



2023
EDITION

INTELLECTUAL DISABILITY

QUALITY HEALTH RELATED INFORMATION CAREFULLY SELECTED BY YOUR LIBRARIES

 **Biblio-
Santé**



Better informed to live better.

ABOUT

Biblio-Santé is a program of the Quebec Public Library Association. The ABPQ is made up of 182 member municipalities and corporations, for a total of 320 autonomous libraries. Biblio-Santé is available in more than 660 participating public libraries as well as associated health libraries throughout Quebec. Visit our website to see if your library participates in the program.

ACKNOWLEDGMENTS

Biblio-Santé is an initiative of the Charlemagne, L'Assomption and Repentigny libraries that was started under the name Biblio-Aidants. The Quebec Public Library Association would like to thank these three cities for allowing it to extend the program to the rest of Quebec by transferring the copyright.

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VISIT OUR WEBSITE

You will find all of the Biblio-Santé booklets and additional information.

bibliosante.ca

The information provided does not replace a diagnosis or medical examination by a physician or qualified health professional. The content of this booklet was verified in the spring of 2023 and will be updated on an annual basis.

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Legal Deposit – Bibliothèque et Archives nationales du Québec, 2023

ISBN 978-2-925272-45-8

Association des bibliothèques publiques du Québec

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HOW DO WE SELECT THE INFORMATION?

Each document for inclusion in the Biblio-Santé thematic booklets is evaluated with impartiality, based on Librarianship practices in place in public libraries, using various general selection criteria.

First, the booklets are carefully designed to primarily meet the needs and interests of health system users and caregivers. Every title is evaluated according to relevance and quality of its content for the general public, in the Quebec context. If of equal value, Quebec materials are always preferred. The credibility and reputation of the author, creator, illustrator, publisher or producer are also of great importance. Furthermore, special attention is given to the timeliness and long-term relevance of the subject as well as the accuracy of the information.

With regard to documentaries, works by health professionals (doctors, nurses, occupational therapists, psychologists, etc.) are given preference. However, titles based on lay or experiential knowledge are not rejected outright, especially those involving support by a caregiver.

Finally, each thematic booklet is considered as a whole in order to respect the diversity of the topics covered and allow for a balanced presentation of viewpoints. For more information on the selection criteria for Biblio-Santé, please visit bibliosante.ca/criteria



CAREGIVERS

CAREGIVERS BOOKLET

This booklet is complementary to all booklets of the Biblio-Santé Program. It highlights useful resources to support caregivers.

OTHER BOOKLETS AVAILABLE



**ALZHEIMER'S
DISEASE**



**AUTISM SPECTRUM
DISORDER**



BEREAVEMENT



CANCER



**CHRONIC
PAIN**



DIABETES



**END-OF-LIFE
CARE**



**HEART DISEASE
AND STROKE**



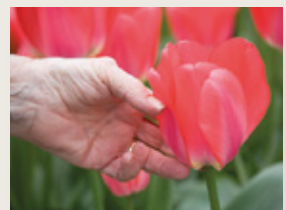
**INTELLECTUAL
DISABILITY**



**MENTAL
HEALTH**



**MULTIPLE
SCLEROSIS**



**PARKINSON'S
DISEASE**



**PHYSICAL
DISABILITY**



**PULMONARY
DISEASE**



**SENIORS
AND AGING**

RESOURCE DIRECTORY

ORGANIZATIONS AND ASSOCIATIONS

General

CANADIAN DOWN SYNDROME SOCIETY (CDSS)

Toll free 1 800 883-5608
Website <http://cdss.ca/>

The Canadian Down Syndrome Society (CDSS) provides a whole range of resources for parents, families and individuals living with Down syndrome. The CDSS provides information about Down syndrome at every stage of life, from birth until retirement.

CANADIAN THERAPEUTIC RIDING ASSOCIATION (CANTRA)

Phone 519 767-0700
Website <http://cantra.ca/en/>

The Canadian Therapeutic Riding Association promotes therapeutic horse riding. The website provides information on the benefits of equine therapy (therapy with horses).

CENTRE PHILOU

Phone 514 739-4861
Website <https://centrephilou.com/en/>

Centre Philou, located in Montreal, offers various services to children aged 0 to 29 with multiple disabilities, including those with an intellectual disability: respite, psychosocial support and family assistance, summer stimulation day camp, stimulation workshops and specific services. The “Parent’s Corner” section of the website offers a comprehensive list of resources for families.

L'APPUI POUR LES PROCHES AIDANTS

Toll free 1 855 852-7784
Website www.lappui.org/en

The 17 regional Appui offices offer a professional helpline as well as support and reference services tailored to the needs of caregivers serving seniors. Each region provides information, training and respite services. The goal of the Caregiver Support hotline is to provide caregiver support, help you through the different steps, and offer guidance on resources available in your community. The website also includes a directory in which you can search by region and type of need required (respite, psychosocial support, etc.).

MIRIAM FOUNDATION

Phone 514 345-1300
Website <https://www.miriamfoundation.ca/>

The Miriam Foundation is a non-profit organization with a mission focused on development of services, research and knowledge transfer, as well as various programs to help people with autism spectrum disorders and developmental disabilities. The Centre offers training, courses, programs and conferences. It also offers the MateriatTech service, whereby members can borrow games, toys and teaching tools.

OFFICE DES PERSONNES HANDICAPÉES DU QUÉBEC (OPHQ)

Toll free 1 800 567-1465
Website www.ophq.gouv.qc.ca

The Office des personnes handicapées provides support, advice and assistance to people with disabilities and their families. It publishes information brochures for family caregivers that can be downloaded in the “Publications” section of the website. Website in French.

Publications in English

Website <https://www.ophq.gouv.qc.ca/publications/publications-in-english.html>

This page contains the English versions of the documents produced by the Office.

PARENTS POUR LA DÉFICIENCE INTELLECTUELLE (PARDI)

Phone 514 376-6644
Website <https://pardi.quebec/>

Created by parents for parents, PARDI, Parents for Intellectual Disabilities, aims to promote the interests and defend the rights of families and individuals with intellectual disabilities.

PROCHE AIDANCE QUÉBEC

Phone 514 524-1959
Website <https://procheaidance.quebec/>

Proche aideance Québec brings together 124 community organizations whose mission is to improve the living conditions of caregivers. You will find the complete list of organizations by region on the Proche aideance website. Website in french.

QUEBEC INTELLECTUAL DISABILITY SOCIETY (QIDS)

Phone 514 725-7245
Website www.sqdi.ca/en

The Quebec Intellectual Disability Society rallies, informs and equips those who want to make Quebec a more inclusive society, where everyone has a place and can flourish. More than 80 organizations and associations, over 100 employers and thousands of families from across the province have already joined the movement.

REGROUPEMENT POUR LA TRISOMIE 21 (RT21)

Phone 514 850-0666
Website www.trisomie.qc.ca/about-us/

Regroupement pour la Trisomie 21 (RT21) is a registered charity based in Montreal, but serving hundreds of families in the province of Quebec. Its mission is to foster the full development of people with trisomy 21, promote their contribution in the society and defend their rights in addition of helping the families, caregivers and professionals who support them.

INTERNET RESOURCES

A few tips for critically assessing information found on the Internet

THE SOURCE OF THE INFORMATION (AUTHOR OR AUTHORS)

- Who created the site?
- Is it possible to obtain information about the author or the owner of the site?
- Is it a government or university site or one belonging to a recognized organization?

THE QUALITY OF THE INFORMATION SOURCE

- What is the objective (to inform or sell)?
- Are the sources referenced?
- Are there links to similar sources (to verify the accuracy and objectivity of the information)?
- How frequently is the information updated?

Keep an eye open! Information is shared very quickly, and false news travel just as fast. We should not always rely on content shared online, especially on social networks. You may find articles in which the information is false or exaggerated. It is therefore important to check the quality of information before you believe it and share it.

General

ASSOCIATION DES CAMPS DU QUÉBEC (ACQ)

Specialized camps for people with special needs

<https://campsquebec.com/familles/camps-besoins-particuliers-handicap>

Many ACQ certified camps specialize in children and adults with special needs. By using the ACQ search engine it is possible to find these camps.

CANADIAN DOWN SYNDROME SOCIETY – RESOURCE HUB

<https://cdss.ca/resources/>

In this section of the website, you will find many publications and information packages for new parents, families, educators and employers.

CENTER FOR PARENT INFORMATION AND RESOURCES – INTELLECTUAL DISABILITY

www.parentcenterhub.org/intellectual/

Information on what is a disability, its causes, signs, diagnosis, help for parents, educational considerations, tips, and more.

COMPANION LEISURE CARD (CAL)

www.carteloisir.ca/en

This website provides information regarding the Companion Leisure Card (CAL). This card gives free access (in participating institutions) to the companions of people aged 12 and older with a permanent disability and who require assistance. A permanent disability includes, but is not limited to, physical, intellectual, developmental and sensory disabilities, as well as mental illness.

CONNECTABILITY.CA

<http://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 core of our community is accessible, self-directed access to valuable information and tools, ready on demand.

ÉDUCATION ET ENSEIGNEMENT SUPÉRIEUR DU QUÉBEC: ALLOWANCE FOR SPECIAL NEEDS PROGRAM – YOUTH

www.quebec.ca/en/education/student-financial-assistance/allowance-special-needs-youth/

If your child has special needs that limit his or her learning activities, this program will enable him or her to obtain the material resources required at home to pursue his or her studies, provided those needs are not already covered by another program or organization.

GOUVERNEMENT DU QUÉBEC - SERVICES FOR PERSONS WITH A PHYSICAL OR INTELLECTUAL DISABILITY OR AN AUTISM SPECTRUM DISORDER (ASD)

<https://www.quebec.ca/en/health/health-system-and-services/assistive-devices-disabilities-and-handicaps/services-for-persons-with-a-disability/>

This website explains how to benefit from certain services offered by the Ministère de la Santé et des Services sociaux. These services assist persons with a physical or intellectual disability or an autism spectrum disorder with their social independence. Some of these services are intended for caregivers.

HEALTHY PLACE – INTELLECTUAL DISABILITY

www.healthyplace.com/neurodevelopmental-disorders/intellectual-disability/what-is-an-intellectual-disability-0

Definition of intellectual disability, its causes, types, related articles, and more. United States context.

INCLUSIVE EDUCATION CANADA (IEC)

www.inclusiveeducation.ca

This website promotes the Canadian vision for inclusive education. It has been designed as a meeting place for parents, family members, teachers, education officials and community members who are committed to making inclusive education a reality in our communities.

PROCHE AIDANCE QUÉBEC

Taking care of yourself... while taking care of your loved one

<http://ranq.qc.ca/wp-content/uploads/2014/02/GuideLavalanglais.pdf>

The need for caregivers to take care of themselves no longer has to be demonstrated. By consulting this guide, you will know that you are not the only ones living with this commitment, and that numerous resources have been set up to help you take care of yourself while taking care of a loved one.

READY, WILLING & ABLE

<http://readywillingable.ca/>

RWA is designed to increase the labour force participation of people with an intellectual disability or Autism Spectrum Disorder (ASD), providing information about why hiring a person with an intellectual disability or ASD is good for business, individualized assistance to help you become a more inclusive employer, and more.

REGROUPEMENT POUR LA TRISOMIE 21

How to talk about sex

<https://drive.google.com/file/d/17UgUDIDeKtUdMWY9QrgvSqBUeg2ggw-B/view>

21 questions about trisomy 21

https://drive.google.com/file/d/0B_60sIMEnUMbMG9mOVdmaTh0bFdDd3RCRWQ0UmZOWnVuYWdz/view

REVENU QUÉBEC – TAX CREDITS

This site provides information on different tax credits and on financial support.

Amount for a severe and prolonged impairment in mental or physical functions

<https://www.revenuquebec.ca/en/citizens/tax-credits/amount-for-a-severe-and-prolonged-impairment-in-mental-or-physical-functions/>

Disabled individuals

<https://www.revenuquebec.ca/en/citizens/your-situation/disabled-individuals/>

Refundable tax credit for medical expenses

<https://www.revenuquebec.ca/en/citizens/tax-credits/refundable-tax-credit-for-medical-expenses/>

Tax credit for caregivers

<https://www.revenuquebec.ca/en/citizens/tax-credits/tax-credit-for-caregivers/>

Work premium tax credit

<https://www.revenuquebec.ca/en/citizens/tax-credits/work-premium-tax-credits/>

SPECIAL OLYMPICS CANADA

Active Start and FUNdamentals are two initiatives developed by Special Olympics Canada for young athletes. Active Start is a activity program for children with an intellectual disabilities ages 2-6. FUNdamentals is a continuation of the Active Start and is for children ages 7-12.

Active Start

<https://www.specialolympics.ca/programs-gamesprograms/active-start>

FUNdamentals

<https://www.specialolympics.ca/programs-gamesprograms/fundamentals>

SPECIAL OLYMPICS QUÉBEC

<https://www.olympiquesspeciauxquebec.ca/en/>

Special Olympics Québec aims to improve quality of life, primarily through the Healthy Athletes Program, which supports athletes in managing their health. It also offers various opportunities for social inclusion.

TEACHINGSEXUALHEALTH.CA – SEXUALITY AND DISABILITY

<https://teachingsexualhealth.ca/app/uploads/sites/4/Sexual-and-Development-Disability-Guide-2016.pdf>

A booklet developed by Alberta educators and health professionals, to help you talk comfortably with your developmentally disabled child or teen about sexual health.

THE INCLUSION CLUB

<http://theinclusionclub.com/>

This website contains audiovisual episodes all about the inclusion of people with disability in sport and active recreation.

HEALTH INFORMATION PORTALS

Sources offering reliable and quality information about health and healthy lifestyle habits.

GOVERNMENT OF CANADA – HEALTH

www.canada.ca/en/services/health.html

Offers reliable, easy-to-understand health and safety information for Canadians.

GOUVERNEMENT DU QUÉBEC – HEALTH

www.quebec.ca/en/health/

Offers simple, practical and reliable information to help manage health problems and make better use of Quebec's health services.

MAYO CLINIC

www.mayoclinic.org/patient-care-and-health-information

The Patient Care and Health Information section of the Mayo Clinic offers the general public factual, practical and objective information on disease prevention and adopting healthy lifestyle habits. With the collaboration of 3,300 physicians, scientists and researchers, this site offers quality content.

MEDLINEPLUS

www.medlineplus.gov

MedlinePlus is an authoritative resource offering detailed information on many health issues and is produced by the National Library of Medicine (Maryland, United States).

HEALTH DATABASES

Open access databases

Here is a selection of resources to help you find relevant information. **The databases below are accessible at no charge and no subscription is required.**

PUBMED CENTRAL

www.ncbi.nlm.nih.gov/pmc

PubMed Central (PMC) is a digital repository of scientific health-related articles that were submitted to a peer review process (collective activity of researchers who critically assess the work of other researchers). Articles are freely accessible.

Databases with access restricted to subscribers

Would you like to refine your search for health information? Bibliothèque et Archives nationales du Québec (BAnQ) offers remote consultation of several health databases. We have selected those aimed at a large audience. Please note that certain resources are only in English. The interface language and the language of the content of the resource are indicated at the end of each description.

In order to access the BanQ databases, you must subscribe to remote services.

To subscribe: www.banq.qc.ca/formulaires/abonnement

To view the resources available in the BAnQ digital collection, log in first using your subscriber number and password for the library.

Guides and a selection of essential resources are available to help you find your way around on the platform: <http://numerique.banq.qc.ca/apropos/debuter.html>

E-CPS (COMPENDIUM DES PRODUITS ET SPÉCIALITÉS PHARMACEUTIQUES EN LIGNE) / COMPENDIUM OF PHARMACEUTICALS AND SPECIALTIES ON LINE

<http://numerique.banq.qc.ca/ressources/details/6020>

This database provides access to more than 2,000 monographs of drugs, vaccines and natural products available in Canada. It contains information such as indications, contraindications, warnings, adverse reactions, drug interactions and dosage. This resource also includes directories (poison control centres, health organizations, manufacturers), a product identification tool and glossaries. Bilingual resource.

MAGILL'S MEDICAL GUIDE

<http://numerique.banq.qc.ca/ressources/details/5809>

Magill's Medical Guide gives online access to articles that are easy to understand for the general public on various medical topics: diseases, disorders, treatments and preventive measures. Contains an alphabetical index on the subjects covered as well as capsules on recent developments in medical science. Interface and content in English.

READING SUGGESTIONS

YOUR LIBRARY DOESN'T
HAVE THE BOOK THAT YOU
ARE LOOKING FOR?

LEARN ABOUT THE
LOAN SERVICE BETWEEN LIBRARIES.

YOUR LIBRARY CAN THEN OBTAIN
THE DOCUMENT YOU WOULD LIKE
FROM ANOTHER LIBRARY.

Books available in different formats

Did you know that you can borrow books in different formats for free from your libraries?



LARGE PRINT BOOKS

Large print books are designed to optimize reading comfort for the visually impaired, the sick, people with eye strain and young dyslexics. You will find many of them in public libraries.



AUDIO AND DIGITAL AUDIO BOOKS

Audio and digital audio books are voice recordings of the text of a book made by a narrator. These books are read by recognized interpreters. They are recommended for both beginning readers and people with visual impairments.

Audio books are recorded on CD or MP3 CD and can be found on the shelves of libraries that offer them.


Digital audio books are available on the prenumerique.ca platform. They can be listened to on all devices using a recent version of a web browser and a reliable Internet connection. This does not require the installation of a reader application.



DIGITAL BOOKS

Digital books are available via the pretnumerique.ca platform.

On the pretnumerique.ca website of libraries participating in the Biblio-Santé program, you will find the **digital Biblio-Santé collection**. Each book suggested in the booklets that is available in digital format is identified by the following mention:

 Also available on pretnumerique.ca

These digital books are chronodegradable, that is to say that they deactivate automatically at the end of the loan period. Downloaded books can be read on different devices: e-readers, tablets, computers, smartphones, etc. The service is accessible anytime and anywhere, as long as you have access to an Internet connection.

[Pretnumerique.ca](http://pretnumerique.ca) also offers a dedicated free reading application, available in iOS (Apple) and Android format. This allows you to consult the digital catalog of your libraries as well as to borrow, reserve and easily read your digital books and your digital audiobooks from the same application.

Your reading device gives you access to features to promote its accessibility and facilitate your reading.

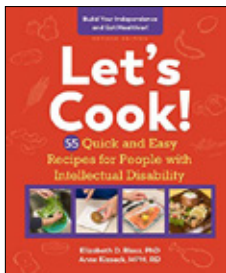
For help borrowing an eBook, visit the [Aide en ligne Prêt Numérique](#) page.

*The supply of books in different formats varies from one library to another.

Find out what your library has to offer!

NON-FICTION

General works

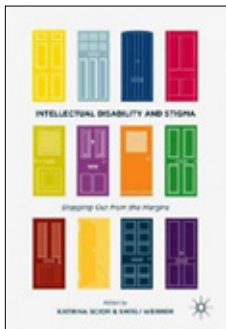


LET'S COOK: 55 QUICK AND EASY RECIPES FOR PEOPLE WITH INTELLECTUAL DISABILITY

Elizabeth Dunkman Riesz and Anne Kissack. New York: The Experiment, 2021, 135 p.

A cookbook designed to help people with intellectual disability prepare their own meals with success.

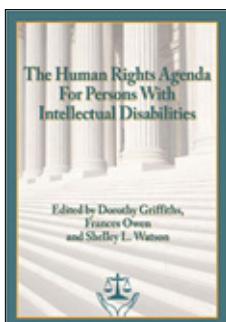
 Also available on pretnumerique.ca



INTELLECTUAL DISABILITY AND STIGMA: STEPPING OUT FROM THE MARGINS

Katrina Scior and Shirli Werner. London: Palgrave Macmillan, 2016, 230 p.

This book examines how intellectual disability is affected by stigma and how this stigma has developed. This book provides a framework for tackling intellectual disability stigma in institutional processes, media representations and other, less overt, settings. It also highlights the anti-stigma interventions which are already in place and the central role that self-advocacy must play.

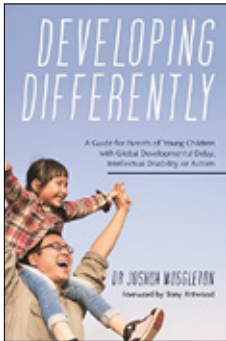


THE HUMAN RIGHTS AGENDA FOR PERSONS WITH INTELLECTUAL DISABILITIES

Dorothy M. Griffiths, Frances Ann Owen and Shelley L. Watson. Kingston: NADD Press, 2012, 244 p.

This book explores ways in which the spirit of the UN Convention on the Rights of Persons with Disabilities may be enacted in the lives of individuals who have intellectual and developmental disabilities in a Canadian context. A broad range of rights issues and research is examined related to health, education, the law, sexuality, parenting, and daily living, with the goal of exploring the history of concerns and barriers to rights enactment. Examples of rights promotion programs are described and strategy recommendations are provided for organizations and self-advocates committed to the promotion of the authentic enactment of human rights.

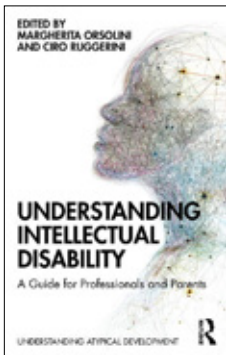
Accompaniment of a family member or friend



DEVELOPING DIFFERENTLY: A GUIDE FOR PARENTS OF YOUNG CHILDREN WITH GLOBAL DEVELOPMENTAL DELAY, INTELLECTUAL DISABILITY, OR AUTISM

Joshua Muggleton. London: Jessica Kingsley Publishers, 2022, 288 p.

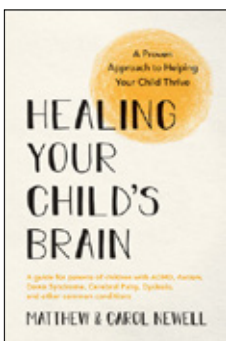
The book outlines how to provide the right environment for your child to learn and grow, how to model and encourage new skills, how to organise routines, and how to make these strategies work in family life. By getting things right for your child early on, you can help prevent emotional and behavioural challenges before they arise, and will be better able to understand and support your child when they do.



UNDERSTANDING INTELLECTUAL DISABILITY: A GUIDE FOR PROFESSIONALS AND PARENTS

Ciro Ruggerini and Antonina Pellegrino. Abingdon: Routledge, 2022, 224 p.

This book supports professionals and parents in understanding critical concepts, correct assessment procedures, delicate and science-infused communication practices and treatment methods concerning children with intellectual disabilities.



HEALING YOUR CHILD'S BRAIN: A PROVEN APPROACH TO HELPING YOUR CHILD THRIVE

Matthew and Carol Newell. Dallas, TX: BenBella Books, Inc., 2021, 278 p.

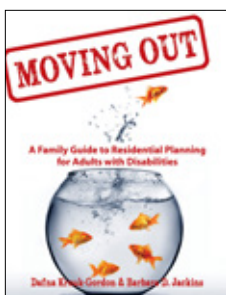
From the moment your child is diagnosed with a special needs condition, you are plunged into a world of doctors, specialists, and therapists. But the most important person on your child's care team is you. In *Healing Your Child's Brain*, child development experts Matthew and Carol Newell arm parents with the knowledge, confidence, and tools they need to help their special-needs child flourish. Most treatments focus on managing symptoms, but don't address underlying neurological issues. This book guides readers through the stages of brain development and how they affect functioning, showing what wellness looks like at each level and how to identify, and tackle, problems. In these pages, parents will learn: the seven key developmental areas that contribute to how well your child functions in daily life; how to evaluate your child's capabilities and challenges; how to create an environment tailored to your unique child, meeting them where they are, rather than where they are "supposed" to be.



GOING SOLO: WHILE RAISING CHILDREN WITH DISABILITIES

Laura E. Marshak. Bethesda: Woodbine House, 2015, 374 p.

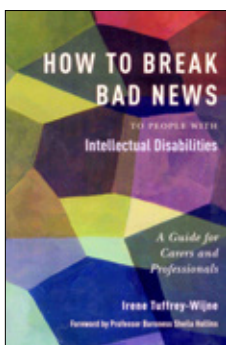
It's a fact that children with disabilities are more likely than other children to be living in single-parent homes. If you're raising a child with disabilities on your own – solo parenting – whether by choice or circumstance, you'll find a wealth of support, affirmation, and practical ideas in this guide to living well.



MOVING OUT: A FAMILY GUIDE TO RESIDENTIAL PLANNING FOR ADULTS WITH DISABILITIES

Dafna Krouk-Gordon and Barbara D. Jackins. Bethesda: Woodbine House, 2013, 225 p.

Finding the right residential situation for an adult child with an intellectual disability doesn't have to be overwhelming. Discover the universal consideration most families should face before putting plans in place. This guide helps you make educated decisions to secure the housing that's best for your child and family.

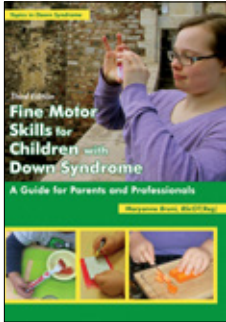


HOW TO BREAK BAD NEWS TO PEOPLE WITH INTELLECTUAL DISABILITIES: A GUIDE FOR CARERS AND PROFESSIONALS

Irene Tuffrey-Wijne. London: Jessica Kingsley Publishers, 2013, 189 p.

This book offers unique and adaptable guidelines that can be used by practitioners to ease the process of breaking bad news to people with intellectual disabilities. It provides tips and support that will help social workers, counsellors and caring professionals relay all types of bad news as sensitively and successfully as possible.

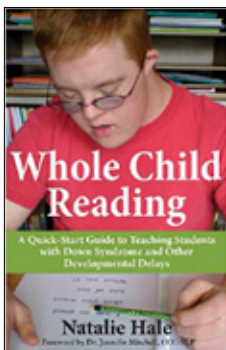
Disorders



FINE MOTOR SKILLS FOR CHILDREN WITH DOWN SYNDROME: A GUIDE FOR PARENTS AND PROFESSIONALS

Maryanne Bruni. Bethesda: Woodbine House, 2016, 310 p.

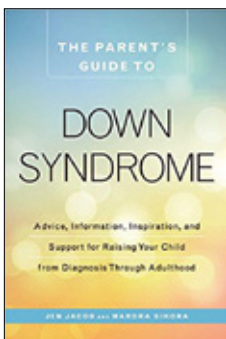
The author, an occupational therapist and parent of an adult with Down syndrome, describes how the characteristics of Down syndrome can impact the acquisition and progression of fine motor skills. She presents a thorough overview of the building blocks of fine motor development, from infancy through to adulthood. Throughout the book, the author suggests ways to incorporate fine motor skill development opportunities into as many day-to-day activities as possible, recognizing how impractical it is to constantly be in therapy mode with a child.



WHOLE CHILD READING: A QUICK-START GUIDE TO TEACHING STUDENTS WITH DOWN SYNDROME AND OTHER DEVELOPMENTAL DELAYS

Natalie Hale. Bethesda: Woodbine House, 2016, 186 p.

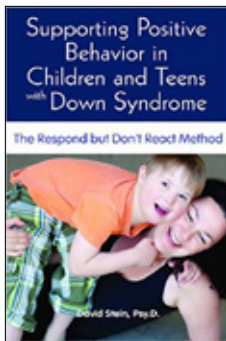
Discover the keys to teaching children and adults with Down syndrome and other developmental disabilities how to read for meaning. Written for today's busy parents and teachers, this easy-to-use guide explains how to “go in through the heart” to hook beginning and struggling readers with high-interest, individualized materials – flashcards, personal books, and modified trade books. The simple strategies described are designed to “teach to the brain” and are based on research about how we learn most easily and naturally.



THE PARENT'S GUIDE TO DOWN SYNDROME: ADVICE, INFORMATION, INSPIRATION, AND SUPPORT FOR RAISING YOUR CHILD FROM DIAGNOSIS THROUGH ADULTHOOD

Jen Jacob and Mardra Sikora. Avon: Adams Media, 2016, 255 p.

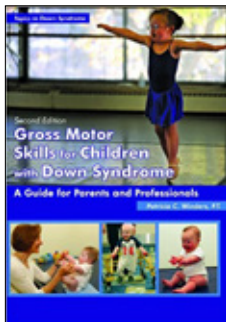
A guide for parents whose kid(s) have Down syndrome.



SUPPORTING POSITIVE BEHAVIOR IN CHILDREN AND TEENS WITH DOWN SYNDROME: THE RESPOND BUT DON'T REACT METHOD

David Stein. Bethesda: Woodbine House, 2016, 140 p.

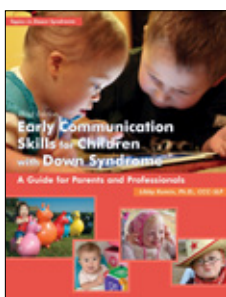
This book examines how the brain of a person with Down syndrome works, how those differences impact behavior, and why bad behavior should not be viewed as a willful act. Governed by this new awareness, parents are in a better position to change and manage their child's behavior using these guiding principles: Be proactive, not reactive; Be consistent; Use visual schedules & Social Stories to direct behavior; Develop a token reward chart; Keep gut reactions in check; Teach siblings to ignore bad behavior; Learn effective disciplinary techniques; and Know when professional help is needed.



GROSS MOTOR SKILLS FOR CHILDREN WITH DOWN SYNDROME: A GUIDE FOR PARENTS AND PROFESSIONALS

Patricia C. Winders. Bethesda: Woodbine House, 2014, 2nd ed., 522 p.

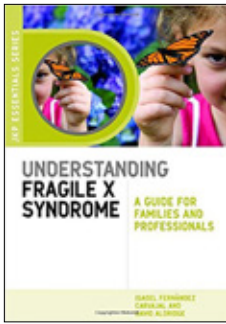
In parent-friendly language, the author explains the many physiological reasons that children with Down syndrome experience delays in their gross motor development and presents a physical therapy treatment plan for birth to age 6. Over 400 photos accompany step-by-step instructions to help readers assess a child's gross motor readiness and teach skills for head control, sitting, crawling, standing, walking, using stairs, running, kicking, jumping, and riding a tricycle.



EARLY COMMUNICATION SKILLS FOR CHILDREN WITH DOWN SYNDROME: A GUIDE FOR PARENTS AND PROFESSIONALS

Libby Kumin. Bethesda: Woodbine House, 2012, 391 p.

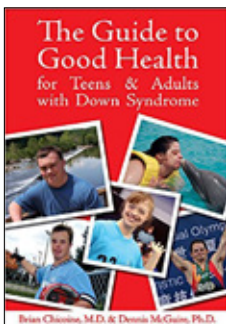
Parents and teachers learn how to work through characteristic challenges, including hearing loss, intelligibility issues, apraxia (difficulty planning oral-motor movements), or a slower pace of development.



UNDERSTANDING FRAGILE X SYNDROME: A GUIDE FOR FAMILIES AND PROFESSIONALS

Isabel Fernández Carvajal and David Aldridge. London: Jessica Kingsley, 2011, 109 p.

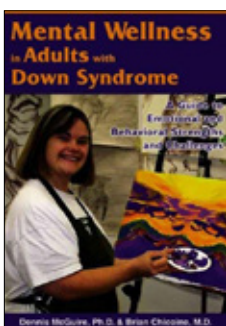
Fragile X syndrome is one of the main causes of child developmental delay and autism spectrum disorders. This book breaks down the complex science of this genetic disorder and provides the facts and advice that every bewildered parent or professional needs to support individuals with Fragile X syndrome. This is a straightforward introduction that clearly explains the condition on both a scientific and practical level. With sections on diagnosis, symptoms and treatment, as well as discussions of various emotional and behavioural considerations, this guide covers all aspects of Fragile X syndrome, its implications, and the possibilities open to families affected by it.



THE GUIDE TO GOOD HEALTH FOR TEENS & ADULTS WITH DOWN SYNDROME

Brian Chicoine and Dennis Eugene McGuire. Bethesda: Woodbine House, 2010, 391 p.

A practical guide to health care for adults and adolescents with Down syndrome, highlighting health problems that are more common to people with the syndrome, and looking at the unique ways in which health problems sometimes present themselves in people with Down syndrome.



MENTAL WELLNESS IN ADULTS WITH DOWN SYNDROME: A GUIDE TO EMOTIONAL AND BEHAVIORAL STRENGTHS AND CHALLENGES

Dennis McGuire and Brian Chicoine. Bethesda: Woodbine House, 2006, 431 p.

This book provides parents, mental health professionals, teachers, and caregivers the keys to understanding how to promote mental wellness and resolve psychosocial problems in people with Down syndrome. This book is written by the founding directors of the Adult Down Syndrome Center of Lutheran General Hospital in Park Ridge, Illinois. The authors draw on nearly 30 years of combined experience, treating more than 3000 adolescents and adults with Down syndrome aged 12 to 83. This book clarifies what the common behavioral characteristics of Down syndrome are, how some could be mistaken for mental illness, and what bona fide mental health problems occur more commonly in people with Down syndrome.

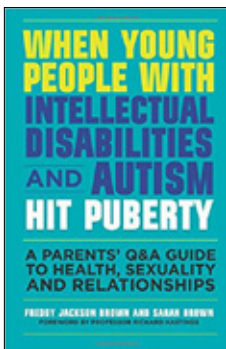
Love and sexuality



WHAT IS SEX?: A GUIDE FOR PEOPLE WITH AUTISM, SPECIAL EDUCATIONAL NEEDS AND DISABILITIES

Kate E. Reynolds and Jonathon Powell (ill.). London: Jessica Kingsley Publishers, 2022, 34 p.

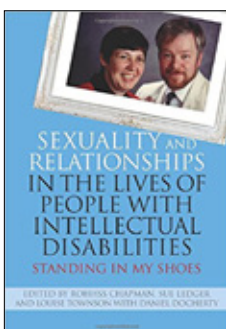
This book helps readers to understand the physical processes as well as important issues such as consent and sexual safety, helping them to develop positive relationships. It frankly explains sex so that the reader has a clear understanding of what constitutes sex, knowledge of the proper names for sexual organs and sexual activities, and is aware of the potential physical consequences of having sex.



WHEN YOUNG PEOPLE WITH INTELLECTUAL DISABILITIES AND AUTISM HIT PUBERTY: A PARENTS' Q&A GUIDE TO HEALTH, SEXUALITY AND RELATIONSHIPS

Freddy Jackson Brown and Sarah Brown. London: Jessica Kingsley Publishers, 2016, 192 p.

Written for parents and carers of young people with an intellectual disability or autism, this guide provides answers to the questions that you may have felt too uncomfortable to ask before. Supported by case studies, the authors offer professional guidance on supporting and responding to your child's emerging sexuality.



SEXUALITY AND RELATIONSHIPS IN THE LIVES OF PEOPLE WITH INTELLECTUAL DISABILITIES: STANDING IN MY SHOES

Rohhss Chapman. London: Jessica Kingsley, 2015, 320 p.

Wide-ranging, authoritative and grounded in the expertise of people with intellectual disabilities, this book offers an authentic account of the challenges those with intellectual disabilities face in their relationships and sex lives across the globe and explores what society needs to do to respect their rights. Offers both an international and a UK perspective.



BOYFRIENDS + GIRLFRIENDS: A GUIDE TO DATING FOR PEOPLE WITH DISABILITIES

Terri Couwenhoven. Bethesda: Woodbine House, 2015, 118 p.

The book covers the biggest questions and smallest concerns of every would-be dater, including: Who is an appropriate dating partner & who is not; How to read signals & judge whether the interest is mutual; How to ask someone out on a date; How to turn down a date; How to handle rejection; What sexual feelings are; How to work through problems in a relationship; and What to do when a relationship is not working.

LIFE STORIES, BIOGRAPHIES AND TESTIMONIALS



UNEXPECTED: PARENTING, PRENATAL TESTING, AND DOWN SYNDROME

Alison Piepmeier, with George Estreich and Rachel Adams. New York: New York University Press, 2021, 171 p.

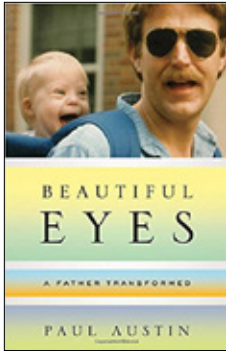
When Alison Piepmeier—scholar of feminism and disability studies, and mother of Maybelle, an eight-year-old girl with Down syndrome—died of cancer in 2016, she left behind an unfinished manuscript. In *Unexpected*, George Estreich and Rachel Adams pick up where she left off, honoring Piepmeier’s research, as well as adding new perspectives to her work. Based on interviews with parents of children with Down syndrome, as well as women who terminated their pregnancies because their fetus was identified as having the condition, *Unexpected* paints an intimate, nuanced picture of reproductive choice in today’s world. Piepmeier also takes us inside her own daughter’s life, showing how Down syndrome is often misunderstood, stigmatized, and condemned, particularly in the context of prenatal testing.



LIFE AS JAMIE KNOWS IT: AN EXCEPTIONAL CHILD GROWS UP

Michael Bérubé. Boston: Beacon Press, 2016, 224 p.

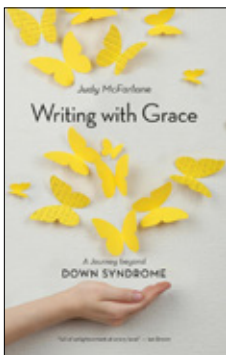
At four, Jamie is like many young people his age, but his Down syndrome leads most people to see him only in terms of his disability. Twenty years later, Jamie is no longer little, though he still loves the Beatles, pizza, and making lists. In this book, the author chronicles his son’s growth and his growing love of the world, writing as both a disability studies scholar and as a father. He follows Jamie through the transitions within his family and home life, through his school years, through the complicated process of entering the workforce with a disability. In a book that joins stirring memoir and sharp philosophical inquiry, Bérubé guides us through the labyrinth of ethical issues surrounding how we approach disability and uses Jamie’s story to argue for a deeper understanding of disability that challenges us to move toward a more just, more inclusive society.



BEAUTIFUL EYES: A FATHER TRANSFORMED

Paul Austin. New York: W.W. Norton & Company, 2014, 284 p.

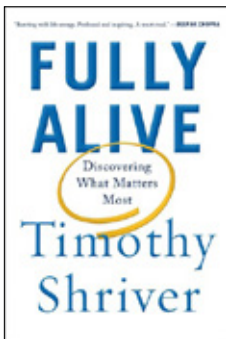
Tells the story of a father's journey toward acceptance of his daughter with Down syndrome, chronicling her coming of age while confronting his own limitations as a father.



WRITING WITH GRACE: A JOURNEY BEYOND DOWN SYNDROME

Judy McFarlane. Madeira Park: Douglas & McIntyre, 2014, 208 p.

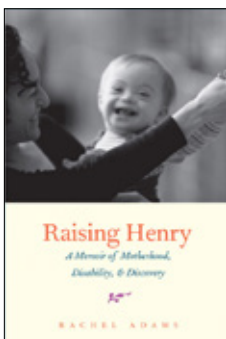
Writing with Grace is an inspiring story of the journey Grace and Judy have taken together. McFarlane relates the often dark history of Down syndrome and delves into what it takes to face one's own prejudice, what it means to live a full life and believe you are worthy. From a young woman who is marginalized by society, McFarlane learns how much courage it takes to follow a dream when everyone tells you it's impossible.



FULLY ALIVE: DISCOVERING WHAT MATTERS MOST

Timothy Shriver. New York: Sarah Crichton Books, 2014, 287 p.

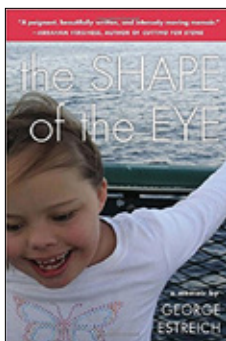
A memoir and history of the Special Olympics and a meditation on what one can learn about how to live from people with intellectual disabilities, by the chairman of the Special Olympics.



RAISING HENRY

Rachel Adams. New Haven: Yale University Press, 2013, 258 P.

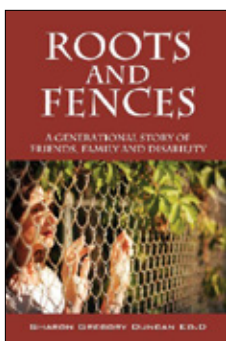
A mother chronicles the first three years in the life of her son, who has Down syndrome, and her own transformative experiences that stemmed from raising a disabled child in a world with conflicting attitudes toward disabilities.



THE SHAPE OF THE EYE

George Estreich. New York: Penguin, 2013, 314 p.

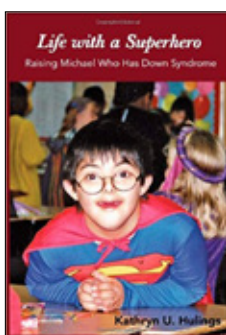
The author discusses the raising of his daughter, Laura Estreich, with Down syndrome.



ROOTS AND FENCES: A GENERATIONAL STORY OF FRIENDS, FAMILY AND DISABILITY

Sharon Gregory Duncan. Denver: Outskirts Press, 2013, 251 p.

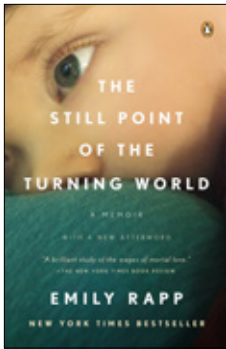
Meet Jackie, Chuck, Jonathon, and Jamee – four people intricately linked by the common thread of disability. *Roots and Fences* tells of their life experiences, as well as their friends and families, from a phenomenological perspective. It's a compelling collection that exposes the reality of life for those with intellectual disabilities and the people who love them. Through these connective stories spanning over 50 years, you will laugh, cry, share in the adventures, meet the families, and perhaps even change your views about those who are labeled "disabled".



LIFE WITH A SUPERHERO: RAISING MICHAEL WHO HAS DOWN SYNDROME

Kathryn U. Hulings. Denton: University of North Texas Press, 2013, 260 p.

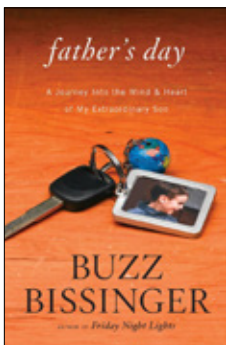
Over twenty years ago, in a small town, a desperate mother told a remarkable lie. She told her friends and family that her newborn child had died. That lie became the catalyst for the unfolding truth of the adoption of that same baby – Michael – who is, in fact, very much alive and now twenty-two years old. He also has Down syndrome. When Kathryn Hulings adopted Michael as an infant, she could not have known that he would save her life when she became gravely ill and was left forever physically compromised. Her story delights in how Michael's life and hers, while both marked by difference and challenge, are forever intertwined in celebration and laughter.



THE STILL POINT OF THE TURNING WORLD

Emily Rapp. London: Two Roads, 2013, 272 p.

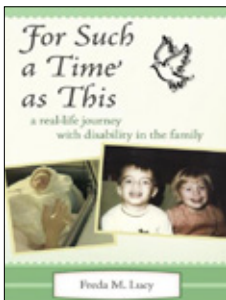
Like all mothers, Emily Rapp had ambitious plans for her first and only child, Ronan. He would be smart, loyal, physically fearless, and level-headed, but fun. He would be good at crossword puzzles like his father. He would be an avid skier like his mother. Rapp would speak to him in foreign languages and give him the best education. But all of these plans changed when Ronan was diagnosed at nine months old with Tay-Sachs disease, a rare and always-fatal degenerative disorder. Ronan was not expected to live beyond the age of three; he would be permanently stalled at a developmental level of six months. Rapp and her husband were forced to re-evaluate everything they thought they knew about parenting. They would have to learn to live with their child in the moment; to find happiness in the midst of sorrow; to parent without a future.



FATHER'S DAY: A JOURNEY INTO THE MIND AND HEART OF MY EXTRAORDINARY SON

Buzz Bissinger. Boston: Houghton Mifflin Harcourt, 2012, 242 p.

Buzz Bissinger's twins were born three minutes – and a world – apart. Gerry is a graduate student at Penn, preparing to become a teacher. His brother Zach has spent his life attending special schools. He'll never drive a car, or kiss a girl, or live by himself. He is a savant, challenged by serious intellectual deficits but also blessed with rare talents: an astonishing memory, a dazzling knack for navigation, and a reflexive honesty that can make him both socially awkward and surprisingly wise. Buzz realized that while he had always been an attentive father, he didn't really understand what it was like to be Zach. So one summer night Buzz and Zach hit the road to revisit all the places they have lived together during Zach's twenty-four years. Zach revels in his memories, and Buzz hopes this journey into their shared past will bring them closer and reveal to him the mysterious workings of his son's mind and heart.

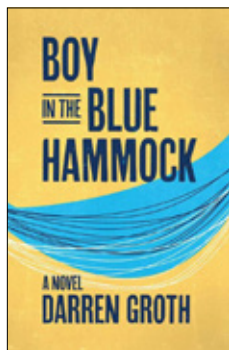


FOR SUCH A TIME AS THIS: A REAL LIFE JOURNEY WITH DISABILITY IN THE FAMILY

Freda M. Lucy. Bloomington: WestBow Press, 2012, 124 p.

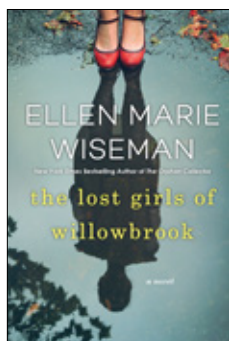
A realistic look at life with a Down syndrome child over a journey of four decades. Any parent, parent-to-be, educator, medical personnel, church affiliate, and individual in general can learn how to help parents of children with a disability, both physically and intellectually disabled.

NOVELS

**BOY IN THE BLUE HAMMOCK**

Darren Groth. Gibsons, British Columbia: Nightwood Editions, 2022, 207 p.

In a house on the fringes of the decimated hamlet, Tao – a failed service dog turned pet – wakes to find his leash tied to the stairs, his hind leg broken and his family killed. With the world he knows shattered, there is one course of action: lay with his slain masters and wait for the enemy – the “hounds” – to return and end his life. But it is not the hounds that find him – it is Kasper, fifteen years old, disabled, limited ability to speak, sole survivor of the family. With the discovery of Boy, Tao understands he now has a duty: guide the last living member of his pack through the ravaged streets of Gilder to safety.

**THE LOST GIRLS OF WILLOWBROOK**

Ellen Marie Wiseman. New York, NY: Kensington Publishing Corp., 2022, 369 p.

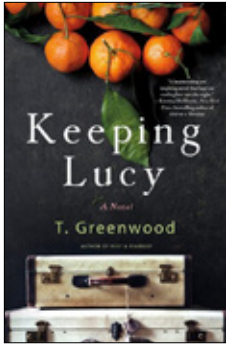
Sage Winters always knew her sister was a little different even though they were identical twins. They loved the same things and shared a deep understanding, but Rosemary – awake to every emotion, easily moved to joy or tears – seemed to need more protection from the world. Sage knows little about Willowbrook State School, where Rosemary was secretly committed several years earlier. It’s always been a place shrouded by rumor and mystery. A place local parents threaten to send misbehaving kids. With no idea what to expect, Sage secretly sets out for Willowbrook, determined to find Rosemary.

**SUMMER BROTHER**

Jaap Robben. New York: World Editions, 2021, 288 p.

Thirteen-year-old Brian lives in a trailer on a forgotten patch of land with his divorced and uncaring father. His older brother Lucien, physically and mentally disabled, has been institutionalized for years. While Lucien’s home is undergoing renovations, he is sent to live with his father and younger brother for the summer. Their detached father leaves Brian to care for Lucien’s special needs. But how do you look after someone when you don’t know what they need? How do you make the right choices when you still have so much to discover?

 Also available on pretnumerique.ca



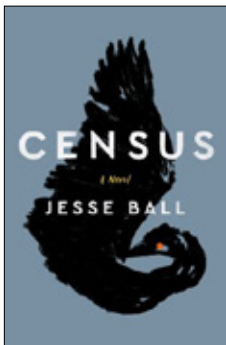
KEEPING LUCY

T. Greenwood. New York: St. Martin's Press, 2019, 301 p.

GINNY Richardson's heart was torn open when her baby girl, Lucy, born with Down Syndrome, was taken from her. Under pressure from his powerful family, her husband, Ab, sent Lucy away to Willowridge, a special school for the "feeble-minded." Ab tried to convince Ginny it was for the best. That they should grieve for their daughter as though she were dead. That they should try to move on. But two years later, when Ginny's best friend, Marsha, shows her a series of articles exposing Willowridge as a hell-on-earth – its squalid hallways filled with neglected children – she knows she can't leave her daughter there. With Ginny's six-year-old son in tow, Ginny and Marsha drive to the school to see Lucy for themselves. What they find sets their course on a heart-racing journey across state lines – turning Ginny into a fugitive. Racing from Massachusetts to the beaches of Atlantic City, through the Blue Ridge Mountains of Virginia to a roadside mermaid show in Florida, *Keeping Lucy* is a searing portrait of just how far a mother's love can take her.



Also available on pretnumerique.ca



CENSUS

Jesse Ball. New York: Ecco, an imprint of HarperCollinsPublishers, 2018, 241 p.

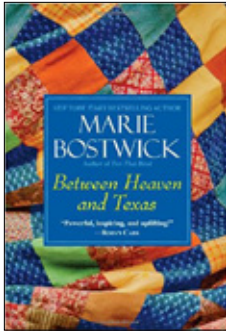
Learning that he does not have long to live and will need to figure out how to provide for his developmentally disabled adult son, a widower signs up as a census taker for a mysterious government bureau and leaves town with his son on a cross-country journey.



321 DOWN STREET

Keven Card. Sainte Augustine: Storehouse, 2015, 281 p.

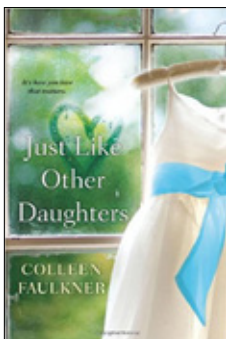
When Sara and Jacob find out they're pregnant with a baby boy, nothing could make them happier. However, their hopes are dashed when the doctor gives a recommendation for Sara to take an AFT. Five words change their destiny forever... "Your son has Trisomy 21." Their perfect love story unexpectedly spirals into panic, and their dream shatters with it. Their love, marriage and future suddenly start to fall apart; sending them both on very different journeys and into the life of a boy named Alex. Can a chance meeting with a boy prodigy change their destiny?



BETWEEN HEAVEN AND TEXAS

Marie Bostwick. New York: Kensington Books, 2013, 368 p.

Mary Dell Templeton is determined to one day turn her love of sewing into a business. Meanwhile, she'll settle for raising babies with her new husband, Donny. But that dream proves elusive too, until finally, Mary Dell gets the son she always wanted – a child as different as he is wonderful. And as Mary Dell is forced to reconsider what truly matters in her family and her marriage, she begins to piece together a life that, like the colorful quilts she creates, will prove vibrant, rich, and absolutely unforgettable.



JUST LIKE OTHER DAUGHTERS

Colleen Faulkner. New York: Kensington Books, 2013, 274 p.

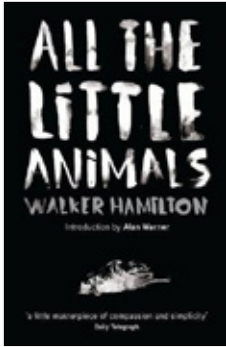
When her adult daughter with Down syndrome, Chloe, begins to have a relationship with Thomas, another mentally challenged person, Alicia Richards prepares herself to help Chloe through the moments of heartbreak and joy that this new stage in her life will bring.



THE UNFINISHED CHILD

Theresa Shea. Victoria: Brindle & Glass, 2013, 304 p.

When Marie MacPherson, a mother of two, finds herself unexpectedly pregnant at 39, she feels guilty. Her best friend, Elizabeth, has never been able to conceive, despite years of fertility treatments. Marie's dilemma is further complicated when she becomes convinced something is wrong with her baby. She then enters the world of genetic testing and is entirely unprepared for the decision that lies ahead. Intertwined throughout the novel is the story of Margaret, who gave birth to a daughter with Down syndrome in 1947, when such infants were defined as “unfinished” children. As the novel shifts back and forth through the decades, the lives of the three women converge, and the story speeds to an unexpected conclusion.

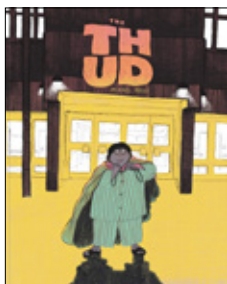


ALL THE LITTLE ANIMALS.

Walker Hamilton. Glasgow: Freight, 2012, 117 p.

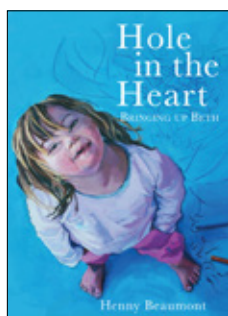
Bobby is a 31-year-old man with the mind of a small, frightened boy. He has run away from his privileged but abusive London home to rural Cornwall. Through an accident of fate he meets Mr. Summers, a man with a terrible secret who, in atonement, has dedicated his life to burying all the little animals. Together they embark on a bizarre mission, and a savage act of revenge.

COMICS

**THE THUD**

Mikaël Ross. Seattle, WA: Phantagraphics Books, 2021, 123 p.

There's a village in Germany called Neuerkerode that is entirely operated by people with mental disabilities – the local restaurant, the local bar, the local supermarket. The author spent two years living there 3 to 4 days a week, researching and getting to know its townsfolk. The result is this empathetic depiction. *The Thud* is told entirely from a developmentally impaired boy's perspective. Noël lives with his mother in Berlin, until one day tragedy strikes and he finds himself alone for the first time. A man with a beard tells him he can't stay in his apartment anymore and takes him to a place with so many strangers – Who can he trust? Who does he like? And who loves him?

**HOLE IN THE HEART: BRINGING UP BETH**

Henny Beaumont. University Park: Pennsylvania State University Press, 2016, 238 p.

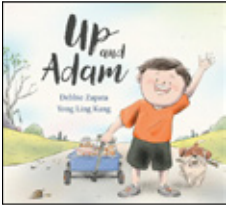
A memoir, in graphic novel format, of the author's emotions and the challenges and decisions she faces in raising a child with Down syndrome.

**DOWNTOWN**

Noël Lang and Rodrigo García. Philadelphia: KettleDrummer books, 2012, 136 p.

Blo has a girlfriend, a colorful imagination, a certain favorite record by Petula Clark that he carries with him everywhere, and a unique perspective on life. Blo also has Down syndrome, but he doesn't let a little chromosome keep him from living large. This charming story of Blo and his extraordinary group of friends welcomes readers into the distinctly special outlooks and anecdotes of special needs individuals. Based on the author's uncle with Down syndrome, the delightful illustrations and story offer an entertaining read as well as an educational resource – providing insight into a sometimes misunderstood social group and contributing to the normalization of individuals troubled with the negative connotations of “disability” surrounding them.

YOUTH LITERATURE



AGES 3 TO 7

UP AND ADAM

Debbie Zapata and Yong Ling Kang (ill.). Toronto, ON: Kids Can Press, 2022, 32 p.

It's the morning after the big storm. Adam and his dog, Up, are finishing breakfast when Adam sees the mayor on TV asking everyone to pitch in with the cleanup. She says, "Now, it's time to get to work. Up and at 'em!" When Adam hears the mayor tell him and Up to get to work, he's on it! "We can help!" he says. All day, the pair do what they can – clearing the sidewalk, fixing a birdhouse, passing out cookies. But it turns out, Adam's most important contribution to his community is one he doesn't even think about – his smile. Because when anyone sees Adam smile, they smile, too. And as Adam says, "A pair of smiles can make a difference."



AGES 3 TO 7

DIFFERENT – A GREAT THING TO BE!

Heather Avis and Sarah Mensinga (ill.). Colorado Springs: WaterBrook, 2021, 40 p.

Macy is a girl who's a lot like you and me, but she's also quite different, which is a great thing to be. With kindness, grace, and bravery, Macy finds her place in the world, bringing beauty and laughter wherever she goes and leading others to find delight in the unique design of every person.



Also available on pretnumerique.ca



AGES 4 TO 8

GOOD MORNING, SUNSHINE!: THE JOEY MOSS STORY

Lorna Schultz Nicholson and Alice Carter (ill.). Ann Arbor, MI: Sleeping Bear Press, 2022, 40 p.

The biography of Canadian Joey Moss, a man born with Down syndrome who worked with the NHL Edmonton Oilers hockey team, and was an inspiration for neurodiverse people and an advocate for inclusivity.



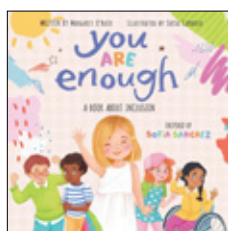
AGES 4 TO 8

OUT INTO THE BIG WIDE LAKE

Paul Harbridge and Josée Bisailon (ill.). Toronto: Tundra Books, 2021, 48 p.

A picture book about Kate, a girl with Down syndrome who spends the summer at her grandparents' lakeside home and learns to become more self-reliant.

 Also available on prenumerique.ca

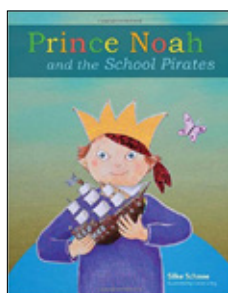


AGES 4 TO 8

YOU ARE ENOUGH: A BOOK ABOUT INCLUSION

Margaret O'Hair and Sofia Cardoso (ill.). New York: Scholastic Inc., 2021, 40 p.

This inclusive and empowering picture book inspired by Sofia Sanchez – an 11-year-old model and actress with Down syndrome – reminds readers how important it is to embrace your differences, be confident, and be proud of who you are. Imagine all of the wonderful things you can do if you don't let anyone stop you! You are enough just how you are. Sofia is unique, but her message is universal: We all belong.



AGES 4 TO 9

PRINCE NOAH AND THE SCHOOL PIRATES

Silk Schnee and Heike Sistig (ill.). Walden: Plough Publishing House, 2016, 32 p.

Prince Noah, who has Down syndrome, lives in a kingdom where children go to school on great sailing ships segregated by gender and mental and physical abilities, but when the students are kidnapped by pirates, they must work together to escape.

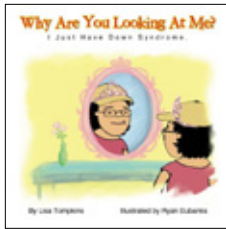


AGES 5 TO 10

JANINE

Maryann Cocca-Leffler. Chicago: Albert Whitman & Company, 2015, 60 p.

Janine is one of a kind. She focuses on the positive while navigating life with disabilities. She makes a difference just by being herself.



AGES 5 TO 10

WHY ARE YOU LOOKING AT ME?: I JUST HAVE DOWN SYNDROME

Lisa Tompkins. Bloomington: Authorhouse, 2013, 29 p.

This story is about the life of a child with Down syndrome that wants to be your friend. Lynn may look different than most children, but has many of the same likes and dislikes. Help your child discover what it means to accept and embrace a relationship with people who are different.

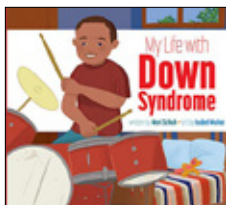


AGES 5 TO 10

PLEASE DON'T CALL ME SPECIAL NEEDS

Lois Sharon. Baltimore: Publish America, 2012, 26 p.

I don't want to be called special needs because I don't look at myself as special needs. I'm a talented, smart fashion diva. I'm a lot of things that make me special, but not special needs. I have dreams just like every other nine year-old. I don't like the word handicap, disabled, and retarded. All of these words are words I just ignore. When you read about me, you will see how special I am.

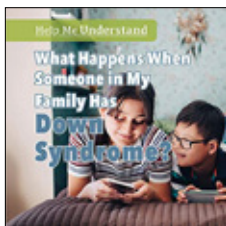


AGES 6 TO 9

MY LIFE WITH DOWN SYNDROME

Mari C. Schuh and Isabel Muñoz (ill.). Manako, MN: Amicus, 2021, 24 p.

Meet Peter! He loves the drums and gym. He also has Down Syndrome. Peter is real and so are his experiences. Learn about his life in this illustrated narrative nonfiction picture book for elementary students.

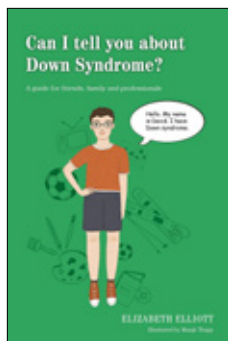


AGES 7 TO 10

WHAT HAPPENS WHEN SOMEONE IN MY FAMILY HAS DOWN SYNDROME

Jill Keppeler. New York: PowerKids Press, 2020 24 p.

This title will help children who have questions about Down syndrome. What is it and how is their family member different? How can young readers respond to questions from their own friends about their family member? The age-appropriate text and full-color photographs presented in this sensitively written book will help children tackle questions and situations that might arise.

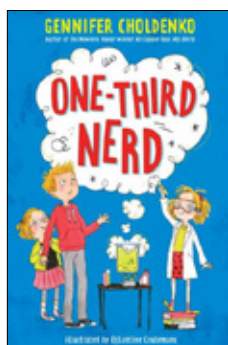


AGES 7+

CAN I TELL YOU ABOUT DOWN SYNDROME?: A GUIDE FOR FRIENDS, FAMILY, AND PROFESSIONALS

Elizabeth Elliot and Majit Thapp (ill.). London: Jessica Kingsley, 2016, 46 p.

David invites readers aged 7+ to learn about Down syndrome from his perspective, helping them to understand what Down syndrome is and how it affects his daily life. He tells us why he sometimes needs extra help at home and at school, and describes the ways that those around him can help him to feel supported.



AGES 8 TO 12

ONE-THIRD NERD

Gennifer Choldenko and Eglantine Ceulemans (ill.). New York: Wendy Lamb Books, 2019, 211 p.

Ten-year-old Liam and his two younger sisters, precocious third-grader Dakota and second-grader Izzy, who has Down syndrome, face the possibility of losing their beloved dog, Cupcake, who keeps urinating on their apartment's carpet.



AGES 8 TO 12

JUST UNDER THE CLOUDS

Melissa Sarno. New York: Alfred A. Knopf, 2018, 229 p.

Since her father's death, Cora, twelve, longs for a permanent home for herself, her special-needs sister, and their mother while navigating middle school and studying trees using her father's field notes.



AGES 8+

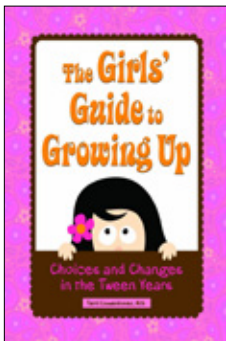
SUNNYSIDE PLAZA

Scott Simon. New York: Little, Brown and Company, 2020, 197 p.

Sally Miyake can't read, but she learns lots of things. Like bricks are made of clay and Vitamin D comes from the sun. Sally is happy working in the kitchen at Sunnyside Plaza, the community center she lives in with other adults with developmental disabilities. For Sally and her friends, Sunnyside is the only home they've ever known. Everything changes the day a resident unexpectedly dies. After a series of tragic events, detectives Esther Rivas and Lon Bridges begin asking questions. Are the incidents accidents? Or is something more disturbing happening?



Also available on pretnumerique.ca

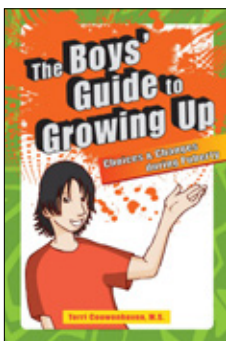


AGES 9 TO 13

THE GIRLS' GUIDE TO GROWING UP: CHOICES & CHANGES IN THE TWEEN YEARS

Terri Couwenhoven. Bethesda: Woodbine House, 2012, 62 p.

Presents a guide for girls with intellectual disabilities as an introduction to the physical and emotional changes they will encounter during puberty.

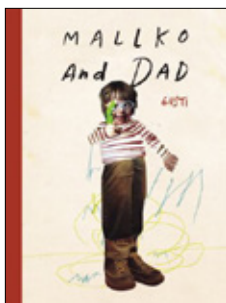


AGES 9 TO 16

THE BOYS' GUIDE TO GROWING UP: CHOICES & CHANGES DURING PUBERTY

Terri Couwenhoven. Bethesda: Woodbine House, 2012, 64 p.

This book gives practical advice on commonplace concerns such as shaving, what to do about zits, and how to smell nice. More complex and essential topics are covered too, such as how to know when flirting is reciprocated (or not!), how to hide or discourage an erection in public, what information is okay to share with others versus what should remain private, and how to stay safe. It's a must-have book for boys on the brink of puberty, teens who are in the midst of it, and the adults who care for them.

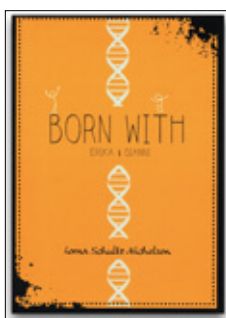


AGES 10 TO 13

MALLKO AND DAD

Gusti. New York: Enchanted Lion Books, 2018, 120 p.

A father, Gusti, expounds upon life with his son Mallko, who has Down syndrome.

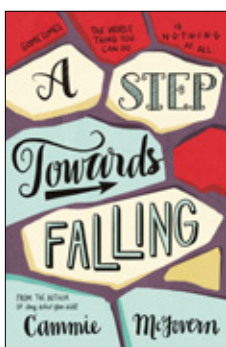


AGES 12+

BORN WITH: ERIKA AND GIANNI

Lorna Schultz Nicholson. Richmond Hill: Clockwise Press, 2016, 232 p.

Meet Erika and Gianni. One is a fifteen-year-old girl who loves to dance and sing and have fun with her friends. She tells people that she was born with an extra gene, but her sister has to buy hers at the mall (ha, ha!!). Being in three dance numbers in the school production of *Grease* is a big job, but with the help of her Best Buddy, Gianni, Erika knows she can be a star. The other is a Grade 11 boy with a secret. Like his Best Buddy, Erika, who was born with Down Syndrome, Gianni loves to sing and dance. He also knows that he was born different from the other boys in his school – but is he that different from Bilal, the cool, handsome fellow actor in the school play? Or is he just imagining that the sparks between them are mutual? And will the rough gang of guys at school also pick up on who he really is?

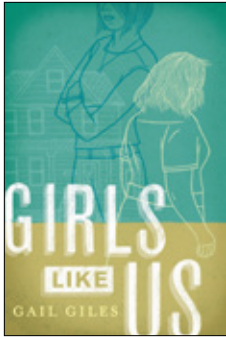


AGES 14 TO 18

A STEP TOWARD FALLING

Cammie McGovern. New York: HarperTeen, 2015, 364 p.

After failing to come to Belinda's aid while she was being attacked, Emily and another classmate are punished by being forced to work at a community center for people with disabilities, but they are put to the ultimate test when Belinda finally returns to school and they must find a way to make amends to her.

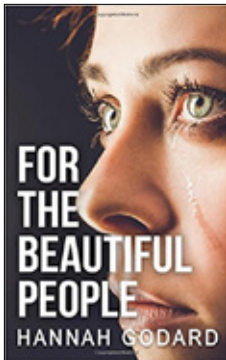


AGES 14 TO 18

GIRLS LIKE US

Gail Giles. Somerville: Candlewick Press, 2014, 210 p.

Graduating from their school's special-education program, Quincy and Bidy are placed together in their first independent apartment and discover unexpected things they have in common in the face of past challenges and a harrowing trauma.

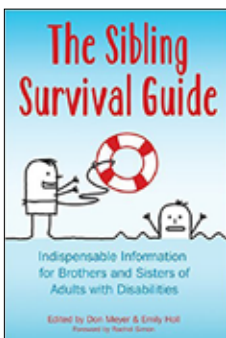


AGES 14+

FOR THE BEAUTIFUL PEOPLE

Hannah Godard. Canada: Lulu, 2014, 213 P.

Adeline Jamieson has been bullied by her used-to-be best friend ever since grade seven. Payton takes every chance she can to make Adeline feel worthless. When her life seems like it's in a downhill spiral, Adeline befriends a captivating girl with Down's Syndrome. Karlee shows her that life does go on and that you can't give up on that small glimmer of hope. Like a runner, you have the smallest bit of energy left, just waiting until the end so you can blast ahead. But when things start to go downhill again, will Karlee teach Adeline to forgive and push ahead, or will she crumble under the weight of her world?

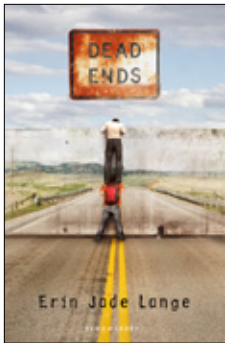


AGES 14+

THE SIBLING SURVIVAL GUIDE: INDISPENSABLE INFORMATION FOR BROTHERS AND SISTERS OF ADULTS WITH DISABILITIES

Don Meyer and Emily Holl. Bethesda: Woodbine House, 2014, 210 p.

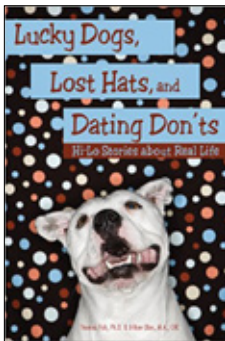
If you're a teenager or adult brother or sister of someone with a disability, then this book is expressly for you. It offers a sense that you're not alone, tips on how to talk to your parents about plans for your sibling, and a crash course in guardianship, medical & legal issues, and government benefits if you're already caring for your sib.

**AGES 14+**

DEAD ENDS

Erin Jade Lange. New York: Bloomsbury, 2013, 328 p.

When Dane, a bully, refuses to hit Billy D because he has Down Syndrome, Billy takes that as a sign of friendship and enlists Dane's help in solving riddles left in an atlas by his missing father, sending the pair on a risky adventure.

**AGES 14+**

LUCKY DOGS, LOST HATS, AND DATING DON'TS: HI-LO STORIES ABOUT REAL LIFE

Thomas Fish and Jillian Ober. New York: Scribner, 2012, 962 p.

Middle schoolers through adults will identify with the book's true-to-life stories and their characters (some with developmental disabilities, some without), who want to live as independently as they can. And just like real life, there are episodes of hilarity, poignancy, messiness, responsibility, longing, fulfillment, and adventure. From roommate troubles to wanting a pet, and from seeking a girlfriend to going camping with friends, these appealing short stories engage readers and impart subtle life lessons.

FILM, SERIES AND PROGRAM SUGGESTIONS

DID YOU KNOW?

LIBRARIES HAVE RICH COLLECTIONS OF DVDS AND BLU-RAYS THAT CAN BE BORROWED. THEY ALSO OFFER ONLINE ACCESS TO MOVIES, SERIES AND PROGRAMS. CHECK WITH YOUR LOCAL LIBRARY.

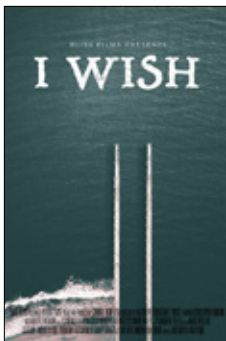
FICTION



THE PEANUT BUTTER FALCON

Tyler Nilson and Michael Schwartz. 2019, 97 min.

The Peanut Butter Falcon is an adventure story set in the world of a modern Mark Twain that begins when Zak (22), a young man with Down syndrome, runs away from the nursing home where he lives to chase his dream of becoming a professional wrestler by attending the wrestling school The Salt Water Redneck.



I WISH

Kathryn Ferentchak. 2019, 11 min.

Adapted from the 1973 short story by award-winning novelist Bill Pronzini, *I Wish* is a tale about David, an inquisitive teenager with Down syndrome, who escapes from his mother's watchful eye for a few hours to explore a lonely stretch of Lake Ontario shoreline. Eager for the freedom to pursue his own fantastical adventures, David has no way to suspect the adventure of a lifetime is about to change him forever.



WHERE HOPE GROWS

Chris Dowling. 2015, 95 min.

Drama (United States). A baseball player whose professional career was cut short due to his personal problems is suddenly awakened and invigorated by a young man with Down syndrome who works at the local grocery store.



G UNSUITABLE
FOR YOUNG
CHILDREN

GABRIELLE

Louise Archambault. 2013, 104 min.

Drama (Quebec). The musically gifted but developmentally challenged Gabrielle lives in a group home with four other adults who have similar disabilities. Like all young women, Gabrielle wants her independence, but, of course her situation is exceptional. When she falls in love with a similarly challenged young man in her choir, she discovers that both the families and the social workers are alarmed; can these two handle an adult relationship?



G

JIMMY

Mark Freiburger. 2013, 97 min.

Drama (United States). Jimmy's world is a place where a boy can grow to be a man, even if he is "special". Where angels hover, mostly unseen. Where danger can happen, and hearts can falter – but love is never wasted. Jimmy knows he's different from the other teenagers in Piney Grove, Georgia.

JOHN AND MICHAEL

Shira Avni. 2004, 10 min.

Online: www.nfb.ca/film/john_and_michael/

This animated short pays tribute to two men with Down syndrome who shared an intimate and profoundly loving relationship that deeply affected the filmmaker. Narrator Brian Davis brings the characters to life with great sensitivity.





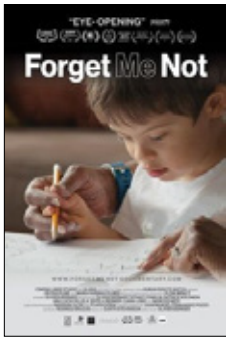
THE EIGHTH DAY

Jaco Van Dormael. 1996, 118 min. (Original title: Le huitième jour)

Comedy (France, Belgium). Harry is a successful executive who is failing miserably at life. Then he meets Georges, an irrepressible man with Down syndrome who helps Harry remember how it feels to be alive.

DOCUMENTARIES

General

**FORGET ME NOT: INCLUSION IN THE CLASSROOM**

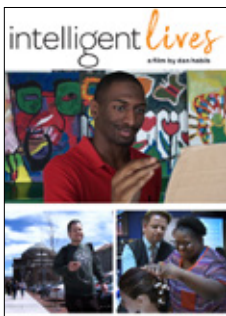
Olivier Bernier. 2022, 100 min.

Documentary (United States). As 3-year-old Emilio prepares to start school, his family finds itself embroiled in a challenge all too common for children with disabilities – to secure the right to an inclusive education. Cornered in one of the most segregated education systems, New York City public schools, filmmaker Olivier and his wife Hilda turn the camera on themselves and their child with Down syndrome, as they navigate a byzantine system originally designed to silo children with disabilities.

**A PONY AND HIS BOY: THE STORY OF BERRY & JOSH**

Julianne Neal. 2018, 26 min.

A Pony and His Boy: The Story of Berry and Josh shows the power of a pony and the effect that he has had on Josh, an 8-year-old with Down Syndrome. Josh had always been afraid of horses until he met a 28-year-old pony named Berry.

**INTELLIGENT LIVES**

Dan Habib. 2018, 100 min.

From award-winning filmmaker Dan Habib comes *Intelligent Lives*, a catalyst to transform the intellectual disability label from a life sentence of isolation to a life of possibility for the most systematically segregated people in America.



PETRA'S POEM

Shira Avni, National Film Board of Canada. 2012, 4 min.

Online: www.nfb.ca/film/petras_poem/

Documentary (Canada). In this short film, Toronto artist Petra Tolley, who has Down syndrome, performs a soliloquy that encapsulates her distinctive take on the social self. Drawing from her emotional experiences, she illustrates what it feels like to be “in the middle.” Employing rotoscoping, hand-drawn animation techniques and subtle stereoscopic 3D, the film captures Petra as she engages the camera with unflinching directness and dignity.



INSEPARABLE

Daniel Léger, National Film Board of Canada. 2011, 52 min.

Online: www.nfb.ca/film/inseparable/

Documentary (Canada). In their small country home in New Brunswick, Jean-Paul and Anne, who suffer respectively from physical and intellectual impairments, share an unwavering love for each other. Declarations of love, little gifts, jokes and affectionate nicknames highlight their deeply moving relationship, a relationship that transcends difference. Together, they look after Jean-Paul's ailing parents. With great respect for those who confide in him, Daniel Léger presents love through the eyes of two people with disabilities, and in so doing, creates an inspiring lesson in happiness.



TYING YOUR OWN SHOES

Shira Avni, National Film Board of Canada. 2009, 16 min.

Online: www.nfb.ca/film/tying_your_own_shoes/

Documentary (Canada). This short animated documentary offers an intimate glimpse into the exceptional mindsets and emotional lives of four adult artists with Down Syndrome. An artful, four-way essay about ability, film explores how it feels to be a little bit unusual.



THEY HAD THIRTEEN CHILDREN...

Anika Lirette. 2008, 26 min.

Online: www.nfb.ca/film/they_had_thirteen_children/

Documentary (Canada). In this short documentary, filmmaker Anika Lirette retraces the unusual life of her Acadian grandparents, who had 13 children. Of the 13, eight had intellectual and physical disabilities – all caused by phenylketonuria, a genetic disorder now known to be easily managed through diet. Through first-person accounts and archival photography, the film traces the history of her family as it struggled with the consequences of the disorder, at a time when the Catholic Church condemned birth control and medical services were virtually non-existent. In French with English subtitles.



INTELLECTUAL DISABILITIES

Moving On (CBC). 2006, 23 min.

This episode from CBC's acclaimed *Moving On* series deals with people with intellectual disabilities. It discusses past treatment, current standards and the difficulties those with intellectual disabilities face as they age. The program features Louise, who lived for decades in the Dixville home for people with intellectual disabilities. After leaving at the age of 51, she visits schools to share her experience at Dixville with kids like Ethan, a six-year-old with Down Syndrome.

TAKING PART IN ONE'S HEALTH CARE

This section can be found in every Biblio-Santé thematic booklet. The resources have been selected with a patient-as-partner approach that aims to help the health system users to actively participate in their health care and to make informed decisions.

WHAT DOES PATIENT-AS-PARTNER MEAN?

A patient-as-partner is a person who progressively becomes able as they receive treatment to make informed and independent health choices. Their experience related knowledge is recognized and their care related competences are developed with help from the team. Respected in all aspects of their humanity, they are a full member of this team when it comes to the care and services offered to them. While fully recognizing the expertise of the team members, the patient-as-partner can direct the team's concern towards their particular needs and long term well being.

Source: Faculté de médecine de l'Université de Montréal

ORGANIZATIONS AND ASSOCIATIONS

General

CENTRE OF EXCELLENCE FOR PARTNERSHIP WITH PATIENTS AND THE PUBLIC (CEPPP)

Phone 514 890-8000, ext. 15488
Website <https://ceppp.ca/en/>

The CEPPP aims to make collaborating with patients and the public a science, a culture and the new standard to improve the health of all and the (health) experience of each. Its purpose is to integrate the patient into their care team and the citizen into their healthcare system.

HEALTHCARE EXCELLENCE CANADA

Toll free 1-866-421-6933
Website <https://www.healthcareexcellence.ca/en/>

Healthcare Excellence Canada is an organization with a relentless focus on improving healthcare, with – and for – everyone in Canada. It brings together the Canadian Patient Safety Institute and Canadian Foundation for Healthcare Improvement. Several of its programs are aimed directly at patients and their families in order to improve their safety and the quality of health services.

Legal information

CHAMBRE DES NOTAIRES DU QUÉBEC

Phone 514 879-1793
Toll free 1 800 263-1793
Website www.cnq.org/en/home.html

The Chambre des notaires offers basic legal information, including information about powers of attorney, mandates in case of incapacity, wills and successions.

COMMUNITY JUSTICE CENTERS

Website www.justicedeproximite.qc.ca/en/

The Community Justice Centers provide services in six regions in Quebec. They inform you about your legal rights and obligations. They support you by helping you in the identification of your legal needs and the options available to address them. They also refer you to the legal resources available related to the legal system or the community, so you can choose the service that best suits your needs.

CONSEIL POUR LA PROTECTION DES MALADES

Phone 514 861-5922
Toll free 1 877 276-2433
Website <http://cpm.qc.ca/en/home/>

You can contact this organization free of charge to get information about the rights of sick people or to report an abuse or a situation which affects the rights of health and social service network users. Every call will be kept strictly confidential.

CURATEUR PUBLIC DU QUÉBEC

Phone 514 873-4074
Toll free 1 844 532-8728
Website quebec.ca/en/government/departments-and-agencies/curateur-public

The Curateur public ensures the protection of incapacitated persons. It educates the public about the protection needs associated with incapacity and supports families and close friends who are representing incapacitated persons, administering the property of an incapacitated person or a minor, or serving as members of a tutorship council. The site provides information about incapacity (protection mandate, tutorship, curatorship, etc.).

FÉDÉRATION DES CENTRES D'ASSISTANCE ET D'ACCOMPAGNEMENT AUX PLAINTES

Toll free 1 877 767-2227
Website <https://fcaap.ca/en/>

Complaint assistance and support centers assist the user in any process to file a complaint with an establishment, a CISSS, a CIUSSS or the Protecteur des usagers. They accompany the user for the duration of the appeal, including when the complaint is referred to the Council of Physicians, Dentists and Pharmacists of an establishment. You can find on the FCAAP website the list of assistance centers as well as information on your rights.

JURISTES À DOMICILE

Phone 514 944-9929
Website www.juristesadomicile.com

Juristes à Domicile guides and supports its members who find themselves in a difficult situation, or who are vulnerable, when it comes to ensuring that their rights are respected. The organization can also facilitate access to low cost legal services, if needed. As the name of the organization suggests, the team's lawyers come to their homes. Website only in French.

PROTECTEUR DU CITOYEN

Toll free 1 800 463-5070
Website <https://protecteurducitoyen.qc.ca/en>

The Protecteur du citoyen conducts investigations into complaints or reports involving individuals, groups, organizations or undertakings who claim that they were treated unfairly or improperly by a Quebec Government department or public agency, or by Health and Social Services network authorities. The Quebec Ombudsman is independent of the government, neutral and unbiased. All complaints are treated as confidential. The services are free and easily accessible.

REGROUPEMENT PROVINCIAL DES COMITÉS DES USAGERS (RPCU)

Phone 514 436-3744
Website www.rpcu.qc.ca/en/

The Regroupement provincial des comités des usagers defends and protects the rights of all users of the Health and Social Services network. Visit the website of the Regroupement for more information on the rights and recourse of the loved one you support.

INTERNET RESOURCES

General

CANADIAN MEDICAL ASSOCIATION – PATIENT VOICE

<https://www.cma.ca/patient-voice>

Patient Voice is a group of patients who lend their perspectives and experience to the Canadian Medical Association's (CMA) advocacy work. The 15-member group offers ideas on how to make Canadians healthier and contribute to the medical profession, highlighting issues that matter to the public and giving insight into the best ways for the CMA and physicians to engage with patients. Their web page features information about the group's current members, contact information for obtaining more information or getting involved, as well as a definition of Patient Partnered Care.

CHOOSING WISELY CANADA

<https://choosingwiselycanada.org/>

Choosing Wisely Canada is the national voice for reducing unnecessary tests and treatments in health care. The website provides information related to treatments and medication. It offers recommendations and resources by specialty for health professionals and patients. Patient Pamphlets are also available under the "Patient Resources" tab.

COLLÈGE DES MÉDECINS DU QUÉBEC

<http://www.cmq.org/hub/en/services-au-public.aspx>

The "Services for the public" section of the Collège des médecins du Québec provides information on various aspects of consultations with a doctor (access to a doctor, medical fees, complaints, etc.) and on the role of other health professionals.

GOVERNMENT OF CANADA

How older adults can use social media safely

<https://www.getcybersafe.gc.ca/en/blogs/how-older-adults-can-use-social-media-safely>

This blog post gives tips on how to navigate social media safely.

GOVERNEMENT DU QUÉBEC

Info-Santé 811

<https://www.quebec.ca/en/health/finding-a-resource/info-sante-811/>

Info-Santé 8-1-1 is a free and confidential telephone consultation service. Dialling 8-1-1 promptly puts you in contact with a nurse in case of a non-urgent health issue. The service is available 24 hours a day, 365 days a year. Anyone living in Quebec can call Info-Santé 8-1-1 for themselves or a family member.

Service Organization

<https://www.quebec.ca/en/health/health-system-and-services/service-organization/>

This web page of the Government of Quebec presents a portrait of the organization of services in Quebec as well as relevant information for each service offered.

HEALTH BOOKLET

<https://carnetsante.gouv.qc.ca/portail>

The Québec Health Booklet is your one-stop reference to your health information, accessible anywhere. It gives you access to the results of your medical imaging examinations, the history of your pharmacy medications and the results of your samples, including blood and urine tests. It allows you to schedule an appointment for family medicine online.

HEALTHCARE EXCELLENCE CANADA

Engaging Patients in Patient Safety – a Canadian Guide

<https://www.patientsafetyinstitute.ca/en/toolsresources/patient-engagement-in-patient-safety-guide/pages/default.aspx>

The Engaging Patients in Patient Safety Canadian guide is presented to you in detail on this web page. You will discover who is this guide for, its purpose and what is included inside. You also have the option to download it.

Patient, Family and Caregiver Engagement and Partnerships

<https://www.cfhi-fcass.ca/WhatWeDo/PatientEngagement/PatientEngagementResourceHub/Results.aspx>

On this page of the Canadian Foundation for Healthcare Improvement, you will find information about the participation and collaboration of patients in their health care, including the Bridge-to-Home project that allows improve the quality of care, as well as the experience of patients, caregivers and providers during transitions from hospital to home.

Shift to Safety

<https://www.patientsafetyinstitute.ca/en/about/programs/shift-to-safety/pages/public.aspx>

The “Public” section of SHIFT to safety program aims to help you take an active part in the safety of your healthcare. It offers resources on a range of topics for making informed care choices, links to other patients, and tips for working with health care providers based on personal needs.

HEALTH CHARITIES COALITION OF CANADA – “HOW TO” HEALTH GUIDE

www.healthcharities.ca/resources/how-to-health-guide.aspx

The “How To” Health Guide was developed to assist patients, caregivers, friends and families in managing information about the Canadian health care system, which can often be challenging to navigate. If you, or someone you love and care for, are trying to find health services, support or information for an illness or disease, there are actions you can take to help get the best possible health care. The Guide provides basic information about how to speak to those working within the system on a range of issues. A link to download a copy of the guide is available at the bottom of the page.

HEART & STROKE FOUNDATION – BEING A PARTNER IN YOUR HEALTH CARE

https://www.heartandstroke.ca/heart-disease/recovery-and-support/talking-to-your-doctor?_

This section of the Heart & Stroke foundation website provides an overview of what you need to know to prepare well for a medical appointment.

INSTITUTE FOR SAFE MEDICATION PRACTICE CANADA – SAFEMEDICATIONUSE.CA

<https://safemedicationuse.ca/newsletter/index.html>

ISMP Canada SafeMedicationUse.ca newsletters contain information for consumers to promote the safe use of drugs in all areas of health. One of their objectives is to make recommendations to prevent medication-related accidents.

MCGILL UNIVERSITY HEALTH CENTER

Patient Safety and Physical Restraints: What You Need to Know

http://www.muhcpatienteducation.ca/DATA/GUIDE/349_en~v~patient-safety-and-physical-restraint.pdf

This booklet aims to help you understand physical restraints.

MERCK MANUAL (CONSUMER VERSION) – MAKING THE MOST OF HEALTH CARE

<https://www.merckmanuals.com/en-ca/home/fundamentals/making-the-most-of-health-care>

This web page offers you valuable tips for participating actively in your health care, such as when to see your doctor, how to get the most out of a consultation, and investigating a disease.

ORDRE DES PHARMACIENS DU QUÉBEC – PROTECTION DU PUBLIC

<https://www.opq.org/protection-du-public/que-fait-lordre-pour-me-protoger/>

The “Protection du public” section of the Ordre des pharmaciens du Québec website allows you to find a pharmacist, obtain advice related to the protection of the public as well as better understand the role of the pharmacist and what pharmaceutical care is. Website only in French.

OTTAWA HOSPITAL RESEARCH INSTITUTE – PATIENT DECISION AIDS

<https://decisionaid.ohri.ca/AZinvent.php>

The A to Z Inventory of Decision Aids is designed to help you find a decision aid to meet your needs.

RÉGIE DE L'ASSURANCE MALADIE – CITIZENS

<https://www.ramq.gouv.qc.ca/en/citizens/health-insurance/Pages/health-insurance.aspx>

The RAMQ website provides you information on health insurance, prescription drug insurance, aid programs and temporary stays outside Quebec. You will find the services available online as well as the forms necessary to benefit from the services offered.

SANTÉ ET SERVICES SOCIAUX QUÉBEC

Quick Reference: I'm taking care of my Health

<https://publications.msss.gouv.qc.ca/msss/fichiers/2016/16-909-01A.pdf>

This checklist offers you some tips to help you prepare for meetings with health professionals.

SENIORS' GUIDE TO STAYING CYBER SAFE DURING COVID-19

<https://www.getcybersafe.gc.ca/en/resources/seniors-guide-staying-cyber-safe-during-covid-19>

This guide helps seniors protect their identity by helping them create strong passwords, enable multi-factor authentication, and warn them about phishing attempts.

HAVE YOU HEARD OF DEPRESCRIBING?

Deprescribing means reducing or stopping medication. Its goal is to maintain or improve quality of life.

WHY RESORT TO DEPRESCRIBING?

Medication controls symptoms, cures illness and can even extend lifetime. However, it can cause side effects or interactions that can be harmful. The more medication we take, the higher the risks of negative effects. It's also important to know that as we get older, changes in the body make us more sensitive to medications, which increases the risk of suffering from negative side effects.

HOW DOES IT WORK?

For all these reasons, it's recommended to regularly review your medication with your health care provider. They will be able to determine whether the risk of taking a specific medication is higher than its benefits and if deprescribing is an option. **Deprescribing is a planned process that must always be done with the help of your doctor, nurse or pharmacist.**

Source: Canadian Deprescribing Network

CANADIAN DEPRESCRIBING NETWORK

www.deprescribingnetwork.ca

The Canadian Deprescribing Network provide you information about medication safety, deprescribing and safer alternatives to risky medications. Different articles and resources on the subject are proposed on the website of the Network.

Legal information

COMITÉ DES USAGERS DU CENTRE DE SANTÉ ET DE SERVICES SOCIAUX DE LAVAL – THE RIGHTS AND THE RESPONSIBILITIES

<http://www.cucssslaval.ca/user/the-rights-and-the-responsibilities>

The various rights in terms of health and well-being in Quebec and everyone's responsibilities in this area are grouped together on this web page.

ÉDUCALOI

Caregivers: Practical Legal Tools

www.educaloi.qc.ca/en/caregivers-practical-legal-tools

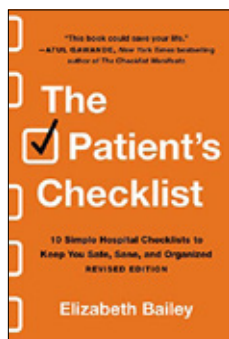
In this web guide, Éducaloi provides clear and useful legal information intended for caregivers.

Health Topics

www.educaloi.qc.ca/en/categories/health

This section of the Éducaloi website clearly explains the rights and responsibilities of doctors, patients, partners, caregivers, etc., within the Quebec health care system. Topics covered include the public health system, filing a complaint, access to medical records, making medical decisions, incapacity, and loss of autonomy.

READING SUGGESTIONS



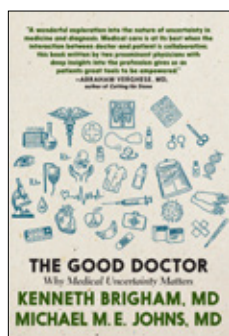
THE PATIENT'S CHECKLIST: 10 SIMPLE HOSPITAL CHECKLISTS TO KEEP YOU SAFE, SANE, AND ORGANIZED

Elizabeth Bailey. New York: Hachette, 2020, 161 p.

Whether you're addressing the rising chaos of a pandemic or preparing for a scheduled surgery, having checklists prepared to guide you through a hospital visit can often mean the difference between comfort and pain, personal and distant care – and even life or death. In today's hospital system, you can face a series of obstacles to satisfactory care, from overworked healthcare providers to understaffed facilities. This series of essential, easy-to-use checklists will help you better manage, monitor, and participate in your own healthcare. These include: Before You Go, What to Bring, Master Medication List, Discharge Plan, and more. It is more important than ever to have a protocol, including a detailed plan for hygiene and communications while hospitalized. You can trust the medical staff, but you also need to trust yourself or a loved one to be your own best advocate.



Also available on prenumerique.ca



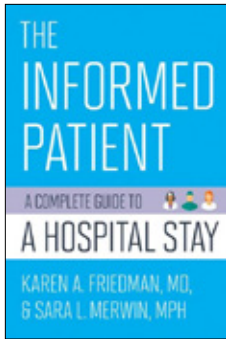
THE GOOD DOCTOR: WHY MEDICAL UNCERTAINTY MATTERS

Kenneth Brigham and Michael M.E. Johns. New York : Seven Stories Press, 2020, 238 p.

What makes a good doctor? It's not what people think. A doctor willing to face their own uncertainty in the face of illness and treatment might just be the best medicine. In *The Good Doctor*, Ken Brigham, MD, and Michael M.E. Johns, MD, argue that we need to change the way we think about health care if we want to be the healthiest we can be. Counterintuitive as it may seem, uncertainty is integral to medicine, and you want a doctor who knows that: someone who sees you as the unique case you are, someone who knows that data isn't everything, someone who is able to change her mind as the information changes.



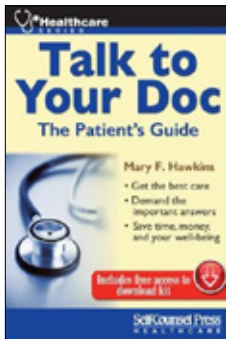
Also available on prenumerique.ca



THE INFORMED PATIENT: A COMPLETE GUIDE TO A HOSPITAL STAY

Karen A. Friedman and Sara L. Merwin. Ithaca: ILR Press, 2017, 228 p.

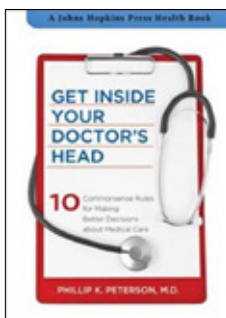
Even the most capable individuals are challenged when confronted with the complexity of the modern hospital experience. *The Informed Patient* is a guide and a workbook, divided into topical, focused sections with step-by-step instructions, insights, and tips to illustrate what patients and their families can expect during a hospital stay. Anyone who will experience a hospital stay – or friends or family who may be in charge of a patient's care – will find all the help and advice they could need in the detailed sections that cover every aspect of what they can expect.



TALK TO YOUR DOC: THE PATIENT'S GUIDE

Mary Hawkins. North Vancouver: Self-Counsel Press, 2015, 163 p.

Doctors are busier than ever and the Internet produces more information than ever for patients. Getting the right treatment can be challenging if you don't have the right approach. Mary Hawkins helps patients advocate for the best care with a guide on how to discuss your condition with your doctor.



GET INSIDE YOUR DOCTOR'S HEAD: 10 COMMONSENSE RULES FOR MAKING BETTER DECISIONS ABOUT MEDICAL CARE

Phillip K. Peterson. Baltimore: The Johns Hopkins University Press, 2013, 130 p.

In simple direct language Dr. Peterson tells readers how to understand their doctors' recommendations and ask intelligent questions about their validity.



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