Patterns of change in children with Autism Spectrum Disorders who received community based comprehensive interventions in their pre-school years:

a seven year follow up study

ABSTRACT

There are few long-term follow-up studies of children with Autism Spectrum Disorders (ASD) who attended intensive intervention programmes in their pre-school years. Thirty-six children with ASD enrolled in relatively intensive, specialist pre-school programmes (minimum of 15 hours intervention per week for two years at a mean age of 3.4 years) were assessed after two years (mean age 5.5 years) and again after a further five years (mean age 10.3 years). Cognitive, language and adaptive behaviour skills and severity of autism symptoms were assessed at intake (Time 1) and subsequent follow-ups (Times 2 & 3). Children made significant increases in raw and age equivalent scores in most areas of development assessed, although mean standard scores remained stable or decreased over time. Time 1 IQ, language and adaptive behaviour skills were predictive of outcome at Time 3. Although there were marked individual differences in the rate and patterns of change over time, many children continued to show increases in test scores over the course of the study. This study highlights that whilst overall group improvements may be evident, the rate and nature of these improvements is highly variable across individual children. Further investigation of the specific child characteristics that affect treatment effectiveness is required.

Abstract word count: 199

Improvements in the early recognition and diagnosis of autism spectrum disorders (ASD) has led to an increasing number of children with ASD receiving intensive, comprehensive interventions in their pre-school years. A number of early intervention programmes, using a variety of approaches, has reported significant gains in cognition, language and adaptive behaviour, and significant decreases in the severity of behavioural difficulties during the course of treatment (for reviews see Technology Evaluation Center, Blue Cross Bluefield Special Report, 2009; Eldevik et al, 2009; Howlin, Magiati & Charman, 2009; Ma, 2009; Makrygianni & Reed, 2010;Ospina et al., 2008; Rogers & Vismara, 2008; Spreckley & Boyd, 2009; Virues-Ortega, 2010). Early, intensive, home based behavioural intervention programmes (EIBI; Lovaas, 1987) have shown significant benefits, as have other more developmentally oriented programmes and those that target specific autism-related difficulties. These include the Early Start Denver Model, (Dawson et al., 2010); the Pre-school Autism Communication Trial (Green et al., 2010), and programmes that focus on joint attention, symbolic play (Kasari, Paparella, Freeman & Jahromi, 2008), social communication and parent child interaction (Aldred et al., 2004; Yoder & Stone, 2006) and imitation (Heimann, Laberg & Nordøen, 2006). Reported areas of improvement vary across studies but include increases in IQ test scores, verbal and non-verbal communication measures, adaptive behaviour, social and self-care skills assessments and, in some studies, decreases in behavioural problems, as measured by standardised assessments and rating scales. There is less evidence of a significant impact on core autism symptoms (Dawson et al., 2010; Green et al., 2010).

However, intervention strategies are variable as are the methods and instruments used to assess outcome. There is considerable individual variability, too, in the extent and rate of progress that is achieved, with some children making marked progress in most areas of

development while others gain few new skills, at least as measured by standardised instruments (Howlin et al., 2009; O'Connor & Healy, 2010; Ospina et al., 2008).

Importantly, the one consistent feature of most early intervention research is a lack of data on long term outcomes, with most studies reporting outcomes only one to three years after the start of the intervention (for exceptions see Harris & Handleman, 2000; McEachin et al., 1993; Sallows & Graupner, 2005; Smith, Groen & Wynn, 2000). Given the cost of many of these programmes, in terms of time, money and professional and parental input, a crucial and as yet unanswered question is how children who received such interventions in their early years develop subsequently.

Follow-up studies of children with ASD suggest that their cognitive abilities and verbal competence, in particular, are likely to increase significantly over time (Eaves & Ho, 2004; Howlin, Goode, Hutton & Rutter, 2004; Lord & Schopler, 1989; Sigman, 1998; Turner, Stone, Pozdol & Coonrod, 2006; Venter, Lord & Schopler, 1992). Furthermore, while the diagnosis of autism or ASD using standardised diagnostic instruments is relatively stable (Billstedt, Gillberg & Gillberg, 2005; Cox, et al., 1999; McGovern & Sigman, 2005; Moss, Magiati, Charman & Howlin, 2008), the severity of ASD symptoms tends to decrease with age (Charman et al., 2005; Fecteau, Mottron, Berthiaume & Burack, 2003; Moss et al., 2008; Starr, Szatmari, Bryson & Zwaigenbaum, 2003). With regard to changes in adaptive behaviour, findings are inconsistent with some studies reporting improvements in adaptive behaviour measures (i.e. Freeman, Del'Homme, Guthrie & Zhang, 1999; McGovern & Sigman, 2005), while others report increases in age equivalent scores but no change or decreases in standard scores (i.e. Fenton et al., 2003; Klin, Aulnier, Sparrow, Cicchetti, Volkmar et al., 2007; Perry, Flanagan, Dunn Geier & Freeman, 2009). Generally, the increases made on formal assessments in these areas are reported to be greater in children

who are initially more able but there is significant individual variability (i.e. McGovern &, Sigman, 2005).

Background to the present study

The present study was conducted in order to address the lack of long term data on the progress of children with ASD who have received intensive, comprehensive interventions in their pre-school years. Participants were 36 children who were involved in a prospective study of the long-term effectiveness of early, intensive, autism specific interventions. All had been enrolled in autism specific, specialist nursery provision or community-based behavioural programmes for at least 15 hours per week between the ages of two to four ½ years. Children were assessed at intake (T1; mean age 3.4 years, SD =0.6, range 2.3-4.6 years), after two years (T2; mean age 5.5 years, SD =0.6, range 4.3-6.7 years) and again after four to five years (Time 3-T3, mean age 10.3 years, SD=.08, range 8.8-12.0 years). At T2, although progress was less marked (especially with respect to IQ) than in some other, highly controlled university based programmes, children showed significant increases in mean age equivalent scores on assessments of language, cognitive ability and adaptive behaviour. However, standard scores changed little over time and there was wide individual variation in progress, with intake IQ and language level best predicting overall progress after two years of intervention. Further details of outcome at the T2 follow-up are reported in Magiati et al. (2007).

The present study

▪ This six to seven year follow-up study was conducted in order to investigate the outcomes in middle and later childhood for children with ASD who received intensive, comprehensive interventions in their pre-school years and to explore whether the progress made during the two years of intensive early intervention was maintained subsequently. Patterns of change and individual differences in progress in language,

cognitive ability and adaptive behaviour measures over the course of the follow-up period were also explored. Finally, pre-school child factors associated with outcome in middle and later childhood were examined.

1. METHOD

1.1 Participants

Participants were selected for inclusion according to the following criteria:

1. Independent diagnosis of autism or ASD from qualified clinician.

2. Meeting ADI-R criteria for autism or ASD (cf Risi et al., 2006) at T1.

3. Enrolled in a specialist comprehensive pre-school intervention programme (home-based EIBI or school-based autism-specific nursery provision) for a minimum of 15 hours per week at T1.

4. Aged between 22-54 months at onset of pre-school intervention.

5. English the main language spoken at home.

6. No major additional medical diagnoses.

No exclusion criteria were set for cognitive or language levels.

Sixty-three participants responded to the initial invitation to take part in the study. Of these, 19 failed to meet all inclusion criteria, leaving a sample of 44 at T1 intake assessment. (see Magiati et al., 2007 for more details). At T2, all 44 participants were re-assessed. At T3, 6-7 years since the start of their early interventions, 36 children (81.8% of the original sample) were traced and re-assessed (two individuals had left the UK; two had subsequently been diagnosed with major additional medical diagnoses (brain tumour; Duchen muscular dystrophy); three had moved and could not be contacted via their family doctor or school; one did not respond to attempts to re-establish contact).

The 36 participants for whom data were available at all three time-points were included in this study (see Table 1). There were no significant differences in T1 child, family or socio-economic characteristics between individuals who participated in the study at all three time points and those who did not participate at T3 (all p>.10) indicating that the children included in this phase of the study were representative of the initial sample.

Table 1 about here

1.2 Early Interventions

Full details of the pre-school nursery and home based EIBI programmes in which the children were initially enrolled are presented in Magiati et al., 2007 and are only briefly summarised here. The mean age of initial enrolment in T1 intervention was 38.9 months (SD =7.1; range 27 -55 months). Mean time per week spent in intervention at T1 was 29.8 hours (SD=7.5; range 15-40). Average time in intervention (i.e. school education *and/or* home based EIBI) at T2 was 30.7 hours per week (SD=5.1; range 19-40 hours). The EIBI programmes ranged in duration from 22 to 90 months (mean=57.9 months, SD=21.2) and were based on the UCLA Young Autism Project model (Lovaas, 1987), with therapists receiving variable rates of supervision and consultation from various UK based ABA providers or independent consultants from UK, Norway or USA. Children in the autism-specific nursery provision group received an eclectic mix of teaching approaches/ practices in small groups, including Treatment and Education of Autism and related Communication handicapped Children (TEACCH based strategies, (Schopler, 1997); Picture Exchange Communication System (PECS; Bondy & Frost, 1994); Makaton (Grove & Walker, 1990); other behavioural and developmental programmes; speech and language therapy; music and occupational therapy (see Author et al, 2007 for details; citation blind to protect author anonymity). At T3, 35

children were in full time, state provided mainstream or specialist elementary schools, with one child continuing to receive home based EIBI on a part-time basis.

1.3 Other treatments/ interventions followed

Twenty seven children had received one or more specific additional or alternative treatments during the course of the study (T1-T3) including special diets (N=20); other biological treatments (N=19); extra-curricular Speech and Language therapy (N=27); music or play therapy (N=17) and parent training programmes (N=9).

1.4 Measures

Intervention and Education: A parental questionnaire specifically developed for the study provided information on family, child and past/ current intervention characteristics. A teacher questionnaire provided information on the types, intensity and other characteristics of school-based provision following the cessation of the specialist intervention period.

1.4.1 Cognitive skills: As far as possible children were assessed with the same measure over time, in order to minimise difficulties from comparing scores derived from different measures (Magiati & Howlin, 2001; Matson, 2007). However, for some children different tests were required and at each time point the choice of test was determined by the child's chronological, developmental and verbal age. At T1 and T2, the *Bayley Scales of Infant Development* (Bayley, 1993) was used with the majority of participants. For those above the age ceiling of the Bayley, the *Wechsler Pre-school and Primary Scale of Intelligence (*WPPSI-R; Wechsler 1990*)* was attempted at T2 and the *Wechsler Intelligence Scale for Children (*WISC-IV; Wechsler, 2004) and WPPSI-III (Wechsler, 2003) were attempted at T3. However, many children were unable to score above basal on the Wechsler tests and assessment of cognitive

functioning in these cases was based on the *Merrill-Palmer Scale of Mental Tests* (MP; Stutsman, 1948). Despite its elderly standardisation data and focus on visuo-spatial cognitive skills, it is a good predictor of later functioning (Lord & Schopler, 1989; Howlin, Goode, Hutton and Rutter, 2004) and the materials are engaging for young children with developmental delays. To facilitate comparisons over time, a "best test" estimate of cognitive level was used for each child based on the most developmentally appropriate/ best standardised test available at each time point according to the following hierarchy: WISC> WPPSI (higher level)> Bayley> MP> WPPSI (lower level). At T1, the "best estimate" IQ was based on the Bayley for 21 participants, the MP for 14 and the WPPSI for one. At T2, the "best estimate" IQ was based on the Bayley for 27 participants and the WPPSI for 9. At T3, the "best estimate" test was the WISC for 10 participants and the MP for 26.

1.4.2 Adaptive Behaviour: Adaptive behaviour was assessed by the *Vineland Adaptive Behavior Scales* (VABS, Survey form; Sparrow, Balla & Cicchetti, 1984). The VABS-II was not available when the study began.

1.4.3 Language: Language Comprehension was assessed by the *British Picture Vocabulary Scales – 2nd Edition* (BPVS; Dunn, Dunn, Wheton & Burley, 1997). Expressive language was assessed using the *Expressive One Word Picture Vocabulary Test* (EOWPVT; Gardner, 1990; Brownell, 2000). Both tests were affected by floor effects, especially at T1 when 26 (72%) and 29 children (81%) failed to score on the BPVS and the EOWVT respectively. Although standard scores or age equivalents are preferable to raw scores, in this sample so many children failed to score above basal at T1 the only appropriate statistical alternative was to use raw scores in the analyses (cf. also Green et al., 2010; Remington et al., 2007).

1.4.4 Severity of autism symptoms: The "Current" algorithm of the *Autism Diagnostic Interview- Revised* (ADI-R; Lord et al., 1994) was used to monitor changes in Verbal and Non-Verbal Communication (VC; NVC), Reciprocal Social Interaction (RSI), and Restricted, Stereotyped and Repetitive Behaviours (RSRB) over time (the diagnostic algorithm was used to confirm severity of ASD symptoms at T1). As few children scored on the VC domain at T1, NVC domain scores were used to calculate an overall ASD symptom severity score based on the ADI- R algorithm (i.e. ADI-R total=RSI + NVC + RSRB).

1.5 Procedure: The study was approved by the Ethical Committees of St George's Hospital Medical School, University of London and the Institute of Psychiatry, King's College London. T1 assessments were conducted by the first author and a Research Assistant. At T2, the first author completed all evaluations. At T3, assessments were carried out by the first and second authors. All examiners had extensive prior experience of assessing children with ASD and were trained in the administration and scoring of all assessments, including the ADI-R. Examiners were independent of treatment delivery, although not blind to the children's intervention status.T1 and T2 assessments took place at home or school. At T3, all but four assessments were carried out at school. Parental interviews (Vineland and ADI-R) were completed within two months of the child's assessment.

1.6 Reliability: T1 and T2 reliability data are reported in Magiati et al. (2007). At T3, the first and second authors independently viewed and scored 23 randomly selected videotaped standardised tests (five WISC, four WPPSI, five MP, five BPVS and four EOWPVT), blind to the other assessor's scores. Intra-class correlation coefficients for raw scores were r= 1.0, *p* <.001. Inter-rater reliability was also conducted for six randomly selected T3 ADI-R interviews,

in which the raters were blind to the children's identity, initial intervention group status and their ADI-R scores (Kappa coefficient for ADI-R cut off score = 1.0).

*1.7 Data analysis***:** Repeated measures ANOVAs and paired t test post hoc analyses were conducted to evaluate change in cognitive, language and adaptive behaviour functioning and autism severity across the three time points. Non-parametric Friedman tests and pairwise Wilcoxon Signed Ranks tests were used where data were not normally distributed and McNemar tests were conducted where data were categorical. The *p* value for significance of change over time was set at ≤.01 due to the number of comparisons conducted; for pairwise post hoc tests, the accepted significance level was .05. Hierarchical multiple regression analyses were conducted to determine the specific effects of T1 variables on T3 scores.

In order to determine the progress of individual children on those variables in which significant group progress was identified, we applied the criteria outlined by Jacobson and Truax (1991) to establish the thresholds for reliable significant change on MA, language, adaptive behaviour and a global composite score calculated using these variables[1]. The reliable change index score indicates the threshold at which the degree of change is unlikely (95% chance) to be accounted for by measurement unreliability or variability in scores. Calculating reliable change requires the standard deviation score at the baseline from which change is being assessed and an indication of the stability of the measure being used. Since there are few standardised data specifically for children with ASD on any of the measures used, we used data from the current study sample in the following equation (Evans, Margison & Barkham, 1998; Remington et al., 2007):

$$\textit{Reliable Change Index} = 1.96* (SE_{diff} = SD_1 \sqrt{2} \sqrt{1\text{-}r})$$

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[1] Detailed analysis of change in ADI-R scores can be found in Moss et al., 2008;

where SD_1 is the standard deviation of the baseline data and r is the

reliability/stability of the test based on the study sample data.

When identifying reliable change index between T1 and T2, standard deviation scores from T1 and the T1 to T2 test-retest reliability (correlation coefficients) were entered into the above equation. When identifying reliable change index between T2 to T3, standard deviation scores from T2 and the T2 to T3 test-retest reliability (correlation coefficients) were entered into the equation.

2. RESULTS

2.1 Educational Placements at follow-up

At T3, 35 children were in full time elementary school (mean 30.3 hours per week; SD = 2.3; range 29-33 hours). One child was in school education for 20 hours per week only. Six children (17% of the sample) were in mainstream provision of whom five received specialist individual support for 15-30 hours per week; one received no additional support. Amongst the remaining 30 children, 2 were placed in specialist units within mainstream settings (a specialist ASD Unit and a Language Unit respectively); 14 were in autism-specific provisions and 14 were in schools for children with moderate and/or severe learning disabilities.

At T3, 35 teachers completed a brief questionnaire on each child's current school provision. This information indicated considerable variability in educational placements. Class size ranged from 2-35 children (mean=10.4, SD=8.2), with 1-7 teachers and learning support assistants (mean=3.5, SD=1.4) per class. The amount of one-to-one teaching ranged from 0 to 32.5 hours per week (mean=10.9 hours, SD=12.5; data missing for 10 children).

2.2 Changes in cognitive, language, adaptive behaviour and severity of autism scores over time

Insert Table 2 about here

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Table 2 presents scores and analyses on measures of IQ, MA, adaptive behaviour skills and severity of ASD difficulties at T1, T2 and T3. At T1, 32 children met ADI-R algorithm diagnostic criteria for autism in all three domains; four children met ADI-R algorithm criteria in two out of the three domains, thus meeting Risi et al.'s (2006) criteria for broader ASD. At T3, 29 children met full autism ADI-R criteria based on the "current" behaviour algorithm, three met Risi et al's (2006) broader ASD criteria; two scored above cut off in only one domain; and two children scored below cut-off in all three ADI-R domains. A repeated measures ANOVA and paired t test post hoc analyses revealed that ADI-R total scores were significantly lower at T2 and T3 compared to T1 ($p =.002$; post hoc $p<.05$). There was no difference between T2 and T3 ADI-R total scores. Further detailed analyses of ADI-R scores can be found in Magiati et al., (2007) and and Moss et al. (2008).

Overall, significant increases (T3>T2>T1) across each time period were found for MA, expressive and receptive language skills raw scores and adaptive behaviour composite and subdomain age equivalent scores (Table 2). Significant decreases in scores over time were identified for IQ (T2<T1 only; $p<.001$) and adaptive behaviour composite standard scores (T3< T1=T2; $p<.001$), indicating that although children acquired new skills and abilities (as reflected by increases in age equivalent scores), they did so at a rate slower than their typically developing peers. Figure 1 shows the pattern of change over time between T1, T2 and T3 on MA, IQ, language and adaptive behaviour skills. McNemar tests revealed significant increases in functional language (as measured by the ADI-R item 19) with only 3 children (8%) using functional, spontaneous phrase or sentence speech at T1, increasing to 13 (36%) at T2 ($p=.002$) and 18 (50%) at T3, although this was not a statistically significant improvement from T2.

Insert Figure 1 about here

2.3 Initial child variables associated with T3 outcomes:

Hierarchical multiple regression analyses were conducted to determine the specific effects of T1 variables on T3 scores. Most T1 child variables (cognitive, language and adaptive behaviour skills and autism symptom severity) were significantly associated with T3 outcomes (all r=.36-.92, all p<.05) and were thus selected for subsequent regression analyses. Chronological Age (CA) at T1, hours and type of intervention and family SES were not included in the regression analyses, as they were not correlated with T2 or T3 outcomes (Pearson r correlation coefficients <.3; all *p* values >.10). A T3 "best outcome rank" variable was created in SPSS by summing T3 outcome ranks in each of the key variables (cognitive, language, adaptive behaviour and autism severity scores). Predictor variables were entered in two steps: T1 IQ was entered as Step 1, while T1 language raw scores, adaptive behaviour standard scores and ADI-R raw scores were entered as Step 2. For T3 best outcome rank, T1 IQ (Step 1) accounted for 55% of the variance (adjusted R square; F(1,27)=34.7; p<.001). When T1 language, VABS ABC and ADI-R scores were entered (Step 2), an additional 15% of variance was accounted for (F(5,23)= 14.1; p<.001). With all variables entered in the full model, T1 receptive language raw score and Vineland ABC SS significantly contributed to the model (β=2.5, p=.03 and β=2.7, p=.02 respectively).

2.4 Individual differences and patterns of change over time

Figure 2 about here

As found at T2 (Magiati et al., 2007), there were large individual differences in T3 outcomes. Some children showed significant increases in test scores in the developmental domains assessed over the course of this study, whilst others made very limited measurable progress. Figure 2 shows the change scores and reliable change indices separately for those variables in which significant group improvements were identified (MA, receptive and expressive language raw scores and adaptive behaviour age equivalent scores). Table 3 summarises the number of children who made reliable change at T1-T2 and T2- T3.

Insert Table 3 about here

Figure 3 about here

The overall pattern of change in each child's trajectory of development between T1 – T2 and T2-T3 was summarised by calculating reliable change on a global composite score (MA+ adaptive behaviour + language (receptive and expressive) raw scores). Data were available for all variables included in the global composite score at all three time points for 30 participants. Figure 3 shows the global composite change scores and reliable change indices for T1-T2 and T2 –T3. In all cases, reliable changes reflected increases in assessment scores (i.e. gains in developmental skills measured or decreases in autism severity scores). Almost half the sample (14 children, 47%) showed reliable change both during the first two years of early intervention (T1-T2) and subsequently (T2-T3). Five children (17%) showed reliable change during T1-T2 but not thereafter; four children (13%) showed no reliable change during T1-T2 but did improve reliably between T2-T3. Seven children (23% of the sample) made no reliable change either during or after the first two years of intervention. Table 4 describes the T1 participant characteristics according to reliable change made on global composite scores. Statistical analysis of differences in the initial characteristics of children in each of these sub-groups was not possible due to the small group sizes. However, visual inspection of Table 4 suggests that the fourteen participants who made reliable

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progress between T1-T2 *and* T2-T3 had better language, cognitive and adaptive behaviour skills at T1 than all other groups. There were very few apparent differences between those children who made reliable change during T1-T2 only and those who made no change either during or after the first two years of intervention. The seven children who showed reliable change only between T2 to T3 had better cognitive and adaptive behaviour scores than those who made no change at either time point and those who only made reliable change during the intervention period.

Insert Table 4 about here

3. Discussion

This study investigated change over six to seven years in children with ASD who had received intensive pre-school intervention (either home based behavioural programmes or autism-specific nursery provision). Our analyses showed that raw and age equivalent scores on tests of cognitive functioning, language and adaptive behaviour had significantly increased with many children showing reliable increases during the intervention phase (T1 to T2) *and* at this follow up four to five years later (T2 to T3). However, standard scores in these domains tended either to remain stable or to decrease, indicating that while significant progress was made by many children, the *rate* of progress was not in keeping with typical developmental norms. Many children continued to show delays in most areas of functioning assessed and required specialised educational provisions at T3. Although the children in this study generally showed less progress than reported in highly intensive, university based programmes (cf. Eikeseth, Smith, Jahr & Eldevik, 2007; Howard, Sparkman, Cohen, Green & Stanislaw, 2005; Sheinkopf & Siegel, 1998; Sallows & Graupner, 2005; Rogers and Vismara, 2008), other community based studies have recorded similar results to our own, with little change or a

decline in standard scores being reported (e.g. Ben-Itzchak and Zachor, 2009; Bibby, Eikeseth, Martin, Mudford & Reeves, 2002; Boyd & Corley, 2001; Fisch, Simensen and Schroer, 2002; Gabriels, Hill, Pierce & Rogers, 2001; Smith, Eikeseth, Klevstrand & Lovaas, 1997). Other longitudinal studies following up children with ASD from their pre-school years through to childhood and adolescence have also documented stability or decline in IQ and adaptive behaviour standard scores over time (i.e. Lord & Schopler, 1989; Charman et al., 2005; McGovern & Sigman, 2005), although some researchers have reported significant increases in these areas (i.e. Turner et al., 2006).

Severity of autism behaviours as measured by the ADI-R decreased somewhat over the first two years of intervention and then remained relatively stable over time. Although three children scored below cut-off in two or all three ADI-R domains at T3, indicating that the severity of their autism behaviours may have decreased considerably over time, diagnostic stability based on ADI-R was high (cf. also Moss et al., 2008; Turner et al., 2006). Ben Itzchak and Zachor (2009) also reported overall diagnostic stability based on the ADOS classification, but interestingly looked at the 15 children in their sample of 68 18-35 month olds who changed from autism to ASD or off-spectrum (n=2) classification after one year of comprehensive intervention. They found that this group had better baseline receptive language scores than the unchanged classification group; they . also gained significantly more in cognitive and adaptive behaviour test scores and showed greater reduction in stereotyped behaviours than the unchanged group. These findings highlight the importance of exploring the complex interactions between children's initial measured skills, their diagnosis, the treatment approach followed and subsequent progress (see also Zachor and Ben Itzchak (2010).

In terms of communication and language development, a particularly encouraging finding was the fact that the gains made in children's functional use of language between T1

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and T2 continued subsequently. At T1, most children were severely delayed in their language development, with only 8% having any functional phrase speech. By T3, many more children (50%) had acquired functional phrase speech. Turner et al. (2006) also report similar positive improvements in communication in their follow up of two-year old children with ASD at age nine.

3.1 Predictors of long-term outcome and Individual differences in progress over time:

In the current study, the variables that predicted post-intervention outcome were initial receptive language skills, IQ and adaptive behaviour. These findings are consistent with previous reports (Lovaas, 1987; Harris & Handleman, 2000; Remington et al., 2007; Lord & Schopler,1989; Smith et al., 1997). Although initial ADI-R total scores correlated with T3 outcome, suggesting that children with initially *less severe* symptoms made better progress, T1 ADI-R scores did not significantly predict outcome at T3 in the regression analyses. There was no indication in this study that age at intake, intensity or type of early intervention, or family socio-economic status (SES) were related to T3 outcomes.

As described in Figure 2, in all developmental domains there was marked variation in the rates and patterns of change shown by individual children, with a minority making substantial gains on the standardised measures administered and most making relatively small gains. The present findings accord with other published studies reporting large individual differences and variability in progress following early intervention (see Lord et al., 2005; National Research Council, 2001; Rogers & Vismara, 2008 for reviews and discussion). However, unlike most other intervention studies we also assessed progress 4-5 years after the first 2 years of intervention in order to examine the children's longer term rates and patterns of change. Among the children (N=30) for whom it was possible to compute a composite change score (based on changes in mental age, language and adaptive

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behaviour), approximately half showed reliable improvement during both the first two years of intervention (T1-T2) *and* 4-5 years later (T2-T3). Around a quarter showed no change either during or after T1-T2 while 17% made reliable improvement during the first two years of the intervention period, but not thereafter, and 13% showed improvement only after T2. The varying rates and patterns of change across individual children identified in this study are consistent with the heterogeneous and multifaceted nature of ASD.

3.2 Methodological challenges and limitations

The findings of this study should be considered with the following limitations in mind: Firstly, data were obtained primarily from standardised assessments which impose a number of limitations and constraints. This is particularly the case for cognitive assessments, many of which have narrow age ranges and focus on different aspects of cognitive functioning. It could be argued that failure to find improvements in cognitive standard scores over time could be due to the limitations of the cognitive scales employed, particularly the Merrill-Palmer, or to the fact that for some children it was necessary to use a different cognitive test at different time points. Most measures of cognitive ability are designed for typically developing children and as such may be less sensitive to progress in children with developmental delays, especially over long periods of time. Secondly, as these were community-based interventions delivered by a range of service providers, systematic information about the exact nature and implementation of the community-based interventions and school-based provisions the children followed during the course of the study was limited. The longitudinal nature of the study was an additional complicating factor preventing adequate and detailed monitoring of intervention delivery. Nevertheless, the study also has a number of strengths. This was a naturalistic opportunity to gather important information on long-term outcome among children in receipt of intensive, community based programmes in their early years. Additionally, all

members of the research team were independent of treatment delivery and had no connections with any service providers. The combination and range of measures used, the variety of sources from which information was collected (children, parents and teachers; direct testing and observation, interviews and questionnaires) and the range of developmental and functional domains assessed, also provided a comprehensive assessment of functioning over time (see Matson, 2007 for a discussion of measurement issues and for recommendations on how to determine, measure and report treatment outcome in early intervention research) .

3.3 Implications for Research, Practice and Policy

This longitudinal study has added to the growing body of knowledge with regard to long-term outcomes in later childhood of children who received intensive, specialist early interventions in their pre-school and early school years. It is important that future studies also adopt a longitudinal perspective in empirically documenting change and progress over time. Recent studies have begun to adopt a more comprehensive, complex approach in interpreting longitudinal data (i.e. Siller & Sigman, 2008; see Gibbons, Hedeker, & DuToit, 2010 for a review of advances in analysis of longitudinal data). The next challenge facing researchers and clinicians is to identify the "active key ingredients" in specialist treatments and to explore how these interact with child characteristics in the long-term (see Rogers & Vismara, 2008). Identifying children who show "rapid", "moderate" or "minimal" response to different autism-specific approaches over time and tailoring these approaches to meet their individual needs is a priority for research and clinical practice. To benefit children with ASD and their families, the next generation of research will need to concentrate on investigating the differential impact of interventions of comparable levels of potential effectiveness (see Kasari, Paparella, Freeman & Jahromi, 2008; Yoder & Stone, 2006; for examples of how this can be done) and to explore

more systematically whether children receiving different early interventions in their early years show differential trajectories of change and outcomes as they grow older.

Text word count: 5105

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