# Approach to developmental disabilities in newcomer families

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#### **Abstract**

**Objective** To provide a framework for primary care providers to approach developmental disabilities in both refugee and nonrefugee immigrant populations.

Sources of information Ovid MEDLINE was searched from January 2005 to February 2017 using subject headings developmental disability, developmental delay, refugee, and immigrant for relevant English-language articles. Most of the content and recommendations in this review are derived from the Canadian Paediatric Society's Caring for Kids New to Canada website.

**Main message** As family physicians, it can be daunting to care for newcomer families who arrive without previous developmental disability or delay screening and diagnoses. Disruption to families and education, decreased health literacy, witnessed traumatic events, and culturally specific barriers can affect the presentation of developmental concerns among refugees and immigrants. Surveillance and screening for developmental concerns in a culturally sensitive manner using evidence-based tools are cornerstones of early intervention.

Conclusion For refugees in particular, in light of the inequities they have faced before migration and during their migration trajectory, screening for developmental disabilities and intervening provides an opportunity to help achieve equitable outcomes for refugee children and optimize their health and well-being.

anada has been an exemplary host to refugees from many areas of the world over the years. In the context of the global refugee crisis, more than 40000 Syrian refugees have arrived in Canada since November 2015. This number includes government-assisted, blended visa office-referred, and privately sponsored refugees. Refugees are not excluded based on their health status, as their acceptance is predicated on humanitarian grounds. Pre-migration factors, such as living in conflict ridden areas, a loss of health care infrastructure, and a lack of access to care, mean that families often arrive with children who have not undergone developmental screening.2 Often, children or even adults identified as having delays have not received appropriate diagnoses or support. This can be daunting for primary care providers who encounter newcomer families who arrive and hope for care they could not receive in the process of migration. We hope to provide a framework for primary care providers to approach developmental disabilities in both our refugee and our nonrefugee immigrant populations, recognizing that challenges for both newcomer groups might overlap.

#### **Case descriptions**

Patient A. is an 18-month-old child of Nepalese-Bhutanese descent who arrives as a government-assisted refugee. He arrives for an initial assessment and it is apparent that he is considerably small for his age, at less than the second percentile for both height and weight. He is unable to walk and has no words, but gestures when he wants things. He has some features typical of trisomy 21. His family was told in the refugee camp in Nepal that he would be diagnosed and treated once he arrived in Canada.

## **Editor's key points**

- With the global refugee crisis, more than 40 000 Syrian refugees have arrived in Canada since November 2015. Refugees face many barriers to health care upon arrival, and the challenges are even greater for refugees with developmental disabilities and their families. This review provides an approach to developmental disabilities in newcomer families to help primary care providers support this marginalized group.
- ▶ Barriers to the identification of developmental disability in newcomer children are discussed, and various screening tools and resources are suggested. Approaches to management are outlined, including the need for culturally competent and traumainformed care and recognition that there are differences in decision making within families across different cultures.
- ▶ Individuals with developmental disability are often socially isolated, and studies show that children with intellectual disabilities coming from immigrant families have very few opportunities for social engagement. Management must, therefore, also consider the importance of lessening social isolation.

Patient B. is a 4-year-old girl who arrives with her 3 siblings and mother from her native Somalia via a refugee camp in Kenya. She had frequent ear infections while living in the camp and also had a history of an illness characterized by high fever and decreased level of consciousness, likely meningitis, that required hospitalization. She is not speaking in sentences and has several unintelligible words.

#### Sources of information

We searched Ovid MEDLINE from January 2005 to February 2017 using the subject headings developmental disability, developmental delay, refugee, and immigrant. English-language papers were identified and relevant articles were selected. Most of the content and recommendations in this review are derived from the Canadian Paediatric Society (CPS) Caring for Kids New to Canada website.3 This article should not be considered a formal systematic review and does not provide a quantitative synthesis of the field.

### Main message

Definitions and scope of the issue. We use the term newcomer to Canada to refer to both immigrants and refugees. Since Confederation in 1867, more than 17 million immigrants have settled in Canada.4 Since the early 1990s, the number of accepted new immigrants has averaged more than 230000 per year.4 Immigrants include both economic migrants (people who seek a better life for themselves and their families) and family reunification migrants (people who wish to unite with family already living in Canada). The number of resettled refugees in Canada from January to September 2016 was approximately 36455.5 Since November 2015, Canada has welcomed more than 40000 refugees from Syria itself.1 As per the United Nations High Commissioner for Refugees (UNHCR) Convention and Protocol Relating to the Status of Refugees, a refugee is defined as "someone who is unable or unwilling to return to their country of origin owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group, or political opinion."6

Developmental disability itself is defined as the "set of abilities and characteristics that vary from the norm in the limitations they impose on independent participation and acceptance in society."7 We use the term to include disability present since birth or disability that develops before age 18; it includes physical or intellectual disabilities, sensory-related impairments (eg, hearing or vision loss), and communication and language delays.7 Developmental delay is the "inability of a child to acquire developmental milestones at the expected age."8

Globally, the rates of childhood developmental disability range from 5% to 20%, 9,10 but it is difficult to know the exact scope of developmental disability and delay among refugees and immigrants in Canada. While there

are good data from UNHCR on acquired injuries in wartorn areas causing physical disability, the prevalence of developmental disability in our refugee populations is unknown, as there have been no epidemiologic studies on this. There is a population profile report that was published in 2015 on the Citizenship and Immigration Canada government website that provides aggregate health data on a group of Syrian refugees who underwent the immigrant medical examination (refugees receive the same medical assessment as other immigrants) before being resettled in Canada. Prevalences of 0.8% and 0.5% are reported for "cognitive/behaviour/ nervous system disorder" (which includes behavioural disorder, autism, mental retardation, etc) and "other" (which includes developmental delay and congenital anomalies), respectively.11 However, these are not comprehensive data, as more-subtle disabilities and delays were likely not accounted for, and these numbers were derived from a sample size of only 1439 Syrian refugees.11 With respect to the immigrant population, it is worth noting that there is an "excessive demand clause" under Canada's Immigration and Refugee Protection Act, which virtually bans disabled immigrants who might "reasonably be expected to cause excessive demand on health or social services."12 This theoretically limits the number of disabled immigrants accepted into Canada; however, refugees are accepted on humanitarian grounds and are protected by law from this clause.

Despite unknown prevalence, delays in diagnosis and referral for developmental services have been well documented across ethnic minority groups in North America and Europe.8 The UNHCR reports that refugee and resettlement experiences might affect critical stages of physical, intellectual, social, and emotional development.6,13 Walker and Barnett characterize factors affecting children of newcomer families including pre-existing health inequities and poor health status, particularly among refugee children; challenges in acculturation and adjusting to a new land; history of exposure to environmental toxins and physical or sexual violence in conflict areas; and suboptimal development in nutritionally and environmentally impoverished environments.2

Barriers to identification of developmental disability. In general, newcomers to Canada experience several barriers to adequate health care that include limited prearrival health care, limited language skills and health literacy, complex health insurance eligibility rules, lack of familiarity with our health care system and resources, fear of deportation for the undocumented, and poor financial situations.3,14 For families dealing with developmental disabilities, barriers might also include different perspectives on typical child development, lack of awareness that schools provide accommodations to those with disabilities, and cultural factors.3 Some cultures focus on social conformity, for example, and

so disabilities presenting with behavioural challenges such as autism spectrum disorder (ASD) might be identified more readily than more-subtle communication deficits. Other cultures might view direct eye contact as disrespectful, and mild ASD might go undiagnosed.3 Although there is a range of adherence to beliefs within any culture, within some cultures there might be a tendency to view disability as a punishment for past or present sins or a consequence of evil spirits inhabiting the child's body. The stigma associated with disabilities can make it less likely for some individuals within these cultures to seek professional help.3,13

On the other hand, a qualitative American study by Bogenschutz reports strong resilience among interviewed immigrant families with a family member diagnosed with a developmental disability, illustrating their willingness to navigate hurdles in a complex health care system to help their loved ones.14 The author identifies the importance of a "medical home"—a concept promoted by the discipline of family medicine in Canada.14 Cross-cultural competence or cultural humility is crucial: providers must be aware of their own biases, beliefs, and values; understand different cultural backgrounds of newcomer patients; and engage with these patients using approaches that are sensitive to patients' cultural views.3

Screening tools. The American Academy of Pediatrics and the CPS both recommend that primary care physicians engage in developmental surveillance and have proficiency in early identification of and referral for developmental disabilities (level III evidence).3,15 The current standard of care includes surveillance and standardized developmental and behavioural screening (SDBS), with the recognition that higher-risk and marginalized populations might need more vigilance. Of interest, guidelines published in 2016 by the Canadian Task Force on Preventive Health Care (CTFPHC) recommended against screening for developmental delay using SDBS in children aged 1 to 4 years with no apparent signs or concerns of delay (strong recommendation, low-quality evidence).16 The recommendation does not apply to children with signs or symptoms or those whose parents have concerns or who are at high risk. The CTFPHC stated there was no evidence from randomized controlled trials that screening improved health outcomes and no evidence that SDBS consistently identified unrecognized cases of developmental delay.16 Despite CTFPHC recommendations, we heed the CPS and American Academy of Pediatrics guidelines.

The Rourke baby record is embedded in many electronic medical records, facilitating its use for preschool children up to age 5. The Nipissing District Developmental Screen is also widely available for those aged 1 month to 6 years and should be completed in Ontario at the enhanced 18-month well-baby visit, enabling early intervention including referrals

to pediatric consultants or speech and language therapy in cases of positive screening results. The Parents' Evaluation of Developmental Status (PEDS), a 10-item questionnaire for parents, and the Ages and Stages Questionnaire (ASQ) are additional self-report screening tools that can also be used for children from birth to 11 years and 4 months to 5 years, respectively.<sup>17</sup> The PEDS and ASQ take 5 minutes and 15 minutes, respectively, to complete (excluding time for scoring) and have been translated into several languages (eg, more than 35 languages for PEDS), but there is a cost associated with these versions. For older children aged 6 to 17, the Greig Health Record can be used, as it has a small psychosocial history and development inquiry section. Other than the Greig Health Record, specific screening tools are recommended depending on clinical suspicion. For example, for ASD, the Autism Diagnostic Observation Schedule, the Modified Checklist for Autism in Toddlers, or the Childhood Autism Rating Scale can be used. Identification of delays in older children and occasionally newcomer teenagers or young adults requires eliciting concerns about gross- or fine-motor, communication, language, problem-solving, or social skills from families or patients themselves. Interpreters are required in cases where a language barrier is present (interpreters can occasionally be provided by resettlement agencies free of charge), and provider administration of screening might be necessary among refugees with low literacy.<sup>3,13</sup>

Most developmental screens rely on self-reporting by parents, and parental interpretation of what is a concern can vary across cultures. In a study by King et al that looked at the use of the PEDS questionnaire in Southeast Asian populations versus American-born preschool children, parental concern levels were culturally determined, with higher self-reporting in this study among Southeast Asian families.18 Despite the authors of this study cautioning that context be used to interpret screening results in different cultures, there are studies that confirm the general validity of the PEDS and other screening tools in various languages. A study by Huntington et al recently confirmed the equal validity of the PEDS in English and in Spanish. 19 In a qualitative study by Kroening et al, participants from Bhutanese-Nepali, Burmese, Iraqi, and Somali backgrounds thought that the PEDS would be well received for developmental screening within their cultural communities.<sup>13</sup>

It is worth noting that some items within the ASQ are sensitive to cultural differences in child rearing and the tool does allow for alternate experiences. A double asterisk on the tool is used to mark items that might not be common to all cultures. Developmental differences might reflect culturally based experiences that the child has had rather than truly signify a delay. These situations afford an opportunity for dialogue and teaching. Speech and language skills are also specific to a child's first language. While responses of no must be interpreted with

caution when the checklist is not administered in the family's first language, a referral to speech and language pathology might still be prudent.

Barriers to SDBS for primary care providers include time, cost (as SDBS tools are typically available without cost only in English or French), not knowing what to do with a positive screening result, and lack of timely referral services.

Differential diagnoses and investigations. In 2011, the CMAJ published a comprehensive set of evidencebased clinical guidelines by Pottie and colleagues for immigrants and refugees, providing recommendations for screening for infectious diseases (measles, mumps, rubella; diphtheria, tetanus, polio, pertussis; varicella; hepatitis B; tuberculosis; HIV; hepatitis C; Strongyloides, Schistosoma, intestinal parasites; and malaria), chronic and noncommunicable diseases (diabetes mellitus, iron deficiency anemia, dental disease, and vision health), women's health (contraception, cervical cancer, and pregnancy), and mental and emotional health (depression, posttraumatic stress disorder, child maltreatment, and intimate partner violence) (level III evidence).20

Regarding a clinical framework specifically for developmental disability or delay in newcomer patients, the CPS recommends taking a full history including a history of the pregnancy and delivery, current developmental status including SDBS, migration history, nutritional assessment, and early education experience.3 A subsequent full physical examination with particular attention to anthropometric indices (weight, height, and head circumference in infants) and dysmorphic features is prudent (level III evidence).3

Newcomers' pre-migration lives might have included living in war or natural disaster zones or poverty, or experiencing domestic abuse or neglect. Children might not have undergone newborn biochemical screening for metabolic or endocrine disorders routinely tested for in Canada. Table 1, based on the CPS recommendations, outlines specific screenings and investigations primary care providers should consider to ensure treatable diseases are not missed (level III evidence). 3,20-22 This table can be used in conjunction with the guidelines for immigrant and refugee health published in the CMAJ, as well as American guidelines published by the Centers for Disease Control and Prevention. 20,22 New-arrival screening should include mental health and developmental screening; screening for dental, hearing, or vision concerns; dietary and growth assessment; screening for environmental (such as pesticide or lead toxicity) or occupational exposures; infectious disease testing (eg, cerebral malaria can have developmental sequelae); catch-up immunizations; and screening for conditions such as hemoglobinopathies common in certain regions (eg, sickle-cell anemia, thalassemias, and glucose-6-phosphate dehydrogenase deficiency).3 Micronutrient deficiencies such as iron or B12 can have considerable

effects on a child's neurodevelopment. Iron deficiency has been linked to impaired psychomotor and mental development in infants as well as cognitive impairment in adolescents.<sup>23,24</sup> In low- or middle-income countries, randomized trials have shown iron supplementation can prevent or correct impairments in psychomotor development in infants, toddlers, and preschool children.25

Regarding mental health and psychosocial screening, as listed in Table 1,3,20-22 while Pottie et al recommend screening for depression in newcomer adults if an integrated treatment program is available, guidelines recommend against routine screening for exposure to traumatic events, child maltreatment, or intimate partner violence, as this might result in more harm than good (level III evidence).20 However, the CMAJ guidelines and the CPS do suggest mental health screening if there are unexplained somatic symptoms such as sleep disorders, academic or behavioural difficulties, or clinical suspicion of a mood disorder.3,20 The CPS recommends screening in cases of developmental disability or delay to rule out an underlying psychiatric disorder as the cause.3 In these cases, mental health screening tools such as the Child Depression Inventory can be used to screen refugee and immigrant children in a culturally sensitive manner.3 For the pediatric population, if there is any suspicion of ongoing child maltreatment, providers must inquire and report to their local child protective service as deemed appropriate.

*Management.* There are some overriding principles that might help guide the management of developmental disability in newcomer families. Culturally competent and trauma-informed care is important, as is the recognition that there are differences in decision making within families across different cultures. Cultures that value collectivism, independence of the family, or a patriarchal hierarchy might find their models at odds with Western delivery models that value the autonomy of the individual.3 The use of an interpreter or a cultural broker can help ensure validity of communication. Health beliefs regarding the genesis of the condition and hopes and expectations for treatment can be elicited through thoughtful and culturally competent inquiry. A number of qualitative studies have highlighted the importance of a collaborative culturally competent team in providing support to newcomer families of children with developmental disabilities.<sup>26</sup>

Individuals with developmental disability are often socially isolated, and studies show that children with intellectual disabilities coming from immigrant families have very few opportunities for social engagement. This might be attributable, in part, to lower socioeconomic status or less connectedness, or the result of greater stigma of intellectual disabilities in these communities.<sup>27</sup> Management must, therefore, also consider the importance of lessening social isolation. Further, there are

### Table 1. Investigations and screening to consider at an initial assessment of newcomer children and youth: Comprehensive checklists and follow-up recommendations are available from www.kidsnewtocanada.ca.<sup>3</sup>

#### INVESTIGATION AND SCREENING TESTS AND MANEUVERS

#### Laboratory investigations

- CBC
- Hemoglobin electrophoresis
- · G6PD screening (and subsequent quantitative level if screening result is positive) for patients from Africa, Asia, or the Mediterranean
- TSH
- Serum B12 level
- Iron studies
- · Lead testing
- · Infectious disease testing\*:
- -Hepatitis A IgG
- -Hepatitis B surface antigen and hepatitis B surface antibody
- -Syphilis testing (VDRL or RPR test) in those ≥ 15 y of age or in younger children in cases of suspected congenital syphilis or suspected sexual activity or assault
- -VZV IgG in those ≥ 13 y of age
- -Stool ova and parasite testing (2 samples)
- -TB testing (Mantoux skin test)
- -Malaria smears (RDT) if febrile and from an endemic area up to 12 mo
- -HIV serology for those from an endemic area<sup>†</sup> (ie, sub-Saharan Africa, Central Asia, and the Caribbean) ≥15 y of age; those with an infected or deceased parent or sibling; if there is suspected sexual abuse or a history of blood product transfusion; or if the patient is not accompanied by the birth mother
- -Hepatitis C serology if from an endemic area<sup>†</sup> (ie, North Africa, Asia, the Middle East, and Europe) -Strongyloides and schistosomiasis serology testing if from an endemic area<sup>†</sup> (ie, Africa and
- Southeast Asia)
- Consider creatinine and vitamin D levels and LFTs

#### Screening and focused physical examination

- Mental health and psychosocial screening (see text for clarification)
- · Vision (includes age-appropriate visual impairment screening and assessing for strabismus and red reflex)
- Hearing (otoacoustic emission testing)
- Dental (includes inspection for caries and gum disease)
- Growth (height, weight, head circumference for infants)
- · Assessment of dysmorphic features, infectious signs (eg, hepatomegaly, rashes, etc) and hallmarks of micronutrient deficiencies

CBC—complete blood count, CCIRH—Canadian Collaboration for Immigrant and Refugee Health, CDC—Centres for Disease Control and Prevention, G6PD—glucose-6-phosphate dehydrogenase, IgG—immunoglobulin G, IME—Immigration Medical Examination, LFT—liver function test, RDT—rapid diagnostic test, RPR-rapid plasma reagin, TB-tuberculosis, TSH-thyroid-stimulating hormone, VDRL Venereal Disease Research Laboratory, VZV varicella zoster virus.

\*Note that the IME includes a limited number of public health investigations such as TB testing. However, aside from results not being available to

<sup>1</sup>Endemic regions are based on prevalence cutoffs detailed in the CCIRH guidelines; such regions might change over time.<sup>21</sup> Data in this table are complementary to the CCIRH guidelines by Pottie et al.<sup>20,21</sup> Another similar checklist is also available on the CDC website.<sup>22</sup>

often lower rates of preventive care services both for people with developmental disability and for newcomers. Ensuring equitable access for those affected by this "double disability" is crucial.28

Referrals for occupational therapy, physiotherapy, optometry, speech and language therapy, dentistry, and social work might require facilitation when newcomers are less familiar with resources in the community. It is beneficial to gain an awareness of local organizations working with newcomers and to link families to available resources. A brief list of useful resources is provided in Box 1. It is also beneficial to understand the extent of health coverage provided by the Canadian government for both immigrants and refugees. While immigrants pay out of pocket or require private insurance during a waiting period of up to 3 months before receiving provincial or territorial government health insurance, refugees are

granted Interim Federal Health Program coverage for up to 12 months after arrival. The Interim Federal Health Program basic coverage is identical to provincial or territorial health insurance and also covers all the medications on provincial drug benefit formularies (as well as additional antiprotozoal and antiparasitic medications), urgent dental care, limited vision care, and ancillary services (physiotherapy, occupational therapy, speech therapy, psychotherapy, home care, prosthetics and orthotics, and mobility and assistive devices).29

#### Case resolutions

Patient A. A diagnosis of trisomy 21 was made and appropriate cardiac and other screening was performed. Accepting that this was not "curable" was difficult for the parents but, over time, they are learning to accept this. Integration into the educational

#### Box 1. Additional resources

The following are web links to various resources that might be useful

- Evidence-based guidelines and tools for caring for immigrant populations recommended by the Canadian Collaboration for Immigrant and Refugee Health: www.ccirhken.ca
- Literature on refugee health recommended by the CMAJ: www.cmaj.ca/cgi/collection/canadian\_ guidelines\_for\_immigrant\_health
- Comprehensive list of online resources by province compiled by Caring for Kids New to Canada: www.kidsnewtocanada.ca/beyond/resources
- · Citizenship and Immigration Canada information on the Interim Federal Health Program: www.canada.ca/ en/immigration-refugees-citizenship/services/ refugees/help-within-canada/health-care.html
- Growing Up in a New Land. Strategies for Working with Newcomer Families: beststart.org/resources/hlthy\_ chld\_dev/pdf/Growing\_up\_new\_land\_FINAL.pdf
- Resources for newcomers who settle in Ontario by Settlement.Org: www.settlement.org
- Parents' Evaluation of Developmental Status questionnaire, which helps parents determine their children's development: www.pedstest.com
- Ages and Stages Questionnaire for developmental, social, and emotional screening of children: http://agesandstages.com

system with special support from a dedicated educational assistant has been key to this acceptance.

Patient B. Hearing testing revealed profoundly affected hearing. Her language delay was, in part, due to hearing loss and, in part, due to developmental delay caused by meningitis. Hearing aids along with speech therapy have accelerated language development. Placement in school has also helped to accelerate development.

#### Conclusion

As family physicians, it can be daunting to care for newcomer families who arrive without previous developmental disability or delay screening and diagnoses. Disruption to families and continuous education, decreased health literacy, witnessed traumatic events, and culturally specific barriers can affect the presentation of developmental concerns among refugees and immigrants.<sup>2,3,13</sup> Surveillance and screening for developmental concerns in a culturally sensitive manner using evidence-based tools are cornerstones of early intervention. For refugees, in particular, in light of the inequities they have faced before migration and during their migration trajectory, screening and intervening provides an opportunity to help achieve equitable outcomes for refugee children and optimize their health and well-being.

We are in a unique position to provide a medical home for our newcomer patients with developmental disabilities. The College of Family Physicians of Canada's Patient's Medical Home is a physical or virtual network of health care providers looking after a patient in which the family physician plays a central role in linking patients, in the case of children with developmental disabilities, to developmental pediatricians, early intervention programs, allied health services, and community resources. This will hopefully better patient outcomes. 14,30

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#### Competing interests

None declared

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