

Social Determinants of Health

How Poverty , Intellectual
Disability and
Cultural Factors can Impact
Health Outcomes

Collaborative Team from Special Interest Focused Practice (SIFP)

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Conflict of Interest Declaration

- The SIFP Chairs met in December 2013 at a SIFP Board meeting and agreed to work collaboratively to present this workshop.
- There is no commercial sponsorship of this workshop.
- The presenters have no conflict(s) to declare.

Learning Objectives

By the end of this session, The participant will be able to:

1) DISTINGUISH how social determinants of health (poverty, lack of education, lack of social supports) can impact clinical health and child developmental outcomes.

Learning Objectives (cont)

- 2) DEMONSTRATE strategies to be used in screening proactively (intervening early) and SUMMARIZE HOW to modify high risk social factors in families, teens, children and pregnancy visits.
- 3) GENERATE an action plan for families at high risk for management of medical conditions by linking them to community resources to improve clinical outcomes.

Social Determinants of Health : Definitions

Ottawa Charter for Health Promotion :

Peace, shelter, education, food, income, stable ecosystem sustainable resources, social justice and equity

World Health Organization :

Social (class health) gradient, stress, early life, social exclusion, work, unemployment, social support, addiction, food and transport

Center for Disease Control and Prevention :

Socioeconomic status, transportation, housing, access to services, discrimination by social group in g(ie race, sex or class) and social or environmental stressors

Health Canada:

Income and social status, social support networks, education, employment and working conditions, physical and social environments, healthy child development, health services, sex and culture.

(Pediatric Child Health Vol 15 No3 March 2010)

Social Determinants of Health: National Conference/Public Policy Impact

- Early Life
- Education
- Employment and Working Conditions
- Food Security
- Health Services
- Housing
- Income and its Distribution
- Social Exclusion
- Social Safety Net
- Unemployment and Job Insecurity
- Sex
- Aboriginal Culture

(Pediatric Child Health Vol 15 No3 March 2010)

Case History Part 1

- Zara arrives at the office for a “check up” and update of her vaccinations. She is accompanied by her grandmother who is her primary caregiver and an aunt who acts as an interpreter.
- Zara’s parents were killed in a traffic accident 3 years before while visiting their home country overseas.
- Zara and her grandmother and live in a large home with extended family in an suburban neighborhood. Zara shares a bedroom with her grandmother and is happy with the supportive environment.
- Zara is 15 years of age, has an intellectual disability and has been successful in a special needs co-educational class integrated in the local high school. She has several close school friends and attends many afterschool activities.

Questions to Consider

- What strategies and clinical tools will you use for this clinical visit?
- How will you handle the cultural issues in this case?

- What issues will you explore with grandmother?
- What issues will you explore with Zara herself?

- How will you conduct this visit with respect to confidentiality knowing that Zara has an intellectual disability?
- How do Social Determinants of Health Impact this visit?

More questions to consider

- What potential pitfalls does the need for an interpreter signal?
- How can you gauge your understanding of the patient's (and family's) cultural expectations?
- What tools and strategies can you use to ensure a culturally congruent approach?

Culture and Immigration

- Evidence-based clinical guidelines for immigrants and refugees
Kevin Pottie et al. CMAJ June 7, 2010
- EA Berlin and WC Fowkes. A Teaching Framework for Cross-cultural Health Care—Application in Family Practice. West J Med. Dec 1983; 139(6): 934–938.
- Listen
- Explain
- Acknowledge
- Recommend
- Negotiate



<http://www.martapuigsamper.com/en/wp-content/uploads/2012/12/top10-400-white1.jpg>

Poverty Interventions
for Family Physicians

POVERTY:

Poverty requires intervention like other major health risks: The evidence shows poverty to be a risk to health equivalent to hypertension, high cholesterol, and smoking. We devote significant energy and resources to treating these health issues. Should we treat poverty like any equivalent health condition?

Of course.

A clinical tool for primary care in Ontario

“There is strong and growing evidence that higher social and economic status is associated with better health. In fact, these two factors seem to be the most important determinants of health.”¹

- Public Health Agency of Canada

Poverty accounts for 24% of person years of life lost in Canada (second only to 30% for neoplasms).²

Income is a factor in the health of all but our richest patients.

Family & Community Medicine
UNIVERSITY OF TORONTO

Three ways to address poverty in primary care: 123

1. SCREEN

Poverty is not always apparent... we can't make assumptions

Poverty is everywhere ... In Ontario 20% of families live in Poverty.¹

Poverty affects health on a gradient: There is no health poverty line. Income negatively affects the health of all but the highest income patients.⁴

Screen everyone!!!

“Do you ever have difficulty making ends meet at the end of the month?”

(sensitivity 98%, specificity 64% for living below the poverty line)⁵

2. ADJUST RISK

Factor poverty into clinical decision-making like other risk factors. Consider the evidence:

Cardiovascular disease:

- Prevalence: 17% higher rate of circulatory conditions among lowest income quintile than Canadian average.⁶
- Mortality: If everyone had the premature mortality rates of the highest income quintile there would be 21% fewer premature deaths per year due to CVD.⁷

Diabetes:

- Prevalence: Lowest income quintile more than double highest income (10% vs. 5% in men, 8% vs. 3% in women).⁸
- Mortality: Women 70% higher (17 vs. 10/100); men 50% higher (27 vs. 17/100).⁹

Mental illness

- Prevalence: Consistent relationship between low SES and mental illness, e.g. depression 58% higher below the poverty line than the Canadian average.^{10,11}
- Suicide: Attempt rate of people on social assistance is 10 times higher than higher income individuals.¹²

Cancer:

- Prevalence: Higher for lung, oral (OR 2.41), cervical (OR 2.08).^{13,14,15}
- Mortality: Lower 5-year survival rates for most cancers.¹⁶
- Screening: Low income women are less likely to access mammograms or Paps.¹⁷

Other chronic conditions:

- Prevalence: Higher for hypertension, arthritis, COPD, asthma, higher risk of having multiple chronic conditions.^{18,19}
- Mortality: Increased for COPD.²⁰

Infants:

- Infant mortality: 60% higher in lowest income quintile.^{21,22,23,24}
- Low birth weight: If all babies in Toronto were born with the low birth weight rate of the highest income quintile there would be 1,300 or 20% fewer singleton LBW babies born per year.²⁵

Highest risk groups:
Women, First Nations, people of colour, LGBT.

Growing up in Poverty:
We must intervene to improve income early. Growing up in poverty has been associated with increased adult morbidity and mortality resulting from: stomach, liver, and lung cancer; diabetes; cardiovascular disease; stroke; respiratory disease; nervous system conditions; diseases of the digestive system; alcoholic cirrhosis; unintentional injuries; and homicide.^{26,27}

Some examples of how the evidence might change your practice:

1. If an otherwise healthy 35 year old comes to your office, without risk factors for diabetes other than living in poverty, you consider ordering a screening test for diabetes.
2. If an otherwise low risk patient who lives in poverty presents with chest pain, this elevates your pre-test probability of a cardiac source and helps determine how aggressive you are in ordering investigations.

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Poverty-Screen and Adjust Risk

- “There is strong and growing evidence that higher social and economic status is associated with better health. In fact, these two factors seem to be the most important determinants of health.” (Public Health Agency of Canada)
- Poverty requires intervention like other major health risks: The evidence shows poverty to be a risk to health equivalent to hypertension, high cholesterol, and smoking.
- Screen everyone!!! “Do you ever have difficulty making ends meet at the end of the month?” (Sensitivity 98%, Specificity 64% for living below the poverty line)

3. INTERVENE

7 simple questions to help patients living in poverty

FOR EVERYBODY:
Have you filled out and mailed in your tax forms?

- Tax returns are essential to access many income security benefits e.g. GST / HST credits, Child Benefits, working income tax benefits, and property tax credits.
- Even people without official residency status can file returns.
- **Drug Coverage:** Extended Health Benefits or Trillium for those without Ontario Drug Benefits.
See www.drugcoverage.ca for a guide to federal and provincial drug insurance programs.

For seniors living in poverty:
Do you receive Old Age Security and Guaranteed Income Supplement?

- Most people over age 65 who live in poverty should receive at least \$1400/month in income through OAS, GIS, and grants from filing a tax return.

For families with children:
Do you receive the Child Benefit on the 20th of every month?

- This can get some low income single parents over \$6000 more per year, and can lead to a number of other income supports.

For people with disabilities:
Do you receive payments for Disability?

- Eight major disability programs: ODSR, CPP Disability, EI, Disability Tax Credit, (DTC), Veterans benefits, WSIB, Employers' long term protection, Registered Disability Savings Plan (RDSP).
- The DTC requires a health provider to complete the application form. It provides up to \$1600 per year in tax savings (plus retroactive payments), and is required to receive other benefits including the BDISP.
- RDSP: Up to 300% matching funds. Or disability bonds up to \$20 000 for those without resources to save money.

For Aboriginals:
Do you have Status and have you used Non-Insured Health Benefits?

- Aboriginals with the Status designation may qualify for Non-Insured Health Benefits through the federal government. These pay for drugs, and other extended health benefits not covered by provincial plans.

For social assistance recipients:
Have you applied for extra income supplements?

- Mandatory Special Necessities Benefits (MNBs) b/w KOS-4 for \$250:
 - Medical supplies, and health-related transportation (includes e.g. AA, psychotherapy).
- Limitation to Participation (MNBs b/w KOS-2 for \$15): Disability can exclude a recipient from mandatory job search and training programs.
- Special Diet Allowance (MNBs b/w KOS-3 for \$20): some health conditions will qualify a recipient for extra income.
- Other benefits available: Employment supports, Drug & Dental, Vision, Hearing, ADP Co-payment, Community Start-Up \$6 Maintenance, Women in Transition/Interval Houses, Advanced age allowance, Community Participation (\$1 00 per month extra for volunteering), "Discretionary Benefits".

Applications and benefits available through a patient's OCN/OOSP worker

If you might qualify, have you applied for ODSP?

- ODSP application (MNBs bill KOS-0 for \$100): provide as much information as possible, including about the impact of a person's disability on their lives.
 - Include all collateral, expedite necessary referrals, and write a detailed narrative on the last page. Consider obtaining a detailed functional assessment, and having an allied health provider assist with filling in details.
 - If denied, refer to nearest legal clinic – acceptance rates on appeal are very high.

www.deo.on.ca/english/pub/ocn/pubs/PDFsocialAssst/ods-prof.pdf for a good ODSP tip sheet for health professionals.

Remember:
Health providers are not the gatekeepers for income security programs. Our job is to provide complete and detailed information that accurately portrays our patients' health status and disability.

For references, please visit www.ocfp.on.ca/cme/povertytool

Poverty Tool-7 Questions to Help

- Have you filled out and mailed in your tax forms?
- Do you receive Old Age Security and Guaranteed Income Supplement?(Seniors)
- Do you receive the Child benefit on the 20th of every month?(Children)
- Do you receive payments for Disability?(Disabilities)
- Do you have Status and have you used Non-Insured Health benefits? (Aboriginal Families)
- Have you applied for extra income supplements?(Social Assistance Recipients)
- Have you applied for extra income supplements?(ODSP)

Income Referral Resources

Patient-oriented, easy to use government websites:

Service Canada: www.servicemacchi.gc.ca. Catch-all site for federal programs, including for newcomers, seniors (OAS, GIS), First Nations, Veterans, Employment (e.g. SIN), EI, GST Credit, Canada Child Tax Benefit, organized by population group, life events, and subject.

Canada Benefits: www.canadabenefits.gc.ca. Provides a full listing of income and other supports, organized by personal status (e.g. "parent," "aboriginal") or life situation (e.g. "unemployment," "health resources"), and provides with links to the relevant program websites, and to application forms. A good website for health providers to explore!

Ontario Tax Benefits: www.ontario.ca/taxes-and-benefits/taxes-and-benefits. Provides information on provincial tax credits and benefits by topic and population group.

Ontario Ministry of Community and Social Services social assistance:

www.mcmss.gov.on.ca/en/mcsd/programmesocial. Overview of Ontario Works and OASFP – application process, details about all benefits and supports available and eligibility requirements.

Local Employment and Social Services:

e.g. www.toronto.ca/socialservices/ for Toronto: links to employment assistance services, benefits available to Ontario Works recipients, housing supports. Direct online application for Ontario Works.

One-on-one services:

Free Community Income Tax Clinics: dhwsmc.ca/locations.

Call or browse www211ontario.ca or local 2-1-1 service.

Call CRA to set up an appointment: 1-800-959-8281;

www.cra-arc.gc.ca/ind/index/individual/benefits-eng.html

Local organizations with support and social workers: Call or browse www211ontario.ca or local 2-1-1 service. Allows searches for specific advocacy organizations, based on topic and location.

Legal Clinics: www.legalaid.on.ca or 1-800-668-8258 to find the closest Legal Aid Clinic or for a guide to Legal Aid supports by specific need.

Local Direct Income Advocacy Organizations: e.g. www.ocfp.ca. Advocacy with social assistance or subsidized housing.

St. Christopher House: www.stchristopher.org. 416-868-7880.

Gold standard for financial advice... Excellent for complicated income support situations.

Issue-specific individual financial advice:

Welfare, www.welfarehelp.ca, for individuals with cancer.

Parsons with AIDS Foundation, www.pwafontario.org, for individuals with HIV.

Advocacy-Oriented Organizations:

Community Legal Education Ontario (CLEO): www.cleo.on.ca.

Excellent plain language materials on legal and social issues. Available in multiple languages.

CLEONet: www.cleonet.ca. Well-organized, comprehensive clearinghouse for educational materials on legal and social issues, gathered from organizations across Ontario.

Income Security Advocacy Centre (ISAC):

www.incomesecurity.org. Frequently updated information sheets and backgrounders on issues regarding income security, including rapidly produced guides to changes in major income supports.

ARCH Disability Law Centre: www.archdisabilitylaw.ca.

Legal clinic advocating for the rights of disabled people. Excellent links.

Advocacy Centre for the elderly (ACE):

www.aceoc.on.ca/centraldir/eng/; legal clinic advocating for the rights of seniors. Good links and basic information.

Aboriginal Legal Services of Toronto (ASAC):

www.aboriginallegal.ca; legal clinic advocating for the rights of aboriginal people. Good links to support and information organizations.

A brochure is available for your patients, with these resources and more.

This can be ordered through the Ontario College of Family Physicians.

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Developed by Dr. Gary Bloch MD CCFP,
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St. Michael's
Inspired Care. Inspiring Science.

HEALTH
RESEARCH
ADVANCING
POVERTY

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For more information and references visit:
www.ocfp.on.ca/cme/povertytool

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Case History Part 2

- 1 year later, you receive a notice from the local After Hours Clinic about a visit that Zara made 2 days earlier. The clinical note states that Zara's aunt was present at the visit.
- Urinalysis shows positive for nitrates, blood and white cells. Exam reveals discomfort over her bladder. A Diagnosis of urinary tract infection is made and antibiotics are prescribed.
- You recall that Zara's grandmother was admitted to hospital one month before for a major CVA and is currently in the local rehab facility.

Questions to Ponder

- What concerns do you have for Zara?
- What type of follow-up will you plan for this clinical encounter?
- Does the change in health status of the grandmother change your management of Zara's clinical care?
- Who would you contact if you have questions about Zara's health status?
- How does confidentiality play into your clinical decision- making?

Resources for Periodic Care Visits

Modifications for Developmental Delay

- Rourke Baby Record (rourkebabyrecord.ca)
- Greig Health Record (cps.ca/tools-outils/greig-health-record)
- Immunization Info Public Health Agency of Canada (www.phac-aspc.gc.ca/publicat/cig-gci/index-eng.php)
- Surrey Place (www.surreyplace.on.ca/)
- SIFP website (www.cfpc.ca/SIFP)
- Caring for Kids New to Canada (cps.ca)

Transition Readiness Checklist

- A questionnaire that assesses the health care skills of the youth with developmental disabilities (DD) and their caregivers.
- The youth and primary caregiver should complete the questionnaire together.
- The tool looks at four different health skill areas:
 - Knowledge of Health Condition(s), Medication and Treatment
 - Taking Charge of Health Condition(s), Medication and Treatment
 - Taking Charge at the Doctor's Office
 - Daily Living Skills and Thinking About the Future

Transition Readiness Checklist and Transition Toolkit Created by:

- Developmental Disabilities Primary Care Initiative (DDPCI) Transition Working Group
 - **Dr. Ullanda Niel**, Family physician practicing in developmental disabilities (mdtransition@gmail.com)
 - **Jessica Wood**, PhD student, Surrey Place Centre
 - **Maureen Kelly**, Nursing Surrey, Place Centre
 - **Dr. William F. Sullivan**, Family physician, clinical director and chair of DDPCI

Readiness Checklist and Toolkit are Available at CFPC.CA

- An updated version of the Transition Tool is posted on the Surrey Place Website:
<http://www.surreyplace.on.ca/docman-menu-item-required/public-files/resource-and-publication/primarycare/tools-for-primary-care-providers/312-transitiontool-printv-english-june2014/file>

Transition Readiness Checklist

DDPCI – Transition Readiness Checklist

Name: _____ DOB: (dd/mm/yyyy): _____

	✓ Yes, I do this	✓ I am learning how to do this	✓ I need to learn how	✓ I need someone to help me do this – who?	✓ Does not apply to me
Knowledge of Health Condition(s), Medication and Treatment					
1. I can explain my health problems/ disability					
2. I can name my medications and treatments and I can tell others what they are for.					
<i>Health Knowledge: Discussion and plan (consider both the youth and their caregiver).</i>					

DDPCI – Transition Readiness Checklist

Name: _____ DOB: (dd/mm/yyyy): _____

	✓ Yes, I do this	✓ I am learning how to do this	✓ I need to learn how	✓ I need someone to help me do this – who?	✓ Does not apply to me
Taking Charge of Health Condition(s), Medication and Treatment					
3. I am ready to make decisions about my health.					
4. If I get sick, I know who to call or how to get help.					
5. I know what to do if I have a medical emergency.					
6. I keep track of my doctor and dental appointments					
7. I keep my important health information.					
8. I take my own medications.					
9. I know how much I should take of each medication.					
10. I know what to do if I miss a dose of medication.					
11. I know the side effects of my medication(s) and what to do if I have these side effects.					
12. I call in my medication refills					
13. I know how my medications and treatments are paid for.					
14. I take care of my treatments (asthma treatments, G-tube care, CPAP machine, catheterization).					
15. I take care of my medical equipment and supplies (e.g. wheelchair).					
<i>Taking Charge of Health: Discussion and Plan (consider both the youth and their caregiver).</i>					

Transition Toolkit

- Builds on the Transition Readiness Checklist
- Explains the skills needed in each area of readiness
- Suggests tools that will help the person with DD and their caregivers to achieve each skill.

Using The Transition Toolkit

The Transition Skills and Resources Toolkit

Tools marked ☺ are designed for **youth** with developmental disabilities (and are useful for caregivers, too!)

Tools marked 👤 are designed for caregivers.

<p>16. I carry my health card in my wallet and bring important health information with me to doctor's appointments/ the emergency department (e.g., Portable Health Record, Health Passport or Emergency Information Form).</p>	<ul style="list-style-type: none"> Keeps a portable health record and brings this to health care appointments and emergency department and shares it with health care team members. Recognizes that a health card is required and brings it to clinical appointments. If appropriate, has a Medic-Alert bracelet or necklace. 	<p>Available online:</p> <ul style="list-style-type: none"> ☺ 👤 Portable Patient Profile. Surrey Place Centre, DDPCI www.surreyplace.on.ca/Primary-Care/Pages/Tools-for-care-givers.aspx ☺ 👤 My Health Passport. Hospital for Sick Children. www.sickkids.ca/Good2Go/Transition-Interventions-Tools/MyHealth-Passport/index.html 👤 Emergency Information Form. American Academy of Pediatrics. http://www2.aap.org/advocacy/blankform.pdf 👤 Medic-Alert – bracelet or necklace. www.medicalert.ca/en/index.asp
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Examples of Tools

Portable Patient Profile – My Health Information

I will fill out this form and carry it with me to health care appointments. I will keep this form up to date, with help from my doctor and family or caregiver, and will make sure the information is correct.

Information completed (dd/mm/yyyy):

Name: _____ DOB: (dd/mm/yyyy): _____
 Address: _____ City/Town: _____
 Postal Code: _____ Home Phone: _____ Cell/Work Phone: _____
 _____ Other Health Insurance: _____

____ (SDM): _____ Phone: _____
 _____ Phone: _____
 _____ Phone: _____

Developmental Disability: Cause, if known: _____
 Level of adaptive functioning: Mild Moderate Severe Profound _____ health and medical information with my doctor:
 _____ Phone: _____

Major Surgeries and Hospitalizations:

Where? _____	Why? _____	Year: _____	Phone: _____
Where? _____	Why? _____	Year: _____	Phone: _____
Where? _____	Why? _____	Year: _____	Phone: _____

Allergies (Include medicine, food, environment, contact or other. Also describe what happens.):

1. _____ What happens: _____ Year: _____
 2. _____ What happens: _____ Year: _____
 3. _____ What happens: _____ Why? _____ Year: _____

____, contact or other. Also describe what happens: _____
 What happens: _____
 What happens: _____
 What happens: _____

What I am attaching to this form:

List of my current medications Latest lab results
 List of latest immunizations Other: _____
 Other: _____

 None

My main language is: _____
 If not English, do I understand English? Yes No Speak English? Yes No
 I communicate with: words sentences gestures sign language pictures other: _____
 I understand and learn best by: simple explanations written words pictures
 sign language other: _____

Special Care Needs

I have problems with:
 vision _____
 hearing _____
 movement/mobility _____

I use the following medical equipment and/or mobility equipment:

Things that may make me anxious or upset me in medical appointments (e.g., medical exams, blood work, needles, noise, lighting, smells, colours, textures, crowds, waiting):

Things that help when I get anxious or upset: _____

Health care plans or protocols that I/my caregivers use (e.g., for bowels, seizures, crisis) – *please attach a copy*: _____

My doctor should have the following information/cautions: _____

Phone: _____ E-mail: _____
 I'd like to add:

Adapted from New York State Department of Health, H.L.Doc. – www.nyhealth.gov/commntc/special_needs

Strengths and Limitations of the Readiness Checklist and Toolkit

Strengths

- Provides a method of assessment of skills AND the tools to build the skills
- Brief listing of 1-2 tools per skill
- Tools are available and accessible (many online, free)
- Many tools are designed specifically for the youth or adults with DD to complete themselves
- Some tools are designed for caregivers of people with DD
- Many tools are Canadian
- Tools are evidence based or based on best clinical practice

Limitations

- Very health oriented
- Not exhaustive
- Has not yet been formally evaluated in a primary health care setting but has been used in the practice of the creator Dr Ullanda Niel

Suggested Sections for Family/Caregiver Health Care Binder

Health Issues and Diagnoses

- Portable Patient Profile
www.surreyplace.on.ca/Primary-Care/Pages/Tools-for-care-givers.aspx
- My Health – 3-Sentence Summary
www.sickkids.ca/Good2Go/Transition-Interventions-Tools/Easy-interventions/32716-Three-Sentence%20Summary%20BOOKMARK%20formatted%20for%20website.pdf
- MyHealth 3-Sentence Summary with DD-specific examples
www.surreyplace.on.ca/Primary-Care/Pages/Tools-for-care-givers.aspx
- Caregiver Health Assessment
www.surreyplace.on.ca/Primary-Care/Pages/Tools-for-care-givers.aspx
- Medic-Alert information – www.medicalert.ca

and Procedures

- Genetic assessment
- Psychological assessment (needed for access to adult services in Ontario for people with DD)
- Functional assessments
- Copy of MRI or CT scan results, if ever done
- Copy of any blood tests and urine tests done in the past year, or the most recent, if none done in the past year
- Copy of reports of any X-rays or any other tests, procedures and assessments

Medications and Treatments

- Current medications person is taking (pharmacy can print)
- List of other medications taken in the past and why they were discontinued
- Equipment and supplies needed (name of item, ordering information, e.g., supplier's name and contact person, catalogue number, quantity, cost, forms to submit for reimbursement, if covered by health benefits)

Transportation Scheduler

Completed by: _____ Date: _____

How will you get to your appointment?

Family/Friend
 Support Worker
 Taxi/WheelTrans*

When you are phoning the person who is driving you, have these things ready:

Phone number of the person who is driving you
 Name and address of the doctor
 Date and time of your appointment
 Your address and telephone number
 Calendar

When you phone the person who is driving you, say the following:

Hello, this is (say your name).

I need a ride to get to my doctor's appointment on (say date and time).

I am going to (give name and address of the doctor).

I will need a ride back to (give your address).

Can you do this? (If not, call _____).

What time will you pick me up? (Write down the time.)

Who do I call if there is a problem? (Write down the phone number.)

* If you are taking a taxi or WheelTrans, don't forget to bring money to pay for the trip.

Mark on your calendar:

Location of doctor's appointment.
 Date and time for transportation pick up.
 Phone number to call if there is a problem.

Modified from www.HealthyTransitionsNY.org
New York State Institute for Transition Training

Case History Part 3

- 3 months later Zara arrives at the office with her grandmother and her aunt who interprets for the visit.
- The grandmother expresses concern that Zara has not had a period in 3 months and that she is gaining weight.
- Social history reveals that Grandmother has been home for one month while Zara has been happy living with extended family and continues to attend her special needs class and after- school programs.
- Zara's aunt stepped in as caregiver while the grandmother was in hospital and rehab.

Questions to Ponder

- What questions do you have for Zara, her grandmother and the aunt?
- How will you approach this case?
- What clinical investigations would you consider useful?
- What other topics of discussion would you consider important?
- Are there any legal issues you need to consider?
- How do cultural factors influence your clinical decisions?

Suggestions for Optimizing Care

- Consider sex and sexuality with all patients and caregivers of individuals with Developmental Delay
- Consider benefits of menstrual suppression in young women at risk
- Explore family plans to address unintended pregnancy

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FREE ONLINE RESOURCES

Sexuality and Disability – Guide for Parents

A 23-page Canadian resource for parents. Includes community resources and topics for discussion. Sponsored by teachingsexualhealth.ca.
<http://teachers.teachingsexualhealth.ca/wp-content/uploads/Sexual-and-Development-Disability-Guide-2013.pdf>

Sexuality and Developmental Disability – A Guide for Parents

A 6 page Canadian resource for parents including Tips and Strategies as well as online and local resources.
http://cpri.ca/uploads/section000033/20101209120903_668p_Sexuality_and_Developmental_Disability.pdf

Sexuality Education for Children and Adolescents with Developmental Disabilities

An 81-page American instruction manual for parents or caregivers of and individuals with developmental disabilities. Addresses sexuality across the lifespan. Sponsored by the United States Department of Health and Human Services, Administration on Developmental Disabilities and the Florida Developmental Disabilities Council.
www.albany.edu/aqing/IDD/documents/parentworkbook.pdf

Introduction to Sexuality Education for Individuals Who Are Deaf-Blind and Significantly Developmentally Delayed

A 120-page free online resource sponsored by DB-LIN K, The National Information Clearing house on Children Who Are Deaf-Blind, and the U.S. Department of Education, Office of Special Education Programs. It specifically addresses sexuality in people who are deaf-blind with normal cognitive function, and with people with severe developmental disabilities.
www.nationaldb.org/documents/products/sex-ed.pdf

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PROFESSIONAL RESOURCES

Tend to be expensive; good for purchase by a clinic or an agency.

Developmental Disabilities and Sexuality Curriculum: Sexuality Education for Adults with Developmental Disabilities

An education and curriculum set for teachers, health professionals and self-advocates developed by Planned Parenthood of Northern New England. Includes a manual, the curriculum and a pre/post test package. Cost is \$250.

www.plannedparenthood.org/ppnne/development-disabilities-sexuality-31307.htm

Life Horizons I and II

An education and curriculum set for teachers and health professionals designed by James Stanfield Company, specialists in special education and transitions readiness training. Life Horizons I focuses on anatomy and physiology of sexuality. Life Horizons II focuses on self-esteem, relationships, and responsibilities. Cost \$500 each. <http://www.stanfield.com/products/family-life-relationships/life-horizons-program/>

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ORGANIZATIONS

From the University of Michigan *YourChild Development and Behaviour Resources*
[<http://www.med.umich.edu/yourchild/topics/disabsex.htm>]

- [SIECUS](#) (Sexuality Information and Education Council of the United States)
- [SexEdLibrary](#) is a project of SIECUS, and offers lesson plans, including [lessons for parents](#).
- [NICHCY](#) (National Information Center for Children and Youth with Disabilities)
- [Sexuality Education for Persons with Developmental Disabilities](#): Selected Resources, from dbpeds.org.
- [Parent Centers](#)
- [The ARC](#)
- [The American Association on Intellectual and Developmental Disabilities \(AAIDD\)](#)

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BOOKS

From the University of Michigan *YourChild Development and Behaviour Resources*
[<http://www.med.umich.edu/yourchild/topics/disabsex.htm>]

- **Sexuality: Your Sons and Daughters with Intellectual Disabilities**, by Karin Melberg Schwier and Dave Hingsburger.
- **The Facts of Life... and More: Sexuality and Intimacy for People with Intellectual Disabilities**, by Leslie Walker-Hirsch.
- **Abuse of Children and Adults With Disabilities: A Risk Reduction and Intervention Guidebook for Parents and Other Advocates**, by Nora Baladerian.
- **Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality (Topics in Down Syndrome)**, by Terri Couwenhoven.
- **An Easy Guide for Caring Parents: Sexuality and Socialization: A Book for Parents of People with Mental Handicaps**, by Lynn McKee and Virginia Blackledge.
- **An Easy Guide to Loving Carefully for Men and Women**, 4th edition, by Lyn McKee, Winifred Kempton, Lynne Stiggall-Muccigrosso.
- **Enabling Romance: A Guide to Love, Sex, and Relationships for the Disabled (and the People who Care About Them)**, by Ken Kroll and Erica Levy Klein
- **Taking Charge: Teenagers Talk about Life and Physical Disabilities**, by Kay Kriegsman, Elinor Zaslow and Jennifer D'Zmura-Rechsteiner.
- **Caution: Do Not Open Until Puberty! An Introduction to Sexuality for Young People with Disabilities**, by Rick Enright.

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BOOKS

From the University of Michigan *YourChild Development and Behaviour Resources*
[<http://www.med.umich.edu/yourchild/topics/disabsex.htm>]

- **Sex Education for Parents of Children with Autism Spectrum Disorder**, by Mark Steege and Shannon L. Peck.
- **A Training Manual for Direct Care Staff**, by Mark Steege and Shannon L. Peck.
- **Social Skills & Sex Education – Self Care for the Developmentally Delayed Adult**, from Steege Publications.
- **Asperger's Syndrome And Sexuality: From Adolescence Through Adulthood**, by Isabelle Henault.
- **Doubly Silenced: Sexuality, Sexual Abuse and People with Developmental Disabilities**, by Patricia Miles Patterson.
Published in 1991 by the Wisconsin Council on Developmental Disabilities.
- **Easy for You to Say: Q and A's For Teens Living With Chronic Illness or Disabilities**, by Miriam Kaufman
- **Changes in You: A Clearly Illustrated, Simply Worded Explanation of the Changes of Puberty for Boys, and Changes in You: A Clearly Illustrated, Simply Worded Explanation of the Changes of Puberty for Girls**, both by Peggy C. Siegel.

Conclusions

- Different organizations define Social Determinants of Health in different ways
- Common themes are that how children and their caregivers live impacts health outcomes
- Poverty is a key determinant
- Childhood living circumstances (ie Developmental Disabilities) set children on health related pathways and can immediate effects on their health and health status as adults.