



My Health Care:
**A Health Literacy and Communications Training Program
for Adults with Intellectual or Developmental Disabilities**

Year 4 Evaluation Report

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Background

Health and wellness are the foundations that allow people to fully participate in many of the most important aspects of life.¹ For almost 54 million Americans who self-identify as having a disability,² maintaining good health and reducing secondary conditions are especially important for good quality of life and participation in multiple life roles.¹ Yet, research has consistently documented that, as a group, people with disabilities experience worse health than the general population; that is, they are more likely to experience potentially preventable secondary conditions, chronic conditions, and early death than those without disabilities.²

In 2011, the Health Care and Prevention Task Force, Florida Developmental Disabilities Council, Inc. (FDDC) launched an initiative to improve health outcomes for adults with intellectual or developmental disabilities (I/DD). FDDC partnered with the University of South Florida (USF), University of Florida (UF), and Syracuse University to explore ways to empower individuals with I/DD to better meet their own health and wellness needs. In preliminary formative research, self-advocates, health care providers and other stakeholders identified *improved communication* as a strategy to help Floridians with I/DD become more independent in managing their medical and health care needs.

Based on these findings, a multidisciplinary project team of researchers, health care professionals and educators conceptualized the development of a health literacy and communication training curriculum for adults with I/DD. An extensive literature review highlighted numerous high quality communication-related materials; however, no single package incorporated all of the elements identified as essential to the FDCC program. Guided by a panel of self-advocates and advisors with expertise in I/DD, the team created a training curriculum entitled *My Health Care* that consisted of existing material and original content, and began a multi-phase, iterative process of testing, assessing, and refining the program.

FDDC established a goal to implement the training program in eight diverse areas of Florida by 2015, and to assess impact of the curriculum on learner knowledge and advocacy skills. Program partners were selected based on an organizational mission to help individuals with I/DD become more self-sufficient, type of structured setting offered at the site, capacity to support program participants over time, geographic location, and diversity of the individuals served.

In 2012-2013 (Year 2), *My Health Care* was implemented in the first two communities, Jacksonville and Tampa. In 2013-2014 (Year 3), these two sites continued with implementation among both new and returning learners, and the curriculum was introduced in three new communities: Boca Raton, Orlando, and Panama City. During the final year of the project, 2014-2015, the program expanded to six new instruction sites that included Boynton Beach and Stuart. This report describes findings from process and impact evaluation data in Year 4 among 11 learning groups, with a focus on recommendations for program improvement and sustainability.

Curriculum Description

My Health Care is organized around the mnemonic “GLADD,” a teaching model developed at UF’s Institute for Child Health Policy.³ GLADD serves as a reminder about important skills for communicating with health care providers and others: **G**ive (information), **L**isten, **A**sk (questions), **D**ecide, and **D**o (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
- Paying attention to body language
- Using rating scales and visual aids to communicate health issues
- Learning negotiating skills; providing feedback to the physician
- Utilizing caregivers to assist with communication
- Recording communication with physician to enhance information recall and comprehension
- Utilizing technology to improve health care communication and self-management
- Learning other easy-to-remember mnemonics such as SLANT (Sit up-Lean in-Ask questions-Nod-Track the speaker; to use when talking to a provider) and Handy High 5 (Who-What-When-Where-Why; to use in describing a medical event or condition).

The 22-hour curriculum employs a multi-modal teaching approach to accommodate diverse learner needs, incorporating skill-building, modeling, games, role play and practice activities throughout the course. It is comprised of nine modules divided into multiple sessions, using PowerPoint slides with embedded video, web-based resources and print materials for learners, and step-by-step guidance for instructors that corresponds to the PowerPoint slides and other classroom materials. An Instructor’s Guide and training video reviews standard teaching tools used in the curriculum (e.g., role play, mind mapping, pair-share) and outlines resources needed to implement the program.

My Health Care is structured to implement in 2½ – 3 hours per week over nine weeks, in a classroom or other group setting. A three-person instructor team includes two professional instructors and a self-advocate with I/DD. The self-advocate, in addition to sharing responsibility for instruction, plays an important role as a mentor to learners, sharing personal experiences and lessons learned. The three-person team is designed to support a class of 15-25 learners, though level of support may vary with the needs of specific learner groups.

New content is introduced sequentially by instructors in the first eight modules and includes out-of-classroom activities for learners; the last module is a review of material. The PowerPoint slides and learner materials are highly visual and designed for individuals with low reading proficiency. Technology requirements for implementation include internet access and audio-video equipment for classroom presentations (i.e., computer, LCD projector, screen).

Year 4 Intervention

In Year 4, the curriculum was implemented among 182 learners in 11 learning groups. Participating sites encompassed six new classes and five continuation groups from 2013-2014: five adult day training (ADT) classes; four young adult transition classes (two were university-based); one high school class; and one community-based class. The following partners participated in the final year of the project.

1. St. Andrew Bay Center (SABC) in Panama City conducted one class for SABC clients and one community-based class at Gulf Coast State College.
2. Quest in Orlando administered one class.
3. Palm Beach School District in Boca Raton conducted a class at Boca Raton Community High School and one at Florida Atlantic University (FAU) ACCESS Program. The FAU transition class was moved last year from Lynn University, and included several students who participated in 2013-2014.
4. Gulfstream Goodwill conducted one class for clients living in the Treasure Coast area (Stuart, Vero Beach and surrounding areas).
5. Transition to Life Academy conducted one class in Boynton Beach. This program is affiliated with Gulfstream Goodwill but is an autonomous transition charter school.
6. Arc Jacksonville conducted classes at four sites: On Campus Transition Program at University of North Florida, Downtown, Westside, and Xperience, a young adult transition program that meets in the community (local church) rather than university.

ADT and young adult transition classes were comprised of adults with I/DD enrolled at their respective programs/agencies and not employed full time. Enrollees typically attend the majority of life-skills activities offered by their site, which include a combination of structured education classes, hands-on learning experiences, and self-directed components. While participation in *My Health Care* was not mandatory for enrollees, site directors encouraged participation among individuals whom they thought would benefit from the training. The public high school class was comprised of students ages 14 -18 with I/DD and/or Autism Spectrum Disorder (ASD). The community-based class was open to any adult with I/DD who lived in Panama City area and wasn't enrolled at SABC. Curriculum participants completed all nine weekly modules in either a single 2 ½ - 3 hour block or split into shorter segments across the week.

Among 182 learners, there were 165 new learners and 17 returning learners from continuation sites (i.e. 16 learners also completed the curriculum in 2013-2014). Ten instructor teams comprised of 25 professional instructors and self-advocates facilitated learning. Most instructors were already employed at their respective I/DD site and were well acquainted with the learner groups; many self-advocates were high functioning current or former clients. Instructors viewed a one-hour training video and reviewed curriculum materials prior to a training teleconference led by project team members; the teleconference was conducted approximately one week before curriculum start. The project team continued to provide technical assistance and support throughout the implementation period via weekly teleconference calls with instructors.

Sites were provided with CDs for learners and instructors that contained all learning materials, printed guides for each instructor, and portfolios (document organizer) for learners to use during and after the course. In addition, each site was paid a fee to cover the printing cost for learner materials.

Evaluation Methods

Several broad questions guided process and impact evaluation activities:

- To what extent does the program increase learner knowledge, self-efficacy and skills in health care communication and self-management?
- What are perceived value and relevance of the curriculum among learners and instructors? Were they satisfied with the program?
- Do learners apply knowledge and utilize skills learned in *My Health Care*?
- How can the curriculum be improved for future implementation and sustainability?

A combination of quantitative and qualitative research techniques were used to collect data from learners and instructors who participated in the study. Particular attention was given to assessing their experiences with the curriculum in order to refine and improve program components.

Pre/Post Learner Survey

We used a non-randomized pre/posttest research design to assess change in learner knowledge and self-efficacy as a result of the intervention. A paper questionnaire (see Appendix A) was administered by instructors to 182 new and returning learners one week prior to start of the curriculum (pre-test) and approximately 30 days following completion of the course (post-test). Instructors assisted participants who had difficulty reading or responding to the questions independently.

The learner survey encompassed four domains:

- 1) Self-report of confidence (self-efficacy) in communicating with providers. The assessment section was a 10-item Likert-type scale in which learners rated their ability to advocate for themselves in encounters with health care providers and to manage their own health care.
- 2) Knowledge of key concepts and content from the curriculum. This section was comprised of 24 questions about important health communication strategies, terms, and tools, in the form of multiple choice, true/false, and matching items.
- 3) Demographic information included gender, age, ethnicity, living arrangement, program, new vs returning learner, and whether assistance was provided in completing the survey. Learners were asked their names for the purpose of matching pre- and post-tests, but all study data was kept confidential.
- 4) Satisfaction with curriculum (post-test only). Learners rated the degree to which the curriculum was useful and enjoyable.

Descriptive and correlational statistical methods were used to compare pre- and post-test scores for knowledge and confidence. A paired samples t-test was used to determine if there was a statistically significant increase in scores among new learners, using GraphPad InStat version 3.00 for Windows 95, GraphPad Software, San Diego California USA, www.graphpad.com.

Year 2 Learner Survey

Learners who completed the program in 2013-2014 at one of the five continuation sites were asked to complete a survey concerning utilization of skills. In addition to general demographic questions, Year 2 learners were asked whether they had used skills from the curriculum at a physician visit sometime in the last 12 months. The 10-item activity questionnaire is attached in Appendix B. Year 2 learners who repeated the course in 2014-2015 (current implementation year) completed both this questionnaire and the Pre/Post Learner Survey.

Instructor Questionnaire

Instructors were asked to provide verbal and written responses to questions concerning curriculum content, structure, utility, clarity and other features. They completed an 11-item Likert-type rating scale along with three open-ended questions following the completion of each module (see Appendix C). They also participated with project team members in a weekly group teleconference to elaborate on their survey responses and to address specific problems or concerns. Instructor data were analyzed using descriptive methods.

Learner Focus Group

A convenience sample of learners were invited to attend a focus group following completion of the curriculum. They were asked about their perceptions of the program, least/most important information in the course, least/favorite activities, and ways to improve the module (See Appendix D). The group was facilitated by the project team leader and analyzed using a priori codes.

Limitations in Methodology

There are some noteworthy limitations in research methodology. Absence of a non-intervention comparison group limits the degree to which change in learner knowledge and confidence can be attributed to the curriculum. The use of self-report measures raises questions of accuracy of the data. Further, written questionnaires may not be an adequate measure of knowledge and performance for individuals with I/DD due to generally low reading proficiency among the population. Whereas instructors were advised to assist learners in completing surveys by reading questions and/or recording learner responses (only), the protocol poses some threat to validity.

The USF Institutional Review Board determined the study was program evaluation rather than generalizable research, so IRB oversight was not required. Consent was explained verbally to participants so they would fully understand their voluntary participation in the study. Signed consent/assent was obtained from adults with I/DD or their legal guardians (see Appendix E).

Results

Pre/Post Learner Questionnaires

A total of 97 matched, useable pairs were completed by new learners. Due to learner absences and scheduling difficulties, several participants were unable to fully complete both pre-and post-tests, and several questionnaires were not useable, e.g., substantial missing data, multiple responses to questions, etc. Table 1 shows demographic characteristics of study subjects (new learners only) who completed both the pre- and post-test.

Table 1. Demographic profile of new learners with matched pre- and post-survey

Learner Pre/Post Survey	Total n=97
Gender	
Male	42 (43%)
Female	55 (57%)
Age	
Median	31.1 yrs
Range	14 - 73 yrs
14-17 yrs	6 (6%)
18-29 yrs	51 (53%)
30-49 yrs	27 (28%)
50-65 yrs	10 (10%)
65+ yrs	3 (3%)
Living Arrangement	
With parents	54 (56%)
With other relatives	10 (10%)
With roommates	17(18%)
In a group home or facility	9 (9%)
Other	7 (7%)
Race/Ethnicity	
Black or African-American	23 (24%)
Hispanic or Latino	9 (9%)
White or Caucasian	54 (56%)
Asian or Pacific Islander	1 (1%)
Multiracial	1 (1%)
Other	3 (3%)
Don't know	6 (6%)
Program	
Arc Jacksonville	
OCT/UNF	6 (6%)
Westside	9 (9%)
Downtown	6 (6%)
Xperience	5 (5%)
St. Andrew Bay Center	
SABC	19 (20%)
Gulf Coast State College	9 (9%)
Quest	3 (3%)
Palm Beach County School District	
Boca Raton Community High School	7 (7%)
FAU ACCESS Program	1 (1%)
Gulfstream Goodwill	6 (6%)
Transition to Life	26 (27%)
Completed Questionnaire	
By myself	27 (28%)
With help from a teacher or friend	70 (72%)

Table 2 summarizes pre- and post-test measures of knowledge and self-efficacy. In a paired samples t-test at $\alpha < .05$, post-test knowledge scores among 97 respondents ($M = 15.17$, $SD = 4.93$) were significantly higher than pre-test scores ($M = 11.67$, $SD = 4.75$) [$t(96) = 6.83$, $p < .0001$, one-tailed]. This represents a 15% gain in knowledge scores from pre- to post-test.

Similarly, a paired samples t-test at $\alpha < .05$ showed post-test confidence scores ($M = 2.16$, $SD = 0.55$) were significantly higher than pre-test confidence scores ($M = 1.96$, $SD = 0.59$) [$t(96) = 3.65$, $p = .0004$, one-tailed]. With higher scores for every item from pre- to post-test, learners gained 7% in confidence scores.

Table 2. New learner pre-and post-test mean scores for knowledge and confidence

Learner Pre/Post-Questionnaire	n=97	
	Pre	Post
All Knowledge Questions (24 maximum score)	11.67	15.17
Confidence Key: 3=I'm sure I can do it 2= I can do it sometimes 1=I can't do it at all		
Ask questions of doctor or nurse.	2.12	2.20
Tell nurse or doctor how you feel.	2.31	2.42
Answer questions asked by doctor or nurse.	2.22	2.36
Take part in decision-making about treatments.	1.87	2.21
Use strategies to help you remember instructions.	1.99	2.10
Get information from web sites and resources.	1.69	2.06
Use technology to communicate with doctor or nurse.	1.63	1.95
Follow through on instructions.	2.23	2.25
Communicate with doctor or nurse without help.	1.90	2.14
Make list of questions before appointment.	1.61	1.99
All Confidence Questions	1.96	2.16

Table 3 below shows the degree to which learners said the curriculum was helpful and enjoyable. Overall, there was a high level of satisfaction, with a mean score of 2.80 among learners, based on a scale of 1 to 3.

Table 3. Post-intervention measure of learner satisfaction with curriculum

Learner Post-Questionnaire	Total n=44
Satisfaction Key: Yes=3, Maybe=2, No=1, Don't know=0	
Topics are helpful.	2.92
Topics will help you become more independent in health care.	2.73
Skills learned in curriculum will help you in other areas.	2.75
You enjoy the activities.	2.80
All Satisfaction Questions	2.80

Year 2 Learner Questionnaire

A total of 35 learners who participated in the program in 2013-2014 completed a Year 2 survey. Among those, 12 learners repeated the curriculum in Year 4 (current year). Table 4 lists characteristics of Year 2 respondents.

Table 4. Profile of Year 2 learners

Year 2 Learner Questionnaire	Total n=35
Gender	
Male	18 (51%)
Female	17 (49%)
Age	
Range	20 – 62 yrs
Median	38.5 yrs
Program	
Arc Jacksonville	
Westside	6 (17%)
Downtown	5 (14%)
St. Andrew Bay Center	6 (17%)
Quest	13 (37%)
FAU ACCESS Program	5 (14%)
Completed Questionnaire	
By myself	12 (34%)
With help from a teacher or friend	23 (66%)

Table 5 shows Year 2 learner responses when asked whether they used skills from the curriculum at a physician visit sometime in the last 12 months. Only 23% said they utilized technology to communicate with doctors; when asked about specific technology used, two respondents said *iPad*. Other curriculum skills or information that learners reported using were: *talk to doctor, listen, ask questions, follow directions, use SLANT, and make appointments.*

Table 5. Year 2 learners' utilization of skills learned in curriculum

Year 2 Learner Questionnaire (Yes/No response)	# of "Yes" Responses n=35
Asked questions of doctor or nurse if you didn't understand	23 (66%)
Described to doctor or nurse how you felt	34 (97%)
Answered questions asked by doctor or nurse	31 (89%)
Took part in decisions about medical treatment	33 (94%)
Used strategies to help remember instructions	29 (83%)
Used web sites learned about in "My Health Care"	15 (43%)
Used technology or equipment to communicate with doctor	8 (23%)
Followed through on instructions from doctor or nurse	33 (94%)
Made a list of questions before an appointment	26 (74%)
Used other information learned in "My Health Care"	23 (66%)

Instructor Questionnaires

A total of 21 instructors completed weekly questionnaires. Quantitative results from the instructor survey are outlined in Table 6. Overall, instructors rated the curriculum favorably, with a mean score of 4.45, based on a scale of 1 to 5.

Table 6. Instructors' quantitative assessment of curriculum

Instructor Assessment <i>Key: Agree=5... Don't Agree=1</i>	Mean Score n=21
Reading level is appropriate.	4.12
Images are appropriate.	4.55
Learners can understand key concepts.	4.32
Content flows smoothly and logically.	4.39
There is adequate time to complete the module.	4.41
Content is complete.	4.61
Key concepts are useful for learners.	4.57
Module exercises facilitate participant interaction.	4.49
The Instructor Guide is clear and easy to follow.	4.52
Lesson materials in the Appendix are easy to find.	4.49
The instructor training session is adequate.	4.55
All instructor questions	4.45

Qualitative responses from instructors (e.g., open-ended survey responses and verbal feedback from weekly teleconference calls) included several suggestions to improve the program. Highlights are listed below:

- It took a long time to flip back and forth between session pages in the Instructor's Guide and the Appendix. Some instructors also were unclear about which materials should be copied for learners. There were several suggestions to incorporate Appendix pages within the Instructor's Guide, adjacent to respective lesson plans.
- High school teachers said ongoing assessments are needed to measure student retention. They suggested adding weekly quizzes to the curriculum (e.g., short multiple choice, fill in the blank questions)
- The Bingo game took a long time for many, and the instructions were a little confusing.
- Some students had a difficult time developing personal goals. It may be helpful to give more examples of sample goals.
- One instructor team said it was useful use an ipad to videotape classroom role play activities, then play back and discuss with learners.
- At times, lower functioning students required more time for practice, causing classes to run long.
- Some terms and concepts used in the curriculum were not familiar to learners, and these items may need to be modified or explained in more detail.

Learner Focus Group

One learner focus group was conducted with six FAU students. Resulting themes were aligned with questions addressed to participants: value of the curriculum, interest, and satisfaction.

Value. The majority of learners said the curriculum taught them important information that their families do not typically address. Participants reported the most important lessons were learning about making doctor appointments, giving information to doctors, and taking notes at visits. One learner had already used *My Health Passport* at a health care encounter. Several learners said, “*Everything is important!*”

Interest. Learners said their favorite activities were role playing and Jeopardy. They enjoyed learning how to use voice recorders but had not yet used the technique during a physician visit.

Satisfaction. Most learners were enthusiastic about their participation in the course and reported a high level of satisfaction. All participants said they would recommend it to other learners, and the majority said they would like to take the class again. Of note, they were particularly enthusiastic about the possibility of mentoring other students, now that they had completed the class. They felt this was an important outcome of the program.

Conclusion

Outlined below are answers to our four evaluation questions.

To what extent does *My Health Care* increase learner knowledge, self-efficacy and skills in communication and self-management?

Overall study results suggest a positive impact on knowledge and self-efficacy. In a paired samples *t*-test among 97 new learners, data show a statistically significant increase in health-related knowledge and self-efficacy after participation in the curriculum. Among these learners, knowledge scores increased 15% and confidence scores increased 7%.

What are perceived value and relevance of the curriculum among learners and instructors? Were they satisfied with the program?

In a focus group, students reported that the most important lessons in *My Health Care* are about making doctor appointments, giving information to doctors, and taking notes at visits. All participants said they would recommend the program to other learners, and the majority of new learners said they would like to take the class again. Interestingly, students said an important program outcome – one that they were looking forward to – is mentoring other learners.

Data from learner surveys showed a high degree of satisfaction with a mean score of 2.80, based on a scale of 1 (low) to 3 (high). Instructor questionnaires resulted in favorable overall satisfaction ratings with a mean score of 4.45 based on a scale of 1 (low) to 5 (high).

Do learners apply knowledge and utilize skills learned in My Health Care?

Among 35 learners who participated in Year 3 of *My Health Care* (in 2013-2014), survey results show the majority of learners used the skills they learned from the curriculum at a physician visit in the previous 12 months. Among 10 activities/skills listed in the survey, all were utilized by at least 65% of learners, with the exception of two: 43% used web sites presented in the curriculum, and 23% used technology or equipment to communicate with doctor. Specific curriculum content that learners reported using were: *talk to doctor, listen, ask questions, follow directions, SLANT, and make appointments*. When asked about specific technology used, two respondents said *iPad*.

How can it be improved for future implementation and sustainability?

Based on feedback from learners and instructors:

- Reformat the Appendix for easier dissemination and use of learner handouts.
- Expand guidance in the Instructor's Guide about learner materials and resources needed to implement the program; advise instructors to adjust time required to complete lessons based on learner abilities; encourage creativity in adding activities and practice exercises, based on learner needs.
- Explain more fully and/or modify terms used in the curriculum that are not familiar to learners.
- Clarify Bingo instructions.
- Modify weekly KWL exercise (Know-Want-Learned) to include weekly quizzes that assess learner retention and meet Florida secondary education requirements.

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Appendix A
Learner Post-Survey

Confidence Scale. For each question below, circle the number that best fits your confidence level in doing the activity. Choosing “1” means that you **don’t** think you can do the activity at all, “2” means you **can do it sometimes**, and “3” means that you are confident or **sure you can do** the activity.

How confident are you that you can do the following?	I can't do it at all.	I can do it sometimes.	I'm sure I can do it.
1. Ask questions of your doctor or nurse if you don't understand something they say.	1	2	3
2. Describe to your doctor or nurse how you feel. (for example, describing what hurts, where it hurts and what it feels like)	1	2	3
3. Answer questions asked by your doctor or nurse.	1	2	3
4. Take part in decisions about how to treat your medical symptoms (for example, deciding which medication or treatment is best for you).	1	2	3
5. Use strategies to help you remember instructions from your doctor or nurse (for example, using a smart phone to remind you to take medications).	1	2	3
6. Get information about your health condition or health care from web sites and community resources.	1	2	3
7. Use technology or equipment such as a voice recorder to help you communicate with your doctor or nurse.	1	2	3
8. Follow through on instructions from your doctor or nurse (you do what they tell you to do).	1	2	3
9. Communicate with your doctor or nurse without help from others.	1	2	3
10. Make a list of questions before an appointment with your doctor or nurse.	1	2	3

Multiple Choice: For each of the following questions, circle the letter of the answer that best answers the question.

1. The letters in "GLADD" represent important skills to use when communicating with your doctor or nurse. "G" in GLADD means
 - A. Great job
 - B. Give information
 - C. Good grief
 - D. Grand time

2. Non-verbal communication is
 - A. Facial expressions
 - B. Body movements and posture
 - C. Eye contact
 - D. All of the above

3. When we use pictures or signs to communicate we are using
 - A. Verbal communication
 - B. Visual communication
 - C. Aural communication

4. Facial expressions can show
 - A. Happiness
 - B. Anger
 - C. Frustration
 - D. All of the above

5. A sender and receiver are
 - A. The same person
 - B. Two different people
 - C. Not needed to communicate
 - D. The name of a Country Western band

6. "A" in GLADD means
 - A. Anything goes
 - B. Add up your choices
 - C. Action speaks louder than words
 - D. Ask the questions you have about your health care

7. When you ask questions,
 - A. You should be clear
 - B. Prepare ahead of time
 - C. Make a list
 - D. All of the above

8. "Ask Me 3" is
 - A. Not important to follow
 - B. Can be useful to understand problems
 - C. Doesn't get specific answers
 - D. Takes too much time

9. When negotiating, both persons need to behave
 - A. In an uncooperative, miserable, and rude way
 - B. With respect, honesty, and cooperation
 - C. With an attitude and not give in
 - D. Listen but not give into what the other say
10. The second "D" in GLADD means
 - A. Don't make decisions on your own
 - B. Do your part in following the plan
 - C. Dive into any situation without knowing what's ahead
 - D. Decide when to leave the doctor's office
11. Being prepared when you go to the doctors allows you to
 - E. Ask questions
 - F. Take notes
 - G. Tape record your session
 - H. All of the above

True or False: For each statement, circle True or False.

- | | | | |
|-----|--|------|-------|
| 12. | Sign language is a form of verbal communication. | True | False |
| 13. | Not paying attention is using the SLANT technique | True | False |
| 14. | Preparing a list of questions for your doctor before an office visit is a good use of time. | True | False |
| 15. | A "Consent to Treat" form gives your doctor permission to examine you, diagnose, and administer medical treatment. | True | False |

Fill in the Blank: For each sentence below, copy a term from the word bank in the box that correctly completes the sentence.

remembering	what	assertive	health care	sender
-------------	------	-----------	-------------	--------

16. There are 4 parts of communication: _____, receiver, message and feedback.
17. One important part about listening is _____.
18. "Handy High 5" can be used to describe who, _____ where, when and why.
19. The best way to communicate your needs is to be _____.
20. "My Health Passport" is designed to be shared with many types of _____ providers.

Finally, please tell us what you thought about the *My Health Care* class. Circle one answer for each question.

- | | | | | |
|--|-----|-------|------------|--------------|
| 21. Did you find the topics helpful? | Yes | Maybe | Not really | I don't know |
| 22. Will learning about these topics help you become more independent in your own health care? | Yes | Maybe | Not really | I don't know |
| 23. Would these skills help you in other areas? | Yes | Maybe | Not really | I don't know |
| 24. Did you enjoy the class activities? | Yes | Maybe | Not really | I don't know |

Sometime in the last 12 months, did you:		
1. Ask questions of your doctor or nurse if you didn't understand something they said?	Yes	No
2. Describe to your doctor or nurse how you felt (for example, described what hurt, where it hurt and what it felt like)?	Yes	No
3. Answer questions asked by your doctor or nurse, even if a family member or caregiver was with you?	Yes	No
4. Take part in decisions about your medical treatment (for example, discussing which medication was best for you)?	Yes	No
5. Use strategies to help you remember instructions from your doctor or nurse (for example, using a smart phone to remind you to take medications)?	Yes	No
6. Use any of the web sites that you learned about in <i>My Health Care</i> (such as www.healthytransitionsny.org or www.floridahats.org)?	Yes	No
7. Use technology or equipment such as a voice recorder to help you communicate with your doctor or nurse? If yes, what equipment did you use? _____	Yes	No
8. Follow through on instructions from your doctor or nurse (did what they told you to do)?	Yes	No
9. Make a list of questions before an appointment with your doctor or nurse?	Yes	No
10. Did you use any other information you learned in <i>My Health Care</i> ? If yes, please describe what you used: _____ _____ _____ _____ _____ _____	Yes	No

Appendix C
Instructor Questionnaire



Instructor Feedback Forms

Attached are **Instructor Feedback Forms** for the curriculum. Each instructor (including self-advocates) should complete the weekly form as soon as possible after implementing the lesson so that your thoughts are fresh! The **Lead Instructor** should keep the completed weekly forms together and I'll collect them following the last week of the session.

There are several areas we'd like you to consider for each module. We'll ask:

- In your opinion, is the curriculum content appropriate for most learners with respect to
 - readability? Are the reading level and images in the PowerPoint appropriate?
 - ease of understanding? Can students understand important concepts?
 - structure? Do the activities flow smoothly and in logical order? Are they too repetitive for most learners?
 - complexity? Is there enough time to complete the module in the allotted period?
 - completeness? Are there any concepts within this topic area that are missing?
 - relevancy? Are the main concepts and associated exercises useful?
 - facilitating interaction? Do the exercises stimulate participant communication?
- From a teaching perspective,
 - was the training session adequate?
 - are instructions clear and easy to follow/understand? Is there enough detail?
 - is it easy to find materials for the lessons? Is there a smooth flow between the instructor guide, PPT, and appendix materials?
- Are there any corrections, issues and/or concerns about items in the module?
- Do you have any suggestions to improve the module?

Please don't hesitate to contact me if you have any questions, jhess@health.usf.edu or (813) 259-8604. Thanks for your participation!

Appendix D

Learner Focus Group Questions

1. Let's first talk about the content of the curriculum. Do you think students need to receive instruction in a class like this about communicating with doctors or nurses? Why or why not?
2. Think about how you might use this information in your life. What do you think is the most important information in the course? What do you think is the least important information in the course?
3. Now let's talk about the way the lessons are designed. That may include how easy or hard it is to read the material, the length of time you spent on each unit, the way the test questions are written, and the activities in each unit.
4. What do you like most about the lessons and activities? What do you like least about the lessons and activities? How could they be improved for other students who take the course?
5. Do you have any other suggestions about how to make the course more interesting or more helpful to students?

Appendix E

Informed Consent for Participants with Decision-Making Authority

FORM #1 2014



Consent to Participate in an Evaluation Study



You are being asked to take part in an evaluation study. It contains information to help you decide whether you should participate. Please read this carefully. If you do not understand anything, ask the person in charge of the project.

Title of research study: Evaluation of *My Health Care*, a Health Literacy and Communications Training Program

Person in charge of study: Janet Hess, DrPH, MPH, jhess@health.usf.edu, (813) 259-8604

Where the study will be done: Participating sites throughout Florida

General Information about the Study

The purpose of this evaluation study is to assess the effectiveness of a curriculum entitled *My Health Care*. It was designed to empower adults with intellectual and developmental disabilities to become more independent in managing their own health care. You are being asked to participate in the evaluation because you are enrolled in a program that was selected to receive the instructional module. Approximately 150-175 individuals will receive the curriculum in this phase of the study.

Plan of Study

As part of the 9-week curriculum, you will complete pre- and post-intervention questionnaires. It will take approximately 30 minutes to complete each questionnaire, or 60 minutes total. Researchers will review and evaluate the survey data after they are administered and collected by the course instructor. Survey questions will focus on knowledge, skills and confidence concerning health-related communication and health care self-management. The questionnaire will include some general demographic information, such as age, gender, and race/ethnicity.

In addition, you may be asked to participate in a focus group for approximately 45 minutes, upon completion of the 9-week curriculum. The focus group will be conducted by a moderator. During the focus group, the moderator will ask questions about the curriculum, such as what participants did or didn't like about it, what they thought was most valuable, and how they would improve it. Group members will have a discussion about the questions that the moderator addresses to the group. The moderator will take notes on what is said during the discussion. The session also will be tape recorded so that comments are documented correctly. Individual names will not be linked to any specific comments that are offered.

All data will be aggregated so that individuals are not identified in the study.

Here is what needs to be done

If you participate in a focus group, you will need to listen to the questions that the moderator asks. You may choose to contribute answers to each question and participate in the discussion, or choose to sit out of the discussion if particular questions are uncomfortable.

Payment/Costs for Participation

You will not be paid to participate in this study, nor will it cost anything to participate.

Potential Benefits of Taking Part in this Study

By taking part in this study, you can help increase our knowledge about ways “My Health Care” can help adults with intellectual and developmental disabilities become successful health care consumers.

Risks of Being a Part of this Study

There are no known risks to participate in the study.

Privacy and Confidentiality of Records

We will keep the records of this study private by storing them in a locked file cabinet or office of the study’s Principal Investigator.

The results of this study may be published. However, the data obtained from each learner will be combined with data from other study participants. The published results will not include learner names or any other information that could personally identify individual participants.

Volunteering to Take Part in this Study

Your decision regarding participation in this evaluation study is completely voluntary. You are free to participate in the study or to withdraw at any time. There will be no penalty for non-participation or to withdraw from the study; you can still receive instructional material in the *My Health Care* curriculum.

Questions and Contacts

- If you have any questions about this study, contact Janet Hess, jhess@health.usf, 813-259-8604.

Consent to Take Part in This Study

By signing this form, you agree that:

- You have fully read or have had read and explained to you this consent form describing this research project.
- You have had the opportunity to question one of the persons in charge of this project and have received satisfactory answers.

Signature Page

- If you understand the risks and benefits for participation that are outlined in this form and agree to participate, please sign in the appropriate section on the next page and return to the program instructor.



Informed Consent Signature Page

For Participants in the Evaluation Study

If you decide to take part in this study, please return this signed page to the program instructor.

<p>I _____ (your name) agree to take part in this evaluation study. I understand the information I have been provided.</p>		
<p>_____</p> <p>Signature of Participant</p>	<p>_____</p> <p>Printed Name of Participant</p>	<p>_____</p> <p>Date</p>

Statement of Person Obtaining Informed Consent (Program Instructor/Administrator):

I certify that participants have been provided with a consent form that explains the nature, demands, risks, and benefits involved in participating in this study. I further certify that a phone number has been provided in the event of additional questions.

<p>_____</p> <p>Signature of person obtaining consent</p>	<p>_____</p> <p>Printed Name of person obtaining consent</p>	<p>_____</p> <p>Date</p>
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