Asperger Syndrome in Adulthood: A Guide for Clinicians

Kevin P. Stoddart, PhD, RSW
The Redpath Centre and University of Toronto

Lillian Burke, PhD, C Psych
The Redpath Centre

Robert King, MD
Pathways to Independence

A Social-Communication Spectrum

As with any condition identifiable only from a pattern of abnormal behaviour, each element of which can occur in varying degrees of severity, it is possible to find people on the borderlines of Asperger's syndrome in whom diagnosis is particularly difficult. Whereas the typical case can be recognized by those with experience in the field, in practice it is found that the syndrome shades into eccentric normality, and into certain other clinical pictures.

Lorna Wing (1981)

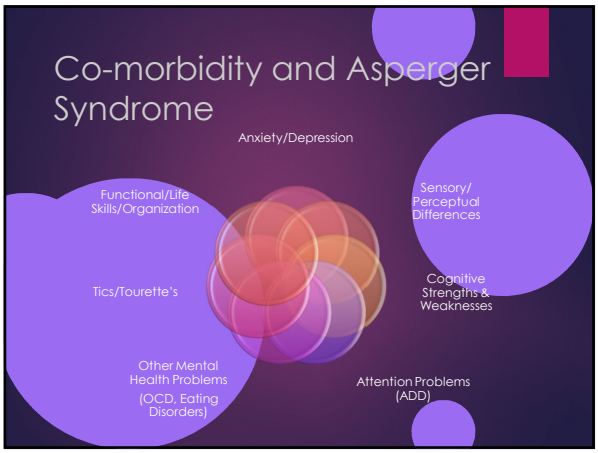
A Social-Communication Spectrum

Autism not only comes in degrees, but . . . it blends seamlessly into the general population. . . . Today the notion of an autistic spectrum is no longer defined by any sharp separation from 'normality'

Baron-Cohen (2009)

Although some individuals with AS are high-achieving in their various fields of work, others struggle in relationships and in work well into adulthood.

Stoddart, Burke & King (2012)



"If you build it, they will come"

Our experience at The Redpath Centre (Toronto & London):

- Increase in adults seeking a diagnosis of AS
- Increase in functioning level of those accessing services
- Increase in the need for marital and family therapy
- Increase in proportion of females seeking a diagnosis
- In 2009, 250 files opened
- In 2010, 350 files opened
- In 2011, 500 files opened
- IN 2012, 550 files opened and a 3 to 5 month waiting list
- We have served individuals from across Ontario, across Canada and outside of Canada

Who are adults with ASDs?

1. Those diagnosed with ASDs as children or teens and who have reached adulthood;
2. Those diagnosed as adults at various life stages due to a crisis, psycho-social problems, recognition by self, friends, or family
3. Parents/extended family members of children and youth with Asperger's or ASDs who recognize symptoms in themselves
4. Adults in the developmental disabilities system, justice or mental health system who have been incorrectly/ undiagnosed or previously diagnosed with "autistic features"
5. Those yet undiagnosed

Epidemiological Study of Adults

(Brugha et al., 2011)

- In Phase 1, 20 items of the Autism-Spectrum Quotient was used
- In Phase 2, respondents completed a face-to-face clinical assessment based on module 4 of the ADOS-4
- In Phase 3, the Autism Diagnostic Interview-Revised (ADI-R) and the Diagnostic Interview for Social and Communication Disorders (DISCO) were administered to participants
- "ASD affects approximately 1% of the adult English household population and there was no evidence of statistically reduction in prevalence of ASD as a function of age"
- All of those adults identified had not previously been diagnosed with an ASD

The 'Asperger Spectrum'

Experience *considerable and chronic difficulties* with daily ADULT expectations and needs extensive support, usually diagnosed in childhood or adolescence (over-lap with the HFA group?)

Experience *some difficulties* with daily ADULT expectations and needs some support, may struggle with work and relationships, although has experienced both. Mental health issues are common and cause struggles, at times more than AS

Experience *minimal difficulties* with ADULT expectations and may be high-achieving in their field of work, have advanced degrees and be married, diagnosed later in life and receive minimal support (overlap with parents/BAP?)

Poor functioning ⟷ Moderate functioning ⟷ Well functioning

Existing Outcome Research

- Outcome studies are available, but not prevalent
- May not be discrete as to the type of ASD studied
- Typically summarize the outcome of those diagnosed as children and youth versus those individuals diagnosed later in life, seen in case studies
- Existing outcome studies do indicate which factors predict the degree and direction of outcome
- They generally do not offer a high degree of optimism
- Regardless of problems inherent in a well-characterized adult presentation of AS, such a presentation is important to further effective identification and treatment

Does Quality of Life Matter?

- Renty and Roeyers (2007) suggest that QofL may offer a "more comprehensive, multi-dimensional outcome measure" for adults
- Allows input from the individual with ASD related to his or her sense of satisfaction and well-being.
- Participants who participated in their study represented individuals across the spectrum, but none had an ID
- 25% of participants had a college or university education, and a comparable number had competitive employment.
- 70% were single; the remaining was in or had been in a relationship
- 75% were in a living situation where they received home support either by parents or by a service agency
- Support characteristics were related to Q of L (accounting for 60% of variance) but disability characteristics did not

Moving Outcome Research Forward

- It is inherently problematic to assume that we can arrive at a uniform description of AS in adulthood
- We have observed that variability in the presentation of the syndrome is broad in children and even broader in adults
- The variability in adult presentation is increasing beyond that which we would have predicted even a decade ago
- This increase is due to factors such as early intervention, the presence of knowledgeable and effective services, the presence of comorbid disorders, and awareness that symptom expression can be present in many individuals despite high achievement

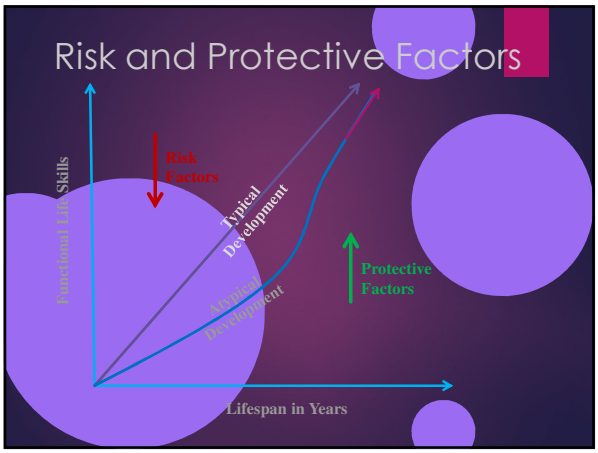
Risk and Protective Factors

Risk factors are conditions or variables associated less likelihood of positive outcomes and a higher likelihood of negative or socially undesirable outcomes, quality of life, or functioning

Protective factors enhance the likelihood of positive outcomes and lessen the likelihood of negative consequences from exposure to risk variables and result in better quality of life and functioning

Risk and protective factors in ASDs may include language skills, social behaviour, IQ, level of supports, ASD severity, age of diagnosis and (appropriate) intervention

Risk and protective factors in AS are not well understood; our recent experience leads us to look to good and excellent outcomes



Understanding Trajectories in ASDs

- Studies of outcome often examine living circumstances of the person, educational achievement, housing, relationships, level of support required, employment, psychiatric functioning, as well as variables specific to the disorder (Engstrom et al., 2003; Renty & Roeyers, 2007)
- Determinants of outcome in children with autism may be different than for children with AS (Szatmari et al.,2003, p. 526)
- Seltzer et al., (2004) noted that few studies look at "contextual variables" as predictors of outcome such as psychiatric disorders and medical conditions
- Case studies and autobiographical books are now providing us with further insights into the 'well-functioning' group of adults with AS

Influencing Trajectories in ASDs

Services for Adults with AS may include:

- Therapy
- Psychopharmacological intervention
- Psychoeducation
- Family therapy
- Couple and parenting therapy
- Occupational therapy
- Behavioral therapy and coaching
- Case management
- Employment counseling
- Groups /group involvement
- Academic advising
- Inpatient treatment

Influencing Trajectories in ASDs

Common risk factors/reasons for intervention include:

1. Poor social skills and social insight
2. Inability to understand emotions (their own and others)
3. Sensory-processing differences (seeking or avoiding behaviors)
4. Poor executive functioning/organizational difficulties
5. Idiosyncratic learning/information-processing/output profile
6. Restricted and repetitive interest-related behaviors
7. Problems with emotional regulation and mental health
8. Poor fine or gross motor development
9. Difficulty navigating life transitions
10. Problems with changes/inflexible cognitive style

Psychosocial Problems in AS

Common psychosocial problems include:

- behavioral problems and legal involvement
- finding and keeping intimate relationships
- expression of sexuality/gender identity
- parenting
- employment
- postsecondary education
- aging
- housing and life skills

Themes in Therapy

Common themes in therapy include:

- Social interaction
- Restricted interests
- Mental health
- Self-care
- Addictions
- Post-secondary education
- Trauma and loss

Learning from Research, Practice & Policy

- Ontario is not prepared for increasing incidence of ASDs
- Service deficiencies cut across MULTIPLE ministries
- The societal and personal costs are immeasurable
- There are NO mental health services that are funded in the province for adults with higher-functioning ASDs and generic mental health services lack expertise and training
- Services that do exist are piecemeal and not integrated
- The recently introduced *"Inclusion of Persons with Developmental Disabilities Act"* will not address the needs of this group

Assessment and Diagnosis

- Assessments provide information which allows an individual to receive treatment or access services and support
- Often those with symptoms of ASDs who are More Able go undiagnosed and do not receive needed supports in spite of attempts to do so
- If services and supports are not obtained it may impact on one's quality of life and ability to achieve dreams

Individual Seeking Diagnosis

"I am 51 years old and just figured out this year why I have been having such awful difficulties all my life. Last year I found out I have Tourette's syndrome. But it still didn't explain why I am so different. I stumbled upon Asperger Syndrome, and the list of characteristics could have been written about me! After my family had me check off quite a few more items than I thought I should check, I am exhibiting at least 90% of those characteristics. I have also done all the tests by reputable Asperger specialists I found on the Internet and my scores are, without fail, well above the average for people with AS. I need a formal diagnostic assessment now by a professional"

Parent Seeking Diagnosis

"My daughter is now 34 years old, unemployed, alone, friendless and desperately unhappy - a 'square peg' who, with courage and persistence tries futilely to fit herself into the 'round holes' offered by the world. I firmly believe she has either Asperger Syndrome or Non-Verbal Learning Disorder...

Her behavior is inexplicable and frustrating to her family: distant, uncommunicative, intelligent but lacking in 'common sense', resistant even to positive change, persistent in efforts proven to be unproductive or counterproductive."

Why Assess Adults: The Need

- Many were not assessed/diagnosed as children
- Less recognition in past that ASDs could occur in those with a mild ASD
- Females presentation different – get missed
- Inadequate training of professionals in the past
- Other labels used (both diagnostic and descriptive)
- More info in the media lead individuals and professionals to request diagnostic assessments
- More colleges and universities recognizing symptoms and referring students

Who comes for Assessment?

- Those who received diagnosis & interventions as children & have new difficulties or problems obtaining services/support
- Those who had symptoms recognized as children but a formal diagnosis was not given & information was ignored or lost
- Those whose symptoms were never recognized, have had problems in finding work/funding, have behavioural and relationship difficulties or have been maintained by a family who can no longer do so

To diagnose or not...

A diagnosis in adulthood may:

- provide access to funds or programs (e.g., disability benefits)
- promote a more positive self-understanding
- provide opportunities to compensate for comorbid concerns
- facilitate better relationships
- improve health (e.g., awareness of food sensitivities)
- provide opportunities to affiliate with others similarly affected
- enable the individuals to receive specialist treatment, and
- alert them to the presence or potential of mental health concerns

The Process of Diagnosis

- Requires extensive interview, from multiple informants, and use of multiple measures lasting four to eight hours or more
- Is not only based on observation (you cannot 'see' AS)
- 12 themes that should be a part of a comprehensive diagnostic assessment in adults: (1) developmental and service history, (2) cognitive profile, (3) communication skills, (4) social functioning, (5) interests and repetitive behaviors, (6) adaptive and life skills, (7) executive functioning, (8) sensory functioning, (9) motor functioning, (10) theory of mind, (11) mental health, and (12) emotional understanding

Are diagnostic assessments all the same?

Assessments may vary depending on:

- Age and Functioning of Person
- Ability to participate in Assessment
- Interest in participating (e.g. if referred by family)
- Specific Referral Questions
- Agency/Person doing the Assessment
- Difficulties in finding Appropriate Assessment Tools

What an Assessor Looks For

- Developmental History
- Health / Mental Health
- Cognitive Ability / Understanding / Memory
- Academic Achievement i.e. Possible concurrent LD
- Executive Function
- Theory of Mind
- Speech, Language, Communication & Pragmatics
- Concept Development
- Organization & Planning
- Adaptive/Functional Skills

What an Assessor Looks For

- Social Skills, Awareness & Judgment
- Relationships
- Emotional Awareness & Reactions
- Activity Level
- Sensory Processing
- Motor Planning
- Behavioural Symptoms
- Obsessive Traits/Routines
- Range of Interests

Observations & Interview

Assessor asks questions not only to gain information, but to observe for:

- the social & communication understanding and abilities of the person
- his/her emotional response
- learn about specific or obsessive interests
- look for signs of executive functioning difficulties
- look at theory of mind
- learn about specific areas of difficulty for that person.

Tools and Processes Used

- Developmental / Medical / Social History
- Interview with the person and others
- Observation
- Reports from other professionals
- Standard Tests, Checklists and Screening Instruments:
  - Wechsler Adult Intelligence Scale-IV Advanced Clinical Solutions
  - Wechsler Individual Achievement Test-III
  - Adaptive Behavior Assessment System-II
  - Behavior Rating Inventory of Executive Function
  - Adolescent Adult Sensory Profile
  - Scales re mental health/emotional issues
  - Rating scales& measures specific to ASDs

Why Involve Family & Friends?

- Provide and clarify information
- Offer comfort and support to person
- Clarify clinician's observations
- Allows for observation of interactions with a familiar person
- Helps the person understand feedback & diagnosis & ensure the information is used appropriately

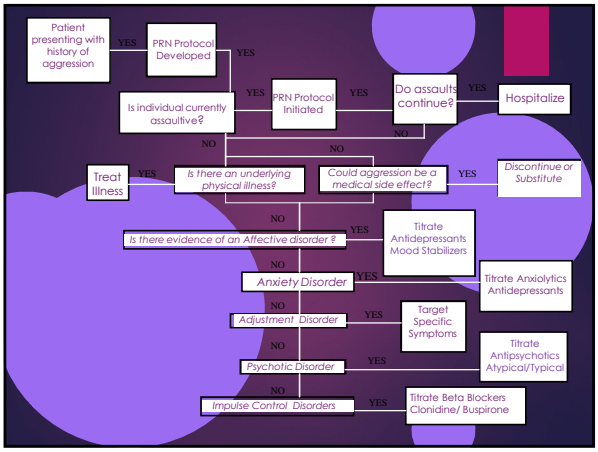
Products of an Assessment

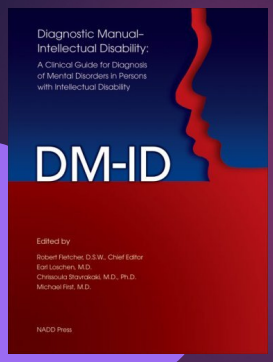
An assessment should:

- answer specific questions
- provide information in manner the person can understand
- include concrete and realistic recommendations
- provide information about any disorder identified
- include referrals or information about other services or resources

Mental Health Concerns

- Anxiety Disorders
- Affective (Mood) Disorders
- Psychotic Disorders
- Personality Disorders
- Eating Disorders
- Gender Identity Disorders
- Attention Deficit Hyperactivity Disorder





Fletcher, R., Loschen, E., Stavrakaki, C., & First, M. (Eds.). (2007).

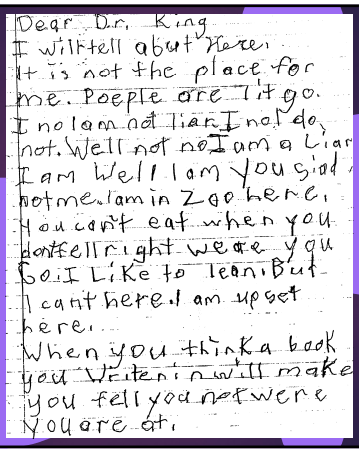
Diagnostic Manual -- Intellectual Disability (DM-ID): A Clinical Guide for Diagnosis of Mental Disorders in Persons with Intellectual Disability. Kingston, NY: NADD Press.

There is no cataclysmic event that triggered her suicide. There was no portentous statement made in the days leading up to it. She left no note.

Kamrin Nazeer

This is a typical deteriorated schizophrenic in the fat, fatuous, flabby, futile and possibly flatulent stage of this complaint. She can also be thought to wish to participate socially as she likes to have staff around, yet she has no one to whom she relates individually and this is no doubt something that angers her.

MD, FRCP (c)


Dear Dr. King
I will tell about here.
It is not the place for
me. Poeple are lit go.
I no lon not lian I not do,
not. Well not no I am a Liar
I am Well I am you sid,
not me. I am in Zoo here.
You can't eat when you
don't tell right were you
go. I Like to lean. But
I can't here. I am upset
here.
When you think a book
you Writen in will make
you fell you not were
You are at.

Repetitive Behaviors in ASD

Symptom Category	Univariate Analysis F (df=1, 98)	Univariate Analysis p	Relationship with Autism group
Repetitive behavior			
Cleaning	12.96	0.0005	Inverse
Checking	29.90	0.0001	Inverse
Repeating	2.00	0.16	Positive
Counting	6.53	0.01	Inverse
Ordering	6.26	0.01	Positive
Hoarding	13.07	0.0005	Positive
Need to tell or ask	2.79	0.10	Positive
Touching	24.42	0.0001	Positive
Self-damaging	19.06	0.0001	Positive

McDougle, Kresch, Goodman, Naylor, Volkmar, Cohen & Price. (1995). Am J Psychiatry;152:772-777

DSM-IV Diagnosis of OCD

Compulsions as defined as:

- Repetitive behaviors (for example hand washing, ordering, checking) or mental acts (for example praying, counting, repeating words silently) that the person feels driven to perform in response to an obsession or according to rigid rules
- ***Compulsions*** are aimed at reducing distress or preventing some dreaded event; however, these compulsions either are not connected in a realistic way with what they are designed to neutralize or are clearly excessive

DSM-IV diagnosis of OCD

Obsessions as defined as:

- Recurrent and persistent thoughts, impulses or images that are experienced as intrusive and inappropriate and that cause marked anxiety or distress
- Not simply excessive worries about real-life problems
- The person attempts to ignore or suppress the obsessions, or to neutralize them with other thoughts or actions
- The obsessions are recognized as a product of his or her own mind

Variables Distinguishing Repetitive Behaviours in Individuals with PDD

	Voluntary (V) Involuntary (IV)	Onset	Rhythm	Observed Behaviour	Associated Conditions
STEREOTYPIES	V Non-goal directed	Slower, no obvious antecedents	Repetitive, rhythmic	Whole / partial body movement Object manipulation	MR, OCD,TS,BPD
INSISTENCE ON SAMENESS	V	Slower, intentional and goal directed	Rigid, repetitive	Routines, repeated routes, resistant to change	
OBSESSIONS	IV Irrational Intrusive	Abrupt	N/A	Thoughts, impulses, images	OCD
COMPULSIONS	V	Slower, intentional, following rules or goal directed	Repetitive	Ordering, touching, checking, hoarding, need for symmetry	OCD

Variables Distinguishing Repetitive Behaviours in Individuals with PDD

	Voluntary (V) Involuntary (IV)	Onset	Rhythm	Observed Behaviour	Associated Conditions
SELF-INJURY	V/IV	Variable	Variable	Single or complex muscle movements	MR, OCD, TS, Borderline PD
TICS	IV	Abrupt, rapid non-goal directed	Non-rhythmic	Simple or complex, motor or phonic	TS, drug induced metabolic disorders
DYSKINESIA	IV	Variable, non-goal directed	Chorea-jerky, non-rhythmic *Athetosis* – slow writhing *Dystonia* – slow, sustained	Orofacial, extremities less common	Spontaneous Metabolic disorders, brain injury Degenerative disorders i.e. Huntington's chorea
AKATHISIA	IV	Insidious, non-goal directed	Non-rhythmic	Limbs	
Echolalia / Verbal Perseveration	IV	Immediate or delayed	Repetitive	Speech	TS

Neurodevelopmental Issues Complicating Psychiatric Diagnosis

- Executive Dysfunction
- Sensory Integration Dysfunction
- Prosopagnosia
- Synesthesia
- Lack of Central Coherence
- Scotopic sensitivity
- Theory of Mind

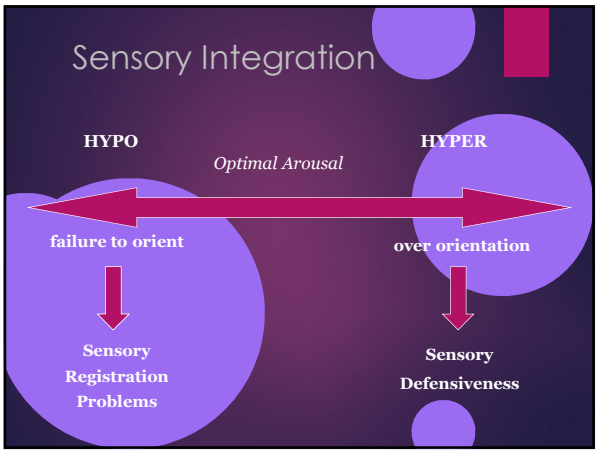
Minna

Executive Functioning

- Impairment in the frontal lobes
- Planning, organizing, (setting a goal, create a strategy, managing and organizing resources including thoughts and ideas, monitoring progress)
- E.g. Goal get mail, walk to mailbox without being distracted, need shoes, coat, get mail, success
- **Tips:** checklists for tasks, self-monitor, written schedule of what needs to be accomplished, structure, break down tasks to smaller parts, minimize distractions, alternate activity with quiet time, reduce clutter, use computers, use ADHD coach, limit noise in workspace, use colour coding, work away from open doors, or windows, paper and pen for instructions, prioritize work, use earplugs or headsets,
- Attention, memory, motor skills

Executive Functioning

- Difficulty with trial and error learning, consequences
- Can't deal with unpredictable situations, changes in plans or routines, difficult to deal with
- Can't inhibit inappropriate behaviour
- Problems interacting with others, honesty, no filter



Theory of Mind

- Problems inferring the intentions of others
- Lack of understanding that behaviour impacts how others think and or feel
- Problems with Joint attention and conversation skills
- Problems differentiating fiction from fact (naive)
- Tendency to rely only on concrete information

Theory Of Mind

- Difficulty explaining own behaviour
- Difficulty understanding emotions of others
- Difficulty predicting the behaviour or emotional state of others
- Problems understanding the perspectives of others

Synesthesia

"Mine is an unusual and complex type through which I see numbers as shapes, columns, textures, and emotions. This sensory experience has allowed Daniel the ability to calculate high numbers in his head without undue effort, ultimately allowing him to set a world record by memorizing pi (the ratio of a circle's circumference to its diameter) to 22,314 digits"

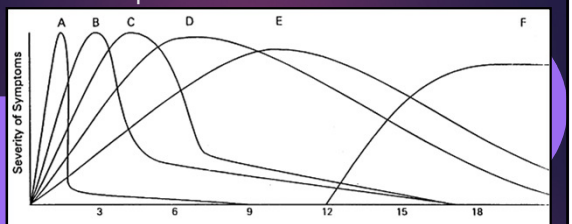
Tammet, D., 2006

Adverse Effects of Risperidone in Children with Autistic Disorders

Event	Risperidone (N=49)	Placebo (N=51)†	P Value‡
Increased appetite — no. (%)			
Mild	24 (49)	13 (25)	0.03
Moderate	12 (24)	2 (4)	0.01
Nasal congestion — no. (%)	25 (51)	20 (39)	0.32
Fatigue — no. (%)	29 (59)	14 (27)	0.003
Enuresis — no. (%)	15 (31)	15 (29)	0.93
Drowsiness — no. (%)	24 (49)	6 (12)	<0.001
Vomiting — no. (%)	16 (33)	12 (24)	0.43
Insomnia — no. (%)	7 (14)	15 (29)	0.11
Anxiety — no. (%)	12 (24)	10 (20)	0.73
Diarrhea — no. (%)	9 (18)	11 (22)	0.88
Constipation — no. (%)	14 (29)	6 (12)	0.06
Sleep problems — no. (%)	11 (22)	9 (18)	0.73
Skin irritation — no. (%)	11 (22)	7 (14)	0.38
Drooling — no. (%)	13 (27)	3 (6)	0.02
Headache — no. (%)	9 (18)	6 (12)§	0.52
Stomachache — no. (%)	5 (10)	9 (18)	0.43
Dry mouth — no. (%)	9 (18)	5 (10)	0.34
Increased thirst — no. (%)	6 (12)	5 (10)	0.94
Dizziness — no. (%)	8 (16)	2 (4)	0.05
Dyskinesia — no. (%)	6 (12)	3 (6)	0.45
Nausea — no. (%)	4 (8)	5 (10)	0.95
Decreased appetite — no. (%)	3 (6)	5 (10)	0.76
Tremor — no. (%)	7 (14)	1 (2)	0.06
Tachycardia — no. (%)	6 (12)	1 (2)	0.06
Upper respiratory tract infection — no. (%)	5 (10)	2 (4)	0.40
Earache — no. (%)	2 (4)	4 (8)	0.71
Muscle rigidity — no. (%)	5 (10)	1 (2)	0.11
Sore throat — no. (%)	5 (10)	1 (2)	0.11
Restlessness — no. (%)	3 (6)	3 (6)	0.71
Weight gain — kg	2.7±2.9	0.8±2.2	<0.001

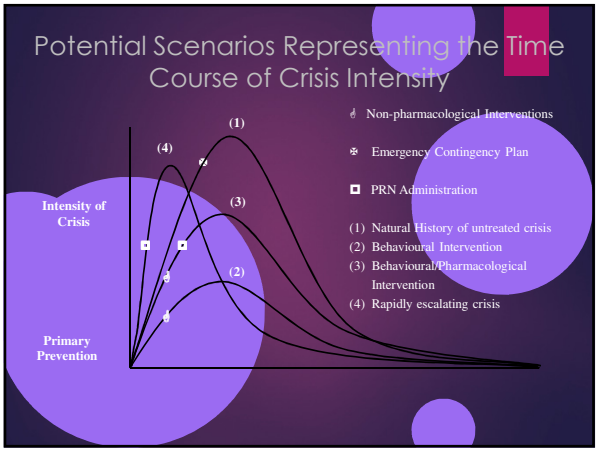
Research Units on Pediatric Psychopharmacology Autism Network. (2002). New England Journal of Medicine, 347(5): 314-321.

Neurological Side Effects of Neuroleptics



A: Dystonic reactions: uncoordinated spastic movements of muscle groups (e.g., trunk, tongue, face)
B: Akinesia: decreased muscular movements
C: Rigidity: coarse muscular movement; loss of facial expression
D: Tremors: fine movement (shaking) of the extremities
E: Akathisia: restlessness, pacing (may result in insomnia)
F: Pisa Syndrome and Rabbit Syndrome

Pro Re Nata
Optimal Use of PRN
Psychotropic Medication


Potential Scenarios Representing the Time Course of Crisis Intensity
Intensity of Crisis
Primary Prevention
(1)
(2)
(3)
(4)
Non-pharmacological Interventions
Emergency Contingency Plan
PRN Administration
(1) Natural History of untreated crisis
(2) Behavioural Intervention
(3) Behavioural/Pharmacological Intervention
(4) Rapidly escalating crisis

PRN Protocols
GOALS
I. Consistent caregiver response to crisis
II. Minimize escalation of crisis intensity
III. Reduce Psychological consequences of crisis for client and caregivers