Autism Spectrum Disorders Multidisciplinary Panel: Screening, diagnosis, physical and mental health, adult ASD

Family Medicine Forum - CPFM-Developmental Disabilities Series

Wednesday, November 14, 2018 from 10:00 to 12:15
Toronto Convention Centre

Dr. Mohammad Zubairi, Developmental Pediatrician
Dr. David Ng, Child Psychiatrist
Jessica Faith, Occupational Therapist
Dr. Kevin Stoddart, MSW, PhD, RSW, Director, Redpath Centre
Dr. Liz Grier, Family Physician

Thank you to the
Ontario Working Group on Mental Health & Adults with Autism Spectrum Disorder
for supporting this presentation

http://www.adultasd.ca/

McMaster University
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McMaster Children's Hospital
DEVELOPMENTAL PEDIATRICS AND REHABILITATION PROGRAM

Reflections on working children and youth with autism & their families: A Developmental Pediatrics Perspective

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Developmental Pediatrician
Ron Joyce Children's Health Centre
Assistant Professor, McMaster University

November 14, 2018

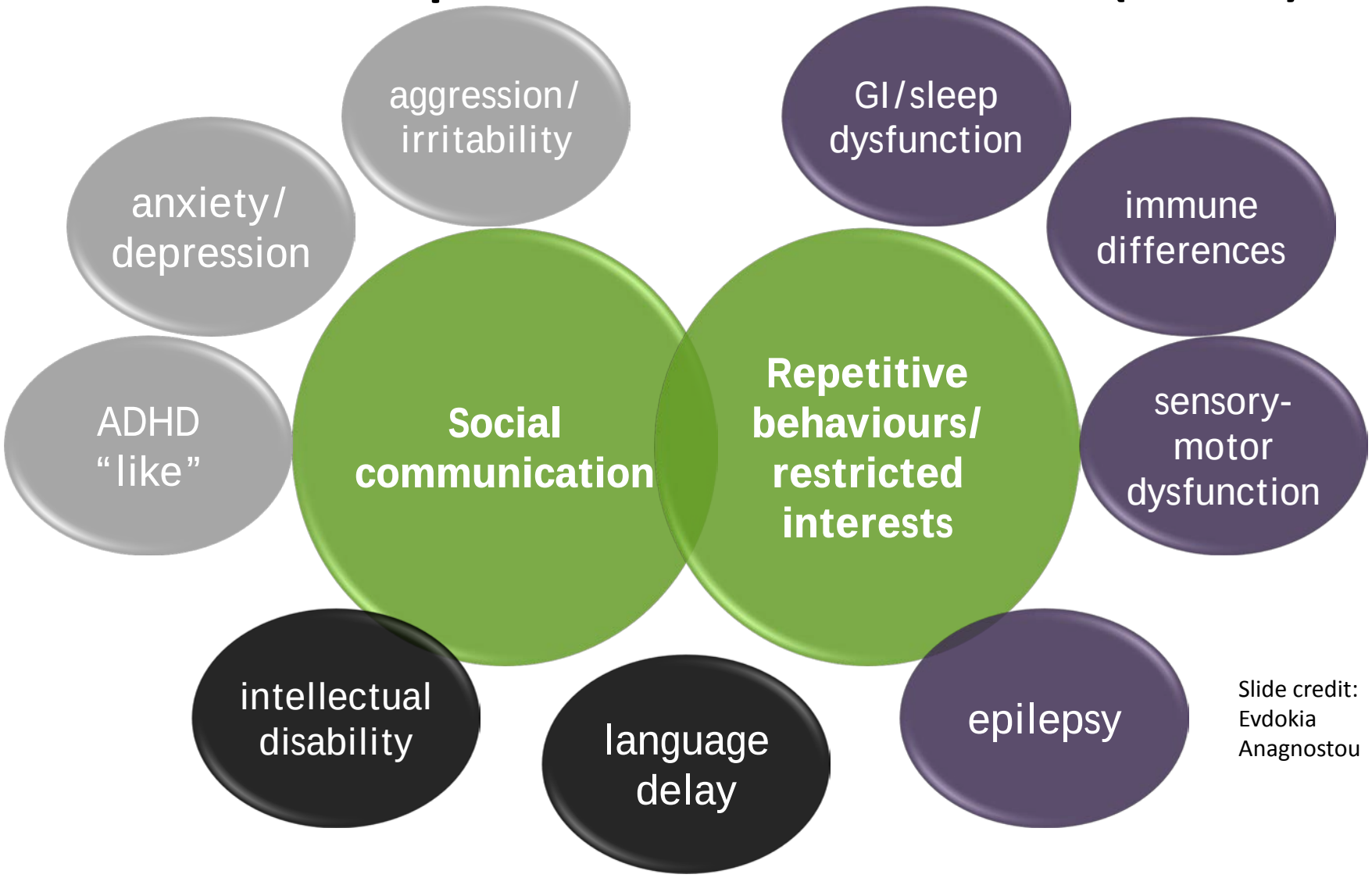
Faculty Disclosures

- Faculty: Mohammad Zubairi
  - Board of Director, SAAAC Autism Centre
  - Treasurer, PONDA Network

Role of a Developmental Pediatrician

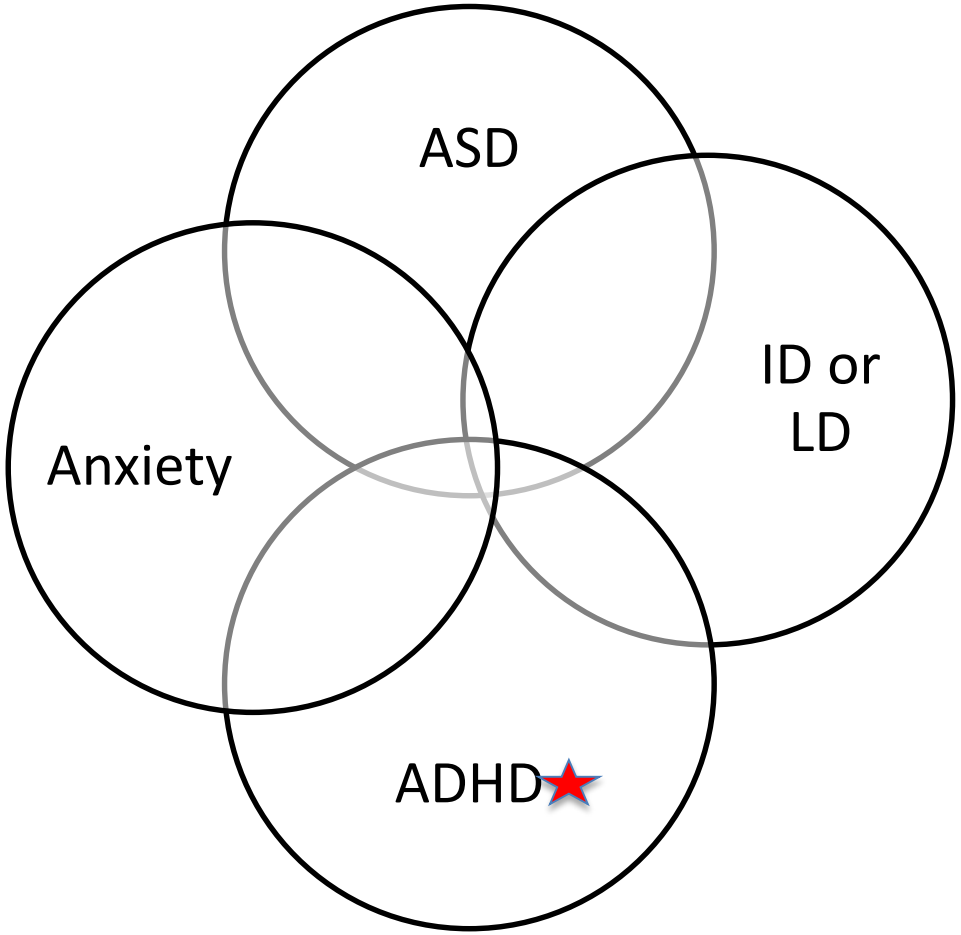
- Context of work - CTCs, Office-based, Academic
- The most common referral question I get: “Query autism? Language delay. Normal hearing. ”
  - Source of referrals can vary depending on catchment area (e.g. Pediatrician vs. Family Doctor)
  - Therapists will often suggest referral for developmental assessment
- Who can make or suggest a diagnosis?
- How do we arrive at a diagnosis?
  - Criteria and assessment tools

Autism Spectrum Disorder (ASD)



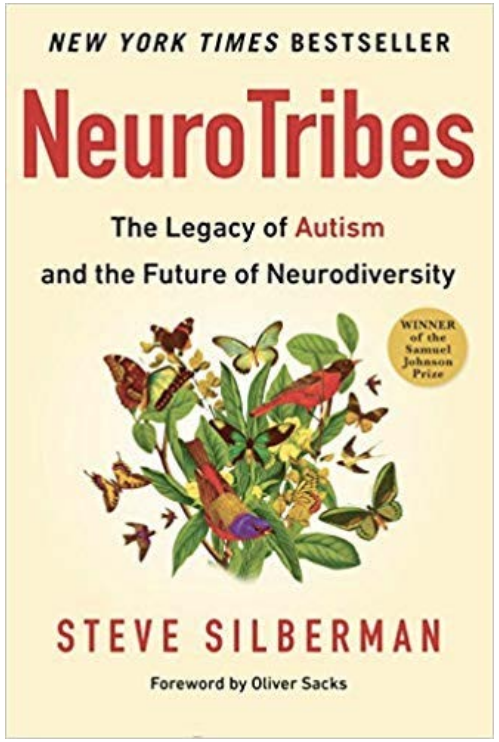
Slide credit: Evdokia Anagnostou

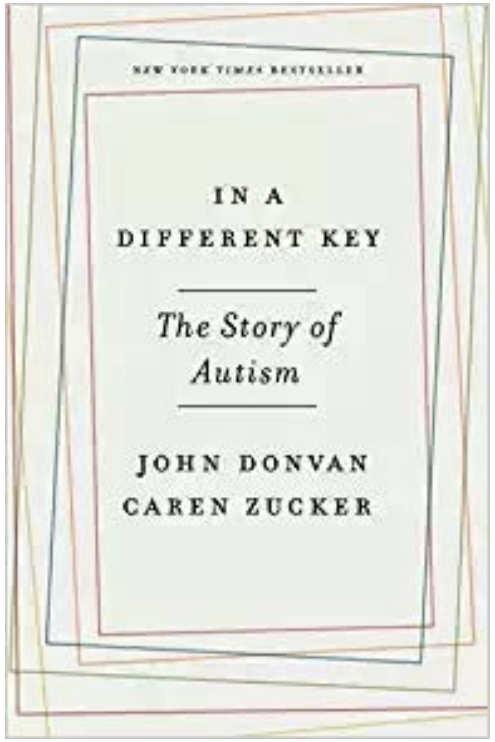
Understanding Complexity

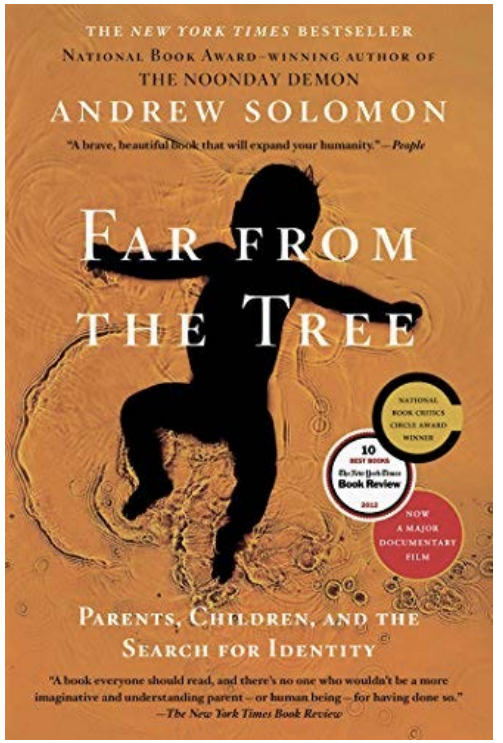


Sleep and other Medical Issues

New Conversations







The 3 most common questions/scenarios that come up after a diagnosis:

- 1) “Will (or Can) the autism go away?”
- 2) “I have read autism is a spectrum. What level does my child have?”
- 3) “I don’t want my child to have a label. What should I tell the school? What should I tell my family?”

The Power of Metaphor & Language

- How to best explain concepts about childhood development?
- Who has the responsibility to assist families in digesting the information that I may provide (If not me)?
- Getting the best developmental snapshot at that particular moment (over single or multiple visits)
  - Snapshots can vary over time
  - Collaborating with other providers

Diagnosis vs. Functioning:

ACSF:SC Tool

Autism Classification System of Functioning: Social Communication

Version 2016

Level V - In the last month, a Child in Level V may be observed...

Playing with objects or talking to themselves.

Trying to initiate or react to other people's specific words or physical actions. The purpose of their communication may only be understood by their primary caregiver or highly experienced teacher/therapist.

Level IV - In the last month, a Child in Level IV has been observed...

Trying to initiate communication with their primary caregiver(s) by requesting to have their needs met.

Trying to respond to communication initiated by people they know (could be as simple as the use of a facial expression) but may not be responding to people they don't know.

Level III - In the last month, a Child in Level III has been observed...

Initiating communication with people they know, mostly to request having their needs met.

Trying to initiate communication for social purposes using simple, practiced or scripted requests (verbally or non-verbally) about their preferred interests/activities.

Responding to communication from others (such as when asked simple questions like 'What's that?') but the communication is not sustained.

Level II - In the last month, a Child in Level II has been observed...

Initiating and responding to communicate for social purposes about their preferred interests/activities with most people.

Sustaining communication until the other person changes the topic/activity or they are not being understood.

Level I - In the last month, a Child in Level I has been observed...

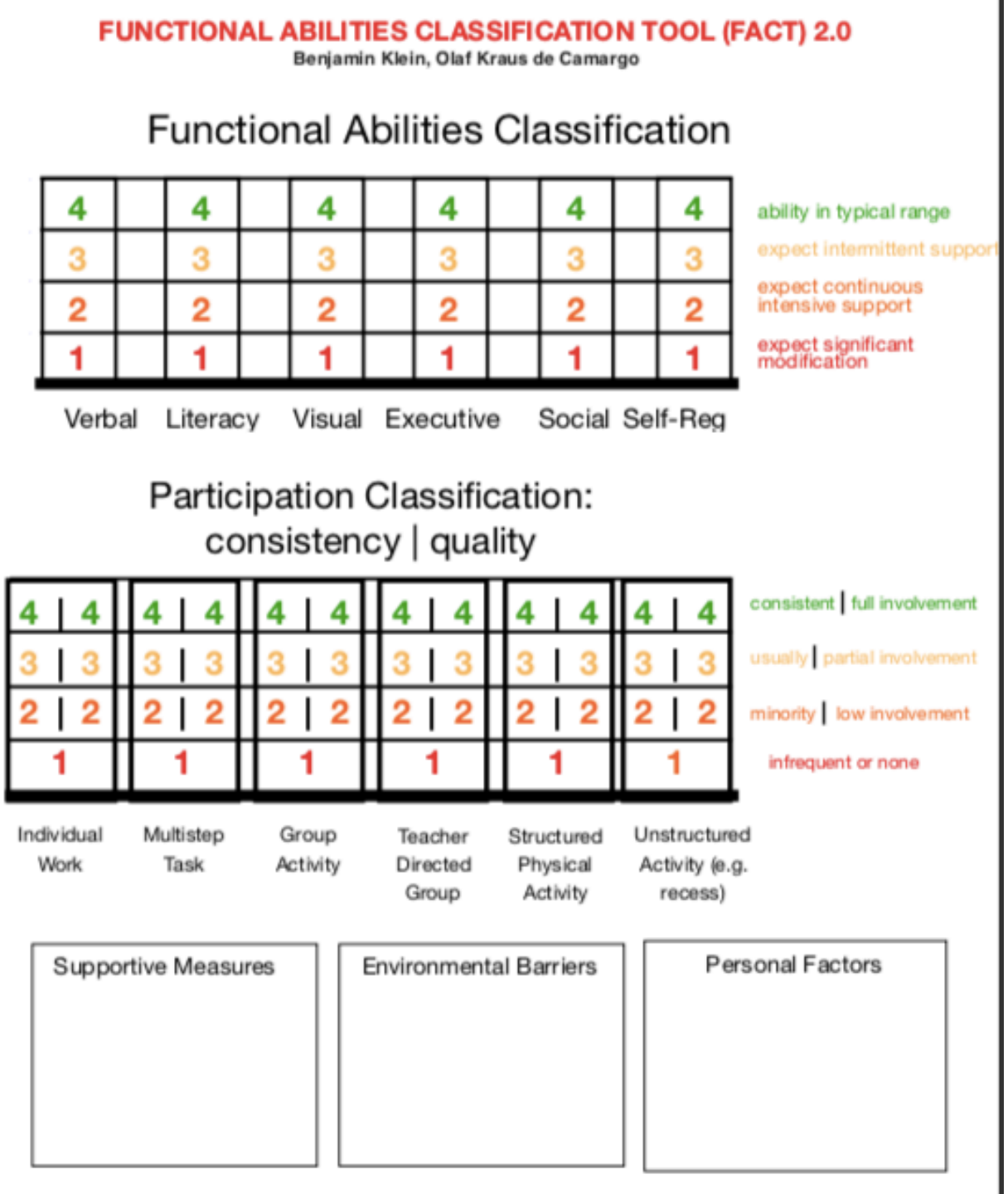
Initiating and responding to communicate for social purposes about more than just their preferred interests/activities with most people.

Sustaining communication with most people. Although they may have some difficulty, they will try to respond to the change in topic/activity or use effective communication strategies to be understood.

Diagnosis vs. Functioning:

A Proposed Functional Abilities Classification Tool for Developmental Disorders Affecting Learning and Behaviour

Frontiers in Education, Feb 2018



Writing Letters

Thinking about interventions

TABLE 2
Management of concerns arising from developmental surveillance*

Developmental sector of concern	Management
Deficient performance in any sector	Hearing, vision screens Lead screen if mouthing or pica Early Intervention Program or specialized preschool program for sector-specific evaluations and treatment services by therapists, psychologist, and/or teacher Paediatrician referral
Communication skills (Consider speech-language impairment)	Speech-language pathologist, audiologist
Multiple sectors (Consider intellectual disability, cerebral palsy)	Psychologist for tests of intellectual abilities and adaptive functioning, speech-language, and/or physical and occupational therapist Consider developmental paediatrician, neurologist
Communication and social-emotional skills (Consider autism spectrum disorder or language impairment with mental health difficulties)	Psychologist, speech-language pathologist, mental health therapist Consider developmental paediatrician, neurologist
Motor skills (Consider movement disorder)	Physical or occupational therapist Developmental paediatrician, neurologist
Self-help skills	Parent training, consider social worker
Academic skills (Consider learning disabilities [eg, reading, math in context of average intellectual abilities])	Psychologist for tests of intellectual abilities and academic achievement
Social-emotional skills (Consider mental health condition)	Psychologist, mental health therapist
Strengths in multiple areas (Consider intellectual giftedness, academic talent)	Psychologist
Colour-naming task	Colour-blindness test if fails to point to named colours

**Adapted with permission from reference 21*

Source: Canadian Pediatric Society

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DEVELOPMENTAL PEDIATRICS AND REHABILITATION PROGRAM

zubairm@mcmaster.ca

QUESTIONS?


#autismspearls

ASD

Adolescence to Young Adulthood

David Ng MD, FRCP(C), CCFP, DCP

Medical Director, Child & Adolescent Psychiatry Program, Markham Stouffville Hospital ; Physician-in-charge, Dual Diagnosis and ADHD Programs at The Scarborough and Rouge Hospital

Assistant Professor, Queen's University

STATEMENT OF POTENTIAL CONFLICTS OF INTEREST

Relating to this presentation, there are no relationships that could be perceived as potential conflicts of interests

OUTLINE:

- Assessment
  - Diagnostic Detractors
  - Psychiatric Comorbidities

- Management
  - Pointers
  - Medications

ASD DETRACTORS:

- Gaming addiction:
  - 25 to 40% with ASD, ADHD (CAMH)

- School avoidance:
  - Bullying
  - Gifted / LD ; photo realistic visual thinking / object visualizer (i.e. good at geometry, poor in algebra)
  - Social anxiety

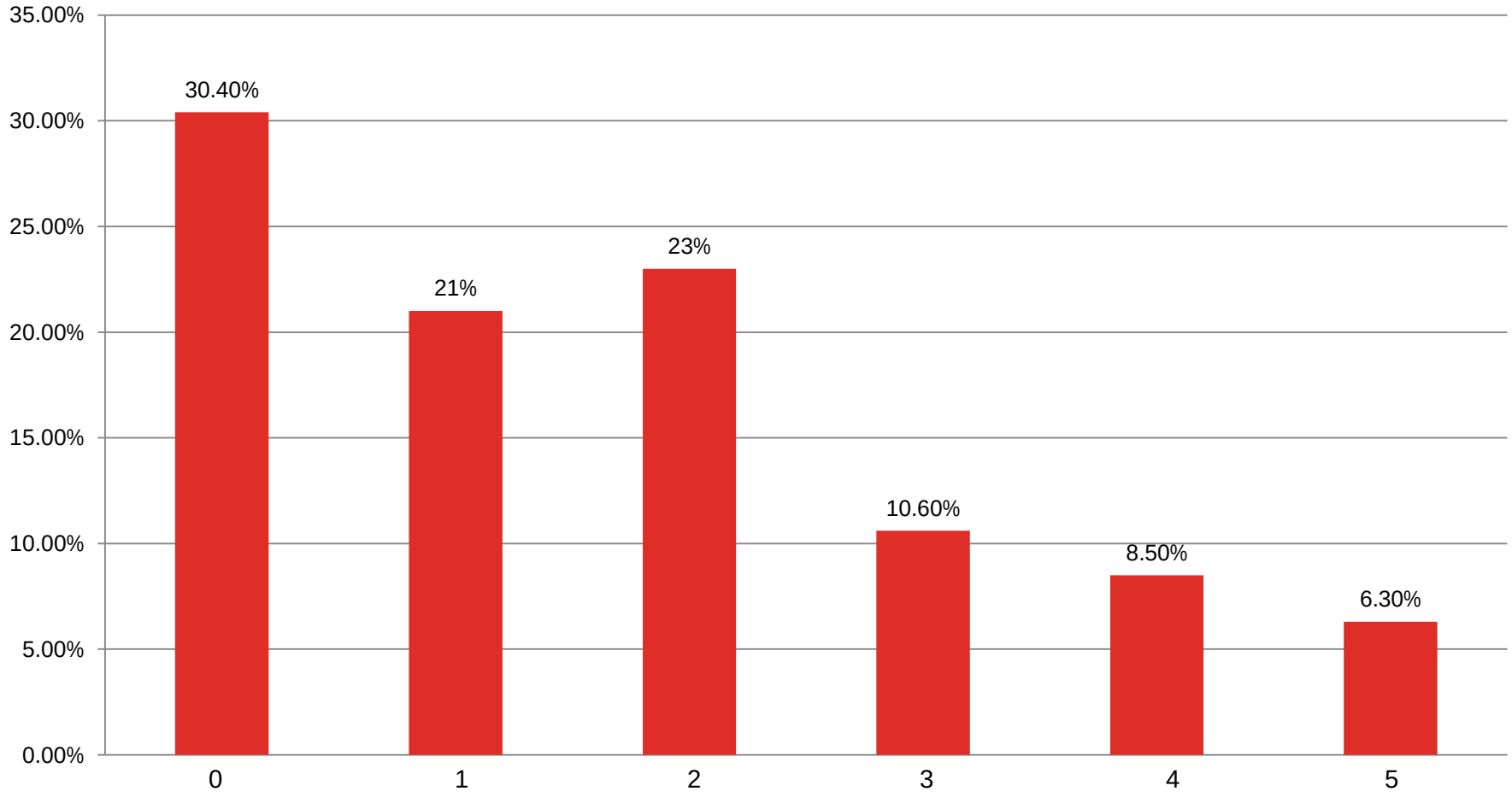
ASD DETRACTORS

- Defiance:
  - Cognitive rigidity
  - Home, school

- Female:
  - “Chameleon-like”
  - More open to talking about feelings
  - Can socialize in small doses
  - Meltdowns when socially overloaded

ASD & MENTAL HEALTH

- 54 to 70% ≥ 1 comorbidities



PSYCHIATRIC COMORBIDITIES

- ADHD: 30-60% [4-6% pop]
- Anxiety (gen, social, OCD, PTSD): 11-42% [15% pop]
- Depression: 26% [7% pop]
- Psychosis / Schizophrenia: 4-35% [1-9% pop]
- Bipolar disorder: 6-27% [4% pop]

PSYCHIATRIC COMORBIDITIES

- LD: 21.5% [4-15% pop]
- Substance use disorders: 5-6% (>37% tried alcohol and drugs)
- Gender Dysphoria: ?% [0.002-0.014% pop]
- Eating Disorders: 2.5% [0.4-1.5% pop]

MANAGEMENT

- Multi-disciplinary: access regional (private) ASD programs, school board / on campus supports
- Treat comorbidities
- Challenging behaviours (ASD + ID):
  - risperidone, aripripazole, ziprasidone
  - fluvoxamine, sertraline, clomipramine
- Solution-focused, schematic diagrams

ASD and Sensory Differences:

November, 2018

Jessica Faith,
OT Reg(Ont.)

Sensory Differences and ASD

- Sensory Processing
- Mono Processing
- Delayed Processing
- Synaesthesia
- Sensory Distortions

Sensory Processing and ASD

Recognition related to:

- Kanner & Asperger
- First-hand and parental accounts
- Research investigating sensory processing
- Neuroanatomical findings
- OT and Theory of Sensory Integration

First Hand Accounts

- Temple Grandin (1984, 1986)
- Georgina Stelhi (1991)
- Donna Williams (1992, 1994)
- Thomas McKean (1994)
- Lucy Blackman (1999)
- Lianne Willey (1999)
- Tito Mukhopadhyay (2003)
- Carly Fleishman, 2012
- Naoki Higashida, 2013

“ I was intensely preoccupied with the movement of the spinning coin or lid. I saw nothing and heard nothing. I did it because it shut out sound that hurt my ears. No sound intruded on my fixation. It was as if I was deaf”

Temple Grandin, A is for Autism

“You don’t know what it feels like to be me, when you can’t sit still because your legs feel like they are on fire, or it feels like a hundred ants are crawling up your arms……I want something that will put out the fire.”

Fleishman, 2012

Carly Fleishman

On covering her ears, moaning, and rocking:

“It’s a way for us to drown out all sensory input that overloads us all at once. We create output to block out input.”

“Bright lights, mid-day sun, reflected lights, flickering lights, florescent lights; each seemed to sear my eyes. Together, the sharp sounds and the bright lights were more than enough to overload my senses. My head would feel tight, my stomach would churn, and my pulse would run my heart ragged until I found a safety zone.”

Willey, 1999

Sensory Processing Research

- 50-90% of individuals with Autism Spectrum Disorders
- 5.3% of all typically developing kindergarten children
- 35% of children referred to out-patient mental health services

ASD and Sensory Processing

DSM-V, 2013

Symptoms of Autism Spectrum Disorder now include:

Hyper or hypo reactivity to sensory input or unusual interest in sensory aspects of the environment.

Sensory Processing

"*Organization of the senses for use*." Ayres,79

Sensory integration is the neurological process that receives, organizes, connects and interprets information from the body and the environment and enables individuals to function competently and with comfort.

Sensory Systems

- Vestibular system
- Proprioceptive system
- Touch or tactile system
- Visual system
- Auditory system
- Olfactory or smell system
- Gustatory or taste system
- Interoception

Components of Sensory Processing

1. Registration
2. Orientation
3. Interpretation (perception)
4. Response to sensory input

Sensory Processing Continuum

Reduced awareness and orientation

Heightened awareness and hyper-vigilance

Examples of Over-Responsivity

- Becomes carsick easily
- Fearful of playground equipment
- Avoids messy play (eg. finger paints)
- Dislikes certain clothing and food textures
- Over-reacts to unexpected and/or loud noises especially motorized appliances
- Gags in response to certain smells or tastes

Behavioural Reactions to Over-Responsivity

- Increased anxiety, distractibility, arousal, activity level
- Actively creates strategies or rituals to avoid uncomfortable sensory input
- Highly responsive to and distressed by changes in the environment
- Designs and implements structure

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Behavioural Reactions to Over-Responsivity

- Goes into “shut down” – appears passive, self-absorbed
- Aversion to many self care tasks
- Sensory seeking behaviours in an attempt to inhibit hyper-reactive responses and for self-calming

Sensory Defensiveness

Hyper-reactivity to sensory input where the individual responds to harmless sensations as being potentially harmful often resulting in a flight-fight response, avoidance of sensory input, anxiety and aggression.

Hypo-Responsivity and Sensory Seeking

“I can’t feel my body unless it is moving.”

Tito Mukhopadhyay, 2003

Jim Sinclair

“It wasn’t enough to figure out just once how to keep track of my eyes and ears and hands and feet all at the same time. I’ve lost track of them and had to find them over and over again.”

“Do you have to find your legs before you can walk?”

Examples of Under-Responsivity

- Engage in excessive swinging, spinning, jumping
- Apparent lack of awareness of risk or danger related to heights
- Unaware of food on their face
- Lack of orientation to loud noises
- Unresponsive to noxious smells

Behavioural Reactions to Under-Responsivity

- Passive, self-absorbed, low arousal and activity level
- Limited responses to changes in environment
- Limited responses to facial expression or gestures
- Over-focus on objects
- Clumsiness

Sensory Processing Disorder

- Not currently recognized in DSM-V
- Not currently recognized in ICD-10
- Recognized in ICDL (200. Regulatory-Sensory Processing Disorder)
- Recognized in ZERO TO THREE (2005)
- No consensus within literature regarding SPD classification system
- OTs report on sensory challenges or atypical sensory processing
- Developmental paediatricians, psychologists increasingly using SPD

Sensory Challenges Impact

- Motor skills
- Activities of Daily Living
- Behaviour (self-regulation)
- Emotions and Social interaction
- Communication
- Cognition/Information Processing
- Perception

Tito Mukhopadhyay

“Holding a spoon was another circus for me. I would hold the spoon, try picking up the food, and by the time it reached my mouth, things would spill out.”

How Can I Talk If My Lips Don’t Move, 2011

Ros Blackburn, Age 32, A.S.

Discussing dislike of currant buns.

“It’s the texture When you bite through the bready bit, and then suddenly squish into the currants. You can hear it as well, as you get a noise in your mouth. Some of these fruity things have almost got a gritty noise and a feeling that’s foul.”

The Links Between Sensory Processing and Behaviour

Atypical sensory processing impacts:

- Arousal and activity levels
- Self-regulation
- Anxiety
- Attention
- Social Interaction
- Flexibility and insistence on routines
- Stereotypic behaviours

Common Behaviours in SPD

- Need for routine and sameness
- Problems with transitions
- Resistance to new items or experiences
- Rigid thinking
- Emotional lability
- Poor self-regulation
- Use of sensory motor behaviours to calm, alert or organize

Common Behaviours in ASD

- Need for routine and sameness
- Problems with transitions
- Resistance to items and experiences
- Rigid thinking
- Emotional lability
- Poor self-regulation
- Use of sensory motor behaviours to calm, alert or organize

Sensory Gifts vs Challenges

“Every design problem I have ever solved started with my ability to visualize and see the world in pictures.”

Temple Grandin, 1995

“Images came to me like motion pictures on the screen and I enjoyed the sensation that came from thinking life was something set forth for me to enjoy at my leisure. I could jump in when I felt like it, slip away if that fit, or sit back and observe as a wandering passerby world.”

Willey, 1999

Michael Moon

“Often if I want to hear something I close my eyes or I look at nothing and my vision goes blank. This can work for me, for when I go into that trance like state where everything else disappears, the beauty I experience is profound. I hear sounds most people don’t hear and see patterns shapes and colors most people can’t. There is such sensitivity to sensual stimulation and the detail within it.”

SENSORY EVALUATION

Standardized Assessments

- The Sensory Challenge Protocol (McIntosh,Miller, Shyu & Hagerman, 1999)

- Sensory Integration and Praxis Tests (Ayres, 1989)

Standardized Sensory Questionnaires

- Sensory Profile and Short Sensory Profile (Dunn, 1999)
- Adolescent/Adult Sensory Profile (Brown and Dunn, 2002)
- Infant and Toddler (Dunn, 2002)
- School Companion (Dunn, 2006)
- Sensory Processing Measure (2007)

Non-Standardized Questionnaires

- Analysis of Sensory Behaviour Inventory (Morton & Wolford, 1994)

- Sensory Screening in Office

Managing Sensory Challenges

1. Reduction of Sensory Hyper-Responsivity

    - Wilbarger Therapressure Protocol
    - Therapeutic Listining
    - Bean Bag Tapping

Managing Sensory Challenges

2. Sensory Motor Interventions
    - Environmental accommodations
    - Activity accommodations
    - Sensory Diet
    - Graded sensory exposure

Managing Sensory Challenges

3. Cognitive Strategies

   - “How Does Your Engine Run?” Alert Program for Self Regulation
   - The Incredible 5 Point Scale
   - Zones of Regulation

Managing Sensory Challenges

4. Activities of Daily Living Accommodations
    - Task Analysis
    - Visual Aids
    - Clothing Accommodations (eg. Pant loops, highlight openings
    - Weighted spoons, pencils

Adults with Autism Spectrum Disorders

KEVIN STODDART, MSW, PHD, RSW

FOUNDING DIRECTOR, THE REDPATH CENTRE

ADJUNCT PROFESSOR, FACTOR-INWENTASH FACULTY OF SOCIAL WORK, UNIVERSITY OF TORONTO

CO-CHAIR, ONTARIO WORKING GROUP ON MENTAL HEALTH AND ADULTS WITH ASD

CO-CHAIR, ONTARIO PARTNERSHIP FOR ADULTS WITH AUTISM AND ASPERGER

Historical Sketch: Two Silos, Increased Prevalence

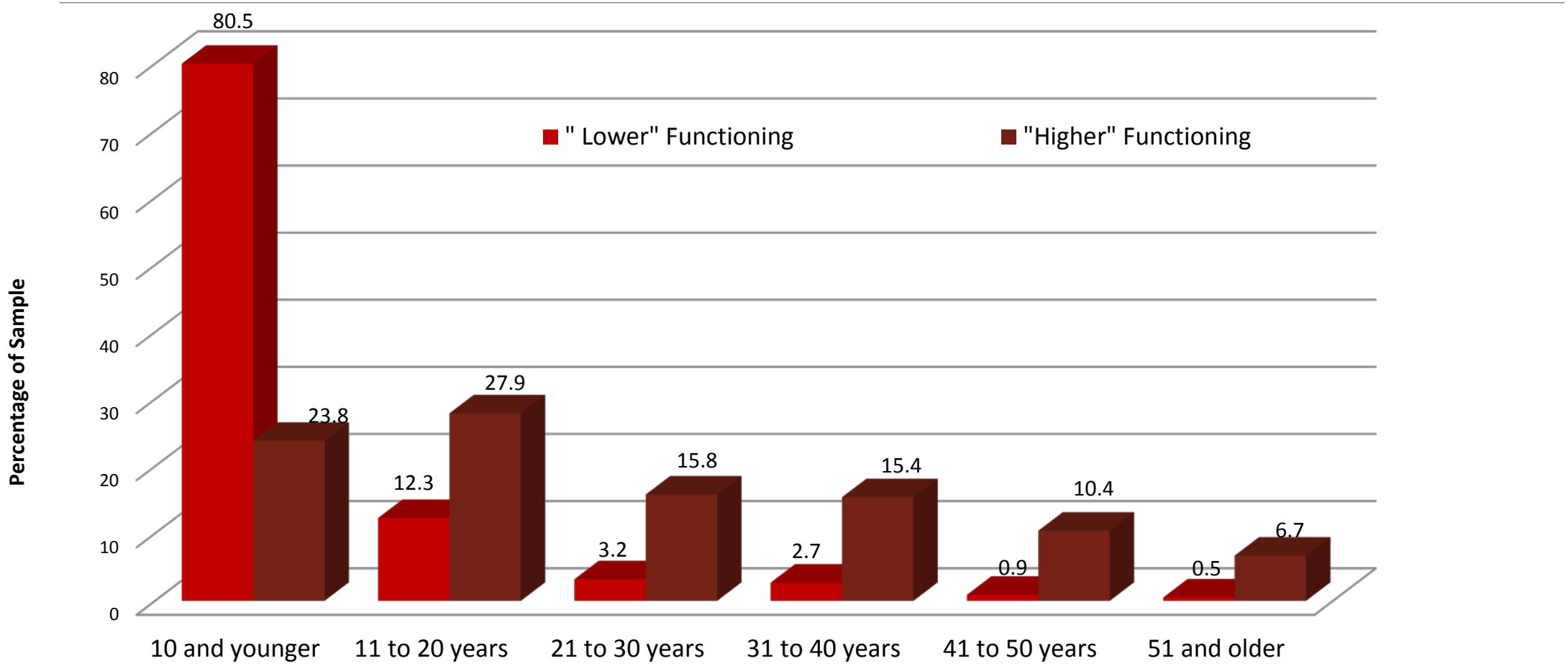
- Prevalence is higher than 1%; this in part, resulted from a wider range of profiles included in the spectrum, primarily higher functioning individuals
- Historically, autism agencies in Ontario focused on residential services and gained autism and behavioural expertise, but not necessarily mental health awareness
- Autism services developed independently; children and adult mental health services did not have the expertise in autism
- Fortunately, there has been greater knowledge transfer between these sectors, through specialized projects and groups, but the expertise exchange needs to continue
- Numerous studies and reports are highlighting the “crisis” that developmental disabilities and autism services are facing (e.g., Stoddart et. al, 2013; Ontario Ombudsman, 2016)
- Adults with ASD and no intellectual disability now have little access to government funded clinical services—one of the results of this is poorer prognosis and more contact with other sectors (e.g.., long-term hospitalization, forensic system, homelessness, ODSP)

Who are Adults with ASDs?

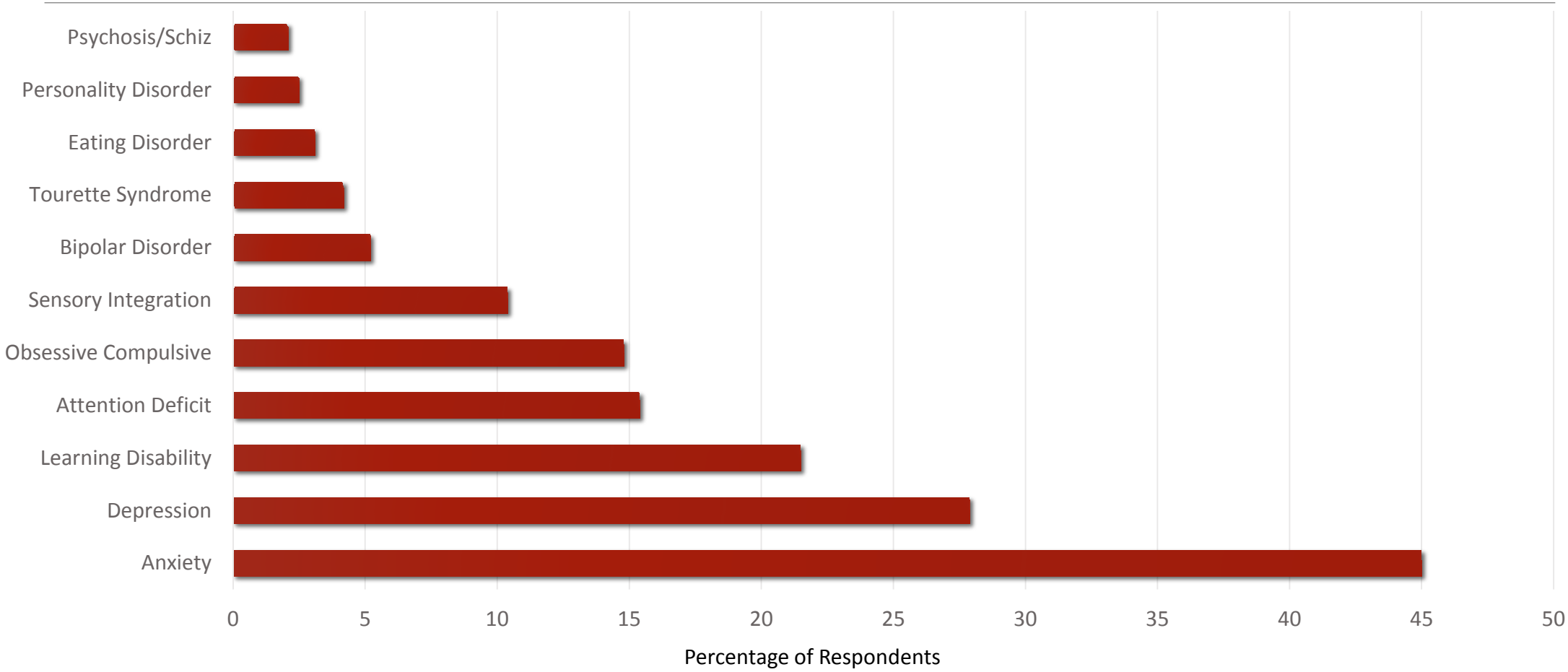
1. Those diagnosed with ASDs as children or teens and who have reached adulthood;
2. Those diagnosed as adults at various life stages due to a crisis, psycho-social problems, recognition by self, friends, or family
3. Parents/extended family members of children and youth with Asperger's or ASDs who recognize 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

Youth and Adults with ASD: Age of Diagnosis

(N= 480; Stoddart et al., 2013)



Youth and Adults with ASD: Mental Health Diagnoses
(Stoddart et al., 2013)



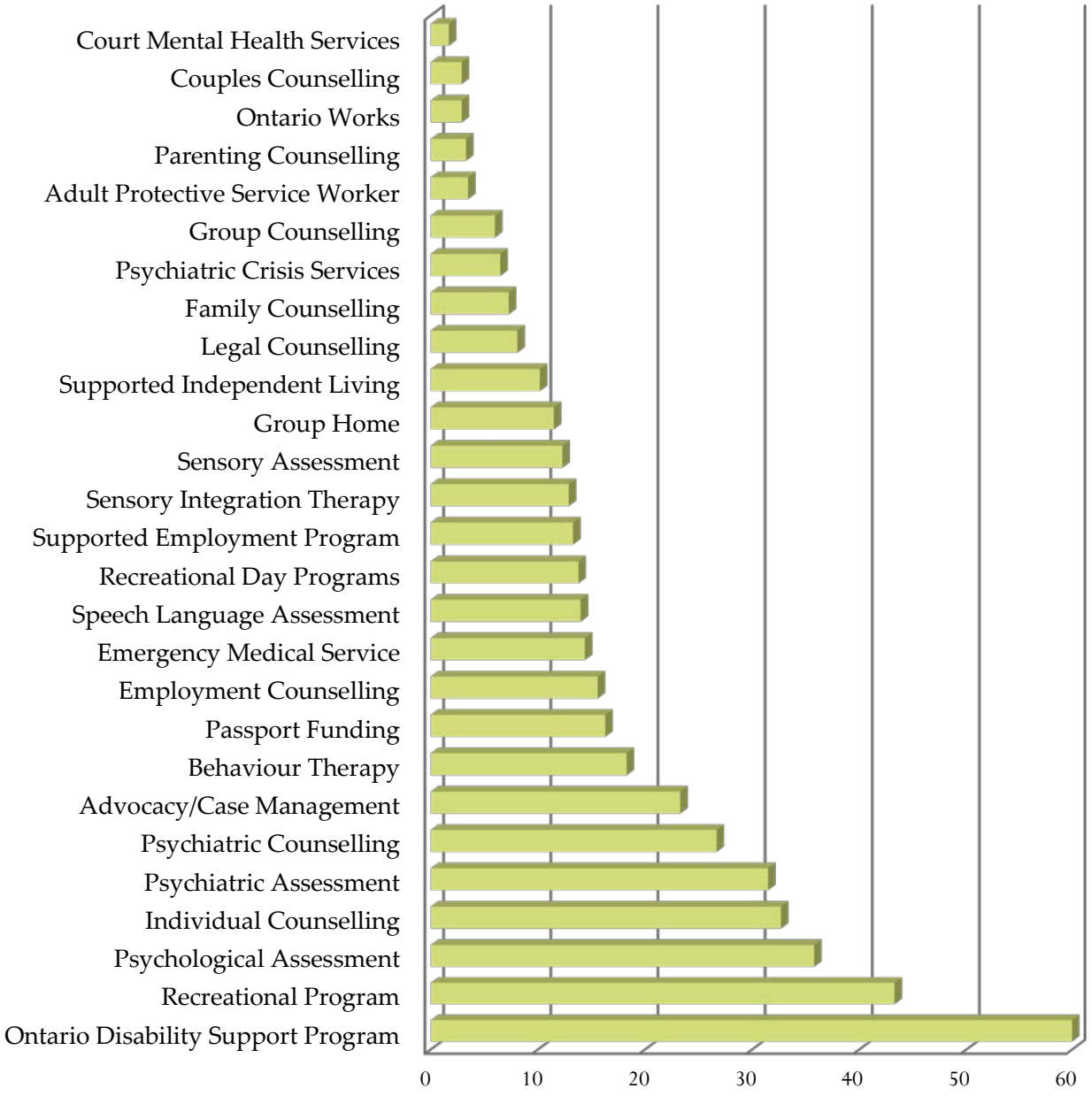
Prevention and Treatment Supports and Services

A range of connected, multidisciplinary services and supports must be available for this group:

- Individual therapy
- Psychopharmacological intervention
- Psychoeducation (Mental Health, CBT, mindfulness, etc.)
- Family therapy
- Couple and parenting therapy
- Occupational therapy
- Behavioural therapy and coaching
- Case management
- Employment counseling
- Social, support and psychoeducational groups
- Academic advising
- Inpatient treatment

Current Service Use by the Youth and Adults

(Stoddart et al, 2013; N=480)



Emerging Issues: Aging with ASD

- Older adults with diagnosed or suspected ASD are appearing for clinical services at The Redpath Centre: majority are not diagnosed but suspected of having ASD by a spouse or family member
- Diagnosis after 40 can be helpful psychologically, medically, inter-personally; recently have seen people in their 60's, 70's and 80's for therapy; transition to retirement can be stressful!
- There is little empirical evidence in the field about the health status of these individuals and what exists is most likely clouded by the heterogeneity of samples studied (e.g. ASD with and without intellectual disability)
- Recently received funding for exploratory research which included a 'think tank' of aging and ASD researchers, qualitative interviews of professional caregivers and people with AS over 60
- Immediate needs necessitate the education of family members, affected individuals and professional caregivers (including retirement and long-term care facilities) about traits of ASD, ensuring inclusive environments, assisting in differential diagnosis WRT neurological/health issues

Emerging Issues: Legal Involvement and ASD

- Clinical experience suggests that inappropriate behaviour while in pursuit of sexual-romantic relationships is a leading cause of difficulties, as is isolation, obsessive behaviour, anger
- Charges in the past five years in practice include possession and distribution of child pornography (several), sexual assault (child & adult), assault, arson, murder, human trafficking
- There is wide variation as to how law enforcement and the justice system deals with these matters; recent case of overturning minimum mandatory for a sex offence by autistic adult
- Clinicians, Crown, lawyers, probation and parole are not well-educated as to the unique needs of the ASD group; they may recommend intrusive assessment/intervention methods (e.g., sex offender groups, custodial sex offender treatment, etc.)
- Many of these problems would be prevented through appropriate socio-sexual education
- Inappropriate use of the internet/electronic devices has enabled inappropriate communication (cyberstalking, sexting, etc.) and ability to access ‘private’ information about targets of interest

Learning from Research, Practice & Policy

- Ontario is not prepared for increasing prevalence of diagnosed ASDs
- Service deficiencies cut across MULTIPLE ministries
- The system and societal costs in inaccessible services are immeasurable
- There are few funded mental health services in the province specialized in adults with higher-functioning ASDs; Generic mental health services lack expertise and training (See: www.adultasd.ca)
- Services are piecemeal and not integrated (OPAAA, 2007; Ombudsman, 2016)
- Introduction of the "*Inclusion of Persons with Developmental Disabilities Act*" will not address the needs of the higher functioning group of adults with ASD
- Responsive policy models exist in other jurisdictions (UK)

Medical Homes for Adults with ASD in Primary Care

Queen's University | Department of Family Medicine | Intellectual and Developmental Disabilities Program

November 14, 2018

Family Medicine Forum, Toronto

Dr. Liz Grier, MD, CCFP

Senior Advisor, Developmental Disabilities,
Department of Family Medicine, Queen's University

(I have not conflicts of interest to disclose)

The health status of adults on the autism spectrum

Croen et al. *Autism* 2015, Vol 19 (7) 814-823

Studied frequency of psychiatric and medical conditions among a large, diverse, insured population of adults with autism from 2008 – 2012 vs age and gender matched controls (ASD cases N=1507, control cases N=15070)

Adults with ASD had significantly increased rates of psychiatric disorders including depression, anxiety, bipolar disorder, OCD, schizophrenia and suicide attempts*(fivefold higher rate with only 50% of patients who attempted suicide reporting depression)*

Nearly all medical conditions sampled were significantly ($p<0.0001$) more common:
-pituitary gland and hypothalamic control (1.33% vs 0.21%)
-thyroid disease (7% vs 3%)
-constipation (4.45% vs 1.39%) and diarrhea (5.24% vs 1.39%)
-upper GI tract disorders (13% vs 8%)
-dyssomnia (16% vs 8%)
-organic sleep apnea (4.25% vs 2.68 %)
-seizure disorders (12% vs 0.73%) – (ASD male 9.4%, ASD female 19.0%)
-obesity (34% vs 27 %)
-dyslipidemia (23% vs 15%)
-diabetes (7.56% vs 4.33%) - (ASD male 6.6%, ASD female 10.1%)
-hypertension (26% vs 16%)

…even rarer conditions including stroke and Parkinson's disease, also hearing, vision impairments and vitamin deficiencies

Factors possibly contributing: i) difficulty communicating symptoms, difficulty tolerating physical examination and other investigations leading to delayed diagnoses, poorer doctor-patient communication, ii) core impairments of ASD affecting social determinants of health, iii) genetic factors, iv) medications

Autism Health Watch Table (Bradley, Loh, Grier, Korossy and Cameron 2014)

Queen's University
DEPARTMENT OF FAMILY MEDICINE
Intellectual and Developmental Disabilities Program

Google: "Autism Health Watch Table"

Or find on the Surrey Place Primary Care Website:
www.**surreyplace**.on.ca/**primary-care**

Evidenced Based Consensus Guideline and Anticipatory Care Tool for Primary Care of Children and Adults with ASD in Canada

Health Watch Table — Autism Spectrum Disorder (ASD)

Bradley, Loh, Grier, Korossy and Cameron 2014

Contents

Importance of Self Advocate Narrative Accounts

While these most commonly address autism friendly environments in schools and workplaces, this information is also relevant for special approaches and accommodations made in health care settings.

Judy Endow

http://www.judyendow.com/

The reason I jump (Naoki Higahsida)

Additional examples of self-narratives are available at http://researchautism.net/pages/autism_autistic_asperger_spectrum/personal_accounts_autism/index.

Case Presentation – Part One

You are asked to see Susan, a 17 year old woman in your family medicine practice, to renew one of her medications. You know Susan's mother, who is also your patient, fairly well but don't see Susan often as she is mainly followed by her general pediatrician.

You know that Susan lives with her mother and step-father full time and requires 24 hour supervision and support for almost all activities of daily living.

Your file indicates Susan's diagnosis as Autism Spectrum Disorder. She has no allergies nor history of hospitalizations or surgeries.

Her medications are Risperidone 0.25 mg three times per day and PEG3350 1 TBSP per day. She also takes Melatonin 5 mg OTC for sleep.

Her mother has come requesting that you renew the PEG3350 so that it will be covered under their drug plan.

What more would you like to know about Susan?
Are their any investigations or interventions that you would suggest?

….now with updated baseline information

***Medical History*:**

Autism Spectrum Disorder

Moderate Intellectual Disability (psychoeducational re-assessment at age 11)

Genetics (unknown etiology – autism microarray normal – 2015, MRI normal 2007)

Additional Diagnoses:

Primary Sleep Disorder

Constipation

Overweight

GI issues, Sleep Problems and Obesity in ASD: special considerations for adults

Queen's University
DEPARTMENT OF FAMILY MEDICINE
Intellectual and Developmental Disabilities Program

- **Despite history of longstanding constipation, still need to consider new diagnoses**

(chronic: hypothyroidism, new medication; acute: bowel obstruction, volvulus (unusual presentation of C Difficile)

- **PEGlyte, COlyte sometimes prescribed for longterm use in Ontario because ODB covered while PEG 3350 without electrolytes is not (risk of electrolyte imbalance, seizure risk with colyte use)**

- **For sleep disturbance, again revisit underlying physical problem that is new (GERD, pruritis ani)**
- **Consider new diagnosis of OSA (may present as agitation during the day, rather than hypersomnolence)**

- **Obesity - unique contributors and barriers to exercise (Curtin et al.)**

-history of food used as reinforcement

-preference for energy dense foods: chicken nuggets, hot dogs, and peanut butter in the protein group; cake, french fries, macaroni, and pizza in the starch group; and ice cream in the dairy group, fewer fruits and vegetables

-more daily servings of sugar-sweetened beverages (SSBs) - high addictive potential and public advertisements are a trigger, high caffeine intake affects sleep, behaviour, anxiety

-social communicative and behavioural impairments as well as motor planning difficulties, low tone affect participation in organized sports

-family stress

-increased sedentary time - video games, TV

Recent study showed gender and age, parental education, family income, ethnicity, ASD severity, social functioning, psychotropic and complementary medication use of children and youth with ASD were not statistically associated with their weight status (Granich et al.)

… and don't forget to reassess hearing, vision and dental care!

Case Presentation - Part 2

Several months later, you receive a report from an emergency department visit for Susan. She had an isolated tonic clonic seizure lasting 45 seconds and was brought to the ER by ambulance. She was otherwise well with no precipitant for the seizure.

Susan's mother recalled that 5 years prior there was an 'episode' where a babysitter reported that Susan fell down and started shaking. When they had been seen in the ER that time it was felt that this was a vasovagal (fainting) episode.

At the mother's urging, an EEG and MRI have been ordered by the ER. A consult to neurology has also been placed, however, the wait is about 6 months to be seen.

Susan's mother brings Susan to your office a week later worried that she is showing more signs of agitation that remind her of how she was in the hours leading up to the seizure.

What more would you like to know about how Susan is presenting?

Seizure Disorders … previous understanding

- estimated prevalence is 20-35% of adult and 7-14% of children
- all types of seizures can be found but complex partial seizures are most commonly reported
- complex partial seizures can be difficult to distinguish from atypical body movements and behavioural patterns often seen in association with ASD (some of these may be due to other medical conditions ex. GERD)

- any behaviour such as staring off spells, cessation of activity, eye fluttering or eye deviation to one side associated with confusion or fatigue or sleep should prompt EEG

Seizure Disorders – newer longitudinal data (Bolton et al.)

-onset age 10 - 18

-Generalized Tonic Clonic seizures represented 88% of sz type

-female more so than male (2x likely)

-associated with fhx of ASD but not fhx of epilepsy

-associated with ID, poor verbal abilities

-relatively infrequent 1/wk to 1/mo

-controlled generally on 1-2 medications

-association with psychotropic use

(also this was more common in women rather than men with ASD in the sample - ? confounder)

Case Presentation - Part 2 con't

Susan is seen by a neurologist and started on Topiramate 25 mg bid gradually titrating up to target dose of 100 mg bid. Topiramate is chosen in hopes of preventing weight gain associated with atypical antipsychotic. Despite titrating to target dose, Susan continues to have a seizure ~ once every 4 weeks and is having regular 'paroxysmal' behavioural outbursts.

Topiramate is titrated down and Lamotrigine started with much improved efficacy for seizure control. You see Susan's mother for a routine blood pressure check and she reports as an aside that Susan seems to be doing much better with behavioural outbursts on the Lamotrigine and is sleeping a bit better.

Several months later, you get a call from the family. Susan has transitioned back to school after being off for the summer. She has a new class and different EA and has not been doing well. She is having behavioural outbursts at home and school and refusing to attend activities she would normally enjoy, (ex. Swimming).

Her mother was not sure what to do and tried increasing Risperidone to four times per day which seems to be helping a bit. The medication will run out earlier than the pediatrician's prescription and would need to be refilled at the higher dose. The pediatrician is away this week and the prescription will run out tomorrow.

As the family physician, what more would you like to know?
Do you have concerns about prescribing this increased dose of medication?

Case Presentation – Part 3

You renew Susan's Risperidone prescription at four times a day for a 6 week period with the request that it be reduced down to three times a day once adjustment to the new classroom has occurred. You ask that Susan be booked to see her pediatrician and also place a referral to a pediatric interprofessional mental health team.

You also ask that Susan's mother track the behavioural outbursts on a calendar and correlate to any physical symptoms (ex. Constipation) or a stressful life event.

A few months later, Susan's mother brings her calendar to show you a pattern of behavioural outbursts occurring about Day 24 of the menstrual cycle and lasting until her period starts. As soon as her period starts, Susan feels much calmer. Susan typically complains of 'stomach cramp' for the first day of her period and her mother has always given her Tylenol which seems to help a little bit.

What more would you want to know?
How would this alter your diagnostic and treatment approach?

- Cyclical behavior symptoms are more common in women with autism than general population

- 62.5-91% dysmenorrhea, with 75-96% endorsing symptoms of PMS
- 92% of women with autism fulfilled DSM criteria for late luteal phase dysphoric disorder, compared to 11% from control group
- 33% showed “ASD specific menstrual symptoms”

- **PMDD rate in a single study - 92%**

- Women with autism are more likely to present with cyclical behavioral or mood changes compared to women with other developmental delays including Down Syndrome and cerebral palsy

Symptoms, Diagnosis and Management

Common presenting complaints of behavioral changes include:

Aggressivity, self injury, increased stimming, repetitive movements and obsessive behaviors, restlessness or agitation, social withdrawal

Diagnosis of PMS depends on demonstration of true cyclicity of symptoms

Documentation (daily charting, questionnaires) becomes the main aspect of the diagnostic process

Education: Menarche preparation, books, videos, schedule, visual charts

Medication

- **1st line: NSAID (Ibuprofen or Naprosyn)**
- **2nd line:Hormonal manipulation (Monophasic oral contraception, Depo-Provera)**
- **3rd line: Antidepressants- SSRI (Paroxetene, Fluoxetene)**

College of Family Physicians of Canada Vision for the Patient's Medical Home (College of Family Physicians of Canada, 2014):
Adaptations for patients with ASD (Grier)

1.Patient Centred –
But also 'Person Centred' (and family-centred), autism friendly clinic environment,

2. Ensure that every patient has a personal family physician who will be the most responsible provider (MRP) of his or her medical care –
Involve the family physician and primary care team during the pediatric years to lessen issues in transition

3. Offers a broad scope of services carried out be teams or networks of providers –
Also need for behavioural therapists and others outside of traditional family health team model, e-consultation? Mentorship models?

4. Ensures timely access to appointments and advocacy for and coordination of timely appointments with other health and medical services –
ASD friendly booking strategies, appointment reminders, advocacy for wait times for services, interventions while waiting

5. Provides patients with a comprehensive scope of family practice services
Comprehensive Autism Health Watch Table guided annual reviews

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6. Provides continuity of care, relationships and information for its patients –
Dr. Patient Relationship strengthened by understanding and accommodating socio-communicative needs

7. Maintains electronic medical records for its patients
Medications tried in the past with side effects/efficacy well documented, highlight communication and other access issues on referrals, requisitions etc.

8. Serves as ideal sites for training medical students, family medicine residents and carrying out research
Lack of Adult ASD specific education,– need for hands on experience

9. Evaluation of the effectiveness of its services as part of its commitment to continuous quality improvement (CQI)
Need for primary care research for what indicators to use – rates of psychotropic prescribing? Rates of annual health reviews?

10. Will be strongly supported i) internally through management structures, and ii) externally by all stakeholders, including governments, the public, and other medical and health professions and their organizations across Canada.
importance of government and all stakeholder support for these efforts, advocacy role of Geneva Centre, Autism Ontario and Developmental Service Sector

Also…Ontario Ministry of Health and Long Term Care – ***Health Links Program*** *for Complex Patients*
Please advocate for program this to help our adult patients with ASD!

REFERENCES:

Croen et al. The health status of adults on the autism spectrum Autism 2015, Vol 19 (7) 814-823

Bolton et al. Epilepsy in autism: features and correlates *Br J Psychiatry.* 2011 Apr; 198(4): 289–294.

Curtin et al. Obesity in Children with Autism Spectrum Disorders *Harv Rev Psychiatry*. 2014 Mar-Apr; 22(2): 93–103.

Granich et al. Obesity and associated factors in youth with an autism spectrum disorder *Autism* November 2016, Volume20(Issue8) Page p.916-926

Pilling et al. Recognition, referral, diagnosis, and management of adults with autism: summary of NICE guidance BMJ June 27 2012;344:e4082

Howlin et al. Adults with Autism Spectrum Disorders Can J Psych May 2012; 57(5):275-283

Fombonne, E. Autism in Adult Life Can J Psych; May 2012; 57(5) p.273

Bauman, M. Medical Comorbidities in Autism: Challenges to Diagnosis and Treatment Neurotherapeutics 2010; (7) p.320-327

Furuta et al. Management of Constipation in Children and Adolescents with Autism Spectrum Disorders. Pediatrics 2012;130;S98

Woolfenden et al. A systematic review of two outcomes in autism spectrum disorder-epilepsy and mortality Developmental Medicine and Child Neurology 2012, 54:306-312

Howlin et al. Frith Guidelines 3rd Edition Autism Spectrum Disorders Chapter 2012

Coury et al. Gastrointestinal Conditions in Children with Autism Spectrum Disorder: Developing a Research Agenda Pediatrics 2012;130;S160

Johnson et al, Assessment and Pharmacologic Treatment of Sleep Disturbance in Autism Child Adolesc Psychiatric Clin N Am 2008 17:773-785

Malow et al. A practice pathway for the Identification, Evaluation, and Management of Insomnia in Children and Adolescents with Autism Spectrum Disorders Pediatrics 2-12;130;S106

REFERENCES CONTINUED:

Dove et al. Medications for Adolescents and Young Adults with Autism Spectrum Disorders: A systematic review Pediatrics 2012;130;717

Olivie, H. Clinical Practice: The medical care of children with autism Eur J Pediatr 2012 171:741-749

Buie et al. Recommendations for the Evaluation and Treatment of Common Gastrointestinal Problems in Children with ASDs Pediatrics 2010;125;S19

Buie et al. Evaluation, Diagnosis and Treatment of Gastrointestinal Disorders in Individuals with ASDs: A Consensus Report Pediatrics 2010;125;S1

Mazzone et al. Psychiatric comorbidities in asperger syndrome and high functioning autism: diagnostic challenges Annals of General Psychiatry 2012, 11:16

Coury et al. Use of Psychotropic Medication in Children and Adolescents with Autism Spectrum Disorders Pediatrics 2012;130;S69
Shattuck et al. Services fro Adults with An Autism Spectrum Disorder Can J Psych May 2012; 57(5): 284-291

Kodak et al. Assessment and Behavioural Treatment of Feeding and Sleeping Disorders in Children with Autism Spectrum Disorders Child Adolesc Psychiatric Clin N Am 2008 (17):887-905

Fletcher, R., Loschen, E., Stavrakaki, C., & First, M. (Eds.). (2007). *Diagnostic Manual -- Intellectual Disability (DM-ID): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability.* Kingston, NY: NADD Press.

Grier L. Medical Home. Chapter 7.14 in: Rubin IL, Merrick J, Greydanus DE, Patel DR. Rubin and Crocker 3rd Edition: Health Care for people with intellectual and developmental disabilities across the lifespan, Dordrecht, Springer, projected 2015.

College of Family Physicians of Canada (CFPC), A vision for Canada family practice. The patient's medical home, 2011. URL:http://www.cfpc.ca/uploadedFiles/Resources/Resource_Items/PMH_A_Vision_for_Canada.pdf

References continued – Cyclical Behaviour/Menstrual Issues

- Lee, D. Menstrually related self injurious behavior in adolescents with Autism. J AM Acad Child Adolesc. Psychiatry 43:10 october 2004.
- Quiet EH The treatment of cyclical behavior changes in women with menstrual disabilities. J pedatr adolesc gynecol 12:139-142 1999.
- Kirkham Y. Trends in menstrual concerns and suppression in adolescents with developmental disabilities. Journal of Adolescent health 53: 407-412 2013.
- Obaydi H. Prevalence of premenstrual syndrome in Autism: a prospective observer rated study. Journal of International medical research 36:268-272 2008
- Hamilton A. Autism spectrum disorder and menstruation. Journal of adolescent health 49:443-445 2011.
- Burke L. Gynecologic issues of adolescents with Down Syndrome, Autism and cerebral Palsy. J pediatr adolesc gynecol 23:11-15 2010
- Kyrkou M. Health issues and quality of life in women with intellectual disability. Journal of intellectual disability research 49:10 october 2005.
- Bettendorf B, Dysmenorrhea: contemporary perspectives. Obstet Gynecol Surv 2008; 63:597
- Sullivan B & Developmental Disabilities Primary Care Initiative Co-editors (2011). *Women's menses yearly monitoring chart In: Tools for the primary care of people with developmental disabilities.* Available from http://www.surreyplace.on.ca/primary-care?id=135.(Accessed February 20 2016)

Thank you!

Questions?

Reflections/Issues arising in practice?