My Health Care

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

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*No relationships to disclose*
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Project Team Members:

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Funding:
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
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!
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?

Good Questions for Your Good Health
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, α< .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:
Adoption and Dissemination
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
- Make available to all secondary and post secondary schools
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
  - 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
The goal of My Health Care is to empower patients with intellectual or developmental disabilities (ID/DD) 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 “GLADID,” a teaching model developed at University of Florida’s Institute for Child Health Policy. GLADID 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 GLADID 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 peers 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 GLADID to guide skill building, learners are introduced to other fun and easy-to-remember mnemonics such as SAMIT (Sit up, Lean In, Ask questions, Make note, Track the speaker to use when talking to a provider) and Handy High Fives (What-When-Who-Why; to use in describing a medical event or condition).

www.cpalms.org/project/my_health_care.aspx