

Autism in Australia

Jacqueline Roberts
University of Canberra
University of Sydney

- Identifying autism; is there an epidemic?
- Getting a diagnosis
- How understanding autism impacts on treatment
- Getting early intervention; issues of type, cost and intensity
- Funding and the Federal *Helping Children with Autism* package

Identifying autism; is there an epidemic?

Is there an epidemic of autism?

In the past Autistic Disorder 4: 10,000

Currently Autistic Disorder 25:10,000

Epidemiological surveys of PDDs

- Bertrand et al 2001, AD/10,000 40.5,
all/10,000 67.5
- Baird et al 2000, AD/10,000 30.8,
all/10,000 57.9
- Chakrabarti & Fombonne 2001, AD/10,000 16.8,
all/10,000 61.3

Recent Australian study

- **Australian Prevalence Study (2007) core finding; estimated prevalence of autism spectrum disorders in Australia of 62.5 per 10,000 for 6-12 year old children.**
- **One child with an ASD on average in every 160 children in this age group = 10,625 children aged between 6 and 12 years with an ASD in Australia.**

Possible explanations;

- Something in the water...MMR vaccine, heavy metal poisoning, leaky gut/peptides
- Widening of the spectrum, changing definitions, changing diagnosis
- Increased awareness
- Genetics and geeks
- Increase in services and funding

Diagnostic criteria for Asperger's Disorder:

- Intelligence generally within the average to high range
- Restricted and repetitive patterns of behaviour, interests and activities
- Impairment in social interaction
- No significant delay in language onset

DSM IV
ICD-10

• Communication impairment

- Motor clumsiness

Gillberg, Atwood
Wing.

Comparison Asperger's Disorder & Autistic Disorder (DSM)

Asperger's Disorder

- No intellectual disability
- Often fluent speakers no developmental delay
- Usually restricted interests rather than repetitive behaviours

Autistic Disorder

- Intellectual disability common
- Obvious communication impairment
- Usually repetitive behaviours rather than restricted interests

HFA & AS same/different?

- Long term outcomes findings conflicting
Starr et al (2003) support difference at 2 year follow up
Howlin (2003) retrospective study of adults matched for IQ fails to support difference

Getting a diagnosis

Trends in diagnosis and intervention

- Earlier identification (under 2 years)
- Assessment of referencing and joint attention;
 - CSBS (Wetherby and Prizant, 2002)
 - Early Social Communication Scales (Mundy et al. 2003)
- Focus on early Early Intervention
- Can we teach joint attention?
- Implications of genetic research?

Need for family focus: Early identification; < 3yrs

- Characteristics of autism are being recognised earlier (Dawson & Osterling, 1997)
 - difficulty orienting to social stimuli
 - impoverished social gaze
 - impairments in joint attention
 - impairments in motor imitation
- Focus on parent programs for toddlers

Developmental processes

Social orienting	First 6 mo
Reciprocity (shared affect)	First 6 mo
Referencing	First 6mo
Joint attention	From 6mo
Imitation	6-12 mo
Symbol development (language)	12- 16mo
Theory of Mind	4years

Early provision of services essential

- As soon as child is identified
- Need coordinated approach
- Issues of delays/difficulties getting assessment and diagnosis, especially in regional/rural areas
- Multidisciplinary approach to assessment essential for referral to services (Jordan, 2001) multi/transdisciplinary service provision ideal.
- Lack of services for adolescents and adults

Family Support

- Parents/families key in short and long term
- Parents rate support; spouse 1, family 2, professionals 3 (Neil, 2002)
- EI increasingly parent focused, education not so
- Embedded intervention requires active participation for family members in assessment and intervention.
- Discrepancy between recommended practice (NRC, 2001) and common practice
- Necessary for individual planning to focus on family participation in child outcomes & be based on family identified priorities and concerns.

Focus on families

Families want to know what can be done to enable child to develop to full potential. The challenge may be understanding what this might be.....

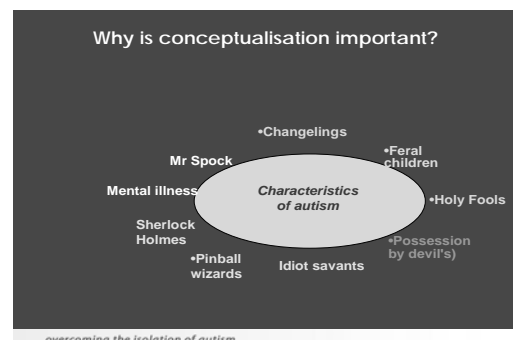
Programs should:

Be integrated into the child's daily routine

- Include and empower parents and families,
- Provide families with information about services
- Increase parent/family knowledge and understanding of autism.
- Increase parent/family skills, competence and confidence.

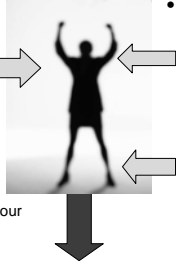
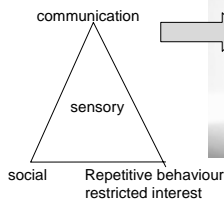
How our understanding autism impacts on treatment

Understanding autism



Mismatch between autism and the environment

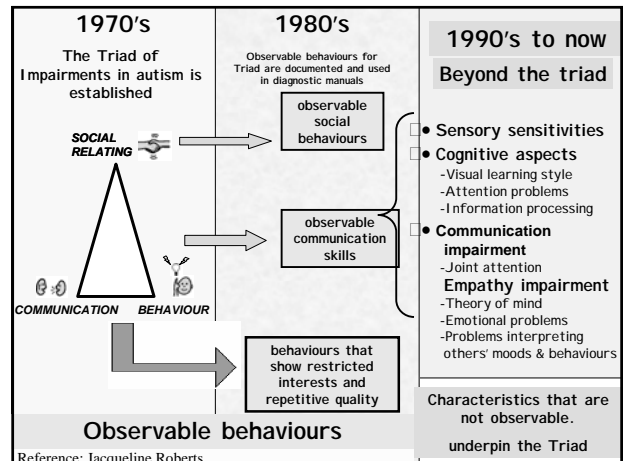
- Autism Triad



- Environmental Characteristics**
 - communication and social demands; adults and peers
 - sound, light and touch, taste and texture
 - unpredictability
 - too much detail

Confusion, anxiety and FEAR

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Echolalia

- 60s Psychoanalytic approach.** Lack of speech viewed as hostile, echolalia as lack of ego development
- 70s Behaviourism:** Focus on speech and imitation training rather than on communication, echolalia viewed as self stimulatory
- 80s focus on pragmatics,** the function of echolalia.
- 90s + focus on early language development,** autism associated with gestalt style

2000s -Mirror neurone theory

- Neurons in frontal cortex.
- Show activity in relation to;
 - specific actions performed by self
 - matching actions performed by others.
- Provide a potential bridge between minds.
- Mal-development results in imitative disturbance involving difficulties
 - in copying actions
 - inhibiting more stereotyped mimicking, such as echolalia.

Echolalia: Function

may be used for:

- turn taking,*
- affirming,*
- requesting*
- commenting*

- Is related to comprehension
- Is a means of expression, coping, learning language
- Can be stress related

Echolalia may increase...

- During unstructured, unpredictable, or transitional periods
- When tasks or situations are unfamiliar, difficult or challenging
- During activities or situations that cause anxiety, fear, distress or excitement
- When the language used by the speaker is too complex
- When the present context triggers a specific memory and the associated language is recalled.

Getting early intervention; issues of type, cost and intensity

Interventions, treatment and management for autism: “fad magnets for off the wall treatments” (Matson 2007)

A Review of the Research to Identify the Most Effective Models of Practice in Early Intervention for Children with Autism Spectrum Disorders

Jacqueline Roberts Ph.D. University of Sydney
Margot Prior Ph.D. FAPS University of Melbourne

www.health.gov.au/intrnet/wcms/publishing.nsf/content/mental-child-autrev

Review document and booklet sent on request

Background to review

- Australian Government Department of Health and Aging; Assistant Minister Christopher Pyne
- 2005 forum
- Update and extension of report commissioned by NSW DADHC in 2004
- 2 parts:
 - Review of research literature
 - Survey
- Outputs, 2006 review document and brochure; available on request

Aims

- Why the review?
- How could it be useful?
- Research shows families need information
- Confusing range of interventions and programs out there
- Many make unsubstantiated claims
- Families very vulnerable; especially at time of diagnosis
- **Faith based compared to Evidence based interventions**

Australian ‘Helping Children with Autism’ Package 2008

- Families, Housing, Community Services and Indigenous Affairs
- Health and Ageing
- Education Employment and Workplace Relations
- 190 million for early intervention, Medicare rebates, play groups, professional development for school staff, parents/carers
- 6 autism-specific child care centres

Evaluation of Outcomes of Early Intervention Programs for Children with Autism and Their Families

University of Sydney,
Centre for Early Interventions
Autism Spectrum Australia, (Aspect)
and New Children's Hospital, Westmead

*Jacqueline Roberts, Susan Dodd,
Trevor Parmenter, David Evans, Mark
Carter, Natalie Silove, Katrina Williams,
Trevor Clark, Anthony Warren, and
Emma Pierce*

The Study

- ARC funded
- Collaboration between industry; Autism Spectrum Australia) & The University of Sydney
- Background:
 - increasing demand for services
 - broad range of programs/interventions
 - lack of reliable objective information re type of program, cost effectiveness

Issues of interest

- Level of intensity
- Individual versus small group focus
- Context (home versus centre based)
- Type of parent education and support
- Child outcomes
- Family outcomes

Interventions in order of popularity:

Sp Path 71%,
Preschool 52%,
dietary sup 43%,
child care 38%,
OT 37%,
gluten free 31%,
casein free 30%,
generic EI 29%,
medication 23%

Interventions (cont.)

- alt therapy 14%
- ABA 14%
- EI class school 10%

Less than 10%

play group, Hanen, GSS EI & Play Steps, RDI, music therapy, Connect therapy, play therapy, Floortime, parent groups/programs Jigsaw Aspect, auditory training, Behavioural optometry

Who wants to be NT?

- What do we know from people with autism about the impact of the condition on daily life, on the way people with autism perceive the world and in particular their relationships with others?
- What are the implications of this insight for families and professionals?
- Do we have the right to impose a neurotypical perspective as the only valid way of being in the world on people with autism?

Understanding Neurotypicality; Frank Klein

- "**Neurotypicality** is a pervasive developmental condition, probably present since birth, in which the affected person sees the world in a very strange manner.
- It is a puzzle; a enigma that traps those so affected in a lifelong struggle for social status and recognition.
- Neurotypical individuals almost invariably show a triad of impairments, consisting of **inability to think independently of the social group, marked impairment in the ability to think logically or critically, and inability to form special interests** (other than in social activity).
- It is my hope that this article will help us understand the very different world of the neurotypical."

Autism Rules.....OK

- ‘Whereas autistic differences, which are at the profound level of how we perceive the world and learn from it, are not and have never constituted a disease, disaster, or tragedy, and in fact encompass in *all* autistics strengths unavailable to the typical population;
- **Oopswrongplanet at ww.isn.net/~jypsy/**

Jim Sinclair 1993

“Autism” is a way of being, It is pervasive, it colours every experience, every sensation, perception, thought, emotion and encounter, every aspect of existence. It is not possible to separate the autism from the person- and if it were possible, the person you had left would not be the person you started with”.