A CONTROLLED TRIAL OF A TRAINING COURSE FOR PARENTS OF CHILDREN WITH SUSPECTED AUTISM SPECTRUM DISORDER

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Objective To evaluate a training course for parents, designed to help them understand autism spectrum disorder and to facilitate social communication with their young child.

Study design Controlled trial for 51 children aged 24 to 48 months, whose parents received either immediate intervention or delayed access to the course. Outcome was measured 7 months after recruitment in parents’ use of facilitative strategies, stress, adaptation to the child; and in children’s vocabulary size, behavior problems, and social communication skills.

Results Taking into account scores at recruitment, child’s level of ability, diagnostic grouping, and the interval between assessments, a significant advantage was found for the intervention group in parents’ observed use of facilitative strategies and in children’s vocabulary size.

Conclusions The training course is well received by parents and has a measurable effect on both parents’ and children’s communication skills. (J Pediatr 2005;147:335-40)

Recent increase in the awareness of autism spectrum disorders (ASD) among the general public, primary care teams, pediatricians, and other health care professionals has led to a rise in the numbers of very young children being referred to community child health and mental health services for assessment, diagnosis, and support.1-3 Epidemiologic studies suggest that the rate of ASD in preschool age children is 6 per 1000.4-6

Much research activity in recent years has been directed toward early identification of the features that are characteristic of autism to inform the development of appropriate early intervention strategies.7,8 Joint attention and imitation ability are positively associated with later development of language and with fewer social communication deficits.9 Problems in joint attention are likely to make pleasurable interaction difficult for parents to sustain, with consequent stress and feelings of failure.10 Therefore intervention strategies are required that aim to improve interaction through alerting parents to ways of facilitating their child’s shared attention to activities. Such intervention strategies potentially have direct benefits for children and indirect benefits through changing parents’ knowledge and confidence.11

There is limited research evidence concerning the effectiveness of early intervention approaches that involve parents. Most researchers have not used randomized group comparison designs because of the practical and ethical difficulties in randomly assigning children and families to treatment groups.12-14

The More Than Words program was recently developed by the Hanen Centre in Canada for families of children with ASD.15 The group training program aims to facilitate parents’ skills in social interaction with their child and to build successful communication through enhancing parents’ ability to observe, to engage the child in structured routines (such as action songs with the child), and to use natural opportunities such as household and child-care tasks for joint attention during the day. Parent involvement as cotherapists for

See editorial, p 283.
their autistic child, with positive outcomes both for communication and behavior, has a considerable history but may also involve potential risk for parents if the child does not improve as anticipated. An understanding of the coping strategies of parents of young disabled children suggests that social support is of high importance, and interventions that involve groups of parents working together have the potential to lead to parents developing continuing support networks. Therefore the independent evaluation of parent group training programs such as More Than Words should incorporate measurement of outcomes that include specific child behaviors such as social communication skills, parent-child interaction strategies, and broader outcomes for parents.

**METHOD**

**Hypothesis**

Parents who attend a More Than Words course will use more facilitative interaction strategies and be less stressed, and their children will have better language and communication skills, and fewer behavior problems, than parents who have not attended this course.

**Design**

The study compared the outcomes for parents of preschool-aged children with suspected ASD who either started on a 3-month More Than Words course shortly after recruitment (immediate intervention) or had to wait for a course because one was not available at the time their child’s difficulties were identified (delayed control). Thus the design makes use of a naturally occurring opportunity for controlled comparison. Outcome measures were taken at recruitment (time 1) and approximately 7 months later (time 2). (Children were followed up on 2 further occasions, but this article reports only the immediate outcomes.)

**Participants**

Fifty-one preschool-aged children and their parents were included in the study. Courses offer 2 places for parents, or 1 parent and another care giver; however, for the research the main care giver was chosen as the parent to be filmed interacting with their child (49 mothers, 2 fathers). Inclusion criteria: serious organic medical disorder; about to start an intensive home program.

Over a 2-year period (1999 to 2001), course leaders in 6 local authorities of the North East of England approached 108 families whose child met the first inclusion criterion and agreed to attend a More Than Words course. A firm diagnosis of autism was not required, thus allowing the intervention to be offered as soon as the child’s difficulties were identified. Exclusion criteria: serious organic medical disorder; about to start an intensive home program.

From the 88 families recruited, 5 children did not have assessments at Time 2 (2 moved away, 1 started an intensive intervention, 2 withdrew consent).

**Intervention**

The format of the More Than Words course is weekly sessions (total 20 hours) of group instruction and practice of facilitative strategies, with the aim of increasing fun interactions between parent and child. In addition there are 3 home visits for individual discussion and feedback. The course brings together approximately 8 sets of parents/care givers of preschool-age children who are likely to be experiencing similar difficulties and who train together as a group. This provides an opportunity for mutual support and sharing of information. The course content aims to teach parents to structure the child’s environment to motivate them to communicate, to create structured routines with opportunities for their child to initiate or respond, and to use visual cues to aid the child’s comprehension (Table I; available online at www.jpeds.com).

Courses developed by the Hanen Centre for parents of children with communication difficulties (such as “It Takes Two to Talk”), with adaptations for children with ASD, have been running in North East England since 1995. Before the start of the project, the course leaders attended an additional “More Than Words” training course with a Hanen Centre trainer. Throughout the study the course leaders continued to meet at 4-month intervals to ensure that a common protocol for delivery of the courses was maintained. Courses were offered in each authority at 6- to 9-month intervals.

**Child Descriptive Measures (At Time 1)**

**ABILITY.** The Vineland Adaptive Behavior Scales is a parent interview about the child’s abilities in socialization, communication, daily living skills, and motor skills. The adaptive behavior composite is a standard score with mean of 100 (sd 15).

**DIAGNOSTIC GROUP.** A detailed interview with parents, the Autism Diagnostic Interview (ADI-R), was undertaken at recruitment. The Autism Diagnostic Observation Schedule (ADOS) was administered to the child. This is a semi-structured play-based assessment undertaken by a trained examiner, who presents the child with a series of materials and play activities, using a variety of social presses, and makes ratings of the child’s communication, social interaction, imagination, and repetitive behaviors. Algorithm scores were calculated for the ADI-R and ADOS and compared with published cut-offs for Autism (and ASD, ADOS only). A “best-estimate” clinical diagnosis was then agreed on by the senior authors (HM, ALC), blind to study group allocation, drawing on all available clinical and research information including all time 1 research assessments. Several of the
Child Outcome Measures (At Time 1 and 2)

VOCABULARY. The MacArthur Communicative Development Inventory (MCDI) is a checklist of words and phrases, marked by the parent to indicate which the child understands and produces. The total speech production score was used.

SOCIAL COMMUNICATION SKILLS. The ADOS was developed primarily as a diagnostic tool for ASD. However, it has been used recently as a measure of change with intervention. The standardized diagnostic algorithm score for reciprocal social interaction and communication was used in analysis, with lower scores representing better skills. Interrater reliability for total ADOS item ratings was maintained for the duration of the study at more than 75% agreement.

BEHAVIOR PROBLEMS. The Behavior Screening Questionnaire (BSQ) is a parent interview about 12 areas of behavioral difficulties in preschool-age children, such as sleep, activity level, and compliance. The score range is from 0 to 24.

Parent Outcome Measures (At Time 1 and 2)

PARENT'S USE OF FACILITATIVE STRATEGIES. The Joy and Fun Assessment (JFA) (unpublished) was created for this study. It is an observational checklist of the extent to which parents use the positive strategies taught in the More Than Words course, rated from a 5-minute video of toy-based interaction between parent and child. Nine parent strategies are rated: use of fun words (to attract attention, such as “wheee!”), simplified language (parentese), musicality of speech, fun physical contact, praise, pretend games, smiles and laughter, turn-taking routines, and imitations and expansions. The total score has a maximum of 36. Interrater reliability on a 15% sample of tapes was \( r = 0.88 \).

STRESS. The Questionnaire on Resources and Stress (QRS-F) has been used extensively in research on parental stress in children with disabilities. It measures 4 components of parental perceptions: parent and family problems, pessimism, child characteristics and physical incapacity. The last was excluded in this study, as well as 3 items of child characteristics that were inappropriate for the preschool-age group. The score range for the adapted questionnaire is 0-43, with higher scores representing more stress. The scale had good internal reliability, with a Cronbach’s alpha of .91.

ADAPTATION TO THE CHILD. The Parent Feelings Questionnaire (PFQ) is an adaptation of the Judson scale, a 22-item, 7-point scale used as an outcome measure in several studies of families of young children with disabilities. For this study, 8 items were added relevant to parent-child communication, and the salience of diagnosis (eg, “It’s easy to play with my child….It’s difficult to play with my child”). The total score range is 30-210, with higher scores representing more adaptation. The scale had good internal reliability with a Cronbach’s alpha of .88.

Process Measures

ATTENDANCE. The percentage of the group sessions attended by the primary caretaker.

OTHER INTERVENTIONS. At time 2, the parent was asked about their child’s attendance at mainstream and specialist educational programs over the preceding months since recruitment. A “substantial ASD-specific” program was defined as a minimum of 6 hours per week in a class or unit for children with ASD, or in a specialist school for children with severe learning disabilities, over the 3 months before time 2.

Procedure

The study was approved by the Northern and Yorkshire Multi-centre Regional Ethical Committee and all relevant Local Ethics Committees. Informed consent to take part in the study was obtained by the course leaders at the time of offering the More Than Words course to the parents. Support with child care and transport was offered to parents in conjunction with a local voluntary organization.

Children were seen for assessment in their own homes, with 1 research worker (VR, developmental psychologist) conducting all but 3 of the ADOS assessments. Before the ADOS was carried out, parents were provided with a standard set of toys, including a ball, a tea-set, 2 tambourines, a push-and-go truck, and a toy typewriter, and asked to play as they normally would with their child for at least 5 minutes. This interaction was video-recorded for later rating of parent strategies (JFA), conducted by trained psychologists blind to group allocation or time. The ADOS was also video-recorded for later rating and reliability checks. Parents were interviewed about adaptive behavior and behavior problems, and 3 questionnaires (MCDI, PFQ, and QRS-F) were given to parents with a stamped addressed envelope for later completion and return.

The time 2 assessments were conducted approximately 7 months after time 1, 4 months after the end of a course. The gap between assessments therefore varied where the start dates of some “immediate” courses were unavoidably delayed.

Analysis

Analysis of covariance was performed to compare time 2 outcome measures between immediate intervention and delayed control groups, making adjustment for the time 1 scores for each outcome measure, the time interval between assessments, the adaptive behavior level and the diagnosis of the child. The statistical package Stata 8.0 was used for the analysis.
Interval between the assessments in months (SD)

<table>
<thead>
<tr>
<th>Diagnostic group</th>
<th>Intervention (n = 26)</th>
<th>Control (n = 25)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number of boys</td>
<td>21</td>
</tr>
<tr>
<td></td>
<td>Child mean age in months (SD)</td>
<td>38.12 (6.54)</td>
</tr>
<tr>
<td></td>
<td>Autism</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>NCA</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Vineland Adaptive</td>
<td>66.42 (11.44)</td>
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<tr>
<td></td>
<td>Behavior Scale</td>
<td>8.65 (1.50)</td>
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<tr>
<td></td>
<td>Composite (SD)</td>
<td>5.16 (1.31)</td>
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</table>

RESULTS

There was no significant difference between the characteristics of children in the immediate intervention and the delayed control groups (Table II). However, a greater proportion of children in the intervention group met criteria for a diagnosis of core autism. The groups were significantly different in terms of the interval between assessments.

The parents in the intervention group on average attended 90.5% of the course sessions. All of the children had attended some kind of playgroup or educational program concurrently with the More Than Words course, varying from 2 hours to 30 hours a week. Seventeen children in the intervention group and 16 in the delayed control group had received some specialist provision in the previous 7 months. However, this amounted to “substantial ASD-specific” provision for only 8 children in the intervention group and 3 in the control. Thus use of other services did not differ significantly between the groups.

Taking into account scores at time 1, child's level of adaptive behavior, diagnostic grouping, and the interval between assessments, a significant difference was found at time 2 between intervention and control groups in terms of children's vocabulary size (MCDI). The autism control group reported on average −50.3 (95% CI: −92.0, −8.6) words less than the intervention group (P = .019), and the NCA control group on average −114.6 (95% CI: −160.6, −68.6) words less than the intervention group (P < .001). Children's vocabulary progress was not significantly related to having been in substantial ASD-specific educational provision (t = 1.273, P = .210) (Table III).

There were no significant group differences found for the social-communication algorithm score (ADOS) nor for child behavior problems (BSQ). For the parents, a significant advantage was found for the intervention group in parents' use of facilitative strategies (JAFA). The group comparison for the children with autism shows that the control group parents had a significantly lower score at time 2 (mean difference −3.6, 95% CI: −7.2, 0, P = .05) than the intervention group parents; however, the group comparison was not significant for the parents of children with NCA (mean difference 1.4, 95% CI: −2.5, 5.3, P = .47) (Table IV). There were no significant differences in the regression model for parental stress (QRS-F), nor for adaptation (PFQ) between intervention and controls, for either diagnostic group.

DISCUSSION

This short-term controlled study aimed to determine effects for parents and for children with ASD of parents' attendance at a More Than Words course. There were 2 main study findings. First, parents are able to learn the interaction strategies that are likely to be facilitative for their children's development of communication, particularly the parents of children with a clear diagnosis of autism. Second, the children whose parents attended a course had larger reported vocabulary, whatever the child's diagnostic grouping. Because the More Than Words course lasted for 3 months, and the time 2 assessment was undertaken around 4 months after the course ended, it can be suggested that parents' enhanced strategies had a positive effect on their children's development of vocabulary, although a causal link cannot be proved with the current study design.

However the study and its findings have some limitations. First, the sample of children and parents involved in the study is around half of the potential population identified. The research group is slightly but significantly more economically advantaged than the “refusers” (unpublished). The extent of the bias that this might exert on the results is not known, particularly because intervention studies in autism almost never describe the socioeconomic characteristics of the population from which their samples are drawn. Second, the group allocation was not randomized. The groups did not differ in parental willingness to take part, because the More Than Words courses were part of on-going services in the various authorities, and timing was solely determined by the availability of the next course. The groups differed significantly only in regard to the interval between research assessments, although the distribution of diagnostic groupings approached significance. These differences were taken into account by the regression model used in the statistical analysis; however, other unknown sources of bias cannot be completely ruled out. Third, the follow-up time reported in this article is necessarily short, because the controlled part of the study design used the natural opportunity of parents having to wait for a course to begin. Fourth, the delayed control group were receiving some degree of individual services from their speech and language therapists while waiting, that is, they were not a “no intervention” control group. This may have reduced the power of the study to detect differences. However, it is a truer reflection of “real life” in provision of services and so indicates the extent of added value of the course.

Finally, the child outcome measure that showed a significant effect of intervention (MCDI) relies on parental report. The direct measure of children's skills (ADOS) did not.
Although the ADOS was originally designed as a diagnostic tool, the social-communication algorithm score has been used to measure change successfully in one study at 12-month follow-up in children with core autism receiving individual language-based intervention. The children in this study had a wider range of levels of impairment and a shorter duration of follow-up. Further detailed analysis being undertaken in this study indicates that specific groupings of ADOS ratings are sensitive to change over a longer follow-up time, indicating a specific positive effect of the intervention on child skills (unpublished).

The JAFA was developed to be a measure of parents’ use of facilitative strategies in interaction relevant to the More Than Words course content but also to other early communication interventions for parents of young children with impairments. On average at time 1, parents were equally able to use fun strategies with their children whatever their severity of impairment in social communication, yet only the parents of children with core autism changed significantly by time 2. Because children in both diagnostic groupings improved in vocabulary when their parents attended a course, this raises the possibility that the JAFA is less sensitive to change where children are more able and more likely to take the initiative in interaction. This possibility will be clearer in follow-up analysis of findings for the whole group after intervention. However, it seems likely that the impact of the course may indeed be greater for parents of children with core autism, where the strategies introduced are particularly empowering, after they have struggled to capture the attention of their child, have found their child’s self-directed behavior hard to interpret as communication, and so may have felt unable to interact or play with their child.

This study adds to the small evidence base concerning useful early interventions for children with ASD. Nevertheless, future studies need to be multicenter to use randomized designs, to have greater power, and ideally to allow comparison between alternative programs for families and children. The More Than Words course is well received by families in terms of consistent attendance, and their comments when interviewed. Nevertheless, it is a short-term intervention, with a total of 11 group and individual contacts over 3 months. It did not have a significant

### Table III. Comparison of time 1 and time 2 child measures between intervention and control groups

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<tr>
<th></th>
<th>Intervention</th>
<th>Control</th>
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<tbody>
<tr>
<td></td>
<td>Autism n = 17</td>
<td>NCA n = 9</td>
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<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
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<tr>
<td>Expressive vocabulary MCDI</td>
<td></td>
<td></td>
</tr>
<tr>
<td>T1</td>
<td>34.65 (62.74)</td>
<td>188.22 (159.18)</td>
</tr>
<tr>
<td>T2</td>
<td>72.6 (100.07)</td>
<td>271.38 (148.43)</td>
</tr>
<tr>
<td>Social-communication ADOS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>T1</td>
<td>17.35 (2.45)</td>
<td>4.33 (2.78)</td>
</tr>
<tr>
<td>T2</td>
<td>14.82 (6.47)</td>
<td>6.00 (3.87)</td>
</tr>
<tr>
<td>Behavior BSQ</td>
<td></td>
<td></td>
</tr>
<tr>
<td>T1</td>
<td>11.59 (4.70)</td>
<td>9.33 (4.21)</td>
</tr>
<tr>
<td>T2</td>
<td>12.50 (5.05)</td>
<td>8.44 (3.40)</td>
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</tbody>
</table>

Significant difference at time 2 in bold, taking into account time 1 scores.

### Table IV. Comparison of time 1 and time 2 parent measures between intervention and control groups

<table>
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<tr>
<th></th>
<th>Intervention</th>
<th>Control</th>
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<tbody>
<tr>
<td></td>
<td>Autism n = 17</td>
<td>NCA n = 9</td>
</tr>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Interaction JIFA</td>
<td></td>
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<tr>
<td>T1</td>
<td>11.18 (4.30)</td>
<td>10.89 (2.98)</td>
</tr>
<tr>
<td>T2</td>
<td>13.94 (4.68)</td>
<td>11.11 (3.44)</td>
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<tr>
<td>Stress QRS-F</td>
<td></td>
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<tr>
<td>T1</td>
<td>19.53 (9.50)</td>
<td>18.44 (9.88)</td>
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<tr>
<td>T2</td>
<td>21.93 (7.58)</td>
<td>16.33 (14.50)</td>
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<tr>
<td>Adaptation PFQ</td>
<td></td>
<td></td>
</tr>
<tr>
<td>T1</td>
<td>145.00 (20.40)</td>
<td>150.33 (26.06)</td>
</tr>
<tr>
<td>T2</td>
<td>145.92 (20.69)</td>
<td>161.88 (27.45)</td>
</tr>
</tbody>
</table>

Significant difference at time 2 in bold, taking into account time 1 scores.
effect (either positive or negative) on parental stress or adaptation to the child and perhaps should not have been expected to given its brevity and specific focus; children with ASD pose a range of challenges to their parents. However, More Than Words does enable parents to build a foundation of positive communication strategies with their child.

We are very grateful to the parents and children who took part in the research, and who welcomed us into their homes. The research progress depended on the dedication and cooperation of the course leaders: Jan Raine, Alison Eggett, Val Dean, Lynne Bennett, Beryl Downing, Marie Sewter, Linda Dixon, Judith Booth, Judy Crow, Diana Finlay and Bev Wilson. The Hanen Centre (Director: Elaine Weitzman) gave encouragement for the research. Fern Sussman conducted the training with the course leaders, and Anne McDade, UK and Ireland Hanen representative, was an invaluable member of the project Steering Group. Barry Ingham and Emma Honey did detailed work on three of the measures.

REFERENCES