

A diagnostic and intervention package for young children with autism: what are the critical components?

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The booklets for parents, described in the article, can be ordered from this address. Since writing this article Susie Chandler has taken up a post as Research Assistant on the autism prevalence project, Newcomen Centre, Guy's Hospital, St Thomas Street, London SE1 9RT.

Introduction

The Elizabeth Newson Centre (formerly Early Years Diagnostic Centre), administered by Autism East Midlands (formerly The Nottingham Regional Society for Autistic Children and Adults), has recently carried out a three-year research project, funded by a charitable trust, developing and evaluating a diagnostic and intervention package for very young children with autism. The project was initiated by Elizabeth Newson and Phil Christie, who have closely collaborated for a number of years through their work at Nottingham University, Sutherland House School and the Early Years Diagnostic Centre. Wendy Prevezner, who has also had a long association with Sutherland House and the development of interactive approaches, joined the project as a consultant and music specialist. The research team was completed by Susie Chandler, who had previously worked at the centre as part of the diagnostic and assessment team, and was appointed as the research psychologist for this project.

The project followed an action research design by setting up a service that had a clear approach, based on a reasoned set of principles, but with enough flexibility to be responsive to what was learnt from practice. While evaluation of all aspects of work was an integral part of the project, it was not the intention to test a specific method by using a controlled experimental design, but rather to develop a model of good practice for working with very young children (Chandler, 1998). Always at the front of the research team's thinking was how others could use the methods and materials that were being developed as part of what has become known as the Frameworks for Communication approach (Chandler et al., 2002). A critical part of this was keeping in mind the 'real world'; how parents could use the approach at the same time as carrying on with their daily lives, how the intervention could run alongside the existing services being offered to a family and how another agency might adapt the model according to their available resources and inter-agency working arrangements. To this end, part of the evaluation was intended to tease out what the parents involved in the project thought were the critical components of the service.

Background and rationale

The development of the diagnostic and intervention package was based on a number of key principles:

- as awareness and understanding of autism has grown, so has the ability of professionals to make an early diagnosis
- a diagnostic assessment should be linked to intervention; indeed the assessment process should be an integral part of that intervention
- early intervention is effective, especially if it addresses the key impairments of autism
- Working in **partnership with parents** is important in any intervention, crucially so when the child is young

Early diagnosis

The work of Simon Baron-Cohen and others involved with the development of the CHAT has confirmed the reliability of some of the indicator, for autism as early as 18 months (Baron-Cohen et al., 1992). Howlin and Moore (1997) in a survey of over 1200 families suggested that over 93% of parents of children with autism recognised that there were problems before their child's third birthday. Sadly, they also noted that, despite the encouraging reduction in the age at which diagnosis is typically made, the average for children aged 10 at the time of the study, was after the child's fourth birthday.

Linking diagnostic assessment with intervention

Parents so often describe the feeling of 'being in limbo' once a diagnosis is made and before any support or intervention is offered. The final conclusion of the Howlin and Moore survey is the need to accompany diagnosis with direct practical help and support for parents to enable them to develop skills that they can make use of as the child grows up. As part of this, one of the needs most frequently expressed by the parents of young children with autism is for a positive involvement in helping their own child, so that they are not completely reliant on professionals (Christie & Hall, 1992). It is perhaps the failure of pre-school services to do this consistently that has stimulated so much parental interest in intensive home-based programmes such as the Option (Kaufman, 1994) and Lovaas approaches (Lovaas, 1987).

Early intervention to address the deficits of autism

There seems to be a general consensus that early intervention can make a difference, even if there is less agreement on which approaches, or elements of approaches, are the most effective with particular children (Jordan et al., 1998). The view of the research team is that at the heart of autism is an impairment in the pragmatics of language (social empathy, social timing, using language for communication and shared understandings), which ordinarily develops from very early infancy through active participation in pre-verbal dialogue between parent and child. Early intervention needs to be directed at this deficit by trying to find ways in which the child is enabled to participate more easily in these reciprocal exchanges. These understandings have informed the development of interactive approaches, including musical interaction, at Sutherland House school (Christie et al., 1992). There is insufficient space to describe the approach in detail but essentially it stresses the use of physical play, songs and music to engage the child in dialogue with a familiar adult. Pointing is also explicitly taught as a way of enabling communication and shared understanding. The action research project provided an opportunity to develop these principles and methods, and to gauge their effectiveness, when applied to working with younger children in a home setting.

Partnership with parents

The view that parents should be partners in their child's assessment and educational provision, and of seeing them as an invaluable resource and 'experts' on their own child, has long underpinned the working practice of the research team. This view is shared by more recent government legislation and guidance, including the revised Code of Practice (DfES, 2001), which states the following:

'Parents hold key information and have a critical role to play in their children's education. They have unique strengths, knowledge and experience to contribute'

to the shared view of a child's needs and the best way of supporting them. It is therefore essential that all professionals (schools, LEAs and other agencies) actively seek to work with parents and value the contribution they make.'

While there is great variation between different regions and different professionals, our experience from seeing families from throughout the country, is that many parents still feel ill-informed and lacking appropriate support. The key attitudes in relation to working with parents in the project included the following.

- respecting the individuality of each child and family
- being responsive to their needs, beliefs and circumstances
- creating a language of partnership, including the way in which written material, such as the booklets, was presented.

Key features of the package'

Children and families

A total of 10 children were involved in the intervention, from 31 enquiries and referrals in all. It was a requirement that all children were aged 33 months or less, at the time of the initial assessment. The ten children selected ranged in age from 22 months to 2 years 9 months, the average age being 2 years 4 months. The other main requirements were that the family lived within 45 minutes of the diagnostic centre, to make the home visits and consultation sessions manageable. One of the child's main carers also needed to be able to take part in what was essentially a home-based intervention and, while parents were actively encouraged to make use of all available services (eg play groups, speech and language therapy, pre-school teaching service), the family should not be engaged in any conflicting interventions.

Diagnostic assessment

Following an initial home visit to discuss the project and to ascertain whether or not the child met the criteria for age and the nature of his or her difficulties, a play-based diagnostic assessment was arranged. The play-based assessment (Newson, 1995) involved the child and the research psychologist playing together in a large, specially equipped playroom, while observations were made on language and communication, reciprocal play, problem-solving and symbolic (pretend) play. During the play session, the parents observed their child via a large, one-way mirror as they discussed their child's past and present history with the Consultant Psychologist leading the assessment team. Further information was obtained through the use of the Psyche Cattell Infant Intelligence Test and by a pre-verbal communication checklist and Pragmatics Profile (Dewart and Summers, 1988) which were completed during a subsequent home visit. All of this information was used to formulate the diagnosis, explain how this related to the individual child, to obtain a developmental baseline and identify the child's strengths, together with immediate priorities for development. This was encapsulated in a very detailed report, which provided the 'jumping off' point for the intervention.

Intervention components

Weekly home visits

Following on from the diagnostic assessment, the research psychologist visited each family at home on a weekly basis; the visit lasting about two hours. During this time, she would work with the child, alongside the parent, in structured play sessions following the principles of the

interactive approach, discuss strategies and concerns, and plan individual objectives with the parents. These objectives focused on **reciprocal play** (sharing, tum-taking and interaction), **receptive language** (understanding) and **expressive language** (how the child communicates). The parents would then continue this work during the week in a way that was practical and appropriate to their circumstances. Parents also had access to a small specialist toy library based at the diagnostic centre.

Written information

The intervention package included the provision of material specifically written by the research team for parents of this age group under the overall heading of '*Enabling communication in young children with autism*'. Titles include '*Interactive play*', '*Teaching pointing*', '*Understanding language*', '*The beginnings of structure*' and '*Moving towards spoken language*'. Further titles are also being produced in response to parental evaluation.

Consultation sessions

About once every six to eight weeks the family would return to the diagnostic centre for a consultation session, which included the music specialist. This varied in the way that it was used, but provided an opportunity for more intensive musical interaction to extend and progress some of the interactive games developed at home and assist in planning communication objectives.

Parent workshops

All parents were able to participate in a course of 8 once weekly workshops to supplement the information and ideas given in the written material and during the home visits. The first part of the course introduced more structured approaches and behavioural methods, within a negotiative framework. Sessions also gave a more theoretical context to interactive methods and discussed parents feelings and emotions. As well as the information that they received, parents were able to discuss their own child with parents of children of a similar age and gain enormously from the mutual support that this fosters.

Evaluation

Evaluation has been an integral part of the project and, following the principles of action research, has fed into the development of the package. Children's progress was monitored using video records, parental diaries and six-monthly checklists, together with parent interviews. Parent interviews during and after the intervention have also been used to evaluate how effective the various components of the package were. Additionally, interviews were carried out with families in another part of the country, whose children had not received this type of intervention, by way of comparison. The major outcomes of this evaluation have been reported elsewhere, both in terms of the children's progress and the benefits for parents (Chandler et al., 2002). The remainder of this paper concentrates on what the parents felt were the critical components of such a package.

Identifying the critical components

During the course of the project, evaluations were carried out with three groups of parents and professionals: parents from the intervention group; parents from a comparison group; and parents and professionals from an information only group. The following sections provide an overview of the feedback from these three groups with regard to identifying the critical components of a diagnostic and intervention package. The numbers in brackets represent the frequency of response; selected quotes are presented to illustrate these responses.

Intervention group (n=10)

Parents from the intervention group were interviewed at 6 months and 12 months into the intervention programme and 6 months after they had reached the end of their 18 month programme. The interviews were carried out by an independent interviewer.

From interviews at 6 months ...

When asked how helpful they found the weekly home visits, 9/10 said 'very helpful' and one parent, said 'fairly helpful'. When asked what was the best thing about these sessions, parents responded:

- * being given new ideas for working with their child (10)
- * someone coming to the home (8)
- * feedback on the work they were doing (5)

'I learn by seeing ... You also realise more about what you're doing when there's someone else there. You become a bit more conscious and she gives me tips on things, ways to help T or make it easier for him to understand ...And she suggests how we can help him to do more, when we can expect more from him.'

'The fact that it's a 'home visit' ... we have someone to relate to ... it's a structured part of (our child's) week. Its his best environment ... breakthroughs usually happen in the home. The visits are so regular so that (the research psychologist) can get an overview rather than just a snapshot of him ... she helps us by updating the 'things to do' each week.'

When asked how helpful they found the written information (the '*How to ...*' booklets), nine parents said, 'very helpful' and one parent said, 'fairly helpful'. They added that providing practical guidelines in written form allowed them to:

- * share information with others (5)
- * absorb things at their own pace (5)

'They're helpful for giving to other people who work with him ... like grand-parents and nursery because they explain what we are doing and why it's important.'

'With pointing ... it covers all the different stages. You could just read a section that was most relevant to you. It was quite clear.'

'You have them to refer back to ... it's a good reference. They explain things simply ... it makes it easier to explain things back to my husband especially as he's not here when we have the sessions.'

When asked, '*What has been the best thing about the intervention?*' parents comments repeatedly focused on the following two features of the package:

* flexibility of the approach, while maintaining integrity (8)

- approach able to take child's individual needs into account
- is possible to apply principles and strategies within everyday activities as well as focused play sessions.
- clarity of approach; specific to autism

* weekly input (8)

- enables child to practise and develop new skills within a familiar environment
- parents are provided with regular support

'Everything is geared to autism, and also to your specific child, not just special needs in general. We wanted to see someone who knew a lot about autism but who could also get to know (our son).'

'The flexibility and the way you can work it into everyday activities as well as the work sessions. Other approaches ... felt very rigid and untailored to the child.'

'The weekly sessions. It's back-up, knowing someone is there and is going to come and keep you going.'

When asked how other services available could be improved, parents suggested:

*increase the intensity of support services already available (8)

* better co-ordination of the diagnostic process within health and education services (7)

- For support to be home-based rather than centre-based (7)

* advice on 'things to do' (7)

'They need to improve the diagnostic procedure and improve the level of support overall. The biggest problem was getting someone to sit down and define the problem in the first place.'

'We were given lots of information about where he could go (to nursery) ...but nothing about how we could do things to help.'

'More time (from pre-school support) ... and more frequent contact so that he can build relationships. For example the (pre-school) teacher comes once a fortnight in term time but this isn't enough to build a relationship with the child or with the parents. I think what's needed is more help in the home ... rather than having to take your child elsewhere, for example, to see a speech therapist.'

From interviews at 12 months ...

When asked how well they felt the workshops fitted with the work they were doing at home, three parents said, 'fairly well' and seven parents said, 'very well'. When asked what they felt the workshops added to the intervention, parents' responses included:

- * contact with other parents of children with autism the same age (6)
- * more theory (5)
- Broader knowledge of autism (3)

'They provided emotional support ... we realised we weren't alone.'

'They added more theory ... before that the intervention had just been at a practical level.'

'Because the intervention is a sort of week by week thing ... it gave me a broader picture of what autism is.'

Parents were also asked '*If a health or education authority was to provide this diagnostic and intervention with fewer resources, what would be the best thing to leave out?*' The majority of responses to this question suggested reducing the level of input rather than actually leaving something out (eg the consultation sessions, the toy library). One said,

'I suppose they could run the intervention for a year instead of eighteen months.'

When asked what they would add on, if an authority had better resources, most parents suggested increasing the intensity of input and continuing the support for longer than the 18 months. For example:

'More regular music (consultation) sessions and have it continue right up until she goes to school full-time!'

Comparison group (n=7)

Seven families were recruited through the Advisory Teacher Service from a different geographical area. These families all had children aged between 3 ½ and 4½ years with a diagnosis of autism. The children were in their first term of school or nursery having received no previous autism specific intervention (although some had received support from pre-school support services). When asked about what they would have ideally liked, in terms of support following their child's diagnosis, they focused on the need for:

- * information (7)
 - Practical help at home (6)
 - Support in coming to terms with the diagnosis (6)

'We never had anyone to speak to ... it's a lot to come to terms with ... I would have liked a lot more information ... and something for him ... some kind of support to help him.'

'We would have liked a programme detailing the things we could try'

'Well, home visits someone who could come and work with both us. We both wanted to see what techniques we could use for working with him.'

Asked how the health and education services that were available to them could be improved, they emphasised the need for early diagnosis to be closely linked with early intervention. More specifically they expressed a need for:

*health visitors to recognise and pick up the early signs (5)

* someone to visit at home, give practical help and advice, and answer questions (7)

* more information (5)

'Better co-ordination of the final diagnosis ... health visitors should be trained to recognise the early signs, and doctors too. There's no support after the diagnosis. More follow-up after diagnosis. Once you've You could do with something like a social worker to bridge the gap between the community paediatrician and where you stand.'

'More follow-up after diagnosis. Once you've got the diagnosis, you seem to get forgotten. For instance, we had speech therapy before he got his diagnosis but once he'd got a diagnosis they seemed to stop it ... it all dried up, no-one seemed interested.'

'...the one-to-one support at home ... I really would've have liked this at the start. He has a Portage teacher who comes once a week. More information on how to handle him ...'

Information only group (8 parents and 18 professionals)

A total of 28 parents and 86 professionals were identified by the centre's Information Service records as having received the '*How to...*' booklets, and were subsequently sent a questionnaire asking them to evaluate the booklets; the booklets were included on the centre's publications list from which parents and professionals can order a range of information sheets, booklets and papers. Parents and professionals within this group did not receive any other input from the intervention package, but would have bad access to a wide range of local services.

Completed questionnaires were received from 8 sets of parents and 18 professionals. All of those who responded said that they found the booklets 'fairly useful' or 'very useful'. When asked '*As an intervention 'package' for young children with autism, what other forms of input would you like to see added to the series of booklets?*' parents and professionals chose from a list of possible types of input (see Table 1).

Table 1: Other forms of input mentioned by parents and professionals which would be useful following diagnosis

Form of input	Parents (n=8)	Professionals (n=18)
Training video	5	13
Diagnostic assessment	4	9
Series of home visits	4	8
Consultation sessions with developmental psychologist/ speech and language therapist	4	5
Training workshops for professionals	n/a	9
Toy library	3	6
Parent workshops	3	8

When asked to identify their first choice of additional input, parents' responses were as follows:

* home visits (3)

* diagnostic assessment (2)

* consultation sessions (1)

Two parents did not respond to this question.

Professionals' first choices were:

- Training video (4)

* workshops for professionals (3)

* parent workshops (2)

*consultation sessions (1)

* diagnostic assessment (1)

- Home visits (1)

*conference links (1)

Five professionals did not respond to this question When asked what these types of input would add to the practical guidelines provided in the booklets, both parents and professionals emphasised

the need for advice and support to be presented in an interactive way. For example:

'Support and encouragement. Having a child diagnosed with autism is very lonely experience. There are no obvious support networks - in our experience we have had to find out everything ourselves.' (parent)

'A human face, and a feeling of not being alone-' (parent)

'Would help parents to put them (the guidelines) into action.' (professional reflecting on usefulness of home visits)

'Openings for discussion. Awareness raising for all staff' (professional reflecting on workshops and training video)

The critical components

Examination of the feedback from each of the three groups allowed for the identification of four features which were viewed as being critical to the development of support services for families with pre-school children with autism. These were:

1 Integrating diagnostic and support

services

Support needs to follow on from the diagnosis and focus on the defining criteria of that diagnosis. Parents need to be informed of the diagnosis in such a way that the specific impairments of autism are thoroughly understood, thereby allowing the implications for intervention to be made equally clear.

The comparison group and the intervention group expressed a need for the services available in their areas to improve the diagnostic process and, importantly, for this to be linked to follow-up support. They also said that local services could be improved if support was more autism-specific. Parents who had received the written information only, also expressed a need for a package which combined a diagnostic assessment with follow-up home visits. It is also worth noting that parents from the intervention group (who were supported by a package which aimed to integrate diagnosis and intervention in this way) did not express the same difficulties in coming to terms with the diagnosis as those in the comparison and information only groups.

2 Allowing for flexibility whilst maintaining integrity

Having a clear approach which is specific to autism but can allow for flexibility in its uptake will be especially important in the development of home-based programmes.

Parents in the intervention group felt that while the intervention approach was specific to autism and had a clear focus, it was also flexible enough to take into account the child's individual needs and those of the family. They also found it useful to be able to apply the interactive techniques and principles within everyday activities such as mealtimes as well as within the structured play sessions; this meant that families could continue to apply the intervention (albeit at a lower level) at times when other demands were placed on them (eg holidays, illness).

3 Providing support at home on a weekly basis

This would allow the child to practise and develop communication skills within a secure and familiar environment; parents also need to be provided with support and feedback on a regular basis. Parents from the intervention group, the comparison group, and the information-only

group, stressed the need for follow-up support to be home-based, and for it to concentrate on providing parents with practical guidelines for working with their child. They also suggested that local services could be improved by increasing the frequency of home visits provided by pre-school support teams to weekly.

4 Complementing individual work with parent workshops

The research team felt that individual work with families was the priority following diagnosis, although the benefits of parents meeting as a group were also recognised.

Parents from the comparison group and information-only group reported that they had felt particularly lonely and isolated during the time following their child's diagnosis, and that they would have liked to have been put in touch with other parents of children with autism. Parents from the intervention group certainly valued the workshop element of the package: they commented on how meeting other parents through the workshops provided them with emotional support and allowed them to share ideas and experiences with other parents who had a child with autism of a similar age. They added that the workshops provided the theory to the practical work they were doing at home.

Conclusions

There is growing evidence to support the view that the identification and diagnosis of autism is becoming more common and some believe that the incidence of the condition is rising. Evidence presented to the All Party Parliamentary Group on Autism in May 2000 by Fiona Scott, described findings in Cambridgeshire of a prevalence rate of 1 in 175 and a suggestion that 1 in 8 children with special educational needs have an autistic spectrum disorder (NAS, 2000). A report by Loynes (2001) found that 100 LEAs of the 115 who responded to the survey said there had been an increase in the number of children diagnosed with autism or Asperger syndrome in the last five years.

Over recent years local education authorities have developed a range of ways to enhance their provision for school-aged children with autism; by supporting mainstream and special schools, establishing specialist provision and working with voluntary agencies. LEAs are now under increasing pressure to improve their provision for pre-school children and are also concerned with the number of families pressing, through SEN tribunals and other means, for access to intensive home-based intervention programmes such as Lovaas and Option.

The outcomes from the action research project have supported the principles that underpinned its delivery and this is evidenced both by the progress made by the children (Chandler et al., 2002) and the views of their parents. While the numbers in the study are comparatively small, the evidence from all three groups of parents gives some clear pointers to the ways in which they would like to see services develop.

This model of delivery seems to fit well with the legislative priorities of parental partnership, early intervention and inter-agency models of working and does not involve enormous resources in its delivery. Since the completion of the project the Nottingham Regional Society for Autistic Children and Adults (now Autism East Midlands) has been working in collaboration with Nottinghamshire LEA and Community Health Services to set up the Early Communication and Autism Pilot (Christie, 2002). Provision is now being made for children aged three and under, in two areas of the county, based very closely on the approach and principles developed during the project. This pilot is to be externally evaluated and will provide an exciting opportunity to see if the model can be adapted

to work when delivered by a partnership between the voluntary sector and statutory agencies, as well as seeing how the home-based service can be extended on into the child's educational provision.

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