

An evaluation of EarlyBird and EarlyBird Plus over seven years: the benefits of parents and school staff being trained together

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Editorial comment

Evaluating data over a seven year time span or looking at the effects of a programme delivered across several groups of parents and staff is rarely done. More often, authors report on interventions which have occurred within a fairly short time-frame and often with just one or two groups of participants. This paper is a welcome departure as such data strengthens the conclusions that can be drawn from practice. The EarlyBird programmes lend themselves to being evaluated as questionnaires for parents are built into the process. Often data are not collected about interventions because professionals do not have the time to write and develop the tools to do this. Good practice would be to create a set of questions for parents, staff and individuals with autism to provide feedback on what they value or find difficult with the services or interventions they receive – so that modifications can be made. In this paper, such questions led to new ideas on how the material might be altered and which staff might be recruited to the EarlyBird plus programmes. It also showed the real benefits of parents and staff attending training events together.

Introduction

This evaluation focuses on the effectiveness of the EarlyBird and EarlyBird Plus programmes developed by the National Autistic Society (NAS) to support families with a child with autism. From April 2004 to July 2011, the local authority delivered 12 EarlyBird programmes to 66 families and 9 EarlyBird Plus programmes to 54 families and 48 school staff working with children with autism. The length of the training for each of the EarlyBird and EarlyBird Plus programmes was 3 months. Parents' views were gathered using a standard post-programme questionnaire immediately after the training and another questionnaire 6 months later, in accordance with NAS evaluation requirements.

Previous evaluations of EarlyBird programmes have generally relied solely on parent-reported data (Whitaker, 2007; Shield and Simpson, 2004). More recently, Halpin, Pitt and Dodd's (2011) evaluation of EarlyBird in South Staffordshire included a pilot study involving professionals who worked with the families. Their pilot explored the effect of the programme on parents' interactions with other professionals and the parents' ability to benefit from the professional input they were receiving outside of the EarlyBird sessions. The results of this pilot suggested that after attending the programme, parents approached situations from a more informed perspective, were more relaxed, had developed their ability to reflect, observe and analyse their own interactions with their child and understand the reasons for the child's behaviour. They also found that they had developed greater self-awareness and acceptance of their feelings and were better able to work in partnership with professionals. Halpin, Pitt and Dodd (2011) highlighted the need for more extensive research into the effects of the programme on parents' interactions with other professionals, that could give

rise to new outcome measures for EarlyBird and similar interventions.

For this evaluation, the perspective of the trainers delivering EarlyBird and EarlyBird Plus was also sought, through the medium of a focus group. The themes from Halpin, Pitt and Dodd's (2011) research were used to create a series of open-ended questions for the trainers to refer to when analysing the parents' post-intervention questionnaires.

Background to EarlyBird and EarlyBird Plus

Since 1997, the NAS EarlyBird programme has been available to groups of parents and carers of preschool children with autism. The programme aims to support parents in the period between diagnosis and school placement and develop their confidence in working with their child. It combines group training sessions with individual home visits which are designed to help parents understand their child's autism, develop their communication skills and establish good practice at an early age. In 2003, a second programme, called EarlyBird Plus, was launched. This three-month programme is geared towards families whose child is aged between 4 and 8 years who has been identified with autism at a later stage. It combines the training of parents with the training of a school professional involved with the child. Group training sessions and individual home visits are designed to enable teams to problem solve together, to provide the child with a consistent approach between home and school. EarlyBird Plus uses the established framework of teaching about autism before considering how to develop communication and understand behaviour. Two NAS EarlyBird or EarlyBird Plus licensed trainers are required to run each programme.

Support for schools

Since April 2004, the local authority has supported 23 schools and 48 school staff working with a child with autism to do EarlyBird Plus training. Following a funding agreement with another local authority, another family was also included in the most recent EarlyBird programme delivered in April 2011. The children included in this evaluation attended a range of local authority provision including mainstream nurseries/schools, specialist resourced provisions for children with social communication difficulties in mainstream schools and special schools. Some children attend out of borough specialist autism schools.

An audit of placements undertaken in Summer 2011 indicated that the majority of children whose families received EarlyBird or EarlyBird Plus attended local authority provision. For EarlyBird training, 3 children out of the 66 children (5%), attended out of borough specialist schools and 63 out of 66 (95%) attended local authority schools. For EarlyBird Plus training, 5 children out of 54 (9%) attended out of borough specialist schools and 49 out of 54 (91%) attended local provision.

Number of families receiving EarlyBird and EarlyBird Plus

Figure 1 below shows that from 2004 - 2011 there has been a general trend towards an increase in the number of families taking part in either EarlyBird or EarlyBird Plus programmes. It appears that the demands for EarlyBird have fluctuated over the years. From 2007 to 2009, two EarlyBird programmes were run each year and in the past two years there has been one EarlyBird programme a year. Since EarlyBird Plus started in 2006 there has been a general increase in its provision. In 2008, there was a marked increase in the number of families participating in EarlyBird Plus and over the past three years there has been a regular demand for two EarlyBird Plus programmes a year.

Data analysis

From April 2004 to July 2011, twelve EarlyBird programmes were delivered in the authority. Parental post-intervention questionnaires were available for nine of the groups with the data for one, two and five being unavailable. Table 1 below illustrates the pattern of attendance of the families at EarlyBird programmes, where the attendance data was available.

Table 1: The pattern of attendance of the families at EarlyBird programmes

Group	Year	Number of families	Attendance
Group 12	April 2011	6	92%
Group 11	Sept 2010	4	100%
Group 10	January 2010	6	100%
Group 9	September 2009	5	95%
Group 8	January 2009	5	80%
Group 7	September 2008	6	85%
Group 6	January 2008	6	96%

The average attendance of families on the EarlyBird programmes from January 2008 to September 2010 was 93%. From January 2007 to March 2011, nine EarlyBird Plus programmes were delivered. Parental post-intervention questionnaires were available for eight of the groups. Table 2 shows the pattern of attendance of the families and school staff at EarlyBird Plus programmes, where the attendance data was available.

Table 2: The pattern of attendance of the families and school staff for EarlyBird Plus

Group	Year	Number of families (Number of school staff)	Attendance of 1 or 2 family members	Attendance of school staff
Group 9	January 2011	6 (6)	93%	79%
Group 8	April 2010	6 (5)	97%	100% (There were no staff present for one child, so attendance was 83% if this is taken into account)

Group	Year	Number of families (Number of school staff)	Attendance of 1 or 2 family members	Attendance of school staff
Group 6	April 2009	6 (6)	83%	83%
Group 5	January 2009	6 (6)	85%	98%
Group 4	September 2008	5 (5)	97%	96%
Group 3	May 2008	6 (5)	83%	96% (There were no staff present for one child, so attendance was 79% if this is taken into account).
Group 2	January 2008	6 (6)	100%	96%
Group 1	January 2007	6 (6)	90%	94%

The average attendance of family members on the EarlyBird Plus programme from January 2007 to January 2011 was 91%. The average attendance of school staff on the EarlyBird Plus programmes was 93%, if the two occasions when the school did not send a member of staff are not included in the figures. When the absence of two staff members is included in the figures, the average attendance figure was 91%.

Core themes from parents and professionals

Post programme questionnaires were completed by family members and school staff who participated in the EarlyBird and EarlyBird Plus programmes, from April 2004 to July 2011. Although missing data from both the 3-month and 6-month follow-up questionnaires limited the depth of analysis possible, eight core themes emerged. These are described below.

Theme 1: Experiencing a shared understanding of autism

Parents felt that both programmes explained autism clearly and through discussion, they experienced a shared understanding of autism.

"The opportunity to talk to other parents and share experiences and techniques".

(EarlyBird Plus Group 9)

Parents felt able to share their understanding with other close family members, including partners, parents and parents-in-law. They reported on the positive effect this had on the child.

"My family are more understanding and have adjusted their communication too"

(Parent, EarlyBird Group 9)

The importance of understanding autism from the child's perspective was a recurrent theme.

"See into an autistic child's life and give encouragement and support".

(Parent, EarlyBird Group 7)

Theme 2: Moving towards an acceptance of the diagnosis

The combination of an emotionally supportive group and increased understanding of autism appeared to help parents develop an acceptance of their child's needs.

"It is hugely supportive and reassuring to be with other parents who totally understand the lives we face in day-to-day life. It really helped me to accept his diagnosis".

(Parent, EarlyBird Group 11)

In one case it appeared to give the parent permission to approach situations in a way that met the needs of their child.

"It is OK to adapt to the child rather than try to make them conform and that by adapting to the child, it is actually easier to slowly change behaviour one at a time"

(Parent, EarlyBird Group 11)

EarlyBird and EarlyBird Plus appeared to help parents come to a realisation of their child's needs.

"I think it should be more widely promoted. It might help parents who are looking for a 'cure' and don't realise the progress that can be made".

(Parent, EarlyBird Group 4)

There were individual differences in terms of how soon after the diagnosis they wanted to access the programme and how much time they needed to reflect on the diagnosis before they were ready to embrace new ideas. For instance, parents varied in their response to the question of 'When would be the best time for parents to attend the EarlyBird or EarlyBird Plus programme?'

"The best time is straight away even before a diagnosis so that parents have an idea what to expect with their child's behaviour".

(Parent, EarlyBird Group 10).

"When the parents have accepted the problem of their child and are ready to help their child, the programme should be available to them. Each parent is different. Each takes a different time to get them ready for it. They should be informed about the EarlyBird programme".

(Parent, EarlyBird Group 8)

The process of accepting and adjusting to the diagnosis appears similar to the process of coming to terms with a loss. It appears that individual differences and timescales need to be taken into account with each family individually.

Theme 3: Perceiving an increase in emotional well-being and reduced isolation

A consistent theme over the years and across both EarlyBird and EarlyBird Plus was the emotional benefit of parents sharing their understanding of autism and their experiences with others.

"For me the best part of the EarlyBird course has been meeting other parents in the same situation, and also getting support from the people who run the course. I feel I have support and people who understand around me".

(Parent, EarlyBird Group 12)

Parents also perceived that they felt more relaxed. These feelings may be linked to an increased ability to

understand situations from the child's perspective, to predict what might cause behaviour and therefore to feel more in control.

"This has been a fantastic course and it has really helped our family. We are calmer as parents".

(Parent, EarlyBird Plus Group 9)

Theme 4: Perceiving an increase in problem-solving skills (i.e. the ability to reflect, observe and analyse their own interactions with their child and the reasons for the child's behaviour)

All of the parents commented on the shift in the way they processed situations at home and their increased use of reflective problem-solving strategies. For instance, parents referred to problem-solving approaches such as using the STAR analysis (looking at Settings, Triggers, Actions and Results of behaviour) and the 'Iceberg model' to enable them to think through the underlying causes of behaviour needs. Parents likened the problem-solving process to 'being a detective'.

"The iceberg approach was very useful to think about and looking at "STAR" was a good exercise to do. I recognise more that his behaviour has an underlying cause which is not always obvious".

(Parent, EarlyBird Group 7)

The parents all emphasised the value of adapting the language they use with their child, to enhance communication and understanding.

"The system we found to be the most effective was the use of language. By making it simpler, using shorter sentences and emphasizing key words, opened up a new way of understanding for us and our son. This simple tool has been invaluable in improving our son's behaviour and learning".

(Parent, EarlyBird Group 7)

Theme 5: An increase in self-awareness of their feelings and understanding of autism

The parents thought the videos were an important method for increasing their awareness of situations and reactions in a more objective light. This increased self knowledge and helped them to cope in future situations.

"Home videos help me to recognise certain problems and avoid them in the future; when sharing videos it helps you to see things which you wouldn't usually see".

(Parent, EarlyBird Group 4)

One parent reported on the usefulness of the video clips to enable them to identify changes in behaviour and identify progress over time.

"Group sessions and video clips have been helpful from the first video to the last. I can see how he has changed".

(Parent, EarlyBird Group 10)

One parent reported feeling a little overwhelmed by the amount of information. Two parents wanted increased time to discuss video feedback and to have group discussion on the topics. They commented on the need for additional time to digest information.

Theme 6: Perceiving an increase in home and school partnership

All the school staff commented on the importance of participating in the programme and acknowledged their increased awareness of autism and of parents' experiences at home. They felt there was improved communication between home and school as a result of the programmes.

"It helped bring down the barriers between school and parents. It offers a pathway to share problems and find ways together to solve these problems".

(School Staff, EarlyBird Plus Group 8)

"Fantastic as now we know each other and feel we can speak about most things comfortably, also understanding all the problems we have".

(Parent, EarlyBird Plus Group 5)

In cases where the school staff member was proactive in disseminating information to school staff back at the school, the benefits of the programme could be generalised to other situations

"Feedback to the class teacher has inspired things like a home/school book, more prompts and pre-empting situations".

(School Staff, EarlyBird Plus Group 9)

"This has provided a platform for a good and strong relationship between parents and teacher. There have been many opportunities for communicating and sharing ideas. This has benefited (my son) by there now being a very clear and consistent message of expectations from me and the teacher".

(Parent, EarlyBird Plus Group 2)

In two cases where the school did not send a member of staff to work with the parents, the school and home liaison did not occur. Both of these families nevertheless commented positively on the programme and reported gaining from the practical advice and knowledge.

"We loved coming to the course and found the practical advice very helpful and the wealth of knowledge meant that all experiences were understood".

(Parent, EarlyBird Plus Group 8)

The parents and school staff felt it was "vital" for the success of the programme for both parents and a representative from school to be present. It enabled home and school to understand the child's behaviour in different settings and understand the child as a whole.

"Vital! We were very fortunate to have the professionals attending the course, as we have to work together to make a difference".

(Parent, EarlyBird Plus Group 4)

"If I had gone on the course without the parents I wouldn't have had the understanding of him as a whole person.nd it was great way to get to know the parents and therefore make it easy to approach them after school with any concerns we might have – and indeed to share his achievements!"

(School Staff, EarlyBird Plus Group 3)

The importance of selecting a representative from the school, who was able to follow through strategies in the school setting, was very useful in developing consistency across settings. In one case the parent reported on the lack of generalisation in the school setting, which appeared to be related to the school's selection of the staff member who attended, who did not have regular involvement with the child during the school day. Parents were asked the question, 'Was it helpful for parents and professional to attend the NAS EarlyBird Plus programme together?' In two cases the parents reported that for this to be really effective, the staff member should have daily contact with their child in school. One said,

"It was difficult for me as my Teaching Assistant didn't deal with him on a daily basis".

(Parent, EarlyBird Plus Group 8)

The programme provided parents with a greater understanding of their child's progress in school. The need for regular dialogue between home and school was highlighted by another parent.

"It is the only chance to really find out what goes on at school. He (i.e. My child) tells me nothing and I get no feedback other than at parents' evenings".

(Parent, EarlyBird Plus Group 2)

Theme 7: Maintaining the strategies after the programme has ended

All parents reported on their wish to continue their contact with people on the programme and their need for adult support to facilitate this contact with group members after the programme had ended. The 6-month follow-up questionnaire from the EarlyBird groups found that 71% of parents had maintained regular contact with other programme members. A third of the parents reported their wish to maintain contact but had difficulty in doing so, due to time constraints.

"We see each other on a monthly basis and try to support one another".

(Parent, EarlyBird Group 8)

"Unfortunately I have had no other contact with anyone but I feel this is partly due to everyone's life being so busy".

(Parent, EarlyBird Group 10)

Several parents used the EarlyBird book to help them recall processes and strategies after the programme had ended.

"My husband and I refer to the book on a regular basis, especially when my child shows anxiety around something. We look back on the book to remind us on how to analyse what may have prompted his behaviour".

(Parent, EarlyBird Group 10)

Theme 8: Developing the programme

All of the parents commented extremely positively on the programme and stated that they gained in their understanding of autism, their problem-solving skills and experiencing a shared understanding. They commented on the positive support they had received from the programme facilitators.

"We were always encouraged to speak and never rushed and we always got a very helpful response and I felt very supported".

(Parent, EarlyBird Group 4)

Parents provided suggestions regarding ways to further develop the EarlyBird programme. They felt it could be made even more accessible to a wider range of people in the child's family and that a programme for managing transition to secondary school and the teenage years would be welcome.

One parent reported on the need for a more visual and experiential approach to the presentation of information. For instance, she commented on ways of providing parents with practical methods to enable them to understand autism from the child's perspective.

"Employ some practical methods to give better empathy of what an autistic child feels (e.g. more seating places around in coffee break; provide blue biscuits; play a high pitched noise in the background as the talk goes on".

(Parent, EarlyBird Group 10)

One parent commented that EarlyBird was more accessible for people with English as their first language. The importance of addressing the needs of siblings and extended family members and helping them understand autism was raised by several parents. Parents recognised that different family members were at different stages in their acceptance of the diagnosis and thus different stages in the grieving process.

“Do a practical session on explaining autism to another person, (e.g. grandparent in denial or sibling)”.

(Parent, EarlyBird Group 10)

Core themes from trainers

The perspectives of the trainers of the EarlyBird (n = 8) and EarlyBird Plus (n = 6) programmes was gained through a focus group meeting. The fourteen trainers consisted of four Portage workers, a Nursery Nurse, a Higher Level Teaching Assistant, two Special Educational Needs Coordinators, three Speech and Language Therapists, an Advisory Teacher for Speech and Language Therapy and an Educational Psychologist.

Three evaluation questions were presented to the trainers, who divided into two groups to discuss their perspectives on the two programmes. Four core themes emerged from their discussions and are described below.

Theme 1: Developing a shared language and understanding of autism

The trainers said that a valuable outcome of the training was the development of shared language and a shared understanding between the parents and professionals. They commented that this enabled parents to feel empowered to take their learning to situations outside of the programme and to talk with other professionals regarding their child’s needs.

The attendance of the school staff at the EarlyBird Plus group programmes was viewed as key in establishing mutual trust, developing a working partnership between home and school and increasing understanding of the child’s needs in school and home settings. The trainers commented positively on the value of the school’s Special Educational Needs Coordinator attending a programme and in disseminating information to the school staff team, as appropriate.

Both EarlyBird and EarlyBird Plus trainers also commented on the shift in parents’ perspective of the child’s needs, from sometimes a negative perspective towards an understanding of the underlying causes of their child’s behaviour.

Theme 2: The benefits of a multi-agency training team

The training team for the EarlyBird and EarlyBird Plus programmes consisted of professionals from a variety of professional backgrounds. The multi-disciplinary team provided parents with a diversity of perspectives and skills. The trainers highlighted their need to receive supervision, to support them in managing the needs of the group. The educational psychologist on the training team provided supervision for two trainers in managing the dynamics of the group and an individual parent’s needs.

Theme 3: Parents need for a safe and consistent space

The trainers emphasised the need to provide a safe, consistent space to deliver the programme and to arrange a crèche for the parents’ children. They were sensitive to the group dynamics and monitored the needs of different group members. They emphasised the need to monitor the balance between, delivering information and giving parents’ time to talk and share experiences.

The home visits were viewed as important in providing parents with a safe space to discuss issues relevant to their child. Within these environments, parents reported feeling emotionally held and developed confidence in learning from each others experiences.

Theme 4: Developing the delivery and content of the programme

The trainers highlighted their role in facilitating ongoing contact and meetings between parents and encouraging parents to maintain contact after the programme, as appropriate. The practical issues of ensuring consistent involvement from a school representative at the EarlyBird Plus programmes during busy times in the school year, was raised. The suggestion of a school rota was made to facilitate attendance.

With regards to the EarlyBird and EarlyBird Plus programme materials, the language within the materials need some adaptation for parents with English as an Additional Language. The relevance for all parents of explaining the issue of hyperlexia, was questioned by some of the trainers and the need for updating the programme video materials in line with developments in technology was highlighted.

Concluding comments

Parents and school representatives provided positive feedback about the benefits of attending both the EarlyBird and EarlyBird Plus programmes. Every family reported an increase in skills, in understanding of autism and increased problem-solving skills. The parents particularly commented on the emotional benefits of feeling supported within a small group context, experiencing a shared understanding and a feeling of not being alone.

The parental-school partnership theme was strong throughout the EarlyBird Plus programmes. The majority (97%) of families reported the benefits to both families and staff working together to understand their child and to provide consistency across home and school settings. Only in a tiny minority of cases (3%) did this home-school partnership not occur consistently..

To further increase the consistency of support that families receive, an EarlyBird Plus School Protocol may be developed. The protocol may provide schools with guidance on selecting the school representative fo(e.g. someone who is in a position to be consistently involved in the child's school life and willing to communicate and share information with other school staff members). Ideally the school would allocate that person time to disseminate information to staff, to jointly problem-solve with parents and to maintain positive communication channels with parents, as appropriate.

All the families commented positively on the programme trainers, course contents and materials. The families and trainers reported the need to consider additional visual materials and more activities for families whose first language is not English.

The EarlyBird and EarlyBird Plus programmes appear to be a cost effective use of resources, increasing the skills of families and schools, improving the home-school partnership and providing an emotional holding place for parents in the process

of understanding their child's autism. The process of accepting and adapting to a diagnosis appears similar to a grieving process and different family members may experience this process in different ways. Parents' views indicate that families would gain from being well-informed about the programmes, so that they can make an informed choice about when they are ready to attend. Giving parents the opportunity to choose when they are ready to receive the programme allows them to take some control during an emotionally difficult time in their lives.

Reference

Halpin, H, Pitt, S and Dodd, E (2011) EarlyBird in South Staffordshire: reflections on an innovative model of interagency working to deliver an intervention for families of preschool children with autistic spectrum disorder British Journal of Special Education 38 (1), 4-8.