




My Health Care

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

1



Acknowledgements

Project Team Members:

- 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

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2

Program Description

3



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

4



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

5



Content

- ▶ Organized around the mnemonic 'GLADD'
- ▶ Teaching model to remember important skills when communicating with providers and others
 - G**ive information
 - L**isten and learn
 - A**sk questions
 - D**ecide
 - D**o follow through

6

Content

- ▶ **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



7

Structure

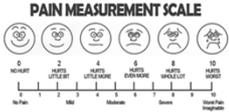
- ▶ **22-hour classroom curriculum**
 - PPT presentations with imbedded videos
 - Interactive role play, modeling, games, practice activities
 - Implement in 2 1/2 - 3 hours per week over 9 weeks; divided into sequential modules and lessons
 - Step-by-step Instructor's Guide and training video
 - Recommended class size of 15-25 learners
- ▶ **3-person instructor team**
 - Includes a self-advocate



8

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


9

Practice good listening skills

- ▶ Pay attention to body language

SLANT

- Sit up
- Lean in
- Ask questions
- Nod
- Track the speaker

10

Prepare questions ahead of time

- ▶ **Be prepared with questions and issues to discuss at office visits**
 - Write questions on paper
 - Record them on a voice recorder
- ▶ **If you don't understand what you're being told:**
 - Let your doctor/nurse know
 - Ask them to explain in a different way
 - Ask for written instructions or materials to take home
 - Keep asking until you understand
- ▶ **There's no such thing as a DUMB question!**

11

Tools to Assist





12

Tools to Assist



Short Videos with step-by-step instructions



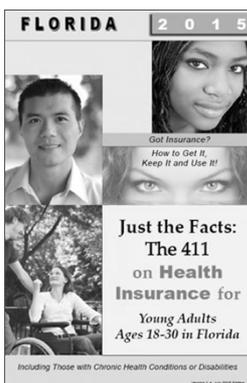
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Tools to Assist



FloridaHATS Web Site and Service Directory
www.FloridaHATS.org

▶ 14



Health Insurance

- ▶ Plan for change in insurance coverage
 - Medicaid
 - Parents' plan
 - Employer-based
 - Marketplace plans

▶ 15

Evaluation Studies

16

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

▶ 17

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?

▶ 18

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

▶ 19

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

▶ 20

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.*

▶ 21

Evaluation Report



- ▶ Full results: www.floridahats.org/wp-content/uploads/2010/03/Evaluation-Report_8-30-15.pdf



▶ 22

Adoption and Dissemination

23

Dissemination



- ▶ Introduced to 13 evaluation sites in Florida over 4 years
 - Institutional adoption of program
- ▶ Free downloadable materials
- ▶ Continue to introduce to statewide network programs for individuals with IDD
 - Special Olympics Healthy Communities (3 in Florida)
 - Florida Arc
 - Florida Centers for Independent Living
- ▶ Made available to all secondary and post secondary schools

▶ 24

Instructional Resource for Schools



- ▶ Integrated 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
- ▶ Developed formative assessment rubrics for learners
 - 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



www.cpalms.org/project/my_health_care.aspx