UCEDD Tip Sheets



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UCEDD Tip Sheets are produced by the Association of University Centers on Disabilities (AUCD) through the UCEDD Resource Center (URC).





Product Development and Information Dissemination

What is Addressed in this Tip Sheet?

This tip sheet addresses product development and information dissemination. According to the UCEDD <u>logic model</u>, information dissemination is the distribution of knowledge-based information through UCEDD developed products and activities.

Why is this Important?

Information dissemination is a UCEDD core function, according to the DD Act:

Dissemination of information related to activities undertaken to address the purpose of this title, especially dissemination of information that demonstrates that the network authorized under this subtitle is a national and international resource that includes specific substantive areas of expertise that may be accessed and applied in diverse settings and circumstances

The Administration on Intellectual and Developmental Disabilities (AIDD) specifically mentions the need for each UCEDD to have a written plan for how their program will implement the core functions as outlined in the DD Act (45 C.F.R § 1328.6 2015).

How have other UCEDDs structured their product development and information Dissemination



Partnership for People with Dsiabilities Virginia Commonweath Unversity

The Partnership for People with Disabilities disseminates over 20,000 hard-copy products every year to a variety of stakeholders including people with disabilities, siblings, and families. They use a cultural brokerage

initiative to help adapt their products to reach more diverse groups, since they know that lack of access to adequately translated materials further increases the disparities faced by many of these communities.

A lot of their materials are 50 to 60-page resource guides, which when directly translated to Spanish, make them 80-100 pages. However, many of these translated resources were not being used. To strengthen their product development, they now use a process called localization (Lionbridge, 2012) which ensures that when adapting products, they not only translate language to make the product work functionally and linguistically, but they take culture and customs into account in how things are communicated. An important aspect of this process is to gather feedback from end-users of the adapted document to see if it meets their needs and is in their preferred format.

They use a five-step process of product adaptation:

- 1. Select Material
- 2. Review with Stakeholders
- 3. Translate
- 4. Test
- 5. Layout Design

Some examples of this process in action:

- Adapting a resource on screening for hearing loss at birth: They convened a group of Latina mothers and some graphic designers to make a photo-novella about the resource.
- Adapting "It's About Me" guide, a resource on the IEP
 process: The cultural broker created a support group of
 families to create something that would spark interest in the larger resource and help families
 find which sections of the guide might be useful for them.
- Translating a pamphlet about "Who We Are": working with a group of Arab parents to make one half of the pamphlet in English and the other in Arabic.
- Arab mothers discussed in Arabic, a resource about Medicare that was written in English. The final adapted product was the recorded discussion of the resource.

In developing products, they also consider generational preferences in how people like to communicate and receive information. For instance, on the topic of aging, they did a podcast with an elder aging specialist, made short videos of burning questions about the topic on YouTube, and created a blog post about the elderly specialist's work. They know that different platforms capture different generations preferences, and they also linked all the different formats together.

An important aspect of this process is to gather feedback from endusers of the adapted document to see if it meets their needs and is in their preferred format.

In the midst of COVID-19, they've also seen their Facebook traffic increase, and are working to link zoom capabilities with Facebook live streaming to better communicate in the virtual sphere. One approach that has been particularly popular virtually, is their 2-3-minute short clips to answer a single burning question, which they can promote on their website and over YouTube.

Successes include:

- Using a cultural brokerage initiative to engage the community in adapting a handful of their resources beyond simply direct translation.
- Linking multiple modalities of communications together to reach different generations and communications preferences.
- 2-3 minute "burning questions" videos which address a single topic are their most popular resource especially due to COVID-19 and their shift to virtual disseminations.

Challenges include:

- Determining if the adapted documents are useful to the intended public and if they are being used.
- Translating hard to understand terms related to our field into another language and culture. Sometimes directly translated products end up being much longer and more difficult to use than the original version in English. It is a much longer process to launch products and requires much more investment financially. It often involves more players, for instance working with a graphic designer.



Maryland Center for Deveopental Disablities (MCDD) Kennedy Kreiger Institute

The MCDD is leveraging partnerships to strengthen their product development and cultural and linguistic competency within their

communications. In developing their products and dissemination materials, they partner closely with the Kennedy Krieger Institute's marketing and public relations staff and ensure that all their products follow the same branding guidelines. Common products include fact sheets, brochures, power point slides, posters, and signage.

To center accessibility, the MCDD reviews their products with a committee on their Consumer Advisory Council (CAC) which includes members from a self-advocacy group called "People on the Go." Three members from People on the Go, are also on their UCEDD's staff.

Some examples of product disseminations:

- Fact sheet called "How to Advocate Your Cause": it is available in plain language and is disseminated to patients and families to encourage engagement in advocacy.
- Legislative guide fact sheet: explains the basics of the legislative process in Maryland. They distribute this guide at their Developmental Disability day at the legislature and throughout the year at policy events.
- Popular Brochures: projects they are a part of, estate planning, and "Life After High School: The Transition to Postsecondary Opportunities."

Cultural and Linguistic Competency

In 2018, the MCDD received three days of on-site technical assistance and support from Georgetown

University's National Center for Cultural Competence through the Embedding Cultural and Linguistic Competency (CLC) project. Tawara Goode looked at products, websites, trainings, and engaged senior management and the CAC, on cultural linguistic competency and how it is translated through all of MCDD's work. This has led MCDD to invest in incorporating CLC into all their product development, including a budget line for CLC in their grant applications, and incorporating CLC activities into their staff meetings and trainings.

Resource Finder

MCDD disseminates information through an in-person and virtual resource finder. They have a physical resource center in Baltimore, staffed by a full-time staff person, who assists with information gathering and referrals. The goal of the resource finder is to inform consumers and families about resources, materials, and other information relating to developmental disabilities. The Online Resource Finder is open to anyone and incudes referrals for service providers and specialists, parent resources, and resources on housing and advocacy. MCDD collects data about populations accessing their resources and which resources are requested. The top requests come from service providers and from Kennedy Krieger staff.

Shifts to Virtual

Due to COVID-19, two emerging needs were identified. First, MCDD had requests for how to create advance directives and powers of attorney due to emerging mental health needs. While previously they had done clinics, webinars, and trainings on the topic, during the move to online, MCDD create a tool kit to further assist people in navigating the legal aspects of these alternatives. Also, in response to the pandemic, they created a disability discrimination digital flyer that was concise and visually appealing and was disseminated across the network.

Successes include:

- They have dedicated a full-time staff person who is committed to their dissemination plan and product adaptation. That person works closely with the Kennedy Krieger Institute's communications staff. They are investing resources into doing quality product adaptations, translations, and centering "plain-language" in their dissemination materials.
- In partnership with John Hopkins, they have a sponsorship of an annual conference dedicated to promoting CLC within the Kennedy Krieger Institute.

Challenges include:

- Cost. It is time consuming and takes a lot of resources and effort to ensure that product adaptations are done well, and that the ultimate product is accessible and useful.
- Accepting you will make mistakes but doing your best anyways. There will be errors in a document's translation, a material might not be accessible to everyone, or language may be seen as offensive to one community but not another.

"They incorporate cultural and linguistic competency into all of their product development and include a line for CLC in their grant applications."

Recommendations

Make product adaptation and inclusive information dissemination a priority. Dedicate time and resources to ensure that products and information are developed with everyone in mind and are made accessible and useful to different communities and cultures.

Embed Cultural and Linguistic Competency into your product development and dissemination activities. Add a budget line to every grant to set aside resources for CLC. Embed CLC exercises into staff meetings.

Partner with cultural brokers to acquire knowledge about and engage emerging populations in the adaptation of resources. Work with a cultural broker to go beyond translating materials to adapting them for a particular culture and community. Work with community members, especially people with IDD and their families from marginalized communities, in the development of your resources. Seek input about products from end-users to ensure the products are useful and in a preferred format. Consider creative strategies and preferred communication styles to engage broader audiences.

Engage your CAC in the development and accessibility review of your products. Conduct accessibility checks for all products before disseminating. Include language translation and plain-language adaptation as priorities for promoting accessibility in dissemination. Consider having a subcommittee of your CAC dedicated to product development and dissemination.

What are the Relevant resources?

- UCEDD Logic Model
- Webinar: UCEDD Product Development and Information Dissemination
- Partnership for People with Disabilities
- Maryland Center for Developmental Disabilities
- Resource Finder at Kennedy Krieger
- Georgetown National Center for Cultural Competence

For More Information

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