Adolescents and Adults with ASD: Ensuring access, managing common conditions, supporting transitions

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Objectives:

Learning Objective #1 Learn about the Autism Health Watch Table for anticipatory primary care, as well as important components of accessible and effective patient-centred medical homes for adults with ASD

Learning Objective #2 Learn how to anticipate and manage common genetic, gastrointestinal and neurological conditions in ASD

Learning Objective #3 Learn how to anticipate and manage common women's health issues in the setting of ASD

Learning Objective #4 Learn about the family physician, caregiver and patient's role in supporting transition from pediatric to adult health care

OMA ThoughtLounge Survey - Adults with Autism Spectrum Disorder

Demographics, Living Situation, School/Employment

What percentage of patients 16 years and older in your current practice do you suspect or are diagnosed on the autism spectrum? (52% said > 1%)

Average Age of patients 16 yrs or older? (16-21 (39%), 22-26 (26%), 27-31 (12%), 32 or older (23%))

Living Arrangement (independent (16%), with family (67%), in supervised setting (17%))

Attending School or Employed? (Yes (42%), No (58%))

OMA ThoughtLounge Survey - Adults with Autism Spectrum Disorder

Supports for Family Physicians:

Adequate Tools/Referral Resources/Practice Models (Agree 8%, Neutral 17%, Disagree 75%)

Adequate participation in care: (Agree 30%, Neutral 27%, Disagree 43%)

Caregivers participation in care: (Agree 20%, Neutral 26%, Disagree 54%)

FP knowledge and skills: (Good 18%, Average 55%, Poor 20%)

Resources for improving knowledge and skills: (Excellent 4%, Good 14%, Average 41%, Poor 41%)

Autism Spectrum Disorder 299.00 (F84.0)
Diagnostic Criteria DSM V

A. **Persistent deficits in social communication and social interaction** across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Autism Spectrum Disorder 299.00 (F84.0)
Diagnostic Criteria

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).

3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g, strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).

4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

The health status of adults on the autism spectrum

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

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Intellectual and Developmental Disabilities Program

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)

Table 1. Characteristic of study population: adults 18 years and older from the Kaiser Permanente Medical Care Program in Northern California.

Characteristics	ASD (*N* = 1507)	Controls (*N* = 15,070)	Chi-square *p* value
Age, mean (SD) (years)	29.0 (12.2)	29.4 (12.1)	0.26
Age categories, *N* (%) (years)			1.00
18–24	790 (52.4)	7900 (52.4)	
25–29	193 (12.8)	1930 (12.8)	
30–34	123 (8.2)	1230 (8.2)	
35–39	89 (5.9)	890 (5.9)	
40–44	87 (5.8)	870 (5.8)	
45–49	82 (5.4)	820 (5.4)	
50–54	62 (4.1)	620 (4.1)	
55–59	47 (3.1)	470 (3.1)	
60–64	28 (1.9)	280 (1.9)	
65+	6 (0.40)	60 (0.4)	

Adults with ASD had significantly increased rates of psychiatric disorders including:

depression,
anxiety,
bipolar disorder,
obsessive compulsive disorder,
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 23%)

-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

ASD in Adulthood - Survey of Quality of Life Indicators

- up to 84% diagnosed with identifiable mental illness, 88% on at least one medication
- only 49% in some form of educational or work program
- 14% become married or have a long-term intimate relationship
- 25% had at least one friend

ASD in Adulthood - Prevalence

- affects 1.1% of adults (1.8% of men, 0.2% of women)
- although some many patients are diagnosed in childhood, **for every three known adult cases, it is estimated that there are two individuals without a diagnosis who may benefit from assessment, support and intervention**

ASD in Adulthood - Diagnosis

- particular problems arise in identifying high functioning autism, (Asperger's Syndrome), which may not be recognized until adulthood or may be misdiagnosed as:

  - depression,
  - anxiety
  - personality disorder,
  - or even a psychotic illness

NICE guidelines, U.K. 2012

(National Institute for Clinical Excellence (U.K.)

Consider assessment for possible autism when a person has one or more of the following:

-Persistent difficulties in social interaction

-Persistent difficulties in social communication

-Stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests

NICE guidelines, U.K. 2012 con’t

AND one or more of:

-Problems in obtaining or sustaining employment or education

-Difficulties in initiating or sustaining social relationships

-Previous or current contact with mental health or learning disability services

-A history of a neurodevelopmental condition (including learning disabilities and attention-deficit/hyperactivity disorder) or mental disorder.

Autism Spectrum Quotient
(if score of 6 out of 10 – refer for diagnostic assessment)

	Please tick one option per question only	Definitely agree	Slightly agree	Slightly disagree	Definitely disagree
1	I often notice small sounds when others do not				
2	I usually concentrate more on the whole picture, rather than the small details				
3	I find it easy to do more than one thing at once				
4	If there is an interruption, I can switch back to what I was doing very quickly				
5	I find it easy to "read between the lines" when someone is talking to me				
6	I know how to tell if someone listening to me is getting bored				
7	When I'm reading a story I find it difficult to work out the characters' intentions				
8	I like to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant etc)				
9	I find it easy to work out what someone is thinking or feeling just by looking at their face				
10	I find it difficult to work out people's intentions				

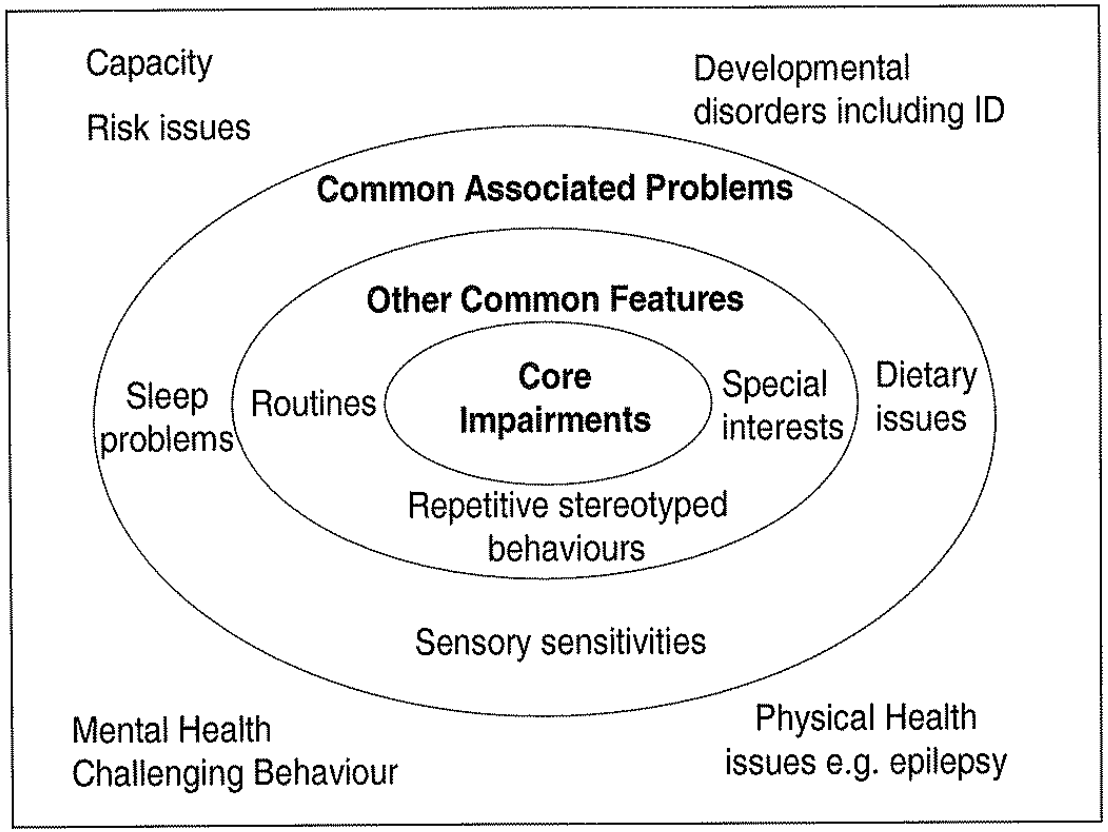
Scoring: Only 1 point can be scored for each question. Score 1 point for Definitely or Slightly Agree on each of items 1, 7, 8, and 10. Score 1 point for Definitely or Slightly Disagree on each of items 2, 3, 4, 5, 6, and 9. If the individual scores more than 6 out of 10, consider referring them for a specialist diagnostic assessment.

This test is recommended in *Autism: Recognition, Referral, Diagnosis and Management of Adults on the Autism Spectrum* (NICE clinical guideline 142). www.nice.org.uk/CG142

Key reference: Allison et al[11]

Howlin et al. Frith Guidelines 3rd Edition 2012

Diagram x.2 Clinical Picture in ASD



Resources:

Self Narrative Accounts:

Judy Endow

http://www.judyendow.com/

Making Lemonade: Hints for Autism's Helpers:

https://www.youtube.com/watch?v=tsBRt8GniEQ

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.

Importance of Identifying Comorbid Health Related Conditions

- improved sense of well being, more effective participation in educational and therapeutic programs
- may help identify phenotypic and genetic clusters of ASD persons with meaningful subtypes

Autism Treatment Network

- **2003 - Autism Treatment Network was established - a network of 14 academically based multidisciplinary centres that would develop protocols to begin assessing the prevalence, presenting features and treatment of comorbid medical conditions in ASD**

Challenges in assessment and diagnosis of physical health comorbidities

- difficulties tolerating physical examination
- individuals who are non-verbal or hypo-verbal or who have difficulties with sensory processing may prevent reporting pain, or localizing discomfort
- atypical presentation of physical symptoms (aggression and self-injury)

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

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

Anticipatory Care for Adults with ASD in the Family Physician's Office:

Autism Health Watch Table – Page 2

i) Checklist for confirmed diagnosis of ASD

Preparation for office visit:
Check out autism needs with care provider prior to visit (Section 5)

Are office accommodations in place to ensure optimal clinical encounter? (5)

Anticipatory Care for Adults with ASD in the Family Physician's Office: Clinical review

Is the aetiology known – review need for genetic reappraisal? (6.1)

Hearing and vision review (6.2)

Seizures? – review as required (6.3)
GI: constipation, eating and nutritional needs? (6.4)
Sleep review (6.5)

Sensory sensitivities? (7.4)
Behaviours of concern? (6.7)
Concerns about mental health? (6.7)
Review psychotropic medications – are they still needed? (6.8)

Are supports and expectations appropriate to individual developmental needs and capacities (are recommendations from psychological and communication assessments being implemented)? (7.2 & 7.3)
Has an autism friendly environment been implemented with appropriate attention to sensory and emotional needs? (5)

Review age and stage transitions (9)
Role of complementary and alternative therapies (10)

Support to care providers and care provider resources (11)

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 diagnoses as Autism Spectrum Disorder and Intellectual Disability. She has no allergies nor history of hospitalizations or surgeries.

Her medications are Risperidone 1.0 mg three times per day and Restoralax 1 TBSP per day.

Her mother has come requesting that you renew the Restoralax 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?

Genetics Assessment

- 10% of cases of ASD are associated with chromosomal or other genetically determined disorders (Fragile X syndrome, tuberous sclerosis subtype)

- Autism Consortium Clinical Genetics-DNA Diagnostics Collaboration recommends chromosomal microarray analysis should be standard practice for evaluation

Psychological Assessment:

Determining baseline functioning is important, particularly when there is concern about changes in behaviour or deterioration in cognition or adaptive functioning. Identifying the individual's current strengths can be used as a platform for development of other skills.

Creating, with the individual and those who know them well, an 'about me' book which can provide an autobiographical journey of the person's life and can alert providers to optimal communication issues.

Behaviour problems occur in a broader context and assessment of the physical and social environment is as important as assessment of the individual.

Autism Health Watch Table, 2014

Psychological Assessment:

Refer to an autism-informed psychologist for assessment of strengths and needs, identify appropriate expectations of the individual from preschool through to adult life and ensure prevention and management/treatment of emotional and behavioural problems.

Work with a psychologist, behaviour therapist and multidisciplinary team to assess daily supports (environmental and care provider) and ensure they are appropriate.

Ensure access to evidence-informed therapeutic interventions for behavioural and emotional issues that arise (eg, therapeutic counselling or cognitive behaviour therapy [CBT] for anxiety; psychotherapy for trauma; behavioural support around problem behaviour [eg, functional analysis, consistency of supports across environments]). Remain available and informed about intervention outcomes, many of which can have a bearing and impact on medical care[76].

Autism Health Watch Table, 2014

Communication Assessment:

A speech-language assessment can provide a more comprehensive view of communication needs and lead to specific intervention recommendations. Advances in literacy instruction and technology have resulted in enhanced communication and learning potentials for many.

The social use of language, interaction and friendship skills are best learned in natural environments with skilled supports.

While language problems persist into adulthood, adults can continue to develop communication skills lifelong.

Autism Health Watch Table, 2014

Communication Assessment:

Consider referral for a joint SLP and Psychologist assessment, especially when problem behaviours arise. Problem behaviours may require a more comprehensive team approach.

Language Regression: If some language skills were well-established and completely lost, without recovery of skills a few months after, referral for assessment and further investigations, such as an EEG during sleep and MRI/MRS brain scans, may be warranted.

Learn what needs (and/or distress) are being communicated through the unique body language of people with ASD. Where possible, teach alternative strategies to communicate these needs and/or assist care providers to understand this communication of distress through body language.

Autism Health Watch Table, 2014

Hearing, Vision and Dental Assessments:

Hearing deficits are common and can be a factor in delay of speech development.

Visual deficits include higher incidence of refractive error, strabismus and differences in ocular motility function.

Hearing and vision difficulties can manifest as a change in behaviour at any age.

Audiological and Optometry assessment prior to diagnosis of ASD and periodically throughout the lifespan and whenever a concern in this regard arises.

Dental: Higher rates of dental caries, incidence of untreated or poorly treated dental caries (ex. Tooth extractions rather than restorations for dental problems)

Higher rates of gingivitis (may relate to mouth dryness associated with medications as well as poor dental hygeine)

Establish good practices in childhood; Accessible dental practices; More frequent hygienist cleanings (q2-3 months); Sedation to facilitate exams/cleanings – some require GA

Motor Difficulties:

Motor clumsiness has often been noted in individuals with ASD (eg, difficulty mastering complex motor tasks; “clumsy”, difficulty tying shoelaces, holding pen/pencil and writing). The aetiology of motor difficulties (eg, fine and gross motor movement, praxis and motor planning) is not well-understood.

Executive functioning difficulties (difficulties organizing, setting goals and completing tasks)

Difficulties in starting, stopping, continuing, combining and switching motor action, speech, thought, memory and emotion are often described by people with autism and are considered by several clinicians and researchers to be associated with sensory-motor (neurobiological) differences in autism

Hypotonia (usually noted by physiotherapists or neurologists), may be a consequence of cerebellar or proprioceptive impairment

Motor Difficulties:

Physical activity should be encouraged according to the individual's interests. Sports with less demand on co-ordination and social functioning, such as bicycling, swimming, running, fitness routines or martial arts, may be preferable.

OT, PT and BT may provide some helpful and pragmatic recommendations for fine and gross motor difficulties.

Refer to neurologist if concerns remain or there is a change in gait or motor behaviours, eg, catatonic-like behaviours or regression in skills.

Gastrointestinal Disorders

- true prevalence is largely unknown with estimations ranging from 9%-70%

- common conditions include chronic constipation, abdominal pain, chronic diarrhea, GERD, H.Pylori infection/peptic ulcer disease/esophagitis, celiac disease

- associated with self injurious behaviour and sleep disturbance
- may present atypically - chest tapping, facial grimacing, intermittent gulping, seeking of abdominal pressure

Constipation

- Autism Treatment Network has produced an algorithm for treatment (Furata et al. Pediatrics 2012)
- Cause: Multifactorial - picky eating, stool withholding behaviour
- Red Flags on history (fever, distention, anorexia, weight loss or poor weight gain, vomiting) and physical exam (abnormal neurological exam, pilonidal dimple, tuft of hair, signs of Hirschprung's)
- Behavioural therapy -including scheduled sitting on the toilet everyday
- PEG 3350 - 1-1.5 g/kg/d for 3 d. for disimpaction, 1 g/kg/d for maintenance

Sleep Disorder

- most common concurrent disorder - prevalence rates of 40-80% (typically developing children 30%)
- sleep onset, sleep maintenance, sleep duration most consistent problems
- also parasomnias, sleep related breathing and movement disorders
- ASD children experience more lengthy periods of night waking (2-3 hrs)
- may laugh, talk, get up and play with toys

Treatment of Sleep Disorders

- Screen all children/adults with ASD
- rule out other disorder (ex. GERD)
- sleep hygiene with clear, regular bedtime routine
- if ineffective, consider medication - Melatonin

Nutritional/Feeding Issues

- children with ASD refuse more foods, require more specific utensils to eat, require food presented in more specific ways, more likely to consume foods at a lower texture, eat a narrower range of foods
- children are unlikely to simply "grow out" of these behaviours
- treated by behavioural therapy, also important to rule out secondary deficiencies
- (Iron, Vitamin B12, Anemia, Calcium, Vitamin D)

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

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- **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!

Sensory Processing Disorder

- a neurological disorder that results from the brain's inability to integrate certain information received from the body's five basic sensory systems
- hyposensitivity and hypersensitivity
- significantly impact anxiety levels, “problem behaviour” and level of functioning
- may be assessed (OT) and sensory diet prescribed

Pain

- Pain may not be recognized if it presents atypically and instead is seen as problem behaviour.
- Atypical experiences of pain and responses to pain may include laughing, humming, singing, removal of clothing and self-injury which could mask the seriousness of the medical condition.
- Agitation and an increase in problem behaviours may be the only clues that the child or adult is in pain.
- Pain may also manifest as changes in food and fluid consumption.
- There is no evidence that people with ASD suffer any less from the presence of a noxious experience.
- (Autism HWT, 2014)

Pain

- Use tools to ascertain presence of pain as outlined in Consensus Guidelines (eg, DisDat for adults).
- Experience of pain may be decreased with music, movement and deep pressure activities (massage).
- Consider symptomatic treatment for perceived pain (eg, acetaminophen or ibuprofen). In individuals with minimal communication, a trial of analgesia, 3 to 4 times a day for 1 to 2 days may be helpful, with monitoring of pain or target behaviours associated with pain.
- Even if target behaviour resolves with analgesia, the underlying cause of the pain needs to be identified and treated.

Back to our case….now with updated baseline information

17 yr F

Medical History:

Autism Spectrum Disorder
Moderate Intellectual Disability
(unknown etiology – microarray normal – 2015, MRI normal 2007)

Primary Sleep Disorder
Constipation
Overweight

Social History:
Living Arrangement: with mother and step father
Decision Making Capacity: dependent/supported for all decisions
Substitute Decision Maker: (mother)

School:
Resource Teacher: Lead EA:
Developmental Service Agency:
Case Manager: Phone:
Additional Services:

SPECIAL NEEDS
Communication: verbal, limited functional speech, benefits from social stories
Sensory Integration: difficulty with loud noises, fluorescent light
Response to Pain/Distress: sometimes localizes pain, may become agitated
How to help: quiet room with caregiver, offer paper and pen to write/draw

Mobility: full
Safety Concerns: road safety, requires 24 hr supervision
Usual response to physical examination: Tolerates with support and clear explanations

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 but Susan's mother had always questioned that it was a seizure.

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

- 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

Seizure Disorders con’t

- 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

Case Presentation - Part 2 con't

Susan is seen by a pediatric neurologist and started on Topiramate.

You see her 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 seizure medication 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.

What more would you like to know?

Do you have concerns about prescribing this medication?

Mental Illness co-morbid with ASD

- sometimes difficult to differentiate core symptoms of autism from symptoms of mental illness
- (ex. preferred ritualistic perseverative behaviour vs. 'egodystonic' obsessive compulsive behaviour)
- essential to rule out underlying physical problem and contribution of social and emotional factors
- No medication is currently recommended for management of the core symptoms of autism in adults

Extent of Psychiatric Morbidity

- up to 84% of adults with ASD suffer from some form of diagnosable mental illness
- most common diagnoses relate to anxiety, OCD and depression (often in combination)
- rates of schizophrenia and other psychoses are no higher than the general population
- environmental factors related to life transitions, loss, inadequate support or social isolation are often, but not always, related to onset of mental illness

Treatment of Mental Health Conditions – Issues in ASD

- reports of up to 88% of adults with ASD being on at least one medication and 40% taking 3 or more medications
- response to medication can be unpredictable and paradoxical (start low, go slow)
- the benefits of cognitive-behavioural therapies for adults with ASD who have significant mental health problems have yet to be demonstrated

Psychotropic Audit Tool: Surrey Place Centre

AUDITING PSYCHOTROPIC MEDICATION THERAPY	Name: DOB:

	Yes	No	Not Sure
1. Has the patient been given a psychiatric diagnosis?	☐	☐	☐
2. Is an interdisciplinary assessment indicated for the concerns for which the medication is being used, and has it been carried out?	☐	☐	☐
3. Is medication treatment consistent with the diagnosis?	☐	☐	☐
4. If patient does not have a psychiatric diagnosis and is being treated for "behaviour problems" are guidelines for problem behaviours being followed?	☐	☐	☐
5. Is the patient capable of consenting to medication treatment? If capable, has he/she given consent? If not capable, has consent been obtained from his/ substitute decision maker?	☐	☐	☐
6. Has the patient and/or his/her substitute decision maker (SDM) been informed regarding anticipated therapeutic medication treatment effects and potential side effects?	☐	☐	☐
7. Has a proper medical assessment been carried out prior to iniitiating medication therapy?	☐	☐	☐
8. Have target behaviours against which to monitor medication effectiveness been defined?	☐	☐	☐
9. Is there a plan to measure these target behaviours objectively and systematically?	☐	☐	☐
10. Is the patient being regularly monitored for side effects?	☐	☐	☐

Psychotropic Audit Tool: Surrey Place Centre

11. Is the patient receiving too many psychotropic agents?	☐	☐	☐
12. Is the patient being under-medicated?	☐	☐	☐
13. Is the patient being over-medicated?	☐	☐	☐
14. Is medication therapy being changed too rapidly?	☐	☐	☐
15. Are PRN and stat doses of medications being used excessively?	☐	☐	☐
16. Are patients treated with antipsychotic agents being regularly evaluated for tardive dyskinesia and metabolic syndrome?	☐	☐	☐
17. Have the psychotropic medication therapy and psychiatric diagnosis or special behavioural pharmacological justification for the medication	☐	☐	☐

Future Directions:
Psychotropic Consent Guide similar to those used for patients with Dementia? (ex. Baycrest Geriatric Health System)
Psychotropic Controlled Substance Agreements?

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 and Autism

Dr Samantha Sacks MDCM CCFP

Epidemiology

- **18% of women with a developmental delay presented to their gynecologist or primary care provider with a complaint of cyclic behavioral change.**
- **women with autism were more likely to present with cyclical behavioral or mood changes compared to women with other developmental delays including Down Syndrome and cerebral palsy**

Quint 1999, Burke 2010

Menarche

- menarche occurs at equivalent age in girls with autism as their peers.
- Little preparation is provided for families and girls concerning this drastic change

Neurotypical women

- **Dysmenorrhea amongst menstruating women has a prevalence rate of 40-90% and in the US it is one of the leading cause of absenteeism from school and work for teenagers and young adults.**
- **Most menstruating women experience at some point some premenstrual symptoms. Of these, 20-40% consider them disruptive or severe enough to seek medical attention**
  - PMDD 3-5%

- **Autism specific studies:**
  - Cyclical behavior symptoms 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%

Kyrkou 2005, Obaydi 2008, Hamilton 2011

Symptoms

- **Common presenting complaints of behavioral changes include:**
  - Aggressively
  - Self injury
  - Increased stimming, repetitive movements and obsessive behaviors
  - Restlessness or agitation
  - Anger
  - Social withdrawal
  - Physical symptoms

Diagnosis

- **Diagnosis of PMS depends on demonstration of true cyclicity of symptoms**
- **Documentation becomes the main aspect of the diagnostic process**
  - Daily charting, questionnaires

Menses (Women's Period) – Yearly Monitoring Chart – Year: _____

Name: _____ DOB: _____ (dd/mm/yyyy)

Put an **X** in the box for each day of the period, each month, e.g.:

X H, P	X N, C

PROTOCOL IN PLACE: ❑ No ❑ Yes
If Yes, *refer to Protocol; mark P when used*

If seen, also include the following:

L = Light (<3 pads a day or <3 tampons a day
H – Heavy (>4 pads a day or >4 tampons a day)
N = Normal (3-4 pads a day or 3-4 tampons a day)
C = Clots (looks like jelly)

B = Please write a "B" if there are any behaviours that depart from the client's baseline on the days leading up to or during the period, since these may be due to hormonal changes (PMS). You can comment on them on the space for notes on the back of this page.

DATE	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Jan																															
Feb																															
Mar																															
Apr																															
May																															
June																															
July																															
Aug																															
Sept																															
Oct																															
Nov																															
Dec																															

Adapted from Community Living Toronto – Scarborough Region and Down Syndrome Society, Canada

NOTES: USE OTHER SIDE →

Symptom Calendar of Behavioral Problems

Please indicate the occurrence of specific behavioral problems (e.g., aggressive behavior, self mutilation), on a daily basis on a scale of 0–5. On the lowest column, please indicate the occurrence of menses.

Month: ______________________________ Name: ______________________________

Days of the month

Symptoms	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5
	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4
	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3
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	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5
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	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0

Menses:

Medications:

0 = no symptoms; 5 = worst symptoms

Quint, 1999

Management

- **Education**
  - Menarche preparation
  - books, videos
    - Social stories
  - Schedule, visual charts

Treatment

- **1st line:**
  - NSAID
    - Ibuprofen or naproxene
- **2nd line:**
  - Hormonal manipulation
    - Monophasic oral contraception
    - Depo-Provera
- **3rd line:**
  - Antidepressants- SSRI
    - Paroxetine, Fluoxetine

Implications

- New onset self injurious behavior or aggression in early adolescence- consider menarche and hormonal changes
- psychiatric diagnoses and inappropriate medication use
- Recognition of cycle and relation to treatment plans

Bibliography

- 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)

Case presentation- Part 4

Giving regular Naproxen starting several days prior to the menstrual cycle along with also starting the oral contraceptive pill help to ease Susan's difficulties around her periods.

Susan comes to have her blood pressure checked and OCP renewed. Her mother let's you know that her pediatrician cannot see her any more as she has turned 18. Her pediatric neurologist also discharged her at the last appointment and suggested that she be referred to adult neurology.

The pediatric mental health team has also indicated that they can only see Susan one more time and then a referral should be placed to an adult mental health team. The wait time for the adult dual diagnosis team is 12-18 months.

How could we have optimized the transfer of care from pediatric to adult care?

Transitions from pediatric to adult care in ASD

Thanks to Dr Niel for the following slides

Dr. Ullanda Niel, MD, CCFP
PGY3 Developmental Disabilities
Family Physician, Scarborough, ON

Transition Readiness Checklist

- **A questionnaire that assesses the health care skills of the youth with developmental disabilities (DD) and their caregivers.**
- **The youth and primary caregiver should complete the questionnaire together.**
- **The tool looks at four different health skill areas:**
  - Knowledge of Health Condition(s), Medication and Treatment
  - Taking Charge of Health Condition(s), Medication and Treatment
  - Taking Charge at the Doctor's Office
  - Daily Living Skills and Thinking About the Future

Transition Readiness Checklist and Transition Toolkit Created by:

- **Developmental Disabilities Primary Care Initiative (DDPCI) Transition Working Group**
  - **Dr. Ullanda Niel**, Family physician practicing in developmental disabilities (mdtransition@gmail.com)
  - **Jessica Wood**, PhD student, Surrey Place Centre
  - **Maureen Kelly**, Nursing Surrey, Place Centre

-Dr. William F. Sullivan, Family physician, clinical director and chair of DDPCI

Readiness Checklist and Toolkit are Available at CFPC.CA

- An updated version of the Transition Tool is posted on the Surrey Place Website: http://www.surreyplace.on.ca/resources-publications?id=263

Transition Readiness Checklist

DDPCI – Transition Readiness Checklist

Name: _____ DOB: (dd/mm/yyyy): _____

	✓ Yes, I do this	✓ I am learning how to do this	✓ I need to learn how	✓ I need someone to help me do this – who?	✓ Does not apply to me
Knowledge of Health Condition(s), Medication and Treatment					
1. I can explain my health problems/ disability					
2. I can name my medications and treatments and I can tell others what they are for.					
Health Knowledge: Discussion and plan (consider both the youth and their caregiver).					

DDPCI – Transition Readiness Checklist

Name: _____ DOB: (dd/mm/yyyy): _____

	✓ Yes, I do this	✓ I am learning how to do this	✓ I need to learn how	✓ I need someone to help me do this – who?	✓ Does not apply to me
Taking Charge of Health Condition(s), Medication and Treatment					
3. I am ready to make decisions about my health.					
4. If I get sick, I know who to call or how to get help.					
5. I know what to do if I have a medical emergency.					
6. I keep track of my doctor and dental appointments					
7. I keep my important health information.					
8. I take my own medications.					
9. I know how much I should take of each medication.					
10. I know what to do if I miss a dose of medication.					
11. I know the side effects of my medication(s) and what to do if I have these side effects.					
12. I call in my medication refills					
13. I know how my medications and treatments are paid for.					
14. I take care of my treatments (asthma treatments, G-tube care, CPAP machine, catheterization).					
15. I take care of my medical equipment and supplies (e.g. wheelchair).					
Taking Charge of Health: Discussion and Plan (consider both the youth and their caregiver).					

Transition Toolkit

- **Builds on the Transition Readiness Checklist**
- **Explains the skills needed in each area of readiness**
- **Suggests tools that will help the person with DD and their caregivers to achieve each skill.**

Using The Transition Toolkit

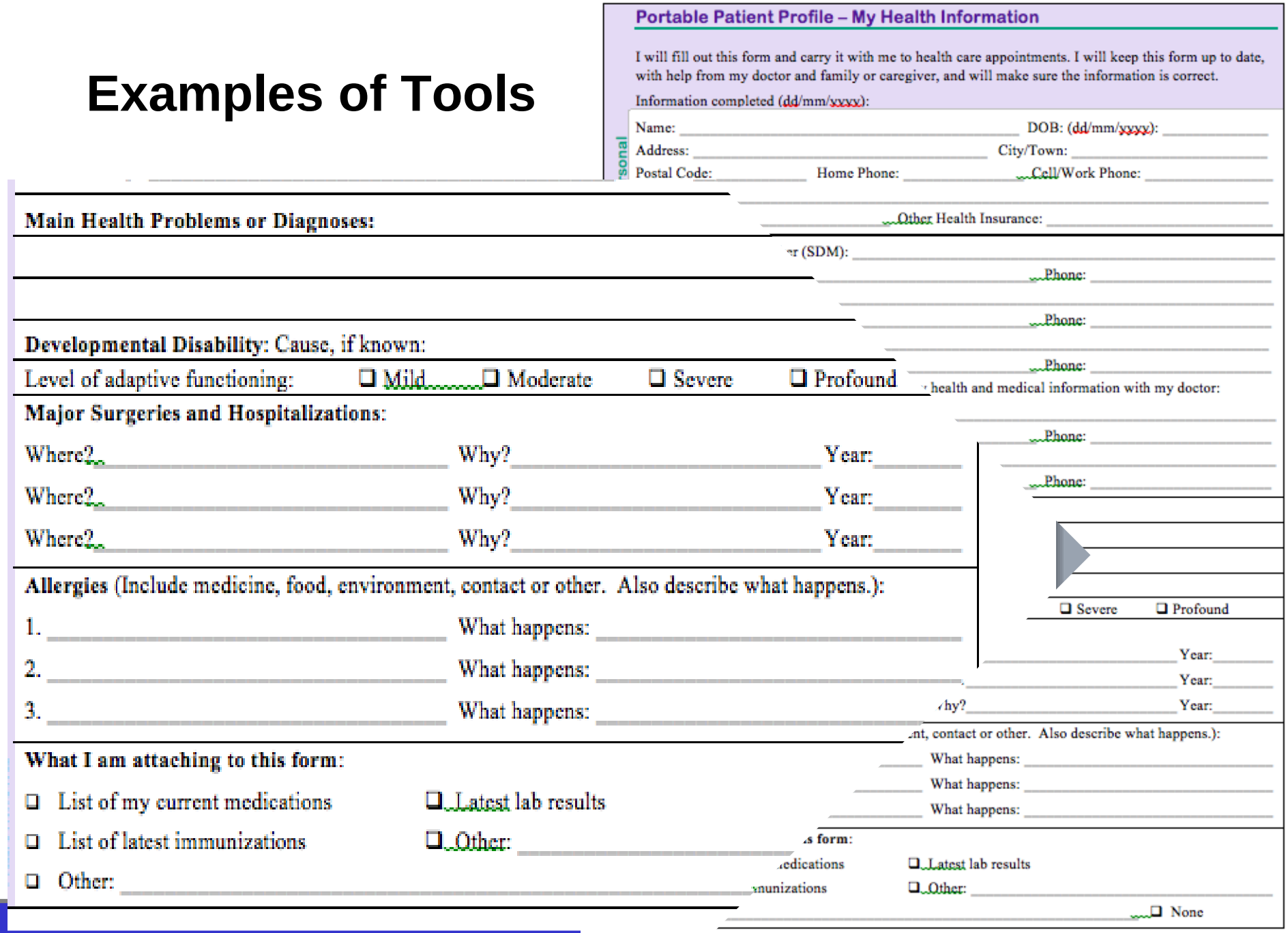
The Transition Skills and Resources Toolkit

Tools marked ☺ are designed for **youth** with developmental disabilities (and are useful for caregivers, too!)

Tools marked 🎗 are designed for **caregivers**.

16. I carry my health card in my wallet and bring important health information with me to doctor's appointments/ the emergency department (e.g., Portable Health Record, Health Passport or Emergency Information Form).	• Keeps a **portable health record** and brings this to health care appointments and emergency department and shares it with health care team members. • Recognizes that a **health card** is required and brings it to clinical appointments. • If appropriate, has a **Medic-Alert** bracelet or necklace.	**Available online:** ☺🎗 **Portable Patient Profile.** Surrey Place Centre, DDPCI www.surreyplace.on.ca/Primary-Care/Pages/Tools-for-care-givers.aspx ☺🎗 **My Health Passport.** Hospital for Sick Children. www.sickkids.ca/Good2Go/Transition-Interventions-Tools/MyHealth-Passport/index.html 🎗 **Emergency Information Form.** American Academy of Pediatrics. http://www2.aap.org/advocacy/blankform.pdf 🎗 **Medic-Alert** – bracelet or necklace. www.medicalert.ca/en/index.asp

Examples of Tools



Portable Patient Profile – My Health Information

I will fill out this form and carry it with me to health care appointments. I will keep this form up to date, with help from my doctor and family or caregiver, and will make sure the information is correct.

Information completed (dd/mm/yyyy):

Name: DOB: (dd/mm/yyyy):

Address: City/Town:

Postal Code: Home Phone: Cell/Work Phone:

Main Health Problems or Diagnoses:

Other Health Insurance:

Phone:

Phone:

Phone:

Developmental Disability: Cause, if known:

Level of adaptive functioning: ❑ Mild ❑ Moderate ❑ Severe ❑ Profound

Major Surgeries and Hospitalizations:

Where? Why? Year:

Where? Why? Year:

Where? Why? Year:

Allergies (Include medicine, food, environment, contact or other. Also describe what happens.):

1. What happens:

2. What happens:

3. What happens:

What I am attaching to this form:

❑ List of my current medications ❑ Latest lab results

❑ List of latest immunizations ❑ Other:

❑ Other:

❑ None

My main language is: _____

If not English, do I understand English? ❑ Yes ❑ No Speak English? ❑ Yes ❑ No

I communicate with: ❑ words ❑ sentences ❑ gestures ❑sign language ❑pictures ❑ other: _____

I understand and learn best by: ❑ simple explanations ❑ written words ❑ pictures
❑sign language ❑ other: _____

Special Care Needs

I have problems with:

- ❑ vision _____
- ❑ hearing _____
- ❑ movement/mobility _____

I use the following medical equipment and/or mobility equipment:

_____

Things that may make me anxious or upset me in medical appointments (e.g., medical exams, blood work, needles, noise, lighting, smells, colours, textures, crowds, waiting): _____

_____

Things that help when I get anxious or upset: _____

Health care plans or protocols that I/my caregivers use (e.g., for bowels, seizures, crisis) – *please attach a copy*: _____

My doctor should have the following information/cautions: _____

_____

Phone: _____ E-mail: _____

I'd like to add:

Adapted from New York State Department of Health, H.I.Doc. – www.nyhealth.gov/community/special_needs

Strengths and Limitations of the Readiness Checklist and Toolkit

Strengths

- Provides a method of assessment of skills AND the tools to build the skills
- Brief listing of 1-2 tools per skill
- Tools are available and accessible (many online, free)
- Many tools are designed specifically for the youth or adults with DD to complete themselves
- Some tools are designed for caregivers of people with DD
- Many tools are Canadian
- Tools are evidence based or based on best clinical practice

Limitations

- Very health oriented
- Not exhaustive
- Has not yet been formally evaluated in a primary health care setting but has been used in the practice of the creator Dr Ullanda Niel

Suggested Sections for Family/Caregiver Health Care Binder

Health Issues and Diagnoses

- Portable Patient Profile
  www.surreyplace.on.ca/Primary-Care/Pages/Tools-for-care-givers.aspx
- My Health – 3-Sentence Summary
  www.sickkids.ca/Good2Go/Transition-Interventions-Tools/Easy-interventions/32716-Three-Sentence%20Summary%20BOOKMARK%20formatted%20for%20website.pdf
- MyHealth 3-Sentence Summary with DD-specific examples
  www.surreyplace.on.ca/Primary-Care/Pages/Tools-for-care-givers.aspx
- Caregiver Health Assessment
  www.surreyplace.on.ca/Primary-Care/Pages/Tools-for-care-givers.aspx
- Medic-Alert information – www.medicalert.ca

and Procedures

- Genetic assessment
- **Psychological** assessment (**needed** for access to adult services in Ontario for people with DD)
- Functional assessments
- Copy of **MRI** or **CT** scan results, if ever done
- Copy of any **blood tests** and **urine tests** done in the past year, or the most recent, if none done in the past year
- Copy of reports of any **X-rays** or any other **tests, procedures and assessments**

Medications and Treatments

- **Current medications** person is taking (pharmacy can print)
- List of other **medications taken in the past** and why they were discontinued
- **Equipment** and **supplies** needed (name of item, ordering information, e.g., supplier's name and contact person, catalogue number, quantity, cost, forms to submit for reimbursement, if covered by health benefits)

Transportation Scheduler

Completed by: _____ Date: _____

How will you get to your appointment?		
❑ Family/Friend	❑ Support Worker	❑ Taxi/WheelTrans*

When you are phoning the person who is driving you, have these things ready:
❑ Phone number of the person who is driving you
❑ Name and address of the doctor
❑ Date and time of your appointment
❑ Your address and telephone number
❑ Calendar

When you phone the person who is driving you, say the following:
Hello, this is (say your name).
I need a ride to get to my doctor's appointment on (say date and time).
I am going to (give name and address of the doctor).
I will need a ride back to (give your address).
Can you do this? (If not, call _____).
What time will you pick me up? (Write down the time.)
Who do I call if there is a problem? (Write down the phone number.)
* If you are taking a taxi or WheelTrans, don't forget to bring money to pay for the trip.
Mark on your calendar:
❑ Location of doctor's appointment.
❑ Date and time for transportation pick up.
❑ Phone number to call if there is a problem.

Modified from www.HealthyTransitionsNY.org
New York State Institute for Transition Training

Case presentation - Part 5

You see Susan and her mother in follow up after working through some of the transition tool.

Susan has been doing fairly well although has been struggling with sleep issues a bit more than at baseline.

You notice that her mother seems less talkative this appointment and her voice is quieter and she is less animated. She also has not brought her normal list of questions and observations that she brings to your appointments with Susan.

What concerns do you have at this stage for the family?

Assessing for Caregiver Burnout

Sleep

Appetite

Functioning

Missed Activities/Self Care

Depression

What supports are available? Respite? Counselling? Is there a safety risk?

Resources:

Dual Diagnosis Teams

Community Care Access Centre

Developmental Services Ontario – Source for Respite Care

Community Networks of Specialized Care – Healthcare Facilitator Program

Health Links Ontario

Family Resources:

Autism Speaks Resources for Families:
https://www.autismspeaks.org/family-services/tool-kits

Anticipatory Care for Adults with ASD in the Family Physician's Office:

Autism Health Watch Table – Page 2

i) Checklist for confirmed diagnosis of ASD

Preparation for office visit:
Check out autism needs with care provider prior to visit (Section 5)

Are office accommodations in place to ensure optimal clinical encounter? (5)

Anticipatory Care for Adults with ASD in the Family Physician's Office: Clinical review

Is the aetiology known – review need for genetic reappraisal? (6.1)

Hearing and vision review (6.2)

Seizures? – review as required (6.3)
GI: constipation, eating and nutritional needs? (6.4)
Sleep review (6.5)

Sensory sensitivities? (7.4)
Behaviours of concern? (6.7)
Concerns about mental health? (6.7)
Review psychotropic medications – are they still needed? (6.8)

Are supports and expectations appropriate to individual developmental needs and capacities (are recommendations from psychological and communication assessments being implemented)? (7.2 & 7.3)
Has an autism friendly environment been implemented with appropriate attention to sensory and emotional needs? (5)

Review age and stage transitions (9)
Role of complementary and alternative therapies (10)

Support to care providers and care provider resources (11)

Resources:

Resources can be found on a single website - www.surreyplace.on.ca/primary-care

Autism Health Watch Table

Psychotropic Audit Tool

Transition Toolkit

Autism Speaks Resources for Families:
https://www.autismspeaks.org/family-services/tool-kits

Ontario Database of Health Information/Statistics for Patients with Developmental Disabilities

Health Care Access Research and Developmental Disabilities -
https://www.porticonetwork.ca/web/hcardd

Thank you!

Questions? Comments?

Break followed by case studies.

REFERENCES:

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

Mahajan et al. Clinical Paractice Pathways for evaluaton and medication choice for Attention-Deficit/Hyperactivity Disorder Symptoms in Autism Spectrum Disorders Pediatrics 2012;130;S125

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)