



Southern Network of Specialized Care

Building Health Care Capacity Initiative

At – Risk Population

- Determinants of Health: poverty, social status, education and literacy, coping skills, social relationships, and biology / genetics
- Higher rates of sickness
- Shorter life expectancy (4 – 6 X Preventable Death)
- More than twice the usual medical conditions (GERD, Epilepsy, Thyroid, Mental Health, Genetic, Swallowing , Constipation, Dental, Vision, Hearing)
- Health disorders with different age of onset, rate of progression, degree of severity, and presenting manifestations
- Too many and inappropriate medication with significant and serious side-effects



Low Utilization of Most Health Resources

- Participation in health promotion activities
- Annual physicals and other “Healthwatch” assessments
- Vision, Hearing & Dental exams
- Preventative disease programs (flu shots, immunizations, tetanus)
- Early detection screening (prostate /breast / cervical / colorectal cancer)
- Referrals to Medical Specialists



Higher Utilization of Some Health Resources

- Emergency Departments of Hospitals
- Visits to Family Doctors
- Alternate Levels of Care usage



Why Does This Happen?

- Difficulty in self reporting and reliance on multiple caregivers to observe, detect, & report
- Behaviour / emotional reaction while waiting and during exam
- Caregiver and health provider attitudes (diagnostic overshadowing)
- Lack of health providers knowledge / experience with unique health and medical needs of the population
- Restrictions (one problem per visit / 10 minutes max)
- Lack of specialists, dentists, and other health professionals willing to work with population

Solutions

- International research, training, and health promotion
- Canadian Consensus Guidelines and associated Toolkits (distributed to all family doctors May 2011)
- Developmental Disability Primary Care Initiative Training and Networking of Graduates
- Developmental Disability Primary Care Initiative Continuing Professional Development and Clinical Support Network
- Community Networks of Specialized Care's Healthcare Facilitators (March 2011)

Health Care Facilitator Role

- *Provide information, education, and training on meeting the unique health care needs of adults who have developmental disability.*
- *Link individuals who have developmental disability with health care services.*
- *Identify barriers and solutions to health care access.*
- *Build connections and collaboration between the health care and developmental service sectors.*

Canadian Consensus Guidelines and Toolkits

www.surreyplace.on.ca/Clinical-Programs/Medical-Services/Pages/PrimaryCare.aspx

How do the Guidelines and Toolkits Help?

- Provide information to Health Care Providers on the unique health care issues of this population, guidelines to assist in better assessment and treatment, and tools to help them implement the guidelines
- Provide information to individuals and caregivers (paid & family) on the unique health care needs of this population, ways to detect and describe health care issues, and ways to access and effectively use the health care system



General Issue Guidelines

- Disparities with general population
- Benefits of etiology
- Benefits of knowing adaptive functioning
- Pain and distress
- Multiple or long term medication use
- Abuse and neglect
- Informed and voluntary consent



Physical Health Guidelines

- Physical inactivity / obesity
- Vision and hearing
- Dental disease
- Cardiac disorders
- Respiratory disorders
- Sexuality
- Musculoskeletal disorders
- Epilepsy, Endocrine disorders
- Infectious disease
- Cancer



Behavioural and Mental Health Guidelines

- Problem behaviour
- Psychiatric disorders
- Psychotic disorders
- Need to solicit input from individual and caregiver to understand issue
- Non-Medication interventions
- Psychotropic medication use
- Antipsychotic medication misuse
- Behaviour crisis and emergency department
- Substance abuse
- Dementia



General Issue Tools

- *Genetic Assessment FAQ*
- *Intellectual and Adaptive Functioning*
- *Psychological Assessment FAQ*
- *Psychological Assessment FAQ*
- *Informed Consent in Adults with Developmental Disabilities*
- *Communicating Effectively*
- *Office Organizational Tips*
- *Today's Visit*



Physical Health Tools

- *Cumulative Patient Profile*
- *Preventative Care Checklists (Male and Female)*
- *Health Watch Tables:*
 1. *Down Syndrome*
 2. *Fragile X Syndrome*
 3. *Prader-Willi Syndrome*
 4. *Smith-Magenis Syndrome*
 5. *22q11.2del Syndrome*

Williams Syndrome

Angelman Syndrome

Smith-Lemli-Opitz Syndrome

Fetal Alcohol Spectrum Disorder

Rett Syndrome



Behaviour and Mental Health Tools

- *Guide to Understanding Behavioural Problems and Emotional Concerns*
- *Managing Behavioural Crises – Family Physician's Role*
- *Risk Assessment Tool*
- *Essential Information for the ED*
- *Guidance about Emergencies for Caregivers*
- *Crisis Prevention/Management Plans*
- *ABC (Antecedent-Behaviour-Consequence) Chart*
- *Ontario Community Resources*
- *Advocacy Role of Primary Care Providers*
- *Psychotropic Medication Issues & Auditing*
- *Rapid Tranquilization*



Key Messages

- Annual Physicals, & Dental, Vision, Hearing assessments may be only way to detect illness
- Behaviour or Emotional distress may be only way of communicating pain
- Knowing the cause of disability helps identify health risks
- Respiratory and Digestive diseases are leading causes of death. Epilepsy is also high. Look for them.
- Medication reviews every three months
- Look for signs of abuse / neglect
- Health Promotion & Prevention is important
- Utilize Bio psycho social model to understand behaviour. Do not assume and treat for psychiatric or psychotic disorder
- Mental health disorders may look different.

Health Watch Table – Down Syndrome

- Vision: 20 – 70 % have refractive errors
- Hearing: 50 – 80 % have hearing deficits
- Cardiovascular: 50 % have cardiovascular concerns
- Respiratory: 50 – 80 % have obstructive sleep apnea
- Gastrointestinal: 50 % GI anomalies, 7 % celiac disease
- Musculoskeletal: 15 % have atlanto-axial instability
- Neurological: 22% of children have epilepsy
- Dementia: 11% of people in their 40's , 77% of people on their 60's
- Mental Health: 30 % develop a psychiatric disorder
- Endocrine: 20 % develop hypothyroidism



Guidelines & Tools - Healthy Aging

- Apply age and gender guidelines for preventative care
- Consider genetic assessment or reassessment to identify health and mental health risks
- Consider medical causes for changes in behaviour
- Regularly review indications, dosages, & effectiveness of medications. Watch for typical and atypical signs of adverse drug effects. Monitor potentially toxic medication or interactions of medications
- Engage in Advanced Care Planning and review plans annually to assist with life transitions, crises, and end of life care
- Involve other health care professionals to address complex health needs

Guidelines & Tools - Healthy Aging

- Vision assessment every 5 years after age 45
- Hearing assessment every 5 years after age 45
- Screen for cardiovascular disease earlier if there is prolonged use of psychotropic medication
- Assess risk of developing osteoporosis earlier given the prevalence and earlier onset than general population. Risks factors include: severity of Dev Dis, low body weight, reduced mobility, genetics, & long term medication use.
- Screening for cancer is an essential aspect of preventative care, yet people with dev. dis. are less likely to self examine, self report or be screened.
- Obtain up-to-date assessment of intellectual and adaptive functioning to establish baseline for dementia, especially with high risk groups

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