

# ***Making Sense of ASD for Families and School Communities***

**Autism, Aspergers and Pervasive Developmental Disorders:  
The Specific Disorders of Social Development (SDSD)**

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1. Problems with the descriptions of Autism
2. Research conceptual shifts in understanding
3. Category, Dimensional or Developmental Disorder?
4. Implications of Developmental Framework
5. Implications for Treatment and QoL
6. SDSDs as a self evident human right

# How is Autism described?

- “Neurotypicals” suggests those with Autism see us as different
- What does it mean to someone to be called Autistic?
- *“a disease, which makes you different to normal people, no one will understand you, you never recover, never make friends, be forever dependent on others, lead to impossible behaviour, there is no proven treatment, not recognised as an intellectual disability, there is no known cause, although with genetic research hope to find a single explanation for this, the purest psychiatric disorder of childhood with the greatest predictive validity”*
- *Lack of species recognition!*
- *Only those non-verbal rocking in the corner of an institution?*

*Such a stigmatising approach is too simplistic!*

*Social Awareness of Social Awareness*

# The Challenge of defining and helping Autism

- First do no harm?
- If you have problems of communication, empathy and imagination, can you be happy, and have a quality of life?
- How do we explain a complex neuro biological predicament accurately, in non-stigmatising terms that both describes the vulnerability, enables access to special resources and intervention but leaves room for enabling a quality of life, adapting to their handicaps, playing to their strengths and developing positive relationships that they can rely on?
- Need accurate labels to access funding for special intervention, but their accuracy and use need to be negotiated.
- Successful Role Models/ASPIs

# How do we make the diagnosis?

- **Autistic Triad:**

1. relative impairment of symbolic encoding or language
2. problems of social relating and empathy
3. preoccupation with sameness
4. Onset before 36 months (onset of what?)

*problems of communication, social interaction and imagination*

- **Predictive validity:** 10% independent lives, 25% improve with age, 70% adults institutionalised:

*A pure condition or lifelong problems?*

# Clinical Diagnosis

- Research Assessments

- a research reliable standard for the diagnosis of Autism.

Diagnostic instruments: ADI-R, DISCO, ADOS, 3Di, SRS

- All instruments have their problems especially when compared against other reliable instruments.
  - ADI-R concentrates on deviancy
  - DISCO promotes a developmental frame of these domains.
  - ADI-R, DISCO not practical in clinical practice
- NSW Gold Standard is 2 Clinicians with experience agreeing.

ADI-R identifies a **single issue as the diagnostic feature of Autism:** *lack of reciprocity...*

*Pervasively in social interaction, communication and interests.*

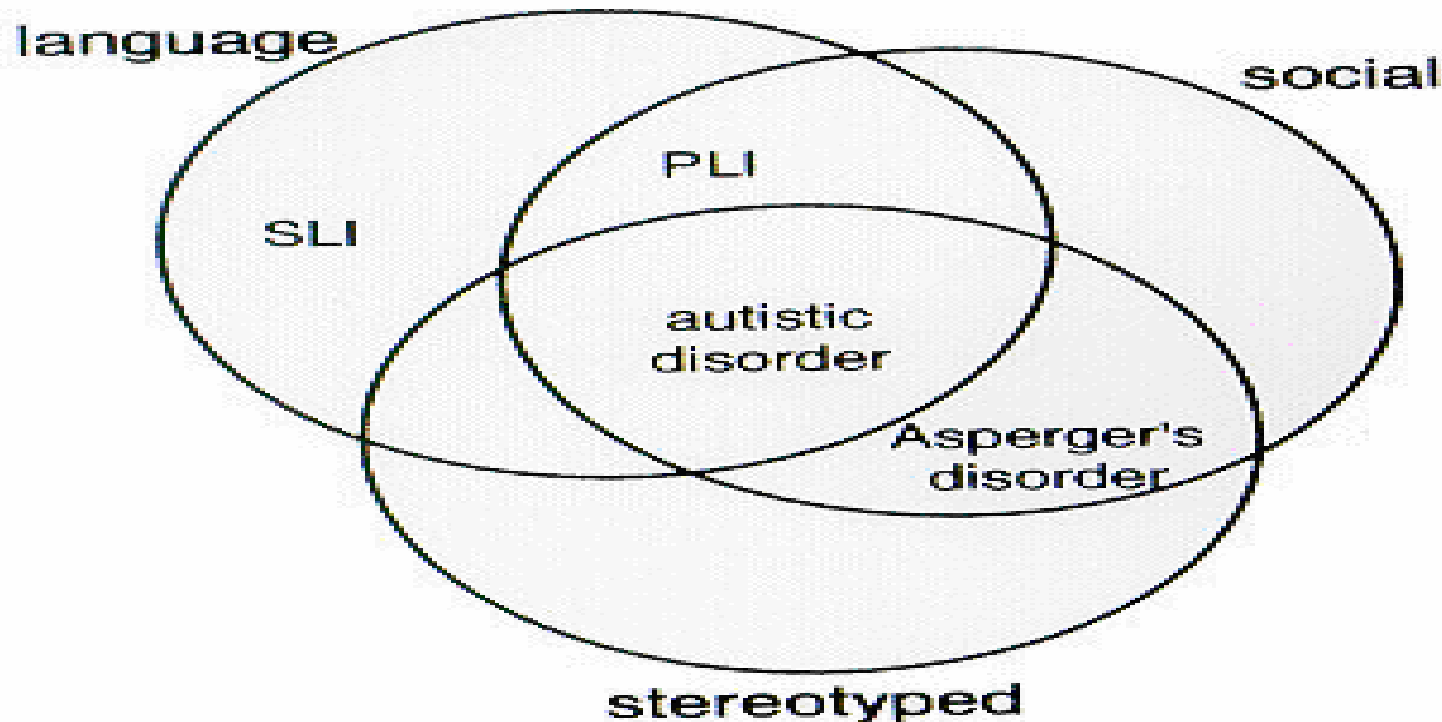
# Conceptual shifts in ASD from “pure Autism”

- **Expansion of diagnostic categories** to include new diagnoses of PDD
  - Asperger’s syndrome,
  - Rett’s Syn,
  - Childhood Disintegrative Disorder
  - Atypical Autism
  - PDDnos, no longer as a diagnosis of exclusion
- **Increased number of symptoms recognised** to be diagnostically relevant in
  - Research Diagnostic Instruments such as ADI-R & DISCO (3 domains of difficulty of communication, social interaction and imagination; 36/110 algorithm symptoms, most sensitive 4-5yrs),
- **clinical descriptions of Aspergers** and related symptoms and clinical contexts eg Tony Attwood, *Problems with:*
  - *appreciation of social cues, use of gesture, ability to give messages with eyes,*
  - *repairing a conversation, literal interpretation, prosody, idiosyncratic use of words,*
  - *vocalising thoughts, eidetic memory, hyperlexia, predominant visual thinking,*
  - *sensory sensitivity of any modality; pretend friends/enemies, extensive imaginary replays*

# Conceptual shifts in ASD from “pure Autism”

- Patterns of **penetrance of ASD** features in genetically at risk groups
  - Monozygotic twins
  - Language Disordered Children, a proportion later develop significant social impairment
  - Family studies show components are genetic not pure syndrome

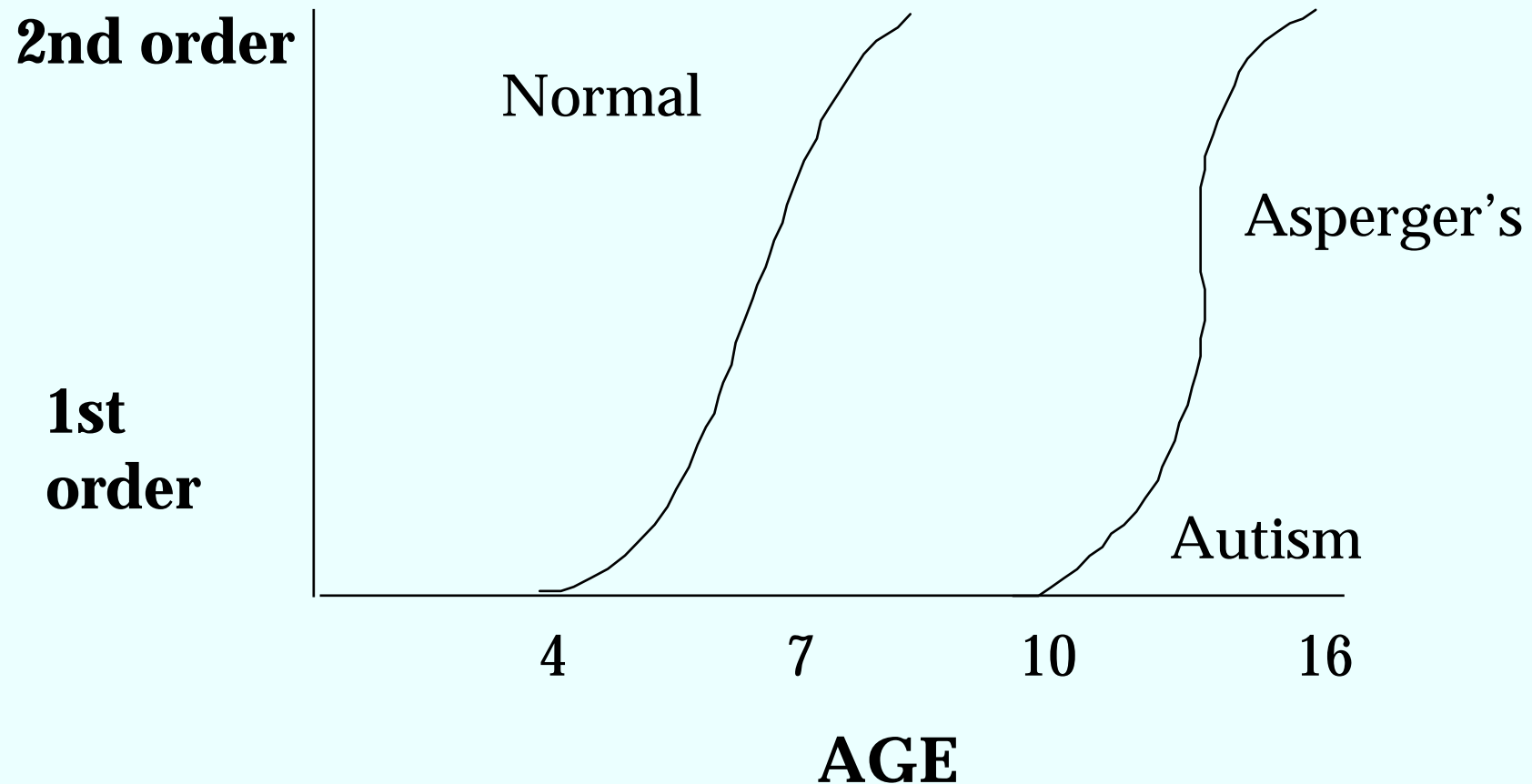
# Three dimensions that may be dissociated (Bishop)



*Figure 2.* Pragmatic language impairment (PLI) in relation to SLI and autistic disorder. The full triad of impairments in language, social interaction, and stereotyped behaviour is seen in autistic disorder, but there may be dissociation between these areas of impairment.

# •New Developmental Concepts:

- Emotional recognition in different modalities
- Theory of Mind



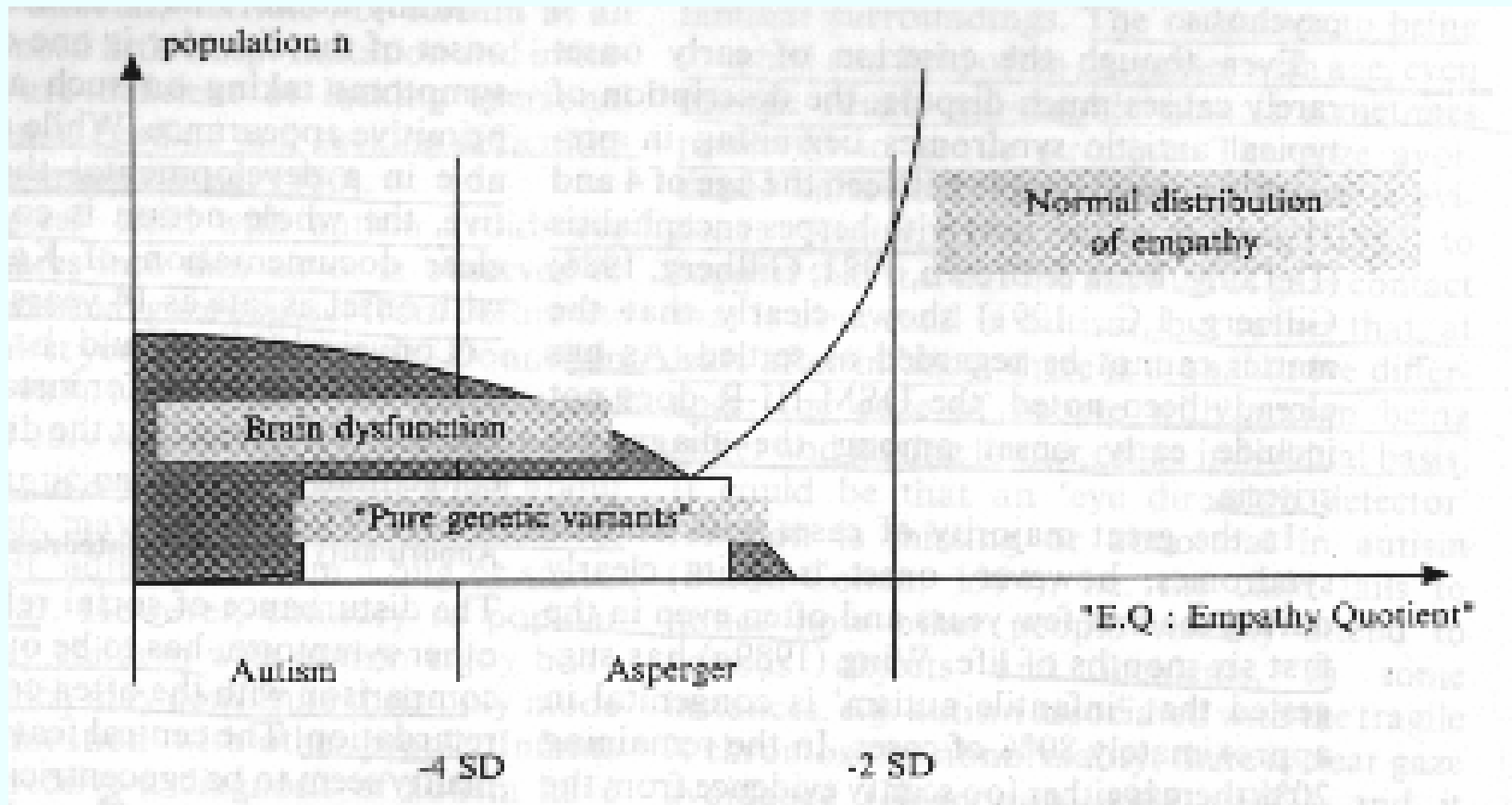
## Conceptual shifts in ASD from “pure Autism”

- The recognition of **new populations** in which ASD are recognised
  - eg 6% Romanian Orphans (“Quasi Autistic”),
  - Children with deafness with hearing parents or blindness (80% lack a theory of mind), (Candida Peterson)
- Recognition of **other specific causes**:
  - Fragile X, Joubert’s, Smith Magenis, Cohen’s,
  - 5%Thalidamide, Fetal alcohol, Rubella,
  - Tuberoze Sclerosis, Kluver Bucy, Landau Kleffner
- Problems of **impaired social responsiveness in young people of “normal” intellect** is 50% (Skuse)
- ASD has stronger genetic association in ID

# Conceptual shifts in ASD from “pure Autism”

- **Acceptance of a dimensional model from a category**
  - Twins Study of Social Responsiveness Scale.
- **The relevance of the diagnosis to adult populations**
  - Schizoid/Schizotypal PD, Obsessional PD, Simple Schizophrenia
  - social impairment as a risk of and predictor of prognosis in Schizophrenia and BPD
- **Extension of concept & Models of positive connotation to**
  - Disorders of Empathy
  - Social Intelligence
  - Central coherence vs pattern recognition
  - “archetypal male or scientific brain” & relationship to testosterone in utero

# Skewed gaussian distribution of Empathy



# Central Coherence

- Autistic difficulty “to see the wood for the trees”, for example in listening to a narrative. The converse to this is that they have a greater attention to detail. This seems to be influenced by genetics.
  - 50% of parents of autistic children have some evidence of weak central coherence. They are sensitive to detail rather than abstract meaning. They do better on perceptual judgement (illusions), visual spatial construction, problem solving (block design, & embedded figures test) and verbal semantics (sentence completion). This was found to reflect non-social interests in detail focused processing.

(Happe F, Briskham J, Frith U. 2001)

## Functional Neurobiological Models

- fMRI shows that autistic children do not process facial expression through superior temporal sulcus and amygdala.
- Snyder hypothesises that idiot savant skills are due to a lack of activity in L temporal lobe area for conceptualisation.

## Positive Reframe

- Architypal Male/scientific brain of pattern recognition eg comparing ratio of more systematising and less empathising: HFA/Asp > Males > Females
- Demonstrated by correlation of in utero testosterone correlating to measures of systematising vs empathising in both male and females in children even at birth

(Baron Cohen)

# NOT PDD but Specific Disorders of Social Development (SDSDs)?

<b>Prevalence of SDSDs (in School years)</b>	<b>Number/1000</b>
• <b>Autism</b> (Profound SDSD)	<b>2-4.5</b>
• <b>Aspergers</b> (Severe SDSD)	<b>3.6</b>
• <b>Pervasive Developmental Disorders</b> Not otherwise spec (Moderate SDSD)	<b>3.5-5</b>
• <b>Sub-threshold</b> autistic features or <b>Disorder of Empathy (Mild SDSD)</b>	<b>? 10-22% single domain, 2.4-6.8% 2 domains</b>
• <b>SDSD in those with Intellectual Disability</b>	<b>2 approx 40% of severe or profound ID</b>
• <b>Atypical Autism</b>	<b>0.1 onset after 36 months</b>
• <b>Degenerative Disorder of Childhood</b> or PIND with an autistic pattern	<b>0.05</b>
• <b>Rett's Disorder</b> (a genetic disorder that always has co-morbid autism)	<b>0.15 girls only; first and only aetiological diagnosis in the DSMIV for mental disorders</b>
• <b>SDSD with language disorders (2-7%)</b>	<b>? assoc with 10% receptive language disorder; semantic pragmatic disorder, elective mutism</b>
• <b>SDSD associated Non-verbal learning disability</b>	<b>? 30% overlap with this ill defined diagnosis</b>
• <b>SDSD associated emotional deprivation</b>	<b>? 6% of Romanian Orphans, +/-with reactive attachment disorder</b>
• <b>SDSD with sensory deprivation, deaf/blind</b>	<b>? 80% of deaf children of hearing parents fail theory of mind; 25% of congenital blind kids</b>
• <b>SDSDs associated with other genetic syndromes</b>	<b>? eg Jouberts Syn, SMS, VCFS, Cohen's Syn, Tuberoze Sclerosis, Landau Klefner Syn</b>
• <b>SDSDs associated with other environmental insult</b>	<b>? eg 5% of Thalidomide children, rubella, alcohol</b>
• <b>SDSDs in other Childhood Psych Disorders</b> ?5-15% of clinic attenders	<b>? ADHD, Anxiety, Depression, OCD, Tourettes, Anorexia Nervosa, self-injurious beh, parasomnias,</b>
• <b>SDSDs assoc with other Multiplex Complex Developmental Disorders</b>	<b>? eg Research conditions: Multi dimensional impaired pre-pubertal children or HIDE (hyperactive, impulsive, distractible, emotional)</b>
<b>SDSDs in other Adult Psych Disorders</b> ?3-5%	<b>? eg, Schizophrenia, Catatonia, OCD and OCPersonality, Schizoid/Schizotypal or Paranoid Personality &amp; ?Psychopathy</b>
• <b>Autistic Association Estimated Total</b>	<b>10 "one in a hundred"</b>

**Autism is everybody's business**

# Are these psychiatric or developmental disorders?

- Autism is described as a developmental disorder but recorded in the DSM for Psychiatric Disorder
- Measures of Emotional Intelligence (Child and Adolescent Social Perception Measure) contribute to variance as much as the IQ and was able to discriminate High Functioning Autism from Controls (Belinda Pratt's PhD).
- Social/emotional intelligence is likely to be multifactorial biological attribute distributed in a Gaussian distribution in Humans. Autism and Aspergers therefore represent  $>3-4SD$  from mean.
- Currently neuropsychology isn't as reliable as clinicians' judgement.
- In common law ASD can qualify as an intellectual disability due to delayed development and unable to fulfil or participate in roles that fit with social norms.
- Social Responsiveness Scale (SRS) demonstrates the dimensional nature of ASD and its contribution to other behaviour disturbance

# Social Responsiveness Scale (SRS)

- 65 item questionnaire of developmental and behavioural items of all different severities; can be filled in by anyone who knows the subject well, without supervision.
- From twin studies, **SRS** has shown the dimensional nature of these features of autism, both in those with autistic disorders and those less severely affected.
- The whole dimension is as genetic as the category of autism.
- Scores (even below the autism threshold) contribute increased variance to the genetic contribution to disturbed beh on CBCL.
- Provides the 1<sup>st</sup> positive means of diagnosing PDD nos.
- Implication: young people presenting with depression, anxiety, disruptive behaviour with mild features of ASD or Disorder of Empathy will have a stronger genetic component to their disturbance, and a worse prognosis.

Constantino JN, Przybeck T, Friesen D, Todd RD (2000). Reciprocal social behavior in children with and without pervasive developmental disorders. J Dev Behav Pediatrics 21:2-11.

Constantino JN, Todd RD (2000). The genetic structure of reciprocal social behavior. Am J Psychiatry 157: 2043-2045.



# Has this child got Autistic Spectrum Disorder?

## A clinician's experience of the Social Responsiveness Scale (SRS)

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### AIM

- To test the clinical value of The Social Reciprocity Scale (SRS), recently renamed the Social Responsiveness Scale.

### Background on SRS

- Research and methodology has over-invested in the importance of Autism as a categorical diagnosis. This was justified on the predictive validity of the diagnosis and the assumption that there might be a single aetiological mechanism.
- Constantino and colleagues from the Departments of Psychiatry and Genetics, Washington University School of Medicine, St Louis, have developed a questionnaire of both mild and severe features of autism and tested it in a range of different clinical and non clinical populations. It comprises of items of: recognition of social cues, interpretation of social cues, response to social cues, tendency to engage socially, core autistic features, language deficits and other symptoms. The Social Reciprocity Scale (SRS) has good psychometric properties. Inter-rater reliability = 0.8; Test retest reliability Pearsons  $r=0.88$ .
- The SRS demonstrates that Reciprocity (as defined by these features of Autism) acts as a dimensional quality rather than a category. Through twin studies, Constantino demonstrates that this dimension is equally inherited as core autism (intraclass correlations of 0.73 vs 0.37 for monozygotic vs dizygotic twins). It provides the first positive measure (score of 101, SD 23) of Pervasive Developmental Disorder, Not otherwise specified, which has been an imprecise diagnosis of cases that did not fit into other subtypes of PDD. It is also correlated with ADI-R correlation coefficients ranged from 0.65-0.77.
- Further, although SRS is not correlated to Axis I diagnoses of ADHD, Conduct, Mood or Psychotic disorder, from the twin study, Constantino et al have shown that measurement of SRS increases the heritability of disturbed behaviour as measured by the Child Behaviour Checklist. These studies show that PDD-NOS features are common: 1.4% of boys; 0.3% of girls, and where reciprocity is affected there are implications for morbidity and prognosis in other co-morbid diagnoses.

### References

Constantino TJ, Todd R. Structure of Reciprocal Social Behavior. Am J Psychiatry 2000; 157:2043-45  
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 Constantino J, Hudziak J, Todd R. Deficits in reciprocal social behavior in male twins: evidence for a genetically independent domain of psychopathology. Am Acad Child Adol Psych 2003; 42: 459-467.  
 Constantino J. et al. Validation of a brief quantitative measure of autistic traits: comparison of the Social Responsiveness Scale with the Autism Diagnostic Interview-Revised. J Aut Dev Disorders 2003; 3(3): 427-433.

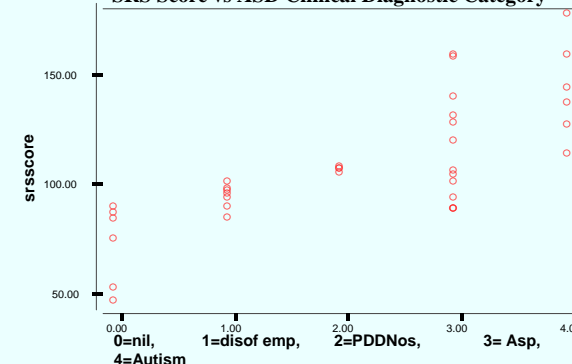
### METHODS

- The SRS was used in 33 routine clinical cases July 02-July03 by the presenter, who made routine clinical multi-axial diagnoses. 6 cases were seen through video-conferencing to rural and remote Australia.
- With regard to Autistic Spectrum Disorders, special attention was given to categorisation:  
**0 = No ASD,**  
**1 = Disorder of Empathy,**  
**2 = Pervasive Developmental Disorder NOS**  
**4 = Aspergers Syndrome,**  
**5 = Autism (The codes in table and graph below)**
- In 8 cases there was more than 1 SRS was rated.

### RESULTS

- The SRS score correlated with the category of Autistic Spectrum Disorder clinical diagnosis  
 - Pearsons Correlation = 0.75,  $p<0.0001$
- SRS score did not relate to IQ category  
 - Pearsons Correlation = -0.021,  $p=0.90$  (NS)
- Despite high correlation with ASD category, in individual cases SRS also showed large variation between informants of clinical relevance, for example:  
 - LS: Father=54, Mother=94, Teacher=84 (paternal under identification, recurrent suspensions from sch)  
 - CN: Mother=127, Teacher=54, (ADHD, Tics & teacher under identification)  
 - TC: Parents= 75, Teacher =143, (severe ADHD, brain damage, Moderate Intellectual Disability, well managed at home, not at school; problems of reciprocity more evident at school)

Scattergram of SRS Score vs ASD Clinical Diagnostic Category



ASD Category	Std Error of Mean	Std Dev'n	Mean	Median
.00	7.50	18.36	71.67	78.50
1.00	5.64	18.69	93.91	95.00
2.00	.63	1.26	105.8	106.00
3.00	8.93	30.93	113.2	112.00
4.00	12.42	32.87	132.6	136.00

### CONCLUSIONS

- SRS provides a 10 minute questionnaire aid to ASD diagnosis
- "Gold standard" measures of autism such as the ADI-R or DISCO take 2-3 hours to complete and are not practicable in clinical practice.
- It is clinically more valuable to collect ASD diagnostic information from more than one source. In complex cases, there are large bias effects that are difficult to identify from a single informant.
- Clinical practice should routinely examine for co-morbid problems of social responsiveness which underly poor prognosis.
- SRS is commended as a valuable instrument in tertiary clinical practice.

# Developmental Assessment of ID & ASD

## A dimensional or developmental disorder?

### Domains of Development

1 **Motor / Physical**

2 **Self care**

3 **Communication: Expressive / Receptive**  
**Verbal / Non-verbal**

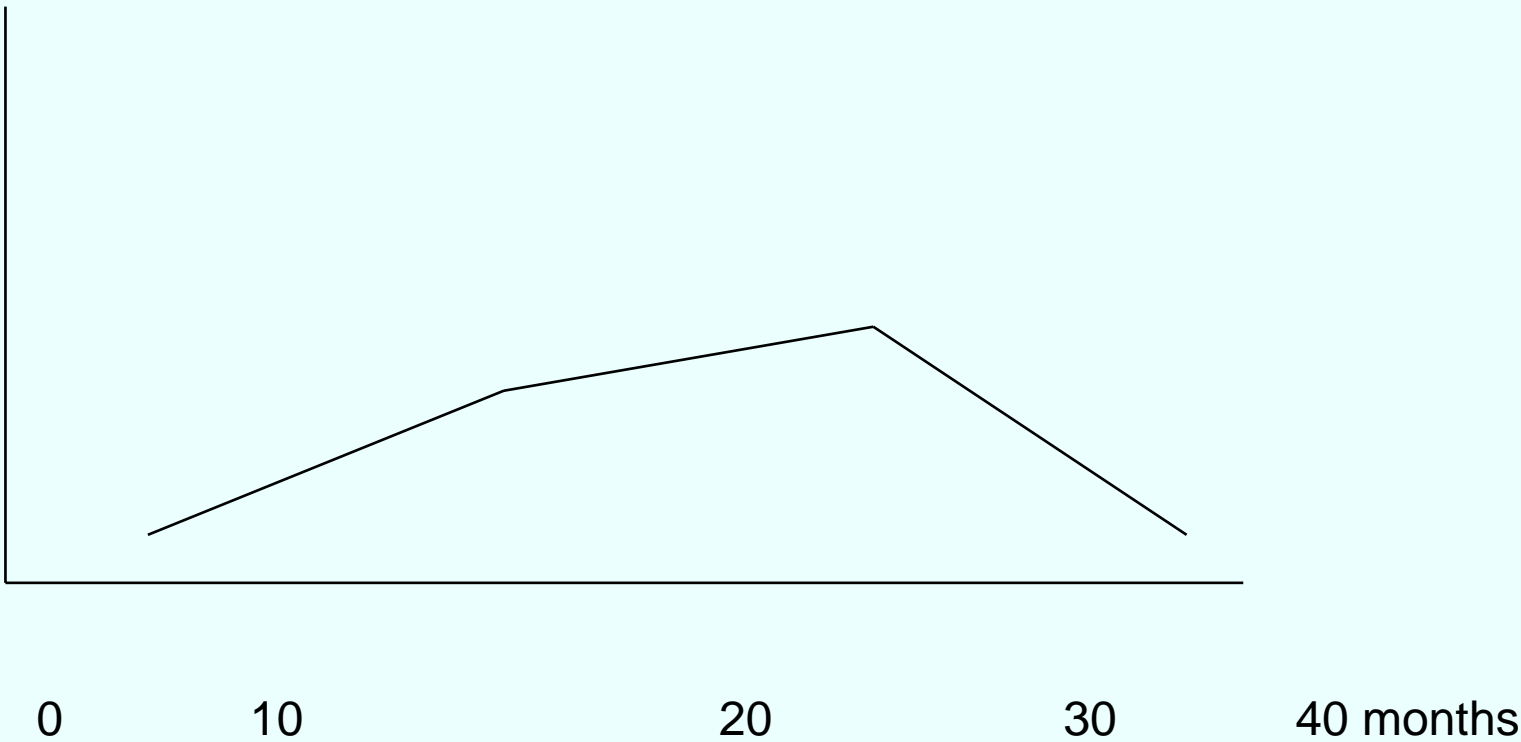
4 **Social / Play**

5 **Educational and Community Skills**

- Development is more likely to be uneven in those with DD
- Handicap Behaviour Skills Schedule (Wing)

# Disturbance vs Mental age

Degree of Behaviour Disturbance



## Evidence of a developmental framework:

### Social communication: the primary variable for ASD

- factor analysis of social communication items of ADI-R resulted in a 3 factor solution
- symptoms falling into 3 domains:
  - Affective reciprocity, (?1st year)
  - joint attention and (?2nd year)
  - theory of mind. (?3rd year)
    - AR was the behavioural propensity to use facial, gestural, vocal and body language in 2 way communication.
    - TOM represented social knowledge in the broadest sense.
- The most severely affected autistic children had impairments on all three domains
- Asp and PDDnos had better affective reciprocity scores than Joint Att, or TOM.
- The least impaired scores were most impaired in theory of mind.
- shows a developmental progression of Autistic Features

## Stages of Social Development

- **0-1yr (Parent oriented)** Development of primary attachment and wariness of strangers. Develop preverbal babble, enjoy rough and tumble, **Affective reciprocity**
- **1-2 yrs (Adult oriented)** Develop capacity for short lived separations; widen range of adult attachments, develop sense of play and humour with adults, such as Peekaboo. Start to develop **joint attention**. Respond to gross non-verbal emotional communication
- **2-2.5 yrs (Toddler Independence)** Copy adults, develop pretend and creative play, become away of peer play in parallel. Sensitive to subtle NVC. Shame
- **2.5-.4 yrs (Peer skill development)** Move progressively towards skills of reciprocity with single age related peer; develop skills of sharing and turn-taking. Initially can turn take if in charge or organised. Becoming less ego-centric; popularity comes from organising positive initiatives. **Theory of Mind**
- **4-8yrs: (Peer Group Association)** Understand reciprocity to maintain friendship and the practical needs a friend fulfils, eg a friend helps you feel happy. Learn to cope with group relations and social organisation by rules. **Second order TOM**
- **9-13 yrs, (Pre-adolescent)**, Learn to challenge and create group rules. Clear gender split, friendships based on similarity, emotional support, and how they might be viewed by others. Capacity for guilt/sense of object constancy
- **13- (Adolescence):** based on trust and self-disclosure and mutual or admired aspects of personality. Abstract cognitive capacity.

## Nilsson & Pelger's (1994) Computer Generated Theoretical Series, Leading to a Fish Eye.

Shows the mathematical **evolution** of a **'photon catcher'** developing from 3 layers of transparent, light sensitive and light impermeable cells. Simple mathematic rules determine the shaping of this computer generated eye, which match evolution in the full spectrum of creation's species: light sensitive, direction sensitive, box camera to finally a lens focusing of an image.

From Climbing Mount Improbable, Richard Dawkins, Penguin 1996

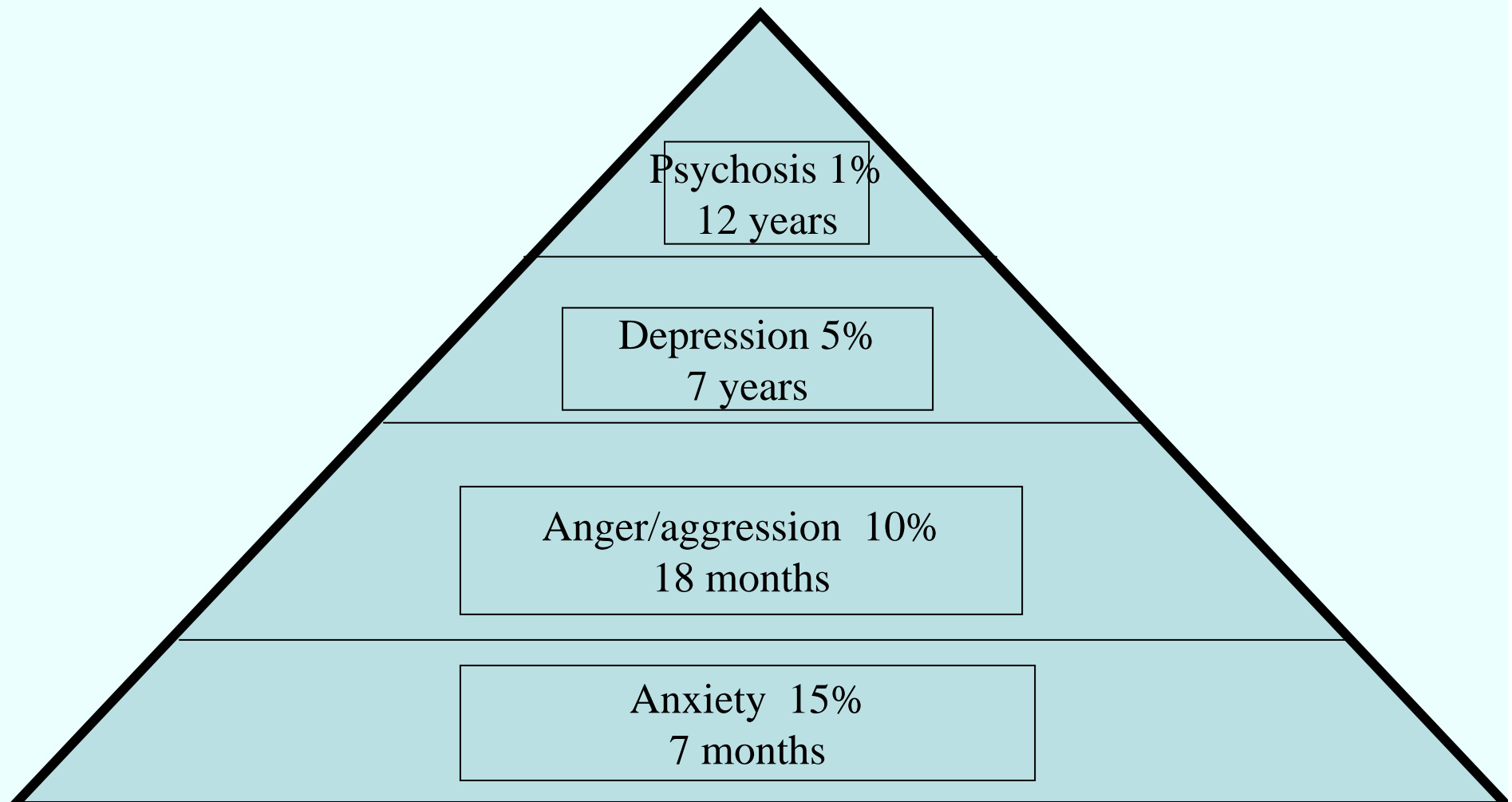


# The Evolution of the 'Photon Catcher': Implications for Social Development & Autism

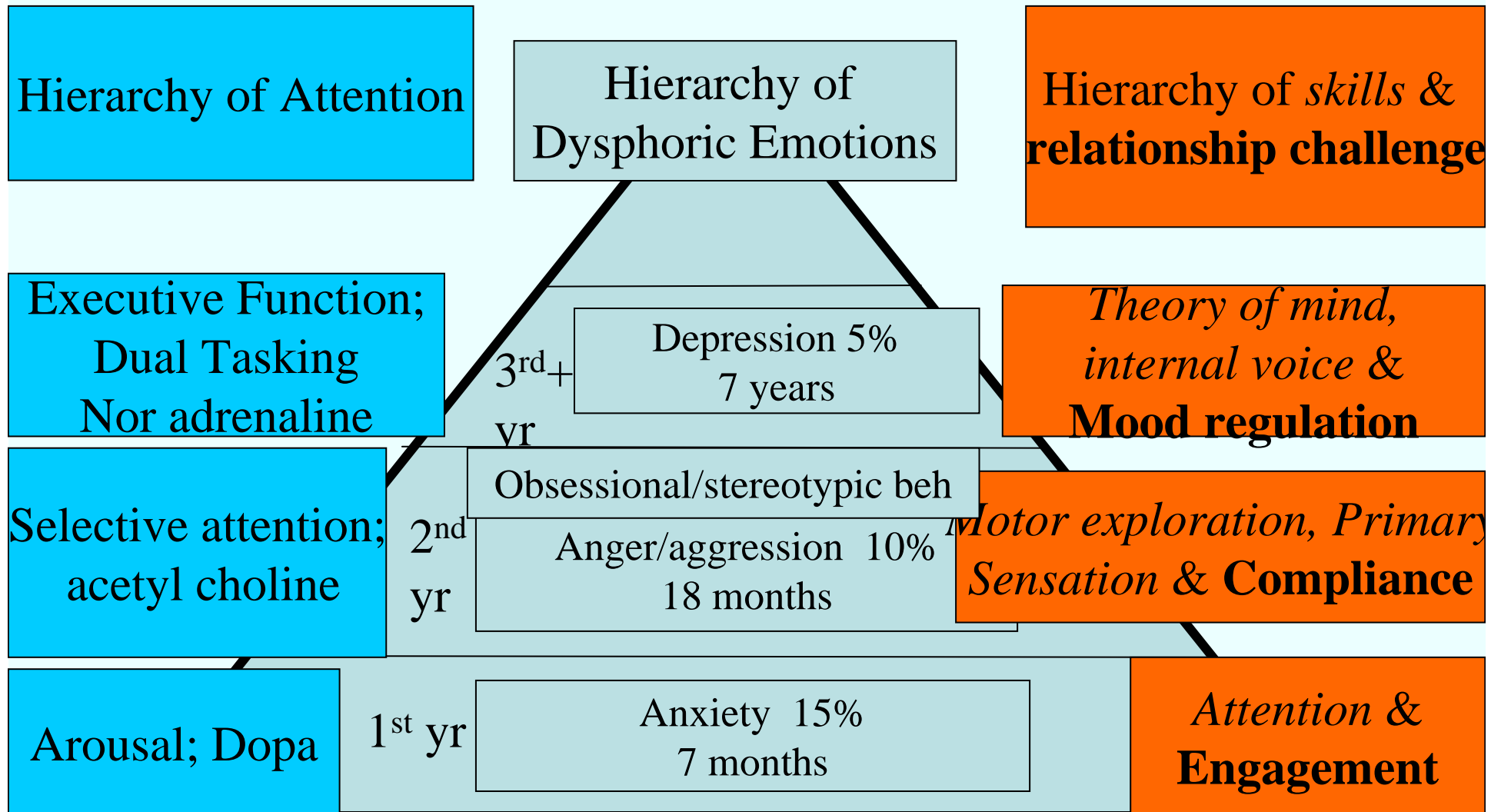
- The evolution of the eye involves progressive functionality and is replicated by a computer program
- **Implications:**
  - Social development arises out of mathematical complexity which can get stuck/delayed;
  - Social dev: due to increasing complexity of networks/mechanisms, no single cause.
  - Developmental Models are helpful & simplify complexity but are difficult to prove
  - Likely to be polygenetic and have multiple causes.
  - Autism is a social developmental age <2 yrs
  - Asperger is a social developmental age <4.5 yrs
  - Studying autism enables us to better understand the development of the consciousness, emotions and the mind
  - Social development and the complexity of emotions are interconnected, and psychopathology are emotions under threat.

## Alternative contributing concepts: DEVELOPMENTAL HIERARCHY OF EMOTIONAL DISORDERS

The Hierarchy of Disorders was originally described by Foulds (1976). The hierarchy has parallels in cognitive, language, conceptual and social development. The pyramid illustrates the general frequency of symptoms of psychological/emotional dysphoria and the developmental age at which this symptom is first recognized



Developmental Sequences:  
 DEVELOPMENTAL HIERARCHY OF EMOTIONS, ATTENTION,  
 INDEPENDENCE AND RECIPROCAL SKILLS



# Implications of SDSDs

- Social development is the most important domain of development
- a normative view of the biological causes of delays in developing peer relationships which can help young people, families and their communities understand and accept: specific strengths and weaknesses; increased need for social support and guidance
- They do make and need attachments, love and care like one of younger social age but have difficulties making friends with age related peer
- Emphasises the importance of social developmental skills and intervention in schools and *special need for protection in peer relns*
- Opens wider the concept of mild SDSDs & social intelligence for further medical/scientific examination,
- What are the General Disorders of Social Development?
  - Failure of social adaptability associated with deprivation, emotional and conduct disorders, ie the emotionally and behaviourally derived sources of poor peer relationships. A parallel to Specific and General Reading Retardation

# Implications for Treatment

- An infant-like social relating capacity leads to extended dependency on familiar/predictable parents/adults
  - Socially
  - For stimulation and skill building
  - Organisation and predictability
  - Building emotional regulation
  - Enabling community access and participation
- Stepping Stones Triple P Parent Training illustrates how practical and normative approaches can promote a developmentally enabling environment.
  - ie. you take the environment to match their developmental needs, matching:
    1. developmental stage such as cognitive, communication and social understanding for developmental promotion
    2. Chronological age such as social norms, age related content and physiological maturity to enable wider social acceptance

Developmental framework of SDDs moves intervention from treatment to developmental appropriateness and understanding

Later it leads to using cognitive skills to learn other empathic skills such as emotional recognition and regulation, theory of mind and practical approaches to friendships

# Implications for Treatment: Case example T

8yo girl with severe intellectual disability, autism, probably ADHD, beh dist & SIB

- Presented with parents, 3 siblings and 15 professionals,
- C/O rages lasting hours, screaming, injuring staff, self injury, running away in response to change or not getting her demands met.
- worse at school than home, extensive use of time out (hours), in a class on her own with two teachers; on a half day enrolment. on indefinite suspension
- Developmental Profile: **Motor Dev: 5yo**: runs away as a communication of wanting things to change, ride a bicycle with trainer wheels but can't catch or throw; a risk taker. hypotonic from birth. **Independence skills: 2yo**; able to take her clothes off but needing help with dressing; **Communication skills: 1yo**: no expressive language other than grunts, groaning and whining; able to functionally communicate using 12 picture communication images. In **social interaction: 1yo**: enjoying rough and tumble with the boys in the family and Peep Bo but with no capacity for copying or playing with peers. obsessed with windscreen wiper rubber.
- Gen Desc: happy sometimes but easily frustrated; enjoys: physical activities eg trampoline and swing, music and DVD's of Wiggles and Hi Five. **short attention span** for any demands put on her attention up to 10 minutes. quite tidy in her room.
- In clinic observed: good physical health but overweight 2nd<sup>o</sup> to risperidone; all behaviours had clear communicative intent, incl. slapping herself, pinching, head-butting, wall banging, screaming, clearly informing others of what she does and doesn't want to do.
- Mother has a regime of short periods of time out in her room to settle her down when she was getting agitated and a timer to help T wait. responds well to commands and distractions.

# Improvement 7 months later

- Ritalin now tds, Risperidone continued, clonidine 50mics tds added
- Change of School, avoid catastrophising;
- **Secure Relationships:** only has familiar staff: expanding familiar staff whom she will accept support from; takes 2 weeks to accept new staff
- **Functional Communication:** the same picture language is used in all settings; use of visual communication for choice and sequencing
- **Building Routines:** “a jobs card” eg when she comes home from school, includes emptying her school bag, putting things away, picking up clothes and even tidying up her sibling’s toys before she has access to her musical DVDs.
- **Expansion of her curriculum at school using rewards:** able to work for 30-40 minutes; after a period of work, is told to go to her room and gets out her choice cards from a jar, bring and show whether it is Hi-Five or the Wiggles she wants to watch and then return it to the jar before being allowed to have the DVD.
- likes to participate with a class group, rather than needing independent attention all the time; now managed by competent classroom aide, less reliant on the teacher’s skills.
- Most aggression and self-injury has abated. Even her screaming without assault tends to decline to a whinge.
- remains extremely vulnerable to relapse; eg an unfamiliar or inexperienced adult involved in managing her. Didn’t cope with school outing for athletics
- **Other components:** Better interagency communication; sharing of multidisciplinary assessment eg speech and sensory; in home and hostel respite to enable family to cope

# Autism as a rights movement

## “diffability” rather than “disability”

- **'It is not a disease, it is a way of life'**: An event run by and for autistic people kicks off in Somerset, the latest act of a burgeoning **autism rights movement**. **The campaign to celebrate difference, rather than cure it. Tuesday August 7, 2007** [The Guardian](#)
- Gareth Nelson, with his wife Amy, who both have AS, are leading the **UK's autism rights movement**. They run their group, [Aspies for Freedom](#) (AFF), from their home; it started as a website three years ago and now has **20,000 members**, most of them autistic.
- **"I don't think you should cure something that isn't purely negative,"** says Nelson.
- The autism rights movement is similar to the civil rights and gay rights movements. Aspies for Freedom even modelled its **Autism Pride Day**, held on June 18 every year, on the Gay Pride movement. **"I don't see autism as a disability, I see it as another human variation."**
- The annual event called **Autescape** in Somerset is a three-day retreat run by and for people on the autistic spectrum, **where behaviours seen as odd by neurotypicals** - such as **stimming** (repetitive movements) and impaired social skills - **are considered normal**. The environment is kept as autism-friendly as possible, with quiet spaces for people to go to and fluorescent lighting, which can be a source of pain or irritation to autistics, kept to a minimum.
- Indeed, among neurotypicals, autism has become a fascination. The success of books such as **The Curious Incident of the Dog in the Night-Time**, by **Mark Haddon**, **Daniel Isn't Talking**, by **Marti Leimbach**, who based the book on her experience of bringing up her autistic son, and **Send in the Idiots**, by **Kamran Nazeer**, has fuelled what one publisher called **"spectrum publishing"**.
- **Second Life**, the **online virtual reality world**, has a place where autistic people go to meet (many of the users would find it impossible to meet face-to-face because of their lack of social interaction skills).
- **Autistic Liberation Front**: buy **T-shirts and badges** affiliated to it with slogans such as **"I am not a puzzle, I am a person"** and **"not being able to speak is not the same as not having anything to say"**.

# Quality of life in SDSDs

- Aim: A 'good enough' quality of life: "how satisfied are you with your life as a whole?"
  - reasonable health,
  - being connected to other significant people, valued relationships
  - being linked to a community
  - contributing a worthwhile role, a sense of purpose, independence and productivity
  - having a hope for the future.
- Psychiatric Disorders are an important influence on quality of life
- **QOL for a child or adolescent with ASD/ID: limited research has similar domains**
- **for the young person with Autism QOL still involves (Cummins):**
  - **a sense of belonging, of friendship, or friendliness or shared activity**
- for the alienated, hostile, neglected young person living in a refuge,
  - family relationships, despite their problems, are still the most important (NSW Commissioner for Children).
- For someone with an intellectual disability,
  - developmental achievement such as walking or functional communication is as valuable to them, as to a UAI of 99
- So what can clinicians contribute to improving the QOL of young people with ASD and their families? They face inordinate challenges
  - provide testimony of the ways others have resolved similar challenges;
  - Demystify jargon and make science relevant and meaningful to a child and family: what works!
  - Help realistic developmental achievement, warm relationships, peer and community acceptance, valid roles
  - be holistic in the biological, developmental, educational, family, social and cultural context of a child
  - guide what families can do to help themselves to help their child with ASD achieve an adequate quality of life.
  - promote skills and even prevent problems occurring.
- Growing literature on how these children and families can get it 'right',

# Conclusions

- Specific Disorders of Social Development is a conceptual framework that normalises the challenge of caring and raising a child with Autism
- All Child Professionals need to be informed and advocate for community understanding, acceptance and support.
- Necessitates a move away from treatment to developmental promotion and support
- These young people can belong, contribute and have a quality of life
- Science may not be able to distinguish between a dimension versus delay, but I find it “a self evident truth” that those with the difference their families and communities can understand.
- This normalising model is likely to become part of framework for the human rights for those with this specific disability.
- The challenge is for our theory of mind to understand what it is like to be someone with Autism

# How do adults with Autism describe their differences?

- It was years before I realised people were guided by emotions not intellect- *Temple Grandin*
- I don't understand why people do things, why they laugh, wave their hands, or change the tone in their voice- *Brad Rand*
- Expressions and body language look different from person to person and have complicated combinations with things called moods- *Brad Rand*
- Speech seemed of no more significance than any other sound- *Therese Jolliffe*
- Humour is so hard to understand- *Brad Rand*
- People with Autism do have emotions but they are like that of a child; my tantrums were circuit overloads- *Temple Grandin*
- At puberty fear became my main emotion. Any change of school schedule caused intense anxiety and a fear of panic attack. Fear fuelled my fixations and my life revolved around trying to reduce it- *Temple Grandin*
- Loud noises were a problem, like a dentist's drill they caused pain. Shampooing hurt my scalp, like rubbing my head with thimbles- *Temple Grandin*
- It's the confusion that results from not being able to understand the world around me which I think causes all the fear. Fear brings a need to withdraw, isolation and despair- *Therese Jolliffe*



# What is being done for SDSDs?

## National Autism Plan (UK) 2003

Published jointly by Royal Colleges of Paediatrics and Psychiatry

- Require every health district needs to identify pathways for Multi-agency Assessment for ASD
- All child orientated professionals need to be trained in alerting signals
- Multi-agency multi-disciplinary teams for assessment and family support
- Access to 15 hours/week early intervention
- On figures of 6/1000, average Health District of 55,000 with 4,000 births/yr would identify 24 new cases/yr and would need \$500,000/yr and need services for over 250 children under the age of 16
- Implications: Services needed for ASD are as great as for ID.
- Mental Health needs of ID are as great as those for Schizophrenia! (Einfeld & Tonge)
- NH&MRC, USA, Scotland and NZ have their national plans/guidelines
- The National Study of Mental Health and Well Being of 4500 young people found major shortages of service provision for mental health needs. This survey did not consider the service needs of autism and ASD as they are less prevalent than depression and DBDs
- NSW: Only specialised service is provided by NGO
- ASPECT's requirement: 2 clinicians with expertise to make the diagnosis.
- Need to open the debate on what child health and mental health clinicians can and should do for this special need population. Their needs should figure large on the agenda for child health and psychiatry.

# What can be done?

- Growing evidence base for treatment but limited RCTs (Pat Howlin)
  - Early intervention in preschools and families are best (eg Silove et al; Bereton & Tonge; Stepping Stones Triple P)
  - Behavioural intervention, functional analysis, ABA,
  - Communication Therapy (eg Hanen), incl PECs
  - Learning thro' electronics and computers
  - Social Skills/ Social Stories: limited by generalisation
  - Psychopharmacology some EB for co-morbid problems (Testimony from Temple Grandin & Donna Williams)
- Expanding Autism Education eg Tony Attwood /CAPTOS/MH-Kids: the clinician: Autism and Acceptance
- Research into Emotion Based Social Skills Training

# My life as Weirdo

My life as a weirdo  
Hasn't been so hard  
Every month I go  
to the hospital ward  
I've seen every doctor  
all they all say  
is see another doctor  
that just makes my day

My life as weirdo  
hasn't been great  
wherever I go  
it isn't so great  
As it seems  
I go to the zoo  
everyone seems  
to be staring at you.

My life as a weirdo  
hasn't been so fun  
All I ever did do  
had always been with a gun  
all I ever see  
are bars in front of my eyes  
so can't you see me  
with your own eyes

That I am a weirdo

By 16 yr old pt.

