Mary Westerhof RN
Developmental Dual Diagnosis Team
St Joseph Hospital
Hamilton Ontario
Once sent to Regional Hospitals to be cared for on Doctor orders .......
Where: Smiths Falls

Description: Opened in 1951
Originally called Ontario Hospital School, Smiths Falls
In 1967, it was renamed Rideau Regional Hospital School
In 1974, the name changed to the Rideau Regional Centre

Resident population in 1971: 2,070
Resident population in 1975: 1,527
Peak residential population: 2,650
Year it closed: March 2009

Oxford Regional Center

Where: Woodstock

Description: Originally opened in 1905 as the Epileptic Hospital and provided residential support to people with epilepsy and tuberculosis.
Renamed the Ontario Hospital School, Woodstock in 1919.
Renamed the Oxford Mental Health Centre in 1968.
Renamed the Oxford Regional Centre in 1974.

Resident population in 1971: 317
Resident population in 1974: 683
Year it closed: 1997
Policy initiative: Ministry's seven-year plan for facility closures:
Challenges and Opportunities (1987)
Where: Palmerston

Description: Originally intended to provide residential supports to children with a developmental disability, however, by the early 1970s, there were more adults than children.

Resident population in 1971: 216
Resident population in 1974: 225
Year it closed: 1998
Policy initiative: Ministry's Community Living Initiative (1996)
Southwestern RC

Where:
Chatham-Kent

Description:
Opened in 1961
Originally named the "Ontario Hospital School for Retarded Children at Cedar Springs"
Provided care for residents of varying degrees of disability and for capacity relief for the overwhelming demand at the Huronia Regional Centre in Orillia

Resident population in 1971: 937
Year it closed: 2008
Huronia Regional Center

Orilla

Description:
Opened in 1876
Ontario's oldest institution for people with a developmental disability
Originally called the Orillia Asylum for Idiots

Resident population in 1971: 1,875
Resident population in 1975: 1,566
Peak residential population: 2,600
Year it closed: March 2009
Now ......living in their home community being cared for by caring professionals
Life Expectancy Lengthens

- Medical care improved with community doctors, dentists, nurses, dieticians, specialists
- Daily care improved with experienced staff
- Quality of life expanded to include programs and community activities
- Experiences expanded with community activities
Complex Medical Issues for a Complex People

• People who have a developmental disability have complex medical issues, some differing from those with the general population.

• Healthcare professionals may not be aware of or understanding the increased risk and need for care for people with disabilities.
Complex Medical Issues for a Complex People

• When a person with a Confirmed Dual Diagnosis (or suspected of one) experiences a difficult time, a thorough health assessment is needed.

• Limited understanding of pain with limited ability to verbalize these uncomfortable feelings can lead to increased or new behavioral activity.
Initiatives

• MCSS and MHLTC agreed to support a five year project spearheaded by Surrey Place in Toronto
• Various professionals were gathered together to develop Primary Care Guidelines with a Tool Kit
• These were developed and published in 2011
• A course for primary care doctors and others was developed and delivered to those who applied to participate.
Health Watch Tables
(available in Manual)

• Down Syndrome
• Fragile X
• Prader Willi Syndrome
• Smith-Magenis Syndrome
• 22q11.2 Deletion (DiGeorge Syndrome)
## Health Watch Table - Down Syndrome

*Forster-Gibson, Cynthia, MD, PhD; Berg, Joseph M, MB, BCh, MSc, FRCPsyCH, FCCMG*

<table>
<thead>
<tr>
<th>CONSIDERATION</th>
<th>RECOMMENDATION</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. HEENT (Head, eyes, ears, nose, throat)</strong></td>
<td></td>
</tr>
</tbody>
</table>

**Children:** ~15% have cataracts; ~ 50% have significant refractive errors; 50 – 80% have a hearing deficit

- Neonatally: refer immediately to specialist if red reflex is absent or if strabismus, nystagmus or poor vision is identified
- Arrange ophthalmological assessment: first by 6 months for all; then annually (or more frequently as needed)
- During childhood: screen with history and exam; refer as needed
- Arrange auditory brainstem response (ABR) measurement by 3 months if newborn screening has not been done or if results were suspicious
- During childhood: screen with history and exam; review risks for frequently occurring serious otitis media
- Undertake auditory testing: first at 9 – 12 months, then every six months up to 3 years and annually thereafter until adulthood

**Adults:** ~15% have cataracts; 5 – 15% have keratoconus; 20 – 70% have significant refractive errors; 50-90% have a hearing deficit

- Arrange ophthalmological assessment every 1 – 2 years, with special attention to cataracts, keratoconus, and refractive errors
- Undertake auditory testing every 2 years
Health Watch Table - Down Syndrome

Forster-Gibson, Cynthia, MD, PhD; Berg, Joseph M, MB, BCh, MSc, FRCPsyCH, FCCMG

- 2. DENTAL
- 3. CARDIOVASCULAR
- 4. RESPIRATORY
- 5. GASTROINTESTINAL
- 6. GENITOURINARY
- 7. SEXUAL FUNCTION
- 8. MUSCULOSKELETAL
- 9. NEUROLOGICAL
- 10. DERMATOLOGICAL
- 11. MENTAL HEALTH/BEHAVIOURAL
- 12. ENDOCRINE
- 13. HEMATOLOGICAL

Included with each table is references including web sites for family education.
Preparing for Appointments

When planning to go to an appointment with your recipient it is important to bring all the information you can so that the professional can see what it is that you see. There are several rules to do this successfully.
One important fact:

It is important to describe what you see;
Not what you think ....
Use language that makes the listener see what you see.
Take them to the scene.
Help them to see what exactly is going on in the life of your recipient.
Do not use diagnostic terms.
Another important fact to remember:

Constipation and urinary tract infection can create an increase in adverse behavior or in behavior that is uncharacteristic of the individual.
Often all the is needed is to obtain antibiotics for urinary tract infection
Or
Find a way to decrease the constipation
And the behavior will dissipate
Collect data:

• Write down the current medical conditions that the person has and how it affects their life.
• Are there any changes in this condition?
• Review health watch tables should any of them pertain to your recipient. Bring the table with you.
• Use data collection tools in this manual.
Bring data with you to appointment

• Write out any changes in:
  – Behavior = Bring behavior plan with you
  – Energy level
  – Appetite
  – Constipation??
  – Sleep pattern
  – Mood
  – Environment
  – Staffing
  – Room / housemate changes
More data:

• How long have the symptoms been occurring
• What interventions have helped?
• Current MAR sheet copy
• Side effects noted from current medications
• Family history?

DON’T FORGET THE HEALTHCARD
DO NOT ......

• Send a new staff with the recipient (staff should know the recipient well)
• Forget to bring data with you
• Say what your opinion is ..just the facts
• Forget to invite the alternate consent giver or family member to the appointment
IMPORTANT

All medical avenues need to be ruled out before psychiatric reasons are looked at.

It is our role to speak out and make sure all avenues are investigated for this very vulnerable population who in most circumstances cannot speak for themselves.
Psychiatric assessments

• All of the information you have collected needs to be brought to the appointment with a psychiatrist should one be needed.
• Also bring any lab testing results the family doctor may have ordered.
• It is important to write down any questions that the recipient may have for the doctor.

Bring the family, caregiver or/and alternate consent giver to the appointments
During the appointment

• It is important to remember the recipient should be able to explain where possible what he/she is feeling.

• It is important for the professionals to include the recipient in the conversation about him/her.

• It is important to remind the professional that the recipient is able to understand what is said.
• It is important to explain the treatment plan to both the recipient and the staff.
• It is very important to have the alternate consent giver at the appointment so treatment can begin quickly. Otherwise treatment will be held up until consent is received.
Misconceptions

• Psychiatrists have unlimited time to spend with each person.
• Psychiatrists will cure the behavior at the first appointment
• Psychiatrists are available at all times
• Psychotropic medications will cure the person
• Psychiatrists are counselors
Considerations

- Using the biopsychosocial assessment model gives a total picture of what is happening in the recipient’s life.
- Medical issues can be at the root of the issues we see.
- Constipation, bladder infection. GERD (stomach issue), pain from headache or tooth decay can mimic behaviors seen in psychiatric symptoms.
- Environmental changes can also create difficulties.
Medication

• Medication is often added or changed when after an assessment with the psychiatrist.
• Often times the medication that our recipients are on have not been assessed or changed in years.
• Blood levels of medication are important to collect frequently at least every six months.
• Not all medications have blood levels that can be monitored
Psychotropic Medication

• A psychotropic medication is one that is capable of affecting the mind, emotions and behavior.

• Classifications are:
  – Antidepressants - Antipsychotics
  – Antianxiety - Sedatives
  – Mood Stabilizers - Stimulants
  – Other ie propranolol
Things to ask before you leave

1. Names of the medication?
2. What are the target symptoms?
3. How and when should it be given?
4. What is the dose?
5. Will it interact with other medications?
6. Are there diet restrictions?
7. Should it be taken with food?
8. What are the side effects?
9. What do we do for the side effects?
10. How long will it take before we see improvement?
11. When do we need to see you again?
Web site for information

- There is a web site where you can check for medication warnings or discontinued information.

  www.hc-sc.gc.ca/dhp-mps/medeff/advisories-avis/index-eng.php

Recent warning sent out about citalopram and doses over 40mg a day.
Side Effects

One must remember that each person or individual can react in different ways to medications.

Print outs from pharmacies are wonderful tools but one must remember that even if the new symptom is not written on a form it could be a side effect from the new medication change. Report it!
Side Effects

• Some side effects are good. These are found during the phases of bringing medication to market.

• One such good side effect was the discovery that some seizure medication can help people with a mood disorder.

• One not so good side effect is the tremor that could result after taking some antipsychotic
• Some medication should be monitored carefully with frequent blood pressures.
• Many medications make people sensitive to sunlight and sunscreen needs to be used at all times when outside.
• Some antipsychotics can cause metabolic disorders such as diabetes.
• Some can cause tardive dyskinesia – involuntary movements of the facial muscles, and/or tongue.
• Some can create akathisia – a pattern of involuntary movements which is seen as restlessness.
PRN Medication

• Pro Re Nata  as circumstances arise
• These medications are not given on regular schedule but are given only when needed.
• If they are given out more than once a day a medication review is warranted.
• Direct support staff in consultation with the prescribing physician are responsible for the protocol and monitoring of the PRN.
Training in Medication Administration

• Each person that assists or gives out medication needs to be trained to do so properly.
• Part of that training should be how to research and understand the medication that you are giving to people.
• The front line staff are the ones who will recognize side effects that might surface when giving medication.
• Using the print outs from the pharmacy is good but not all inclusive of important information.
• Research, ask the doctor, ask the nurse, made research sheets for all the staff to review.
• All staff need to remember to monitor all recipients
The RIGHTS of Medication Administration

• Right person
• Right drug
• Right dose
• Right route
• Right time
• Right documentation

• Right to know information about the drug
• Right to refuse the medication with knowledge of possible results
Controlled Acts

• A nurse can teach a family member to perform a controlled act who can then train others in the family.
• A Unregulated Care Provider (UCP) is different.
• A UCP is any care provider that does not have a regulatory body; this includes PSW, DSW, PCA’s and more
• All UCP’s need to be trained and signed off on all delegated acts and training must be refreshed on a regular basis.
• If a UCP has not been trained by a Regulated Health Professional to perform the act, a plan of action on the training needs to be developed.
Controlled Acts  con’t

• Each act must be delegated individually to each UCP for each recipient that requires such an act.

(2) A “controlled act” is any one of the following done with respect to an individual:
• 1. Communicating to the individual or his or her personal representative a diagnosis identifying a disease or disorder as the cause of symptoms of the individual in circumstances in which it is reasonably foreseeable that the individual or his or her personal representative will rely on the diagnosis.
• 2. Performing a procedure on tissue below the dermis, below the surface of a mucous membrane, in or below the surface of the cornea, or in or below the surfaces of the teeth, including the scaling of teeth.
• 3. Setting or casting a fracture of a bone or a dislocation of a joint.
• 4. Moving the joints of the spine beyond the individual’s usual physiological range of motion using a fast, low amplitude thrust.
• 5. Administering a substance by injection or inhalation.
• 6. Putting an instrument, hand or finger,
  • i. beyond the external ear canal,
  • ii. beyond the point in the nasal passages where they normally narrow,
  • iii. beyond the larynx,
  • iv. beyond the opening of the urethra,
  • v. beyond the labia majora,
  • vi. beyond the anal verge, or
  • vii. into an artificial opening into the body.
• 7. Applying or ordering the application of a form of energy prescribed by the regulations under this Act.
• 8. Prescribing, dispensing, selling or compounding a drug as defined in the Drug and Pharmacies Regulation Act, or supervising the part of a pharmacy where such drugs are kept.
• 9. Prescribing or dispensing, for vision or eye problems, subnormal vision devices, contact lenses or eye glasses other than simple magnifiers.
• 10. Prescribing a hearing aid for a hearing impaired person.
• 11. Fitting or dispensing a dental prosthesis, orthodontic or periodontal appliance or a device used inside the mouth to protect teeth from abnormal functioning.
• 12. Managing labour or conducting the delivery of a baby.
• 13. Allergy challenge testing of a kind in which a positive result of the test is a significant allergic response.
The Controlled Acts that might be affected:

5. Administering a substance by injection or inhalation.
   (ventalin, finger pricks for diabetes, insulin, )

6. Putting an instrument, hand or finger,
   i. beyond the external ear canal, (ear thermometer)
   ii. beyond the point in the nasal passages where they normally narrow,
   iii. beyond the larynx,
   iv. beyond the opening of the urethra, (catheterization)
   v. beyond the labia majora, (infection treatment)
   vi. beyond the anal verge, or (suppositories)
   vii. into an artificial opening into the body.
Training is needed

- Staff can be trained by a registered nurse with detailed documentation.
- Each act must be delegated individually to each UPC for each client that requires such an act.
- A detailed order is needed including directions of what to do if the intervention dose not work with a given time frame and when to seek emergency treatment.
- UCP must have been trained in medication administration.
- UCP must have knowledge on the procedure including anatomy and safety concerns.
- Information about the controlled acts along with information on liability and rights.
- A detailed step by step procedure for performing the act including a decision guide about to do if.
- A document signed by the UCP and the RN teaching the act showing they have completed all the criteria for delegation.
Remember:

Your role:
• is to assist and monitor the recipients.
• to respect and protect the recipients from all harm.
• To make sure the alternate decision maker is informed about any medical suggestions including those from the Family Doctor.
• To learn information and procedures that will benefit recipients and keep them safe.

Make sure that the consent process is complete with signed forms.
Thank You