My Health Care

Health Literacy, Communication & Self-Advocacy for Individuals with Intellectual and Developmental Disabilities
Presenters

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Acknowledgements

**My Health Care Development Team:**
- Pat Slaski, Educational Consultant, NY
- Laurie James, Educational Consultant, NY
- Randy Miller, Educational Media Consultant, FL
- Dr. John Reiss, University of Florida (retired)
- Holly Hohmeister, Florida Developmental Disabilities Council

**Funding:**
Today’s Agenda

- *My Health Care* Program Description
- Evaluation Studies
- Integration with Access Points & Formative Assessment Rubrics
Today’s Outcomes

- **Know**
  - *My Health Care* goals, structure, & supports

- **Understand**
  - Importance of developing independent self-advocacy & communication skills for health care
  - How this instructional resource supports the teaching & learning of Access Points and *vice versa*

- **Do**
  - Identify courses in which to use the *My Health Care* resource
  - Inform stakeholders
Program Description
Project Goal

- To empower adolescents and adults with IDD in Florida to better meet their own health and wellness needs through improved communication with providers, use of adaptive tools and development of self-advocacy skills
Background

- Convened self-advocate and stakeholder focus groups to identify, prioritize needs concerning wellness and health management
  - Communication with health care providers
  - Identify/access community resources

- Developed health communication and self-management curriculum
  - Extensive literature review
  - Reviewed by professionals
  - Tested with young adult learners

- Curriculum was evaluated and refined over 4 years in an iterative, multi-phase process
Content

- Organized around the mnemonic ‘GLADD’
- Teaching model to remember important skills when communicating with providers and others
  
  **Give** information
  **Listen** and learn
  **Ask** questions
  **Decide**
  **Do** follow through
Activities within the GLADD model

- Use rating scales and visual aids to communicate
- Pay attention to body language
- Learn negotiating skills; provide feedback
- Utilize caregivers to assist with communication
- Be prepared with questions for the provider
- Be assertive when communicating
- Provide a health summary to the physician
- Record communication with physician to enhance information recall and comprehension
- Independently schedule appointments, transportation, manage medications, complete medical forms
- Utilize technology to improve health care self-management
Structure

- 22-hour classroom curriculum
  - PPT presentations with imbedded videos
  - Interactive role play, modeling, games, practice activities
  - Implement in 2 ½ - 3 hours per week over 9 weeks; divided into sequential modules and lessons
  - Step-by-step Instructor’s Guide and training video
  - Recommended class size of 15-25 learners

- 3-person instructor team
  - Includes a self-advocate
Communicate how you are feeling

- Describe symptoms
  - Handy High 5: Who, what, when, where, why
  - Keep a medical diary
- Use visual aids if needed
  - Pain Scales
  - Health Pictures, Communication Boards
Practice good listening skills

- Pay attention to body language

**SLANT**

- Sit up
- Lean in
- Ask questions
- Nod
- Track the speaker
Remember what is said

- Write down information
  - Take notes in your diary
- Use a voice recorder to enhance information recall and understanding
  - Free iphone recording apps
  - Always ask for permission before recording
  - Practice before you go to the doctor’s office

Doctor, what you say during our visit is very important to me. Recording this visit would be helpful with remembering what you tell me, and what to do. May I have your permission to record this session?
Tools to Assist

Ask Your Doctor, Nurse, or Pharmacist:

1. What is my main problem?
2. What do I need to do?
3. Why is it important for me to do this?

My Health Passport

If you are a health care professional that will be helping me, PLEASE READ THIS before you try help me with my care or treatment.

My full name is: ____________________________
I like to be called: ____________________________
Date of birth: __/__/____
My primary care physician: ____________________________
Physician’s phone number: ____________________________

My Health Tracker

- Keep a list of all your lab results and vital signs
- Graph results to track progress
- Test personal goals and compare them to your actual results

MyMedSchedule.com

- Easily create and print medication schedules
- Free medication schedules, reminders, and NEW Health Tracker

Good Questions for Your Good Health

- What is my main problem?
- What do I need to do?
- Why is it important for me to do this?
Tools to Assist

Short Videos with step-by-step instructions
Tools to Assist

FloridaHATS Web Site and Service Directory

www.FloridaHATS.org
Health Insurance

- Plan for change in insurance coverage
  - Medicaid
  - Parents’ plan
  - Employer-based
  - Marketplace plans
Evaluation Studies
Implementation

- Diverse learning settings across Florida communities
  - School-based secondary and post-secondary classes
  - Young adult transition programs
  - Adult day training programs
  - Community-based classes

- Number of participating sites and learners increased each year over 4 years
  - 1st Year: 3 learning groups, 45 learners
  - Last Year: 11 learning groups, 182 learners

- Iterative evaluation process with ongoing refinements in course content and measurement tools
Evaluation Questions

1. Does the intervention increase knowledge and self-efficacy in communication and self-management skills?
2. Do learners utilize knowledge and utilize skills over time?
3. What are the perceived value and relevance of the curriculum among learners and instructors?
4. How can it be improved for future implementation?
Methods

- Learner pre-post test
  - 24 knowledge/10 self-efficacy/4 satisfaction questions
- Follow-up questionnaire
  - Learners from previous year
  - 10 questions about use of skills learned in the curriculum
- Instructor questionnaire
  - 14-item survey following implementation of each module: content, structure, utility, clarity, suggestions for improvement
  - 10 weekly post-lesson teleconferences with project team
- Post-intervention learner focus groups
Topline Results from 2014-2015

- Participant median age was 31 yrs; 57% female
- Paired samples t-test ($n=97, \alpha<.05$) showed significant increase in both knowledge and self-efficacy scores from pre- to post-test
- High satisfaction among learners and instructors
  - 2.8 median rtg among learners (1 low - 3 high scale)
  - 4.5 median rtg among instructors (1 low - 5 high scale)
- Among 35 learners from previous year
  - 94% reported taking part in decisions about medical treatment in last 12 months
  - 83% used strategies from My Health Care to remember instructions
  - 74% made a list of questions before an appointment
Learner Quotes

- You need to know how to talk to the doctor by yourself because you won’t have your parents forever.
- I like being independent.
- It’s important because you’re the patient.
- It’s important to speak up for yourself.
- I learned about making my own choices.
- The best thing I've learned ... is what questions to ask and to take notes on those questions so that you understand what the doctor is saying.
Evaluation Report

- Full results:
  
Integration with Access Points & Formative Assessment Rubrics
Instructional Resource for Schools

- Integrate with Florida Standards for special education and transition
  - Identified 87 standards in English Language Arts (45) and Health Education (42) that ‘My Health Care’ supports

- Develop formative assessment rubrics for learners
  - Reduces the multi-grade, multi-complexity level dilemma
  - Measures student mastery of knowledge and skills by standards expectations and module learning objectives

- Accessible through FLDOE’s Curriculum Planning and Learning Management System (CPALMS)
  - Florida’s official source for standards information and course descriptions
Materials on CPALMS

My Health Care

The goal of My Health Care is to empower patients with intellectual or developmental disabilities (IDD) to better meet their own health and wellness needs through improved communication with providers, the use of adaptive tools, and development of self-advocacy skills. The project is funded by the Florida Developmental Disabilities Council, Inc. (FDDC) and was developed in partnership with the University of South Florida.

My Health Care is organized around the mnemonic “GLADD:” a teaching model developed at University of Florida’s Institute for Civil Health Policy. GLADD serves as a reminder about important skills to use when communicating with health care providers and others: Give Information; Listen; Ask questions; Decide; Do (follow through on the action plan).

My Health Care activities within the GLADD model include:
- Being prepared with questions and issues to discuss at office visits
- Providing a health summary to the physician
- Being assertive when communicating and paying attention to body language
- Using rating scales and visual aids to communicate health issues
- Learning negotiating skills: providing feedback to the physician
- Utilizing resources to assist with communication
- Recording communication with physician to enhance information recall and comprehension
- Utilizing technology to improve health care communication and self-management

In addition to using GLADD to guide skill building, learners are introduced to other fun and easy-to-remember mnemonics such as SAVIM (See-up Lean In-Adaptations-Wheel-Track the speaker to use when talking to a provider), and Handy High 5. What-When-Where-Why-to use in describing a medical event or condition.

www.cpalms.org/project/my_health_care.aspx
## Access Point Integration

### Grades 9-10 ELA Access Point Integration

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<td>LAFS.9-10.W.1.AP.2e</td>
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## Access Point Integration

**Give**

Give information about how you are feeling

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### Independent

**HE.912.B.4.In.a**

Describe strategies to communicate effectively with family, peers, and others to enhance health, such as having appropriate voice pitch and volume, maintaining eye contact.

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**HE.912.B.4.In.c**

Use basic strategies to prevent or resolve interpersonal conflicts without harming self or others, such as using effective verbal and nonverbal communication, compromising, and using conflict resolution skills.

### Participatory

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<tr>
<th>HE.912.B.4.Pa.a</th>
<th>Use selected communication strategies to enhance personal health, such as having appropriate volume, maintaining eye contact, and using words and gestures to clarify meaning.</th>
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<td>HE.912.B.4.Pa.c</td>
<td>Use a refusal, a negotiation, or a collaboration skill to avoid or reduce personal health risks or resolve conflicts, such as stating desires clearly, offering alternatives, using “I” messages, expressing emotions, or making direct statements.</td>
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Access Point Integration

Give
Give information about how you are feeling

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Health Access Point Integration

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<th>Supported</th>
<th>Participatory</th>
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<td>HE.912.B.4.In.a Describe strategies to communicate effectively with family, peers, and others to enhance health, such as having appropriate voice pitch and volume, maintaining eye contact.</td>
<td>HE.912.B.4.Su.a Identify strategies to communicate effectively with family, peers, and others to enhance health, such as having appropriate voice pitch and volume, maintaining eye contact, journaling, letter writing, and speaking persuasively.</td>
<td>HE.912.B.4.Pa.a Use selected communication strategies to enhance personal health, such as having appropriate volume, maintaining eye contact, and using words and gestures to clarify meaning.</td>
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<td>HE.912.B.4.In.c Use basic strategies to prevent or resolve interpersonal conflicts without harming self or others, such as using effective verbal and nonverbal communication, compromising, and using conflict resolution skills.</td>
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Access Points with Essential Understandings (EUs)

ELA Access Points with Essential Understandings

Note: Essential Understandings (EUs) describe critical skills needed for mastery of the Access Point itself, but are not part of the Access Point. The EUs provide guidance on where and how students might enter into the learning and eventual mastery of the targeted Access Point. They are dynamic and evolving supports that will continue to grow over time. The EUs provided here are current as of this publication date. Future updates can be found at www.accessstofls.weebly.com.

Grades 9-10

LAFS.9-10.L.3.AP.6b Use newly acquired domain-specific words and phrases accurately.
EUs With guidance and support use newly acquired words to answer questions.

LAFS.9-10.SL.1.AP.1f Engage appropriately in discussion with others who have a diverse or divergent perspective.
EUs Complete sentence stems that promote positive environments during collegial discussions. (Ex: I agree/disagree with..., The text states..., How do you feel about...)
Address appropriate tone, volume, eye contact, inflections, etc.
Identify common agreements and disagreements with others on a common or familiar topic.

LAFS.9-10.SL.2.AP.5a Include multimedia components and visual displays in presentations to clarify claims and findings and emphasize salient points.
EUs Identify from provided choices which multi-media feature matches the information provided in a report (e.g. audio clip, embedded video, maps, diagrams, etc.).
Identify the most important facts/details in a report.
With guidance and support, determine what multi-media features should/could be included in the writer's report to emphasize certain facts or details

LAFS.9-10.SL.2.AP.6a Recognize situations when the use of formal English is necessary (e.g., making a presentation vs. talking with friends)
EUs Identify a given text or conversation as formal or informal English

LAFS.9-10.W.1.AP.2c Provide relevant facts, extended definitions, concrete details, quotations or other information and examples appropriate for the audience.
EUs Sort relevant and irrelevant information related to a given topic into the correct categories.
Identify facts and details related to a specified topic.
Develop the topic by identifying at least one relevant fact, definition, quote, example or detail.
List characteristics of the audience that might change the focus of the writing.
# Formative Assessment rubrics

<table>
<thead>
<tr>
<th>Example(s) of student work</th>
<th>Student misconceptions or errors</th>
<th>Questions to elicit thinking</th>
<th>Instructional implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Get it</td>
<td>None</td>
<td>In what situations might you need to communicate with specific staff?</td>
<td>Become peer model</td>
</tr>
<tr>
<td>Almost there</td>
<td>Student independent engagement in sharing information with the target audience but requires prompting to use appropriate - grammar, - body language, - logical sequence, - relevant facts and/or details</td>
<td>What do you need to say? How should you get _____ attention? What do you need to do now? Who do you need to speak with? Is there another way you could ask/say ___? What are the five elements of the Handy High Five strategy? In what situations would you use the Handy High Five strategy?</td>
<td>Apply skills (generalized) to other domain(s) (e.g., transportation, dining, recreation, on-the-job)</td>
</tr>
<tr>
<td>On your way</td>
<td>Student can distinguish between sender and receiver Understands that it is important to tell others how they are feeling Student requires an open-ended or partial prompt to engage in sharing information with the target audience.</td>
<td>What do you need to say? Who do you need to do next? Who do you need to speak with? Can you show me where (or what) hurts? Can you tell me when (or where) it happened? Do you speak to the ____ or speak to the ____?</td>
<td>Extend in &amp; out of classroom practice Extend wait time for independent initiation Teach appropriate ways to get someone’s attention Provide additional examples and non-examples of non-verbal and verbal communication (e.g., gestures, eye contact, voice, touch, body movements, etc.) Have student identify missing element of the Handy High Five by referencing the visual support Provide additional practice and role play Provide additional visual supports</td>
</tr>
<tr>
<td>Starting out</td>
<td>Student requires a full verbal or physical model to engage in sharing information with the target audience Student uses socially unacceptable verbal and non-verbal communication</td>
<td>Who do you talk to when you do not feel well or something hurts? What do you say when you do not feel well or something hurts?</td>
<td>Work with SLP to establish a socially acceptable communication system Teach appropriate ways to get someone’s attention Practice identifying speaker vs. listener Forward chain 2 or 3 step task analyzed sequence with visual support (e.g., get someone’s attention, tell them you hurt, tell them where you hurt)</td>
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[Handy High Five strategy is a method for teaching and practicing effective communication skills, focusing on clear and relevant expression of thoughts and feelings.]
Where are we?

- **Know**
  - *My Health Care* goals, structure, & supports
- **Understand**
  - Importance of developing independent self-advocacy & communication skills for health care
  - How this instructional resource supports the teaching & learning of Access Points and *vice versa*
- **Do**
  - Identify courses in which to use the *My Health Care* resource
  - Inform stakeholders