



## **Review of Self-Advocacy Activities and Recommendations for DD Councils**

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Office for Performance and Evaluation*

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## Background

Through the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), the State Councils on Developmental Disabilities (SCDD) support programs that promote advocacy, self-determination, integration, and inclusion. As part of the Office of Performance and Evaluation (OPE) contract, Lewin worked with the Administration for Community Living (ACL), SCDDs, and the National Association of Councils on Developmental Disabilities' (NACDD) Technical Assistance Center for Councils on Developmental Disabilities (ITACC) to identify how SCDDs can better develop resources that lead to positive outcomes related to self-advocacy and support individuals with developmental disabilities in realizing their self-advocacy goals. Lewin conducted this research with the following questions in mind:

- What outcomes do Councils and external programs involved in this study track?
  - What are council-specific and external program-specific outcomes?
- How do Councils involved in this study provide self-advocates support and opportunities for participation?
  - Which methods have the greatest impact?<sup>1</sup>
- What criteria should ACL consider for inclusion in future council efforts to ensure evidence-based effectiveness of self-advocacy supports and resources?

Over the course of the research, Lewin observed that DD Councils focus on measuring inputs, activities, and outputs related to their self-advocacy resources. However, few measure the long-term outcomes or impacts of these resources. Overall, DD Councils do not measure whether practices are evidence based or informed. To help Councils and their technical assistance (TA) provider bridge these gaps, Lewin developed an evidence informed framework based on literature and a self-assessment tool to help Councils:

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

Please refer to *A Framework for Assessing Self-Advocacy Outcomes* to review the assessment tool.

## Research Activities/Methodology

To get an inclusive picture of the resources available to self-advocates, Council efforts to promote self-advocacy, self-advocates' needs, and tools that could help Councils create resources that improve long-term outcomes, Lewin conducted a multi-step research approach that included an

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<sup>1</sup> For the purposes of this study, Lewin defines impact as action taken by a self-advocate as a result of participating in or receiving support from a Council resource, initiative, or practice to meet a self-advocacy goal.

environmental scan of resources of self-advocacy, interviews with select Councils and self-advocates, and a review of outcomes tracked by participating Councils and external programs.

***NOTE:** Lewin would like to emphasize that the findings of the environmental scan, interviews, and review of outcomes data reflect a sample of Council activities and are not inclusive of the universe of efforts being undertaken in the area of self-advocacy.*

## Environmental Scan of Resources on Self-Advocacy

Lewin conducted an environmental scan of self-advocacy activities, resources, and products related to self-advocacy to guide the development of criteria that Councils can consider when creating resources that are effective in improving self-advocacy outcomes in the DD community. The environmental scan was guided by the following questions.

- What types of activities are available to self-advocates and their family members?
- What topics and issues within self-advocacy do Councils, and other advocacy organizations focus on?
- How do activities align with the three DD Act requirements and the five ACL pillars, as defined on page six?

Lewin conducted the environmental scan of documents at three levels:

- **Technical assistance (TA) level:** We had a conversation with NACDD about the self-advocacy efforts of their Technical Assistance Center for Councils on Developmental Disabilities (ITACC)
- **Council level:** Activities from the following Councils: Wisconsin, Massachusetts, Vermont, Maryland, District of Columbia, Nevada, Utah, Hawaii, and Commonwealth of the North Mariana Islands
- **External Program level:** Activities and resources from prominent self-advocacy organizations, such as Self-Advocates Becoming Empowered (SABE), Self-Advocacy Resources and Technical Assistance Center (SARTAC), and Autistic Self-Advocacy Network (ASAN)

Please see Appendix A for the results of the environmental scan.

## Interviews with DD Council Executive Leaders and Self-Advocates

In order to understand Councils' goals, efforts, and outcomes related to self-advocacy, Lewin conducted a series of discussions with the Executive Directors of nine Councils. Lewin worked with ACL to identify a diverse set of Councils based on geographic location, population size, and maturity of statewide self-advocacy networks. Topics of discussion included:

- Resources developed to meet self-advocacy needs
- Resources that have the biggest impact
- TA needed to satisfy unmet resource needs
- Methods through which Councils track self-advocacy outcomes

Lewin also held a series of discussions with self-advocates to learn about their experiences using resources and products intended to help them reach their goals. The Councils and ACL assisted Lewin with identifying self-advocates for the discussions. Lewin held a total of 12 discussions with self-advocates from nine states. Topics of discussion included:

- Self-advocate journeys
- Experience working with or receiving support from Councils
- Resources that had the biggest impact
- Resources that the self-advocate would like to have available

Please refer to Appendices B and C for lists of the specific Councils and self-advocates interviewed and summaries of the discussions with Councils and self-advocates, respectively.

Using information collected from the interviews with Councils and self-advocates, Lewin developed a logic model of Council efforts related to self-advocacy and associated outcomes. Please refer to Appendix D for the logic model.

### Review of Outcomes Tracked by DD Councils and External Programs

Because the findings from the environmental scan and interviews with Councils indicated challenges related to tracking long-term outcomes of self-advocacy resources, Lewin and ACL conducted research on and engaged with select DD Councils and external programs for insights into practices that lead to long-term outcomes. Lewin used information from these discussions towards its recommendations to ACL.

For the complete summary of findings from these discussions, refer to Appendix E.

## Takeaways

### DD Council, External Program, and ITACC Self-Advocacy Activities

#### Key Takeaways on DD Council, External Program, and ITACC Self-Advocacy Activities

- Councils and external programs offer a wide array of self-advocacy activities, with educational workshops being the most common for Councils and toolkits, guides, or workbooks being the most common for external programs. All four of ITACC's resources reviewed for this research were organizational support.
- The majority of self-advocacy activities among Councils, external programs, and ITACC focus on citizenship and self-advocacy during adulthood. We did not find any self-advocacy activities which focused on aging individuals with I/DD.
- While a little more than half of external program activities did not relate to any of the DD Act Requirements, Council activities commonly related to the leadership development of individuals with I/DD (DD Act Requirement #2). Almost all of the ITACC activities related to establishing or strengthening state self-advocacy organizations (DD Act Requirement #1).
- Around half of Council activities and external program activities related to connecting people to resources (ACL Pillar #3), while all of the ITACC activities related to strengthening aging and disability networks (ACL Pillar #5).

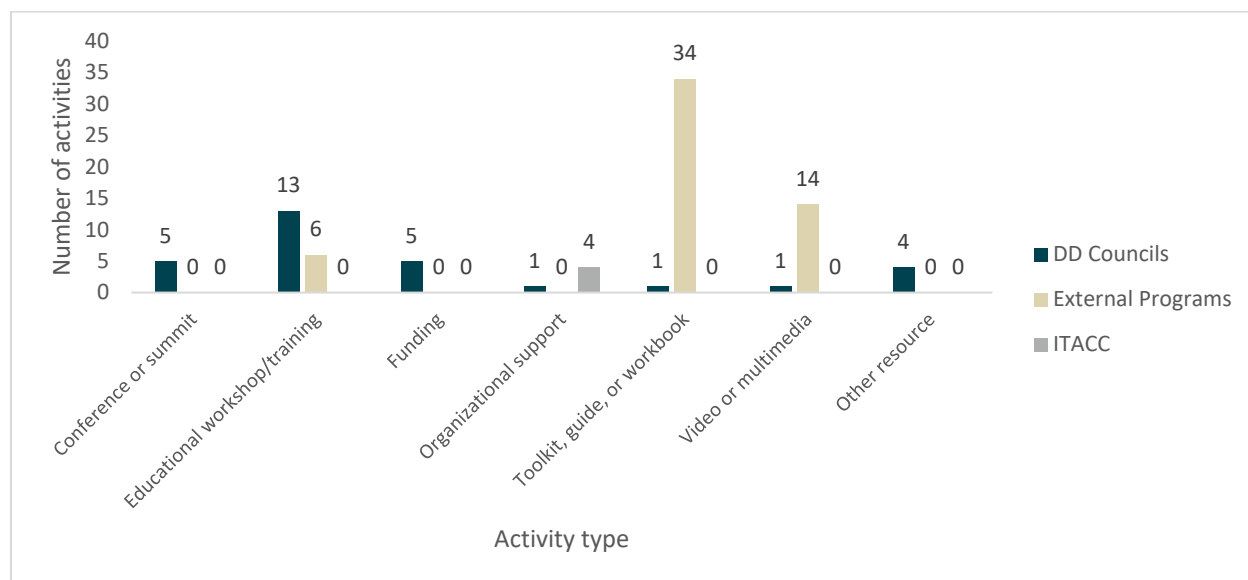
### A. What types of self-advocacy activities do DD Councils, External Programs, and ITACC offer?

We asked this question during the environmental scan and interviews with DD Councils and External Programs. We defined activity types as follows:

- **Conference or summit:** A one- or multi-day series of workshops on self-advocacy.
- **Educational workshop/training:** A one- or multi-hour session focused on educating self-advocates (and at times, their family members).
- **Funding:** Grants offered to individuals with I/DD, their family members, and/or advocacy organizations to carry out projects and programming related to self-advocacy.
- **Organizational support:** Technical assistance activities related to self-advocacy.
- **Toolkit, guide, or workbook:** A published document with one or multiple resources centered on a specific topic.
- **Video or multimedia:** A resource featuring one or multiple experts explaining concepts of self-advocacy.
- **Other resource:** Any activities that may not fit the above categories.

Overall, of the activities examined as part of this research, educational workshops are the most commonly-implemented activity among Councils (Exhibit 1). The most common activities implemented by external programs are toolkits, guides, or workbooks (Exhibit 1). All four of ITACC's resources reviewed for this research focused on organizational support. DD Councils focus their efforts on in-person, face-to-face activities as opposed to external programs, which develop resources that the end-user can utilize on an individual basis.

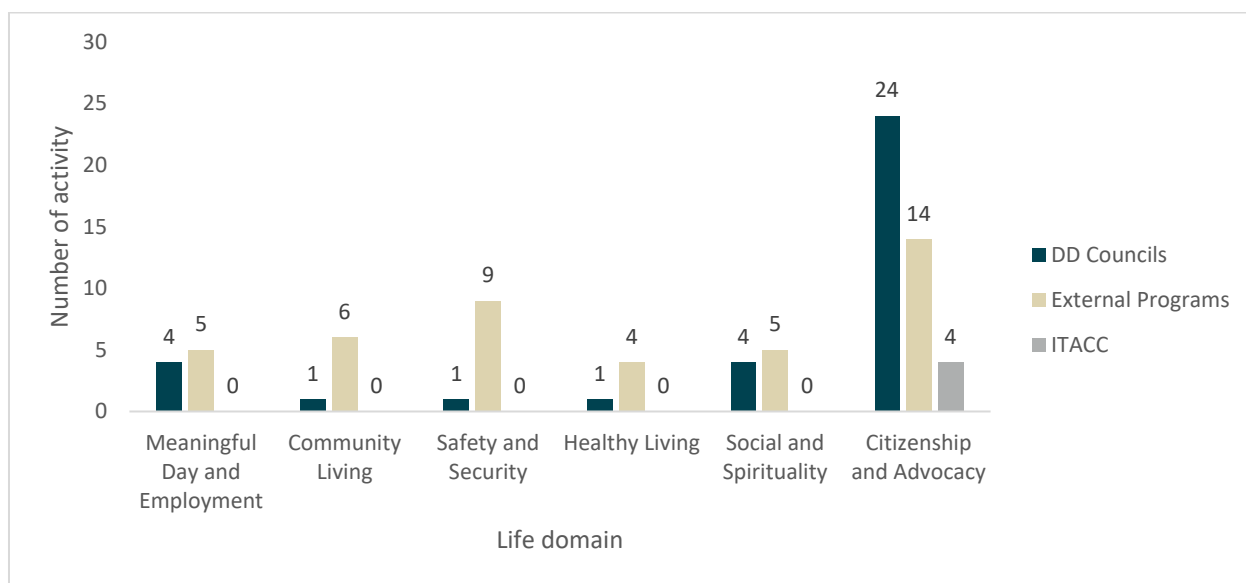
**Exhibit 1. DD Council, External Program, and ITACC Self-Advocacy Activity Types**



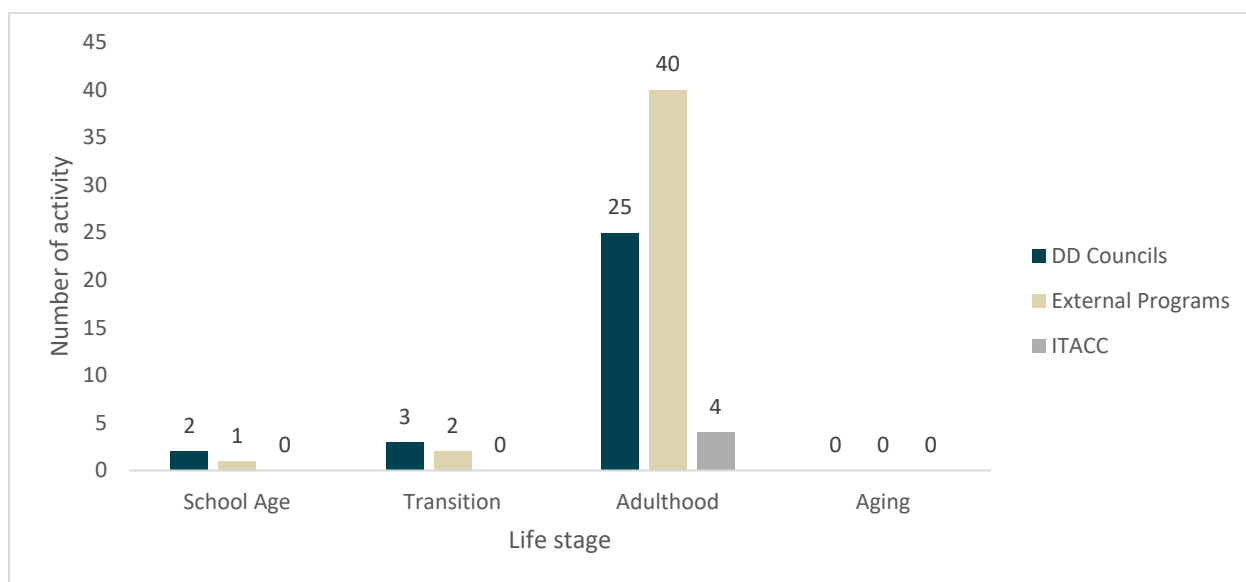
### B. Which life domains and life stages do self-advocacy activities relate to?

Lewin categorized the activities gathered from the environmental scan into the relevant life domains and stages as outlined in the [LifeCourse Framework](#). Most of the activities by Councils and external programs focused on citizenship and self-advocacy during adulthood (Exhibits 2 and 3). All ITACC activities focused on citizenship and self-advocacy during adulthood.

**Exhibit 2. Life Domains of DD Council, External Program, and ITACC Self-Advocacy Activities**



**Exhibit 3. Life Stages of DD Council, External Program, and ITACC Self-Advocacy Activities**





### C. Which DD Act Requirements and ACL Pillars do self-advocacy activities relate to?

We asked this question during the environmental scan. The DD Act Requirements and ACL Pillars listed below.

**Exhibit 4: DD Act Requirements and ACL Pillars**

DD Act Requirement or ACL Pillar Number	Definition
DD Act Requirement #1	Establish or strengthen state self-advocacy organizations
DD Act Requirement #2	Leadership development of individuals with I/DD
DD Act Requirement #3	Support and help expand cross-disability and culturally diverse leadership coalitions
ACL Pillar #1	Support families and caregivers
ACL Pillar #2	Protect the rights of and prevent the abuse of people with I/DD
ACL Pillar #3	Connect people with I/DD to resources
ACL Pillar #4	Expand employment opportunities for people with I/DD
ACL Pillar #5	Strengthen aging and disability networks

- Around 70% of the Council activities that we reviewed related to the leadership development of individuals with I/DD (DD Act Requirement #2). Additionally, Council activities most commonly related to connecting people to resources (ACL Pillar #3).
- Around 56% of external program activities that we reviewed did not relate to any of the DD Act Requirements, but half of the external program activities related to connecting people to resources (ACL Pillar #3).
- Three of the ITACC activities that we reviewed related to establishing or strengthening state self-advocacy organizations (DD Act Requirement #1) and all of the ITACC activities related to strengthening aging and disability networks (ACL Pillar #5).

## Self-Advocacy Activity Outcomes and Characteristics with the Greatest Impact

### Key Takeaways on Measurement of Outcomes for Self-Advocacy Activities

- Almost all Councils and a little more than half of external programs use surveys to measure output, outcomes, and impact data. However, we found that only one Council and three external programs are using longitudinal or follow up surveys.
- Councils and external programs measure similar outcomes, with the most common being: increase in participants who can better say what is important to them, increase in knowledge of services/resources, increase in membership/leadership in self-advocacy groups, increase in advocacy activities following the training.
- Self-advocates say that the main positive outcomes of self-advocacy are: increased self-confidence, increased ability to communicate, increased ability to help others advocate for themselves, becoming a leader, and increased public speaking skills.
- Councils, external programs, and self-advocates also mentioned practice characteristics which lead to the greatest impacts. These characteristics include input from self-advocates, person with I/DD is the trainer, peer-to-peer events, information on how to influence policy, statewide reach, supporting people with I/DD in leadership roles, and using plain language.

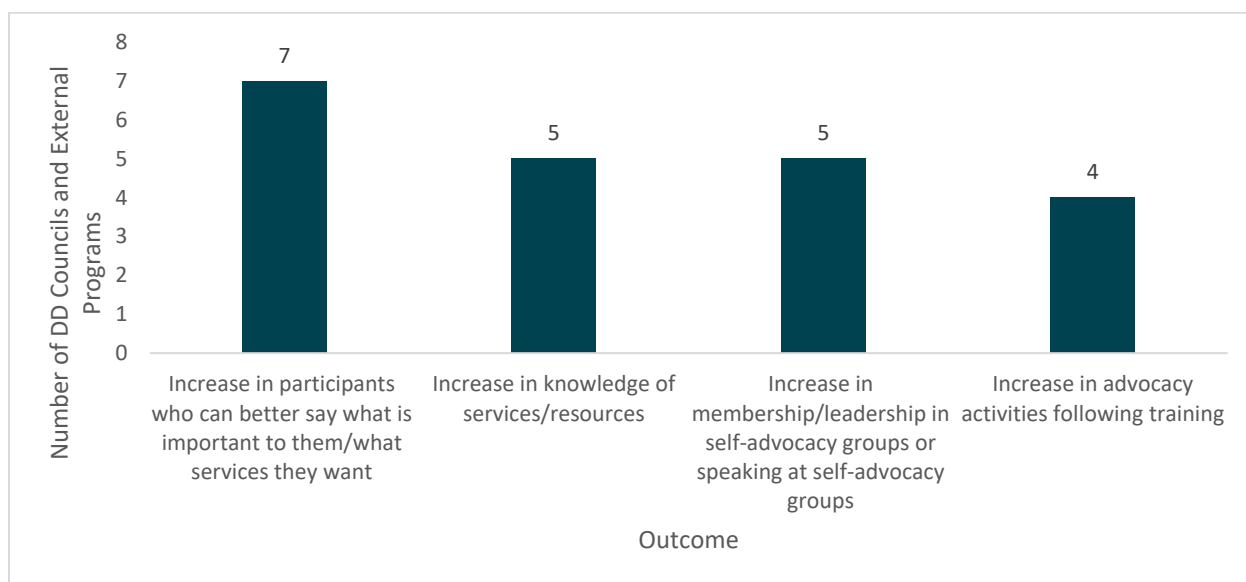
### A. How do DD Councils and External Programs measure outcomes for self-advocacy activities?

Lewin received outcomes data and related information from six DD Councils and eight External Programs. We found that:

- Almost all DD Councils (Alaska, Maryland, Oklahoma, South Carolina, and Tennessee) and a little more than half of the External Programs (Disability Rights Idaho, Missouri Project STIR, Ohio Project STIR, TPSID, and Virginia LEAP) are using surveys to measure output and outcomes data. Most DD Councils developed their survey questions based on ACL performance measures.
- Only one DD Council (Tennessee) and three External Programs (Missouri Project STIR, TPSID, Virginia LEAP) are using longitudinal or follow-up surveys to collect outcomes data.
- DD Councils and External Programs tend to measure immediate outputs, rather than long-term impacts. Councils need additional resources and guidance on how to best track long-term outcomes.

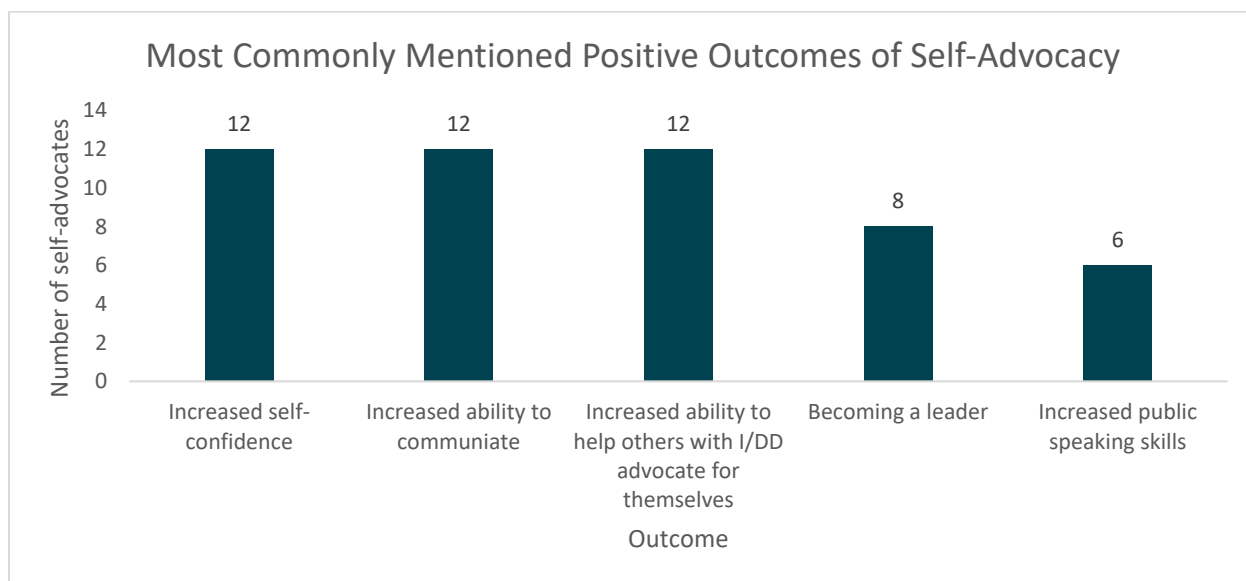
### B. Which outcomes are DD Councils and External Programs measuring for self-advocacy activities?

The Councils and External Programs that participated in the study are largely measuring similar outcomes. The low number of Councils reporting tracking increases in advocacy activities following trainings is partially attributed to a lack of resources to conduct follow-ups with self-advocates more than six months following the trainings. The most common outcomes they measure are presented below (Exhibit 5).

**Exhibit 5. Most Common Outcomes Measured by DD Councils and External Programs**

### ***C. What do self-advocates say are the positive outcomes of self-advocacy?***

We conducted interviews with 12 self-advocates and each self-advocate elaborated on positive outcomes that resulted from self-advocacy efforts. The most common outcomes mentioned are presented below (Exhibit 6).

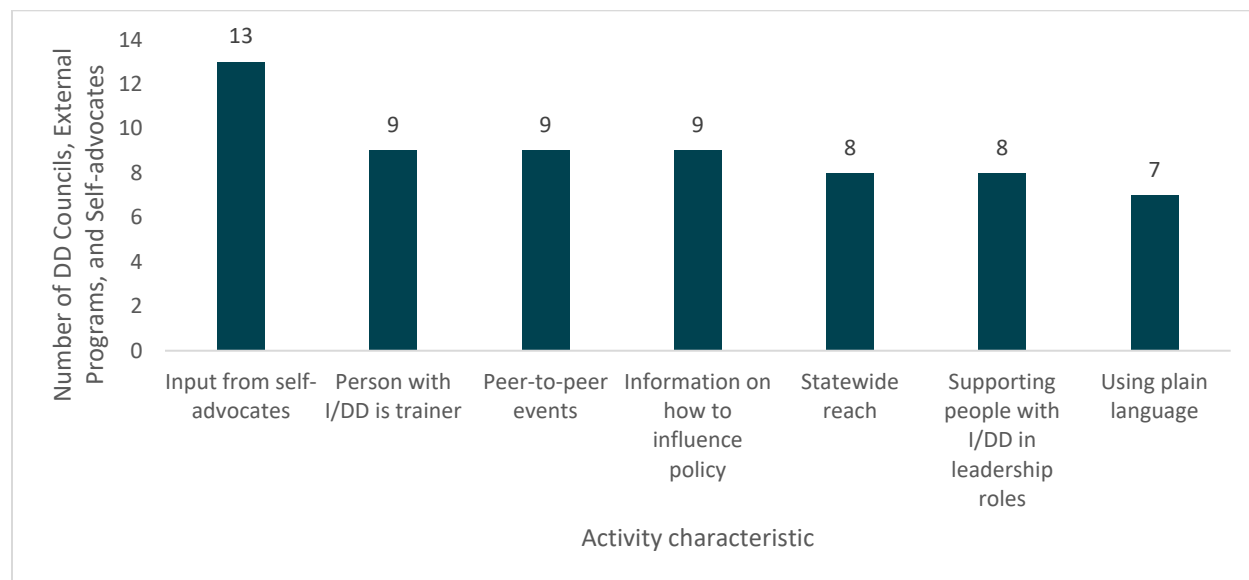
**Exhibit 6. Most Commonly Mentioned Positive Outcomes of Self-Advocacy**

### ***D. Which characteristics of self-advocacy activities do DD Councils, External Programs, and self-advocates think have the greatest impact?***

We conducted interviews with Nine DD Councils and 12 self-advocates, all of which provided information on their perspectives on which activity characteristics have the greatest impact or success based on feedback from end-users. Additionally, we gathered perspectives on this topic

from six external programs. The most commonly mentioned characteristics are presented below (Exhibit 7).

**Exhibit 7. Activity Characteristics that have the Greatest Impact**



### Criteria for Evidence-Based Effectiveness for Developing Self-Advocacy Practices

Over the course of interviews with Councils and self-advocates, Lewin learned that there is a lack of a uniform set of criteria that Councils can look to in order to develop practices that impact long-term self-advocacy outcomes for individuals with intellectual and developmental disabilities. Lewin leveraged information collected from self-advocates, Councils, external programs and existing literature to develop a list of criteria that Councils can consider in their practice development efforts. The criteria are outlined below.

## Exhibit 8. SCDD Self-Advocacy Evidence-Informed Criteria

SCDD Self-Advocacy Evidence-Informed Practice Criteria <sup>2</sup>	
<b>The practice:</b>	
<b>I.</b>	<b>Is consistent with the latest knowledge and practice that DD Councils and Self-Advocates have.</b> <ul style="list-style-type: none"> <li>Encompasses research findings, technology, and lived experiences of self-advocates.</li> <li>Aligns with relevant activities from other DD Councils, the TA provider, or other advocacy organizations.</li> <li>Correlates with state needs and characteristics obtained from sources such as data analysis, outreach to self-advocates and families, or focus groups.</li> </ul>
<b>II.</b>	<b>Has been reviewed or accepted by an independent expert.</b> <ul style="list-style-type: none"> <li>Reviewed and accepted by the TA Provider or External Program.</li> </ul>
<b>III.</b>	<b>Incorporates the use of a logic model to document inputs, goals, and outcomes (short, medium, and long-term).</b>
<b>IV.</b>	<b>Is supported by measures for sustainability to maintain it.</b> <ul style="list-style-type: none"> <li>Funding, accessibility, or assigned activity leads.</li> </ul>
<b>V.</b>	<b>Is developed, assessed, and modified based on impact.</b> <ul style="list-style-type: none"> <li>Evaluation, re-evaluation, quality improvement.</li> </ul>
<b>VI.</b>	<b>Builds upon relevant literature on quality and quantity to contribute to an emerging or established research area.</b>
<b>VII.</b>	<b>Has proven reliability and fidelity.</b> <ul style="list-style-type: none"> <li>Delivered as intended and produces results that are consistent and accurate.</li> </ul>
<b>VIII.</b>	<b>Demonstrates positive outcomes.</b> <ul style="list-style-type: none"> <li>Increased capacity for self-advocates and self-advocacy organizations to impact policy and system change.</li> </ul>
<b>IX.</b>	<b>Embeds the participant's values, preferences, and goals.</b> <ul style="list-style-type: none"> <li>Individuals with I/DD may envision their best lives and to have the life they want.</li> </ul>

## Next Steps

During interviews, self-advocates mentioned the following activities and resources that they would like to receive from their DD Council:

- Mentoring programs for leadership roles in self-advocacy
- Creating toolkits on self-advocacy
- Increasing self-advocacy training in rural areas
- Increasing availability of digitally-based training programs

<sup>2</sup>These Evidence-Informed Practice Criteria were 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.

- Offering technical assistance for statewide and local advocacy organizations on how to apply and compete for grants
- Training and resources on employment
- Resources on navigating romance and sexuality for people with disabilities

Additionally, based on our findings, Lewin recommends that DD Councils adopt the following six steps in order to strengthen their self-advocacy activities.

- Increase peer to peer activities
  - A large majority of self-advocates mentioned that peer-to-peer events have a great impact on them, but only one DD Council and one External Program mentioned that peer-to-peer events have a significant impact. DD Councils should consider the perspectives of self-advocates and increase the number of peer-to-peer activities that they offer.
- Increase collaboration with external programs
  - DD Councils offer fewer online materials, such as toolkits, than External Programs. DD Councils can direct self-advocates to External Programs' online resources in many ways, including: featuring resources in newsletters, creating a "helpful resources" website page, and printing hard copies of resources to share at in-person meetings
- Increase funding for local self-advocate led organizations
  - Five self-advocates expressed enthusiasm for grants and other funding models that drive resources from DD Councils to local self-advocate led organizations. These grants and funds help local organizations sustain advocacy-related programs at the grassroots level.
- Create self-advocacy activities for older adults
  - We did not find any DD Council activity focused on the aging stage of life. It is important for older adults with I/DD to learn self-advocacy skills, especially skills related to caregiver death and finances.
- Create self-advocacy activities that relate to DD Act Requirement #3
  - A large majority of DD Council activities relate to the leadership development of individuals with I/DD (DD Act Requirement #2). However, only a couple of DD Council activities relate to the support and expansion of cross-disability and culturally diverse leadership coalitions (DD Act Requirement #3).
- Improve measurement of long-term outcomes and impacts
  - While some DD Councils measure outcomes and impacts, many are only or primarily measuring immediate outputs. Councils should use the following tools to increase their measurement of outcomes:
    - ◆ A Framework for Assessing Self-Advocacy Outcomes – Self-Assessment Tool: this tool can help Councils realize their baseline status for measuring outcomes and track their progress on outcome measurement. Councils can

also use this tool to spark conversations with technical assistance providers about ways to improve outcome measurement.

- ◆ Pre/post-event surveys and longitudinal follow-up surveys: These surveys measure the outcomes and impacts of self-advocacy activities. Pre/post-event surveys measure how the self-advocacy activity helped change participants, while longitudinal follow-up surveys provide information on the lasting impact of self-advocacy activities.

## Appendix A. Self-Advocacy Activities Environmental Scan

To inform the creation of evidence-based effectiveness criteria of activities from State Councils on Developmental Disabilities (Councils), Lewin conducted an environmental scan guided by the following questions:

1. What types of activities are available to self-advocates and their family members?
2. What topics and issues within self-advocacy do ITACC, Councils, and other advocacy organizations focus on?
3. How do activities align with the three DD Act requirements and the five ACL pillars?
4. Based on information from the earlier three questions on activities promoting self-advocacy, what strengths and opportunities exist?

For the purpose of the environmental scan, Lewin defined activities as resources, products, meetings, and technical assistance.

### Approach

Lewin began the environmental scan by identifying activities at three levels:

- **Technical assistance (TA) level:** We had a conversation with NACDD about the self-advocacy efforts of their Technical Assistance Center for Councils on Developmental Disabilities (ITACC)
- **Council level:** Activities from Councils, focusing on states and/or territories recommended by NACDD (Wisconsin, Massachusetts, Vermont, Maryland, District of Columbia, Nevada, Utah, Hawaii, Commonwealth of the North Mariana Islands)
- **External Program level:** Activities and resources identified from Google searches from prominent self-advocacy organizations, such as Self-Advocates Becoming Empowered (SABE), Self-Advocacy Resources and Technical Assistance (SARTAN), Autistic Self-Advocacy Network (ASAN).

Based on the scope of activities available, Lewin narrowed the criteria in two ways: (1) to those that took place or were published online in the last five years (2014-2019), and (2) to those from select Councils and external advocacy programs. Across the three levels, a total of 82 activities were identified as relevant to self-advocacy supports (presented in Appendix A). There were 4 were at the TA level, 30 at the Council level, and 48 at the external program level.

Lewin then catalogued activities by name, date, and summary. To answer the outlined research questions, Lewin categorized activities by type, topic, and correspondence to DD Act and the ACL pillars. This categorization informed the final section of this report that presents preliminary strengths and opportunities for better supporting self-advocates.

Please note that these findings do not encompass all of the available activities to support self-advocates, as a more extensive, methodical search would be necessary. Furthermore, identified activities on the Council level were restricted to only a selection of Councils and public information on their websites.



## Findings

### Key Takeaways

- Councils and external programs offer a wide array of self-advocacy activities, with educational workshops being the most common for Councils and toolkits, guides, or workbooks being the most common for external programs. All four of ITACC's resources reviewed for this research were organizational support.
- The majority of self-advocacy activities among Councils, external programs, and ITACC focus on citizenship and self-advocacy during adulthood. We did not find any self-advocacy activities which focused on aging individuals with I/DD.
- While a little more than half of external program activities did not relate to any of the DD Act Requirements, Council activities commonly related to the leadership development of individuals with I/DD (DD Act Requirement #2). Almost all of the ITACC activities related to establishing or strengthening state self-advocacy organizations (DD Act Requirement #1).
- Around half of Council activities and external program activities related to connecting people to resources (ACL Pillar #3), while all of the ITACC activities related to strengthening aging and disability networks (ACL Pillar #5).

### Question #1: What types of self-advocacy activities do Councils, External Programs, and ITACC offer?

Lewin defined activities by type according to the following definitions in **Exhibit 1**:

- **Conference or summit:** A one- or multi-day series of workshops devoted to self-advocacy, or specific sub-topics related to self-advocacy.
  - *Example:* The Vermont Council in partnership with Green Mountain Self-Advocates hosts a yearly Youth Summit targeted towards youth transitioning to adulthood with sessions on locating self-advocacy groups, continuing education, and pursuing employment.
- **Educational workshop/training:** A one- or multi-hour session focused on educating self-advocates (and at times, their family members) on specific skills or resources related to self-advocacy.
  - *Example:* Massachusetts's Council hosts Independence College, a six-course workshop including sessions on the basics of self-advocacy, self-direction, knowing one's rights, voting, and legislative advocacy.
- **Funding:** Grants offered to individuals with I/DD and/or their family members to carry out a proposed project to increase capacity of self-advocates, or grants offered to advocacy organizations to create programming or supports for self-advocates.
  - *Example:* The Maryland Council provided stipends for participants attending Leading Forward: Training Self-Advocate Educators for First Responders Program where self-advocates learned to speak up for their health needs and how to train first responders and emergency personnel.
- **Organizational support:** In the case of ITACC, this refers to technical assistance (TA) activities related to self-advocacy administered to Councils. In the case of Councils, there are some examples of Councils offering TA to local self-advocacy groups.

- *Example:* In partnership with Green Mountain Self-Advocates, Vermont provides TA to 20+ local-self advocacy groups through the Self-Advocacy Project.
- **Toolkit, guide, or workbook:** A published document with one or multiple resources centered on a specific topic. Some supports of this category have an interactive component where self-advocates can interact with the material and answer questions.
  - *Example:* The Autistic Self-Advocacy Network (ASAN) and Self Advocacy Resource and Technical Assistance Center (SARTAC) created “Real Work for Real Pay: A Self-Advocate’s Guide to Employment Policy” that includes information on employment, self-advocates’ rights, sheltered workshops, and access to fair-pay jobs.
- **Video or multimedia:** A resource featuring one or multiple experts—typically a self-advocate or someone with experience supporting them—explaining concepts of self-advocacy.
  - *Example:* A SARTAC fellow created “Resources for Self Advocates, Families, and Allies About Coming Out,” a set of videos, podcasts, and other multi-media materials focused on LGBTQ+ education, coming out, and allyship.
- **Other resource:** Any activities that may not fit the above categories.
  - *Example:* Utah’s Council offers the Next Chapter Book Club, a weekly in-person and online book club for individuals with I/DD to make social connections and improve literacy and self-advocacy skills.

**Exhibit 1. Identified Activities by Type**

	Resource Type	ITACC	Councils	External Programs
Funding	Conference or summit	Not found (n/f) <sup>3</sup>	5	n/f
	Educational workshop	n/f	13	6
	For individuals or family members	n/f	4	n/f
	For advocacy organizations	n/f	1	n/f
	Organizational support (i.e. TA)	4	1	n/f
	Toolkit, guide, or workbook	n/f	1	34
	Video or multimedia	n/f	1	14
	Other resource	n/f	4	n/f

As shown in Exhibit 1, all ITACC activities were organizational support, the majority of Council activities were educational workshops, and the majority of external program activities were toolkits, guides, or workbooks.

<sup>3</sup> We use the phrase “not found” or “n/f” to indicate that the Lewin team did not find any activities of a certain type or topic within the high-level environmental scan, and that activities of these categories may exist.

## Question #2: Which topics and issues do self-advocacy activities focus on?

Lewin used the Charting the LifeCourse (CtLC) framework to organize activities and identify alignment with key life domains and life stages. The CtLC framework helps individuals and families identify and find supports, assess options, and envision their best lives. The framework is based on the following core belief: “All people have the right to live, love, work, and play and pursue their dreams in their community.” Lewin selected Life Domains and Life Stages, two of the key tools of the framework, to further explore the topics and issues across identified activities.

**Life Domains** represent the multiple facets of life that all people experience regardless of disability or medical need:

- **Meaningful Day & Employment:** Everyday life activities such as school, employment, volunteering, communication, routines, and life skills
- **Community Living:** Housing and living options, community access, transportation, and home modifications
- **Safety & Security:** Emergencies, well-being, guardianship options, legal rights and issues
- **Healthy Living:** Managing and accessing health care, including medical, mental health, behavior, developmental, wellness, and nutrition needs
- **Social & Spirituality:** Building friendships and relationships, leisure activities, personal networks, and faith community
- **Citizenship & Advocacy:** Making choices, setting goals, assuming responsibility, and driving how one’s own life is lived

**Life Stages** represent the various points in time (i.e. childhood, adulthood, aging, etc.) in any person’s life. There are points in time when individuals with disabilities may have unique supports and opportunities suited to a time period. For the purposes of this activity, prenatal and early childhood were excluded.

Lewin categorized activities by life domain and life stage in **Exhibits 2 and 3**, respectively. Some activities were applicable to more than one life domain or life stage, and were counted multiple times.

**Exhibit 2. Identified Activities by Life Domain**

CtLC Domain	ITACC	Councils	External Programs
Meaningful Day & Employment	n/f	4	5
Community Living	n/f	1	6
Safety & Security	n/f	1	9
Healthy Living	n/f	1	4
Social & Spirituality	n/f	4	5
Citizenship & Advocacy	4	24	14

As shown in Exhibit 2, all ITACC activities focused on citizenship and advocacy and the majority of Council and external program activities also focused on citizenship and advocacy.

**Exhibit 3. Identified Activities by Life Stage**

CtLC Domain	ITACC	Councils	External Programs
School Age	n/f	2	1
Transition	n/f	3	2
Adulthood	4	25	40
Aging	n/f	n/f	n/f

As shown in Exhibit 3, all ITACC activities focused on adulthood and the majority of Council and external program activities also focused on adulthood. We did not identify any activities which focused on the aging stage of life.

**Question #3: Which DD Act Requirements and ACL Pillars do self-advocacy activities relate to?**

In addition to categorizing activities by type and topics, Lewin explored alignment to the DD Act requirements and ACL pillars to determine representation and identify opportunities for further development. These results are outlined in **Exhibits 4 and 5**, respectively. Similar to the earlier section, some activities spanned multiple DD Act requirements or ACL pillars and were thus included multiple times.

As shown in Exhibit 4, most of the ITACC activities related to DD Act Requirement #1, while most of the Council and external program activities related to DD Act Requirement #2.

**Exhibit 4. Identified Activities by Relation to DD Act Requirements**

DD Act Requirement	ITACC	Councils	External Programs
Requirement #1: Establishing or strengthening of state self-advocacy organizations	3	7	3
Requirement #2: Leadership development of individuals with I/DD	1	25	16
Requirement #3: Support and expansion of cross-disability and culturally diverse leadership coalitions	1	2	1
None of the above	--	2	25

**Exhibit 5. Identified Activities by Relation to ACL Pillars**

ACL Pillar	ITACC	Councils	External Programs
<b>Pillar #1: Support for families and caregivers</b>	n/f	9	3
<b>Pillar #2: Protections of rights of individuals with I/DD and abuse prevention</b>	n/f	8	13
<b>Pillar #3: Connecting people to resources</b>	n/f	24	26
<b>Pillar #4: Expansion of employment opportunities</b>	n/f	4	4
<b>Pillar #5: Strengthening aging and disability network organizations</b>	4	9	4
<b>None of the above</b>	--	1	2

As shown in Exhibit 5, all of the ITACC activities related to ACL Pillar #5, while around half of the Council and external program activities related to ACL Pillar #3.

#### **Question #4: What are the strengths and opportunities of self-advocacy activities?**

##### *Types of Activities*

Among Council activities, one strength was the multitude of educational workshops. Many of them focused on general self-advocacy skills and included information on the history of the self-advocacy movement within the civil rights movement, key legislation passed, and rights of individuals with I/DD. Other educational workshops focused on applying self-advocacy skills to specialized topics, such as higher education, employment opportunities, public transportation, and forming a local self-advocacy group. These educational workshops are also likely important times for self-advocates and their family members to socialize and develop relationships with other attendees and Council staff.

Across the activities from external programs, online toolkits, guides, and workbooks were another strength. These activities provide information on topics such as Medicaid home and community-based services waivers, housing, supported decision-making, employment, and transportation. Given the goals of external programs such as ASAN, SABE, and SARTAN to develop activities that are accessible to a national audience, this is most easily achieved through published online resources. Another strength of external programs was the category of multimedia activities, such as videos and podcasts. Similar to the toolkits, guides, and workbooks, these activities present on-demand information for self-advocates, and may be more engaging than written documents. A significant number of multimedia activities were supplemented with handouts and presentations for self-advocates to follow along with the video or podcast.

Given that there were fewer Council online materials—including toolkits, guides, workbooks, videos, and podcasts—they could leverage the breadth of activities from external programs through directing self-advocates to them. Councils can consider embedding resources into regular

newsletters, creating a “Helpful Resources” website page, and printing hard copies to disseminate at in-person meetings. This would create easily accessible resources for self-advocates to review on their own time. Councils could also consider using external activities as starting-off points to add specific local context and/or resources.

### *Topics and Issues*

As for CtLC domains and life stages, the majority of activities were focused on citizenship and advocacy during general adulthood, which is in line with what was stated earlier with the majority of Council activities focused on introducing the concepts of self-advocacy. As a result, there appears to be opportunities for Councils to further expand the skills of self-advocacy to other facets of self-advocates’ lives, such as home modifications (Community Living), relationship building (Social & Spirituality), and employment opportunities (Meaningful Day & Employment). ITACC could also disseminate best practices to support self-advocates in specific life domains among Councils.

For self-advocates during the life stages of School Age and Transition, there were some emerging activities from Councils and external programs, such as Youth Summits and transitions guides with information on education, employment, housing, and healthcare. Compared to the general adult audience for other activities, it is important for Councils to continue focusing on this period of life to support self-advocates with their transition and develop self-advocacy and leadership skills early on.

Aside from a few external resources<sup>4,5</sup> providing information on older adults with I/DD, there were minimal activities found that promote self-advocacy skills to this population. Especially as the average life expectancy of individuals with I/DD continues to rise, it is important for Councils and external programs to provide resources and opportunities for older adults with I/DD to learn the skills to advocate for their needs during challenges such as caregiver death, finances, and independent living.

### *Alignment with DD Act and ACL Pillars*

In Council and external program activities, strengths identified include the leadership development of self-advocates (DD Act Requirement #2) and connecting people to resources (ACL pillar #3). In the activities identified, leadership development often took the form of train-the-trainer activities or support in the creation of new local self-advocacy groups—which also aligned with DD Act Requirement #1 and ACL pillar #5.

An area of growth to note is further development of self-advocacy supports that are cross-disability and geared towards a culturally diverse audience. While some of the activities encountered, such as instructional materials on the principles of self-advocacy, are potentially helpful cross-disability resources, there could be more intentional language stating so. On the culturally diverse side, Councils could more readily include public information on their websites on supports for diverse

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<sup>4</sup> A report published by Minnesota’s University Center for Excellence in Developmental Disabilities (UCEDD) can be found here: <https://ici.umn.edu/products/impact/231/231.pdf>

<sup>5</sup> A set of webinar videos directed towards support individuals on the needs and supports for older adults with I/DD can be found here: [https://resourcesforintegratedcare.com/concepts/geriatric-competent-care-and-intellectual-developmental-disabilities/aging\\_idd](https://resourcesforintegratedcare.com/concepts/geriatric-competent-care-and-intellectual-developmental-disabilities/aging_idd)

communities, such as translated materials or presence of translators at in-person meetings or events. In addition to ITACC's current resource with practice suggestions, other opportunity areas include further webinars to share best practices and small state group discussions for those with similar demographics.

Another point to note is that approximately half of external program activities did not fall into any of the DD Act requirements, likely because they were not developed with them in mind. This is as opposed to nearly all of the Council resources that applied to at least one requirement. Across the ACL pillars, while there was a focus on connecting resources to self-advocates, there were at least some activities present for each one. Opportunity areas for growth could be additional attention on employment opportunities.



## Appendix B. Summary of Themes from DD Council Interviews

### DD Councils:

Lewin conducted interviews with key informants from DD Councils in nine states.

State	DD Council Key Informant
Alaska	Kristin Vandagriff, Executive Director Lanny Mommsen, Research Analyst III
Maryland	Rachel London, Esq., Executive Director
Massachusetts	Dan Shannon, Executive Director
South Carolina	Valarie Bishop, Executive Director
Tennessee	Alicia Cone, Director of Program Operations
Texas	Beth Stalvey, Executive Director
Vermont	Kirsten Murphy, Executive Director
Washington	Jeremy Norden-Paul, Executive Director Brian Dahl, Planning Manager Emily Rogers, Contracts Manager
Wyoming	Shannon Buller, Executive Director

### Key Takeaways

- All of the Councils interviewed have at least one avenue through which they receive input from self-advocates about the needs of people with DD in their state.
- Many Councils mentioned in-person trainings as the most utilized type of self-advocacy activity, with leadership trainings that are developed and led by self-advocates as a key focus.
- Many Councils utilize pre/post surveys after trainings or other events to measure outcomes.
- All Councils utilize ACL performance measures to track effectiveness of grantees' activities.

Several themes emerged from the interviews related to how DD Councils identify self-advocacy needs, the types of resources that are developed to meet those needs, most utilized resources, how Councils measure outcomes, and resources with the highest impact. In addition, there were some similarities among the Councils in the types of resources they would like to create and the types of TA needed. The last section of this summary highlights noteworthy innovative methods or products that Councils described during the interviews.

### Identifying Self-Advocacy Needs of People with DD in the State

- All of the Councils interviewed have at least one avenue through which they receive input from self-advocates about the needs of people with DD in their state. These include:
  - Self-advocates who participate as members of the council;
  - Hosting listening sessions or contacting a state-wide list of self-advocates;
  - Direct feedback from self-advocacy organizations, partners, and TA providers; and
  - Feedback from conferences, trainings, and training sessions.



- Seven Councils reported working directly with a statewide group or network, such as a self-advocacy collaborative or coalition.
- Two Councils rely on feedback from local self-advocacy groups or chapters.
- Other ways to receive feedback are from conferences, trainings, and TA sessions.

### **Resources/Activities/Products Developed to Meet Identified Needs**

- Self-Advocacy Summits
  - Two states hold an annual summit that focuses on self-advocacy for people with DD. The Councils provide staff, financial, and other material support. The Summits are led by self-advocates.
- Trainings
  - Council-directed training
    - One council has hired self-advocates as staff members who conduct advocacy-leadership training in a train-the-trainer format.
  - Self-advocate led trainings
    - Three Councils reported supporting trainings that are led by self-advocate organizations.
      - These trainings focus on developing legislation and leadership
- Webinars
  - Webinars are utilized to hold trainings in between annual summits or in-person meetings.
- Documents
  - Two Councils created handbooks on transitioning
  - Two Councils created guides on supported decision making
  - One council developed a rural traditional skills curriculum
- Scholarship Funds
  - One council created a fund to assist self-advocates to participate in educational opportunities they might not otherwise be able to attend
- Newsletters
  - One council's newsletter targeting self-advocates has a circulation of 3,000.

### **Resources/Activities/Products Utilized the Most**

- Many Councils mentioned in-person trainings as the most utilized type of activity, with leadership trainings that are developed and led by self-advocates as a key focus.
- In-person meetings or trainings are used more often than via technology.
- Alaska has developed multiple types of resources and products that they make available electronically on their website and in hard copy format that they find are heavily utilized. These include toolkits, an agency guide for supported decision making, and a transition handbook.

## Criteria or Characteristics that Lead to Desired Outcomes or Greatest Impact

- Resources that are created by self-advocates for self-advocates. The key component is the involvement of the self-advocates.
- Products that are inclusive/accessible.
- Products that are available in multiple mediums.
- Resources developed in a collaborative environment.
- Products that include visuals and are developed in plain language.
- Trainings led by self-advocates and graduates of the Councils' leadership programs.
  - Resources that involve face-to-face contact over handing someone a piece of paper.
  - Those that include demonstrations and practicing of skills.
- Resources that have been socialized/marketed to the target audience.
- Documents or trainings that focus on skill-building.

## Measuring Outcomes of Activities/Resources/Products

- Seven Councils utilize pre/post surveys after trainings or other events to measure outcomes.
- Six Councils conduct outcomes or impact surveys to measure effectiveness.
- All Councils utilize ACL performance measures to track effectiveness of grantees' activities.
- Two Councils developed performance measures in-house.
- Three Councils track dissemination of written materials or website downloads and social media traffic as a way to measure effectiveness.
- Other measures include:
  - Legislation passed as a result of self-advocates' efforts;

## Anecdotal or qualitative data and testimonials/stories; and

- Growth of attendance numbers for trainings and conferences/summits.

## Resources that the Councils Would Like to Create

- Implement technology to reach people and keep engagement in a time of social distancing (how to continue with trainings and prevent social isolation).
- A resource to help self-advocates in the supported decision making process.
- Materials to help people with DD navigate the medical system. This would include information that is written in plain language using lots of visuals.

## TA Requested

- Most Councils expressed a desire for a collaborative way to can learn from one another on implementation experiences, product sharing, and efforts to expand the reach of DD Councils and self-advocacy organizations.

## Innovations

**Alaska:** Alaska had a paradigm shift which is called the DD Shared Vision. It began with a DD systems assessment and is now led by self-advocates. Alaska also holds an annual Self-Advocacy Summit for people with I/DD who are 18 years of age or older. Topics for this summit include: supported decision-making agreements, friendship and healthy relationships, Able Act and the Transition Plan, DD Shared Vision, and budget authority.

**Massachusetts:** Attendees are given homework (two hours a week for 10 weeks) after certain events or trainings and this provides follow-up outcomes data that is used to measure impact. The goal is to give people time to develop self-advocacy skills and apply their learning after attending trainings/events (e.g., actually get a council position).

**Maryland:** The council found that people with DD want to be engaged in self-advocacy but do not use the internet as much as they thought. To meet this need for written materials, they formed a diversity work team to translate TA products (user-friendly one-pagers on the DD system, person-centered planning and advocating for yourself) into Spanish and simple Chinese. Now these materials reach more people.

**South Carolina:** Created a Self-Advocate Coordinator position that is held by a self-advocate. This person takes the lead on the Partners Program and serves as the face of self-advocacy for the state. He also provides valuable feedback to the council on what the self-advocacy needs are around the state.

**Texas:** The council offers translation stipends that organizations can apply for so they can translate self-advocacy materials/trainings, etc. These materials are targeted to the needs of a particular product or audience, or are disseminated in a particular area of the state.

**Vermont:** The council subcontracts with a self-advocacy organization that holds meetings with local chapters of self-advocates and has a dedicated outreach director who makes TA visits to each chapter twice a year. The chapters identify what resources/products they need and the organization develops it. Outcomes data from TA provided is reported back to the council.

## Appendix C. Summary of Themes from Self-Advocate Interviews

### Self-Advocates

Lewin conducted interviews with 12 self-advocates from nine states:

State	Self-Advocate
Alaska	Maggie
Maryland	Ken
Massachusetts	Anne, Dusya, and Tamara
South Carolina	Connie and Derrick
Tennessee	Clancey
Texas	Brooke
Vermont	Max
Washington	Shawn
Wyoming	Jennifer

#### Key Takeaways

- All interviewees stressed that their self-advocacy instilled a greater sense of self-confidence. The interviewees reported their increased ability to communicate and promote their interests. In addition, self-advocacy has enabled many to help other individuals with disabilities advocate for their needs.
- Eight self-advocates reported currently serving or having served as a member of a DD Council. For these individuals, being a member or a Chair of a DD Council was an empowering experience.
- Seven self-advocates described peer-to-peer trainings and peer support programs as highly effective resources for furthering self-advocacy efforts in their state.

Lewin grouped the findings of the interviews with self-advocates into several categories. These include interviewees' introduction to the field of advocacy, challenges encountered along the journey, experiences receiving support from DD Councils, resources with the biggest impact towards realizing self-advocacy goals, and gaps DD Councils can fill moving forward.

### Journeys Towards Self-advocacy

- The interviewees described varied paths to beginning their self-advocacy activities.
  - Five of the interviewees were encouraged to take on self-advocacy through a connection with their respective DD Councils or a local self-advocacy organization. This included having a connection with a member of a DD Council, attending a statewide self-advocacy conference, finding employment in a program administered by a DD Council, or attending a training workshop organized by the local DD Council.
  - Two interviewees reported beginning their self-advocacy journey through encouragement by a close personal friend.
  - One interviewee encountered biases from the education system which inspired him to self-advocate at a young age.

- Four interviewees reported gaining knowledge about self-advocacy through activities led by other organizations. These organizations include local disability rights organizations such as the Asperger's Association of New England (AANE), Centers for Independent Living (CILs) and organizations that educate individuals with developmental disabilities about public policy and how to use their voice to make change in the community.

### Positive Outcomes of Self-Advocacy

- All interviewees stressed that their self-advocacy instilled a sense of fulfillment and greater sense of self-confidence. The interviewees reported their increased ability to communicate and promote their interests. In addition, self-advocacy has enabled many to help other individuals with disabilities advocate for their needs.
- Six interviewees called out how their involvement in self-advocacy activities strengthened their public speaking skills, which helped them serve as a role model for others with disabilities and is a significant source of personal pride.
- Four interviewees reiterated an increase in the number and quality of peer-to-peer connections as a result of engaging in self-advocacy activities.
- Three interviewees reported that engaging in self-advocacy resulted in full-time employment.
- Two interviewees stressed that self-advocacy has given individuals outside of the DD community a perspective on what people with disabilities are capable of achieving.

### Challenges Faced in the Self-Advocacy Journey

- Two interviewees reported a lack of support from state agencies and local authorities in finding meaningful employment although both were qualified for positions they were seeking.
- One interviewee reported a challenge related to the process of onboarding to the DD Council as a member. The interviewee initially experienced hurdles acclimating to the Council's norms and vernacular.
- Another interviewee described challenges balancing the role of DD Council Chair and the inflexible nature of the state's service delivery. This interviewee resorted to paying for personal care services out-of-pocket while traveling on behalf of the DD Council, which is essential to conduct advocacy work in the state.
- One interviewee reported that she had to overcome her fear of speaking up during meetings and group settings. She has been a tour guide for the last five years which has grown her confidence in this area.

### Resources Offered to Self-Advocates

- Four interviewees who are or were members of a DD Council were provided membership-related resources.
  - Two of the individuals received trainings to familiarize themselves with their respective Council's processes, roles within the Councils, and norms.
  - The remaining two individuals received support throughout their tenures as a DD Council member. They received materials to prepare them for Council meetings and were given the opportunity to ask clarifying questions to ensure maximum participation in Council activities.

- Four interviewees found full-time employment within organizations and programs that are directly or indirectly supported by the DD Councils.
  - Three of the interviewees are engaged in implementing training programs that focus on leadership and providing peer-support. The self-advocates lead the development of the training content as well as content-delivery in a peer-to-peer format.
  - One self-advocate reported finding a policy-focused position in a state agency.
- Four self-advocates reported participating in advocacy conferences organized by the DD Councils or statewide advocacy organizations that receive support from DD Councils.
- Five self-advocates received education and training in leadership and independence. These include:
  - Leadership training offered for members of the DD Council.
  - Training on how to engage with policy makers.
  - Classes for people with disabilities to learn important skills that will enable them to be more independent. The curriculum was created by self-advocates as well.
- Three advocates received funding from their respective DD Councils to engage in self-advocacy activities. These include:
  - Stipends to attend conferences that focus on promoting self-advocacy.
  - Funding to organize meet and greets between self-advocates, family members, organizations, and agencies where attendees learn about supports and services that are available throughout the state.
  - Funding where the Council contracts with the statewide self-advocacy organization to provide technical assistance (TA) to local groups across the state. People with disabilities run the program and provide the TA.

## Resources with Highest Impact

- Training and Education on Leadership and Independence
  - Five self-advocates expressed satisfaction with leadership training provided through or supported by their DD Councils. These trainings ranged from an annual conference with leadership topics to an eight-week series of courses. In addition, six self-advocates specifically called out the public speaking training and experience gained through leadership courses as a key component to improving their ability and confidence to speak in front of audiences of various sizes, provide testimony at legislative events, and present at conferences.
- Legislative Activity
  - Five self-advocates attribute high value to the opportunities they have had to connect with local and state leaders in the pursuit of their self-advocacy goals. This legislative advocacy includes:
    - Inter-disciplinary meetings where advocates share their stories and develop relationships with agencies and legislators.
    - Conferences that allowed self-advocates to interact with state and national policy makers.
    - Trainings on effective communication with state legislators and policy makers.
    - Testimonials in front of a State Legislative Committee to advocate on behalf of self-advocates to empower them towards more independence in supportive decision making.
- Leadership Roles in Advocacy Organizations

- Eight self-advocates reporting currently serving or having served as a member of a DD Council. For these individuals, being a member or a Chair of a DD Council was an empowering experience that provided a first-hand opportunity to bring perspectives from the DD community and direct resources to people with disabilities.
- Funding Opportunities
  - Five self-advocates expressed enthusiasm for grants and other funding models that drive resources from DD Councils to local, grassroots advocacy organizations. Through these grants and funds, local organizations are able to organize advocacy conferences, provide TA to local organizations, train people with disabilities in advocacy skill building, and sustain programs that develop advocacy networks at the grassroots level.
- Peer Support Programs
  - Seven self-advocates described peer-to-peer trainings and peer support programs as a highly effective resource to further self-advocacy efforts in their state.

### Recommended Resources for Development

- Increased training for gainful employment for people with disabilities.
- Resources on how to navigate romance and sexuality for people with disabilities.
- Mentoring programs for leadership roles in self-advocacy.
- Toolkits on self-advocacy.
- TA for statewide and local advocacy organizations on how to apply for and compete for grants.
- Increased self-advocacy training in rural areas.
- Increased availability of digitally-based training programs.

### COVID-Related Changes to Self-Advocacy

- Five self-advocates are participating in virtual meetings with their DD Councils and local advocacy organizations. These meetings provide opportunities for inclusion and to prevent isolation in a time of physical distancing. Self-advocates continue to communicate with legislators digitally and plan to organize virtual conferences.



## Appendix D: SCDD Self-Advocacy Logic Model

Inputs (Resources)	Activities (Products, Events, and Methods)	Outputs (Results from Products, Events, and Methods)	Short-Term Outcomes (1-3 years) (Changes in Attitudes, Awareness, Knowledge, Skills, and Behaviors)	Intermediate Outcomes (3-5 years) (Changes in Social Action, Practices, and Sustainability)	Long- Term/Impact (>5 years) (System Change)
<ul style="list-style-type: none"> <li>▪ Funding sources</li> <li>▪ DD Act, program guidance and instructions, performance measures</li> <li>▪ DD Council staff</li> <li>▪ DD Council members</li> <li>▪ DD Council partners</li> <li>▪ People with developmental disabilities and their families</li> <li>▪ Self-Advocates</li> <li>▪ Partners and stakeholders</li> <li>▪ State policymakers and legislators</li> <li>▪ Equipment and supplies</li> <li>▪ Knowledge development, sharing, and transfer</li> <li>▪ Websites and technology</li> </ul>	<ul style="list-style-type: none"> <li>▪ <b>Grants and Funding Opportunities</b> Fund projects, opportunities or positions to enable self-advocates to fully engage and become leaders.</li> <li>▪ <b>Meetings</b> Foster partnerships and stakeholder engagement, establish and develop coalitions, encourage self-advocate participation and leadership, and keep policymakers/legislators informed about disability and advocacy issues.</li> <li>▪ <b>Training and Education</b> Develop and deliver trainings, hold educational courses, workshops, and conferences, and develop/update technical assistance (TA) products and resources such as toolkits, handbooks, videos, webinars, guides, podcasts, presentations, and fact sheets.</li> <li>▪ <b>Outreach and Dissemination</b></li> </ul>	<ul style="list-style-type: none"> <li>▪ # funding opportunities/grants offered and amount awarded</li> <li>▪ # partnerships, coalitions established/developed</li> <li>▪ # meetings held and # of participants</li> <li>▪ # cross-disability and culturally diverse leadership coalitions established/developed</li> <li>▪ # self-advocates participating in meetings</li> <li>▪ # self-advocates participating on cross-disability and culturally diverse leadership coalitions</li> <li>▪ # self-advocates serving in leadership positions at meetings</li> <li>▪ # self-advocates serving in paid positions (supported directly or indirectly by DD council)</li> <li>▪ # peer support programs established and # of participants</li> </ul>	<ul style="list-style-type: none"> <li>▪ Increase in the number of people with DD and family members who have knowledge of how to take part in decisions that affect their lives, the lives of family members, or systems.</li> <li>▪ Increase in the advocacy, leadership and self-determination skills of people with DD.</li> <li>▪ Increase in access to reliable information and resources people with DD need to advocate for and access services and supports.</li> <li>▪ Increase in the number of people with DD and</li> </ul>	<ul style="list-style-type: none"> <li>▪ Continued access to reliable information and resources people with DD and family members need to advocate for and access services and supports.</li> <li>▪ Self-advocate leaders continue to assume leadership roles in their communities.</li> <li>▪ Opportunities for people with DD to participate as leaders in cross-disability and culturally diverse leadership coalitions are supported and expanded.</li> <li>▪ Continued involvement for self, family, and</li> </ul>	<ul style="list-style-type: none"> <li>▪ Self-advocates and family members are an organized and powerful group of leaders who have the support they need to create change, shape policy and public opinion regarding disability issues, and sustain systems that enable people with DD to have the life they want.</li> </ul>



Inputs (Resources)	Activities (Products, Events, and Methods)	Outputs (Results from Products, Events, and Methods)	Short-Term Outcomes (1-3 years) (Changes in Attitudes, Awareness, Knowledge, Skills, and Behaviors)	Intermediate Outcomes (3-5 years) (Changes in Social Action, Practices, and Sustainability)	Long- Term/Impact (>5 years) (System Change)
<ul style="list-style-type: none"> <li>Media outlets (internet, television, radio, newspapers, etc.)</li> <li>Reporting and data systems</li> </ul>	<p>Conduct outreach, disseminate products, encourage self-advocate participation, hold awareness events (e.g., rally, state-wide summit, disability awareness day), develop media products such as newsletters, website updates, social media posts, news releases, and PSAs and disseminate via media outlets.</p> <ul style="list-style-type: none"> <li><b>Collect Data</b> Conduct surveys, develop performance measures, develop outcome measures, collect data, collect testimonials, and track and monitor activities.</li> <li><b>Conduct Evaluation</b> Utilize an evaluation framework to measure self-advocacy efforts against evidence-informed practice criteria.               <ul style="list-style-type: none"> <li>Create, refine and develop self-advocacy practices that meet these criteria.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li># trainings held and # of participants</li> <li># leadership trainings held and # of participants</li> <li># peer-to-peer trainings held and # of participants</li> <li># educational courses held and # of participants</li> <li># workshops held and # of participants</li> <li># conferences held and # of participants</li> <li># legislative engagement opportunities and # of participants</li> <li># public speaking trainings held and # of participants</li> <li># public speaking opportunities offered and # of participants</li> <li># self-advocates leading trainings or presenting at conferences or other events</li> <li># pre/post-training surveys/tests conducted and percent positive feedback and evidence of knowledge gained</li> <li># TA products, curricula, and resources developed/updated with</li> </ul>	<p>family members who are participating on cross-disability and culturally diverse leadership coalitions, policy boards, advisory boards, governing bodies, or serving in leadership or paid positions.</p> <ul style="list-style-type: none"> <li>Increase in the number of people with DD and family members who utilize their advocacy skills at the state level as a result of DD Council work.</li> <li>Increase in the number of people with DD and family members who are involved in advocacy issues across the state.</li> <li>Increased awareness of disability and</li> </ul>	<p>others in taking a stand and giving back.</p>	

Inputs (Resources)	Activities (Products, Events, and Methods)	Outputs (Results from Products, Events, and Methods)	Short-Term Outcomes (1-3 years) (Changes in Attitudes, Awareness, Knowledge, Skills, and Behaviors)	Intermediate Outcomes (3-5 years) (Changes in Social Action, Practices, and Sustainability)	Long- Term/Impact (>5 years) (System Change)
		<p>involvement/input from people with DD</p> <ul style="list-style-type: none"> <li># TA products and resources developed/updated that contain plain language</li> <li># TA products and resources developed/updated that are translated in multiple languages</li> <li># TA products and resources developed/updated that are in accessible formats</li> <li># TA products and resources developed/updated that are culturally diverse</li> <li># outreach events held and # of participants</li> <li># media products developed</li> <li># media products disseminated</li> <li>Amount web page and social media traffic</li> <li># surveys conducted and percent positive feedback</li> <li># testimonials collected and percent positive feedback</li> <li>Amount of and type of data collected</li> <li># performance and outcome measures tracked</li> </ul>	<p>advocacy issues across the state.</p> <ul style="list-style-type: none"> <li>Increase in the number of self-advocates and family members reporting positive experiences or satisfaction with activities.</li> <li>Increase in the amount of self-advocacy work that reflects evidence-informed practice criteria.</li> </ul>		

Inputs (Resources)	Activities (Products, Events, and Methods)	Outputs (Results from Products, Events, and Methods)	Short-Term Outcomes (1-3 years) (Changes in Attitudes, Awareness, Knowledge, Skills, and Behaviors)	Intermediate Outcomes (3-5 years) (Changes in Social Action, Practices, and Sustainability)	Long- Term/Impact (>5 years) (System Change)
		<ul style="list-style-type: none"> <li># monitoring activities</li> <li>Amount of self-advocacy advocacy activities that meet evidence-informed practice criteria</li> </ul>			

## Appendix E. Summary of DD Council and External Program Practices, Outcome Measurement, and Practice Characteristics with Greatest Impact

### Key Takeaways

- The majority of Councils and external programs which we received outcomes data from were using surveys as their outcome collection method. However, only one DD Council and three external programs that sent us outcomes data were using longitudinal surveys.
- DD Councils and external programs are measuring similar outcomes. The most common outcomes they are measuring include the increase in the number of participants who are better able to say what is important to them, the participants' increase in knowledge/services, and increased membership/leadership at self-advocacy groups.
- DD Councils, external programs, and self-advocates also provided information on which characteristics of self-advocacy activities they believe have the greatest impact. The most common responses include input from self-advocates, having a person with I/DD as the trainer, information on how to influence policy, peer-to-peer events, statewide reach, supporting people with I/DD in leadership roles, and using plain language.

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### I. DD Council Self-Advocacy Practices

DD Council	Practice Name	Practice Type	Outcome Collection Method
Alaska	Self-advocacy summit	Summit/training	Pre/post survey
	Various	Various (e.g. legislative meetings, resource guides)	Shared DD Vision Survey
Maryland	Partners in Policymaking	Training	Post-event survey
	People on the Go	Training	Post-event survey
Oklahoma	Various	Various	Annual stakeholder survey
South Carolina	Community Leadership Program	Training	Survey
Tennessee	Partners in Policymaking	Training	Pre/post survey, longitudinal survey
	Youth Leadership Academy	Training	Post-event survey
Washington	EPIC Grant	DD network expansion	Anecdotal evidence

Trainings are the most common self-advocacy activity type among the Councils which provided us with outcomes data. Almost all of the Councils mentioned above use surveys to measure outcomes, but only one (Tennessee) uses a longitudinal follow up survey.

## II. External Program Practices

External Program	Practice Name	Practice Type	Outcome Collection Method
Disability Rights Idaho	Supported Decision Making in Action	Training	Post-event survey
Missouri Project STIR	Project STIR Training	Training	Pre/post survey, 6 month follow up survey
Ohio Project STIR	Project STIR Training	Training	Post-event survey, outcome study
Project SEARCH	Transition to Work	Training	Reporting from program sites
Think College	Future Quest Island Toolkit	Educational toolkit	Unclear
	Peer Mentor Training	Training	Unclear
TPSID	TPSID	Creating inclusive higher education practices	Post-event survey, follow up one year later, staff reporting
Virginia LEAP	Abuse Prevention	Training	Pre/post survey, 3 month follow up
We Stand 4 Something	Charting the Life Course	Life coaching	Unclear

Trainings are the most common self-advocacy activity type among the external programs which provided us with outcomes data. A little more than half of the external programs mentioned above use surveys to measure outcomes, but only three (Missouri Project STIR, TPSID, and Virginia LEAP) are using longitudinal follow up surveys.

## III. Similarities Between DD Council and External Program Practices

- Use of trainings as practice type
  - 67% of the DD council practices and the external program practices mentioned above are trainings
    - 6 out of 9 for DD council practices.
    - 6 out of 9 for external program practices.
- Use of surveys as the outcome collection method
  - All DD council practices which were events/trainings used surveys.
  - 5 out of 9 external program practices used surveys.
- Use of longitudinal follow up surveys
  - To our knowledge, only 4 practices/projects (Tennessee Partners in Policymaking, Missouri Project STIR, TPSID, and Virginia LEAP) used a longitudinal follow up survey.

- Similarities in measures
  - The measures that DD Councils and external programs collect are below. There is significant overlap, but some external programs collect more specific information than the DD Councils on the following:
    - Usefulness of training
    - Skills increased following training
    - Education and employment goals and status
    - Living situation
    - Social life

#### IV. DD Council and External Programs' Measures and Results

The most common outcomes measured by Councils and External Programs are:

- Increase in number of participants who can better say what is important to them/what services they want (7)
- Increased knowledge of services/resources (5)
- Increased membership/leadership at self-advocacy groups or speaking at self-advocacy events/groups (5)
- Increased advocacy following training (4)

Please see Exhibits 1 and 2 for the full list of outputs and outcomes being measured.

**Exhibit 1. Outputs Being Measured by DD Councils and External Programs**

Category	Measure	DD Councils (6 total)	External Programs (8 total)
<b>Self-Determination, Skills, and Confidence</b>	Number of participants at event	All	All
	Number of participants satisfied with training	AK, MD, TN (3)	Disability Rights Idaho (1)
	Number of awards received for self-advocacy	OK (1)	
	Number of participants reporting that the training changed their life		Ohio Project STIR (1)
	Number of participants who use lessons from the training often		Ohio Project STIR, Missouri Project STIR (2)

Category	Measure	DD Councils (6 total)	External Programs (8 total)
	Number of participants reporting the training helped them become a better advocate		Ohio Project STIR (1)
	Number of participants reporting the training helped them become a leader or better leader	Tennessee (1)	Ohio Project STIR (1)
<b>Policy Influence</b>	Number of participants who ran for an elected position	OK (1)	
	Number of participants who spoke to elected officials or policymakers		Missouri Project STIR, Ohio Project STIR (2)
<b>Networking</b>	Creation of a regional/national network of ongoing communication and information sharing	WA (1)	
	Creation of relationships with DD network partners in participating states	MD, WA (2)	
	Number of participants who speak to the community about disability issues		Ohio Project STIR (1)
<b>Employment, Education, and Social Life</b>	Number of participants who have a job	AK (1)	Project SEARCH, Think College (2)
	Number participating in employment or career development activities		TPSID (1)
	Number of participants able to recognize and identify academic strengths/desires		Think College (1)
	Number of participants not living with family		TPSID, Think College (2)

Category	Measure	DD Councils (6 total)	External Programs (8 total)
	Number of participants satisfied or very satisfied with their social life		TPSID (1)

### Exhibit 2. Outcomes Being Measured by DD Councils and External Programs

Category	Measure	DD Councils (6 total)	External Programs (8 total)
<b>Self-Determination, Skills, and Confidence</b>	Training had a positive impact on them	MD (1)	
	Increased advocacy following training	AK, MD, OK (3)	Ohio Project STIR (1)
	Increase in participants feeling better prepared to participate in advocacy activities	OK, TN (2)	
	Increased membership/leadership at self-advocacy groups or speaking at self-advocacy events/groups	AK, MD, OK, SC (4)	Ohio Project STIR (1)
	Increase in number of participants who can better say what is important to them and/or what services they want	AK, MD, OK, SC (4)	Think College, Ohio Project STIR, Missouri Project STIR (3)
	Increased leadership skills	TN (1)	
	Increase in confidence in ability to live independently	TN (1)	
	Increased communication skills		Ohio Project STIR (1)
	Increased ability to problem solve	SC (1)	Ohio Project STIR (1)



Category	Measure	DD Councils (6 total)	External Programs (8 total)
	Increased social skills		Think College (1)
	Increased financial literacy		We Stand 4 Something (1)
<b>Knowledge of and Access to Services/Resources</b>	Increase in knowledge of services/resources	AK, OK, SC, TN (4)	We Stand 4 Something (1)
<b>Policy influence</b>	Increase in number of participants who spoke to an elected official or policymaker	OK (1)	
	Increased comfort level with talking to officials	TN (1)	
<b>Networking</b>	Increase in the number of participants who spoke to the media about disability issues	OK (1)	
<b>Employment, Education, and Social Life</b>	Increased mentoring/volunteering related to disability issues	OK (1)	
	Increased sense of social inclusion	AK, TN (2)	
	Number of participants who had a paid job one year after training/event		TPSID (1)

Additionally, Washington's EPIC Grants focus on providing technical assistance, updating organizations' technical capacities, and creating a website to share resources and conversations between different DDs and organizations.

## V. Self-Advocacy Practice Characteristics with the Greatest Impact

We asked 9 DD Councils, 6 External Programs, and 12 Self-Advocates which characteristics of self-advocacy practices have the greatest impact. The most common responses were:

- Input from self-advocates (13)
- Person with DD is trainer/presenter (9)
- Peer to peer events (9)

- Information on how to influence policy or legislative events (9)
- Statewide reach (8)
- Supporting people with DD taking on leadership roles (8)
- Using plain language (7)

Please see Exhibit 3 for the full list of characteristics mentioned.

### Exhibit 3. Self-Advocacy Practice Characteristics with the Greatest Impact

Factors	DD Councils* (9 total)	External Programs (6 total)	Self-Advocates (Home state) (12 total)
<b>Involvement of people with DD</b>			
Person with DD is trainer/presenter	Massachusetts, Maryland, Tennessee, Alaska, Washington (5)	Ohio Project STIR, Virginia Leap (2)	Derrick (South Carolina), Max (Vermont) (2)
Input from self-advocates	Massachusetts, Maryland, South Carolina, Texas, Tennessee, Washington (6)	Ohio Project STIR, Virginia LEAP, Missouri Project STIR (3)	Anne (Massachusetts), Derrick (South Carolina), Max (Vermont), Tamara (Massachusetts) (4)
Peer to peer events	Texas (1)	Missouri Project STIR (1)	Tamara (Massachusetts), Brooke (Texas), Clancey (Tennessee), Max (Vermont), Dusya (Massachusetts), Jennifer (Wyoming), Derrick (South Carolina) (7)
Supporting people with DD taking on leadership roles			Maggie (Alaska), Anne (Massachusetts), Ken (Maryland), Dusya (Massachusetts), Shawn (Washington), Brooke (Texas), Max (Vermont), Connie (South Carolina) (8)

Factors	DD Councils* (9 total)	External Programs (6 total)	Self-Advocates (Home state) (12 total)
Funding opportunities for people with DD			Derrick (South Carolina), Max (Vermont), Ken (Maryland), Anne (Massachusetts), Brooke (Texas) (5)
<b>Inclusivity and accessibility</b>			
Using plain language	Maryland, South Carolina, Tennessee, Vermont (4)		Maggie (Alaska), Dusya (Massachusetts), Ken (Maryland) (3)
Documents translated in many languages	Maryland, Texas		
<b>Types of learning formats</b>			
Interactive/hands on	Northern Mariana Islands (1)	Virginia LEAP (1)	
Using various learning activity formats	Tennessee (1)	Missouri Project STIR (1)	
In person events	Alaska, Texas, Wyoming, Vermont, Tennessee (5)		
Using visuals or demonstrations	Tennessee, Wyoming (2)		
<b>Practice topic or format</b>			
Information on how to influence policy or legislative visits	Alaska, Oklahoma (2)	TPSID, ThinkCollege (2)	Shawn (Washington), Maggie (Alaska), Dusya (Massachusetts), Ken (Maryland), Clancey (Tennessee) (5)
Train the trainer	Massachusetts (1)		

Factors	DD Councils* (9 total)	External Programs (6 total)	Self-Advocates (Home state) (12 total)
Leadership or independence skills training			Tamara (Massachusetts), Dusya (Massachusetts), Anne (Massachusetts), Max (Vermont), Connie (South Carolina) (5)
<b>Collaboration</b>			
Collaboration/coordination across entities	Alaska (1)	We Stand 4 Something (1)	Derrick (South Carolina) (1)
Statewide reach	Massachusetts, Alaska, Maryland, Texas, South Carolina, Tennessee, Vermont (7)	Ohio Project STIR (1)	

## VI. Methods

The above trends are derived from conversations with the following individuals and information from the following documents.

- Conversations with DD Councils:
  - Kristin Vandagriff, Alaska DD Council Executive Director
  - Rachel London, Maryland DD Council Executive Director
  - Jennifer Grover, Oklahoma DD Council Planning and Grants Management Director
  - Valarie Bishop, South Carolina DD Council Executive Director
  - Wanda Willis, Tennessee DD Council Executive Director
  - Alicia Cone, Tennessee DD Director of Program Operations
  - Jeremy Norden-Paul, Washington DD Council Executive Director
  - Brian Dahl, Washington DD Council
  - Pam Sablan, Northern Mariana Islands DD Council Executive Chairman
  - Beth Stalvey, Texas DD Council Executive Director
  - Kirsten Murphy, Vermont DD Council Executive Director
  - Shannon Buller, Wyoming DD Council Executive Director
  - Dan Shannon, Massachusetts DD Council Director
- Conversations with External Programs:
  - Meg Grigal, Think College Co-Director
  - Debra Hart, Think College

- Jennifer Tozer, We Stand 4 Something
- Kyla Mundwiller, Missouri Project STIR
- Barb Sapharas, Ohio Project STIR
- Mark Lewis, OKSAN
- Molly Dellinger-Wray, Virginia LEAP
- Conversations with Self-Advocates:
  - Alaska: Maggie
  - Maryland: Ken
  - Massachusetts: Anne, Tamara, and Dusya
  - South Carolina: Derrick and Connie
  - Tennessee: Clancey
  - Texas: Brooke
  - Vermont: Max
  - Washington: Shawn
  - Wyoming: Jennifer
- Documents:
  - Alaska 2019 Peer Power Self-Advocacy Summit Summary
  - Alaska DD Systems Alignment to the Vision Survey Report: Self-Advocates.
  - Alaska 2019 Self-Advocacy Summit Survey
  - Disability Rights Idaho Supported Decision Making Trainings 2019-2020 Summary
  - Maryland DD Council Funded Initiatives FY 2020-2021: Partners in Policymaking
  - Maryland DD Council Funded Initiatives FY 2020-2021: People on the Go of Maryland
  - Maryland DD Council Funded Initiative Data: People on the Go
  - Ohio Project STIR Outcome Study 2018
  - Oklahoma Annual Stakeholder Survey, November 2019
  - Project Search Outcome Summary
  - South Carolina Community Leadership Academy Outcome Data Summary 2017-2020
  - South Carolina DD Council Outcomes Survey
  - The Think College Transition Model: Developing Inclusive College-based Transition Services for Students with Intellectual Disabilities and Autism
  - Virginia LEAP Final Report 2014-2016
  - Year Four Annual Report of the TPSID Model Demonstration Projects (2018-2019)
  - Washington DD Council EPIC Grant Final Report 2017