

A FRAMEWORK FOR ASSESSING SELF-ADVOCACY OUTCOMES

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TABLE OF CONTENTS

| BACK | BACKGROUND1 | | |
|-------|---|---|--|
| PURP | OSE1 | L | |
| | URING OUTCOMES OF SELF-ADVOCACY PROGRAMMING: A SELF-ASSESSMENT TOOL FOR SCDDS AND | | |
| OTHE | R ID/DD SERVICES ORGANIZATIONS | 5 | |
| Α. | Organization Information: | 3 | |
| В. | PRACTICE INFORMATION: | | |
| C. | DATA SOURCES (SELECT ALL THAT YOU USE) | | |
| D. | Level of Outcomes (select all that you consider) | ś | |
| ABOU | T OUR DATA SOURCES (COLLECTIVELY) | ; | |
| OVER | ALL CRITERIA FOR EVALUATING STRENGTH OF EVIDENCE-BASED PRACTICE | ; | |
| ουτς | OME MEASURES |) | |
| Α. | Individual-Level Short-Term Outcomes Addressed |) | |
| В. | INDIVIDUAL-LEVEL INTERMEDIATE OUTCOMES ADDRESSED | L | |
| C. | Individual-Level Long-term Outcomes Addressed |) | |
| USING | GYOUR ASSESSMENT RESULTS TO IMPROVE AND CHANGE PRACTICE | ; | |
| APPEI | NDIX A. SCDD SELF-ADVOCACY EVIDENCE-INFORMED PRACTICE CRITERIA (FULL) |) | |

BACKGROUND

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) is intended to empower people with developmental disabilities to shape policy and drive system changes that best meet their needs. The Administration for Community Living (ACL) oversees implementation of the DD Act and supports State Councils on Developmental Disabilities (SCDD) to test innovative programs that encompass advocacy, systems change, and capacity building efforts promoting self-determination, integration, and inclusion. Oversight, in part, is based on The Government Performance and Results Act (GPRA) of 1993 and updated through the GPRA Modernization Act of 2010. The core aim is to measure how well programs work.

Measurement can drive improvement and inform decision making. This *Framework* provides SCDD with a tool to measure self-advocacy outcomes. The framework is built on a logic model foundation. The self-assessment tool in the framework was constructed using available literature on evidence-informed practice and qualitative data obtained from self-advocates, external organizations supporting self-advocacy, and DD council practices. To learn more about this logic model, as well as the research into self-advocacy activities among DD Councils and external programs, please see *Review of Self-Advocacy Activities and Recommendations for DD Councils*.

Currently, many self-advocacy programs focus on measuring inputs, activities, and outputs. However, very few measure the long-term outcomes or impact of products and services. Impacts can be interpreted as action taken by individuals as a result of programs and practices that leads to measurable change. Outcomes are the impacts on those people whom the organizations want to benefit from its programs. Long-term outcomes/impact can be thought of in terms of a) change in behavior due to enhancements in knowledge/understanding/perceptions/attitudes, and behaviors, b) skills (e.g., gaining full-time employment as a result of participating in a training program), and c) conditions (e.g., increase in community participation and health status as a result of participating in a self-advocacy training program). SCDDs can more easily report how many people with DD attend training (the outputs), but some Councils cannot as easily describe whether the training was impactful (how the training impacted action taken by participants) on policy or systems change. While outputs are important, they do not reflect the value of the product or service.

ACL recognizes that measuring outcomes and impacts may appear more difficult due to the need for data collection from multiple sources over time. However, it is not impossible. Working together, ACL and SCDDs can begin to understand outcomes, express these outcomes quantitatively to measure performance, and begin to demonstrate the true impact of products and services.

PURPOSE

The Framework and the self-assessment tool can help an organization:

- Think through current measurement practices and evaluation tools
- Determine if their programming is using evidence-based methods
- Determine where their program is working well
- Determine opportunities for improvement
- Understand more about measurement practices, so meaningful technical assistance can occur

SCDD Self-Advocacy Evidence-Informed Practice Criteria¹

Ideally, self-advocacy practices should:

- Be consistent with the latest knowledge and practice that DD Councils and self-advocates have
- Include the participant's values, preferences, and goals
- Be reviewed or accepted by an independent expert, such as a TA provider or external organization
- Incorporate the use of a logic model to document inputs, goals, outcomes, and impacts
- Have proven reliability
- Demonstrate positive outcomes

Please see Appendix A. for a more detailed and expanded version of these criteria.

This tool can be used by SCDD staff and/or their advisory board alone or in collaboration with a TA Provider to help set the course toward building capacity in the area of outcomes measurement.

¹These Evidence-Informed Practice Criteria are developed and adapted from the Florida Gulf Coast University's (FGCU) definition of evidencebased practice and the FGCU practice model. <u>https://fgcu.libguides.com/EBP</u>. Similar terms for "evidence-informed practice" include evidence-based practice, promising practice, and emerging practice.

MEASURING OUTCOMES OF SELF-ADVOCACY PROGRAMMING: A SELF-ASSESSMENT TOOL FOR SCDDS AND OTHER ID/DD SERVICES ORGANIZATIONS

| DEMOGRAPHICS | | | | |
|---------------------------|--------------|------|--|--|
| A. ORGANIZATIO | ON INFORMATI | ION: | | |
| Organization Name | | | | |
| | | | | |
| Project or Program | | | | |
| Name | | | | |
| Name of Person | | | | |
| Completing Tool | | | | |
| Date of Completion | | | | |
| B. PRACTICE INI | ORMATION: | | | |
| Specify the evaluation ti | meframe | | | |
| | | | | |
| Identify the target popu | ation | | | |

Indicate the type of practice (intervention or program)

□ Training (Peer training)

□ Training (Leadership)

□ Life coaching

 \Box Technical assistance

 \Box Educational toolkit

□ Providing resources

 \Box Other (please describe):

Focus of practice (intervention or program)

□ Self-advocacy

□ Education

Employment

 \Box Resources for voters

□ Independent living skills

 $\hfill\square$ Abuse prevention

 \Box Supported decision making

 \Box Other (please describe):

C. DATA SOURCES (SELECT ALL THAT YOU USE)

□ Practice pre-survey

□ Practice post-survey

□ Participant interview

□ Participant satisfaction survey

□ Participant outcomes or experience survey

 \Box Other (please describe):

D. LEVEL OF OUTCOMES (SELECT ALL THAT YOU CONSIDER)

- □ Individual-level outcomes
- □ Family-level outcomes
- □ Provider-level or program-level outcomes
- □ System-level outcomes

 \Box Other (please describe):

How to score

To complete the following tables, consider the questions in the left columns and provide your answers in the right columns. The tables below provide measures and multiple choice answer options with points values associated. At the bottom of the table there is a place to record your total score and recommendations associated with different scores. The totals offer a target minimum or benchmark. Ideally, a practice or program would be able to track 8-16 short-term and intermediate outcomes and 5-12 long-term outcomes. If a practice is not tracking the specific outcomes described in the tables below, please indicate what other outcomes are tracked. SCDD or TA providers can discuss your totals and how you might be able to strengthen your evaluation efforts.

ABOUT OUR DATA SOURCES (COLLECTIVELY)

This section starts by first understanding the type of data collected. The goal is to collect data that can lead to longterm impact, improve or influence the practice itself by people experiencing the practice, and produce objectively reported results.

| | Measure: Answer Yes, No or In Progress to the following questions. | Answer and Points Value |
|----|--|--|
| 1. | Timing : Do we collect data long enough after the event/practice to speak to longer-term impact (e.g., 4-6 months, 1 year)? | No (0) In Progress (1) Yes |
| 2. | Relevance : Do we use collected outcomes data collected to improve or influence the practice? | No (0) In Progress (1) Yes (2) |

| | Measure: Answer Yes, No or In Progress to the following questions. | Answer and Points Value |
|-------|--|--|
| 3. | Authority : Do we collect data from those people directly impacted by the practice? | No (0) In Progress (1) |
| | | □ Yes (2) |
| 4. | Precision : Does our data address respondent experiences that can be objectively reported (e.g., I have done XYZ in the last month) instead of or in addition to data that are opinion-based or subjective (e.g., XYZ training met my expectations)? | No (0) In Progress (1) Yes (2) |
| Total | Add up the points from your responses. Total possible points = 8. | (Section 1 Total) |

Interpreting Your Score for Data Sources (Section 1)

A score of 7-8 indicates you have a rigorous approach to collecting data and a strong capacity to measure outcomes.

If your overall score is less than 6, or if you answered no to any one question, this should be a priority area on which to focus and seek technical assistance.

OVERALL CRITERIA FOR EVALUATING STRENGTH OF EVIDENCE-BASED PRACTICE

This section builds on data collected by assessing the strength of the practice. The goal is to assess whether the practice meets the pre-determined logic model, is consistent with best practices and available research in self-advocacy, is independently verified, can be sustained over time, is modified based on results, and meets intended outcomes.

| | Measure: To what extent do you agree with the following statements? | Answer and Points Value |
|----|---|--|
| 1. | Our data show that our practice is being carried out in a way that is true to its original plan. Did you reach the target audience? Did you use the intended format (e.g., inperson, on-line, toolkit)? Was it the project type you intended (e.g., self-advocacy training, employment readiness, life coaching)? | Strongly disagree (1) Disagree (2) Neither agree nor disagree (3) Agree (4) Strongly agree (5) |
| 2. | The practice we use is consistent with the latest knowledge and understanding of best practices that DD Councils and Self-Advocates have. Does it encompass research findings, technology, and lived experiences of self-advocates? Does it align with relevant activities from other DD Councils, the TA provider, or other advocacy organizations? Does it correlate with state needs and characteristics obtained from sources such as data analysis, outreach to self-advocates and families, or focus groups? | Strongly disagree (1) Disagree (2) Neither agree nor disagree (3) Agree (4) Strongly agree (5) |
| 3. | The practice we use has been reviewed or accepted by an independent expert. Reviewed and accepted by TA Provider. Our practice was found to be effective in published research or peer-reviewed journal. | No (0) In Progress (1) Yes (2) |
| 4. | Our practice adds to and builds upon relevant literature, contributing to an emerging or established research area. Are the results from other practitioners published in a peer-reviewed publication? Are the results published in an industry publication? | Strongly disagree (1) Disagree (2) Neither agree nor disagree (3) Agree (4) Strongly agree (5) |
| 5. | Our practice incorporates the use of a logic model or driver diagram to document inputs, goals, and outcomes (short, medium, and long-term). | No (0) In Progress (1) Yes (2) |

| | Measure: To what extent do you agree with the following statements? | Answer and Points Value |
|-------|---|---|
| 6. | We are confident our practice is sustainable in the long term. Sustainability can involve, for example, funding, cost-savings, and/or | No (0) In Progress (1) |
| | accessibility. | □ Yes (2) |
| 7. | The practice we use is developed, assessed, and modified based on impact. | □ Strongly disagree (1) |
| | • Do we use quantitative data for outcome | Disagree (2) |
| | measures? Do we systematically collect qualitative data? | □ Neither agree nor disagree (3) |
| | • Do we conduct a post-event evaluation? | □ Agree (4) |
| | Do we conduct an evaluation at least 6- months post-event? | □ Strongly agree (5) |
| 8. | Our data show that the practice delivers intended outcomes. | □ Strongly disagree (1) |
| | Do we use quantitative data for outcome measures? | Disagree (2) |
| | Do we systematically collect qualitative data? | □ Neither agree nor disagree (3) |
| | • Do we conduct a post-event evaluation? | Agree (4) |
| | Do we conduct an evaluation at least 6- months post-event? | □ Strongly agree (5) |
| Total | Add up the points from your responses. Total possible points = 31. | |
| | | |
| | | (Section 2 Total) |

Interpreting Your Score for Evaluating Strength of Evidence-Based Practice (Section 2)

Scores of 24 or more indicate you can be confident you are operating an evidence-based practice.

If your overall score is less than 24, it is unclear if your practice is evidence-based. You may want to consider:

1) doing some research to find more evidence about the effectiveness of your practice

2) modifying your practice to better adhere to the evidence-base

3) working with stakeholders to consider a different more evidence-based practice to adopt

OUTCOME MEASURES

This section assesses the nature of data collection across short, intermediate and long term outcomes enumerated in the self-advocacy logic model (See Appendices A and B). The goal is to ensure that data collected enables the SCDD to measure outcomes and impact of self-advocacy practices.

A. INDIVIDUAL-LEVEL SHORT-TERM OUTCOMES ADDRESSED

Answer yes or no if your organization collects data that address any of the measures below (or another very similar measure) systematically.

| | Measure: Answer Yes or No to the following questions. | Answer and Points Value |
|----|--|-------------------------|
| 1. | Do our data show the number of participants reporting that the practice changed their life? | □ No (0) □ Yes (1) |
| 2. | Do our data show the number of participants who use lessons from the practice often? | □ No (0) □ Yes (1) |
| 3. | Does our practice track the number of awards participants receive for taking some action related to the practice (e.g., awards for advocacy activities)? | □ No (0) □ Yes (1) |
| 4. | Do our data show the number of participants reporting they have taken specific actions because of the practice? | □ No (0) □ Yes (1) |
| 5. | Do our data show the number of participants reporting the practice helped them become a better advocate for themselves in a particular setting (e.g., health care setting, school, work)? | □ No (0) □ Yes (1) |

| | Measure: Answer Yes or No to the following questions. | Answer and Points Value |
|-------|--|-------------------------|
| 6. | Do our data show the number of participants reporting the practice helped them become a better advocate for themselves in general or across all settings? | □ No (0) □ Yes (1) |
| 7. | Do our data show the number of participants reporting the practice helped them become a better leader? | □ No (0) □ Yes (1) |
| 8. | Are we able to use our data to measure the change in participants' communication skills pre/post-practice? | □ No (0) □ Yes (1) |
| 9. | Are we able to use our data to measure the change in participants' ability to problem solve pre/post-practice? | □ No (0) □ Yes (1) |
| 10. | Are we able to use our data to measure the change in practice participants' social skills pre/post-practice? | □ No (0) □ Yes (1) |
| 11. | Are we able to use our data to measure the change in participants' financial literacy pre/post-practice? | □ No (0) □ Yes (1) |
| 12. | Additional: Add any other short-term outcomes you track here and add 1 point for each one. Please describe: | □ No (0) □ Yes (1) |
| Total | Add up the points from your responses. Total possible points = 12. | (Section 3A Total) |

Interpreting Your Score for Individual-Level Short-Term Outcomes (Section 3A)

Scores of 6 or more indicate you have a strong capacity to measure a wide range of intermediate outcomes.

If your score for 3B is less than 6, please consider reviewing the logic model and collecting additional short-term outcomes data. You should consider whether the short-term outcomes you can track now are the most important ones for your program and your participants. If not, you should consider modifying or supplementing your data collection tools to capture more or different outcomes.

B. INDIVIDUAL-LEVEL INTERMEDIATE OUTCOMES ADDRESSED

Answer yes or no if your organization collects data that address any of the measures below (or another very similar measure) systematically.

| | Measure: Answer Yes or No to the following statements. | Answer and Points Value |
|----|---|-------------------------|
| 1. | Do our data show the number of practice participants who talked or wrote to policymakers regarding disabilities issues? | □ No (0) □ Yes (2) |
| 2. | Do our data show the number of practice participants who talked or wrote to community members regarding disabilities issues? | □ No (0) □ Yes (2) |
| 3. | Do our data show the number of practice participants who joined an advisory board, group, or committee as a result of the practice? | □ No (0) □ Yes (2) |
| 4. | Do our data show the number of practice participants who became members of a self- advocacy group as a result of the practice? | □ No (0) □ Yes (2) |
| 5. | Additional: Add any other intermediate outcomes you track here and add 1 point for each one. Please describe: | □ No (0) □ Yes (2) |

| | Measure: Answer Yes or No to the following statements. | Answer and Points Value |
|-------|--|-------------------------|
| Total | Add up the points from your responses. Maximum possible points = 10. | |
| | | (Section 3B Total) |

Interpreting Your Score for Individual-Level Intermediate Outcomes (Section 3B)

Scores of 6 or more indicate you have a strong capacity to measure a wide range of intermediate outcomes.

If your score for 3B is less than 6, please consider reviewing the logic model and collecting additional short-term outcomes data. You should consider whether the intermediate outcomes you can track now are the most important ones for your program and your participants. If not, you should consider modifying or supplementing your data collection tools to capture more or different outcomes.

C. INDIVIDUAL-LEVEL LONG-TERM OUTCOMES ADDRESSED

Answer yes or no if your organization collects data that address any of the measures below (or another very similar measure) systematically.

| | Measure: Answer Yes or No to the following statements. | Answer and Points Value |
|----|---|-------------------------|
| 1. | Do our data show the number of practice participants who became leaders of a committee, | □ No (0) |
| | coalition, board, or another group? | □ Yes (3) |
| | | |
| 2. | Do our data show the number of practice participants who started a paid job or an education program after the training/event? | □ No (0) |
| | | □ Yes (3) |
| | | |
| 3. | Do our data show the number of practice participants who had a paid job or were pursuing further education one year after training/event? | □ No (0) |
| | | □ Yes (3) |
| | | □ NA |

| | Measure: Answer Yes or No to the following statements. | Answer and Points Value |
|-----|---|-------------------------|
| 4. | Do our data show the number of practice | □ No (0) |
| | participants who are participating in employment or career development activities one year after the training/event? | □ Yes (3) |
| | | |
| 5. | Do our data show the number of practice participants who became engaged in competitive paid employment and/or mainstream/inclusive education as a result of the practice? | □ No (0) |
| | | □ Yes (3) |
| | | |
| 6. | Do our data show the number of practice participants who can and identify and articulate their own academic or professional strengths? | □ No (0) |
| | | □ Yes (3) |
| | | |
| 7. | Do our data show the number of practice participants who can identify and articulate their | □ No (0) |
| | own academic or professional desires? | □ Yes (3) |
| | | |
| 8. | Do our data show the number of participants who can identify and articulate their personal | □ No (0) |
| | strengths? | □ Yes (3) |
| | | |
| 9. | Do our data show the number of participants who can identify and articulate what they want | □ No (0) |
| | and need help with? | □ Yes (3) |
| | | |
| 10. | Do our data show the number of practice participants who report they are living in a setting they chose for themselves? | □ No (0) |
| | | □ Yes (3) |
| | | |
| 11. | Do our data show the number of participants who are not living with family? | □ No (0) |
| | | □ Yes (3) |
| | | □ NA |

| | Measure: Answer Yes or No to the following statements. | Answer and Points Value |
|-------|--|---|
| 12. | Additional: Do our data show the number of participants achieving another kind of long term outcome (not listed above). Please describe: | No (0) Yes (3) NA |
| 13. | Additional: Add any other long-term outcomes you track here and add 1 point for each one. Please describe: | No (0) Yes (3) NA |
| Total | Add up the points from your responses. Total possible points = 36. | (Section 3C Total) |

Interpreting Your Score for Individual-Level Long-Term Outcomes (Section 3C)

Scores of 24 or more indicate you have a strong capacity to measure long-term outcomes.

If your overall score is 12-21, you may be capturing everything you need but should consider whether the long-term outcomes you can track now are the most important ones for your program and your participants. If not, you should consider modifying or supplementing your data collection tools to capture more or different outcomes.

If your overall score is 9 or below, you should consider what other data sources you could use or modify your existing data collection tools to begin to capture at least 1-2 additional individual-level long-term outcomes.

Calculating and Interpreting Your Overall Score

To benchmark your progress over time, you can total your scores across the different sections of this tool. Copy your totals from each section below and calculate your overall total score.

Section 1: _____ (out of 8 possible)

Section 2: _____ (out of 31 possible)

Section 3A: _____ (out of 12 possible)

Section 3B: _____ (out of 10 possible)

Section 3C: _____ (out of 36 possible)

TOTAL SCORE: _____ (out of 97 possible)

A total score of 68 or higher indicates a strong capacity to measure outcomes. There may still be room to improve based on your scores in different sections, but you are starting from a place of strength.

A total score of less than 77 indicates there are probably a few different areas of your evaluation activities you could strengthen to better measure your program's outcomes.

Please see the list of ways to use your assessment results below.

USING YOUR ASSESSMENT RESULTS TO IMPROVE AND CHANGE PRACTICE

You can use the results of this self-assessment tool in many ways to improve data collection and overall measurement of self-advocacy practice impact. Below are some examples and links to potential resources you might find helpful.

Facilitate Group Discussions

Individuals can complete the self-assessment and then share their results in a group setting – team discussion helps you to align your practices with current conditions and areas for action. Consider probing group attendees with questions like: "what are the strengths of our practice?", "What are the gaps in measuring practice impact?", "Are there opportunities that you are aware of in the months ahead that can turn our gaps into strengths?", and "What is one action each of us can take to improve practice impacts and how we measure them?"

Resources for Facilitating Group Discussions

- The Guide: NASDDDS Handbook on Inclusive Meetings and Presentations
- <u>Tips on Facilitating Effective Group Discussions</u>



Use as a Component of a Strategic Plan

A facilitator or TA Provider can lead your team through the self-assessment as part of a strategic planning session to collectively identify priorities for change. Consider embedding the self-assessment tool as one component of your one, three or five year planning process.

Resources for Developing a Strategic Plan

- <u>Tips and Tools that Support Strategic Planning</u>
- <u>Strategic Planning in the Public Sector</u>



Ongoing Baselining and Benchmarking

You can save your initial results as a baseline – take it again in 6 months or a year to assess your progress. Use the information to guide action planning for the year or for future years. Or, you can benchmark which means to measure your results against other practices in the self-advocacy field.

Resources for Benchmarking

National Institute of Health Benchmarking

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|---|

Create an Action Plan

You can use resources from ACL and your TA Providers to create an action plan specific to self-advocacy outcomes and impact measurement with timetables and steps toward better measuring your program's outcomes. Use SMART objectives; goals that are specific, measurable, achievable, relevant and time-oriented. This action plan can then feed into your 5-year plan as applicable. Remember that it's possible to achieve the overall goal of the practice by breaking down the larger goals into smaller and shorter achievable targets.

Resources for Creating an Action Plan

- <u>Centers for Disease Control and Prevention Community Action Plan Template</u>
- SMART Goals Guide, Self-Advocacy Resource and Technical Assistance Center
- <u>SMART Goals and Objectives Worksheet, Information and Technical Assistance Center for Councils on</u>
 <u>Developmental Disabilities</u>



Develop a Practice Logic Model

A logic model is a visual explanation of which changes the practice will bring about and how. It can guide evaluation efforts and ensure that measurement of practices is aligned with intended outcomes.

Resources for Developing a Logic Model

University of Kansas Logic Model Guide



Develop a Self-Advocacy Evaluation Plan

Use the self-assessment tool and corresponding results as one component of a larger evaluation of your selfadvocacy efforts or as a component of a broader evaluation of DD Council initiatives.

Resources for Developing an Evaluation Plan

- Introduction to Program Evaluation for Public Health Programs: A Self-Study Guide
- <u>Evaluation Plan Template, CDC</u>

Request Technical Assistance

ACL and their Technical Assistance Provider is available to help. They can support development of outcomes measures, can guide you on planning and evaluation, and engage actively or passively in stakeholder efforts.

Resources for Requesting Technical Assistance

The Information and Technical Assistance Center for Councils on Developmental Disabilities (ITACC)

ITACC Website

Send inquiries to:

- Sheryl Matney: 202-506-5813 ext. 148 or smatney@nacdd.org
- Angela Castillo-Epps: 202.506.5813 ext. 100 or acastillo-epps@nacdd.org

APPENDIX A. SCDD SELF-ADVOCACY EVIDENCE-INFORMED PRACTICE CRITERIA (FULL)

SCDD Self-Advocacy Evidence-Informed Practice Criteria² (Full)

The practice:

- I. Is consistent with the latest knowledge and practice that DD Councils and Self-Advocates have.
 - Encompasses research findings, technology, and lived experiences of self-advocates.
 - Aligns with relevant activities from other DD Councils, the TA provider, or other advocacy
 organizations.
 - Correlates with state needs and characteristics obtained from sources such as data analysis, outreach to self-advocates and families, or focus groups.
- II. Has been reviewed or accepted by an independent expert.
 - Reviewed and accepted by the TA Provider or External Organization.
- III. Incorporates the use of a logic model to document inputs, goals, and outcomes (short, medium, and long-term).
- IV. Is supported by measures for sustainability to maintain it.
 - Funding, accessibility, or assigned activity leads.
- V. Is developed, assessed, and modified based on impact.
 - Evaluation, re-evaluation, quality improvement.
- VI. Builds upon relevant literature on quality and quantity to contribute to an emerging or established research area.
- VII. Has proven reliability and fidelity.
 - Delivered as intended and produces results that are consistent and accurate.
- VIII. Demonstrates positive outcomes.
 - Increased capacity for self-advocates and self-advocacy organizations to impact policy and system change.
- IX. Embeds the participant's values, preferences, and goals.
 - Individuals with I/DD may envision their best lives and to have the life they want.

²These Evidence-Informed Practice Criteria are developed and adapted from the Florida Gulf Coast University's (FGCU) definition of evidencebased practice and the FGCU practice model. <u>https://fgcu.libguides.com/EBP</u>. Similar terms for "evidence-informed practice" include evidence-based practice, promising practice, and emerging practice.