

# Developing health care self-advocacy educational resources for adults with intellectual and/or developmental disabilities (Final Report Date: October 30, 2023)

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## Budget Expenditures

A summary of budget expenditures is provided in Table 1.

## Timeline and Completed Tasks

Our proposed implementation plan is in Attachment A. Following is a description of the work completed by the team.

## Content Development – Self-Advocate Input

We created a 5-person steering committee helping to guide the content creation and participate as self-advocates in our video series. All 5 members identify as adults with disabilities.

In steering committee meeting #1, we discussed the planned video series and played excerpts from existing self-advocacy videos to garner feedback from the committee. They provided their feedback on the content and asked questions about the proposed video series. The team shared an outline of proposed topics for the video series. After this meeting, most members of the steering committee expressed interest in being part of the videos and sharing their experiences. They also shared with the team some tips on the best ways to engage self-advocates in telling their stories.

In steering committee meeting #2, we co-developed an agreement for engagement to ensure all committee members are able to successfully communicate and feel heard in meetings. The agreement for engagement outlines ways in which the group wants to communicate in a respectful and inclusive manner with one another. We asked the committee to review the topics and the format we have outlined for the video series and asked if any committee members know any other self-advocates who would want to participate.

In steering committee meeting #3, we shared drafts of the videos and asked the committee to identify a name for the project. We had difficulty scheduling a time that worked for all committee members so we emailed links to the videos and sent an accessible survey to those who could not attend the meeting. In using the survey, we were able to hear from all five committee members. The final title of the video series and project is: **How to Speak Up for Your Health: Role Models Share Their Stories**. We also asked members for their input on the best ways to disseminate the videos. Members were keen to post them on social media to start a conversation with self-advocates and to encourage them to develop their own stories. See

“Marketing/Dissemination” below for more information about how we incorporated this idea into our plan.

## Content Development – Self-Advocacy Resources:

The project team reviewed existing self-advocacy resources in English and Spanish for self-advocates themselves or for their supporters. It was decided to compile the resources in a Google spreadsheet for accessibility (e.g. works with a screen reader, ability to sort content). Content includes toolkits and guides, trainings, videos, research articles, and government web sites. In addition to the name of the resource, description, how it is accessed, and the intended audience. English- and Spanish-speaking team members

Category	Amount	Status
Personnel/Salaries	\$19,375	Complete
Fringe	\$5,974	Complete
Travel	\$445	Complete
Contracted Services/Professional Services	\$19,661	Complete

Título	Descripción	Cómo acceder	Audiencia principal para recursos	Detalles
Autodefensa: Una habilidad valiosa para su hijo adolescente con DA	Consejos para desarrollar técnicas de autodefensa	<a href="https://www.greatschools.org/greatschools/autodefensa-una-habilidad-valiosa-para-su-hijo-adolescente-con-da/?lang=es">https://www.greatschools.org/greatschools/autodefensa-una-habilidad-valiosa-para-su-hijo-adolescente-con-da/?lang=es</a>	Autodefensores/partidarios	Es importante que los niños aprendan técnicas de autodefensa para tener éxito en todas las etapas de sus vidas. En el pasado la autodefensa era un término aplicado principalmente para adultos con discapacidades, pero recientemente se ha hecho más énfasis en la enseñanza de esta técnica para preadolescentes y adolescentes.
Centro Nacional de Investigación para Padres con Discapacidades	El Centro Nacional de Investigación para Padres con Discapacidades es un proyecto colaborativo de investigación y defensa que tiene como objetivo apoyar a los padres con discapacidades.	<a href="https://heller.brandeis.edu/son/disability/index.html">https://heller.brandeis.edu/son/disability/index.html</a>	Autodefensores/partidarios	Consejos para abogar por sus necesidades para mujeres embarazadas con discapacidades físicas. <a href="https://heller.brandeis.edu/spanish/parents-with-disabilities/support/parenting-strategies/self-advocacy-strategies-normal.html">https://heller.brandeis.edu/spanish/parents-with-disabilities/support/parenting-strategies/self-advocacy-strategies-normal.html</a> Consejos y estrategias para padres con discapacidades. <a href="https://heller.brandeis.edu/spanish/parents-with-disabilities/support/parenting-strategies/index.html">https://heller.brandeis.edu/spanish/parents-with-disabilities/support/parenting-strategies/index.html</a>
Defensa de poblaciones especiales	Este artículo proporciona datos sobre personas con discapacidades e información sobre el riesgo de violencia doméstica.	<a href="https://www.geneshouseshel.org/advocacy-for-special-populations/?lang=es">https://www.geneshouseshel.org/advocacy-for-special-populations/?lang=es</a>	Proveedores/partidarios	El artículo contiene información sobre el primer idioma de la persona, la violencia doméstica y datos generales sobre las personas con discapacidades.
Guía Arc para la autodefensa	Información sobre la autodefensa, cómo defenderse a mi mismo y cómo participar más en la autodefensa.	<a href="https://arcnhs.org/es/our-source/guide-to-self-advocacy/">https://arcnhs.org/es/our-source/guide-to-self-advocacy/</a>	Autodefensores/partidarios	El autodefensa es usar su poder para defenderse a si mismo y educar a otros pa que hagan lo mismo. Incluso con una discapacidad intelectual y del desarrollo (IDD), puede tomar decisiones sobre lo que necesita y desea. Puede ayudar a realizar cambios que mejoren su vida incluso a de los demás.

Figure 1. Resource Guide

the team included a brief

organized the content into English Only, Spanish and English, and Spanish Only sheets. The resource guide is on the “How to Speak up for your Health” web site, just under the videos. See Figure 1 for a screenshot.

### Content Development – Video Creation

The following learning objectives were covered in the videos, which are 3-5 minute “testimonials” in English, Spanish, and American Sign Language: 1. Describe health care self-advocacy; 2. Identify your needs when it comes to health care; 3. Value your health and your health care rights; 4. Prepare for health care visits; 5. Make decisions about health care; and 6. Make decisions about health care in collaboration with supporters. The team met with self-advocates twice to develop the testimonial content in the following sequence: 1) Interviewed participants regarding their overall experience in various healthcare settings; and 2) Follow-up with participants to discuss the themes that were identified in their responses and determine which topics they may be interested in discussing in the video series. On the day of recording, the team reviewed the developed outline with the self-advocate, made any necessary revisions, and then used the learning objectives to guide the discussion (for example, “Tell us how you describe health care self-advocacy”). Videos are broken up by learning objective to make them quick to view and to share. Videos are captioned in English and Spanish. While most of the videos focused on the six learning objectives, two participants (Amber and Karla) wanted to create an additional video addressing health issues of importance to them. Amber’s video focuses on her experiences as a Deaf caregiver when her teenaged daughter was hospitalized. Karla’s video describes how she uses technology tools to support her health management. See **Table 2** for more information about the self-advocates and their videos.

### Marketing & Dissemination

The Sonoran Center’s Communication Team developed a 4-week social media campaign featuring each self-advocate, with an introduction in English and Spanish (Figure 2). Following the promotional campaign, the Sonoran Center will invite social media followers to submit their own videos, recorded on their phone or computer, for sharing on social media. They can share on their own social media feed and tag the Sonoran Center or submit them to the Sonoran Center for posting on the Center’s feeds (with permission).

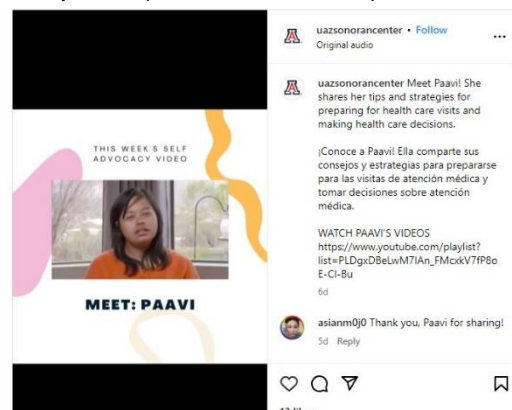


Figure 2. Instagram post

In addition to the social media campaign, the **How to Speak Up for Yourself** resources have been shared nationally with the Association of University Centers for Disability (AUCD) network, and with the Public Health is For Everyone: Inclusive Planning Toolkit for Public Health Practitioners. Locally, the resources have been shared in the Sonoran Center’s newsletter and in a promotional email disseminated to the Center’s statewide mailing list, which includes disability organizations throughout Arizona.

Table 2. Project Deliverables	
Deliverable	Description/Location
Gabe recruitment video	Brief video of Gabe describing the project and encouraging others to join, <a href="https://www.youtube.com/watch?v=ELFqP_rYC3s">https://www.youtube.com/watch?v=ELFqP_rYC3s</a>
Website for project	<a href="https://sonorancenter.arizona.edu/community-programs/health-wellness/how-speak-your-health">https://sonorancenter.arizona.edu/community-programs/health-wellness/how-speak-your-health</a>
Health care self-advocacy resource lists in English and Spanish	<a href="https://sonorancenter.arizona.edu/community-programs/health-wellness/how-speak-your-health">https://sonorancenter.arizona.edu/community-programs/health-wellness/how-speak-your-health</a>
28 short videos with 4 self-advocates (Figure 3)	<ul style="list-style-type: none"> <li>Paavlena, in English with English/Spanish captions: <a href="https://www.youtube.com/playlist?list=PLDgxDBelwM7IAAn_FMckxV7fP8oE-CI-Bu">https://www.youtube.com/playlist?list=PLDgxDBelwM7IAAn_FMckxV7fP8oE-CI-Bu</a></li> <li>Amber, in American Sign Language with English/Spanish captions:</li> </ul>

	<p><a href="https://youtube.com/playlist?list=PLDgxDBelwM7JfF7as_upKB6sk3cujUzsD&amp;si=dOi_7yIZTBScj3vI">https://youtube.com/playlist?list=PLDgxDBelwM7JfF7as_upKB6sk3cujUzsD&amp;si=dOi_7yIZTBScj3vI</a></p> <ul style="list-style-type: none"> <li>• Karla, in Spanish with Spanish/English captions: <a href="https://youtube.com/playlist?list=PLDgxDBelwM7LNqiU-gUpKN1WzHPnsRod1&amp;si=p2IGCFhmml4irsVx">https://youtube.com/playlist?list=PLDgxDBelwM7LNqiU-gUpKN1WzHPnsRod1&amp;si=p2IGCFhmml4irsVx</a></li> <li>• Cody, in English with English/Spanish captions: <a href="https://youtube.com/playlist?list=PLDgxDBelwM7I6K7VkecLlrgAzWZ4puHvN&amp;si=a993UFVGYWKJK9qE">https://youtube.com/playlist?list=PLDgxDBelwM7I6K7VkecLlrgAzWZ4puHvN&amp;si=a993UFVGYWKJK9qE</a></li> </ul>
Presentation at the 2023 American Indian Disability Summit for self-advocates and their supporters	Shared Self-Advocate video with attendees and elicited feedback from the audience.
<u>Scheduled</u> presentation at American OT Association 2024 (Lees, Tosto, Christopher, Armin, Williamson)	Poster to be presented in Spring 2024 at the national meeting of occupational therapists.
Sonoran Center Social Media Campaign to Promote the Videos	<p>Sonoran Center social media accounts hosting the campaign include:</p> <ul style="list-style-type: none"> <li>• Facebook, <a href="https://www.facebook.com/UAZSonoran.Center">https://www.facebook.com/UAZSonoran.Center</a></li> <li>• Instagram, <a href="https://www.instagram.com/uazsonorancenter/">https://www.instagram.com/uazsonorancenter/</a></li> <li>• LinkedIn, <a href="https://www.linkedin.com/company/uazsonorancenter/">https://www.linkedin.com/company/uazsonorancenter/</a></li> <li>• X, <a href="https://twitter.com/Sonoran_UCEDD">https://twitter.com/Sonoran_UCEDD</a></li> </ul>

### Project Impact

We will track website and social media metrics (e.g. YouTube, Instagram, Facebook) to measure the reach of the videos. Further, we will track the frequency of self-advocates' video submissions to the campaign (e.g. videos that tag the Sonoran Center and/or videos that are sent to the Sonoran Center for sharing). This year's ADDPC support has enabled us to continue educating health care professionals about working with people with IDD. Shortly after receiving Year 2 funding, we mentored a student from the Border Latino & American Indian Summer Exposure to Research (BLAISER) program, Brianna Herrera, who worked with us in Summer 2022. Her poster (see attachment B) illustrates the work she conducted with team member Gabe Martinez to determine our method for engaging self-advocates in telling their health care stories. She presented her poster during a summer research symposium at the University of Arizona, attended by future health care providers and researchers. Moreover, in September 2023, Drs. Bassford and Armin conducted a session about IDD for first year UA College of Medicine – Tucson students, which included one of our steering committee members talking about her health care concerns. Finally, members of the team have shared the Year 1 CME project and our current work with self-advocates with the newly formed Division of Developmental Disabilities and Arizona Medical Education Collaborative (DAME). The goal of DAME is to bring stakeholders together to improve the readiness of current and future health professionals to serve adults with developmental disabilities in Arizona.

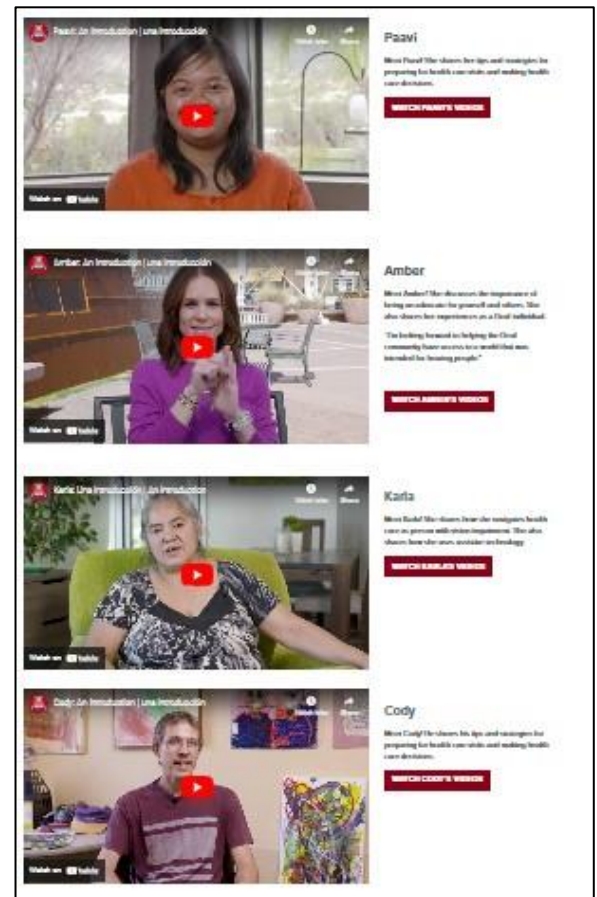


Figure 3 – Self-Advocate Videos

in Arizona.