

Coordinated Care Plans (CCPs): A Guide to Completing (CCPs) for Patients with Developmental Disabilities (DD)

HealthLink

Coordinated Care Plans are part of Health Links, a program in Ontario for patients with complex problems and health care needs. Adults with DD may benefit from this program.

To learn more about Coordinated Care Plans, and how these may be used with complex patients in your area, please visit:

<http://www.health.gov.on.ca/en/pro/programs/transformation/community.aspx>

Find out if there is a HealthLink in your area.

Are patients with DD included?

Background: Patients with developmental disabilities (DD) have special health care needs involving unique accommodations, health access issues, communication challenges and complex co-morbid physical and mental health conditions as well as important social support needs. Patients with DD may present to the emergency department (ED) in crisis due to challenging behavior or other undefined presenting complaint (ex. failure to thrive, lethargy) and it is difficult to determine the cause. The [Canadian Consensus Guidelines for Primary Care of Adults with Developmental Disabilities](#) provide a summary of the ethical, communication, social support, physical and mental health needs for this population (<http://www.surreyplace.on.ca>).

Helpful, concise clinical tools are also available on this site including; communication tips, office organization tips, overview of levels of intellectual disability, and ethical guidelines. Important co-morbidities to consider when a patient presents to the ED are summarized in the “Head to Toes” mnemonic, and issues to consider for evidence-based preventative primary care are summarized in the handout, “[Systems Review in Primary Care for People with DD](#)”.

Involving caregivers while also respecting and engaging the individual with DD as much as possible in the care planning process is the best approach. Caregiver burnout is common and important to inquire about. Patients may also present with challenging behaviour or even depression or anxiety as a secondary consequence of lack of meaningful daytime activities (i.e., no day programming or vocational activity is in place following transition from high school to adulthood).

Developmental services for adults are accessed through Developmental Services Ontario (DSO). They are the “front door” to services and can be approached when the individual is 16 years old to plan for adult services. The array of services is complex to navigate. One additional resource for health care providers supporting patients with DD are the Health Care Facilitators of the Community Networks of Specialized Care (CNSC) of the Ministry of Community and Social Services.

Coordinated Care Plans (CCPs) - *continued*

When completing the CCP form for patients with DD:

- **Physical health problem** list: If there is a cause, or ‘etiology’, for the patient’s DD please write it here (e.g., Down Syndrome, FASD etc.)
- **Mental Health problem** list: Add developmental disability. If the level of disability is known, please specify this in the notes (e.g., **mild, moderate, severe, profound**).
- **“My plan to achieve my goals for care”** section: Please add any health care accommodation needs (difficulty with crowded rooms, fluorescent light etc.), communication needs (sign, picture symbols, iPad etc.) and safety issues (pica, bolting, risk of aggressive behaviour etc.) here.
- Also encourage completion of a **Health Information Passport (HIP)** or another health care communication tool, which outlines information that is essential to the receptionist, triage nurse, paramedic as well as physician staff to know about safety and support issues for the patient. The HIP is a wallet sized card that wraps around the patient’s health card so that it is seen right at the first point of contact. HIP templates and tips for completion can be found on the CNSC website (<http://www.community-networks.ca/health-care/health-information-profile/>). The **About Me**, although longer than the HIP, may be more user friendly and engaging to a patient with literacy issues.

In the recommendations section of the CCP to send to both the patient’s caregivers and family physician’s team please consider including:

For the Family Physician’s team:

- Check that DD is coded as a problem on the patient’s past medical history. This allows the clinic to search for patients with DD as a cohort and facilitates audits to make sure that preventative care is up to date, etc.
- A suggestion to the family physician to see complex patients with DD for an annual Health Check following the evidence based recommendations from the Guidelines for Primary Care for Adults with DD.
- A suggestion to the reception staff to flag the patient’s file with a pop up note that specifies any communication needs and other accommodations and reminds who the substitute decision maker is.

For caregivers:

- Keep a copy of the CCP and bring it to all appointments or ER visits.
- Call proactively to review the CCP with the family physician and to schedule a Health Check.