining use)
- 1 “All Done” visual card (with card explaining use)
- 1 “First and Then” visual card (with card explaining use)

### ***Booklets***

A set of three ideas booklets with accompanying examples of some play items. The booklets covered:

- Play
- Communication and Socialization
- Sensory Awareness

### ***Play items***

#### **Exploratory Play**

- a small selection of objects to explore e.g. spoon / material / film reel/ plastic bowls / coloured eggs.
- 1 miragescope
- 1 water ball.

#### **Physical Play**

- 3 balls varying sizes and textures
- 6 play stepping : jumping mats
- 2 throw-rings
- 1 bean bag\*.

#### **Messy Play**

- 1 painting bag - 2 paint brushes / 1 sponge for sponge painting / 1 crayon for magic pictures / 1 fork for pattern making.
- 1 tub of play-dough / rolling pin / cutters

- 1 spade and rake for sand play

### **Table top play**

- 1 bag of sorting and matching objects:- coloured lolly-pop sticks / coloured pegs / monkey shapes / camera spool cases / material.
- 1 threading bag: - 2 laces / 2 pipe-cleaners / buttons to thread
- Stacking beakers and cone
- Bricks to build and pull apart
- Jigsaw (6 piece)

### **Imaginary Play**

- A bag of farm animals and farm mat.

### ***Suggested Communication and socialisation items***

**Eye contact:** feathers, balls, squeaky toys, bells, balloons, bubbles.

**Attention:** balloons, nesting boxes, stacking beakers, large coloured beads, jigsaws, posting boxes, crayon/paints, books, puppets.

**Imitation:** cups, spoons, bells, stacking rings, building bricks, mirror, toy animals, toy vehicles.

**Turn-taking:** balls, bean bags, posting boxes, stacking toys, fishing games, puppets, bubbles.

**Listening:** spoons/saucepans, blow toys, bells, selection of musical instruments, toy animals and cars.

**Social Play:** Musical instruments, toy animals and cars, echo mike, puppets.

### ***Structured activity kit (for making improvised play activities and aids).***

Velcro      Glue      Coloured pens

Scissors      Blue tac      Masking tape

8 pages of white paper      A sample of empty food containers

1 DIY structured kit instructions and ideas.

### ***Additional materials***

1 Folder of visuals (large and small) with instructions on how to introduce these to your child.

All the materials were stored in a large plastic box that could double as a play-table. Different sets of materials could be introduced across the visits or according to the child's needs.

An attractive publicity leaflet in full colour was produced to advertise the Kit with contact details. Over 1,000 were distributed through training workshops, conference, information queries and resource packs distributed by AutismNI.

## **Keyhole® Rainbow Back Pack Kit**

Following on from the evaluation a more compact ('Back Pack') version of the Kit has been developed. This contains the essential and most helpful items. Its compactness means the Kits can be produced more economically and they are easier to transport and to store.

The Back Pack Kit contains:

- An information Pack on Autism developed by AutismNI.
- 12 Top Tips for Autism as a pin board card.
- A Starter for Life Booklet; Parent-to-Parent booklet and a set of three ideas booklets covering Play; Communication and Socialization and Sensory Awareness
- Animal Hand Puppet
- I Bean Bag
- I Jigsaw (6 piece).
- 1 Jig tray with shape and animal matching puzzle.
- I Distracter Toy (Tangle toy) and how to use card.
- Instruction card on benefits of visual materials for children with ASD along with:
  - a small selection of keyhole rainbow resource kits, visual symbols: "wait, stand, sit, hands down, quiet cards"
  - folder with cards for no, here, all done, first and then turn taking board (NB These were developed from materials produced by the BOCES (Board of Co-operative Educational Services, New York State) and I contalk by Maureen Ryan and Barbara Bloomfield).
- Coloured Play Mat (with instruction card).
- Recipe Card

## Phase 1: Development of the Kit

A core steering group for the project was appointed by Autism NI (see Appendix 2).

In addition an 'operational group' was identified of parents and practitioners who would take responsibility for creating the contents of the Kits. Members from this group, consulted with various groups of parents who had young children with ASD who had been through assessment, diagnosis and intervention to learn from their experiences. From these consultations, three parents worked on and wrote the Parent-to-Parent booklet that has been published by Autism NI and which is included in the Kit. This gives a myriad of tips and advice from the perspective of parents talking to 'new' parents.

Elements of the Kit were piloted by the operational group with children from the target age range as part of the development process.

### Evaluation of the Kit

An invitation letter to parents, Information Leaflets about the Project and referral forms were distributed to community paediatricians working in three different Health and Social Service Boards throughout Northern Ireland. These were given to families at or shortly after diagnosis by their Paediatrician. Each family then applied directly to the Project giving their contact details. Hence all 16 participating families were self referrals. No details are available of the number of the families to whom information was given but who chose not to participate.

Three persons took on the role of practitioners for the families with respect to the Kits: Sue Macleod (Development Officer for the Project) who worked with 10 families (mostly in NHSSB and SHSSB areas); Florence Trotter, Early Intervention Therapist with an AutismNI sponsored project in WHSSB area who worked with three families and Nova Shaw, Assistant Services Co-ordinator with Barnardo's Forward Steps ASD Service in Belfast who worked with three families. All had extensive experience of working with ASD children in the preschool years and were involved in developing the Kit.

After initial contact with families by telephone, a series of visits were planned to the family home. The content covered in each is summarised below.

1. Introduction to Connecting with Autism Project and keyworker.

Basic information gathered about the child and family; Baseline evaluation measures taken.

2. Family introduced to the Starter Kit and the Diary Booklet.
3. Family introduced to Visuals and DIY Structured Activity Kit.
4. Family introduced to:
  - Play Booklet
  - Communication and Social Booklet
  - Sensory Booklet

A few accompanying play materials were provide for each Booklet.

5. Family's final visit by the Keyworker.

Diary returned to Keyworker.

6. Family visited by an external evaluator from the University.

Contact was mainly with mothers as visits tended to take place in day-time. The child was usually present and this provided opportunities for the key workers to model some of the play activities. Each visit lasted around 90 minutes.

The visits were also spaced unevenly: visits 1 and 2 were one week apart; visits 2 and 3 were two-weeks apart as were visits 3 and 4. One month elapsed then until visit 5 and visit 6 took place three months later. This pattern of visits was designed to give families time to establish their use of the materials provided.

### **Evaluation Strategy**

The aim was to undertake both a formative and summative evaluation of the use of the Kit by families using a mix of both quantitative and qualitative methodologies.

This entailed gathering the following information from mothers at the outset of the Project. This was done by the key-workers on their first and second visits using a combination of structured interviews and self-completion questionnaires by mothers that were posted directly to University staff.

- Information on the child's characteristics, particular problems they encountered with the child and services received.
- Details of the play activities the child currently engaged in with various family members as well as alone.
- Issues or concerns to the mothers on which they would like help.
- An assessment, based on parental reports, of the Child's developmental level (as measured by the Vineland Adaptive Behaviour Scales); the child's Autism characteristics (as measured by the Gillian Autism Rating Scale).
- An assessment, based on parental reports of the mother's health (as measured by the General Health Questionnaire – 28 item version) and well-being (as measured by the Parenting Stress Index: Abidon, 1995).

During the project, information was gathered on the mother's use of the materials in the Kit and their reactions to them. This was done by:

- Key-workers recording parental reports on each visit;
- Mothers keeping a diary record of the activities carried out with the child and the information booklet records and their reactions to them;
- Key-workers using a structured interview with the mothers on the final session to ascertain their views on the Kit.

Approximately three months after the last home visit by the key-workers, a researcher from the University of Ulster visited the family at home. The following information was sought from families using structured interviews; rating scales and self-completed questionnaires:

- Their reactions to the Project;
- Details of the play activities the child currently engaged in with various family members as well as alone.
- The child's developmental level and Autism behaviours (using the same measures as described earlier);
- An assessment of mothers' health and well-being (using the same measures as before but with two additional scales added – Parental satisfaction and Parental Social Activities).

Data was obtained for 13 of the 16 families; two mothers declined to participate in the final part of the evaluation and another was not contactable in the time available despite repeated attempts to contact her.

Full details of the families who participated and the results obtained were given in the Evaluation Report on Phase 1 of the Project (McConkey, Truesdale-Kennedy and Poulton, 2005) and these are summarised in Appendix 3. A case-study follows.

Paul is 3 years old and he received a diagnosis of ASD around nine months ago. His parents were desperate for help as they appreciated how important the early years were in their son's life. A few weeks after diagnosis, Paul and his family were offered the opportunity to have the Rainbow Kit. They jumped at the chance as they had no other services available to them and they were extremely keen to do something 'hands-on' for Paul.

When the project worker began visiting the family she found them very anxious and stressed both in terms of parents and siblings. The parents wanted practical activities and guidance on helping their son. Paul's siblings wanted to be able to play and interact with their brother. The simple activities provided in the Kit provided learning experiences for Paul in a fun way. Some activities the parents thought of for themselves with only a little adaptation needed to suit Paul's needs. They were amazed that they didn't need to go out and buy expensive toys. A search of the cupboards and drawers produced lots of useful items to develop play, communication, socialisation and sensory skills. Paul has developed his own skills in play, interaction and communication.

Paul's parents became really confident in playing and interacting with Paul using structuring of activities and visuals. Insight and advice from other parents in the Parent-to-parent handbook and professionals' advice in booklets such as 'Communication and Socialisation' were also a great support to the parents. Working with him became much less of a challenge than it used to be. His siblings too have become knowledgeable in what they need to need. His parents helped his grandparents and extended family to better understand his needs and support his development. Consequently his parents now feel confident to have family members look after Paul from time-to-time. They say the Kit opened not just a door for them but a FRONT Door!

### **Conclusions from Phase 1**

All the children who took part in the study were under five years of age; male and with a confirmed diagnosis of ASD. Most, but not all, showed the classic signs of ASD especially with regard to play, language and relating to people.

Most families had recognised the child's problems by two years of age and health visitors were the professionals they were most likely to approach. Nearly all children had been seen by speech and language therapists in the previous 12 months. The majority of children were attending preschools or schools.

All the families reported having contact with health visitors and/or Speech and Language Therapists. Hence these two groups could be key introducers of the Kits to families; including those families awaiting a diagnosis.

Nearly all mothers found the Kits helpful to their child, to them personally, and to some extent to the wider family. The regular home visits by the project workers were also welcomed.

Mothers confirmed to the University researchers, the benefits of the Kit to families and children and the key role played by the project workers. Many appeared to be still using some the materials although there were things they no longer used. Most would have liked to have had the Kit when their child was younger. A range of different services were named by families as needed in the future although only small numbers of mothers (no more than 3) named particular services. Most of the children were attending some form of community preschool facility by the end of the project.

Mothers reported that the child had fewer problems relating to play as a result of using the Kit. They noted that the children were participating in a wider range of play activities after the project when playing with their mothers, siblings and on their own but there was little change with fathers.

Before the project, many of the play activities reported could be classed as 'time-filling' activities (visits to park, shopping, engaging in household chores) whereas afterwards, mothers were more likely to mention activities that the Kits had included such as puzzles and imaginary play. It is particularly encouraging to find these included also in the activities the children did when playing alone.

Parents reported various ways in which the Kit had helped their child although there were no significant overall improvements in the children's development as measured by standardised scales. Nonetheless some children were reported to have made marked progress. It may be that more specific interventions would benefit certain children and these could be provided beyond the provision of the Kit as part of the wider Keyhole® Programme.

However there was evidence that parents rated themselves as significantly less stressed.

Families identified ways in which the Kits might be improved as well as forms on continuing support they would like to have.

## Phase 2: Dissemination of the Kits

Four main activities formed the work of Phase 2.

1. Training in ASD and in the use of the Kit for service staff throughout Northern Ireland. In addition awareness raising talks were also given to a variety of audiences.
2. Analysis of the Kits distributed.
3. Feedback from professionals who have used the Kit.
4. Impact on children and mothers from using the Kit.

However these activities had to be preceded by the production of 250 Kits which became a time-consuming task. The Project Co-ordinator assisted by other staff at Autism NI had to resource all the component parts of the Kits, including the hand-making of some materials. The contract for assembling the Kits was awarded to a Workshop for People with Learning Disabilities. The final cost of the materials and assembling was £80 per Kit. However the monies from funders enabled the first 250 Kits to be sold at £40 and no charge was made for the training in their use.

### 1. Training for staff

Information about the training courses was widely circulated to all relevant agencies and personnel on the mailing lists held by Autism NI. With a particular focus on Speech and Language Therapist, OTs, Early years Autism Intervention Therapists, Mencap Playworkers and Health visitors.

Two-day training courses were held in the Belfast area on 14 and 21 October 2005 and again on 13 and 20 January, 2006. Furthermore three courses were held in the Western Board area and all participants attending were provided with a Kit as these had been block purchased by the WHSSB. In all 178 people attended the two day training which is more than double the target number set in the project proposal.

The content of the Training courses was developed by Sue MacLeod and Nova Workman. Day 1 was mainly an introduction to autism and is optional for persons who have already attended awareness training on this topic. Day 2 focuses on the Rainbow Kits; the rationale for them; the content and suggestions for using them with families.

The following Tables give details of the participants in these Training Workshops.

**Table 1: The number of participants in training courses**

<b>Course</b>	<b>Numbers attending</b>
Belfast 14 & 21 Oct	30
Belfast 13 and 20 Jan	60
T& F Hospital. Omagh	22
Foyle	30
Omagh	35
<b>Total</b>	<b>178</b>

The job roles of participants was recorded for those attending in the WHSSB area. These are summarised in Table 2.

**Table 2: Number of people attending training in WHSSB (N=87)**

<b>Professional background/work role</b>	<b>Number</b>
Playgroups/ preschools	19
Family Centres/women's groups	8
Creche/Day centres	5
Sure Start	5
Nursery school (Irish speaking)	2
Travellers support	3
Health visitors	14
School Nurse	3
CPN	4
Speech and Language Therapy	10
OT	4
Behaviour Therapy services	3
Social worker	3
Child Guidance/educational psychology	3
Not given	1

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

In addition shorter presentations about the Kits were given to various groups throughout Northern Ireland such as Autism NI branches, early years professionals, health visitors, school staff (totalling nearly 1,000 persons) as well as conference presentations to over 500 persons.

### **Participants' reactions to the Kit**

Reactions to the training was ascertained in two ways: through focus groups held on the second day of the two training courses in Belfast and attended by 21 participants from a range of areas. The findings were reported to the course tutors so that improvement could be made.

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

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

- Practical examples given
- Better understanding and insight to ASD
- Communication strategies
- Visual communication
- Strategies for working with families
- Ideas for activities
- Group discussions

- Hearing other people's experiences

Few suggestions for improvements were given:

- Interruptions from a course member
- Would have liked to have the Kit to take away (*note: this came for a participant in the first course when insufficient Kits were available*).
- Knew the content on Day 1 from previous courses.

However a few participants expressed concerns about how the Kit might be used by people who had little grounding in ASD and suggested that links need to be made with local professionals who had this expertise. Likewise some participants were cautious about using the Kits with parents whose child did not have a confirmed diagnosis (although some parents felt differently on this issue – see later).

### Reactions to the Kits

The overall reactions to the Kits were very positive. Among the features they mentioned in particular:

- Comprehensive
- Well structured
- The materials supplied in one box
- Simple and easy-to-use
- Parent friendly
- Child friendly
- Lots of ideas for play
- Information Booklets supplied
- Teaches child pre-requisite skills

Only a few people noted some concerns about the materials supplied:

- The bulkiness of the box the materials came in.
- The plastic bags used for some items (*note: warnings were provided*)
- Small parts that could be a choking hazard.
- The unprofessional look of some photocopied items.
- Losing parts from some of the sets.

The aspects they identified that would encourage them to make use of the Kit in their work were as follows:

- Success in using it
- Its relevance to the child(ren) they are working with.
- Flexibility – can be used in many different ways
- Tool for getting to know a family and child
- Simple, practical activities using everyday objects and materials.
- Easy for parents to understand.
- Can be used with children who have suspected ASD.

- Play is broken down into steps and can be adjusted to suit child.
- Parents are keen to help their child but don't know what to do for the best.

## Conclusions

The training courses had been attended by a wide range of personnel in the early years sector as well as health visiting, nurses and support services.

The training courses was very well received and there is potential for these to be repeated on a self-funding basis.

The concept of the Rainbow Kits is valued by participants. In particular they liked the practical activities and learning resources provided which were both child- and parent-friendly.

## 2. Analysis of Kits Distributed

Autism NI commissioned a local centre for people with learning disabilities to assemble the Kits but this meant that the Project Worker had to personally source all the materials and oversee their assembly. This proved to be a time-consuming process but was necessary as negotiations with a commercial publisher failed due to the excessive charges involved.

In all 250 Kits were initially ordered with an estimated unit cost of £80. However a charge of £40 per Kit was levied to recoup some of these costs but this also included the two-day training course provided in the use of the Kit.

At 1<sup>st</sup> December 2006 a total of 170 Kits had been distributed as part of the training provided to service staff. As Table 3 shows a wide variety of personnel and services had received Kits with early years education tending to be to the fore. (NB Some agencies had received more than one Kit).

**Table 3: The number of services of each type receiving one or more Kits.**

Service/personnel	Number
<i>Education</i>	
Preschools/Playgroups	17
Nursery Schools	9
Special Schools	8
Schools (type not given)	3
Sure Start Schemes	3
Education and Library Board	1
<i>Health related</i>	
Health centres (health visitors)	10
Speech and Language Therapy	7
Specialist ASD Services	4
Learning Disability Services	4
Family Centres/Women's Groups	4
Disability team	1
CPN Team	1
Early years team	1

Child Guidance	1
School Nurse	1
Behavioural Therapy	1
Traveller's Support Group	1

This suggests that there is wide market for the Kits and one that has been barely tapped into.

### Follow-up

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

Although it is difficult to interpret non responses to the follow-up questionnaire, it seems likely that many Kits are still waiting to be used. This suggests that the uptake of a new resource may not happen immediately. Ways of stimulating usage may have to be considered. For example: a newsletter sent from AutismNI containing case studies of how the Kit has been used; articles about the Kit appearing in professional magazines or the local media; and informing families about the Kits and encouraging them to ask for them through the local services.

However the delay could also indicate a reluctance among certain professionals to utilise a resource designated for children with ASD unless there is a confirmed diagnosis present. Also a lack of managerial direction in the provision of early support for families could also account for the slow uptake. We will return to these point later.

### Conclusions

In less than one year, a commendable number of Kits have been produced and distributed. However there is scope for many more to be sold in the coming years given the variety of purchasers to date. Admittedly the Kits will have repeat usage within educational facilities or with families but even so, there is likely to be demand from new services and individuals.

AutismNI will have to consider how to meet this demand and whether they should sub-contract this to another supplier.

Strategies to encourage the use of the Kit should also be considered.

### 3. Feedback from Professionals who used the Kit.

Two sources of information are available. First from some of the professionals (N=6 who recruited families to participate in the evaluation (see next section) and from those who had purchased Kits (N=11) and reported using them.

Of the eleven respondents who had been trained and who had made use of the Kits, they had used them in the following ways:

	Number Users	Number children
▪ Home visits to families	2	3 children
▪ With parents in clinic/school setting	5	10 children
▪ As a resource in playgroups/preschool	4	Not given

In addition two participants noted using the Kit as a personal learning resource; one had loaned it to colleagues and one to parents without accompanying visits. In addition one person had used it with a Parent Support Group.

Their comments are summarised according to the questions asked.

#### *What do you think is good about the Rainbow Kit?*

The booklets contained in the Kit were most commonly mentioned followed by the variety of activities contained in them. Partnership working with parents was also noted.

Example comments were:

*Advice booklets are well presented and contain lots of early advice which parents can immediately implement (U4)*

*The variety of tasks which are usable with all abilities (U3)*

*I think its main strength is in the working alongside the parents and learning from them about their child (NU6)*

The booklets on communication and parent-to-parents were mentioned as being particularly helpful.

#### *Have you any suggestions for how the Rainbow Kit could be improved?*

A number of themes were present in responses. One dealt with improving the quality of the resources provided and this has been done. Others noted the need to individualise the materials to the child.

*Kits should be used as part of the child's therapy with careful thought and planning going into what the child is being offered. Kits should not be seen as the answer to all the child's difficulties (U2)*

*Activities are too generalised-need to be more specific to meet individual needs (U5)*

*I would appreciate a book/resource on how to develop ideas further-through different age groups-with behaviour management problems (NU6)*

Having more advanced materials was also suggested.

*Another Kit could be developed to include activities for older children with ASD (NU2)*

*Inclusion of toys and games for higher level children (2).*

Various ideas were given for additional materials.

*Some additions to communication/soc pack e.g. clear lidded box so child can learn to exchange to get favoured item, balloons, nursery rhyme tape etc. What about advice on teaching pointing to request? (U4)*

*Perhaps look at adding some Velcro sheets-laminated ones and shoe box task ideas to help independent play. Matching pictures could be improved also (U6)*

*If perhaps some "structured tasks" could be included along with the activities e.g. messy play-suggestions addressing "what child may have to do" or "what you are trying to encourage the child to do"- how much*

*Booklets refer to ASD and autism a lot. For a child who has not received a formal diagnosis by multi-professional team, this is very difficult (2).*

*Maybe a booklet for fathers / partners (3)*

### **Do parents need a supporter to use the Kit?**

All but two professionals felt that parents required a support person and among the reasons they gave were:

*Too difficult for parents to know what to do with the equipment, especially if the child doesn't respond in the expected way. Kit is only a beginning. Professional needs to bring other elements into programme (U4)*

*The professional is on hand to deal with individual concerns (U5)*

*For confidence building, explaining the various activities, purposes, extending play (U7)*

*Parents need guidance and encouragement to use the resources (U9)*

*I felt that the mother gained more from discussing issues about autism and reading booklets (than the actual activities in the Kit) (1).*

*The Kit is too general to expect families to use without help (6).*

One professional felt the contact with the supporter was the main benefit and another felt that families could use the Kit without a supporter.

### **How do you envisage making use of the Kits in the Future?**

Most respondents felt they would use the Kit as a resource but few mentioned using it in the way that it had been developed in Phase 1, that is through a series of home visits to the family.

*As a resource which I will dip into. The booklets will be given to parents on loan. The packs will be shown to demonstrate ideas (U4)*

*I hope to develop this programme within the school early years and nursery group (U6)*

*I will use activities with small groups/individuals withdrawn from classes. Possibly extend a "loan service" to parents (NU2)*

*We would like to use it with the parents of the nursery children-year one, as a joint approach with the teacher and therapist (NU6)*

*Using it when a diagnosis is suspected in young children, while waiting for diagnoses or therapy (NU3)*

*The decision to use the Kit will be based on ability of parents, the needs of the child and absence of a more intense programme (6).*

### **Any other comments you would like to make?**

*Some excellent ideas and resources. Training day was useful (U9)*

*The Kits were a great concept which could be used as part of the process for families experiencing difficulties. However, this concept has been diluted by the widescale sale of the Kits without much thought to who is using the Kits and what quality assurance can be put in place to ensure they are being delivered correctly (U2)*

## Conclusions

The professionals generally were positive about the Kit. The booklets in particular were favourably received. Useful suggestions were made for improvements.

Some professionals appeared to feel it was necessary to adopt a directive role with parents which may be at odds with the intentions of the developer's of the Kit.

There seemed to be little commitment among the respondents to use the Kit in the future in the way it was envisaged by the developers, namely through one-to-one contact with families over a number of sessions. Rather respondents seemed to intend to use it within their present style of work.

The small number of professionals who gave feedback was disappointing. It is possible that those who were more enthusiastic responded whereas others who found the Kit to be less helpful did not do so. However it is more likely that at the time of the evaluation, only small numbers had started to use the Kit.

## 4. Impact on children and mothers

During the training course, participants were given an Evaluation Folder in which they were encouraged to recruit families who would participate in the evaluation of the Kits. In all 21 families were recruited (one more than our target) but it took much longer than initially hoped – nine months in all. This may have been due to delays in purchasing the Kits and the need for many of the professionals to create special arrangements in order work with parents. Also some of the personnel attending training courses did not realise that this expectation was to be placed on them and could not see their way to using the Kits in the way envisaged; namely through one-to-one contact with families, preferably in home settings.

In all 13 different professionals recruited the 21 families and most worked within specialist ASD provision. Families lived in all four Health and Social Service Board areas with most living outside of the Greater Belfast area.

Details about the family were forwarded on the University and the first visit by a University researcher generally took place while they were being introduced to the Kits or soon after. On this visit, a series of rating scales were completed using parental reports (see earlier).

### Characteristics of Families

Of the 21 families 18 (85.7%) respondents were mothers and 3 (14.3%) families included both mothers and fathers. Eighteen (85.7%) were reported to be two parent families and 3 (14.3%) were one parent families. For most (N=16; 76.2%) the mother was the primary carer, four families (19%) reported that both parents were the main carers and only one family reported that the father was the main carer.

The majority (N=11; 52.4%) of families reported to have two children living at home, compared to five (23.8%) families reporting to have 3 children and four (19%) families reporting to have only one child. One parent reported to have 7 children living at home.

Nineteen (90.5%) families reported to have a wage earner in the household compared to two (9.5%) who did not.

The age of the main carer was mostly between the ages of 30-39 (N=16; 76.2%), with 2 carers over the age of 40 and a further 2 (9.5%) carers under the age of 30. Two carers did not report their age. As with the age of the main carers the spouses were mostly

between the ages of 30-39 (N=12; 57.1%), with 5 (23.8%) spouses over the age of 40 and two spouses (9.5%) under 30.

Most (N=7; 33.3%) main carers were reported to have O'Levels / G.C.S.E.'s compared to 6 (28.6%) main carers who had higher education, 4 (19%) who had A-Levels and 4 (19%) who had left school at 15 years of age. The majority (N=7; 33.3%) of spouses were reported to have O'Levels / G.C.S.E.'s compared to 4 (19%) spouses who had higher education, 4 (19%) who had A-Levels and 3 (14.3%) who had left school at 15 years of age. Data was missing for 3 spouses.

### Characteristics of children

The majority (N=18; 85.7%) of the children were male. Three (14.3%) were female. The children were aged between 2 and 6 years (see Table 4).

**Table 4: The number of children in each age grouping (N=21)**

Age of children (years)	Frequency
2	5 (23.8%)
3	11 (52.4%)
4	4 (19%)
6	1 (4.8%)

The majority of children (N=11; 52.4%) were the youngest child in the family; seven (33.3%) children were reported to be the middle child and 1 (4.8%) the middle child. Two (9.5%) of the children were reported to be the only child.

In all nine of the 21 children (43%) had been given a confirmed diagnosis of ASD (usually by community paediatrician) and 10 others stated they were awaiting professional assessment (48%) but two parents (9%) made no mention of ASD commenting on their child's difficulties in terms of social skills delay/feeding difficulties and pronunciation of speech.

Parents were asked which aspects of their child's problem they found most difficult to deal with. One parent reported having no difficulties but the responses of the other 20 are summarised in Table 5.

**Table 5: The number of parents reporting each problem.(N=20)**

Problem	Number mentions
Child's Communication to parent	9
Child's lack of understanding	4
Behaviour; running around	4
Temper tantrums, emotions	4
Supervision and protection from danger	3
Social interactions	1
Toilet training	1
Feeding issues	1

## Use of the Kit

Although 21 families were enrolled in the project, one later withdrew, one was uncontactable and two had only just started to use the Kit at the time of the second interview. In addition, one mother declined to repeat the standardised measures.

Of the seventeen families who had used the Kits, most were introduced to them through home visits but for three it was at the centre or school that the child attended. Each had an average of six visits (range 4 to 10).

One of the project workers contributed this report.

When informed of the project my thoughts of the Kit were very positive. I received the training and was eager to work with a family. Fortunately in my present job I was aware of and had experience of the strategies and theory-based knowledge regarding the content of the Kit. I felt that the leaflets and booklets were of an excellent standard. However the quality of the contents of the Kit needs to be upgraded.

I met my family with a little apprehension. They appeared very knowledgeable about their child and his needs. I saw them once a week at our Centre.

We followed the structure of the sessions and individualised the Kit as much as possible. Mum was very quick to pick up ideas and enquired about suggestions. She would go away and come back at the next session having tried the ideas we suggested but also trying some of her own ideas. She used some of the visual strategies and reported their success. I went through the books with mum and found them good as they were a delightful refresher for me and good source of information for mum to refer to.

I felt satisfied when mum reported that the Kit and my suggestions had empowered her and she had learnt ways of managing and working with her child but also including the siblings in what she was doing. In my opinion, I feel that my particular mum had made the Kit work and the success is definitely dependent on the parents' ability to work with their child and other professionals.

## Feedback on visits

Mothers reported that the worker had gone through all the activities; demonstrating them with the child and discussing with the mother any difficulties and suggesting ideas for their use. Typical comments from mothers were:

- 3. She explained the Kit and demonstrated how to use the things, then she worked with N and worked through any problems that I was experiencing.*
- 8. Came to our home, brought more toys and talked to N.*
- 14. She went through everything I wrote down in the diary, gave out the new pack and explained what was to be done with it.*

Most parents found the visits helpful.

- 2. It got N settled down to do it and it also got him into a routine.*
- 6. An awful lot because when your child is first diagnosed you are longing for information and this is the best thing that has happened so far.*
- 8. She was able to give more ideas on what we could do with the toys, ideas that we would never have thought of.*

9. *Made us feel at ease and told us that there was no right or wrong way of doing the tasks and to enjoy it.*

16. *Provided me with a wealth of information and has helped the relationship between myself and my son so much.*

19. *She brought him on in every way, speech, minor and gross motor and giving structure for his activities.*

A few parents were less satisfied.

10. *I got more help from the books as she didn't really know N to know what works for him.*

11. *She didn't have contact with N.*

13. *N didn't want to have contact with her. There was too long a period between visits and she didn't get to know him.*

A variety of benefits were mentioned for the child although three families reported none as the person had limited contact with the child:

1. *X has helped with N's waiting and understanding.*

2. *Interacting with another person, this has definitely helped with nursery and meeting people and in helping him settle down.*

3. *It brought her out of herself and helped her to mix with others. I have had great reports from school about her playing with other children.*

4. *It gave us new ideas of how to approach things, this was very beneficial.*

6. *I have been able to put things in place to make my child more settled and work with using the symbols all helped me.*

8. *He has developed a great relationship with X. He would get really excited when I would tell him that she was coming. He would sit at the window waiting for her and give her hugs and kisses before she left.*

9. *N would sit and do the task and not move or wonder until it was completed. He even knows to out the play mat down before starting.*

11. *He has become more sociable*

14. *It helped N a lot, he got to know X and now he is in her class at nursery.*

16. *Helping me to understand N's behaviour more and to know that there definitely is a way forward.*

17. *She helped his speech and concentration*

19. *She brought him on in every way, speech, minor and gross motor and giving structure for his activities.*

20. *I think that it has prepared him for preschool.*

21. *It socialised him more, more receptive to adults and she knew how to talk to him.*

All but one parent mentioned benefits for themselves, with 'support' being commonly mentioned. Example comments were:

4. *We realised that we could have fun with N, that this wasn't just a project.*

6. *Feel more confident and less stressed out, I have the answers now.*

7. *It gave me a liaison and a support.*

8. *She was able to give me advice and help with other problems we were experiencing e.g. toileting and statement*
11. *Knowing that there is someone there for support and giving information about the diagnosis.*
13. *She understood our problems and tried to find solutions for us.*
16. *To be more patient and to try another strategy if one fails, and to keep an open mind about learning.*
19. *X has a child herself with speech and language difficulties so it was great to have someone to talk to and to give ideas and information on allowances also.*
21. *Made us feel that we were not on our own and there was someone there to contact if needed.*

### **Follow-up**

The second visit to the family home by the University researcher was intended to take place three months after the contact had ended with the person who had introduced the Kit to them. However due to the late start with some families, the average gap between the two interviews was five months (range 2 to 9 months). On the second visit information was gathered on their ongoing use of the Kit and their reactions to it as well as again completing the various rating scales.

### **Parental reactions to the Kit**

Given the individual variation among the children and families, a range of responses were given to the questions asked. These are mostly produced verbatim as they demonstrated how families benefited in different ways.

#### ***What for you has been the best part of having the Rainbow Kit?***

1. *New ideas for play etc.*
2. *The person that delivers the programmes.*
3. *Learning things that I am able to do with N that I didn't think that she could do. It made me aware of the things that she could do.*
4. *The information for the parents.*
6. *The ideas on how to work with my child and breaking down the different areas of play.*
7. *It was good to see the things that N couldn't do because it highlighted the area that needed development.*
8. *N enjoyed getting new toys to play with every so often. Some of the toys we already had but because they came in the Kit this made it more interesting for him.*
9. *Having one to one time with N, seeing his coordination and concentration improve.*
10. *It made me more aware of the different things that could stimulate N.*
11. *It gave us structure to work to. It was very well laid out and clear. Knowing now that N doesn't learn the same way. It also gave you lots of ideas.*
13. *The sensory part of the Kit because that it was N's biggest issue is.*
14. *To get N to engage in activities with us.*
16. *Structured activities and seeing your child improve day to day with concentration.*
17. *Having something different for him to do and something that I could do with him.*

19. *The strict routine and structure.*
20. *Being able to make the puzzles myself and seeing my little boy doing them, my little boy saying all done after the work and good boy.*
21. *Given ideas of lots of different things to try with N, different strategies and approaches.*

### **What activities and games has your child enjoyed most?**

Overall jig-saws, Play Dough and painting seemed the most popular. Other mentions were:

1. *He has enjoyed most of them especially the bubbles.*
2. *The puzzle type programmes, the use of first then later, they use this at school now.*
4. *The blocks and knocking them down.*
6. *Messy play, inset boards, fuzzy felt.*
8. *The markers, glue, scissors. N loves to draw and make and do, he can spend hours doing this.*
9. *Story time with the felt, physical play, bubbles and giving and shaking things.*
11. *Mostly the physical play – small world objects and figures.*
13. *The sensory materials, also the wait and stop cards.*
14. *The one with the cars is the one that he enjoyed the most.*
19. *The toys, light up ball he loved playing with.*
20. *The matching pictures with postman pat and the Simpsons, a photo visual puzzle that I made.*

There were few things identified that the children did not like although feathers were mentioned by two mothers. Mothers commented:

13. *Parts of the Kit e.g. colour matching, as it was too simple for him and therefore he lost interest.*
14. *There were a couple of things that were just too advanced for him, not that didn't like it, it was just that it was too advanced for him.*
21. *Once he has done something and understands the challenge then he doesn't want to use it again.*

The booklets were well received by families, especially the parent-to-parent booklet but others included:

3. *The guide to parenting from the parents point of view*
4. *The one on unusual behaviour.*
7. *The booklets based on play ideas, imaginative play.*
11. *All were very good, for N's benefit the sensory booklet because it was not something that we had thought about before. Also the physical play because that is what he loves.*
20. *All of them, I didn't know very much until I got the booklets and read them, they were really great and very helpful.*

Mothers had few suggestions for improvements to the booklets but some did note:

3. *More suggestions about how to use the Kit.*

6. Parents booklet could have been written by parents of older kids e.g. regarding toileting, sleep patterns in respect of having more practical advice / examples. More real life examples e.g. this is how I potty trained my child, it worked or it didn't work.

9. That not all strategies work, distraction techniques, turn taking using chart.

### **Have you any suggestions for how the Rainbow Kit could be improved?**

The most common comments was to have the Kit earlier; to have more frequent sessions; for the materials to be better tailored to the child's needs and to have more detailed information. For example:

4. For her age some things were not suitable, they would have been more suitable for younger children. I wish that N could have had it earlier.

6. Maybe more imaginative play even if not the items just more ideas.

10. It would be better if the Kit was more specific / tailored towards the individual child and their interests. There were some things in the Kit that served no purpose to N.

11. I wish that there was other Kits or other stages to work through.

13. It would have been more beneficial to us if there was a focus on toileting and feeding difficulties.

14. More simpler activities that are tailored for younger children.

16. Links with other parents while using Rainbow Kit to share experiences.

### **Were other family members involved in any of the games or activities?**

In all but two families, other family members got involved in the activities, most commonly fathers and siblings but also grandparents, other relatives and Home Start workers.

6. Dad worked with her, he did play dough and fuzzy felt. The Kit was more familiar and mum didn't have to explain it.

8. Mum, brother and Homestart worker. We helped him draw, thread, stick and answered questions about what he was doing etc.

9. Grannies and Aunties. N showed them how to do the activity first and then let them help / or copy.

11. We started with just mum and dad but then involved his brother and sister. They did the creative activities with him, turn taking and posting activities.

14. Gran and Granddad, sister and dad all did the activities with N.

16. Friends and older and younger children involved, and sister.

### **In what ways, if any do you feel your child has improved through your use of the Rainbow Kit?.**

1. He is putting more toys away when finished.

2. The first and later has definitely helped him with starting school. Also the use the left to right processing.

3. N was never bothered with anyone now from using the Kit she can sit and interact with others at the table.

4. It was good for eye contact because it was very structured.

6. *She would initiate that she wants to play with something when she has the Kit. She is more settled and has better concentration, more interaction form child.*
7. *It made N more aware of things that he hadn't noticed before. It brought things to his attention.*
8. *Because he is drawing a lot more, he can express himself more e.g. saying the boy is happy while drawing a picture of a boy with a big smile.*
9. *His concentration has improved slightly and coordination with kicking and throwing a ball.*
10. *The signs and all done signs have really helped.*
11. *Attention to activities and whole play skills*
13. *The 12 second rule has helped us as a family.*
14. *It has improved his social interaction with people and also his motor skills.*
16. *Concentration, communication and learning to share experiences with others.*
17. *His concentration is much better as is his eye contact.*
19. *His motor skills have improved, N now likes different activities like painting, Playdoh, and things that we didn't think that he liked before.*
20. *He now can sit at the table and stay in one place for a few minutes but he had to be in form for this.*
21. *lots of strategies were put into place first and then, 10 second rule, this gives N reassurance.*

### **Do you feel you know more autism?**

Although three mothers reported that they did not know more about autism, the remainder gave a range of answers.

1. *I now understand the temper tantrums more and the purpose for connecting.*
2. *A lot of the terminology has become a lot clearer, they are terms that you hear from the start but it takes you a long time to work out what they mean.*
3. *How to handle N's behaviour better and how to provide her with structure for going out.*
4. *We never knew anything about the repetitive behaviours and also about keeping the language positive.*
6. *Regarding the 'TEACCH' approach and how to use it. The visuals and making up structured activities in relation to ASD.*
7. *That N needs lots and lots of repetition in order to learn.*
8. *That things that we would see as easy are not so easy for an autistic child.*
9. *That every case has different degrees of problems, N is sensitive to loud noises.*
11. *The way that N learns visually and also the contact details of AutismNI*
14. *We understand his perception of the world better.*
16. *General behaviour, learning why N does what he does – fear of haircuts etc.*
17. *Just the way that he thinks differently and the way that he understand things*
20. *We talked about PAPA and I got in contact with them and I now go to local group meetings twice a month.*
21. *Helped us understand what autism is*

Similarly most parents named at least one new teaching skills or way of managing their child.

1. *To stand back when N has a tantrum.*
2. *Always having something to occupy him.*
3. *Using 2-word commands and the clarity of the words that you use.*
4. *The use of positive language.*
6. *Through this the child is sitting better and I have talked things through with teacher. Consistent working between home and school. Told school of timer idea discussed during CWA.*
7. *Being silly and goofy as this is targeted more at his level.*
8. *We let him take the lead most of the time.*
9. *Distraction techniques when out shopping / eating. We always carried the distraction toys with us. We have to word things properly so not to set off tantrums.*
11. *To slow down our language and to use pictures or objects he understands, also learning through play.*
13. *The 12 second rule has been the biggest thing.*
14. *Avoid stressing him out and also how to distract him*
16. *Using PECS cards when verbal communication fails and a tantrum starts usually works.*
17. *The first and then sign, leaving him alone when he has a temper tantrum and the no sign*
19. *Not to say no, focus on what you want him to do, not what you don't want him to do.*
21. *The 10 second rule and the if and then cards*

Also most parents felt that their attitude had changed to their child; mostly in terms of them being calmer and more patient.

1. *I am understanding what is autism and what is normal behaviour.*
2. *Things are a lot calmer.*
3. *I am more patient and calmer. Also more confident in my parenting.*
4. *We are more practical about parenting.*
6. *Particularly the 10 second rule and I am more patient with her.*
7. *Before I had an autistic child now he is just normal.*
8. *We are not as uptight anymore now we know why he is reacting in certain ways.*
9. *N has calmed down a little and is not as demanding. I enjoyed spending time with him doing the tasks.*
11. *We understand him more*
14. *Before I just thought that he was being bad tempered now I know that it is just frustration.*
16. *I have more patience with N and I try to communicate with him further because I know that he will respond to non verbal stimuli.*
17. *Yes I know him better*
19. *I mollycoddled him before now I let him be more independent.*

20. *I am a little bit more calmer, I know now that this is a problem not that he is a bad child.*

21. *I am more patient with him.*

Nearly all respondents felt that the family as a whole benefited from the project?

1. *I am passing my knowledge on.*

2. *Because things are a lot calmer in the home.*

3. *They know now how to help with her behaviour and how to handle N on outings.*

4. *Especially for my husband he is now more aware / accepting of autism.*

6. *We definitely have, child was very withdrawn and now I can work with her and sibling at the same time e.g. working on puzzles etc.*

7. *Seeing the activities that stimulate N.*

8. *N and his brother played together in some of the activities, they normally don't play together.*

9. *N loved the story time with the felt in which he made stories up and explained what he was doing. He even showed his smaller brother what was happening. Since starting the Kit the boys have started to share and play together more.*

11. *Grandmother is more understanding of him.*

13. *Yes from the booklets and the advice given in them.*

14. *The family interact more with N now and are more aware of problems.*

16. *We have learnt that there is a way forward as a family and that the children can play together happily.*

17. *From understanding him more and learning how to work with him*

19. *The way that we talk to N and the way that we phrase questions.*

20. *My eldest son helped me do the puzzles and we were both looking out for ideas, my husband couldn't believe the work that N was doing.*

21. *The family is more laid back and calmer with N.*

Do you feel you could have used the Kit without having anyone's help?

Only a few parents felt they could have used the Kit by themselves.

8. *Yes however we would not have done different games.*

10. *Yes because the books were excellent*

13. *Some of it because it was self-explanatory.*

14. *We could have but it was a lot better with N's help.*

21. *Probably*

Most appreciated having help and some gave as reasons:

6. *Because it were the things like having the breakdown of play, visual structure and ideas that were important. It was probably more the talking that I found most valuable.*

9. *Without X we wouldn't have bothered doing half of the activities.*

11. *It was better to have someone there to explain it.*

16. *Probably not, I needed the guidance of another person.*

17. *I needed someone to show me first.*

### **Would you recommend the Kit to other families who have children like N?**

All respondents said they would recommend it to other families, even the two mothers who had found it less helpful. Some added a few qualifications.

2. *Yes but at a much earlier stage. The Kit focuses on things that you can do with your child and you definitely need this especially at the start when you feel like you have no control.*
3. *Yes. Because it demonstrates how to work with your child.*
6. *Yes - A lot of things that you would not have or think that your child would be interested in.*
7. *Yes, because it gives them something constructive to do that involves the parent.*
8. *Yes – It is great to be able to give your child some special time on a one-to-one basis.*
9. *Yes because it gives you one to one time with your child and helps the child with skills that he / she doesn't excel in. It is great for concentration, thinking and coordination.*
10. *Yes because anything is worth a try.*
11. *Yes because of what I learnt from it and because there is such a big gap from diagnosis, this was something practical to do.*
13. *Yes if it was tailored to suit the individual child.*
14. *Yes – it helps to get the child interacting with family members and other people.*
16. *Yes – It shows you how you can get results and help communication problems.*
17. *Yes – it is a learning process and you both learn together*
20. *The project was there for me when I had no help and it opened my eyes that there is hope.*

### **What further skills or knowledge do you feel you need to deal with your child's difficulties?**

The most commonly mentioned area was help with behaviour management but a few parents also mentioned the need for speech and language therapy. Example comments were:

1. *Eating and tantrums*
3. *Evening classes about how to deal with behaviour.*
4. *A course on how to manage behaviours.*
8. *How to deal with his temper.*
9. *Techniques to defuse the tantrum or calming down whilst mid tantrum.*
10. *Someone to tell me how to deal with his behaviour in certain situations.*
13. *We need a behavioural nurse but CAMS will not take responsibility for N as he is not diagnosed with a learning disability as he has a normal IQ.*
16. *How to help him deal / me deal with the outbursts and to distract him back to normal behaviour.*
21. *I am seeking advice on challenging behaviour.*
11. *Speech therapy at nursery.*
14. *Attending speech and language therapy through nursery.*

## 19. Speech therapy

### Conclusions

Nearly all parents were very positive about the Kits and the support they had received from the professionals who had introduced the Kit to them. Many reported specific improvements in the child as well as changes in their attitudes and increased knowledge about autism. Greater involvement of the family in interacting with child was also reported. However the area of behaviour management seemed to form the greatest continuing need.

### Changes in the children and parents

Measures that had been taken at the start of the project were repeated on the second visit. These are based on parental reports but normative scales were also used.

#### Perceived problems

Using a list of behaviours commonly found with children who have ASD, parents were asked to rate of this was a problem for their child; or if it had been a problem but was now getting better. This was done before and after the Project. On average, parents reported an average of 4.6 problems (range 1-9) before with a small drop to an average of 3.7 problems (range 0-10) afterwards. However the average number of problems that were getting better rose significantly from 1.8 (0-5) before to 3.4 (0-6) afterwards (Wilcoxon  $z = -2.75$ ;  $p < 0.01$ ).

Table 6 gives the percentages of parents who had rated their child on both these indicators, behaviours before and after the Project.

**Table 6: The number and percentage of children with reported problems before and after**

Behaviour	Problem Before	Problem After	Getting Better Before	Getting Better After
Relating to other people	88%	31%	0%	50%
Problems with language	75%	50%	13%	38%
Problems with play	53%	19%	27%	63%
Unusual interest in toys/objects	50%	50%	19%	31%
Unusual reaction to pleasant situations	44%	38%	6%	6%
Problems with sleep/going to bed	44%	31%	19%	25%
Adaptation to change	38%	44%	19%	38%
Difficulty in imitating	19%	31%	19%	38%

The three most commonly mentioned problems before were relating to people, problems with language and with play. The two behaviours that showed the most change over time were relating to people and problems with play. Around half the children continued to have problems with language and had an unusual interest in toys/objects. All four behaviours are symptoms of ASD.

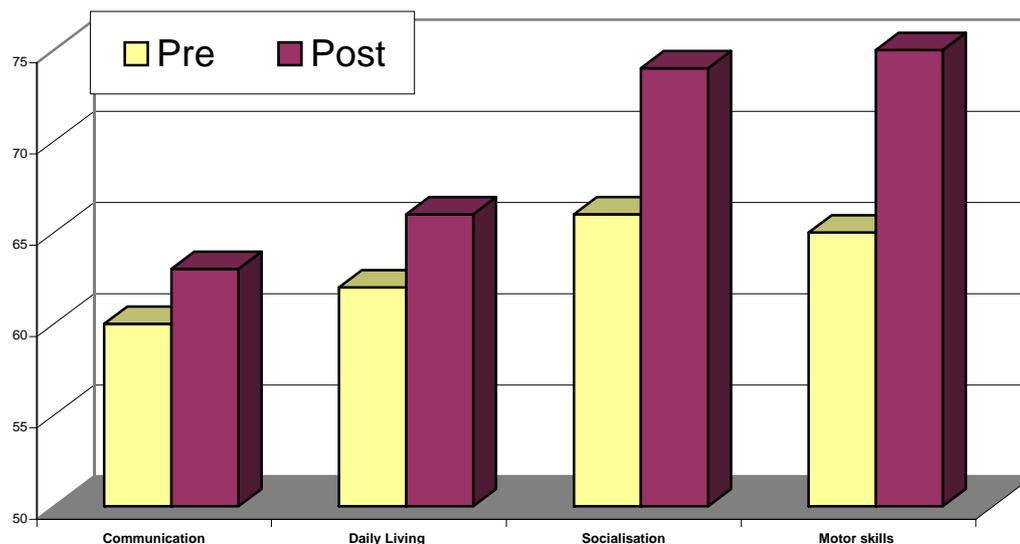
#### Children's Adaptive behaviour scores

The Vineland Adaptive Behaviour Scales were used to assess each child's developmental progress based on mother's ratings. Figure 1 illustrates the mean standard scores for the group of 16 children before and after the intervention.

Although there were increases in all four areas, the increase was only statistically significant in the children's socialisation scores (Wicoxon z score -2.07:  $p < 0.05$ ) although there was a nearly significant increase in motor skills (Wicoxon z score -1.82:  $p < 0.07$ ) and overall Adaptive functioning (Wicoxon z score -1.81:  $p < 0.07$ ). The increased score on socialisation was also apparent in Phase 1 although it was not statistically significant; (see Appendix 3).

On all measures there were large variations in the children's scores which makes it difficult to ascertain an overall effect with small numbers of cases. This also means that certain children showed marked improvements whereas others did not.

**Figure 1: The average standard scores on the four subscales of the Vineland Scale (N=16)**



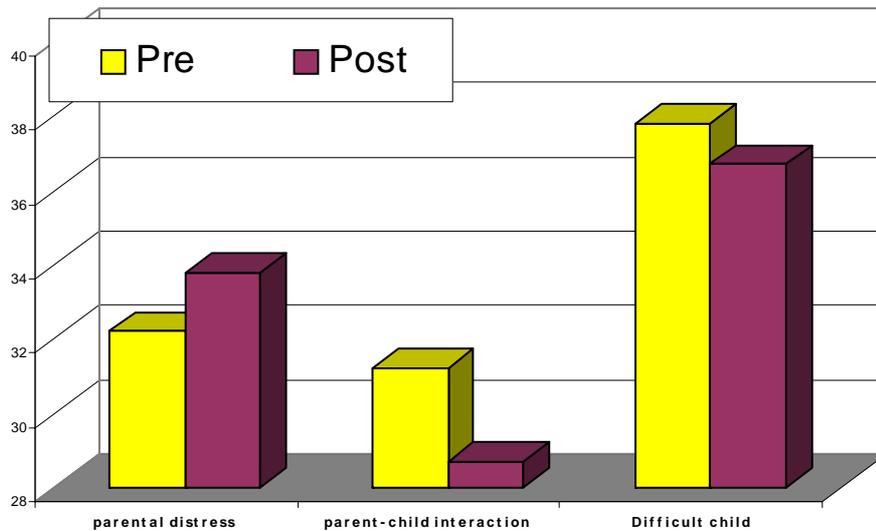
Parents also rated their children on the Gilliam Autism Rating Scales (GARS) which gives an indication of the likelihood that the child has autism; a higher score is more indicative of the ASD. However there were no significant differences in the ratings of autistic behaviours on the GARS scale after the Project. The average autism quotient of the children before was 95 (range 67 – 122) and after was 92 (range 67-137). At both time points, nine of the 16 children had scores that were indicative of autism but the scores of seven suggested milder forms of ASD.

### **Mother's health and well-being.**

Two measures were used to detect possible changes in mothers.

In relation to the mother's health as measured by the General Health Questionnaire (GHQ-28 items), findings indicated that there were no statistically significant differences on the General Health Questionnaire pre and post the Project for the 16 mothers who completed the Questionnaire (mean scores @ 6.00 at both time points). However eight mothers had a lower score afterwards with six mothers (one in particular) having a higher score. Overall at both time points, six mothers scored over the threshold scores which is indicative of poorer mental health and wellbeing.

The second measure looked at the stress associated with having a child who had ASD. Mother's overall scores on the Parenting Stress Index did not change significantly over the two time points but there was a significant reduction in their scores on the parent-child dysfunctional subscale as Figure 2 shows (Wilcoxon z score -1.99:  $p < 0.05$ ). This had been found also in Phase 1 (see Appendix 3). The differences on the other two subscales was not significant.

**Figure 2: The mean scores on three subscales of the Parenting Stress Index**

Information was also collected on mother's positive perceptions of having a child with ASD. The 14 items were taken from past studies in which mothers noted the benefits to them and their family, such as "I get pleasure in providing care for my child" or "*My child gives me a new or increased sense of purpose in life*". The mean number of items that mothers strongly agreed with before the project was 6.7 (range 0-13) and after it was 5.3 (range 0-13). The difference was not significant.

The number of social activities in which mother had participated during the past week or month was also noted (e.g. shopping with friends; going to cinema; visiting others for coffee or meal). Of the 15 items, the mean score before was 1.4 activities (range 0-6) and after was 1.7 (range 0-7). The difference was not significant. This suggests that mother's social lives are very restricted.

## Conclusions

The main change that mothers reported overall in the children was their improved socialisation and relating better to other people, and fewer problems with play. The impact on other features of ASD such as language was less marked. Also mothers were less stressed by the dysfunctional interactions with their child.

There was limited impact on other indicators of mother's stress and overall emotional welling and health. This is not unexpected given the limited time and diffuse nature of the intervention.

However most parents instanced specific ways in which they had personally benefited from the Kit and contact with the person who introduced it to them.

## Conclusions and recommendations

In this section, the main conclusions are summarised from the information gathered in Phases 1 and 2 of the project and a number of recommendations are made for future service developments.

### Conclusions

- There is a need to support families who have a preschool child with ASD and many parents and professionals feel the Kit contributed greatly to this.
- Many parents would like to have had the materials available to them when their child was younger and they suspected there was a problem.
- There is value in making the Kit available as soon as parents feel a concern about their child without a confirmed diagnosis being made. This may mean some re-labelling of the materials to broaden their suitability.
- A wide range of services and personnel have attended training courses and received the Kit. This is likely to continue and mechanisms need to be found for responding to this demand.
- Ongoing promotion of the Kits and training of personnel in its use needs to happen. Autism NI is well placed to do this, possibly on a self-financing basis. They intend to build this into their training plan for the coming year (2007-2008) at a minimum. However it is possible that staff working in ASD services who have been trained by Autism NI and who have used the Kits successfully could fulfil this function for other staff in their locality – notably health visitors; crèche and early years educators. Quality assurance checks may be needed to ensure appropriate advice and guidance continues to be given to parents.
- The Kits contains a valued range of resources to cover the diversity of children's needs within the autism spectrum. However more guidance may be needed in selecting the level of activities that are appropriate to the child; a role that professional staff could play.
- Professional staff felt that parents needed their support in order to use the Kits most effectively and most parents concurred with this. A few parents felt they could have used the Kits without support, although most valued the input from professionals.
- The most consistent evidence of improvement in the children was in terms of their socialisation and relating to other people. There was less impact on other features of ASD such as language and stereotyped behaviours. This is not surprising given the diffuse nature of the intervention and the variation in the usage of the materials by parents as well the differences in the child's characteristics. This suggests that the Kits need to be used alongside other interventions directed to the individual child's needs and these feature on the overall Keyhole® Programme.
- The Kits seemed to make a positive contribution in meeting parents' need for information and reassurance of appropriate actions they may take. In particular maternal stress arising from dysfunctional parent-child interactions was significantly reduced. The Kit also appeared to trigger greater involvement of different family members with the child. Further research could usefully assess the wider impact on families.
- Also there may be value in developing a more advanced version of the Kit, for example introducing basic literacy and numeracy skills to children with ASD.

- Information about the project needs to be published nationally and internationally. A start has been made through a presentation at the World Congress on Autism (Cape Town) October 2006. AutismNI is also part of a European trans-national project on autism. Contacts have also been made with Autism Cymru and the Scottish Society for Autism to extend the project to these countries and with Autism Initiatives in Liverpool. In early 2007, the Kit will be introduced to services in Dublin and New York City. An article about the project will be submitted for publication in an Autism journal.

### **Lessons from the project**

Over the three years we have been involved with this project as evaluators, we must record certain disappointments which are not meant to distract from the Project's achievements but could help guide future developments and evaluations.

The Project's work remained largely an initiative of the voluntary sector (i.e. Autism NI with support from Barnardo's Forward Steps Project, NIPPA and various other voluntary and community groups). The statutory services proved hard to engage in different aspects of the project; from recruiting families; attendance at training workshops and returning evaluation questionnaires.

The Project at times focussed overly on service provision at the expense of development and evaluation; for example time was taken up with the preparation of Kits and the provision of training to large numbers of personnel. A more strategic approach would have targeted key service personnel and tried out different ways of encouraging their participation in the Project.

On reflection insufficient attention and discussion may have been given to evolving a coherent philosophical underpinning for the rationale for the Kits. For example, was the aim to promote play within the family and to empower parents or was it to introduce parents to structured approaches in working with their child on designated tasks? This tension appeared to run throughout the Project and a clearer steer might have been necessary in the training courses on achieving this balance.

More focussed approaches should be adopted to obtaining feedback from the principle informants. The richest data came from family interviews whereas we had poor response to self-completion questionnaires. Telephone interviews and focus groups might overcome this.

### **Recommendations**

In this section we discuss some of the wider issues emerging from the project.

#### **There is a need to support families who have a preschool child with ASD**

In common with past projects of preschool children in Northern Ireland (McConkey et al, 2003, 2004), many parents are aware of their child's difficulties by his/her second birthday and turned mainly to their health visitors for guidance. This usually resulted in a referral to speech & language therapists and community paediatricians and for many there was a long waiting period until their child was assessed and diagnosed.

Nonetheless their child's difficulties had not abated and in particular, the child's play, language and repetitive behaviours were of common concern to parents. Moreover on standardised scales that measure the children's development, marked delays were reported, although there was wide variation across the samples of children. Hence the need for a Project such as this one is well-established by both this and other studies.

## **A family-based approach**

To date, much of the professional response to Autistic Spectrum Disorders has focussed on specialised teaching/training approaches directed by professionals. This project proposed a complementary, if not alternative approach. The basic premise was that families play with children and that these activities could be harnessed to further the child's development. There is clear evidence that families already are playing with the children and they welcomed the provision of suggested play activities and learning activities. Reports from mothers at the start of the project suggested that the children often did not participate in purposeful play activities and they engaged mostly in 'time-filler' activities. However afterwards, a wider range of play activities were reported, particularly in play with mothers and siblings but also when the children were playing alone. This is an encouraging development and may have resulted from increased confidence of mothers (see later).

## **Support for parents**

During the project, the Kits were introduced to mothers in their homes or in preschool centres by project workers most of whom had expertise and experience of ASD. The evaluation suggested that the workers were in themselves a valuable support to mothers because of the information, guidance and emotional support they provided. Only a minority of mothers felt that they could have successfully used the Kit without an introduction from a project worker, citing the good documentation provided. Although families should not be denied access to the Kit on their own, we feel they will benefit more if they have the support of another person in using the resources contained within it. This supporter could come from a range of professionals and perhaps also parents who have successfully used the Kit themselves. However the slow uptake of the Kit by professionals may also be indicative of a lack of commitment of service managers to this form of working. Perhaps future projects should consider entering into a contractual arrangement that places a duty on managers to release staff to provide home-based support to families.

## **Availability of Kits to children without a diagnosis**

For evaluation purposes, all the children in Phase 1 had a confirmed diagnosis of ASD but in Phase 2 only half the children were diagnosed and the remainder were awaiting assessment. These mothers too found the Kit very useful; indeed many still said that they would have liked to have had the Kit when their child was younger. This makes good sense as time spent waiting for a diagnosis can be considered time-wasted.

However the offer to families of a Resource Kit produced by Autism NI may lead them to infer that their child has an ASD when this may not be the case. Hence it needs to be made clear that the activities are designed to help all children who are experiencing some development problems and not just those with ASD. This is indeed true as much early intervention testifies, and the risk of producing any harm through inadvertent use is minimal. Moreover monitoring the child's progress as families make use of the Kit will further inform the making of a diagnosis. Hence we propose that the Kit is not restricted to families who have been given a confirmed diagnosis of ASD.

## **Improving the impact on the children's development**

Although the family's use of the Kit lead to improvements in the child's socialisation and reports of a wider range of play activities, the impact did not extend to other developmental domains affected by ASD, such as language.

In the Keyhole Early Intervention Project (McConkey et al, 2003) and adaptations of it as used in the SHSSB (McConkey and Truesdale, 2004) , there were significant impacts on

this aspect of the children's development. However these schemes involved more home visits and focused more on mothers implementing structured interventions attuned to the child's needs. Either or both of these conditions may be necessary in order to achieve greater changes in the children. In this respect, the provision of the Kit per se was insufficient to attain the aims set out for the project. However the Kit could be an important resource around which other interventions can be built. Hence it is important that personnel involved in early intervention programmes with this client group are made aware of the Kits and how they can be better integrated with the methods they use with the child and family.

Likewise if families are well-established in their use of specific intervention approaches and familiar with ASD, they may feel that the Kit does not have much to offer them, which appeared to be the case for two families in this study.

With these considerations in mind, Autism NI envisage that the Rainbow Kits be one part of a 'Jig Saw' of support to parents in the early childhood years and we commend this approach as an integrated response to family and child needs.

### **Improving the impact on families**

By contrast the project appeared to have produced a significant reduction in mothers' feelings of stress with respect to their interactions with the child; an effect not previously reported in the Keyhole Early Intervention Projects. This is confirmed in comments from the project workers involved with the families and the self-reports of mothers. This likely stems from the information and tangible support given to the mothers through the Kits – the booklets and play equipment – as well as their interactions with the project workers. Indeed the freedom to provide more broad-based support to families may have been possible because there was no emphasis on teaching parents a specific intervention approach.

The important lesson for professionals then is to ensure that they provide time and opportunities to address the needs of mothers and families and not to focus solely on addressing the needs of the child.

However there is some evidence that fathers' play with their child was unaffected by the Kit but then again no measures were taken of their stress and well-being. Our guess is that the impact was likely to have been minimal as fathers tended not to be at home when the project workers visited or they did not attend the centre. Some consideration should be given to ensuring that the project worker introduces the Kit to all the pertinent family members (preferably on the one visit) with an opportunity for them to have their questions and concerns addressed together.

Future research could usefully focus on improved parental health and well-being as outcomes from the provision of the Kit to families as a significant proportion of mothers had elevated scores on measures of stress and poor emotional well-being. Many also appeared to be socially isolated.

### **Maximising the uptake of the Kits throughout Northern Ireland**

The project had estimated that 150 families per year would have access to the Kits over a two-year period. This has proved to be very ambitious largely because the service personnel who were needed to distribute it to families did not undertake this work in the life-time of the project. However it is possible that this target could be reached in the next three years provided:

- Training continues to be provided for personnel interested in using the Kits
- The Kits continue to be marketed at a reasonable cost.

- Accounts of successful usage are widely shared.
- Parents are made aware of the Resource and lobby local services to provide the Kit.
- Key groups are targeted for further information; notably health visitors, community paediatricians, speech and language therapists and playgroup leaders.

However this may require a cultural shift in the mind-sets of professionals towards working in partnerships with parents and focussing less on working solely with the child in either clinic or early years settings. However there is a two-way dynamic here in that the availability of the Kits may help with this transition as well being a condition for its successful use on a wider scale.

### **Further research and development**

Inevitably a project of this kind raises still further questions that deserve further consideration by the funders and Autism NI as well as their service partners. These include:

- What further additions could usefully be made to the Rainbow Resource Kits over the coming years and whose responsibility is this? This is likely to fall to AutismNI.
- What is needed to ensure that every family with a preschool child who has suspected or confirmed ASD has access to the Kit and the support to use it? Whose responsibility is it to ensure this happens? This is more likely to be the responsibility of the statutory authorities. We suspect that health visitors could have a key role to play in this and a preliminary study will be undertaken in 2007 by Professor Brenda Poulton to investigate this option further.
- What are the lessons from the impact that the Kits had on families that could be usefully applied to other interventions with these children, for example the work of speech and language therapists; TEACCH and ABA Programmes? How would this be developed and evaluated? Conference presentations and journal articles will address this in part but the findings need to be incorporated into training in these interventions. Again AutismNI is well placed to do this in its central coordinating role of training within Northern Ireland.
- This evaluation has focussed on the use of the Kits by parents but it is possible that they could be valuable in other settings, such as playgroups and preschools who have children with ASD attending. AutismNI in association with NIPPA (the Northern Ireland Preschool Playgroups Association) might consider undertaking this in the coming years.

In sum, the project has resulted in the development of a valuable resource for parents and professionals alike, the full potential of which will only become realised in the coming years. Autism NI and the funders of the project are to be congratulated for their initiative in making a reality of the idea of a user-friendly resource Kit, designed for parents.

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## Appendix 1: What is autism and what helps?

“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 ameliorable 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 and the sites of the possible relevant genes are starting to be 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 becoming possible to identify those families most at risk of having a child with autism. There is higher likelihood if one child has autism or a member of the wider family circle is affected. Autism is much more common among boys than girls.

### Diagnosing autistic spectrum disorders

Delays in obtaining a diagnosis are a particular source of distress for parents (Quine and Pahl, 1987; Howlin and Moore, 1997). Siegel et al (1988) reported that parents most often expressed their initial concerns to paediatricians, noting delays in language and social behaviour by the age of eighteen months. By age 2.5 years, most parents had sought a diagnostic evaluation but their child was aged 4.5 years on average before they received a diagnosis of Autistic Spectrum Disorder.

In the United Kingdom, children appear to be older before a diagnosis is made. Frith and Soares (1993) found that 76 percent of parents had received a diagnosis by the time

the child was 5 years old. However a more recent study by Howlin and Moore (1997) involving nearly 1300 members of the National Autistic Society, reported that only 53 percent of their children had been diagnosed by this age. Moreover, there were wide regional variations in diagnosis; families in Scotland, Cumbria and Belfast were more likely to receive later diagnosis than their peers in the rest of the United Kingdom.

Christie (1998) in pressing for an earlier diagnosis of these disorders argued that *'to deny parents access to that diagnosis is to deny them a complete under-standing of their child's needs and to restrict their access to information and support'* (p.8). Fraser and Levine (1995) reported that a majority of parents felt relief on confirmation of a diagnosis and they urged professionals to refer parents to appropriate resources.

Nonetheless, the difficulties in arriving at a diagnosis are well documented. Shea and Mesibov (1985) reported that classical cases of autism are greatly outnumbered by cases with mixed, impure and partial characteristics. Happe (1994) noted that it is easier to recognise individuals at the mid-point of the spectrum rather than those at the lower end where the child's level of functioning is so poor that social, communicative and imaginative functioning is in line with general developmental functioning. At the upper end of the spectrum, people may have developed coping strategies that disguise their real problems.

Gillberg (1995) contends that a diagnosis of Asperger's Syndrome should not be made before the child's fifth birthday

Screening and diagnostic tools for use with children under three years are still in the development stage (Votanis et al, 1994). Also reservations have been expressed about the efficacy of primary care services being able to reliably detect such children given the low numbers they are likely to have in their case loads (Peter, 1993).

The value of multidisciplinary working in making a diagnosis is also well attested in the literature, particularly paediatrics, psychology, psychiatry and speech and language therapy (Ellis, 1994). However existing systems often do not allow for this; split as they are between education and health services; with the latter further located in hospital and community settings. Parents often complain of the lack of co-ordination and communication among these agencies and professionals (Stallard and Lenton, 1992; Beresford, 1995).

## **Improving assessment and diagnostic services**

A consultation study in Northern Ireland involving focus groups and questionnaires responses from over 200 carers and professionals (Moore et al, 1999) emphasised the need to invest in appropriately co-ordinated, child focused, inter-professional diagnostic service. More specifically respondents recommended that such services:

- Should be provided locally and integrated as core components of community based paediatric services in each Community HSS Trust.
- They would see children from an early age – generally two years of age,
- They would be enhanced through the provision of responsive pre-school services (with an involvement from educational psychologists) and provide access routes for diagnostic services and follow up support.
- They should aim to foster effective liaison between health and social service agencies, education and schools.
- They should encourage effective liaison between parents and professionals.

Although priority would be given to equipping local services for these tasks, the report did foresee the need to have a specialist autism service that could assess 'difficult to diagnose' individuals; provide a second opinion and give a focus to the acquisition of autism-specific expertise.

### **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.

Recently the National Autism Plan for Children produced by the National Autistic Society (2003) identified key recommendations include a clear timeframe for assessment, a call for urgent training of professionals in knowledge and awareness of autism spectrum disorders, the active involvement of families in care planning and procedures, better multi-disciplinary and multi-agency working, and the setting up of national networks. However these standards are rarely met by existing services (McConachie and Robinson, 2006).

### **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. Recent research suggests that the number of treatment hours does not appear to correlate with outcomes (Gabriels, 2001) and that there has been some over-estimation of the minimum number of hours required per week (Luiselli et al, 2000). Moreover teaching programmes need to adapt to family lifestyles and routines rather than the other way round, if stress in families is to be reduced (Jones, 2000).

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. Latterly increased interest has centred on the use of structured play in home-based interventions (Boucher and Wolfberg, 2003).

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

In recent years a number of significant developments have occurred.

**The formation of Autism NI (formerly known as PAPA):** Formed in 1990, Autism NI is 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. Autism NI 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.

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## Appendix 2: Membership of the Groups

### Steering group

Dr Claire Bailey, Homefirst HSS Trust

Arlene Cassidy, AutismNI

Sue Macleod, AutismNI

Florence Trotter, AutismNI

Nova Shaw (nee Workman), Barnardo's Forward Steps

*In attendance:*

Professor Roy McConkey

Dr Maria Truesdale-Kennedy

Victoria Milligan

Professor Brenda Poulton.

### Operational Group.

Sue Macleod, AutismNI

Florence Trotter, AutismNI

Nova Shaw (nee Workman), Barnardo's Forward Steps

Ann-Marie Cushnion, Parent

Gail Webster, Parent

Ruth Smith, Parent

Kathy Dowis, Occupational Therapist

Anne McCullough, Occupational Therapist

Anne McKee, Speech and Language Therapist

Ciara Sterit, Mencap Play Advisor.

Louise Redding Special Needs Teacher, Tor Banl Schol.

## Appendix 3: Summary of findings from Phase 1.

This Appendix contains information about the measures taken before and after the Rainbow Kits were introduced to families in Phase 1 of the Project. This enables comparisons to be drawn with similar data collected in Phase 2 when the Kits were used by professionals who had not been involved in their design and production.

### Comparisons before and after the project

Measures that had been taken at the start of the project were repeated three months after the last home visit – that is around 7 months later. These are based on parental reports but normative scales were also used.

### Perceived problems

Table A.1 gives the percentages of parents who had rated their child as having problems with different behaviours before and after the Project.

**Table A.1: The number and percentage of children with reported problems before and after**

Behaviour	Problem Before	Problem After
Problems with play	86.7%	23.1%
Unusual interest in toys/objects	78.6%	53.8%
Problems with language	75.0%	53.8%
Relating to other people	66.7%	76.9%
Unusual reaction to pleasant situations	62.5%	30.5%
Adaptation to change	53.3%	30.8%
Problems with sleep/going to bed	40.0%	38.5%
Difficulty in imitating	26.7%	53.8%

The improvements reported by parents were most marked for play and unusual reactions to pleasant situations. Parents also seem to become aware of their child's difficulties in imitation, possibly through the activities used in the Rainbow Kit.

### Play activities

Prior to starting the project, parents were asked to report on the activities that their child enjoyed doing with: mum, dad, with siblings and on their own. This was repeated after the project ended and comparisons can be drawn with mothers' earlier reports. In these tables the different play activities have been grouped into categories but the specific details are given in Appendix 2 for follow-up reports. It should be borne in mind that 16 families contributed to the data at the beginning of the project but 13 afterwards.

### Play with mothers

Type of play activity with mothers	Number mentions Pre	Number mentions Post
Outings – shopping, park, walks	20	3
Physical play	12	13
Social games – cuddling, peek-a-bo, bedtime	7	2
Household chores	6	0
Singing/music	5	0
Art – play dough, painting	4	7

Table-top activities – puzzles	3	9
Books	3	1
TV/video watching	2	2
Messy play – water	2	0
Imaginary play	0	2

### Play with fathers

Type of play activity with fathers	Number mentions Pre	Number mentions Post
Physical play	12	13
Gardening chores; washing car	8	1
Outings – shopping, park, walks	7	1
Social games – cuddling, peek-a-bo, bedtime	5	1
Singing/music	2	0
Art – play dough, painting	2	1
Table-top activities – puzzles	2	3
Books	1	0

### Play with siblings

Type of play activity with siblings	Number mentions Pre	Number mentions Post
Physical play	8	12
Computer, video	3	3
Social games – cuddling, peek-a-bo, bedtime	2	4
Books	2	0
Singing/music	1	0
Outings – shopping, park, walks	1	0
Imaginary play	0	3
Table-top activities – puzzles	0	3

### Playing alone

Play activities when alone	Number mentions Pre	Number mentions Post
Watching TV, computers	12	4
Repetitive playing figures /toys	8	2
Physical play	7	8
Books, photographs	3	2
Messy play	3	1
Singing/music	1	1
Outings – shopping, park, walks	1	0
Table-top activities – puzzles	1	8

Drawing	1	2
Imaginary play	0	2

Overall the most popular activities both pre and post the project were physical activities such as trampolining, jumping, rough and tumble, which is to be expected for preschool boys.

However mother’s reported that the children were participating in a wider range of play activities after the project when playing with their mothers, siblings and on their own but there was little change with fathers.

Before the project, many of the activities noted could be classed as ‘time-filling’ activities (visits to park, shopping, engaging in household chores) whereas afterwards, mothers were more likely to mention activities that the Kits had included such as puzzles and imaginary play. It is particularly encouraging to find these included also in activities the children did when playing alone.

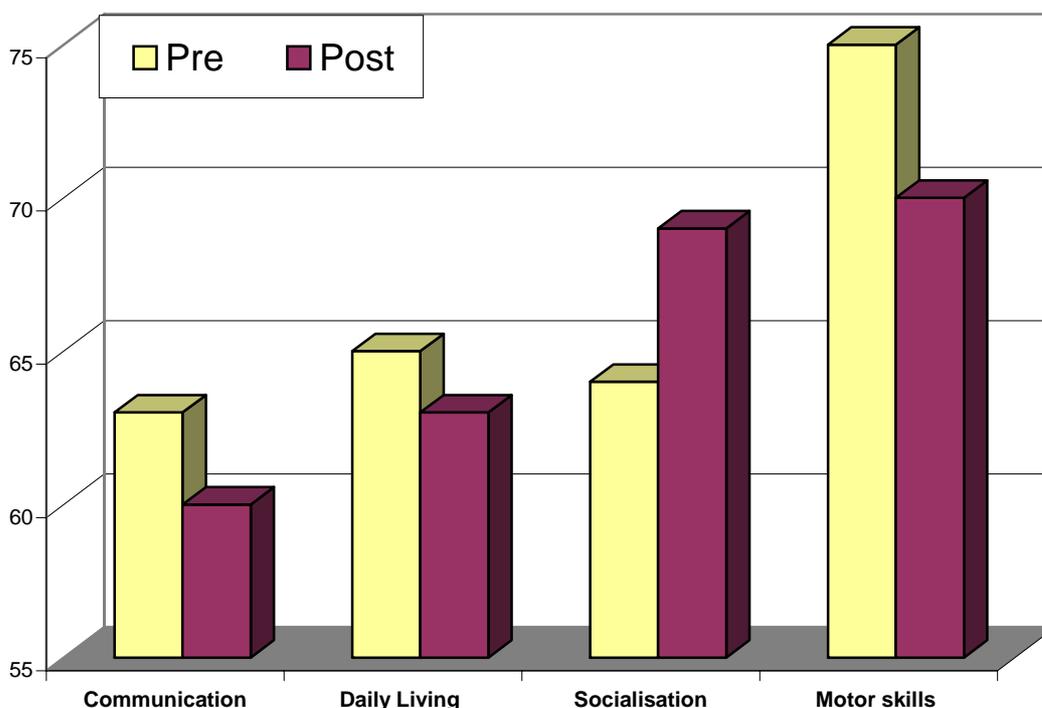
**Children’s Adaptive behaviour scores**

Figure A.1 illustrates the mean standard scores for before and after the intervention.

However none of the differences were statistically significant (However when these scores were added to those of the 16 parents who took part in Phase 2, there was a significant increase in socialisation scores:  $z=0-2.29@P<0.03$ ). On all measures there were large variations in the children’s scores which makes it difficult to ascertain the effect of a diffuse intervention such as the Rainbow Kit.

Likewise there were no significant differences in the ratings of autistic behaviours on the GARS scale.

**Figure A.1: The average standard scores on the four subscales of the Vineland Scale (N=13)**

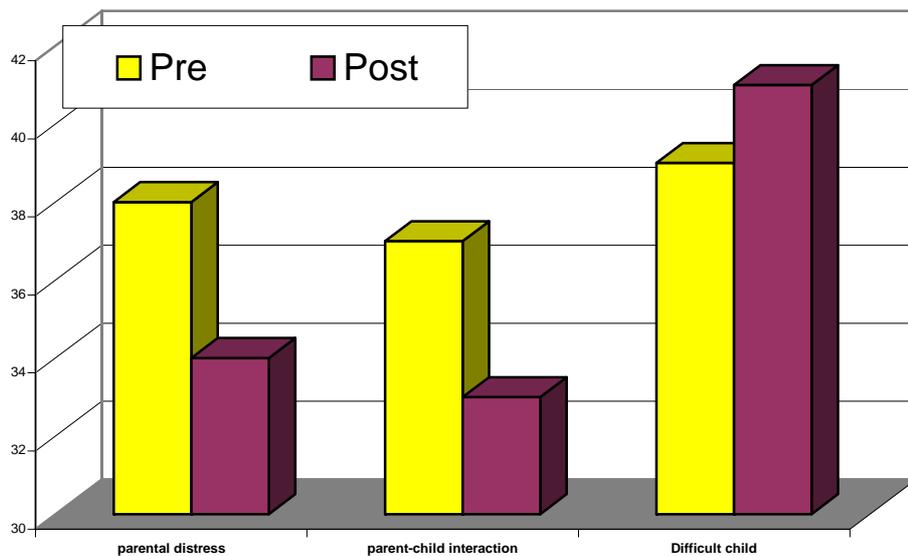


### Mother's health and well-being.

In relation to the mother's health as measured by the General Health Questionnaire (GHQ-28 items), findings indicated that there were no statistically significant differences ( $p>0.05$ ) on each of the four sub-scales of the General Health Questionnaire pre and post the Project for the 11 mothers who completed the Questionnaire. However seven mothers had a lower score post test score with four mothers (one in particular) having a higher score.

However there were significant differences on scores on the Parenting Stress Index as Figure A. 2 shows.

**Figure A.2: The mean scores on three subscales of the Parenting Stress Index**



There was a significant decrease in the parent's perceptions of the child as contributing to a dysfunctional interactions (a finding also found with the Phase 2 sample) however there a significant increase in their ratings of the child as being difficult to manage ( $P<0.01$ ) but this was not found in Phase 2. The decrease in parental feelings of distress was not statistically significant.

Further information was collected solely on the follow-up visits about mother's positive feelings towards their child and the opportunities available to them personally for socialising and relaxing.