



A Framework for Assessing Self-Advocacy Outcomes

ACL AND THEIR PARTNER LEWIN GROUP PRODUCED THIS TOOL THAT CAN BE USED BY DD COUNCIL STAFF AND/OR THEIR COUNCIL TO WORK TOWARD BUILDING CAPACITY IN THE AREA OF OUTCOMES MEASUREMENT.

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

DEMOGRAPHICS

A. ORGANIZATION INFORMATION:

Organization Name

Project or Program Name

Name of Person Completing Tool

Date of Completion

B. PRACTICE INFORMATION:

Specify the evaluation timeframe

Identify the target population

Indicate the type of practice (intervention or program)

- Training (Peer training)
- Training (Leadership)
- Life coaching
- Technical assistance
- Educational toolkit
- Providing resources
- Other (please describe):

Focus of practice (intervention or program)

- | | |
|--|--|
| <input type="checkbox"/> Self-advocacy | <input type="checkbox"/> Abuse prevention |
| <input type="checkbox"/> Education | <input type="checkbox"/> Supported decision making |
| <input type="checkbox"/> Employment | <input type="checkbox"/> Other (please describe): |
| <input type="checkbox"/> Resources for voters | <input type="text"/> |
| <input type="checkbox"/> Independent living skills | |

C. DATA SOURCES (SELECT ALL THAT YOU USE)

- Practice pre-survey
- Practice post-survey
- Participant interview
- Participant satisfaction survey
- Participant outcomes or experience survey
- 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
- 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. Council peers or your TA provider 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 long-term 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)?	<input type="checkbox"/> No (0) <input type="checkbox"/> In Progress (1) <input type="checkbox"/> Yes
2.	Relevance: Do we use collected outcomes data collected to improve or influence the practice?	<input type="checkbox"/> No (0) <input type="checkbox"/> In Progress (1) <input type="checkbox"/> 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?	<input type="checkbox"/> No (0) <input type="checkbox"/> In Progress (1) <input type="checkbox"/> 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)?	<input type="checkbox"/> No (0) <input type="checkbox"/> In Progress (1) <input type="checkbox"/> Yes (2)
Total	<i>Add up the points from your responses. Total possible points = 8.</i>	<div style="border: 1px solid black; height: 40px; width: 100%;"></div> <p style="text-align: center;">(Section 1 Total)</p>

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.	<p>Our data show that our practice is being carried out in a way that is true to its original plan.</p> <ul style="list-style-type: none"> • Did you reach the target audience? • Did you use the intended format (e.g., in-person, on-line, toolkit)? • Was it the project type you intended (e.g., self-advocacy training, employment readiness, life coaching)? 	<input type="checkbox"/> Strongly disagree (1) <input type="checkbox"/> Disagree (2) <input type="checkbox"/> Neither agree nor disagree (3) <input type="checkbox"/> Agree (4) <input type="checkbox"/> Strongly agree (5)
2.	<p>The practice we use is consistent with the latest knowledge and understanding of best practices that DD Councils and Self-Advocates have.</p> <ul style="list-style-type: none"> • 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? 	<input type="checkbox"/> Strongly disagree (1) <input type="checkbox"/> Disagree (2) <input type="checkbox"/> Neither agree nor disagree (3) <input type="checkbox"/> Agree (4) <input type="checkbox"/> Strongly agree (5)
3.	<p>The practice we use has been reviewed or accepted by an independent expert.</p> <ul style="list-style-type: none"> • Reviewed and accepted by TA Provider. • Our practice was found to be effective in published research or peer-reviewed journal. 	<input type="checkbox"/> No (0) <input type="checkbox"/> In Progress (1) <input type="checkbox"/> Yes (2)
4.	<p>Our practice adds to and builds upon relevant literature, contributing to an emerging or established research area.</p> <ul style="list-style-type: none"> • Are the results from other practitioners published in a peer-reviewed publication? • Are the results published in an industry publication? 	<input type="checkbox"/> Strongly disagree (1) <input type="checkbox"/> Disagree (2) <input type="checkbox"/> Neither agree nor disagree (3) <input type="checkbox"/> Agree (4) <input type="checkbox"/> Strongly agree (5)
5.	<p>Our practice incorporates the use of a logic model or driver diagram to document inputs, goals, and outcomes (short, medium, and long-term).</p>	<input type="checkbox"/> No (0) <input type="checkbox"/> In Progress (1) <input type="checkbox"/> 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 accessibility.	<input type="checkbox"/> No (0) <input type="checkbox"/> In Progress (1) <input type="checkbox"/> Yes (2)
7.	<p>The practice we use is developed, assessed, and modified based on impact.</p> <ul style="list-style-type: none"> Do we use quantitative data for outcome measures? Do we systematically collect qualitative data? Do we conduct a post-event evaluation? Do we conduct an evaluation at least 6-months post-event? 	<input type="checkbox"/> Strongly disagree (1) <input type="checkbox"/> Disagree (2) <input type="checkbox"/> Neither agree nor disagree (3) <input type="checkbox"/> Agree (4) <input type="checkbox"/> Strongly agree (5)
8.	<p>Our data show that the practice delivers intended outcomes.</p> <ul style="list-style-type: none"> Do we use quantitative data for outcome measures? Do we systematically collect qualitative data? Do we conduct a post-event evaluation? Do we conduct an evaluation at least 6-months post-event? 	<input type="checkbox"/> Strongly disagree (1) <input type="checkbox"/> Disagree (2) <input type="checkbox"/> Neither agree nor disagree (3) <input type="checkbox"/> Agree (4) <input type="checkbox"/> Strongly agree (5)
Total	<i>Add up the points from your responses. Total possible points = 31.</i>	<div style="border: 1px solid black; height: 40px; width: 100%;"></div> <p style="text-align: center;">(Section 2 Total)</p>

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 DD Council 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?	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (1)
2.	Do our data show the number of participants who use lessons from the practice often?	<input type="checkbox"/> No (0) <input type="checkbox"/> 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)?	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (1)
4.	Do our data show the number of participants reporting they have taken specific actions because of the practice?	<input type="checkbox"/> No (0) <input type="checkbox"/> 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)?	<input type="checkbox"/> No (0) <input type="checkbox"/> 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?	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (1)
7.	Do our data show the number of participants reporting the practice helped them become a better leader?	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (1)
8.	Are we able to use our data to measure the change in participants' communication skills pre/post-practice?	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (1)
9.	Are we able to use our data to measure the change in participants' ability to problem solve pre/post-practice?	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (1)
10.	Are we able to use our data to measure the change in practice participants' social skills pre/post-practice?	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (1)
11.	Are we able to use our data to measure the change in participants' financial literacy pre/post-practice?	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (1)
12.	Additional: Add any other short-term outcomes you track here and add 1 point for each one. Please describe: <div style="border: 1px solid black; height: 40px; width: 100%; margin-top: 5px;"></div>	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (1)
Total	<i>Add up the points from your responses. Total possible points = 12.</i>	<div style="border: 1px solid black; height: 40px; width: 100%; margin-top: 5px;"></div> (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?	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (2)
2.	Do our data show the number of practice participants who talked or wrote to community members regarding disabilities issues?	<input type="checkbox"/> No (0) <input type="checkbox"/> 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?	<input type="checkbox"/> No (0) <input type="checkbox"/> 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?	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (2)
5.	Additional: Add any other intermediate outcomes you track here and add 1 point for each one. Please describe:	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (2)

Measure: Answer Yes or No to the following statements.		Answer and Points Value
4.	Do our data show the number of practice participants who are participating in employment or career development activities one year after the training/event?	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (3) <input type="checkbox"/> NA
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?	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (3) <input type="checkbox"/> NA
6.	Do our data show the number of practice participants who can and identify and articulate their own academic or professional strengths?	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (3) <input type="checkbox"/> NA
7.	Do our data show the number of practice participants who can identify and articulate their own academic or professional desires?	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (3) <input type="checkbox"/> NA
8.	Do our data show the number of participants who can identify and articulate their personal strengths?	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (3) <input type="checkbox"/> NA
9.	Do our data show the number of participants who can identify and articulate what they want and need help with?	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (3) <input type="checkbox"/> NA
10.	Do our data show the number of practice participants who report they are living in a setting they chose for themselves?	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (3) <input type="checkbox"/> NA
11.	Do our data show the number of participants who are not living with family?	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (3) <input type="checkbox"/> NA

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.	<div style="border: 1px solid black; height: 40px; width: 100%;"></div> <p>(Section 3B Total)</p>

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, coalition, board, or another group?	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (3) <input type="checkbox"/> NA
2.	Do our data show the number of practice participants who started a paid job or an education program after the training/event?	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (3) <input type="checkbox"/> NA
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?	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (3) <input type="checkbox"/> 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: <div style="border: 1px solid black; height: 30px; width: 100%; margin-top: 5px;"></div>	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (3) <input type="checkbox"/> NA
13.	Additional: Add any other long-term outcomes you track here and add 1 point for each one. Please describe:	<input type="checkbox"/> No (0) <input type="checkbox"/> Yes (3) <input type="checkbox"/> NA
Total	<i>Add up the points from your responses. Total possible points = 36.</i>	<div style="border: 1px solid black; height: 30px; width: 100%; margin-bottom: 5px;"></div> <p style="text-align: center;">(Section 3C Total)</p>

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.

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 evidence-based practice and the FGCU practice model. <https://fgcu.libguides.com/EBP>. Similar terms for "evidence-informed practice" include evidence-based practice, promising practice, and emerging practice.