COMMUNICATION OF HEALTH CARE NEEDS: PART 1

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Part 1: Overview

• Communication – so what’s the problem?
• What we know – from people and professionals
• USF’s Medical School Disability Training
• The importance of health advocacy
• My Health Passport
Background – Lack of Training

- Special Olympics report (2005) - 52% of medical school deans, 53% of dental school deans, 56% of students and 32% of medical residency program directors responded that graduates were “not competent” to treat people with intellectual disabilities.
- Physicians admit feeling ill-prepared, lacking resources and knowledge (Morrison, George, & Mosqueda, 2008).
- Inadequate training regarding people with disabilities leads to inadequate treatment (Kirschner & Curry, 2009).

Communication – what’s the problem?

- Florida Center for Inclusive Communities conducted a needs assessment of Floridians with intellectual and developmental disabilities (IDD) in 2009.
  - It revealed the need for more appropriate interactions and better communication by health care professionals.
Communication – what’s the problem?

- Recent study of the experiences of people with disabilities with nurses during hospitalization (Smeltzer, Avery, & Haynor, 2012).
- 4 major themes reported – poor communication, compromised care/lack of competence, negative attitudes, fears related to quality of care received.

“If my husband is with me, they talk to my husband and make believe I am not in the room.”

“I could tell them how to pick me up if they’ll listen. A lot of them don’t listen.”

“It’s just their mannerism, their tone of speech, the way that they look at you, the way that they speak to you….They talk to you like you’re a child when you are not a child.”

Communication – what’s the problem?

- Health Workgroup of FCIC’s Community Advisory Committee also highlighted that there might be instances when an individual with IDD or their caregiver may inadvertently forget to share important information.
- FCIC’s CAC also recognized that an individual with IDD may be accompanied by someone does not know them well, and is unable to accurately answer questions posed by health care professionals.
- In any health care setting (but esp. in an emergency/acute health episode)– apprehensive health care professionals coupled with unprepared individuals/caregivers may lead to poor clinical evaluation, poor patient/health care professional interaction, and ultimately inappropriate treatment....

**effective communication is the key!**
Noted Vulnerability for Poor Health Outcomes
CDC - White Paper 2009 “US Surveillance on Health of People with Intellectual Disabilities”. Highlighted disturbing disparities. **Persons with ID** are a particularly vulnerable population. More likely to............

- Live with complex health conditions
- Have limited access to quality healthcare/health prevention programs
- Miss cancer screenings
- Have poorly managed chronic conditions, eg. epilepsy
- Be obese
- Have undetected poor vision
- Have mental health problems

Two ways to tackle the problem!

- Improve training to health care professionals
- Support individuals and caregivers to share health care needs/information
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Training health-care providers

- FCIC’s collaboration with Morsani College of Medicine, University of South Florida, Nisonger Center – Ohio State University.
- Mandatory training for all medical students in the care of people with disabilities.
- Comprehensive clinical/community-based module within primary care clerkship since 2005.

USF Disability Module Background

- Prompted by major curricular reform in the 3rd and 4th years
- Opportunity to include new topics not previously covered
- Recognized that patients with disabilities are encountered by all physicians, regardless of specialty, but most physicians do not receive any training in the care of this population
- Drs. Woodard and Zwygart were also aware that adults and transitioning youth with disabilities had difficulty finding health care providers in the local area (Tampa Bay), they also personally observed that medical students seemed uncomfortable and unprepared when interacting with a person with a disability in the exam room.

Chart 1

Timeline and Overview of a Disability Module Required During a Third-Year Ambulatory Care Clerkship, University of South Florida, Morsani College of Medicine

### Positive Outcomes!

**Evaluation of a Disability Module’s Impact on 245 Third-Year Medical Students’ Knowledge, Attitudes, and Comfort, University of South Florida Health, Morsani College of Medicine, 2008–2010**

<table>
<thead>
<tr>
<th>Measure</th>
<th>Difference (post – pre)</th>
<th>Cohen d</th>
<th>SD</th>
<th>t Value (df)</th>
<th>Significance (two tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge</td>
<td>2.36</td>
<td>1.97</td>
<td>2.40</td>
<td>14.76 (224)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Attitude</td>
<td>4.20</td>
<td>0.49</td>
<td>17.27</td>
<td>3.62 (221)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Comfort</td>
<td>15.00</td>
<td>0.80</td>
<td>37.45</td>
<td>5.95 (220)</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>


“What an eye-opening experience!...Getting to see how a patient with a serious disability goes about their day-to-day activities was very educational and humbling. I really enjoyed having a chance to talk with the pt’s caregiver as well and to better understand what they go through to take care of their loved ones. **Textbooks don’t provide the same emotional impact as person-to-person communication!**”

### Feedback from Medical Students

“I thought this was a wonderful experience. You can learn much more from a patient in their home than in the clinic and you are able to discuss things that you would not be able to discuss in class. I would definitely continue this experience in the future.”

“I learned about the significant social discrimination that occurs affecting people with disabilities. I learned about some of the multitude of resources available for these patients as well as some helpful hints for their medical care.”

“The model patient exercises were very revealing. I would hope that this exercise influenced my approach to patients with disabilities in the future. It was very revealing and demonstrated the importance of taking extra time with these patients.”
Florida Physician’s Education in Developmental Disabilities Project

4 objectives

• Consortium
• Strategic action plan (including a sustainability plan)
• CME seminar series for family physicians
• Residency level training curriculum

Stop Preaching to the Choir!

We need some new recruits in the congregation!!!
Keep Advocating for Greater Awareness Beyond the Field!

Advocate for better preparedness of geriatric care to individuals with IDD

- increase training, preparation, and sensitivity of health care professionals towards persons with intellectual disabilities
- create less dependency on pediatricians who provide care to patients with IDD long after the transition to adult medical services should have occurred, and
- require that curricula (currently there are no requirements) for US medical schools incorporate teaching competency in the provision of lifespan care to persons with intellectual disabilities.


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Promote Utility of Disability Training

Although specialist health care providers in the field of IDD are a much needed resource.... the need to make all health care providers sensitive, and comfortable with providing care to individuals with IDD is crucial. **Inclusion..Inclusion..Inclusion!**

Such skills can only enhance the health care providers ability to interact effectively with all types of patients.

My personal mantra...... **Make the unfamiliar become familiar!!!!!!**
My Health Passport

• Not just another form....
• Designed to be eye-catching, provide information that is useful
• Needed to be comprehensively concise 😊
• Provide health care providers with strategies to modify the environment, or their own behavior
• Appropriate for all ages
• Makes the unfamiliar become familiar!

My Health Passport

- After the demographic information
  
  ...notice that the first thing that is emphasized is how does the person communicate

Does the person avoid eye-contact but attends to everything that is said?
- Do they make idiosyncratic sounds that have a consistent meaning – e.g. Are they able to verbalize yes and no clearly – “e.g. do they make “eee” sound for yes?”
Brief history, medications, allergies: all important to document.

How a person prefers to take medications: established routines to be adhered to, food/drink preferences

Pain/Distress:
- Health care professionals might be particularly apprehensive when presented with an individual in pain/distress with intellectual disability.

- We all experience pain differently, does an individual understands a numeric or picture pain scale.

- When distressed, is there an effective way to can usually allay their fears, comfort them?

<table>
<thead>
<tr>
<th>How I cope with medical procedures: e.g. how I usually react to injections, P.T., physical examinations, oral, oxygen therapy—also note procedures never experienced before or in recent years</th>
</tr>
</thead>
<tbody>
<tr>
<td>How I cope with medical procedures:</td>
</tr>
<tr>
<td>Taking a blood pressure can be a relatively novel experience.</td>
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</table>

Mobility/personal care needs: helps people from “over-assisting”, from lack of knowledge.

Eating/drinking:
- Individuals may have needs that are easily accommodated if only they are shared.

  - E.g. only drinks from a particular cup, only likes to eat from a bowl, does not use a knife!
Food/drink refusal may occur from restricted range of drinks/foods that are tolerated. Certain textures (e.g. jello), odors from certain foods, presentation of unfamiliar food, may contribute to difficulties at meal-times. Food/fluid intake is crucial, so availability of alternative choices is critical.

Hypersensitivities can also be problematic, given clinical environments (e.g. the odor from alcohol swabs), tv’s/music if in a shared room/open ward.

Follow-up appointments:
Request early/late times, pre-examination orientation visits to new clinics/offices. Pictures of the medical/nursing staff that will be seeing the person.

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**My Health Passport**

Demand for *My Health Passport* has been substantial and widespread, with requests from parent and self-advocacy groups, major medical schools, local and state agencies, hospitals, parent and self-advocacy groups, faculty, and health professionals, from over 20 US States, Canada, and even Germany.
Endorsement from a local provider!

“St. Joseph’s Children’s Hospital has been utilizing the Health Passport for one year and this resource has been extremely valuable for patients and families as well as staff. Currently, the Health Passport is being distributed by the Child Life Department in inpatient and outpatient areas following assessment of the child soon after admission.

During the time of distribution of this resource, we inform families to present the passport upon future admissions. Our staff has been educated on this resource and to consult the Child Life team when a family presents with the Health Passport so that a copy can be made and put on the front of the patient’s chart.

Having this resource available has increased communication within the interdisciplinary team and has allowed staff to take into consideration the specific needs of the child—medically, emotionally, and psychosocially—and alter the hospital environment to meet the child’s needs.

It is also beneficial to our families who are “frequent flyers” so that they do not have to repeat information to different physicians and nurses, therefore allowing them to focus on the needs of their child in this sometimes chaotic and unfamiliar environment. Thank you so much for providing us with this resource!”

Leslie Dempsey, Child Life Specialist, St. Joseph’s Children’s Hospital - Tampa, FL.

My Health Passport

• Versatility
  - appropriate for any age
  - relevant to a wide range of healthcare settings
  - alternative uses – emergency/disaster management preparedness, quick “cheat” sheet for new staff members in residential settings, respite care providers
  - format can be adapted to suit different agencies

• User-friendly
• It’s free!!
My Health Passport
Print and/or save file directly from FCIC’s website:

http://flfcic.fmhi.usf.edu/projects/health.htm

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Please do not hesitate to contact me for further information!
Limited quantities of full-color My Health Passports are available.
References


