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Accessible Healthcare for Persons with Intellectual & Developmental Disabilities

A Special Webinar Presentation for the
Statewide Independent Living Council of Illinois
October 25, 2017
Andrés J. Gallegos, Esq.

About the Presenter

Andrés J. Gallegos is a disability rights attorney with the law firm of Robbins, Salomon & Patt, Ltd. in Chicago where he leads the law firm's national disability rights practice. He is the recipient of American Association of People with Disabilities' 2015 Paul G. Hearne Leadership Award, is a past two-term member of the Statewide Independent Living Council of Illinois, and is currently the Chairman of the Board of Directors of Access Living of Metropolitan Chicago, Chicago's Center for Independent Living.

Andrés is a person with a disability and has been living with the effects of a spinal cord injury, resulting in quadriplegia, for the past 20 years.

Andrés is a frequent speaker on accessible healthcare, speaking on the topic before national audiences, and has authored numerous articles in national professional journals on the subject.

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"All people with intellectual and/or developmental disabilities should have timely access to high quality, comprehensive, accessible, affordable, appropriate healthcare that meets their individual needs, maximizes health, well-being, and function, and increases independence and community participation."

The Arc of the U.S., 2012

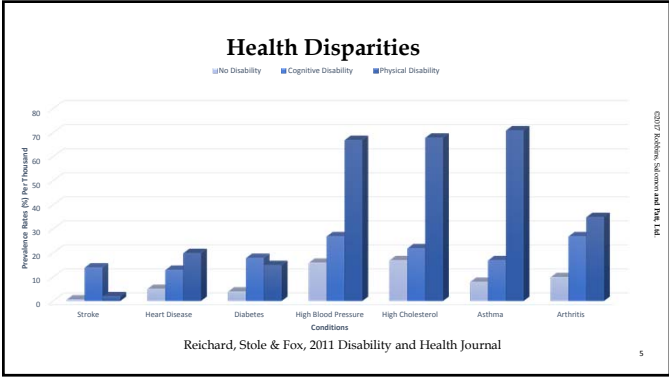
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Let's Talk

- Health Disparities
- Barriers to Accessible Healthcare
- Provider's Obligations & Your Legal and Civil Rights
- Patient Advocacy Strategy: Acting **B-A-D**
- Questions



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Health Disparities

Adults with ID are more likely to:

- Live with complex health conditions
- Have limited access to quality healthcare and health promotion programs
- Miss cancer screenings

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Health Disparities

Adults with ID are more likely to:

- Have poorly managed chronic conditions
- Be obese
- Have undetected poor vision
- Have poor oral care

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Health Disparities

Preventive Care Use

- Women, less likely to have:
 - Cervical and breast cancer screenings
 - Ever visited a gynecologist
- Individuals, less likely to:
 - Visit dentist regularly
 - Get eye and hearing tests
 - Receive timely vaccines

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Barriers to Healthcare

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Barriers to Accessible Healthcare

Barriers Affecting Persons with IDD

- Providers' Attitudes & Beliefs
- Providers' Inadequacies
- Physical Barriers
- Complicated Financing Systems
- Inadequate Number of Network Providers

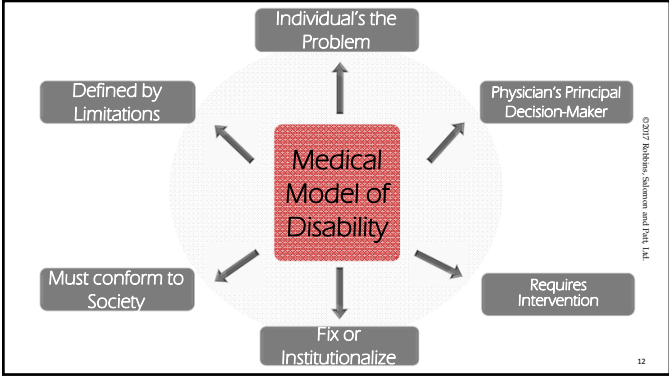
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Barriers to Accessible Healthcare

Providers' Attitudes & Beliefs

- When you see a woman with a developmental disability, can you see her as a: Lover? Mother? Wife?
- If you sustained a severe spinal cord injury, would you be glad to be alive?

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Barriers to Accessible Healthcare

Providers' Inadequacies

- Providers not adequately exposed to this population during training
- Providers lack motivation, competence & confidence
- Providers concerned with liability avoidance
- Treatment of patients with IDD is poorly reimbursed

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Barriers to Accessible Healthcare

Providers' Inadequacies

- Complexity of communication
- Providers often inadequately equipped to collaborate to coordinate care
- Lack cultural competency
- Lack of transitional care


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Physical Barriers: Examination Rooms



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**Physical Barriers:
Examination Tables**



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**Physical Barriers:
Weight Scales**



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Dental Care



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Accessible Healthcare: Providers' Legal Obligations Your Legal & Civil Rights

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Provider's Obligations & Your Legal & Civil Rights



- 3 Federal Laws:
 - Rehabilitation Act of 1973
 - Americans with Disabilities Act
 - Affordable Care Act (Obama Care)

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Provider's Legal Obligations

General Obligations

- Provide an equal opportunity to benefit from their services & facilities
- Provide an equal opportunity to participate in their own healthcare
- Provide services in integrated settings

Specific Obligations

- Modify policies, practices & procedures
- Remove physical barriers
- Provide auxiliary aids & services

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Provider's Legal Obligations

Modify Policies, Practices & Procedures

- Permit pre-visits
- Lengthen times for appointments
- Provide lighting that is natural and nonfluorescent
- Permit patient to have as many persons and whomever he desires to accompany him
- Permit emotional support animals

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Provider's Legal Obligations

Remove Physical Barriers

- Provide accessible examination and treatment rooms
- Provide accessible examination tables & examination chairs
- Provide wheelchair accessible weight scales
- Provide an array of lift & transfer equipment

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Safe Patient Handling



- Applies to Hospitals & Nursing Homes Only.
- Requires:
 - Safe Patient Lifting Team
 - Array of Different Lift & Transfer Equipment
 - Patient's Right to Choose
 - Mobility Assessment Plan

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Some Rights of Persons with IDD

- Receive equal access, care & services
- To be informed
- To receive information in a manner & language preferred
- To refuse care
- To make decisions
- To request and receive explanations of procedures
- Participate in your healthcare
- Receive services in integrated setting
- Receive whatever reasonable assistance or accommodation necessary
- To be free of unwanted restraints
- To be handled safely

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Acting **B-A-D** A Patient Advocacy Strategy



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Acting **B-A-D**: A Patient Advocacy Strategy



- 3-Phase Approach
 - **B**efore the appointment
 - **A**fter the appointment
 - **D**uring the appointment

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Acting B-A-D: A Patient Advocacy Strategy



1st Phase
Before the Appointment

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Before the Appointment

1. Research the hospital or doctors office on website
2. GOOGLE:
 - "Emotional Support Animal"
 - "Sign Language"
 - "Interpreter"
 - "ADA"
 - "Patient Rights"



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Before the Appointment

3. Call the provider's office:
 - Introduce yourself:
 - Who you are
 - What you liked to be called
 - Why you need to see a doctor
 - Ask if they:
 - Can arrange for a pre-visit tour
 - Will allow extra time for the appointment
 - Will permit emotional support animals
 - Have limits on the number of people who can attend



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Before the Appointment



- Ask if they:
 - Have an exam room with natural lighting
 - Can arrange for preferred music or other background noise
 - Can set room temperature to desired setting
 - Cannot wear masks, if that's a concern
 - Have an exam/procedure room to accommodate your needs
 - Will provide ASL interpreter, lift equipment, etc.

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Before the Appointment



4. If permitted, conduct the pre-visit tour and confirm they have all you were assured they have
5. 3-days before your appointment, call and ask if they got what you asked for. If they tell you no...

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Before the Appointment



If They Won't Have What You Need ... Your Choice ...

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Acting B-A-D: A Patient Advocacy Strategy



2nd Phase
During the Appointment

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During the Appointment



1. When you arrive, ask if they are ready for you? Did they give you what you asked for? Large room? Natural light? Interpreter? If they tell you no...

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During the Appointment



If They Don't Have What You Need ... Your Choice ...

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During the Appointment



2. At your appointment with your doctor or nurse, provide feedback – positive and negative
3. If what is provided is not working, then need to tell them right away. Tell them what you need. A different room? Another interpreter?

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During the Appointment



4. After finish your appointment, before you leave, get the doctor's contact information and write down the name of the person who is in charge of "patient's complaints."
 - ADA Coordinator
 - Section 504 Coordinator
 - Section 1557 Civil Rights Coordinator

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Acting B-A-D: A Patient Advocacy Strategy



3rd Phase
After Appointment

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After the Appointment




1. IF they did NOT provide you with an interpreter or what you asked for. Write a letter/email and ask why not?

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After the Appointment


2. In the letter/email:

- Tell them what happened and how it made you feel.
- Ask them to tell you why they did not get what you asked.
- Tell them to make sure it does not happen again.
- You need to tell them what date you want their letter.



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After the Appointment



3. IF they do NOT send you a letter like you asked, or if response is not good... contact:

- Center for Independent Living
- Disability Rights Lawyer
- Equip for Equality
- IL Attorney General
- U.S. Dept. of Justice
- U.S. Dept. Health and Human Services

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Wisconsin Board for People with Developmental Disabilities

Healthcare Toolkit
Available at:
<http://wi-bpdd.org/index.php/bpdd-publications/>

- Advocacy Forms:
 - Setting up your healthcare appointment
 - Health History
 - About Me
 - Today's Visit
 - Summary of Today's Visit

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The ARC of the U.S.

Healthcare Toolkit
Available at:
<http://www.thearc.org/healthmeet/self-advocacy-resources>

- Advocacy Checklists:
 - Selecting your doctor
 - Talking to your doctor
 - Talking to your doctor about women's health issues
 - Talking to your doctor about men's health issues

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Conclusion



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Contact Information

- Equip for Equality, 20 North Michigan Avenue, Suite 300, Chicago, IL 60602; (312) 341-0022; (800) 537-2632 (Voice); (800) 610-2779 (TTY)
- Illinois Deaf and Hard of Hearing Commission, 528 South 5th Street, Suite 209, Springfield, IL 62701, V: 877-455-3323 * 217-557-4495; VP: 217-303-8010; TTY: 888-261-2698
- Illinois Human Rights Commission James R. Thompson Center 100 W. Randolph Street, Suite 5-100, Chicago, Illinois 60601, Tel: (312) 814 - 6269; TDD: (312) 814-4760; Fax: (312) 814-6517

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Contact Information

- Illinois Attorney General, Disability Rights Bureau, Office of the Attorney General, James R. Thompson Center, 11th floor, 100 W. Randolph Street, Chicago, IL 60601, Tel: 312-814-5684; 1-800-964-3013 (TTY); 312-814-3212 (fax)
- Celeste Davis, Regional Manager, Office for Civil Rights, U.S. Department of Health and Human Services, 233 N. Michigan Ave., Suite 240, Chicago, IL 60601; Voice Phone (800) 368-1019; FAX (312) 886-1807; TDD (800) 537-7697
- US Department of Justice, 950 Pennsylvania Avenue, NW, Civil Rights Division, Disability Rights Section - 1425 NYAV, Washington, D.C. 20530; fax: (202) 307-1197; email: ADA.complaint@usdoj.gov; On-line Complaint Form: <http://www.ada.gov/complaint/>

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QUESTIONS?

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