



For more information

the full EarlyBird report can be found at the Ministry of Education's website: www.minedu.govt.nz/goto/earlybirdeval or at educationcounts.edcentre.govt.nz/

For more information

about the EarlyBird programme, contact Autism New Zealand: **0800 AUTISM**
www.autismnz.org.nz

For more information

about other government-funded services for children with ASD and their families:

Phone the Special Education Information Line free on: **0800 622 222**
or visit the Ministry of Education's website:
www.minedu.govt.nz – go to the Special Education section.
The Team-Up website has information for parents: www.teamup.co.nz

Visit the Ministry of Health website: www.moh.govt.nz/disability
where you can find information about how to contact your local Needs Assessment and Service Co-ordination (NASC) organisation.



The National Autistic Society EarlyBird programme for parents of children with ASD

Involving parents is an important part of early intervention for children with autism spectrum disorders (ASD). Parent education programmes have been developed as a way of providing parents with knowledge and skills to support their young child's education and development. In New Zealand, the parent education programme EarlyBird was introduced in 2001, to help parents help their child with ASD, during their child's early years. In 2003–04, a team of researchers from the University of Auckland undertook an evaluation to find out how effective the EarlyBird programme is in New Zealand contexts. This booklet summarises their evaluation.

What are autism spectrum disorders?

Autism spectrum disorders (ASD) are neurological disorders in which a person's ability to interact socially, communicate and use imagination is markedly delayed. The development of skills can be very uneven. For example, a person with ASD may be extremely gifted in some academic areas and yet find other areas very difficult. Another person may find social skills and self-management especially challenging.

The term "autism spectrum disorders" is used because there is a range of disorders that share characteristics. This includes both autism and Asperger syndrome. ASD may affect as many as one in 150 people in New Zealand. It affects them throughout their lives, though the severity and day-to-day impact varies from person to person.

Research shows intervening early can improve outcomes for people with ASD. Research also shows parental involvement is an important feature of early intervention because parents are in a good position to reinforce learning and continue stimulating interactions with their children at home.

This has led to the development of programmes such as the National Autistic Society (NAS) EarlyBird parent education programme.

What is EarlyBird?

The EarlyBird programme was designed in the United Kingdom in 1997, and was introduced in New Zealand in 2001, and subsequently adapted for the New Zealand context. The initiative is jointly funded by the Ministry of Education and the Ministry of Health, and is provided through Autism NZ.

EarlyBird is based on the premise that parents who have a sound understanding of ASD can then use this understanding to help develop their child's communication and social interaction skills, and to manage difficult behaviour. Parents learn about ASD, as well as learning skills and strategies to better manage the impact of ASD on their child and the rest of the family.

Parents attend the programme soon after their child is identified as having ASD. The programme consists of eight sessions involving small groups of parents in which they are taught the various skills. During home visits between sessions, EarlyBird trainers make video recordings which are reviewed at the next session so parents can see the progress they are making in developing their skills.

A shorter, more intensive version, known as the 'condensed' version, has also been developed for New Zealand.

Research by
Professor Dennis Moore, Associate Professor Fred Seymour, Dr Angelika Anderson
and Dr Christina Birkin at the University of Auckland

Summary prepared by
Janet Rivers

Prepared for
Ministry of Education

Reports from Auckland UniServices Limited should only be used for the purposes for which they were commissioned. If it is proposed to use a report prepared by Auckland UniServices Limited for a different purpose or in a different context from that intended at the time of commissioning the work, then UniServices should be consulted to verify whether the report is being correctly interpreted. In particular it is requested that, where quoted, conclusions given in UniServices reports should be stated in full.

This summary was commissioned by the Ministry of Education and presents a summary of the final report of the EarlyBird Evaluation in New Zealand commissioned by the Ministries of Education and Health.

August 2005

ISBN 0-478-13348-0

The Effectiveness of

Early Bird

A summary of New Zealand research evaluating an early intervention programme for parents of children with autism spectrum disorders.





Finding out if EarlyBird works

To find out how well the programme works in New Zealand, the Ministry of Education asked researchers from the University of Auckland to evaluate it.¹

The researchers, Dennis Moore, Angelika Anderson, Christina Birkin and Fred Seymour, developed a questionnaire which they used in a national study to measure how parents benefited from taking part in EarlyBird, and whether the benefits lasted after the programme had ended.

They then did some in-depth case studies of a small number of parents and children who had been part of the national study.

The researchers also looked at how accessible the programme was – did everyone who could benefit from the programme know about it, and were they able to get access to it? This part of the evaluation was funded by the Ministry of Health.

All the studies were carried out over a period of 14 months, between January 2003 and March 2004. Approval from the Auckland University Human Participants Ethics Committee was sought before the start of this work. All participants gave their informed consent; all information was treated with confidentiality, and kept in a secure place.

The development of the Autism: Parent Questionnaire (APQ)

The Autism: Parent Questionnaire (APQ) was developed specifically to measure the effects of the EarlyBird programme. The APQ consists of 25 questions that measure changes in parents' knowledge, attitudes and interactions with their child over time, as a result of taking part in an Early Bird programme.

More information is available about how the APQ was tested as a valid measure of EarlyBird's effectiveness, in the full evaluation report.

¹ National Autistic Society (NAS) EarlyBird Programme – Development of Outcome Measures and Evaluation of Outcomes. Ministry of Education: 2005

The national study

The study used the Autism: Parent Questionnaire and other recognised tests for assessing the child and measuring parental stress,² and also demographic and other information from the families. The national study involved 47 families who took part in a total of 10 EarlyBird programmes held between May 2003 and March 2004. Some of these programmes were shorter, more intensive versions ('condensed' versions) of the full programme.

Parents answered the questionnaires three times: at the beginning of the programme, when the programme ended; and again three months later. Of the 47 families, 20 returned a complete set of questionnaires at all three points in time.

Responses to the questionnaires were used to look at whether parents benefited from taking part in an EarlyBird programme, either directly or indirectly, in the following seven areas:

- parental knowledge about ASD
- developing the child's communication and language skills
- developing the child's play skills
- behaviour management
- parental stress levels
- parental confidence in their ability to cope
- family functioning.

In-depth case studies

Eight families who were part of the national study also took part in the in-depth case studies. Four of these families had participated in a full version of the EarlyBird programme and four in a condensed version.

These parents answered the APQ and the CARS-P² at four different times: 10 weeks prior to starting the programme (the baseline data), when the programme started; when the programme finished; and three months after the programme had finished.

They also filled in two other tests at the same four points in time: the Parental Stress Index and the Family Environment Scale, as well as four 10-minute video-taped play sessions with their children.

The uptake study

This part of the evaluation involved looking at whether the programme was accessible to all families who might benefit from it.

It involved identifying and interviewing families who were eligible to take part in an EarlyBird programme, some of whom had taken part and others who had not.

The researchers wanted to find out how interested parents were in participating in EarlyBird, and to identify any barriers which may prevent families, particularly those from ethnic minority groups, from taking part.

² Child Autism Rating Scales – Parent Version (CARS-P) Part A (symptom rating) and Part B (measure of parental stress associated with those symptoms).



The Results: EarlyBird works

The researchers found that the EarlyBird programme does work. The parents who took part developed a greater understanding of ASD, and developed skills that helped them support their child's learning and manage their child's behaviour. What is more, these skills were maintained three months after participating in EarlyBird, when parents completed the APQ for the final time. The results were the same for the full and the condensed versions of the programme.

However, the evaluation also showed that for a number of parents, their stress levels increased during the EarlyBird programme. It is possible that some of the requirements of the programme, such as the need to make child-care arrangements, are stressful for parents. Three months after completing EarlyBird, however, parents' stress reduced and some aspects of family functioning improved to levels that were better than before the parents had participated in EarlyBird. Nevertheless, the levels of parents' stress were still very high.

Most of the families who took part were New Zealand European, which indicates some ethnic groups are under-represented on EarlyBird programmes. This could be because autism is not identified as early or as often in those groups, or that some ethnic groups do not participate in EarlyBird programmes for other reasons. As far as is known, there is no difference in prevalence of ASD between different ethnic groups.

The eight in-depth case studies supported the findings of the national study that families benefited from participating in the programme.

All the parents who had participated in EarlyBird were positive about the programme and said they would recommend it to others.

Barriers to participating in National Autistic Society (NAS) EarlyBird

The uptake study identified some barriers to participating in the EarlyBird programme. These included:

- parents not knowing about the programme
- long wait-times for enough families in an area for a programme to run, which sometimes meant the child was too old for the parents to be eligible to attend
- reservations about extra work and stress at a time when families were already stressed, had heavy workloads, and limited child-care options, making it difficult for some families to attend the sessions
- the difficulty for some families in attending daytime sessions because of work and family commitments
- culture-specific barriers to gaining access to EarlyBird. Maori and Pasifika children have a later age of diagnosis, with many undiagnosed until they start school, while Korean families may not arrive in New Zealand until their child is of school age. There are also language barriers, and some Pasifika families felt that the 'parents as the advocates for the child' philosophy of the programme did not fit with their cultural values.

Conclusion

The results of the evaluation suggest the EarlyBird programme, as it is provided in New Zealand, works for parents of children with ASD, in that it improves their knowledge of ASD and their skills for supporting and managing their child.

However, the evaluation also shows that not everyone who could benefit from the programme was taking part.

One option for overcoming the barriers to participation is making the programme more accessible to people in rural areas – something Autism NZ is already addressing by offering a condensed version of the programme to families in smaller centres, and which does not require the usual six families for the programme to start.

In addition the programme might need to be further adapted to meet the needs of a range of ethnic groups. Providing weekend and evening courses and providing child care would make it easier for some families to attend.

The researchers conclude by saying they support the EarlyBird programme as an effective part of an integrated and seamless range of services and interventions for children with ASD, and their families, from early childhood through to adulthood.