



Government of South Australia

Department for Families
and Communities

Disability SA

THEORY, PRACTICE, DILEMMAS AND OPPORTUNITIES:

**WORKING WITH PEOPLE WITH AUTISM
SPECTRUM DISORDERS -
THE SA EXPERIENCE**

ASSID 2009

**POWER and PASSION :
PROGRESS THROUGH PARTNERSHIPS**

Overview

➤ The Nature of the Issue

- Impact and prevalence

➤ What we know

- The evidence (what does and doesn't work)
- What families want
- What families need

➤ What is available

➤ Issues

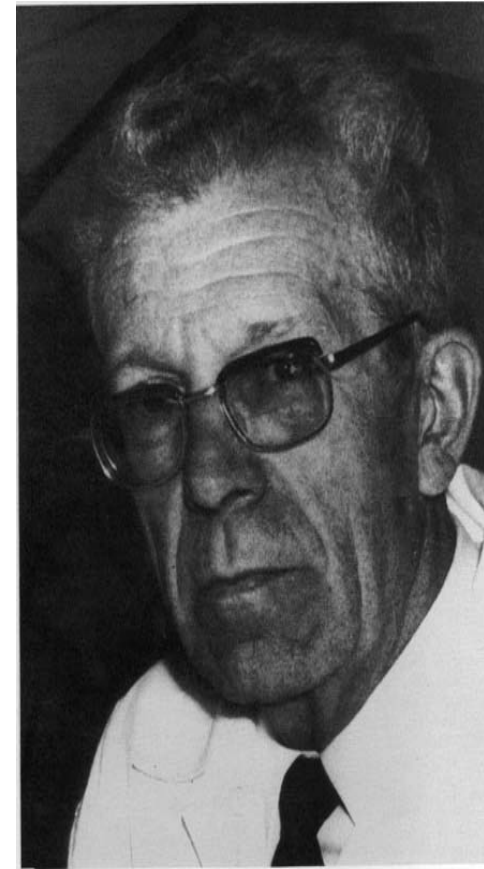
What is Autism Spectrum Disorder ?

Autism is a life long neurological disability of unknown cause.

It is a syndrome consisting of set of developmental and behavioural features that must be present for the condition to be diagnosed.

History

- Kanner's work in 1943
- Asperger 1944 (translated to English in the 1980s)
- Common features but different:
 - Difficulties with reciprocal social interactions
 - Communication
 - Ritualistic and stereotypical routines
 - Usually beginning within the first few years of life



The Triad of impairments

The core features of autism spectrum disorder include impairment in three main areas of functioning:

- i) Social interaction
- ii) Communication
- iii) Restricted repetitive and stereotyped patterns of behaviour, interests and activities

Nature and impact of ASD

Theoretical constructs

- Theory of Mind or Mind Blindness
- Executive Functioning Deficits
- Central Coherence Deficits

DSM-IV definitions

- DSM's pervasive developmental disorders
- ASD concept
- 3 to 4 times more common in males
- Changes throughout life
- Range of IQ

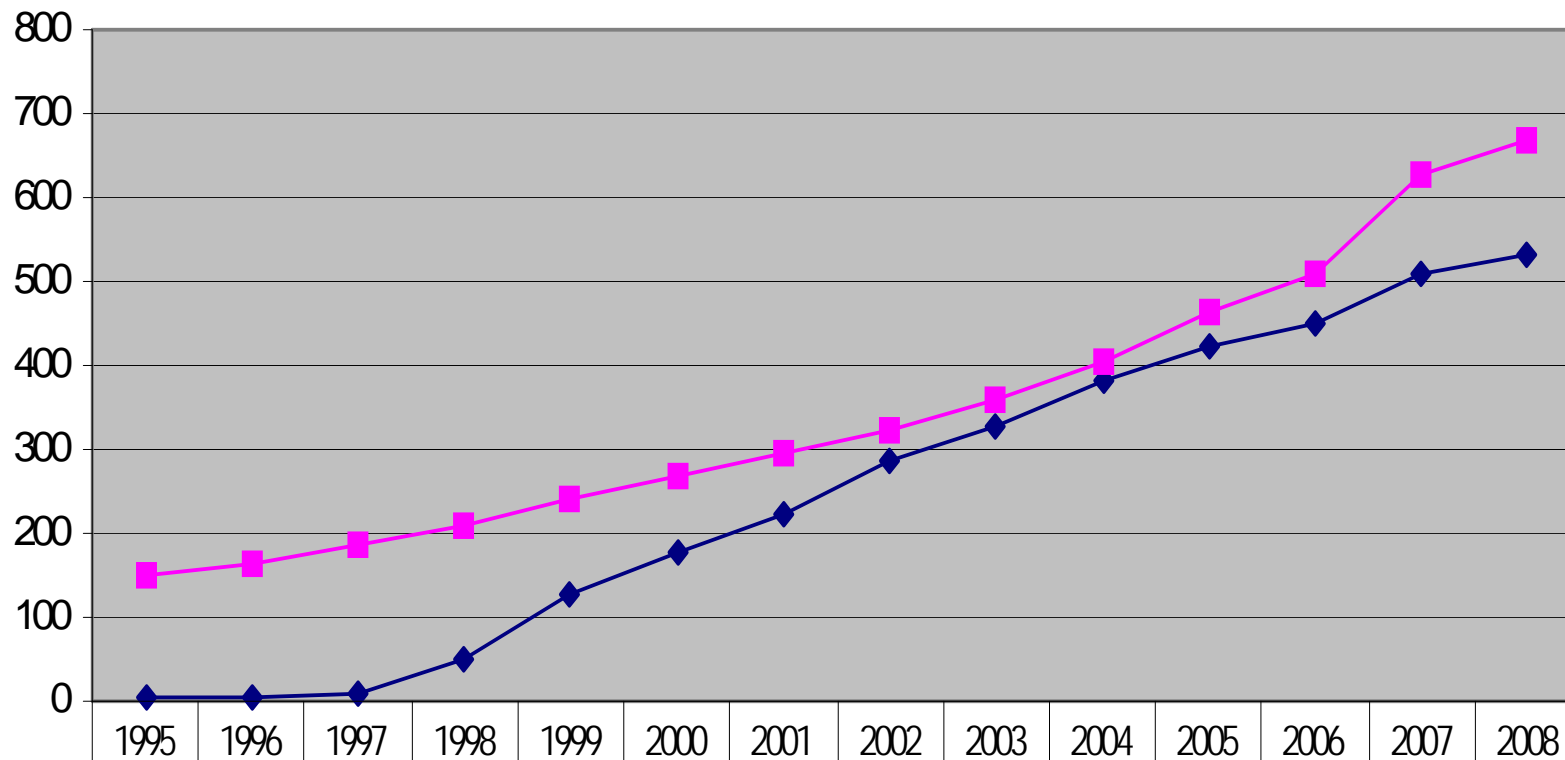
Incidence of ASD

- It appears that the incidence rate of ASD is rising.
- 1966 – 1991 - 4.4 per 10,000

Large % increases (600% to 1300%)

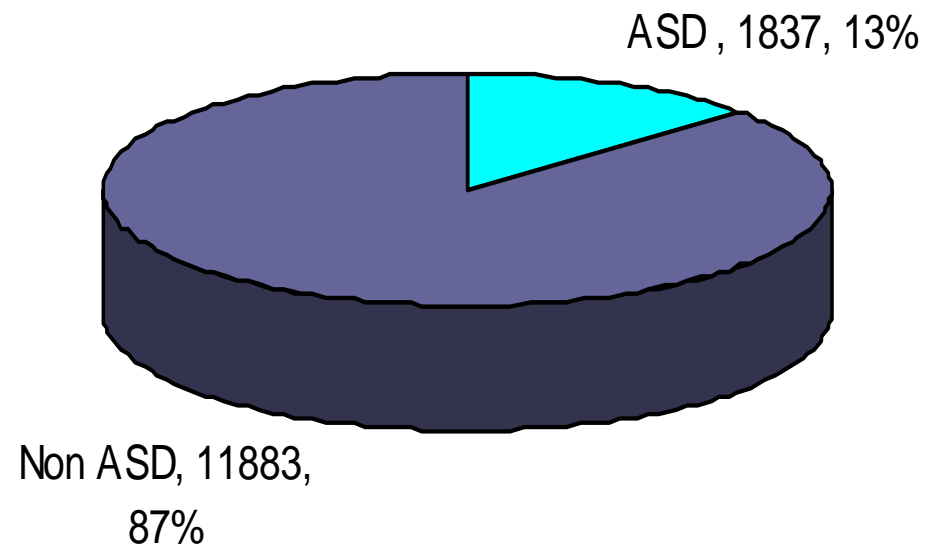
- 60 per 10,000 reported in USA in 2003
- 116.6 per 10,000 reported in the UK in 2006
- Actual rise or cultural factors?

Autism/Asperger Clients 0-25 Yrs 1995-2008



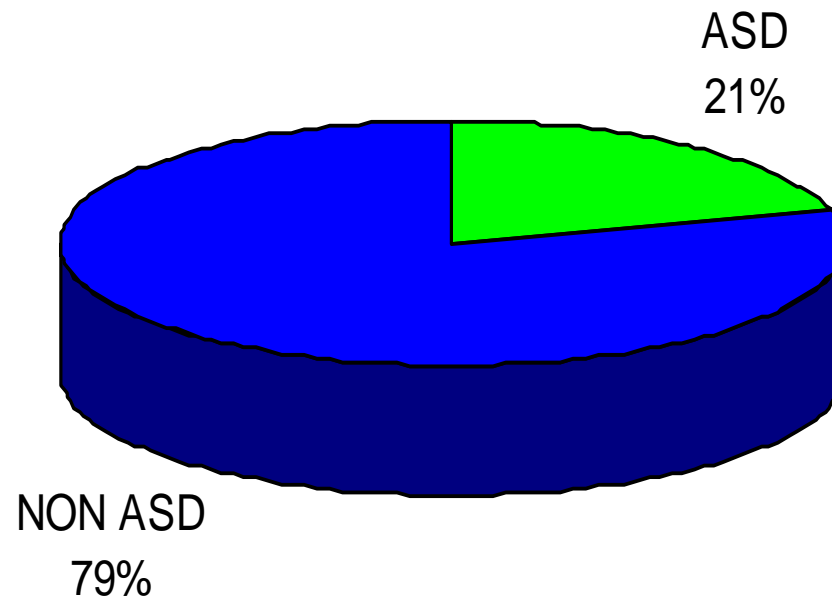
◆ Aspergers Clients	3	4	11	52	128	176	223	288	326	381	421	452	508	531
■ Autism Clients	152	162	187	211	240	268	296	325	358	404	462	509	627	670

ASD clients as percentage of all Disability SA clients



Southern School Age and Youth Program

% CLIENTS OF SAYP with ASD



Impact

- Specialist Intervention Services
Intensive Family Intervention
Programme (60 – 80% of clients they
are working with at any one time)
- Staff predictors of challenging
behaviour
- Literature: parental stress; complexity

Co morbidity issues for people with an ASD

- Children and adolescents with autism may have high levels of anxiety and mood disturbance, disruptive and self absorbed behaviour, that persist through childhood into adolescents (Brereton and Tonge 2004)
- 10%of young people with Aspergers likely to experience significant emotional and behavioural difficulties (Curran 2007)

Learning Strengths

- Take in chunks of information quickly
- Remember information for a long time (excellent long term memory for facts and routines)
- Use visual information meaningfully when taught in meaningful ways
- Learn long routines quickly and motivated to repeat familiar routines
- Understand and use concrete, context free information and rules
- Concentrate on topics of specific interest

Janzen 2003



How to help: Treatment and intervention

No cure or recovery but children with ASD will continue to develop and learn behaviour that will equip them for life.

Outcomes

- In follow up studies verbal skills/cognitive ability best predictor of long term success
- Majority with autism will require some support as adults
- Minority able to live and work independently
- Another minority require high levels of care
- Very difficult to make predictions of how a child with ASD will develop

History of Medical 'breakthroughs'

Oliver Sacks:
"An Anthropologist on Mars"



Evidence based practice:

“ Evidence Based Practice is the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients, integrating individual clinical experience with the best available external clinical evidence from systematic research”

Sackett, D.L (1996)

“ Evidence Based Medicine what it is and what is it isn't”

Reviewing the evidence

- National Autism Forum 2005
- Dept of Health and Ageing :

“A review of the research to identify the most effective Models of practice in early Intervention for children with autism spectrum disorders”

Jacqueline MA Roberts

Margot Prior

July 2006

Possible Treatments: Questions to ask:

- Will the treatment result in harm to the child?
(physical or psychological harm)
- Is the treatment developmentally appropriate for the child ?
- How will failure of the treatment affect my child and family?
- Has the treatment been validated scientifically?
- How will the treatment be integrated in to the Childs current program?

Freeman (1997) cited in Brereton and Tonge
2004

Treatment considerations

- Beware of treatments that promise “cure”.
- Beware of treatments that are said to work for all children with autism.
- Detailed assessment to establish baseline skills should be undertaken before any intervention so that change can be documented and measured.
- Interventions should be sensitive to the developmental level and skills of the child.

Treatment considerations

- “do not become so infatuated with a given treatment that functional curriculum, vocational life and social skills are ignored”

(Freeman 1997)

“A major concern is the large and possibly growing gap between what science can show is effective on the one hand and what treatments parents actually pursue”

(Volkmar et al 2004)

Biological based Interventions

- Medication:
 - Potentially effective symptom relief:
Neuroleptic /Antipsychotics ,Risperidone, the SSRIs,Antidepressants ,Stimulants and Anticonvulsants
 - Harmful: Naltrexone, Secretin and Adrenocorticotrophin Hormone
- Complimentary and alternative interventions-
no evidence of efficacy

Psychodynamic Interventions

- Based on assumption that autism is the result of emotional damage ie failure to develop attachment with a parent.
- debunked

Behavioural interventions

- Applied Behaviour Analysis
 - Discrete Trial Training
 - Lovaas Program
 - Contemporary Applied Behaviour Analysis
-
- Positive outcomes
 - Concerns about level of intensity required (doesn't suit all families)

Developmental interventions

- Floor Time
- Responsive Teaching
- Relationship Development Intervention

- Little evidence of efficacy although discrete components have been demonstrated to be effective.



Therapy based interventions – communication

Visual strategies and visually cued instructions

Manual signing

Picture Exchange Communications system

Social Stories

Speech generating devices

Facilitated Communication

Functional Communication Training



Therapy based interventions - Sensory Motor

- Auditory Integration Training
- Sensory integration



Therapy based interventions

- SCERTS
- TEEACH
- LEAP



Family based interventions

- Family Centered Positive Behaviour Support
- Hanen Program
- Monash Early Learning Program

Characteristics of Effective Programs

- Effective programs tend to contain
 - -autism specific curriculum
 - Highly supportive teaching environment
 - Specific strategies for generalisation of skills
 - Predictability and routine
 - functional communication approach
 - support transitions
 - ensure that family members engaged

Summary

- Different children with ASD respond in different ways to any given intervention program or intervention program
- No “one size fits all”
- There are benefits (short and long term) from early /intensive family based treatment programs (whatever their theoretical basis) as long as the program is appropriately adapted to child patterns of strength and weakness and takes into account family circumstances.

Issues that families identify

- Assistance at times of transition (such as leaving school or looking for work)
- Stressful caring for a person with an ASD who does not become independent
- Staff who work in school/ employers/ co-workers not understanding the behavioural, communication and social difficulties of the person with an ASD
- Family's significant ongoing concerns re their child's behaviour and vulnerability
- The person's future

What works for Families

- Facilitating family choice and control of supports
- Helping families navigate complex service systems
- Helping families to identify and access informal support through family, friends and neighbors
- Considering the family context in the assessment and intervention planning process

What families say they want

- Timely ongoing assistance (continuing once child gets older)
- Clarity about what services were available from whom.
- Parent education programmes
- Having contact with other parents who know what they are going through
- Access to local therapeutic supports
- Assistance in dealing with complex behavioural issues
- Access to a variety of recreation and respite options

What families need: a personal view

The Capacity to Benefit Needs Matrix

Low severity risk family breakdown etc	Low severity risk family breakdown etc
Low capacity to benefit	High capacity to benefit
High severity risk family breakdown ect	High severity family breakdown etc
Low capacity to benefit	High capacity to benefit

(Baker 1995).

What we have

- Disability SA
- Autism SA
- Generic services: CAMHS/ Health /DECs etc
- Existing parent groups
- Private providers
- Medicare rebates
- FACHSIA initiatives
- DEEWR

Disability SA

- Accommodation services
- community teams :
- Early Childhood Program
- School Age and Youth Program
- Adult teams;.
- Specialist intervention teams.
- Access to other generic agencies and services
- ASD : case management services for complex clients

Disability SA

ISSUES

- Capacity
- High volume demand management
- Waiting lists
- Agency of last resort
- recruitment and retention of staff

Autism SA

- A diagnostic service
- Early Development Program
- Autism playgroups
- School awareness program
- Community services: eg day options for adults
- Resources training and development
- peer support program
- Autism Advisory Service



Autism SA

ISSUES

- capacity
- waiting lists
- recruitment and retention of staff

MEDICARE provisions

- Enhanced primary care
- Better Access (Mental Health)
- Helping children with autism

MEDICARE provisions

ISSUES

- Medicos lack of familiarity with the scheme
- Complexity
- Different rates

FaHCSIA funds -

- Child less than 7 years with ASD
- Autism advisor assists to access negotiate services provision (3 in SA)
- \$12,000 (\$6,000 per financial year)
- Early intervention through service provider panel (6 in SA)
- Since its inception nearly 500 families have accessed these services.

FaHCSIA funds - ISSUES

- Families juggling multiple agencies and negotiating increasingly complex service pathways
- Waiting lists of the access to service providers
- Difficulties for consortiums recruiting suitably qualified /experienced staff

Other Commonwealth initiatives

FaCHSIA:

- Play Connect play groups
- Early Learning Centers

DEEWR:

- Teacher training
- Parent Workshops

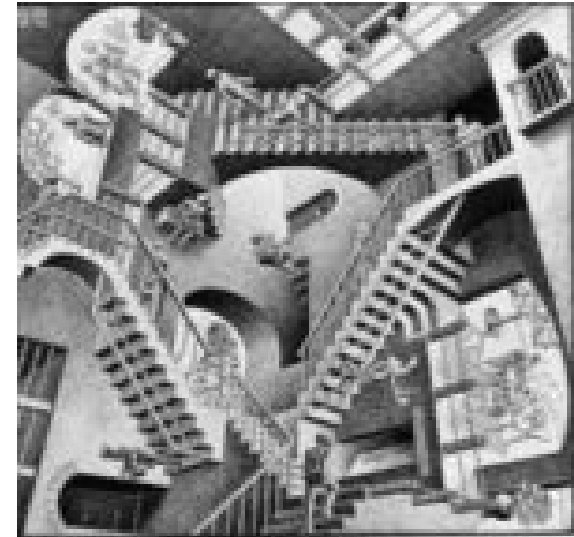


Other resources

- The capacity of families to assist one another
- The talents and abilities of people with an Autism spectrum disorder.

What we need to do

- Clear road map of services
- Collaborative approaches
- Staff with knowledge, skills and capacity to provide targeted intervention
- Access to recreation/respite
- Appropriate accommodation models



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Richard O'Loughlin

richardoloughlin@bigpond.com