My Health Care

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

My Health Care Team:

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Funder


Partner Agencies

FloridaHATS, Children’s Medical Services
University of South Florida
CPALMS
Today’s Agenda

- Program Development
- Content
- Evaluation Studies
- Access to Curriculum
Program Development
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 steps individuals with IDD can take to improve personal health and wellness
  - Communicate more effectively 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
GLADD Model

- Organized around the mnemonic ’GLADD’
- Teaching model to remember important skills when communicating with providers and in health care self-management
  - Give information
  - Listen and learn
  - Ask questions
  - Decide
  - Do follow through
Activities

• 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 video
  - 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

- Be HONEST in giving complete, detailed information
- Describe how your condition affects your everyday life
- Describe symptoms
  - Handy High 5: Who, what, when, where, why/how
  - Keep a medical diary
- Use visual aids if needed
  - Pain Scales
  - Health Pictures, Communication Boards
Tools to Assist

PAIN MEASUREMENT SCALE

0 NO HURT
2 HURTS LITTLE BIT
4 HURTS LITTLE MORE
6 HURTS EVEN MORE
8 HURTS WHOLE LOT
10 HURTS WORST

No Pain Mild Moderate Severe Worst Pain Imaginable
Tools to Assist
Listen and Learn
Practice good listening skills

- Listening includes UNDERSTANDING
- 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?
Learn more about your condition

- Read books
- Explore the Internet
  - Ask your doctor/nurse for recommended web sites
- Considerations for your job
  - Environment
  - Special dietary or medication needs
  - Accessibility
  - Stamina and strength issues
- Talk to people who have the same or a similar condition
GLADD
Ask Questions
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 Me 3

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?

Ask Me 3

AHRQ Question Builder

QUESTIONS ARE THE ANSWER

Question Builder

Be prepared for your next medical appointment. Create a list of questions that you can take with you whether you are getting a checkup, talking about a problem or health condition, getting a prescription, or discussing a medical test or surgery. Whatever the reason for your visit, it is important to be prepared. With the Question Builder, it is easy.

Step 1: Choose the kind of appointment you need

Why are you going to see your doctor? Select one of these options:
- To talk about a health problem
- To get or change a medicine
- To get medical tests
- To talk about surgery

Next »
Decide on a Plan of Care
Participate in developing a plan

- With your health care team and circle of support, set goals for health, work and independent living
  - How will you achieve your goals?
  - What services will you need?
  - Who will provide them?
  - How will they be paid for?

- Explore community resources that may help you
  - Your doctor may need to provide documentation of medical condition/disability to meet program eligibility guidelines
FloridaHATS Service Directory

Health Services Directory for Young Adults

Use the form below to search for health care programs and providers in your area that serve young adults, including those with disabilities or chronic health conditions.

Please help us keep the directory up-to-date. We encourage both consumers and providers to let us know about resources you think should be included. For instructions on how to add a service or recommend a program, please visit our directory submission page. To update an existing entry, first search for listing using the form below. Open the current listing. In upper right-hand corner, click on the “Update this listing” text link. Make corrections on form page then click submit. All information that is submitted will be verified prior to uploading to the directory.

Search By: Categories AND/OR Keyword(s)

City, State, County
--- Any City ---

Health Category
--- Any Health Category ---
Behavioral and Mental Health
Dental
Eating Disorders
...

Search by Keyword(s)

Submit    Reset
Plan for change in insurance coverage

- Medicaid
- Parents’ plan
- Employer-based
- Marketplace plans
Employment

Apply to Division of Vocational Rehabilitation

School to Work Transition Vocational Training

Most teens and young adults look forward to having a job and being independent. For young Floridians with disabilities whose goals include employment, the Florida Department of Education’s Division of Vocational Rehabilitation (VR) can provide critical support services. This federal-state program works with people who have physical or mental disabilities to prepare for, gain and/or retain employment.

Transition planning for individuals whose health conditions interfere with their ability to work should address eligibility for an array of VR programs, including the School to Work Transition program. The School to Work Transition program specifically helps students ages 16-22 prepare for employment and adult life. VR transition activities can help students enter training, continue education, and/or find a job after leaving high school.

Any student with a disability may be eligible for VR services starting at age 16. For students who receive special education services, schools often take the lead in referral to VR as part of the student’s Transition Individualized Education Plan (IEP). However, having an IEP is not a VR eligibility requirement. Students who may benefit from VR services should apply at least 2 years before leaving high school, e.g., apply at age 16 if leaving high school at age 18. VR can also assist students with community work experience while they are still in high school. Applications can be downloaded at http://rehabworks.org/docs/VRapplication.pdf.

VR referrals can be made by anyone by contacting the local VR office at www.rehabworks.org (click on VR Office Directory). To learn more about the School to Work Transition program, visit www.rehabworks.org/docs/SchooltoWork.pdf.

In addition to VR, Workforce Florida offers job training for income eligible clients, including youth ages 14-21 (WIA Youth Programs) and individuals with disabilities. Eligibility requirements vary by local board, so interested persons should contact their local One-Stop Career Center (see www.workforceflorida.com).

For more information about this topic, visit the Tool Box at www.FloridaHATS.com or contact Janet Hess at jhess@health.usf.edu. (813) 259-8604.

Issue no: 2  Revised June 2013
Consider decision-making alternatives, such as health advocate, guardian advocate or guardianship

Explore long-term financial planning options, such as a special needs trust
Practice negotiating skills

- It is important to provide feedback to the physician about your treatment plan
  - Can you follow the plan? If not, why not?
  - Are there alternative treatment options?
- Tips for negotiating
  - Know what you want and why
  - Plan what you will say
  - Be truthful
  - Be assertive
D

Styles of Communication
Styles of Communication

• In order to get what you want, you must be able communicate in a way that makes other people want to listen.

• How you say something is very important in communicating.

• Watch the following video clips. Compare the different communication styles used in each scene.
Three Styles of Communication
Compare and Contrast

• How were the videos the same?
• How were the videos different?
• Any other thoughts?
Communication Skills

3 ways to let others know what you are thinking and feeling

– Passive
– Aggressive
– Assertive
Hold up Your Card Activity

- Distribute a set of three style cards per participant
- Watch each video again
- Hold up the card of the style shown in the video.
Video Scene 1
Video Scene 2
Compare and Contrast

- Which style is best for getting what you want?
- Share an experience where you wished you had been more assertive? Why? Explain how the outcome might have been different.
Role Play

Volunteers act out a short role play with a doctor and patient.
Module “D” Session 2

How to Negotiate
Discussion

• Think a situation when you didn’t get what you wanted, how it made you feel.

• To resolve this situation, you need to negotiate and find a compromise.
Negotiation
Tips for Negotiating

• Know what you want to say and why
• Plan what you want to say
• Be truthful
• And don’t give up!
• Compromise
# Negotiation Skill Steps Checklist

As each student completes a role-play, place a check mark by each skill step that was performed correctly.

|-------------------------------|-----------------------|-----------------------------|----------------------|----------------------------|-------------------------|-----------------------------|--------------------------|----------------|--------------------------------|--------------------------------------|---------------------|

This form was adapted from one used in *The Speak Up! Guide* published by STIR – Steps Toward Independence and Responsibility, and Shifting the Power, projects of the Clinical Center for the Study of Development and Learning, UNC-CH.
Pair Share

- Pick a partner
- Use same scenario or make one up
- Use negotiation skills
- Come up with a compromise
- Share your experience with group
Confidence Meter

I'm Ready to Speak Up for Myself!
- Make Eye Contact
- Shake Hands
- Introduce the Person(s) with Me
- Talk Directly to Person
- Speak Clearly Using a Moderate Voice Tone (not too loud or too soft)

I Now Know What I Want to Say

I Am Unsure of Myself

How to use the Confidence Meter: Participants are asked to rate how confident they are about interacting with various health care professionals. The confidence meter focuses attention on their social skills and language pragmatics. It can be used to generate discussion about the importance of active participation in one’s own health care.
End of Session

Congratulations!
GLADD

Do Your Part
Carry a health summary with you

- Put personal health information in one place and keep it updated
  - Medical history and medications
  - Equipment and supply needs
  - Physician, hospital, emergency contacts
  - Health insurance

- Be able to access it easily
  - Paper copy
  - Thumb drive
  - Electronic Patient Portal
Tools to Assist

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: __________________

This passport has important information so you can better support me when I visit/stay in your hospital or clinic. Please keep this with my other notes, and where it may be easily referenced.

My signature: ______________________ Date completed: __/__/____
You can talk to this person about my health: ______________________ Relationship: ______________________

I communicate using: (e.g. speech, preferred language, sign language, communication devices or aids, non-verbal sounds, also state if extra time/support is needed)

My medical history: (include other conditions e.g. visual impairments, hearing impairment, diabetes, epilepsy, post-operative, allergies, and other medical issues)

My current medications are:

When I take my medications, I prefer to take it: (e.g. with water)

How I cope with medical procedures: (e.g. how I usually react to injections, IV's, physical examinations, x-rays, oxygen therapy--also note procedures never experienced before or in recent years)

I am allergic to: (list any)
If I am in pain, I show it by: (you may fill in a pain scale)

My mobility needs are: (e.g. whether I can walk or use a wheelchair, can I sit, can I stand, need a cane/pole)

My favorite foods and drinks are:

When drinking, you may assist me by:

My pain medication:

When drinking, you may assist me by:

I do not like to eat due to: (list any)

I am very sensitive to: (list any)

How to make future appointments easier for me:

Things I like to do that will help pass the time:
Learn how to schedule and navigate doctor’s visits

- Practice scheduling your doctor’s appointment
- Arrange for transportation
- Fill out paperwork at the doctor’s office
  - Medical history
  - Insurance
  - Consent to Treat
  - HIPAA Privacy form
- Ask questions if you don’t understand, and don’t be afraid to ask for help!
Tools to Assist

Short Videos with step-by-step instructions
Manage your medications

- Learn the correct names of your medicines, when you take them, and why
- Be able to read prescription labels
- Be able to refill your prescriptions
- Bring a list of your medications to doctor visits
- Keep a chart with times you need to take medicine and dosage
- If you take several medications, a pill organizer can help
Tools to Assist

Using MyMedSchedule.com

This video will demonstrate how you can use MyMedSchedule.com, an electronic reminder tool that can help you manage your medication regimen.

View Video
Evaluation Studies
Implementation

- Diverse learning settings across Florida communities
  - Young adult transition and post-secondary programs
    - UNF On Campus Transition Program, Xperience/Arc Jacksonville, Lynn University ACCESS, FAU ACCESS, Transition to Life Academy/Gulfstream Goodwill
  - Secondary 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 confidence 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 confidence/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 confidence 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 curriculum strategies 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:
Access to Curriculum
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 Health Communities (3 in Florida)
  - Florida Arc
  - 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
Materials on CPALMS

My Health Care

The goal of My Health Care is to empower persons 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 strategies 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 SUNRISE (Start up—Learn In-Adaptations—Move) Track the speaker to use when talking to a provider) and HANDY High x Who—What—When—Where—Why (to use in describing a medical event or condition).

www.cpalms.org/project/my_health_care.aspx
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