Preparing for DSP for a Day: Checklist

PRELIMINARY PLANNING:

1. **Discuss your approach top-down within your organization**. Make sure that your Board of Directors, senior management, marketing team, and DSPs know what to expect and agree on goals and messaging. The more everyone is on the same page, the more your event will be successful.
2. **Prepare your DSPs in advance**, letting them know what you hope to accomplish. For example, encourage DSPs who are willing to participate to be candid about the reality of the work, needing two jobs, training needs, etc. so they can be comfortable with their role during the event.
3. **Get permission from consumers.**
4. **Check to see whether someone volunteered to be a lead contact to coordinate visits in your state.** The coordinator role is to avoid multiple, separate requests to one office. Please see the state lead list on ANCOR’s [Digital Advocacy Page](http://amplifier.ancor.org/ancor/IDD_Supports_Digital_Advocacy) to see who your state contact is.

ONCE INTERNAL PLANNING IS COMPLETE:

1. **Contact your legislators, keeping your coordinator in the loop.** ANCOR has provided members of Congress’ contact information, including staff emails, on our [Digital Advocacy Page](http://amplifier.ancor.org/ancor/IDD_Supports_Digital_Advocacy). This information will be updated every 2-3 months to reflect the turnover in Congressional offices.
   1. Materials for legislators (included in this packet):
      1. A sample invitation letter which you can personalize.
      2. A one-pager explaining the DSP for a Day concept.
      3. A one-pager giving more details on the DSP profession.
      4. A sample follow up email which you can personalize.
      5. A sample confirmation email once the meeting is booked.
      6. A sample post-meeting follow up note.
      7. An outline of ANCOR’s 2019 Congressional priorities.
   2. When discussing dates, we recommend asking for time during the August recess when your members of Congress will be in your district.
   3. Please let your state coordinator know when you reach out to your legislator.
2. **Follow-up on your request:**
   1. If you do not hear back from their office in a week, discuss with your state coordinator who should reach out for follow-up, and how frequently to do so.
   2. If you have difficulties getting a response after one or two follow-ups, please reach out to ANCOR’s Director of Legislative Affairs, Sarah Meek, at [smeek@ancor.org](mailto:smeek@ancor.org) for assistance.
3. **When the date/time is set, compile briefing materials for the event**. The following are details that should be covered:
   1. Background on your organization, e.g. individuals supported, number of employees, etc.
   2. Event location.
   3. What services the legislator will be observing.
   4. Dress code, specialized items if any, where to park, how to enter the building, etc.
4. **Let your state coordinator know when your event is confirmed!** Your coordinator will share this with ANCOR, which will allow ANCOR to get a sense of the scale of the DSP for a Day effort on a national level.

AFTER THE EVENT:

1. **Send thank you notes** – thank legislators and their staff for their time and hopefully their support.
2. **Let us know how it went**! Please email ANCOR and your state coordinator feedback from your event, such as what questions the officials / staff asked, information you need for follow-up if you did know the answers to questions, etc. This will allow ANCOR to plan follow-up visits with Washington, DC offices if we see there are opportunities to sign them onto our policy efforts.
3. **Keep building the relationship!** Consider future follow-up opportunities such as in-district office meetings to give updates on policy issues of interest, invitations to organization events such as DSP Recognition week events, legislative breakfasts, etc.
   1. The ANCOR Grassroots Work Group is offers ANCOR members opportunities to engage in Congressional relationship building – please email [dparfaite-claude@ancor.org](mailto:dparfaite-claude@ancor.org) if you are interested in learning more.

PRO-TIP:

**Invite the district staff of targeted legislators to do an advance site visit, to create internal advocates within those offices.** ANCOR members who participated in state-level DSP for a Day efforts shared that officials’ staff who partook in advance visits often saw value in the activity. This gave them the emotional investment necessary to work with the rest of their team to make the longer DSP for a Day visits with the elected official happen. We encourage you to consider reaching out to district staff well in advance of the August Congressional recess for a shorter (e.g. one hour) visit as a preliminary step to your DSP for a Day activities. This will also help you build relationships with that staff, which is important since staff counsel members of Congress on policy and constituent issues.

*Template invitation – find Congressional contact information* [*here*](http://amplifier.ancor.org/ancor/IDD_Supports_Digital_Advocacy)*.*

[GREETING]:

On behalf of [ORGANIZATION], I would like to invite [TITLE, NAME OF OFFICIAL] to join my team members who support people with disabilities and learn firsthand about the work they do. We hope to be able to host the [TITLE OF OFFICIAL] during the August recess, when [HE/SHE] is in the district.

Our event, titled “Direct Support Professional (DSP) for a Day”, seeks to raise awareness of the individuals we support and the important workforce who helps them maintain their independence and quality of life. This is a unique opportunity for [TITLE, NAME OF OFFICIAL] to connect with constituents who might not otherwise have a chance to share their experiences and concerns with your office.

Our event consists of pairing legislators with local DSPs to volunteer their services for one to three hours, whether it be simply through shadowing a member of the organization or through actual interaction with our consumers.

[BRIEF DESCRIPTION OF ORGANIZATION, THE SERVICES YOU PROVIDE, AND THE DEMOGRAPHICS OF THE INDIVIDUALS YOU SUPPORT.]

[OPTIONAL: We understand that your team might want to learn more about our supports and services beforehand to prepare the [TITLE OF OFFICIAL] for this visit. We would be happy to arrange for a shorter pre-visit for your colleagues in the district in the coming weeks. Please have your colleagues contact me directly to make arrangements.]

We look forward to working with you. Please contact me to confirm the arrangement. [Insert contact information]

[Signature]

*One pager to be copied into new doc and shared as attachment to invite after personalizing.*

**The Ask**

**We invite you to pair with a professional in your district who helps people with disabilities live like everyone else, at a date and time of your choosing during the August recess.** Joining us will allow you to see firsthand how the work of Congress and the federal government intersects with the lives of your constituents. This would be for a duration of 2-3 hours.

[INSERT 2-3 SENTENCES DESCRIBING YOUR ORGANIZATION’S WORK AND THE INDIVIDUALS YOU SUPPORT.]

**Introducing “DSP for a Day”**

“DSP for a Day” is an invitation to witness how people with intellectual / developmental disabilities (I/DD) experience life in your district, with the assistance of a Direct Support Professional (DSP).

Funded primarily by Medicaid and focused on people with I/DD, the Direct Support Professional (DSP) workforce is one of the fastest-growing professions in the U.S. due to demographic trends such as the increase in autism diagnoses and longer lifespan of people with disabilities. Despite the ever-growing demand for DSPs, this workforce is experiencing a severe workforce crisis with a national average turnover rate of 45 percent. Turnover can be as high as 60 percent in some states. This is affecting the quality of life of people with disabilities, limiting opportunities for them to live like you and me.

The work DSPs engage in is highly tailored to the needs and wants of the individual supported. Supports can range from job coaching, assisting with daily tasks such as grocery shopping, or helping a medically fragile person stay in their home instead of being in a segregated, state-run institution. **“DSP for a Day” is an opportunity for you to personally learn about the nuances of this intricate and unsung profession, and its vital role in supporting the independence of people with disabilities.**

**What to expect?**

Members of Congress participating in DSP for a Day will:

* **Receive a brief overview** of the host agency’s work and the landscape of Medicaid programs. However, the bulk of the experience will be shadowing.
* **Be introduced to DSP(s) and the individual(s) they support** who volunteered to participate.
* **Tour the facility and shadow DSP(s)**, which will include opportunities for questions and candid discussion about the supports being offered.

We will share logistical information such as parking access once your participation has been confirmed. Photo and media policy will be at the discretion of your office.

**How is this different from other constituent meetings?**

“DSP for a Day” will give you an opportunity to connect with your constituents in a manner that office meetings simply cannot. You will be meeting DSPs and the people they support in their comfort zone, where they will be most open to telling you what is on their minds and how you can help.

*One-pager elaborating on DSPs, also to be copy-pasted into new document and attached to invite. Also available online* ***(***[***link here***](https://cqrcengage.com/ancor/file/lTbhRoO50ux/Explaining_DSPs_OnePager_Online_Version.docx)***)*** *if you prefer to hyperlink.*

**Understanding the DSP Profession**

Direct Support Professionals (DSPs) are frontline staff who help people with intellectual / developmental disabilities live in the community. Here, we will unpack what that means.

**What Do DSPs do?**

DSPs fulfill a wide range of roles because the supports they offer are highly tailored to the needs of the individual supported. These roles include helping someone: a few hours a week at home or in the community with daily tasks such as grocery shopping or cleaning; learn skills necessary to succeed in the workplace; develop social skills in an adult day care setting; or keep track of vital medications and other health needs all day and night.

**Who hires DSPs?**

Many DSPs are hired by provider agencies whose funding comes primarily from Medicaid. Providers then connect DSPs with individuals as needed – some DSPs work exclusively with one individual, others work with multiple individuals. Providers can be public or private entities, non-profit or for-profit, small “mom and pop” organizations or multi-state organizations.

Alternatively, in some supports models DSPs are hired directly by individuals with I/DD and their families, getting assistance from agencies to find DSPs. These are known as consumer-directed models.

**How does the funding stream work?**

Medicaid is a state-federal partnership, with the federal government matching a portion of the state’s Medicaid spending, [ranging](https://www.fec.gov/help-candidates-and-committees/trainings/trade_pac_webinar/) from a 50 percent match to just shy of 77 percent. The state decides what rates it will pay Medicaid providers using that funding – **unlike Medicare providers, Medicaid providers receive fixed, non-negotiable rates for their costs.**

Providers then work within the parameters of these fixed rates to hire DSPs. Because of variation in the federal/state match rate, and in how much states allocate to disability-programs specifically, there is state by state variation in DSP wages and how many benefits providers can afford to offer. The national median DSP wage rate is $12 per hour, ranging for $9 to $14.68.

**Why is there a workforce crisis?**

The DSP workforce is caught between high demand for supports that exceeds what the U.S. labor market can offer, and high turnover (45 percent national average). The turnover is often caused by:

* Wages not being competitive compared to the level of responsibility required for the position, often requiring a DSP to work multiple jobs or combine their earnings with public assistance.
* Limited benefits and shifting schedules making it harder for DSPs to juggle other responsibilities such as caring for their families.
* A limited path for career advancement.
* Feeling unsupported by their supervisors, who might be strained because the high turnover rates often require supervisors to double as DSPs.

**Learn more:** ANCOR, providers’ national trade association, explores the workforce crisis in [this report](http://amplifier.ancor.org/DSPWorkforce?0).

*Template follow-up email - do not hesitate to ping an office multiple times as often that is the only way to stand out for the crowd and get a response. If you have trouble getting a response after a follow-up or two, please reach out to ANCOR’s Director of Legislative Affairs, Sarah Meek, at* [*smeek@ancor.org*](mailto:smeek@ancor.org) *for assistance.*

[GREETING]:

I am checking in to see if you have had time to consider the request my organization, [ORGANIZATION], sent you a week or so ago asking for [OFFICIAL’S TITLE AND NAME] participation in our “DSP For a Day” campaign. As a refresher, the event is to pair the [OFFICIAL] with frontline staff in our agency who support people with disabilities, to raise awareness of people with disabilities and the importance of the staff who help them live life like everyone else. I just wanted to follow up about your office’s interest in this effort.

Thank you for your time and consideration.

Sincerely,

*Template confirmation email*

Dear [STAFFER NAME],

Thank you for help in finalizing our “Direct Support Professional for a Day” event with [OFFICIAL’S TITLE AND NAME]. It is only because of your office’s commitment to causes like this one that we are able to organize such campaigns for the betterment of [STATE NAME] and the individuals that you represent.

The following details confirm your participation. If there are any additions or edits to the information below, please let us know by sending us the updated information.

* Event Date: [insert specific date that the organization selected]
* Time: [when to when]
* Location: [Address]
* Brief description of what they will be doing and who they will be working with
* Attire for the event:
* Lunch/Refreshments will (or will not) be provided
* Any special details:
* Specific directions/requests on parking, getting there, etc.:
* Reminder about background checks/clearances if needed

You will receive an informational packet with additional information about 2 weeks ahead of your event date.

Thank you again for your interest and please do not hesitate to contact us with any further questions.

Signature,

[Name]

*ANCOR Policy Priorities for Reference / If Offices Ask What They Can Help With*

Key Disability Priorities for the 116th Congress

*In 2019, the American Network of Community Options and Resources (ANCOR) hopes to work with your office on the following issues relevant to the disability community:*

**HEALTH:**

**Priorities:**

* **Maintaining the integrity and stability of Medicaid.** Medicaid is the primary program through which the federal government supports people with disabilities’ access to: health care services, including long-term care services and supports; life in the community like everyone else, instead of segregated state-run institutions; employment coaching and assistance; special education programs. It is imperative that Medicaid maintains it current financing and service delivery structure to ensure access to essential supports and services for people with disabilities.
* **Access to essential health care for people with disabilities.** Historically, people with disabilities have not had access to professionals to address basic health needs, including dental care. ANCOR will be supporting innovative solutions to this challenge.

**Relevant legislative efforts in the 116th Congress:**

* **The Money Follows the Person (MFP) program.** Recently, H.R. 259 renewed the Money Follows the Person (MFP) program for 3 months. This program gives 43 states grants to help people with disabilities voluntarily move out of nursing homes and state-run institutions, into the community. However, this was only a short-term extension of a vital program. ANCOR, alongside the disability community, seeks a longer-term renewal in 2019.
* **Balancing Incentive Program (BIP) renewal.** ANCOR is working with the offices of U.S. Representatives Debbie Stabenow (D-MI) and Brett Guthrie (R-KY) on legislation to renew BIP, which provides financial incentives to States to increase access to non-institutional long-term services and supports (LTSS) in keeping with the integration mandate of the Americans with Disabilities Act (ADA), as required by the Olmstead decision.
* **Ensuring Electronic Visit Verification (EVV) implementation does not affect stability of Medicaid disability supports.** The EVV statute within the 21st Century Cures Act (H.R. 34, 114th Congress) required providers to electronically confirm that visits they billed occurred, with an implementation deadline of January 1, 2019 that carried Medicaid penalties for non-compliance. Due to challenges with implementation, such as lack of internet and cell service in rural areas, ANCOR obtained a one-year implementation delay through H.R. 6042 (115th Congress), pushing the deadline to January 1, 2020. ANCOR encourages Congress to continue discussions with the Centers for Medicare and Medicaid Services (CMS) to ensure implementation is not overly burdensome on people with disabilities and those who support them.
* **Ensuring Long-Term Supports and Services (LTSS) programs are protected.** Within the health care space, long term care is an area that has continually challenged policymakers. As new proposals regarding ACA stabilization and health care reform are introduced in the 116th Congress, ANCOR will be educating members of Congress on the effects of these proposals from the disability perspective.
* **Re-introducing the HEADS UP Act (H.R. 6611, 115th Congress).** This bill would designate people with disabilities as a medically underserved population, increasing their access to vital health services such as dental care. Historically, people with disabilities have not received the same level of health care as their peers.

**LABOR / WORKFORCE / EMPLOYMENT:**

**Priorities:**

* **Developing innovative proposals to address the workforce crisis in disability supports.** Direct Support Professionals (DSPs), the frontline workforce who support people with disabilities in daily life activities, have a national turnover rate of 45 percent every year. Without qualified staff, providers are limited in how they offer client-driven services, namely assisting individuals with IDD in living where, with whom and how they choose. This affects not only effects the quality of care provided to people with disabilities, but also their health and well-being of people with disabilities.
* **Ensuring people with disabilities’ access to work is tailored to their needs and wants.** Employment of people with disability improves their quality of life and outcomes but has historically lagged behind that of their peers. This employment lag has continued despite evidence that people with disabilities remain at their jobs longer than their peers, making them valuable to their employers.

**Relevant legislative efforts in the 116th Congress:**

* **ANCOR members will be inviting you to learn about the work of DSPs in your district during the August recess.** Please stay tuned for more details in the coming weeks.
* **Congressional assistance in obtaining DSP-centric federal data.** ANCOR will be exploring requests which Congress could make to the Department of Labor (DOL) for DSP data as a follow-up to its 2018 Congressional letter. That letter, signed by 30 U.S. Representatives, requested that DOL create a data collection category for DSPs because of the dearth of disability-specific workforce data. This data is essential to federal and state decisions, such as what Medicaid rates to set for disability supports.
* **Disability employment proposals.** ANCOR will be educating members of Congress on the disability perspective as proposals emerge to offer people with disabilities employment opportunities.

**CIVIL RIGHTS:**

**Priority:**

* **Protecting and strengthening the Americans with Disabilities Act (ADA).** The ADA is the cornerstone legislation protecting people with disabilities from discrimination, including their ability to access physical locations like their peers.

**Relevant legislative efforts in the 116th Congress:**

* **Proposed reintroduction of H.R. 620.** ANCOR is concerned about this bill, which would restrict people with disabilities’ ability to press civil suits against businesses that do not comply with the Americans with Disabilities Act’s (ADA) physical access provisions (e.g. wheel-chair accessible ramps). It is likely that H.R. 620 will be reintroduced in the 116th Congress. ANCOR asks you to oppose this legislation because of its potential chilling effect on people with disabilities’ access to the community.