

Websites Recommended By Service Providers And Researchers

Please note that websites may use different terminology depending on their origin. Learning disabilities is commonly used in the United Kingdom instead of the North American terms intellectual disabilities or developmental disabilities. Therefore some language modification may be needed for a North American context.

Surrey Place

<https://ddprimarycare.surreyplace.ca/>

Surrey Place provides specialized clinical services to children and adults with intellectual and developmental disabilities in the Toronto Region. Surrey Place is affiliated with academic institutions, and is a teaching site. Their Developmental Disabilities Primary Care Program is a resource to primary care providers regarding health care of people with developmental disabilities. The website includes primary care guidelines and a variety of related tools and resources which providers found very useful.

Developmental Services Ontario (DSO)

<https://www.dsontario.ca/>

DSO is the access point for adult developmental services funded by the Ministry of Children, Community and Social Services (MCCSS) in Ontario.

If you are 18 years old with a developmental disability, you can apply through the DSO to see if you are eligible to receive adult ministry-funded supports.

The website has information on how to access services, information and resources in the community.

Behavioural Supports Ontario (BSO)

<https://behaviouralsupportsontario.ca/>

The BSO website links users to information and tools about behavioural change in older adults and available provincial and regional programs and services.

Mary Centre of the Archdiocese of Toronto (Mary Centre)

<http://www.marycentre.com/>

Mary Centre meets the needs of people with a developmental disability by providing a variety of residential and outreach support services in the Greater Toronto Area, Peel and York Region. Mary Centre welcomes people of all faiths, while reflecting Catholic values.

Reena

<http://www.reena.org/>

Reena is a non-profit organization which promotes dignity, individuality, independence, personal growth and community inclusion for people with developmental disabilities within a framework of Jewish culture and values.

ConnectABILITY

<https://connectability.ca/en/>

A website and virtual community dedicated to lifelong learning and support for people who have an intellectual disability, their families and support networks. The site is organized by age group (kids, youth, adults, seniors) and within these categories are a variety of articles, videos, news releases, resource directories, tips, etc.

Ontario Partnership on Aging and Developmental Disabilities (OPADD)

<http://www.reena.org/training/opadd/>

OPADD is an informal partnership of service providers in the continuum of senior services and Developmental Disabilities (DD). The website includes key papers, reports, research, and resources for planners and caregivers.

Alzheimer Society Canada & Alzheimer Society Ontario

<https://alzheimer.ca/en/Home>

<https://alzheimer.ca/en/on>

These websites provide a wide variety of information and educational resources.

Autism Ontario

<https://www.autismontario.com/>

Autism Ontario is the province's leading source of information and referral on autism and one of the largest collective voices representing the autism community.

Canadian Association for Community Living (CACL)

<https://cacl.ca/>

CACL works in collaboration and shared leadership with our provincial-territorial associations and with other national partners and disability organizations to advance shared agendas for inclusion.

Ontario Association on Developmental Disabilities

<https://oadd.org/>

OADD is a professional organization of people working and studying in the field of developmental disabilities, throughout Ontario.

Canadian Association on Gerontology

<https://cagacg.ca/>

Multidimensional Assessment of Providers and Systems (MAPS)

<https://www.mapsresearch.ca/projects/aging/>

MAPS is a collaboration of researchers and partners seeking to provide evidence to inform actions leading to improved social inclusion, choice and independence among persons with intellectual and developmental disabilities.

Health Care Access Research and Developmental Disabilities (H-CARDD)

<https://www.porticonetwork.ca/web/hcardd>

The H-CARDD program was developed to address disparities in health status and health care access faced by individuals with developmental disabilities in Ontario.

The website contains helpful information including toolkits, videos, and reports clinicians, persons with developmental disabilities, and caregivers.

Institute for Clinical Evaluative Sciences (ICES)

<https://www.ices.on.ca/>

The Seniors Health Knowledge Network (SHKN)

<https://shrtn.on.ca/seniors-health-knowledge-network>

SHKN, (originally the Seniors Health Research Transfer Network or SHRTN) is a network of networks that mobilizes evidence, shares knowledge and brokers relationships across disciplines and sectors among: practitioners, researchers, educators, policy makers, and older adults. The website offers a broad variety of tools and resources, including education and training resources.

brainXchange

<https://brainxchange.ca/>

The website focuses on a wide variety of topics relating to dementia and also includes the Behavioural Supports Ontario (BSO) Resource Site. Providers noted that the presentations found on the website were interesting and helpful.

Bridging Aging and Disability International Network (BADIN)

<http://www.badinetwork.org/>

BADIN is an international, interdisciplinary network of individuals interested in the concept and practice of bridging the fields of aging and disability. The network strives to improve knowledge sharing and collaboration across stakeholders, organizations and fields in care and support for persons with disabilities, their families, and the aging population.

Badin's online network welcomes individuals with disabilities and their families, professional practitioners, researchers and scholars, policy practitioners, and offers a platform to share experiences, a newsletter, notices about events and opportunities to collaborate.

The Caregiver Exchange

<https://www.caregiverexchange.ca/>

This website focuses on resources for caregivers, providing practical videos, articles, and tips on accessing information about services.

L'Arche

<https://www.larche.ca/>

L'Arche creates communities where the members, with and without intellectual disabilities, share life together. Each member receives support to grow, attain their goals, and contribute their gifts and abilities. L'Arche communities support persons with intellectual disabilities in residential and vocational settings.

In the traditional L'Arche home, 2 to 3 assistants “live-in” and make a home with 4 to 6 persons with disabilities. Other “live-out” assistants, family, friends and volunteers also participate in the life of the home.

International Association for the Scientific Study of Intellectual Developmental Disabilities (IASSID)

<https://www.iassidd.org/>

An international special interest group dedicated to the scientific study of intellectual disability.

The National Task Group on Intellectual Disabilities and Dementia Practices

<http://aadmd.org/ntg>

This American coalition is focused on dementia as it affects people with intellectual disabilities and their families. Resources on this website include practice guidelines, an early detection screening tool for providers and family caregivers, and other tools.

Learning (Intellectual) Disability and Dementia

<https://www.learningdisabilityanddementia.org/>

Dr. Watchman (a senior lecturer at the University of Stirling) and her colleagues developed this website as an open access portal to a variety of resources related to people aging with intellectual disabilities affected by dementia. For example, there are references to textbooks on Dementia, on Ageing, Diversity and Equality. Some materials may be downloaded in whole or in part.

Talking End of Life...with people with intellectual disabilities (TEL)

<https://www.caresearch.com.au/tel/tabid/4881/Default.aspx>

Led by Professor Roger Stancliffe and colleagues, this Australian project provides an excellent resource on death and dying with an array of videos, case studies, modules and resources.

Resources show how to teach people with intellectual disability about end of life. The website is designed for disability support professionals (DSPs) but is also helpful for families, health professionals, and educators. With assistance, people with intellectual disability might also find the information helpful.

Research Training Center on Aging with Intellectual and Developmental Disabilities (RRTCADD)

<https://www.nchpad.org/Directories/Organizations/2511/Rehabilitation~Research~Training~Center~on~Aging~with~Intellectual~and~Developmental~Disabilities~~RRTCADD~>

RRTCADD promotes the successful aging of adults with intellectual and developmental disabilities (I/DD) in response to physical, cognitive, and environmental changes. The website contains aging resources for researchers, people with intellectual and developmental disabilities, their families, service providers, policy makers, advocacy groups, students, and the general community.

Scholarly articles for Rehabilitation Research and Training Center on Developmental Disabilities and Health

https://scholar.google.ca/scholar?q=Rehabilitation+Research+and+Training+Center+on+Developmental+Disabilities+and+Health&hl=en&as_sdt=0&as_vis=1&oi=scholar

Trinity Centre for Ageing and Intellectual Disability (Dublin)

<https://www.tcd.ie/tcaid/>

This international and multi-disciplinary research centre examines key issues in aging and the life course, and contains useful material and resources.

The Daughters of Charity Disability Support Services (Dublin)

<http://www.docservice.ie/>

The organization provides supports to persons with an intellectual disability in the Dublin, Limerick and North Tipperary/Offaly areas. In addition to some resources at the bottom of the “Links” section, there is an Assistive Technology section describing devices, technical aids, strategies, services and practices to improving the quality of life of people with disabilities.

The Arc: Center for Future Planning

<https://futureplanning.thearc.org/>

The Center provides information and assistance to individuals with I/DD, their family members and friends, professionals who support them and other members of the community on areas such as person-centered planning, decision-making, housing options, and financial planning.

You can create an account and build a future plan using their template.

Choosing Wisely

<https://www.choosingwisely.org/>

This website is an initiative of the American Board of Internal Medicine (ABIM) Foundation that seeks to advance a national dialogue on avoiding unnecessary medical tests, treatments and procedures. There is educational material for patients and clinicians that can be downloaded.

The Portal of Geriatrics Online Education (POGOe)

<https://www.pogoe.org/>

The Portal of Geriatrics Online Education (POGOe) is free collection of expert-contributed geriatrics educational materials for educators and learners. Materials are available digitally and use various teaching methods. There is a lot of useful information on a variety of topics.

University Websites

As participants in consultation sessions did not always specify why they found these sites useful, we have included some information.

University of Chicago

<https://www.uchicago.edu/>

A search on their website under the A-Z index using the term Down's Syndrome and Aging brings up articles and research.

University of Minnesota

<https://twin-cities.umn.edu/>

If you search "disabil" in the website, a number of interesting articles come up that come from a Impact Newsletter, which appears to be published by University of Minnesota's Institute on Community Integration (ICI).

University of Minnesota's Institute on Community Integration (ICI)

<https://ici.umn.edu/search>

ICI is a designated University Center for Excellence in Developmental Disabilities, part of a national network of similar programs in major universities and teaching hospitals in the U.S. ICI works to build inclusion through an intensive focus on policies and practices that affect children, youth, and adults with disabilities, and those receiving educational supports.

<https://ici.umn.edu/search>

If you go directly to this website you will find a number of helpful resources and courses.

University of Hertfordshire (U.K.)

www.herts.ac.uk

Offers courses relating to learning disabilities

Monash University (Australia)

www.monash.edu

Recommended Academic Journals & How to Access Them


According to Nancy Jokinen, MSW, PhD, and researcher at UNBC School of Social Work, we still have much to learn about how to best support people aging with developmental disabilities and their families so it is important to keep up to date.

Many academic articles report research findings in 'peer reviewed' journals. Be sure to review a journal's table of contents when a new issue is released for articles that may be of interest.

You can arrange for a publisher to notify you by email of new issues or online first articles through the home page of the journal. See as example the home page *Journal of Policy and Practice in Intellectual Disabilities* at

<https://onlinelibrary.wiley.com/page/journal/17411130/homepage/forauthors.html> .

Click on the "Get Content Alerts" link on the menu on the right side. Some journal websites will have a section for staying connected, where you may also find the links to create a content alert.

If you are already on the Table of Contents page, clicking on an article's title will usually bring you to the abstract that highlights the information contained in the article. Some articles are now published as open access (free) and designated with a symbol  Open Access . For other articles, you may have to gain access as a university alumni or ask if your colleagues or agency have access.

In addition to *The Journal of Policy and Practice* mentioned above, here are links to other highly recommended journals specific to intellectual/developmental disabilities:

American Journal on Intellectual and Developmental Disabilities

<https://aiddjournals.org/toc/ajmr/124/6>

Inclusion

<https://www.aiddjournals.org/loi/incl>

Intellectual and Developmental Disabilities

<https://www.aiddjournals.org/toc/mere/57/6>

Journal on Developmental Disabilities

<https://oadd.org/publications/journal-on-developmental-disabilities/>

Journal of Applied Research in Intellectual Disabilities

<https://onlinelibrary.wiley.com/journal/14683148>

Journal of Intellectual Disabilities

<https://journals.sagepub.com/home/jld>

Journal of Mental Health Research in Intellectual Disabilities

<https://www.tandfonline.com/toc/umid20/current>

Research and Practice in Intellectual and Developmental Disabilities

<https://www.tandfonline.com/toc/rpid20/current>

Strategies, Reports, Videos, Toolkits, Courses

A Dementia Strategy for Canada: Together We Aspire (released 2019) (Strategy)

The strategy is available on Canada.ca at the following links:

English – <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-strategy.html>

French – <https://www.canada.ca/fr/sante-publique/services/publications/maladies-et-affections/strategie-demence.html>

Improving the quality of life and care of persons living with dementia and their caregivers (Report)

<https://cahs-acss.ca/improving-the-quality-of-life-and-care-of-persons-living-with-dementia-and-their-caregivers/>.

The Canadian Academy of Health Sciences produced a comprehensive report to inform the development of the national strategy on dementia. You may wish to review Appendix G of the report, which provides an excellent overview of developmental disabilities and dementia as well as relevant and up to date research citations.

How to best support individuals with IDD as they become frail: An international consensus statement [version 1; 1 December 2017]

https://www.mapsresearch.ca/wp-content/uploads/2018/12/IDD-Frailty-Consensus-Statement_Dec2017.pdf

The Canadian Dementia Consortium

In 2019, Dr. Nancy Jokinen (Associate Professor, UNBC), Leslie Udell (L. Udell Consulting in Winnipeg), and Sandy Stemp (Chief Operations Officer, Reena), created the NTG-Canadian Consortium on Intellectual Disabilities and Dementia. The Consortium works with its U.S. partner, The National Task Group on Intellectual Disabilities and Dementia (NTG). The Canadian Consortium has adapted their U.S. partner's dementia capable training curriculum to deliver across Canada. Topics include an introduction to Aging & Intellectual Disability (ID), Understanding Dementia in Adults with ID, Diagnosis, Health Care Advocacy, Understanding Challenging Behaviors, Non-pharmacologic Interventions, Communication Tips & Strategies, Adapting the Environment, and Stage-based Considerations. This past year they piloted 3 sessions in Canada and now have a group of connected NTG-Canada Provincial Trainer leaders, providing a growing network of support and learning. For more information about the Canadian Consortium, contact Sandy Stemp at 905-889-6484 ext. 2227.

Surrey Place Primary Care Guidelines

<https://ddprimarycare.surreyplace.ca/guidelines/>

Providers found the information about how health issues manifest differently for people with DD very useful, and also referenced information/tools about having a successful doctor's visit.

Improving Emergency Care for Adults with Developmental Disabilities: A Toolkit for Providers

<https://www.porticonetwork.ca/web/hcardd/kte/emergency-department-toolkit-v2>

Implementing Health Checks for Adults with Developmental Disabilities: A Toolkit for Primary Care Providers

<https://www.porticonetwork.ca/web/hcardd/kte/health-check-toolkit>

The Nuts and Bolts of Health Care. A Toolkit for Direct Support Professionals

<https://www.nutsandboltstools.com/>

Found on the HCARDD website, this toolkit has many useful tools and checklists for service providers.

Guidelines for Supporting Adults with a Developmental Disability When Applying To, Moving Into and Residing In a Long-Term Care Home

[Guidelines for Supporting Adults with a Developmental Disability When Applying To, Moving Into and Residing In a Long-Term Care Home](#)

The Ministries of Community and Social Services and Health and Long-Term Care developed guidelines to help adults with developmental disabilities who are applying to, moving into and residing in a Long-Term Care (LTC) home. These guidelines provide important information about the developmental services sector, how to apply to LTC homes, and processes that impact LTC home residents.

Addressing Gaps in the Health Care Services Used by Adults with Developmental Disabilities in Ontario. Toronto, ON: ICES; 2019. Lin E, Balogh RS, Durbin A, Holder L, Gupta N, Volpe T, Isaacs BJ, Weiss JA, Lunsky Y. (Report)

<https://www.ices.on.ca/Publications/Atlases-and-Reports/2019/Addressing-Gaps-in-the-Health-Care-Services-Used-by-Adults-with-Developmental-Disabilities>

The report takes an integrated, cross-sectoral approach to study how adults with developmental disabilities differ from other adults in Ontario with regard to five key outcomes: 30-day repeat emergency department visits, 30-day repeat hospitalizations, alternate level of care, long-term care and premature mortality.

The five outcomes are examined by age group, sex, neighbourhood income level and type of developmental disability, as well as by planning regions of the province's health and community services sectors. Recommendations that can enhance policy, practice and intersectoral planning for each of the five outcomes are included.

Adapting and Implementing Friendship Supports for Adults with Intellectual Disabilities (Online Course)

https://rise.articulate.com/share/9OZ3LjwsDcdW6nJA16SQZb1Tk_M6QNAO#/?_k=77w9gr

Suggestions for front-line staff/managers offering social support on how to improve, adapt, and implement friendship supports and strategies.

National Housing Strategy (2017)

<https://www.placetocallhome.ca/>

Part of this strategy includes a co-investment fund which will drive the creation of 2,400 units for individuals with developmental disabilities. Information re applications is on the website.

DSO Housing Toolkit

<https://www.dsonario.ca/resources/housing/welcome-to-the-dso-housing-toolkit>

Supporting Persons with Intellectual Disability & Advanced Dementia Fusing the Horizons of Intellectual Disability, Palliative & Person-Centred Dementia Care (Report)

<https://nursing-midwifery.tcd.ie/assets/publications/pdf/fusing-horizons-of-care.pdf>

A thorough report from the School of Nursing & Midwifery Trinity College Dublin explores the experiences of staff in multidisciplinary teams in intellectual disability and in specialist palliative care service, identifies educational and training needs, and contains useful observations and recommendations.

Improving Health Assessments for People with an Intellectual Disability (Online Course)
<https://www.futurelearn.com/courses/health-assessment/0/steps/42759>

Dr. Eilish Burke is an Ussher Assistant Professor in Ageing and Intellectual Disability at Trinity College Dublin, and the Associate Director of the new Trinity Centre for Ageing and Intellectual Disability. Her three-week course provides valuable knowledge on how to include people with an intellectual disability in health assessments.

Irish College of General Practitioners (Online Courses)

https://www.icgp.ie/go/courses/e_learning

Includes eLearning program on Diagnosis & Management of Dementia in Primary Care

Supporting Persons with Intellectual Disability and Dementia: Quality Dementia Care Standards. A Guide to Practice. McCarron, M and Reilly, E (2010)

<https://pdfs.semanticscholar.org/66cb/e771e50f0a03b0d14172bc10778efe27bbb3.pdf>

The standards were developed to support consistent, high-quality and person-centred care throughout the continuum of dementia, covering 6 areas: training and education, memory assessment service, health and personal care, communication and behaviour, promoting well-being and social connectedness, and supporting persons with advanced dementia.

Intellectual Disability and Dementia International Summit 2016

<https://www.learningdisabilityanddementia.org/id-dementia-summit.html>

The National Task Group on Intellectual Disability and Dementia Practices, the University of Illinois at Chicago, the University of the West of Scotland (UWS), and Alzheimer's Scotland sponsored an 'international summit' on intellectual disability and dementia geared to developing a major international policy statement on a number of areas related to dementia and adults with ID, including human rights and the CRPD, nomenclature, advanced dementia, end-of-life care practices, aiding family caregivers, community dementia-capable care practices, and advocacy for inclusion of persons with ID in national Alzheimer's plans.

The summit resulted in a variety of consensus statements and policy and practice bulletins that can be found by going to the above link.

Open Future Learning.org

<https://www.openfuturelearning.org/index.cfm?fuseaction=login.home>

An online learning provider dedicated to the learning disability workforce.

Books Recommended In Consultation Sessions

Developmental Disabilities in Ontario – 3rd Edition
ISBN: 978-0-9731573-1-4; <https://oadd.org/publications/textbook/>

Mental Wellness in Adults with Down Syndrome: A Guide to Emotional & Behavioral Strengths & Challenges by Dennis McGuire & Brian Chicoine. <https://www.bookdepository.com/Mental-Wellness-Adults-with-Down-Syndrome-Dennis-McGuire/9781890627652>

The Guide to Good Health for Teens & Adults With Down Syndrome by Dennis McGuire & Brian Chicoine. <https://www.amazon.com/Guide-Health-Teens-Adults-Syndrome/dp/1890627895>

Articles

Balancing personal wishes and caring capacity in future planning for adults with an intellectual disability living with family carers: Journal of Intellectual Disabilities Journal-article DOI: [10.1177/1744629519872658](https://doi.org/10.1177/1744629519872658); <https://orcid.org/0000-0002-3394-3991>.

The article describes the Future CareRoad Map (FCRM) pilot study, which sought to enhance future care planning for families of adults with ID. Most people with intellectual disabilities (IDs) live at home with family, and most carers and care recipients wish to continue this arrangement. However, despite worry about what will happen when carers are unable to continue caring, most families do not plan for the future.

Ensuring Canada's first dementia strategy is not shelved and forgotten: Nathan M. Stall, Pauline Tardif and Samir K. Sinha: CMAJ August 06, 2019 191 (31) E851-E852; DOI: <https://doi.org/10.1503/cmaj.190929>

The article provides an overview of the dementia strategy objectives, and also speaks to a key challenge – eliminating the stigma barrier.