

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

HELEN MCCONACHIE, MA, MPhil, PhD, VAL RANDLE, BSc, PhD, DONNA HAMMAL, BSc, MSc,
AND ANN LE COUTEUR, BSc, MBBS, FRCPsych, FRCPC

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

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From the School of Clinical Medical Sciences, University of Newcastle, Sir James Spence Institute, Royal Victoria Infirmary, Newcastle, United Kingdom.

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Reprint requests: Helen McConachie, University of Newcastle, Sir James Spence Institute, Royal Victoria Infirmary, Newcastle upon Tyne NE1 4LP, United Kingdom. E-mail: h.r.mcconachie@newcastle.ac.uk.

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ADI-R	Autism Diagnostic Interview-Revised	MCDI	MacArthur Communicative Development
ADOS	Autism Diagnostic Observation Schedule		Inventory
ASD	Autism spectrum disorder	NCA	Not core autism
BSQ	Behavior Screening Questionnaire	PFQ	Parent Feelings Questionnaire
CI	Confidence interval	QRS-F	Questionnaire on Resources and Stress-Friedrich
JAFA	Joy and Fun Assessment		short form

their autistic child, with positive outcomes both for communication and behavior, has a considerable history^{16,17} but may also involve potential risk for parents if the child does not improve as anticipated.¹⁸ An understanding of the coping strategies of parents of young disabled children suggests that social support is of high importance,¹⁹ and interventions that involve groups of parents working together have the potential to lead to parents developing continuing support networks.^{20,21} 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.¹⁴

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: child identified by the local community pediatrician or speech and language therapist as having language delay and some aspect of concern about social behavior that raised the suspicion of ASD; aged between 24 and 48 months; parent(s) agreed to attend a More Than Words course. A firm diagnosis 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.

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 offered them a place in a More Than Words course, along with support services to increase equity of access to the courses.

Twenty families turned down the offer. Of the 88 remaining, 32 did not consent to participate in the research, citing reasons such as not wanting more professionals making home visits, and too much stress around the time of diagnosis (unpublished). Of the 56 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 Scales²² 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),²³ was undertaken at recruitment. The Autism Diagnostic Observation Schedule (ADOS)²⁴ 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

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