Interagency Partnerships – Promoting Well-being in Children with Dual Diagnosis

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Agenda

- Learning Outcomes
- Context: ID & ASD
- ASD “Plus”
- Health complications
- Caregiver Needs ((Williams & Perkins, 2014)
- Service Gaps
- Service Supports
  - School
  - Paediatrician
  - MCFD
  - Other Community
- Communities of Practice: putting Theory into Practice
  - Case Studies
Disclosure

• We have received no funding nor any non-monetary incentives from any pharmaceutical companies.
• There is no conflict of interest.
Learning Outcomes

- Describe the service needs of children with neurodevelopmental disorders and psychiatric comorbidities
- Validate caregiver burden in families of children in neuropsychiatry, and establish what families may do to connect with school and community resources (e.g., What questions should they be asking?)
- Devise ways to use communities of practice that involve the Ministries of Health, Education, and Child and Family development, to improve service delivery to this population
Intellectual Difficulties

- Approximately 1 percent of the general population (internationally) have an ID (McKenzie, et al., 2016; Maulik et al., 2011)

- Approximately 1.83% of children and adolescents (internationally) have an ID (Maulik et al., 2011)

- Approximately 0.22% to 1.55% of children and adolescents (internationally) have an ID (McKenzie et al., 2016)

- Female-to-male ratio of children and adolescents with ID varied between 0.4 and 1.0 (i.e., four to 10 females with ID for every 10 males with the condition; Maulik et al., 2011; Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2013).
Autism Spectrum Disorder

- 1 in 51 (ages 6 to 18) as of March 2018 (Autism BC)
- ASD is 4.5 times more common in boys (1 in 42) than in girls (1 in 189; Autism BC).
- 1 in 59, 8-year old children as of 2014 (US sample; Baio et al., 2018)
- 1.7 % of children (US sample; Baio et al., 2018)
- Male to female ratio of 4:1 (US sample; Baio et al., 2018)
Autism Spectrum Disorder Plus
(Gillberg & Femell, 2014)

- Intellectual Disability
- Language Disorder
- ADHD
- Oppositional Defiant Disorder
- Developmental Coordination Disorder
- Tic Disorders/Tourette Syndrome
- Anxiety Disorder
Approximately 10% of individuals with ID have ASD/autistic traits (Baio, et al., 2018)
31% (to 35%) of children with ASD had an ID (Baio, et al., 2018)
46% of females with ASD had ID (Baio, et al., 2018)
37% of males with ASD had ID (Baio, et al., 2018)
4 per 1,000 children aged 8 years with ASD who also had ID (Christensen et al., 2016)
Autism Plus Mental Health Issues

- Psychiatric disorders are common and frequently multiple in children with autism spectrum disorders.
- They may provide targets for intervention and should be routinely evaluated in the clinical assessment of this group

(Simonoff, 2008)
Psychiatric Disorders in Children With Autism Spectrum Disorders: Prevalence, Comorbidity, and Associated Factors in a Population-Derived Sample

- 112 Children with Autism 10-14 years old
- Anxiety disorders, depressive disorders, oppositional defiant and conduct disorders, attention-deficit/hyperactivity disorder, tic disorders, trichotillomania, enuresis, and encopresis were identified
  - 70% with at least 1 psychiatric diagnosis
  - 41% with 2 or more diagnoses
  - Social Anxiety disorder (29.2%), ADHD (28.2%), and OD (28.1%) were most common
  - Seizure disorders increased the risk of psychiatric disorders

Simonoff et al., 2008
# Autism Plus Mental Health Issues

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<thead>
<tr>
<th>Psychiatric Diagnosis (ever)</th>
<th>School Age Children</th>
<th>Adults</th>
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<tbody>
<tr>
<td>Anxiety</td>
<td>25%</td>
<td>51%</td>
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<tr>
<td>Depression</td>
<td>6%</td>
<td>32%</td>
</tr>
<tr>
<td>OCD</td>
<td>10%</td>
<td>30%</td>
</tr>
<tr>
<td>Psychosis</td>
<td>1%</td>
<td>5%</td>
</tr>
<tr>
<td>Other</td>
<td>14%</td>
<td>22%</td>
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Individuals with ASD have much higher than expected rates of various medical conditions

- Ear and respiratory infections
- Food allergies
- Allergic rhinitis
- Atopic dermatitis
- Type I diabetes
- Asthma
- Gastrointestinal (GI) problems
- Sleep disorders
- Schizophrenia
- Headaches
- Migraines
- Seizures
- Muscular dystrophy

National Autism Association, 2014
Failure to identify medical conditions is due to:

- Communication impairments
- Ambiguous symptomatology
- Belief that aberrant behaviours and symptoms are ‘just a part of autism’

“Treatment of comorbid medical conditions may result in a substantial improvement of quality of life both of the child and their parents. What investigations should be implemented can vary both within the autism spectrum and individually.”

(Isaksen et al., 2012)
Neurodevelopmental & Behavioural Disorder

Neurodevelopmental and behavioural disorder solely affecting brain functions (psychiatry and neurology)

National Autism Association, 2014
Whole-body Disorder

Core deficits in communication, social interaction, restrictive/stereotypic behaviours, and other commonly seen behaviours noted in ASD

Surface manifestations of a variety of systemic and complex biological processes such as: neuroinflammation and immune dysregulation, abnormal gut flora, autonomic dysfunction, oxidative stress, mitochondrial dysfunction

Widespread Biomedical Abnormalities and Autism

National Autism Association, 2014
Caregiver Assessment Domains: Individual & Interpersonal (Microsystem)

- Co-dependency versus self-determination
  - Self-determination (care recipient/caregiver)
  - Co-residency versus?

- Compound caregiving
  - Additional caregiving responsibilities
  - Impact on relationship
  - Anticipated future caregiving

- Family Cohesiveness and network
  - Who is involved
  - Who can be relied upon (i.e., for assessment planning etc.)

Informal and formal support
- Amount/quality support (family/friends)
- Amount/quality support (providers/agencies)

Health-related quality of life
- Physical and mental
- Personal commitment to
- Stress management/coping

Service utilization
- Satisfaction

Personal and professional goal attainment support (caregiver/recipient)
- Economic security
- Goal attainment support

Future Planning
- Caregiver succession planning
- Short-term contingency plans
- Retirement and financial planning
- Resources

Caregiver Assessment Domains: Organizational & Community (Exosystem)

- Co-dependency versus self-determination in decision making
  - Continued co-residency versus?
- Compound caregiving
  - Anticipated future caregiving
- Family cohesiveness and network
  - Who to rely upon (assessment/planning)
- Informal and formal support
  - Amount/quality support (providers/agencies)
- Future Planning
  - Caregiver succession
  - Short-term contingency plan
  - Retirement and financial plan
  - Resources

Caregiver Assessment Domains: Organizational & Community (Exosystem)

- Health-related quality of life
  - Physical/mental well-being
  - Stress management/coping
- Life satisfaction
  - Personal and professional goal attainment (caregiver and recipient)
- Economic security
- Service utilization
  - Satisfaction
  - Respite care
  - Unmet need/waiting list status
  - Service response to changes in caregiving responsibilities

Caregiver Assessment Domains: Public Policy (Macrosystem)

- Informal and formal support
  - Amount/quality of support (providers/agencies)
- Future Planning
  - Retirement/financial planning
  - Future planning resources
- Health-related quality of life
- Physical/mental well-being
- Life satisfaction
  - Support in goal attainment from existing policies
- Service utilization
  - Unmet need/waiting list
  - Service response to changes in caregiving responsibilities

Education System

- Principal
- Case Manager
- Integrated Case Management
- District Supports
  - Board Certified Behaviour Analyst
  - District Behaviour Specialists
- OT/PTs

- SLPs
- District Principal
- Director of Instruction
- Assistant Superintendent
- Superintendent
- Etc.

<table>
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<tr>
<th>Ministry</th>
<th>Description</th>
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<tr>
<td><strong>HEALTH:</strong></td>
<td>Family Physician/Pediatrician, Psychology/Other. Referral to Developmental Pediatrician and/or Psychiatric services as necessary.</td>
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<td><strong>HEALTH:</strong></td>
<td>Assessment incorporates information from school via the Physician Information Form (BCPeds), for example. Diagnosis Verification Form or Multidisciplinary report is sent to the school principal (or District Student Services).</td>
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<td><strong>EDUCATION:</strong></td>
<td>School Principal assigns Case Manager.</td>
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<tr>
<td><strong>EDUCATION, HEALTH, CHILD &amp; FAMILY DEVELOPMENT &amp; COMMUNITY:</strong></td>
<td>Capacity building (e.g., Literature sharing; Key Worker/Developmental Disabilities Mental Health Services/Child &amp; Youth Mental Health, Education In-service; Other)</td>
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<tr>
<td><strong>EDUCATION, HEALTH, CHILD &amp; FAMILY DEVELOPMENT &amp; COMMUNITY:</strong></td>
<td>Integrated Case Management Meeting (ICM) that includes the Child/Youth (as appropriate), Parents, School (i.e., Case Manager, Classroom Teacher, Educational Assistant, Administrator, Other), District (Behaviour Specialist, Helping/Specialist Teacher, Occupational Therapist, Other), Ministry of Education Provincial Outreach/Resource Program (POP) Representative(s) (POP for Autism and Related Disorders, POP for Fetal Alcohol Spectrum Disorder, Other), Healthcare Providers (e.g., Pediatrician, Psychiatrist, Psychologist, Other), Child &amp; Family Development (e.g., Social Worker, Other), Community partners (Key Worker, Behaviour Consultant, Other), Other. The Educational Team is comprised of the above, and integrated case management occurs over the course of the student’s educational career.</td>
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Navigational Framework
Integrated Case Management

- ICM Process
- ICM Meeting Minutes
- Authorization for Release of Information
- ICM Meeting Agreement Form
- Inter-agency Contact Log
BC Pediatric Society in Schools

- 73% (118) of those currently practicing work with schools and/or care for students who are experiencing school problems and/or learning difficulties

Of these 118 pediatricians:

- Almost all (96%) assess school aged children/youth who are experiencing school problems and/or learning difficulties (76% frequently and 20% occasionally). The remainder do not, although 1% noted/agreed they would if they had more skills/training.

- One-in-two meet or consult with school staff:
  - 52% meet with school based teams to discuss patients
  - 51% act as a consultant to a school – most for their own patients only (44%) – but some also for other patients in addition to their own (7%)
Of pediatricians working with schools and/or students, proportion who...

- Assess school-aged children/youth who are experiencing school problems and/or learning difficulties: 96%
- Meet with school-based teams: 52%
- Act as a consultant to a school: 51%
Of the 44 (27%) pediatricians not already doing school based work:
- **30% (13) would or might be interested in doing so (9% and 21% respectively)**. The remaining 70% would not be interested in doing so at all.

These 13 pediatricians not already doing school based work but interested in doing so, consider the following to be important in their becoming more engaged with schools in their community:

- Level of compensation for this type of work (11)
- *Adequate training for school-based work* (10)
- *Opportunities to participate in team-based care with schools* (9)
School Based Wellness Clinics

September 2015: John Barsby Wellness Centre – JBWC, Nanaimo

• BC Pediatric Society is actively engaging with the Ministry of Education, the Ministry of Mental Health and Addiction, the Ministry of Child and Family Development, and the Ministry of Health to encourage establishment of school based wellness clinics throughout the Province.
What educators and physicians need to know

- School Physician Communication Form
Children & Youth with Special Needs (CYSN)
Social worker

- Autism Funding Program
- Behavioral Support
- Child and Youth Care Workers
- Parent Support
- Respite
- Child Care Subsidy
- At Home Program

Program
- Infant Development Program
- Aboriginal Infant Development
- Early Intervention Therapies Program
- School-Aged Therapies Program
- Supported Child Development Programs
- Transition Planning to Adulthood
Other Community Supports

- Autism Information Services (BC)
- Autism BC
- Autism Community Training (ACT)
- Canucks Autism Network
- Pacific Autism Family Network
- The Centre for Child Development
- Milieu
- POPARD
- POPFASD
- Semiahmoo House Society
- Others?
Case Studies
Discussion Questions:

1) Additional solutions to service gaps?
2) Implementation barriers, how might these be addressed?
3) Other
References


Thank you!