

Social cognitive development in children with autism spectrum disorders: Implications for everyday life

Congrès: L'autisme, jour après jour
Parc des Expositions de Bruxelles
Samedi 25th Octobre 2008
Professor Tony Charman
UCL Institute of Child Health

Outline

- What is autism?
- How our understanding of autism has changed
- How common is autism?
- What are the earliest signs of autism?
- How early can autism be diagnosed?
- Developmental theory and early interventions
- Providing answers to complex questions
 - Challenges to science and to clinical practice

What is autism?

- Difficulties in social relationships
- Difficulties in communication
- Repetitive and rigid behaviours

What is autism?

- Difficulties in social relationships
 - Failure to use eye gaze & gesture
 - Failure to develop friendships
 - Lack of social/emotional understanding
 - Lack of sharing



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 - Impoverished conversation
 - Repetitive language
 - Lack of make-believe play



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- Repetitive and rigid behaviours
 - Preoccupations
 - Preference for routines
 - Motor mannerisms
 - Sensory abnormalities



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Nature never draws a line without smudging it... (Lorna Wing)

- Classic 'Kanner' autism
- Children with some but not the full complement of symptoms
 - 'Atypical autism'/'Pervasive developmental disorder' (PDD)
 - High functioning autism/Asperger syndrome
- Now understood to cover a 'spectrum' of severity
- Terminology used differently in different arenas
 - e.g. Education vs. Health vs. Science
 - Can lead to confusion for parents and practitioners

Our understanding of autism in the 1980s

- Autism was considered a rare condition
 - 4 - 5 children per 10,000 i.e. 1 in 2,000 children
 - ~20 per 10,000 children with the 'triad' of impairments i.e. 1 in 500 children
- Autism was rarely diagnosed until age 3-4 years
- Outcome in most cases was poor
- Autism was a 'unitary' disorder with strong heritable genetic underpinnings

Our understanding of autism now

- Autism is a relatively common condition
 - 100 in 10,000 of children have some form of autism i.e. 1 in a 100 children
- Autism can be reliably diagnosed by the age of 2 years in some cases
- Outcome is very variable and may depend on treatment
- Now understood as a *spectrum* of conditions that have both heritable and sporadic genetic underpinnings + unknown environmental factors?
 - 'autism spectrum disorders' (ASDs)
 - 'the autisms'

How common is autism?

- Picture until the late 1990s
- "Classic" figure of 4 - 5 per 10,000
 - UK: Lotter (1966), Wing & Gould (1979)
 - USA: Ritvo et al. (1989)
 - Europe: Fombonne et al. (1992, 1997)
- More recent figures nearer 10 per 10,000
- Reviews and meta-analyses
 - Fombonne (1999), Gillberg & Wing (1999)
 - 'Best estimate' for autism ~ 10 per 10,000
 - 'Best estimate' for all ASDs ('triad of impairments') ~ 20 per 10,000 (Wing & Gould, 1979; Camberwell study)

3 studies published in 2000/2001

- Baird et al. (2000) - follow-up of sample screened with CHAT at age 7-8 years in South Thames
- Chakrabarti & Fombonne (2001) - 3 to 7 years best practice surveillance study in Staffordshire
- Bertrand et al. (2001) - intensive case-finding study by CDC in Brick Township, NJ, USA.
- All found rates for all ASDs ~ 60 per 10,000
 - Though differences in other characteristics
- Overlap in age of sample and methods

	Baird et al.	Chakrabarti & Fombonne	Bertrand et al.
Population size	16,235	15,500	8,896
Age	7 yrs	2.5-6.5 yrs	3-10 yrs
% Assessed	46%	95%	71%
Autism/10,000	31	17	40
Other ASDs/10,000	27	46	27
All ASDs/10,000	58	63	67
% Boys	88%	79%	73%
IQ <70	22%	26%	49%

3 studies published in 2005/2006

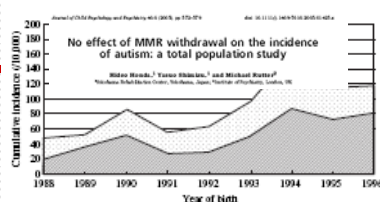


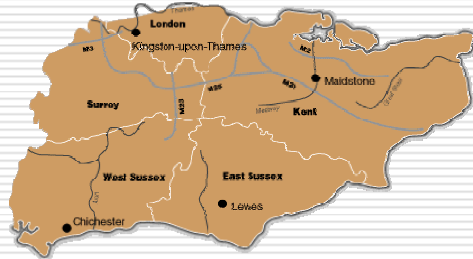
Figure 1 Annual trends in cumulative incidences up to seven years of childhood autism and other ASD

Prevalence of ASD in 1996 birth cohort = 117 per 10,000



Prevalence of ASD in 5-16 year olds = 90 per 10,000

Birth cohort of 57,000 children in South Thames



Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP)

Gillian Baird, Emily Simonoff, Andrew Pickles, Sona Charalambous, Tom Locomo, David Melville, Fany Chamman

Summary Background Recent reports have suggested that the prevalence of autism and related spectrum disorders (ASDs) is substantially higher than previously recognised. We sought to quantify prevalence of ASDs in children in South Thames, UK.

Prevalence of ASD in 9-10 year olds = 116 per 10,000

However, case definition affects prevalence estimates

- Narrow autism 25 per 10,000
- Childhood autism 39 per 10,000
- Other ASDs 77 per 10,000
- Total ASD 116 per 10,000

Also, case ascertainment affects prevalence estimates

- Narrow autism 25 per 10,000
- Childhood autism 39 per 10,000
- Other ASDs 77 per 10,000
- Total ASD 116 per 10,000
- Locally diagnosed 45 per 10,000

Factors that affect local identification

- 64% narrow autism; 58% childhood autism; 23% other ASD cases had a local diagnosis
- Factors that increase prior identification:
 - Parental education
 - IQ > 70 – most unidentified cases had other neurodevelopmental diagnosis: ID/MR, learning disability, DLD, motor or specific learning problem
- Factors **not** associated with prior identification:
 - SES or income
 - Child sex
 - District

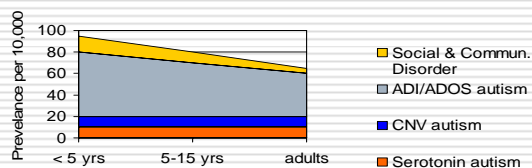
Has autism become more common?

- No definitive evidence that it has
- What might explain the apparent rise?
 - Wider recognition
 - Broader diagnostic concept
 - More thorough studies
 - Inclusion of children with average as well as below-average IQ in studies
 - Use of the diagnosis in previously excluded groups
 - Whilst these factors *may* account for most or all of the apparent increase – other explanations cannot be ruled out, including a true rise in incidence

Case definition and aetiology

- The ASD phenotype may be arrived at by a number of pathogenic routes
 - That presumably overlap somewhere in development
- The spectrum is made up of individuals with different ultimate aetiologies
- Particular biological or genetic markers will not necessarily be present in all cases
- Case definition for the whole spectrum will continue to be reliant on the behavioural picture alone

A possible direction for future epidemiological studies?



What does this mean for Belgium?



- Births per year = 110,000 (UNICEF, 2006)
 - Childhood autism (39/10,000) = 429 children
 - All ASDs (116/10,000) = 1,276 children

Context for early detection

- Autism more common than previously recognised
- Greater public awareness of autism
- Increased recognition of early signs
- Until recently diagnosis was unacceptably late
- Increasing evidence for benefits of early intervention
 - Models of secondary impacts (Dawson, Mundy)
- Recognition of re-occurrence in families and implications for genetic counselling
 - 5% of autism, up to 15% of broader disability



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Volume 39(6), June 2000, pp 694-702

A Screening Instrument for Autism at 18 Months of Age: A 6-Year Follow-up Study

BAIRD, GILLIAN F.R.C.Paed.; CHARMAN, TONY Ph.D.; BARON-COHEN, SIMON Ph.D.; COX, ANTONY F.R.C.Psych.; SWETTENHAM, JOHN Ph.D.; WHEELWRIGHT, SALLY B.A.; DREW, AURIOL M.A.

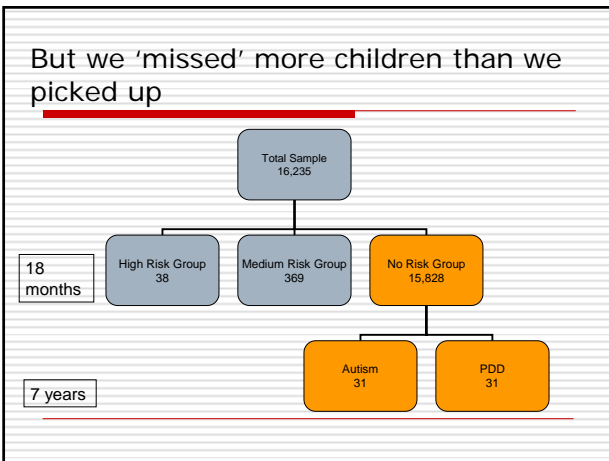
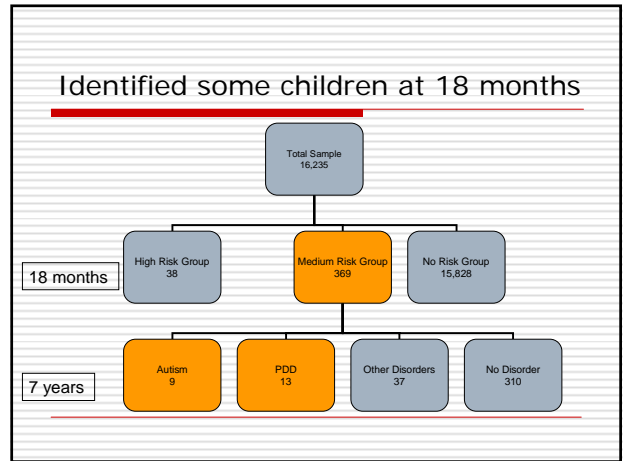
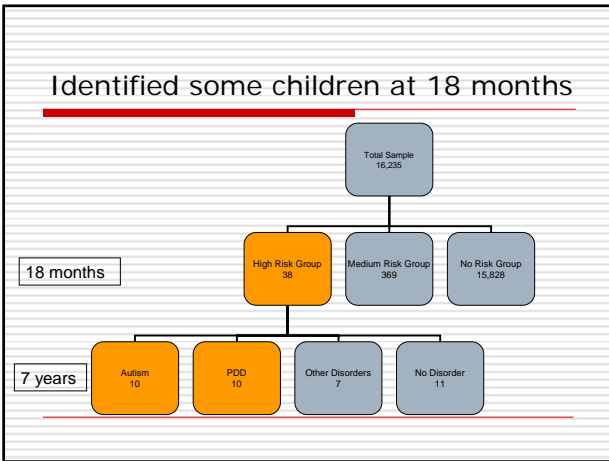
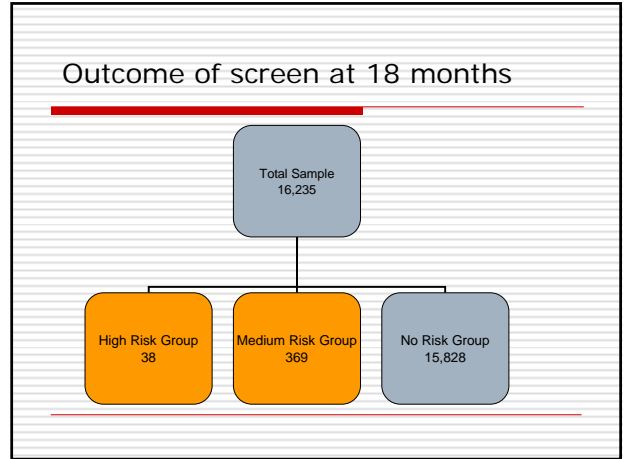
CHAT screening study

- ❑ **C**hecklist for **A**utism in **T**oddlers
- ❑ Screened 16,000 children at 18-month-olds in 10 Districts from South Thames
- ❑ Focused on 'joint attention' behaviours known to be impaired in young children with autism
- ❑ Health Visitor and GP screen at health check
 - *Parent report*: Does your child ever use his/her index finger to point, to SHOW YOU something?
 - *HV/GP observation*: Get child's attention, point to an object and say "Oh look! There's an X!" Does the child look back to see what you are pointing at?

What is joint attention?

- ❑ *Responding* to an adult
 - Following an adult's gaze shift ('gaze monitoring')
 - Following an adult's point
- ❑ *Initiating* a communicative exchange
 - Looking to an object and then back at the adult ('checking out')
 - Pointing to show an object to an adult
- ❑ Critical 'precursor' to language
- ❑ We are all experts at non-verbal communication (without knowing it)
 - Unfortunately, this is not so for children with autism

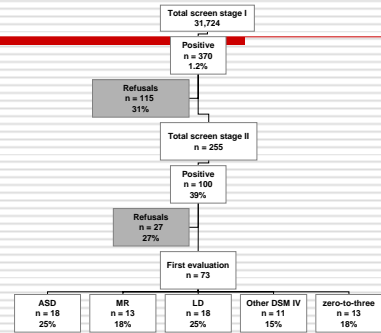




- ### Screening for autism. How did we do?
- ❑ Showed for the first time that it *was possible* to prospectively identify cases of autism
 - ❑ 18-month-olds who by parent report and HV observation do not show joint attention or pretend play are at *high risk* of autism
 - 'High specificity'
 - ❑ However, we detected only 19/50 (38%) cases with autism
 - i.e. we missed more cases than we identified
 - 'Low sensitivity'
 - ❑ Cannot recommend as a population screen but can be used as part of clinical surveillance

Screening for Autistic Spectrum Disorder in Children Aged 14–15 Months. II: Population Screening with the Early Screening of Autistic Traits Questionnaire (ESAT). Design and General Findings

Claudine Dietz · Sophie Swinkels · Emma van Daalen · Herman van Engeland · Jan K. Buitelaar



Summary of ESAT instrument properties

- Higher refusal rate at both stage 1 and stage 2 cf. CHAT study
 - Are parents reluctant to consider a problem in children so young?
- Of those who failed screen II and came to assessment 25% had PDD but 100% had a developmental or psychiatric disorder
- Follow-up will test initial diagnosis and sensitivity (i.e. what proportion of cases were identified prospectively)
- Aim to re-screen whole population at 6 years

'Red flags' for autism

- No big smiles or other warm, joyful expressions by 6 months or thereafter
- No back-and-forth sharing of sounds, smiles, or facial expressions by 9 months or thereafter
- No babbling by 12 months
- No back-and-forth gestures, such as pointing, showing, reaching, or waving by 12 months
- No words by 16 months
- No two-word meaningful phrases (without imitating or repeating) by 24 months
- Any loss of speech/babbling or social skills at any age

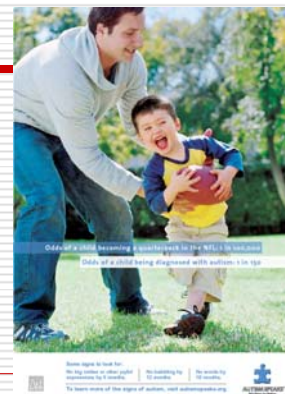
Good web-based information for parents and professionals



<http://www.firstsigns.org/>



<http://www.autismspeaks.org/video/glossary.php>



Clinical assessments of early signs



Recent progress in earlier identification brings challenges

- ❑ Reliability of diagnosis in 2 year olds?
- ❑ Establishment of the utility and limitations of standard assessment instruments with toddlers
- ❑ Ability to indicate prognosis at such an early age?
- ❑ Diagnosis needs to be explained in such a way that parents will recognise their child
- ❑ Parents may be unable to fit the classical picture of autism to their toddler
- ❑ Clinical concept of 'working diagnosis'
- ❑ Clinicians and parents dealing with uncertainty

Journal of Child Psychology and Psychiatry 46:5 (2005), pp 500-513 doi: 10.1111/j.1469-7610.2004.00377.x

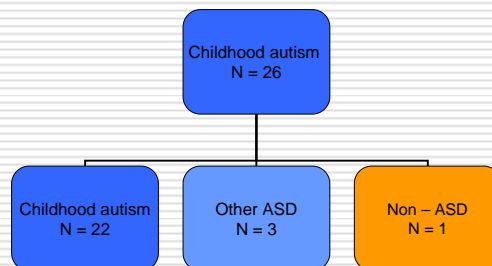
Outcome at 7 years of children diagnosed with autism at age 2: predictive validity of assessments conducted at 2 and 3 years of age and pattern of symptom change over time

Tony Charman,¹ Emma Taylor,¹ Auriol Drew,² Helen Cockerill,² Jo-Anne Brown,¹ and Gillian Baird²

¹Institute of Child Health, University College London, UK; ²Neurosciences Centre, Guy's Hospital, London, UK

- ❑ CHAT screen by community nurses to identify cases
- ❑ Clinic assessment and diagnosis of autism (not broader PDD) at 24 months
- ❑ 26 children seen at 3 timepoints
 - T1 aged 2 years
 - T2 aged 3 years
 - T3 aged 7 years
- ❑ Youngest sample studied prospectively

Stability of diagnosis from age 2 years to age 7 years



Cross-tabulation of Initial Diagnostic Measures and Best-Estimate Diagnoses at Ages 2 and 9 Years

Table 3. Cross-tabulation of Initial Diagnostic Measures and Best-Estimate Diagnoses at Ages 2 and 9 Years*

Age 2 Diagnostic Measure	No. (%)†	Best-Estimate Diagnosis, 2 y			Best-Estimate Diagnosis, 9 y		
		Autism	PDD-NOS	Non-spectrum	Autism	PDD-NOS	Non-spectrum
ADI-R							
Autism	94 (55)	67	19	9	23	16	5
PDD-NOS	45 (26)	15	19	11	20	14	10
Non-spectrum	32 (18)	2	9	32	7	5	21
ADOS							
Autism	111 (85)	80	24	2	62	20	2
PDD-NOS	31 (18)	3	19	9	14	5	9
Non-spectrum	30 (17)	1	3	26	4	5	21
Clinical							
Autism	65 (28)	63	2	0	56	6	1
PDD-NOS	52 (23)	19	33	2	32	18	5
Non-spectrum	54 (23)	2	12	40	10	13	31
Non-spectrum							
Autism	84 (48)				21	12	1
PDD-NOS	48 (27)				27	14	5
Non-spectrum	42 (24)				2	9	37
No. (%)‡		106 (46)	69 (29)	58 (25)	142 (64)	38 (16)	37 (16)

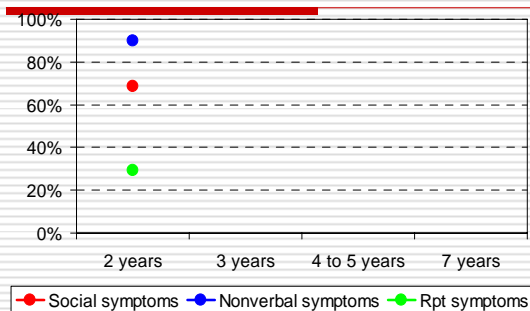
Abbreviations: See Table 2.
 *Values are expressed as number of children unless otherwise specified. The non-spectrum group consists of all children with diagnoses other than autism spectrum disorder. This includes all of the children initially seen in the developmental delay group, as well as some children referred for evaluation.
 †Number and percentages of children seen at age 2 years and at age 9 years.
 ‡Number and percentages of all children seen at age 2 years and number and percentages of children seen at age 9 years.

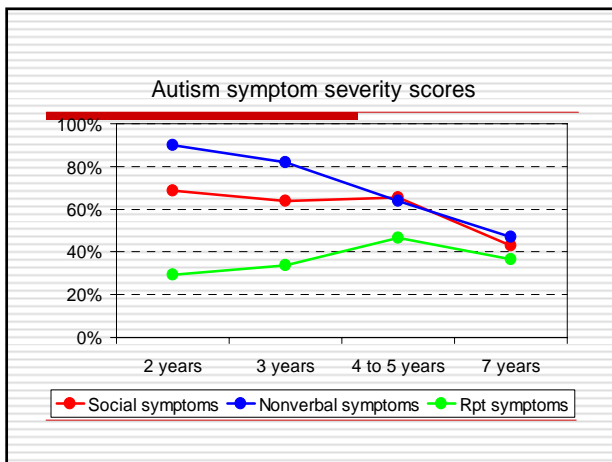
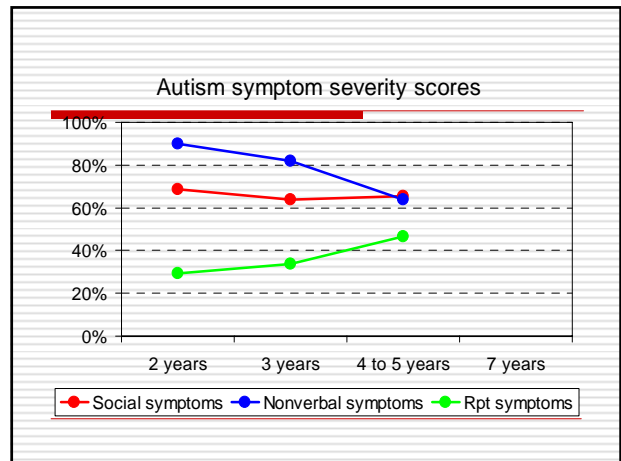
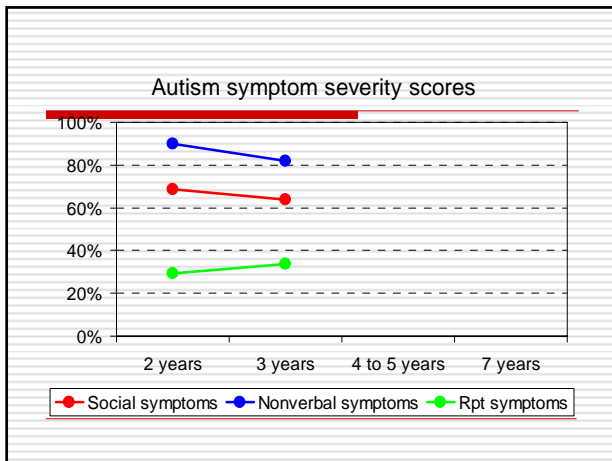
Lord, C. et al. Arch Gen Psychiatry 2006;63:694-701

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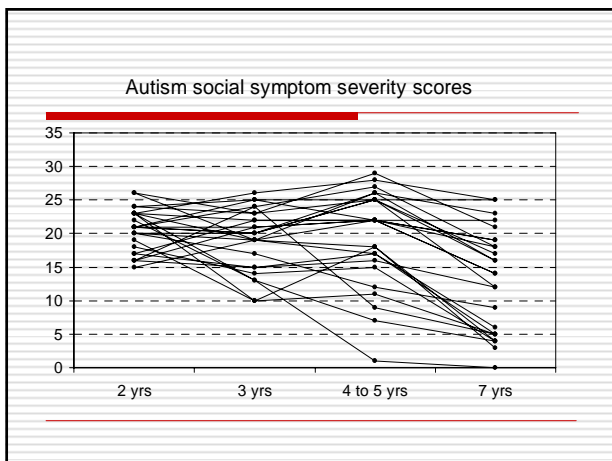
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Autism symptom severity scores





- ### Developmental trajectory of symptoms
- Different trajectory over development in different symptom domains
 - Suggests that they might be separable in terms of causes and outcomes
 - Current interest in how and why features of autism cluster together in populations and clinical samples
 - Over time we see both *increases* (in repetitive behaviours) and *decreases* (in social + communication impairments) in severity
 - This was for the group as a whole
 - What about for *individual* children...?



- ### Outcome is very variable
- Variability increases over time
 - Some children make good progress; others make relatively little
 - Increasing evidence that intervention might play a role in improving outcome
 - What predicts outcome in very young children?
 - What might be the appropriate targets for treatment?

Implications for services?

- Primary healthcare practitioners need to be made aware of early signs
 - Community doctors, community nurses, playgroup and kindergarten staff
- Increase demand/need for appropriate pre-school autism specific therapy, social support and educational provision
- Need to improve understanding of the appropriate behaviours to assess (and treat!) in 2- and 3-year-olds

European Child & Adolescent Psychiatry
11:266–272 (2002) DOI 10.1007/s00787-002-0299-6 ORIGINAL CONTRIBUTION

Auriol Drew
Gillian Baird
Simon Baron-Cohen
Antony Cox
Vicky Slonims
Sally Wheehwright
John Swettenham
Bryony Berry
Tony Charman

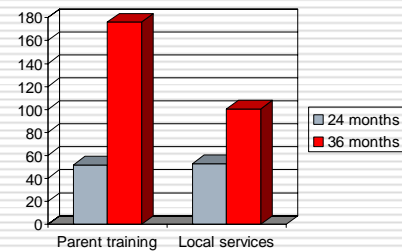
A pilot randomised control trial of a parent training intervention for pre-school children with autism
Preliminary findings and methodological challenges

Pilot RCT with 24 children randomised at 24 months to a parent training programme (N=12) or to 'service as usual' (N=12). Outcome measured 12 months later at age 36 months

Parent training (part focus on JA)

- Monthly sessions and daily homework tasks
- Work on task compliance and management
- Focus on joint-action, turn-taking, joint attention, imitation, use of gestures
- Daily living routines (drink, mealtimes)
- Independence skills (bathtime, dressing)
- Joint play with objects (bring and show, drawing, ball play)
- Joint play without objects (tickle, mirror games, shared action songs)
- Emphasise shared meaning

Number of words comprehended



A new social communication intervention for children with autism: pilot randomised controlled treatment study suggesting effectiveness

Catherine Aldred,¹ Jonathan Green,² and Catherine Adams¹

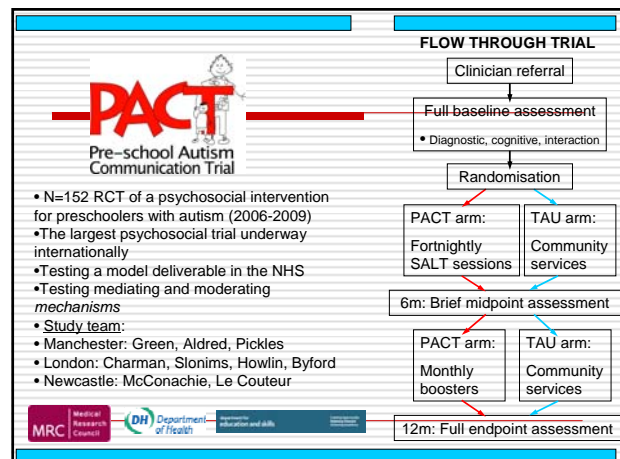
¹Human Communication and Disability Group, University of Manchester, UK; ²Autism Department of Child Psychiatry, South West Children's Hospital, Manchester, UK

ORIGINAL ARTICLES

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

Manuscript accepted 19th April 2006; revised 19th June 2006; accepted for publication 19th July 2006

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 40 children aged 24 to 48 months, whose parents received either baseline information or detailed access to the course. Outcome was measured 7 months after recruitment by parents' use of facilitator strategies, stress, adaptation to the child, and to 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 internal between assessments, a significant advantage was found for the intervention group in parents' observed use of facilitator 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 Child Psychol Psychiatr 2006; 47: 128-40)



Communication-focused RCT

Journal of Consulting and Clinical Psychology
2008, Vol. 76, No. 1, 125–137

Copyright 2008 by the American Psychological Association
0893-3200/08/\$12.00 DOI: 10.1037/0893-3200.76.1.125

Language Outcome in Autism: Randomized Comparison of Joint Attention and Play Interventions

Comrie Kasari, Tanya Paparella, and
Stephanie Freeman
University of California, Los Angeles

Laudan B. Jahromi
Arizona State University

Communication-focused RCT

- N=58 3-to-4-year olds (~20 per group)
- 30 minute session daily in nursery for 6 weeks
- One treatment focused on promoting JA skills the other on promoting symbolic play skills
- ALL children receiving 30 hours a week ABA nursery program (1:1 or 1:2)
- Language outcomes 12 months later

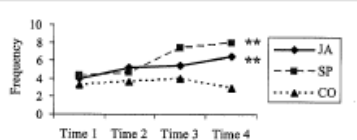


Figure 4. Growth in JA initiation skills in mother-child interactions and Early Social-Communication Scales. JA = joint attention; SP = symbolic play; CO = control group. **JA & SP > CO, $F(2, 164) = 5.35, p < .01$.

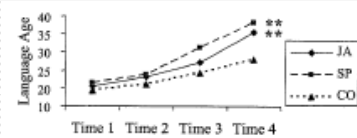
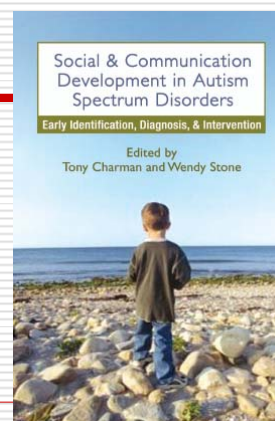


Figure 2. Growth in expressive language, measured in months. JA = joint attention; SP = symbolic play; CO = control group. **JA & SP > CO, $F(2, 164) = 6.34, p < .01$.



Web-based resources for schools



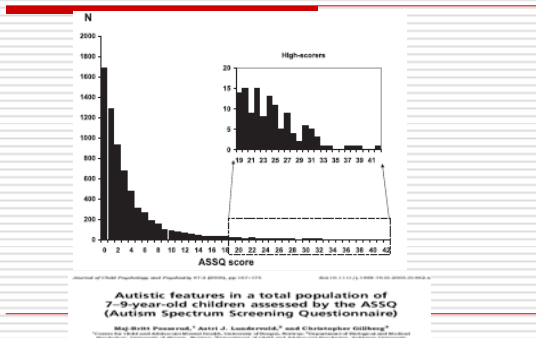
What is autism?
How might a child with special needs be a part of our school?
General Strategies for Intervention
For specific members of the School Community
Resources
Appendix

http://www.autismspeaks.org/community/family_services/school_kit.php

Challenges of phenotypic definition

- Presentation within individuals and within a population changes with development
- Places a heavy load on our ability to measure and establish reliable thresholds
 - Notwithstanding progress, instruments such as the ADI-R and ADOS have limitations
 - Of particular importance is the reliability with which a lower threshold can be set for the boarder spectrum
- Conceptual issue: is ASD a 'lifetime diagnosis'?
 - An individual may move back-and-forward across any diagnostic boundary over time

Is there a boundary between population individual differences?



Challenges of phenotypic definition

PERSPECTIVE

nature
neuroscience

Time to give up on a single explanation for autism

Francesca Happé, Angelica Ronald & Robert Plomin

Exemplar of a complex condition

- Now recognised not to be a unitary disorder
 - In terms of aetiology and symptoms – ‘the autisms’
 - This means that biological and genetic markers will not be present in all cases
- Case definition will continue to be reliant on the behavioural picture alone
- Presentation within individuals and within a population changes with development
- Heterogeneity is a challenge for research
 - e.g. genetics; neuroscience; search for subgroups
- Not universally seen as an impairment
 - ‘Neuroautistic’ vs. ‘Neurotypical’ brain

Challenges for the future

- We need more evidence on what works (for which children?)
- Will increasing understanding of the brain, biology and genetics provide *meaningful* answers for children and families
- What do we know about autism in adulthood?
- How can we change policy and society for the good of people with autism?



think differently about autism

I Exist

Autism also affects adults
Most are isolated and ignored. Think. Act. Transform. Best.



All Party Parliamentary
Group on Autism

APPGA Manifesto

Acknowledgements

- CHAT team: Gillian Baird, Simon Baron-Cohen, Antony Cox, Auriol Drew, John Swettenham, Sally Wheelwright
- SNAP team: Gillian Baird, Emily Simonoff, Andrew Pickles, Tom Loucas, Susie Chandler, David Meldrum
- Other collaborators: Torsten Baldeweg, Sarah-Jayne Blakemore, Patrick Bolton, Michelle De Haan, Francesca Happé, Patricia Howlin, Mayada Elsabbagh, Mark Johnson, Vicky Slonims
- Funded by:



Department for
children, schools and families

