

Working in partnership to promote the early identification of infants and toddlers with an Autism Spectrum Disorder

Cheryl Dissanayake, PhD, MAPS
Associate Professor & Reader
School of Psychological Science



Autism Spectrum Disorders

- More children will be diagnosed with an ASD this year than AIDS, diabetes and paediatric cancer combined (Autism Speaks)
- 1:160 (Australia; 2007)
- 1:110 (USA; 2009)
- 1:100 (UK; 2006)



Autism Spectrum Disorder

- Pervasive Developmental Disorders
 - Autistic Disorder
 - Asperger's Disorder
 - PDD-NOS
- 1. Reciprocal social interaction
- 2. Verbal and non-verbal communication skills
- 3. Stereotyped behaviour, interests, and activities



Importance of early signs

- Early developmental processes
- Early behavioural phenotype
- Early experiences → brain development
- American Academy of Paediatrics (2007) → all children monitored from 12-months onwards



Disorder of post-natal development

- Dawson (2008): Disorder of post natal development
- Risk factors (genetic and environmental) → risk processes (e.g., abnormal attention) which precede full symptom set → epigenetic consequences
- 'Experience-expectant' programming begins to derail



Early identification

- Early identification of risk processes → intervene → prevent full symptomatic picture
- Early intervention → minimize disruption of neural development → foster typical development
- Helt et al (2009) found that early identification and early behavioral intervention → 'recovery' (optimal outcome)



Diagnosis

- Can be difficult because:
 1. the behavioural symptoms are expressed differently in different children (individual variability); and
 2. the behavioural symptoms are expressed differently at different chronological ages and mental ages



Diagnosis is often late because:

- of late referral
 - the physical appearance of these children is mostly "normal"
 - some children have "special" skills and abilities which lead parents and others to think that the child is actually "gifted".
- all the characteristic behaviours that are currently used in diagnosis are not apparent before 3 years of age



YET...

- Nearly fifty percent of parents of children with autism report that they suspected a problem in development before 12 months of age
- the mean interval between first concerns and seeking professional help is about 6 months
- BUT
- 50% of parents were reassured and told not to worry
- The average interval between parent's first concerns and a definitive diagnosis of autism is almost 4 years



Studies of early development

- Retrospective videotape studies
- Retrospective parent report studies
 - Clifford, S.M., & Dissanayake, C. (2008). The early development of joint attention in infants with Autistic Disorder using home video observations and parental interview. *Journal of Autism and Developmental Disorders*, 38, 791-805.
 - Clifford, S.M., & Dissanayake, C. (2009). Dyadic and triadic behaviours in infancy as precursors to social understanding and social responsiveness in young children with Autistic Disorder. *Journal of Autism and Developmental Disorders*, 39, 1369 – 1380.



Studies of early development contd.

- Studies of high risk infant sib samples
- Prospective community based studies

Development in the first year

- Social disinterest
 - Eye contact
 - Orientation to name
 - Responsive smiling
 - Emotional expression
 - Undemanding
 - Conversational babble
 - Imitation
 - Social gestures (clapping, waving, head nods & shakes)
 - Peek-a-boo



Development in **first year** cont.

- Atypical object use
 - Visual exploration
 - Spinning & rotating
- Increased mouthing
- Aversion to touch
- Odd body movements

Development in the **second year**

- Joint attention
 - gaze monitoring
 - following a point
 - pointing to things for the purpose of sharing (i.e., showing and directing behaviours)
- Pretend play
- Other
 - Transition
 - Motor control

Self recognition

- Immediate (mirror) and delayed (video) self-recognition is unimpaired in young children with autism.
- **Nielsen, M., Suddendorf, T., & Dissanayake, C. (2006).** Imitation and self-recognition in autism: In search of an explanation. In S. J. Rogers & J. Williams (Eds.), *Imitation and the social mind: Autism and typical development*. New York NY: Guilford Publications.
- **Dissanayake, C., Shembrey, J., & T. Suddendorf, T.** (2010, in press). Delayed Self-Recognition in Children with High Functioning Autism and Asperger's Disorder. *Autism*

Studies of attachment in children with autism

- Sigman & Ungerer (1984)
- Sigman, Mundy, Sherman & Ungerer (1986)
- Shapiro, Sherman, Calamari & Koch (1987)
- Sigman & Mundy (1989)
- Rogers, Ozonoff, & Maslin-Cole (1991)
- Rogers, Ozonoff & Maslin-Cole (1993)
- Capps, Sigman & Mundy (1994)
- Buitelaar (1995)
- Dissanayake & Crossley (1996)
- Dissanayake & Crossley (1997)
- Dissanayake & Sigman (2000)

Children with autism show:

1. differential attachments to their caregivers
2. attachments that are functionally similar to those shown by typically developing children
3. the same individual variation in the quality of these attachments as do other groups of children

Development in the **second year** cont.

- Regression (approx. 20%)
 - Loss of language and/or social skills
 - 13-to 18-months
 - Most common in AD
- **Social Attention and Communication**

Clifford & Dissanayake (2008)

Gaze

- Parents reports
 - diffs in gaze from as early as 6 m
 - abnormality scores increased across the first two years
- Video investigation
 - less frequent eye contact
 - diff in quality of eye contact
 - Abnormality scores higher in second year

Clifford & Dissanayake (2008)

Affect

- Parents reports
 - diffs in initiation of smiles
 - diffs in responsive smiles
 - diffs in appropriate use of emotions
 - abnormality scores increased across the first two years
- Video investigation
 - no sig diffs in frequency of smiling
 - diff in quality of shared affect
 - increase in abnormality scores across 2-years (ns)

Screening

- **Checklist for Autism in Toddlers** (CHAT; Baron-Cohen, Allen & Gillberg, 1992)
- Baron-Cohen et al. (1996)
 - 16,000 18-month-olds
 - Three items were successful in identifying children who later received a diagnosis of autism
 - protodeclarative pointing
 - gaze monitoring
 - pretend play
- Baird et al. (2000)
 - 6-year follow-up
 - 38 diagnosed with autism
 - 44 diagnosed with PDD-NOS

Screening cont:

- **M-CHAT** (Robins et al., 2001) relies on parental reports of child's behaviour at 24-m
- 6-items
 - Does your child use his index finger to point to indicate interest in something?
 - Does your child ever bring objects to you to show you something?
 - If you point to something, does your child look at it?
 - Does your child take an interest in other children?
 - Does your child respond to his name when you call?
 - Does your child imitate you?

Screening cont:

- **CHAT-23** (Wong et al., 2004)
- **Q-CHAT** (Allison et al., 2008)

Screening cont:

- **The Early Screening of Autistic Traits Questionnaire** (ESAT- 14 items; Willemsen-Swinkels et al., 2006)
- 31,724 children aged 14- to 15-m screened at well-baby clinics
- Items most predictive of ASD:
 - bringing/showing objects
 - smiling
 - reacts when spoken to
- Items most sensitive to ASD:
 - eye contact
 - stereotypical movements
 - interest in people (Dietz et al., 2006)

Screening contd:

- **Autism Observation Schedule for Infants** (AOSI; Bryson et al., 2008)
 - 6- to 18-m
 - 18-items
- **Communication and Symbolic Behaviour Scales** (CSBS; Wetherby & Prizant, 2002)
 - Infant Toddler Checklist (ITC)
 - Behaviour Sample

Screening contd:

- **Screening Tool for Autism in Two-year-olds** (STAT; Stone & Ousley, 1997)
 - 14- to 24-m
- **Autism Detection in Early Childhood** (ADEC; Young et al., 2007)
- **Pervasive Developmental Disorders Screening Test** (Siegal, 1996, 1998)

Research to date

- "No instrument has yet proved sufficiently robust to recommend universal screening" (Charman, 2003, p.1)
- Barbaro & Dissanayake (2009) Autism Spectrum Disorders in infancy and toddlerhood: A review of the evidence on early signs, early identification, and early diagnosis. *Journal of Developmental and Behavioral Paediatrics*, 30, 447-459
 - Measures all used at one time point in development
 - Same tool used across ages
- Remains a need for more prospective studies of infants, which are conducted in community based centres

Question?

- Can routine monitoring within the MCH service of a set of behaviours, previously identified as key markers of autism, be used to prospectively identify infants who will receive a diagnosis of ASD by at least 18-months of age?



The Social Attention and Communication Study (SACS)

Prospective Identification of Autism in Infancy

Dr Cheryl Dissanayake
Ms Josephine Barbaro
School of Psychological Science

Ms Lael Ridgway
School of Nursing and Midwifery

DHS Early Years Office for Children
Autism Victoria
Telstra Foundation Community Development Fund Grant
LTU & DHS Human Ethics

Developmental Surveillance

- 241 nurses from 184 MCH Centres in 17 LGA's
- 8-, 12-, 18-, 24-month assessments
- Level I Screening - identify infants who may be at risk for autism (within the MCH centre)
- Level II Screening - identify infants who are likely to have autism (at La Trobe)
- All referred infants are followed up at 6-monthly intervals until 24-month

Developmental Surveillance

- 22,168 children through the MCH system. The break down of the ages is:
 - 6140 8-month olds
 - 5653 12-month olds
 - 5693 18-month olds
 - 4682 24-month olds

Items at MCH consultations

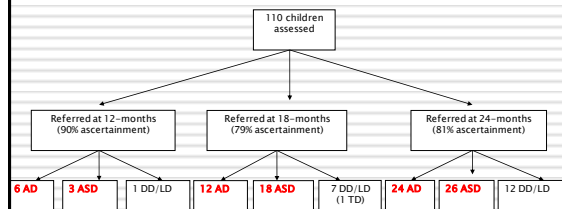
Behaviour	Age at which behaviour monitored			
	8-months	12-months	18-months	24-months
Eye contact	✓	✓	✓	✓
Turning to name call	✓	✓	✓	✓
Use/understanding of language	✓	✓	✓	✓
Imitation	✓	✓	✓	✓
Social smiling	✓	✓	✓	✓
Peek-a-boo	✓			
Pointing		✓	✓	✓
Gestures		✓	✓	✓
Joint attention – following point		✓	✓	✓
Pretend play			✓	✓
Social communication (“showing” behaviours)			✓	✓
Loss of skills			✓	✓

RED ticks indicate “KEY” items

Numbers

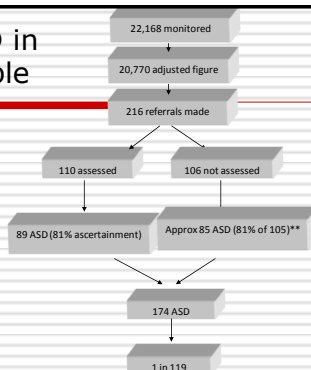
- 216 referrals made by nurses; 124 consent forms received
- 110 children tested
- 89 met criteria for AD/ASD
 - (81% ascertainment rate)
- 20 have DD/LD
- 1 TD (he was extremely shy!)

Numbers contd.



Where a child has not been seen at 24-months, a best estimate classification was given based on their last assessment

Rate of ASD in SACS sample



** If 50% = 1:146

- Barbaro, J., Ridgway, L., & Dissanayake, C. (2010, in press). Developmental surveillance of infants and toddlers by Maternal and Child Health nurses in an Australian community-based setting: Promoting the early identification of Autism Spectrum Disorders. *Journal of Paediatric Nursing*.
- Barbaro, J., & Dissanayake, C. (2010, in press) Prospective identification of Autism Spectrum Disorders in infancy and toddlerhood using developmental surveillance: The Social Attention and Communication Study. *Journal of Developmental and Behavioral Paediatrics*.

Recent letter from a parent

- Our daughter was part of the Social Attention and Communication Study last year which is when we found out she was on the Autism Spectrum.
- Our lives have changed greatly since then and it has been for the most part a positive change. Without that study it would have taken us years longer to realise, as our Paediatrician at the time insisted there was nothing out of the ordinary and we should wait until our (then 2.5yo) was 5 for formal assessments.
- Needless to say we now have a new paediatrician, we are attending Kalparrin early intervention centre and our daughter actually communicates with us (which is something I treasure more than I have the words to say).

Where should we go?

- Promote universal developmental surveillance of early signs of autism
- Educate all primary health and care professionals who see children during the first two years of life about the early signs of autism
- Work with government to promote very early intervention for those identified to maximize developmental outcomes

Early Start Denver Model



ESDM is a developmental, behavioural and relationship-based intervention program, designed for use within naturalistic interactions. It is suitable for children aged 12 – 60 months.

ESDM equips therapists / parents with the necessary intervention skills to engage, communicate with, and teach their very young children with or at risk for autism.



Early Start Denver Model

- **Dawson G, Rogers S, et al. (2009).** Randomized controlled trial of an intervention for toddlers with autism: The Early Start Denver Model. *Pediatrics*
- **Rogers, S., & Dawson, G. (2009).** Early Start Denver Model for Young Children with Autism: Promoting Language, Learning, and Engagement.
9781606236314 297 pp;2009; Aus \$ 73.00 (Available from Footprint Books)

... climate of optimism ...

- The importance of public education about the early characteristics of autism, and the value of early identification and intervention cannot be underestimated

THANK YOU

