

Creating Resources for Navigating Change: Partnering with Self-Advocates in the Development of Informational Materials

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Making Choices, Becoming Empowered

As mandated in the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), University Centers for Excellence in Developmental Disabilities (UCEDDs) implement the core function of information dissemination to enhance advocacy, build capacity, and effect change in policies and service systems. The ability of people with developmental disabilities and families to successfully navigate state service systems, provide input into federal and state policies, and advocate for the types of supports they want hinges upon clear and accurate information. Partnering with self-advocates in the development and design of reader-friendly publications helps to ensure that informational resources are accessible and actionable.

The **Making Choices, Becoming Empowered** series of informational guides was created by The Boggs Center on Developmental Disabilities, in partnership with people with developmental disabilities, to help them and their families advocate for and choose the services and supports they want.

The UCEDD's process in determining the need for informational materials, developing content, and revising and refining based on self-advocate feedback can be utilized by centers across the network.



Determining Need For Materials

Working in partnership with self-advocates to create resources for navigating change begins with determining a need for informational materials. Frequently, The Boggs Center's Consumer Advisory Council (CAC) provides suggestions around informational needs. In addition, the Center assesses the need for materials based on patterns in information and referral requests, as well as in collaboration with the State's Division of Developmental Disabilities.

Development by Content Experts

Developing content to address informational needs begins with content experts at The Boggs Center. After a first draft is complete, content experts review and consider if there are acronyms, jargon, or just too many words involved that would make the resource difficult to understand for those "not in the know."

Self-Advocate Review and Guidance

The Boggs Center has utilized focus groups with CAC members, or members of existing self-advocacy groups to review the content, design, and format of its publications. Some focus group strategies include:

- Reading content aloud and asking reviewers, "what do you think we are trying to say or ask?"
- Asking "how could we say this differently to get the point across?"
- Asking "what would make the format easier to follow?"
- Compensating reviewers for their time and effort.

Refining Content

Through self-advocate review, we've received suggestions to improve the format of our publications by adding a table of contents or breaking a guide into concrete sections and steps. We've also learned that often times, we're not saying what we think we are. For instance, when we say things like "resources" and we really mean "activities and places." Some examples of how content has been refined based on self-advocate review and feedback include:

