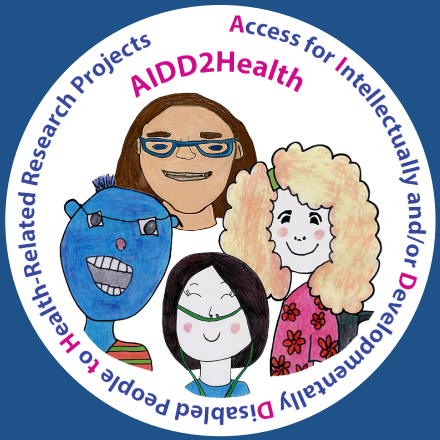
THE UNIVERSITY OF ARIZONA
COLLEGE OF MEDICINE TUCSON
Sonoran Center for
Excellence in Disabilities

A Guide to Using Universal Design for Learning (UDL) to Enhance Inclusive Health Research

Assembled by the *AIDD2Health* Team:

Access for Intellectually and/or Developmentally Disabled People to Health-Related Research Projects



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The contents presented in this guidebook are solely the responsibility of the author(s) and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute® (PCORI®), its Board of Governors or Methodology Committee.

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Introduction

Health research often excludes people with disabilities. Yet, people with disabilities may experience poor health outcomes, often the result of unequal practices, programs, and policies that discriminate.[1]

Health equity and justice mean everyone should have the chance to be as healthy as possible, no matter who they are or their situation.[2]
To achieve this, we need to:

- Challenge our ideas about health and who is centered in health research.
- Bring new perspectives about health into healthcare research.
- Make research and care more inclusive to serve **a more diverse population**, including people with disabilities.

The research process should be clear and easy to understand so that people from diverse communities can participate. This helps researchers better understand their health needs and improve health outcomes for everyone.

This guidebook is designed for researchers seeking knowledge, skills, and resources for **inclusive research practices**. While it specifically focuses on working with people with **intellectual and/or developmental disabilities (IDDs)**, the information is applicable to all people through the use of Universal Design for Learning (UDL) as a framework.

Serving a more diverse population means that research includes different people with different backgrounds and experiences.

Inclusive research practices, as defined here, refer to the broad concept of involving people with disabilities (or your focused population) in different phases of the research process. We will describe the concept of inclusive research in Ch 4.

Intellectual and/or developmental disabilities (IDDs) are usually present at birth and may affect a person's physical, intellectual, and/or emotional development. While intellectual disabilities may affect people's cognitive abilities and adaptive (e.g. life) skills, developmental disabilities refer to a broader set of challenges.

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1. Pérez-Stable, Eliseo & Otto Valdez, Robert. Announcement of Decision to Designate People with Disabilities as a Population with Health Disparities, National Institute on Minority Health and Health Disparities Press Release, September 26, 2023. People with Disabilities Designated as HD Population, Accessed 12/18/24.

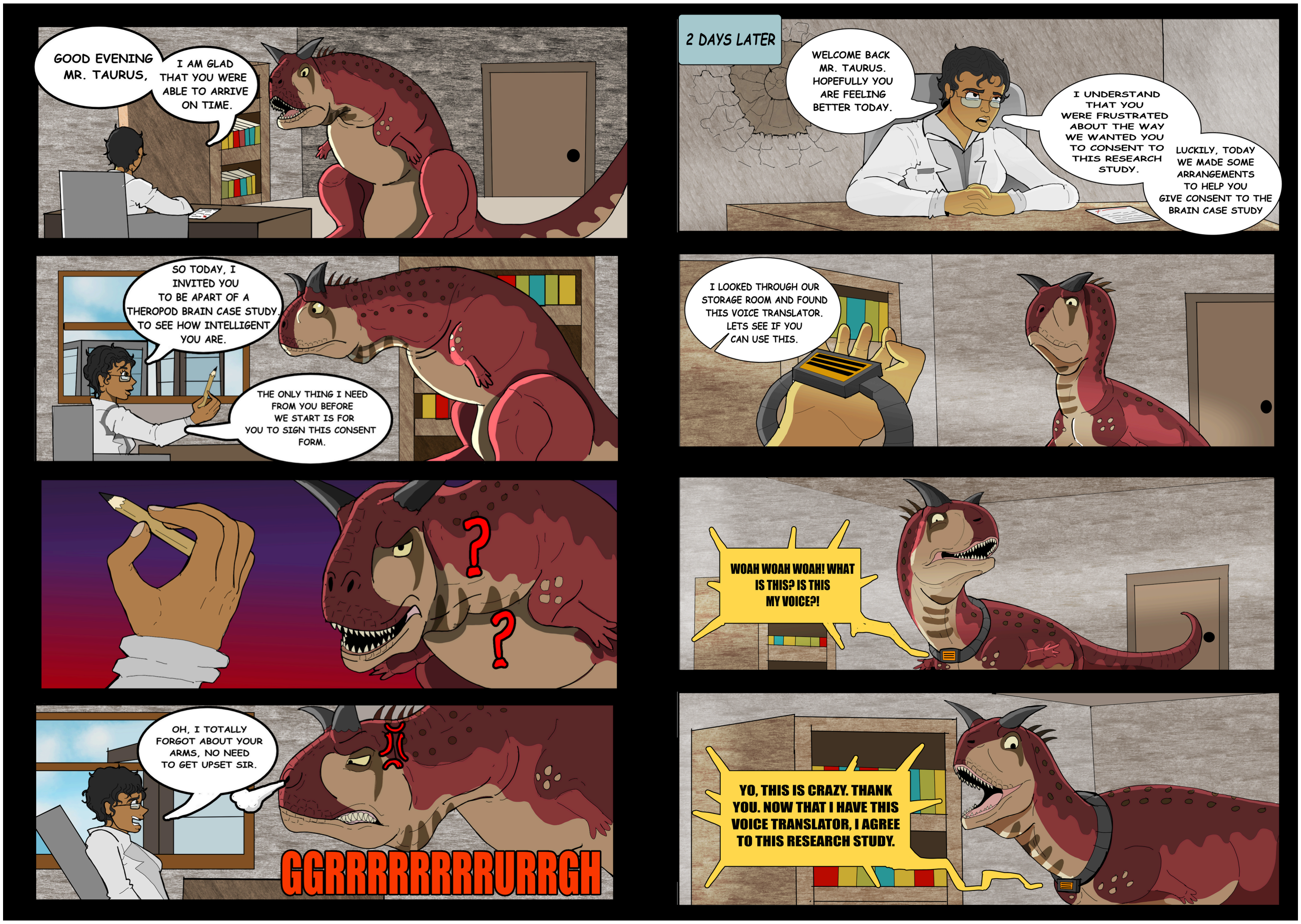
2. U.S. Centers for Medicare and Medicaid Services. (n.d.). Health Equity. CMS.gov. https://www.cms.gov/priorities/innovation/key-concepts/health-equity, Accessed 12/18/24

Why did you decide to join the AIDD2Health Project?

Mr. Taurus

Jamelle, comic illustrator & self-advocate

“Here is an example of what not to do and how you can adapt to meet Mr. Taurus’s needs to participate in your research”- Jamelle



Comics by Jamelle

Chapter 1a: Background

Why Health Researchers Should Use an Inclusive Approach to Research

The **National Institute on Minority Health and Health Disparities** designated people with disabilities as **a population with health disparities** in 2023.

- This designation means that federal agencies, like the National Institutes of Health (NIH), provide research funding to address specific issues and promote equitable access to quality health care for people with disabilities.

National Institute on Minority Health and Health Disparities (NIMHD) is part of National Institutes of Health. The NIMHD helps all groups of people have a fair chance at living healthy, long lives. They do this by giving money for health research, training new health workers, and working directly with communities.

The U.S. Department of Health Services has updated **section 504 of the Rehabilitation Act** rules **requiring inclusionary practices** for any clinical trial receiving federal funds in 2024.[3]

Section 504 of the Rehabilitation Act of 1973 is a federal civil rights law. The law intends to prevent discrimination against individuals with disabilities in programs and activities that receive federal funding.[4]

3.National Council on Disability | NCD applauds HHS final rule updating Section 504: https://acl.gov/news-and-events/announcements/nih-designates-people-disabilities-population-health-disparities, Accessed 12/18/24

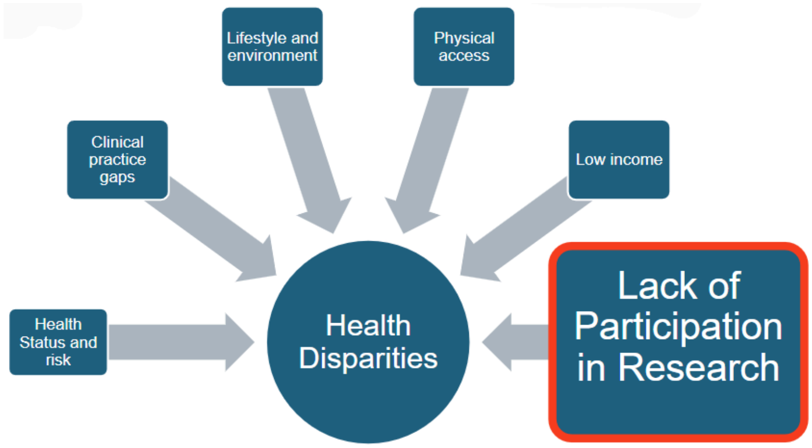
4.National Council on Disability. National Report 2024: Section 504 of the Rehabilitation Act: https://acl.gov/sites/default/files/Section_504_of_the_Rehabilitation_Act_of_1973-Final_Rule_Slides-R.pdf, Accessed 12/18/24

Health Disparities in People with Intellectual and/or Developmental Disabilities (IDD)

People with IDD can experience different things that affect their health:[5]

- **Health status and risk** (e.g., chronic health conditions, co-occurring conditions)
- **Clinical practice gaps** (e.g., insufficient clinician training, biases)
- **Lifestyle and environment** (e.g., limited access, choices and control in daily activities and food intake)
- **Physical access barriers** (e.g., access to transportation, inaccessible facilities and equipment)
- **Low income** (e.g., leading to increased exposure to environmental and life stressors, limited access to community resources and activities, other risk factors)
- **Lack of participation in health research by people with IDD**

Figure 1: Factors contributing to health disparities among people with IDD



This guidebook addresses one of the risk factors: research gaps, specifically the exclusion of people with IDD from research studies.

Health Status and Risk: People with IDD often have chronic health conditions, like diabetes, obesity, high blood pressure, and co-occurring conditions. This means they have different health problems at the same time.

Clinical practice gaps: Healthcare providers are often not well-trained to understand the concerns of people with disabilities or how to support them. They may misunderstand the conditions or abilities of people with disabilities.

Lifestyle and Environment: People with IDD often have limited opportunities for community participation and/or are not given the chance to make choices for themselves.

Physical Access Barriers: People with IDD often have difficulty accessing healthcare because of transportation barriers and inaccessible facilities and equipment at doctors' offices.

Low Income: People with IDD often have fewer options to plan for a safe and healthy lifestyle due to having limited money.

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[5] *Anderson LL, Humphries K, McDermott S, Marks B, Sisirak J, Larson S. The state of the science of health and wellness for adults with intellectual and developmental disabilities. Intellect Dev Disabil. 2013 Oct;51(5):385-98. doi: 10.1352/1934-9556-51.5.385. Erratum in: Intellect Dev Disabil. 2013 Dec;51(6). doi:10.1352/0047-6765-51.6.fmii. PMID: 24303825; PMCID: PMC4677669.* *https://acl.gov/news-and-events/announcements/nih-designates-people-disabilities-population-health-disparities*

People with Disabilities Are Excluded from Research

In a review of 97 clinical trials:[6]

- Only 18% of studies invited people with disabilities to use forms of support (e.g., physical access, hearing aid, support for participating in study protocol).
- 85% of studies used broad criteria for determining eligibility, relying on researcher's assessment of participants' abilities (e.g., understanding), vulnerability (e.g., frailty), or potential negative impact on the study (e.g., having other health conditions that are perceived to be confounding).

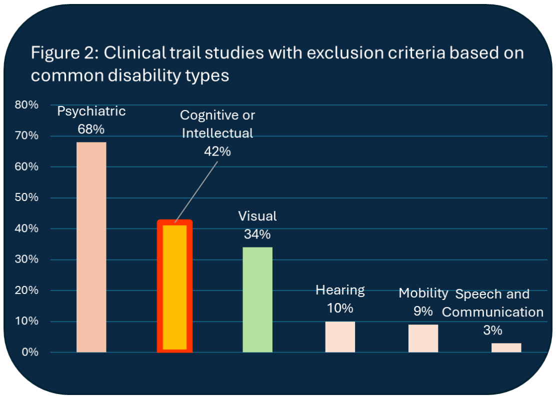
Figure 2: Clinical trail studies with exclusion criteria based on common disability types

Figure 2 is based on the interpretation of DeCormier et al.'s (2022) study findings.

Among common disability types, people with cognitive or intellectual impairments are the second most likely to be excluded from research studies. *See figure 2.*

In a review of 248 clinical trial protocols' eligibility criteria,[7]

- **184 studies** (74.6%) directly or indirectly excluded people with IDD from the study.

In 184 out of 248 studies, people with IDD were not included in research studies. This was because of their disabilities (direct exclusion) or what researchers thought they could not do, or other things related to disabilities (indirect exclusion). For example, researchers assumed people with IDD could not understand the study, or the research required participants to read or communicate well without support.

- 81 studies (33%) **directly excluded** people with IDD, with exclusion criteria such as consent capacity, cognitive capacity, diagnosis, and cognitive capacity to engage in activities.
- 103 studies (42%) **indirectly excluded** people with IDD based on research staff discretion, functional capacity, ability to read/write in English, and access to supportive technology.

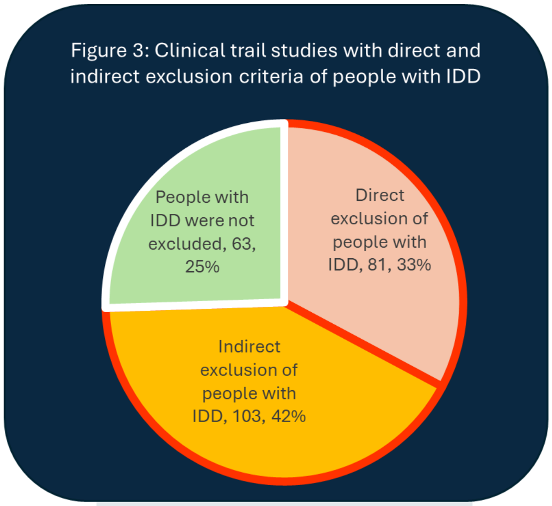
Figure 3: Clinical trail studies with direct and indirect exclusion criteria of people with IDD

Figure 3 is based on the interpretation of McDonald et al.'s (2022) study findings.

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6. DeCormier Plosky, W., Ne'eman, A., Silverman, B. C., Strauss, D. H., Francis, L. P., Stein, M. A., & Bierer, B. E. (2022). Excluding People With Disabilities From Clinical Research: Eligibility Criteria Lack Clarity And Justification: Study examines factors and practices that exclude people with disabilities from clinical research. Health Affairs, 41(10), 1423-1432.

7. McDonald, K. E., Schwartz, A. E., & Sabatello, M. (2022). Eligibility criteria in nih-funded clinical trials: Can adults with intellectual disability get in? Disability and Health Journal. https://doi.org/10.1016/j.dhjo.2022.101368

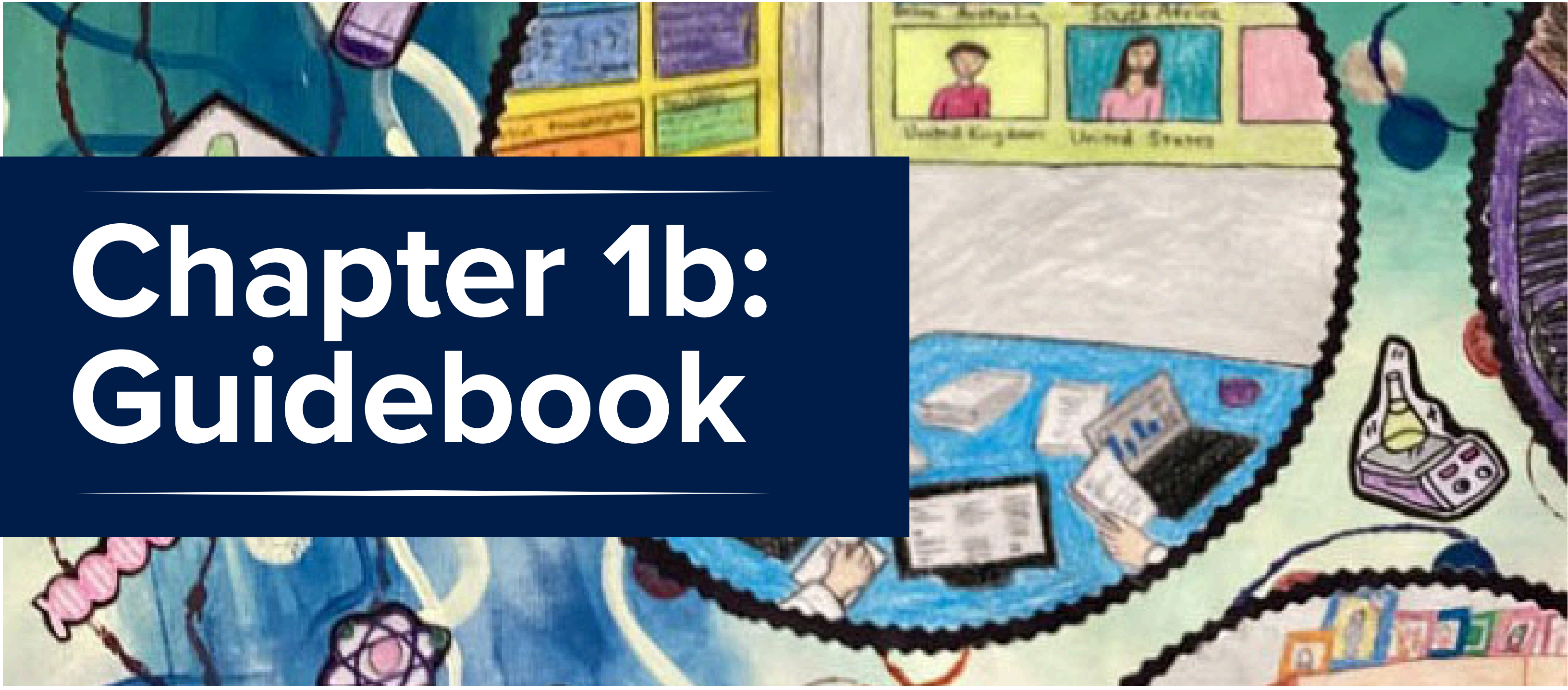
Health Researchers Identify Barriers to Including People with IDD in Research

The AIDD2Health Team sent out a survey to health researchers across the country (*N*=21). We wanted to learn about researchers' experiences and their thoughts on potential challenges in including people with IDD in their studies.

- Those who had experience providing accommodations for people with disabilities (*n*=6, 28.6%) described several **accommodation methods**:
    - Videos translated into American Sign Language
    - Use of technology (e.g. screen readers) to enhance communication
    - Multiple methods of meeting with study staff (e.g., meeting in-person, via online meeting-platform)
    - Provide support during the consent process so participants understood the study activities and had the information to make an informed decision to participate.

- Health researchers described the following **barriers**:
    - **Unsure of inclusion/exclusion**: Researchers are not aware of including/excluding people with IDD
    - **Limited population access**: Researchers lack knowledge about effective recruitment strategies for people with disabilities
    - **IRB process uncertainty**: Researchers have questions about consent procedures and IRB guidelines for enrolling people with disabilities*
    - **Cost of accommodations**: Researchers are concerned about expenses for support services like Communication Access Real-Time Translation (CART)*
    - **Research complexity concerns**: Researchers worry about participants' ability to complete study activities*

**Also identified as barriers in DeCormier et al. (2022) and McDonald et al. (2022)*



Chapter 1b: Guidebook

About the Guidebook

This guidebook was designed together with the project team that included self- and family-advocates as authors, as well as community and professional partners who provided insights and feedback throughout the process. This guidebook:

- Is designed for researchers seeking knowledge, skills, and resources for inclusive research practices.
- Provides effective and practical strategies, outlines available resources, and offers examples.
- Demonstrates how to design and facilitate inclusive research projects using Universal Design for Learning (UDL) as a guiding framework.
- Highlights the benefits and importance of inclusive research processes with self-advocates and family-advocates by providing insights, processes, and reflections from our project activities.
- Focuses on working with people with IDD, but the information is applicable to all research participants through the lens of UDL.

To model Universal Design for Learning (UDL), this guidebook minimizes technical terms (jargon) and uses clear communication throughout. It uses plain language and visual elements with color, illustrations, and figures to demonstrate inclusive practices for non-academic audiences like advocate co-researchers and community members. For our primary audience of researchers, we use 1) **descriptive,** 2) **UDL, and** 3) **parallel boxes** to introduce specific terms and concepts, providing examples and additional descriptions.

Descriptive Box explains bold words and phrases that you'll find in the main text.

UDL **UDL Box** shows how UDL ideas are used in the main text to make it more accessible for everyone.

Parallel Boxes:
show important ideas in two ways. One uses technical terms, and one uses plain language.

Technical Language:	Plain Language:

Chapter 2: Universal Design for Learning (UDL)

UDL Principles

Universal Design for Learning (UDL) is a framework that promotes inclusivity and accessibility in learning and other environments (e.g., research). Its principles aim to ensure that everyone -- regardless of their abilities, backgrounds, or learning styles -- has equal opportunities to succeed. UDL increases access and reduces known and unknown barriers, including those that are rooted in biases and systems of exclusion affecting people with and without disabilities.[8]

The goal of UDL is to empower learners (e.g., research participants) by ensuring their voices are truly heard and valued, promoting beneficence, justice, and respect through fully informed autonomous participation and agency.[9] The UDL framework and principles guide designers (e.g., health researchers) to provide multiple means of engagement, representation, and action & expression.

UDL across the research process ensures that research is meaningful to the participants, leading to:

- Quality data that
    - Includes underrepresented people in health research
    - Encourages clear communication between researchers and participants
- Reduced attrition (fewer participants dropping out from the study)
    - Participants are engaged because the information is accessible, understandable, and relevant

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8. CAST (2024). Universal Design for Learning Guidelines version 3.0. Retrieved from https://udlguidelines.cast.org, Accessed 12/18/24

9. Belmont Report (n.d.): https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html, Accessed 12/18/24

- Representation of underrepresented participants in research data (e.g., people with disabilities) leads to:
  - Improved generalizability of research results
  - Customized/specialized studies addressing the unique needs of underserved populations

Universal Design for Learning (UDL) is a conceptual framework that proactively creates equity and meets the needs of diverse learners. This design meets known and unknown needs through flexibility, minimizing barriers, and recognition of people's varied talents, skills, and abilities. [8, 10]

As stated by CAST (n.d.), "The goal of UDL is learner agency that is purposeful and reflective, resourceful and authentic, strategic and action-oriented." [8]

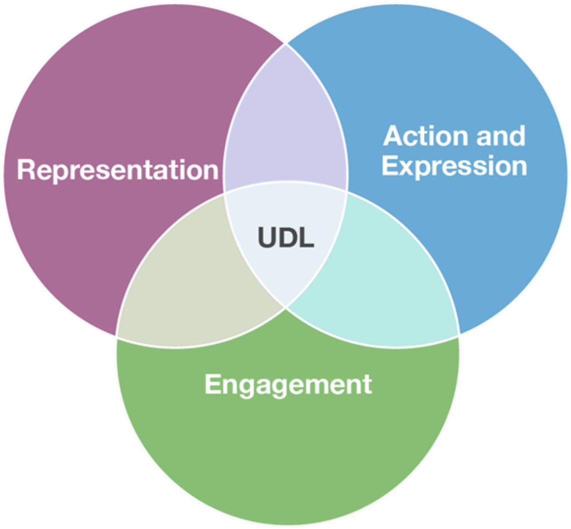

Figure 4 is based on the interpretation of https://udlguidelines.cast.org/

Multiple Means of Engagement: The WHY
Multiple Means of Representation: The WHAT
Multiple Means of Action and Expression: The HOW

Principle of UDL: Engagement

The principle of engagement in UDL helps create environments where individuals feel valued and safe by centering, affirming, and sustaining participants' interests and identities, which promotes inclusivity and authenticity.[8]

All about inclusivity

Does the topic promote participant engagement by:

- Welcoming interests and identities by optimizing autonomy and addressing biases?
- Sustaining effort and persistence by clarifying the meaning and the purpose?
- Supporting emotional capacity by recognizing expectations, beliefs, and motivations?

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8. CAST (2024). Universal Design for Learning Guidelines version 3.0. Retrieved from https://udlguidelines.cast.org

10. Thompson, M. & Temple, P. (2023, June). Utilizing the Principles of UDL to Foster Equity and Creativity for Artists with IDD. Poster presentation at the American Association on Intellectual and Developmental Disabilities (AAIDD) 2023 Conference. Pittsburgh, PA.

Principle of UDL: Representation

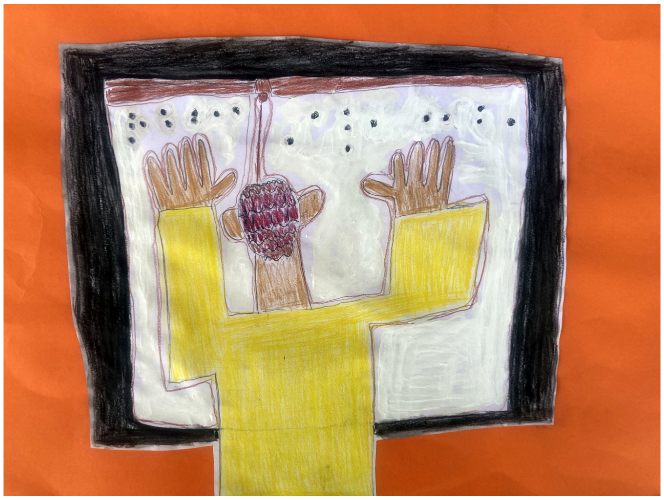
The principle of representation in UDL recognizes the importance of representing a diversity of perspectives, identities, and narratives by presenting and valuing multiple ways of knowing and meaning-making.[8]

All about access

Is information communicated to participants:

- Through multiple ways to increase understanding of information?
- Through language and symbols that are clearly communicated?
- Is new learning connected to prior knowledge?

Illustrations by Jack



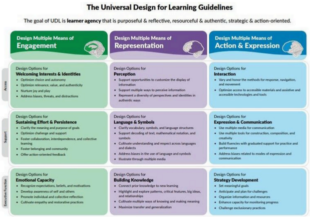
Principle of UDL: Action & Expression

The principle of action & expression in UDL honors and values all forms of expression -- equity in communication.

All about voice and agency

Are participants able to communicate and act on their ideas through:

- Optimizing interaction through availability of access to accessible materials and tools?
- Multiple and diverse types of expression and communication?
- Taking action (strategy development) by setting meaningful goals?



The Universal Design for Learning Guidelines

The goal of UDL is **learner agency** that is purposeful & reflective, resourceful & authentic, strategic & action-oriented.

	Design Multiple Means of **Engagement**	Design Multiple Means of **Representation**	Design Multiple Means of **Action & Expression**
Access	Design Options for **Welcoming Interests & Identities** • Optimize choice and autonomy • Optimize relevance, value, and authenticity • Nurture joy and play • Address biases, threats, and distractions	Design Options for **Perception** • Support opportunities to customize the display of information • Support multiple ways to perceive information • Represent a diversity of perspectives and identities in authentic ways	Design Options for **Interaction** • Vary and honor the methods for response, navigation, and movement • Optimize access to accessible materials and assistive and accessible technologies and tools
Support	Design Options for **Sustaining Effort & Persistence** • Clarify the meaning and purpose of goals • Optimize challenge and support • Foster collaboration, interdependence, and collective learning • Foster belonging and community • Offer action-oriented feedback	Design Options for **Language & Symbols** • Clarify vocabulary, symbols, and language structures • Support decoding of text, mathematical notation, and symbols • Cultivate understanding and respect across languages and dialects • Address biases in the use of language and symbols • Illustrate through multiple media	Design Options for **Expression & Communication** • Use multiple media for communication • Use multiple tools for construction, composition, and creativity • Build fluencies with graduated support for practice and performance • Address biases related to modes of expression and communication
Executive Function	Design Options for **Emotional Capacity** • Recognize expectations, beliefs, and motivations • Develop awareness of self and others • Promote individual and collective reflection • Cultivate empathy and restorative practices	Design Options for **Building Knowledge** • Connect prior knowledge to new learning • Highlight and explore patterns, critical features, big ideas, and relationships • Cultivate multiple ways of knowing and making meaning • Maximize transfer and generalization	Design Options for **Strategy Development** • Set meaningful goals • Anticipate and plan for challenges • Organize information and resources • Enhance capacity for monitoring progress • Challenge exclusionary practices

For more information, visit:
https://udlguidelines.cast.org

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8. CAST (2024). Universal Design for Learning Guidelines version 3.0. Retrieved from https://udlguidelines.cast.org

Clear Communication and Plain Language

What is clear communication?

Clear communication means giving information in a way that is easy to understand and act on right away. In research, it helps participants know what the researcher wants from them and what their rights are. Clear communication can include plain language, pictures, illustrations, graphs, icons, and other ways of sharing information.

Clear communication has been promoted as best practice in medical settings for several decades. Until recently, we did not have a standard for how to use clear communication. Coleman et al. list their top practices to provide clear communication:[11, 12, 13]

- Use qualified medical interpreters.
- Use plain language and avoid unnecessary jargon.
- Avoid information overload and encourage questions.
- Use a teach-back method that asks patients to explain what they understand.

What are the benefits of using clear communication and plain language in research?

Clear communication and plain language help researchers share information in a way that many more people can understand. This makes research more accessible to different groups of people.[14]

Researchers should use clear communication and plain language to make the research process fairer, more equitable, and easier to understand. This helps everyone:

- Understand the purpose and process of the research study.
- Decide if they would like to join a specific research study.
- Know what they need to do as a participant.
- Understand the results and what they mean.
- Apply the research to their lives.
- See how research can improve community health.

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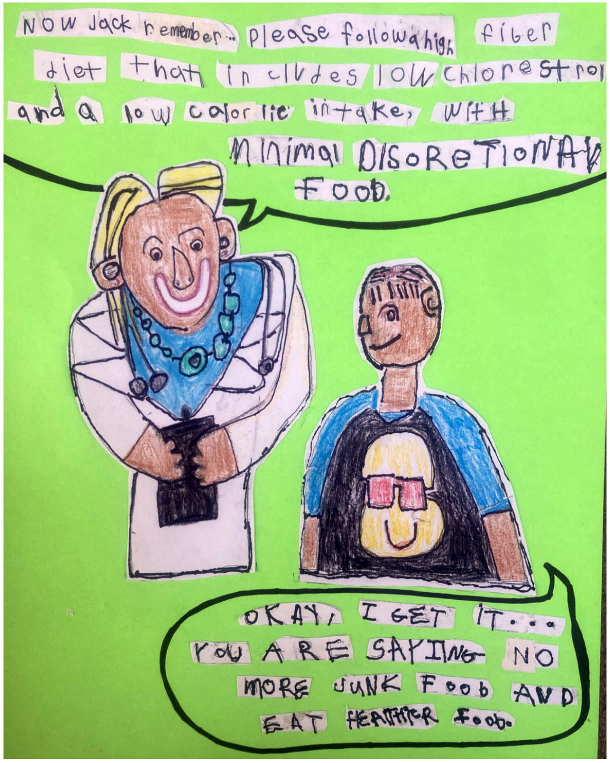
11. Coleman, C. A., Hudson, S., & Maine, L. L. (2013). Health Literacy Practices and Educational Competencies for Health Professionals: A Consensus Study. Journal of Health Communication, 18(sup1), 82–102. https://doi.org/10.1080/10810730.2013.829538.
12. Coleman, C., Hudson, S., & Pederson, B. (2017). Prioritized health literacy and clear communication practices for Health Care Professionals. HLRP: Health Literacy Research and Practice, 1(3). https://doi.org/10.3928/24748307-20170503-01.
13. Coleman, C. (2020). Health literacy and clear communication best practices for telemedicine. HLRP: Health Literacy Research and Practice, 4(4). https://doi.org/10.3928/24748307-20200924-01.
14. Gross, Z. (2024, April 17). AIR-P Presents: Introduction to Plain Language Writing for Academics and Researchers. YouTube. https://youtu.be/5atNQ_kTEx4?si=HordOfRpjBycWozf.

Clear Communication and Plain Language Strategies and Tips:

- **Keep sentences and paragraphs short; focus on one subject per sentence and one topic per paragraph** - Longer sentences/paragraphs can distract from the point and be confusing.[15]
- **Use common words or explain any difficult words** - Your message will be understood by more people if you use common words. [15]
- **Say expectations explicitly, instead of using indirect statements** - This causes fewer misunderstandings and helps everyone understand what needs to happen.[15]
- **Avoid figurative language, like metaphors, idioms and other interpretative expressions -** Figurative language often represents abstract concepts that can be more easily misunderstood. Being literal will help a wider audience understand your message.



Illustrations by Jack

- **Organize information based on the intended audience** - Some audiences need or use different information.[15]
- **Leave out or move less-important information** - Too much information can be confusing and distract from the important information.[14]
- **Use active voice instead of passive voice (the subject does the action)** - Passive voice can be vague and confusing.[15]
- **Use examples and different formats to give information** - Presenting information in different ways allows people to process what they are hearing or reading in the way that works best for them.[15]
- **Write out contractions and abbreviations** - Abbreviations are often specific to a field and may not be known to a wider audience. Contractions can slow a reader down.[14]
- **Use illustrations, graphs and images to communicate information visually**.
- **Use talk-back (teach-back) and comprehension checks** - Ask open-ended questions and have participants repeat and rephrase information to check for understanding.[13]

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13. Coleman, C. (2020). Health literacy and clear communication best practices for telemedicine. HLRP: Health Literacy Research and Practice, 4(4). https://doi.org/10.3928/24748307-20200924-01.

14. Gross, Z. (2024, April 17). AIR-P Presents: Introduction to Plain Language Writing for Academics and Researchers. YouTube. https://youtu.be/5atNQ_kTEx4?si=HordOfRpjBycWozf.

PlainLanguage.gov, Federal Plain Language guidelines (2011). United States.

15. PlainLanguage.Gov. Plain Language Makes It Easier for the Public to Read, Understand, and Use Government Communications. https://www.plainlanguage.gov/, Accessed 12/18/24

Communication Considerations for Working with Marginalized Groups

More than one-third of all Americans have low health literacy and many more are at risk for low health literacy.[13] Some people:

- Need definitions or explanations of specific medical words and advice.
- Understand better with shorter sentences.
- Benefit from picture examples.

We should always ask people how they like to get information (e.g., audio, verbal instruction, text, visuals). When people join research, they might need different ways to understand things, so it is good to use different types of clear communication. This is the best way to help everyone. Using plain language along with tools like videos and screen readers can make research easier for everyone to understand (see the UDL section).

Comics by Jamelle

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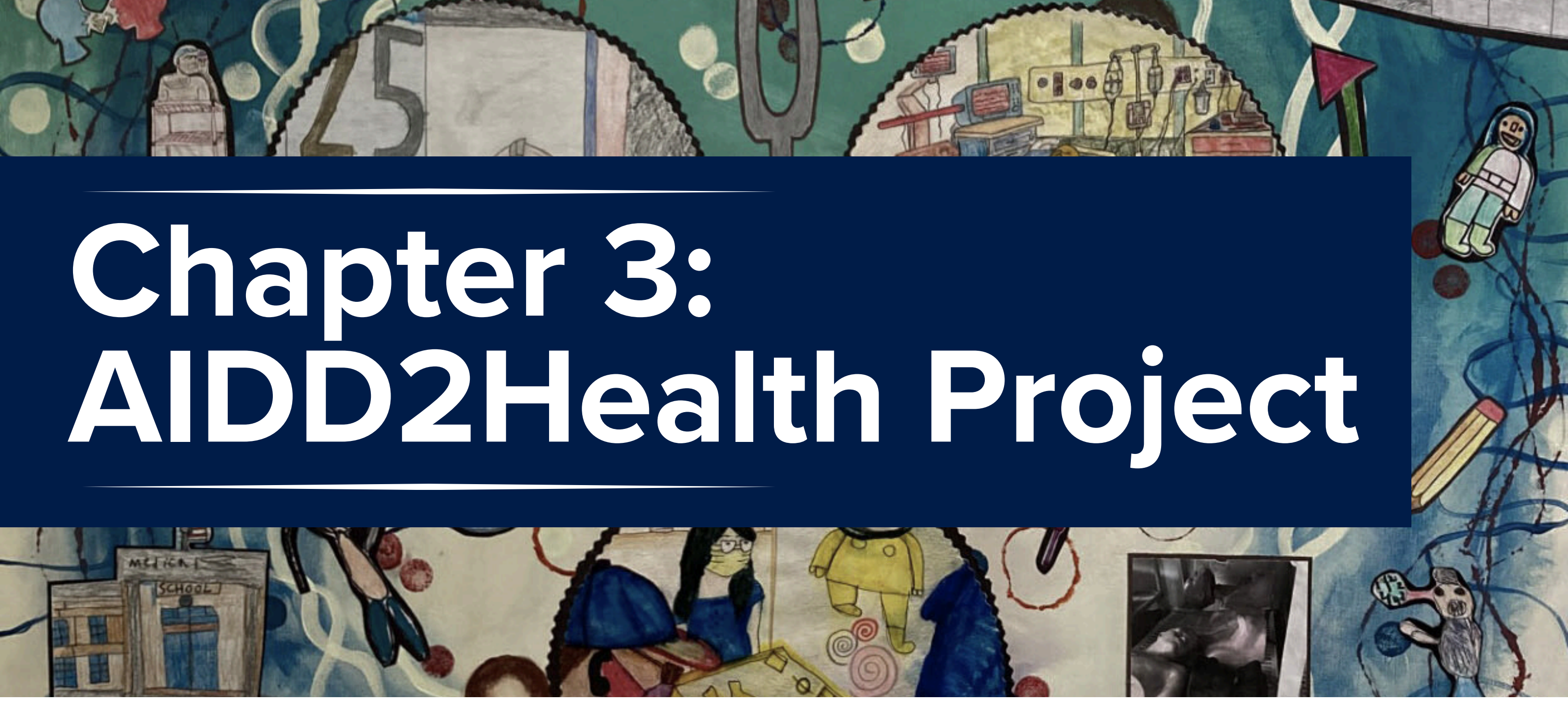
[13] Coleman, C. (2020). Health literacy and clear communication best practices for telemedicine. HLRP: Health Literacy Research and Practice, 4(4). https://doi.org/10.3928/24748307-20200924-01.



Chapter 3: AIDD2Health Project

Mission, Vision, and Objectives

Mission

Our mission is to support health-related research that addresses what intellectually and/or developmentally disabled people want for healthy living. This includes physical and mental health, direct services, policy development, education, and other issues related to health and community living. We want to support research that is accessible, inclusive and ethical. We are self-advocates, supporters, and researchers in Arizona. We are working to develop strategies, tools, and models that others around the U.S. can use. These strategies, tools, and models use Universal Design for Learning principles.

Vision

We want to make sure that intellectually and/or developmentally disabled (IDD) people are included in all areas of health research. Inclusion will help people with IDD have fair access to good health and community living. This means disabled people and their supporters will get help from: fair policies, ethical practices, accessible information, and culturally responsive approaches.

Objectives

- Make sure that people with IDD can access health-related research projects that are important to them.
- Teach researchers and the Institutional Review Boards (IRB) at Universities about IDD-inclusive research practices and how to use them in health-related projects.
- Create a library of resources and tools that promote inclusion of people with IDD in research.

Project Team

Core Team Members

Dr. Yumi Shirai (PI), PhD

Researcher & Practitioner

With my background in dance/movement training, my passion is integrating creativity and arts into support and educational programs for and with adults with IDD and their supporters. As the project lead, I oversee all aspects of the AIDD2Health project and this guidebook on integrating UDL approaches to promote inclusion of people with IDD in health research. I'm Japanese and love white rice!

Dr. Julie Armin (Co-PI), PhD

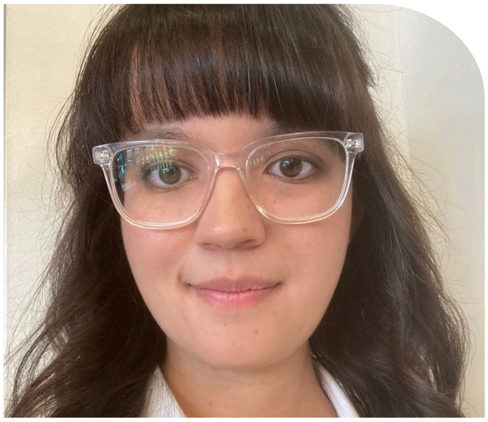
Researcher & Ally

I joined the team because I’m passionate about addressing cancer health equity for people with IDD. I helped with the introduction, plain language and case studies sections. I do yoga, weightlifting, and cardio workouts to stay healthy, which make me feel okay about occasionally eating chocolate chip cookies!

Dr. Michelle Thompson, PhD, OTR/L

Researcher & Practitioner

I am passionate about empowering people with disabilities and their families. As an occupational therapist, health researcher, mom to three young adults with learning disabilities, and someone who identifies as neurodivergent, I truly believe in inclusive research with all voices represented and heard. I guided our team's discussions through the UDL lens. I enjoy hiking and chasing sunsets with my husband and 2 dogs.



Claire Adams, AA

Self-Advocate

Claire is a 24-year-old Autistic advocate. She is a senior majoring in Rehabilitation Studies & Services at the University of Arizona. Clair worked on the video for the Health Needs Survey as well the Plain Language section of the guidebook. She is the Chair of Arizona Statewide Independent Living Council and an alum of Arizona Leadership Education in Neurodevelopmental Disabilities. Her motto is "Be the person you want other people to be." Her favorite cookie is chocolate chip.

Michael Sanderfer (daughter–Kiera), MPA, MEd

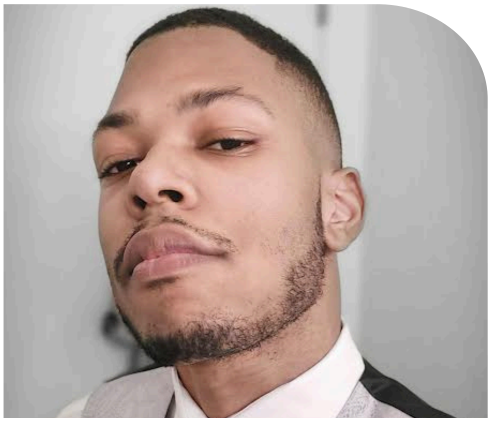
Family-Advocate

I joined the team to support and be my daughter's voice. I have provided insight of supporting a non-verbal individual and my over 40 years of experience working with Special Needs populations. I enjoy writing; my favorite cookie is peanut butter. I manage a good diet, hike, bike and walk to stay healthy.

Sarah Worthington, MA

Educational Therapist; Self- & Family-Advocate

I study cognitive diversity and help students with learning and thinking differences such as ADHD and autism achieve academically and thrive socially and emotionally. Many neurodivergent individuals like myself and my teen experience co-morbid health conditions and struggle to find adequate care and treatment. I joined the team to help lessen that struggle. I worked on the advocate voices' handbook section and came up with the project name, AIDD2Health. I enjoy coffee ice cream and like to cycle and hike.



Jamelle Texeria Jr.

Comic Illustrator & Self-Advocate

I decided to join the team because I wanted to be an advocate to people with autism but also for people of color on the spectrum. I want to help these communities know that there are resources willing to understand them and their situation and help give them advice on what to do in similar situations, especially in social settings. I helped with the illustrations; all the dinosaur-related ones are mine. My favorite cookies are homemade snickerdoodles. I stay healthy by walking outside between my work projects.

Susie Turrey

Mom & Disability Advocate

I'm a mom of two, including a son with autism, and a dedicated disability advocate. As a community organizer, I lead a cross-disability peer mentorship program with Arizona Achieve and I contributed to AIDD2Health, working to break down barriers between researchers, doctors, and the IDD community. My goal is to inspire change, foster inclusion, and support families like mine. I love chocolate chip cookies and I stay healthy with movement classes.

John "Jack" McHugh Jr.

Self-Advocate, Artist

My name is John McHugh Jr. but you can call me Jack. I joined the team because Yumi, my ArtWorks director, offered the opportunity. I was nervous at first but then it felt important that I join because I wanted to help people with IDD talk about their experiences and be heard by their doctors. I helped with the illustrations, all the people-related ones are mine. My favorite cookie is chocolate chip and I do softball to stay fit and I come to ArtWorks to stay happy.

Linda Nazifi, BA

Program Coordinator, Educator, Practitioner

I joined the PCORI team to aid in the clerical and administrative processes. My favorite cookie is a peanut butter cookie. To stay healthy, I've tried to cut out sugar (peanut butter cookies) from my diet, and go for longer walks.

Elizabeth Vargas, BFA

Program Coordinator, Artist, Educator, Practitioner

I joined AIDD2Health when my co-worker, and other former AIDD2Health project team member, retired. I took over her section which included the illustration portions of the guidebook; so, as a working artist and art teacher for the IDD community, it was a good fit. Fun facts: my favorite cookie is an chocolate chip oatmeal and to stay healthy I do circuit training 4 times a week, drink plenty of water and give myself the me-time I need.

Student Team Members

Freya Abraham, BS

Medical Student Researcher

I joined this team because I care deeply about health equity for people with intellectual and developmental disabilities. I am very excited about the work we're doing to expand access to health research. I helped with the research tools section of the guidebook. A fun fact about me is that I love chocolate chip cookies! I stay healthy by getting in movement throughout my day.

Jack Algier, BS

Student Researcher

I joined the team because I believe in the mission of the AIDD2Health project and the spirit of the ArtWorks community. I helped the team by cleaning interview transcripts, formatting bios, and giving feedback on applying UDL principles throughout the guidebook. I have loved every minute of working directly with our wonderful ArtWorks artists and advocates. My favorite cookies are peanut butter. I like to stay healthy by trail running!

Nicholas Amjadi

Student Researcher

My passion in working with people with IDD led me to join this team. I want to help address health disparities for people with IDD globally. In the guidebook, I assisted with screening for articles regarding patient-reported measures specific to the IDD as well as non-IDD population. My favorite cookie easily has to be a soft and chewy cinnamon cookie. I try to work out five times a week to be active and healthy through weight lifting and running.

Lexicon Espinoza

Student Psychology Researcher, Self-Advocate

I joined the AIDD2Health team because as a disabled student, I am familiar with some of the ways disabled people experience health disparities. I wanted to learn more about the experiences of people with IDD and increase accessibility to health information and research. I worked on the plain language and clear communication section of this guidebook. My favorite cookie is pumpkin chocolate chip. I like to cook nice dinners that consider my diet needs to stay healthy.

Jeffrey Greenfield, BS

Medical Student Researcher

I am a medical student at the University of Arizona College of Medicine - Tucson, but have been fortunate enough to have joined this team in undergrad. I love the perspectives that different team members bring to the table and that this group appreciates how everyone can share their experiences to make an impact. I helped with various stages of this project and my favorite way to stay healthy is to play sports with friends!

Anne Lednicky, BS

Medical Student Researcher

I joined the team because of my interest in medicine and disability, and to work on my thesis for my undergraduate degree. I helped with the research for the health disparity section. My favorite cookie is chocolate chip, which is a classic for a reason! I stay healthy by walking and hiking.

Ree Lee

Student Researcher, Inclusive Healthcare Advocate

As someone with various intersectional identities, a neurodivergent, and queer individual of Hispanic and Asian culture, I recognize the importance of truly inclusive healthcare. My personal and community experience, alongside my education, has shown me how critical it is to bridge the gap between inclusive research and impactful health care. I worked on screening articles for inclusive health measures in the guidebook. My favorite cookies are frosted chocolate orange cookies that my family and I make at Christmas.

Jeciana Rivera

Student Researcher

I joined the team after volunteering at ArtWorks on campus where I was introduced to this project. I decided to join because I have always had an interest in addressing health disparities and was immediately intrigued by this topic! My favorite cookies are double chocolate cookies! To stay healthy, I do yoga and go to the campus recreation center with my friends :)

Karlie Smith

Student Researcher

I am an undergraduate student who joined the team to help further the inclusion of people with IDD, as I aspire to continue pursuing research with this population in the future. I am on the Narrative Review team, working to identify articles that study health measures used for people with IDD. Fun facts; my favorite cookie is chocolate chip, and I enjoy doing yoga to stay healthy.

Noah Weaver, BS

Medical Student Researcher

I worked on the Plain Language project with Dr. Armin and Lexicon. I graduated this past May from the UofA and am currently at UA College of Medicine-Tucson. I have a strong passion for working with the IDD population, listening and learning from all to see how we can work to create a more inclusive and education-friendly environment. I would have to say my favorite cookie is chocolate chip, but I enjoy the dough more than the actual cookie. I try to run every day to stay healthy and eat healthy.

Other Contributors

Dr. Tammie Bassford MD

Family Practice Doctor

I am a family doctor who cares for adults with IDD. I volunteer with Special Olympics and teach health science students and family medicine residents about developmental medicine. In this project, I reviewed methods and materials to ensure medical content is accurate, relevant, and reflects concerns of health care providers. My favorite cookies are my mother's cream cheese cookies. I love to travel with my family, and enjoy cooking new recipes that I encounter on those trips for my family and friends.

Madison Harper

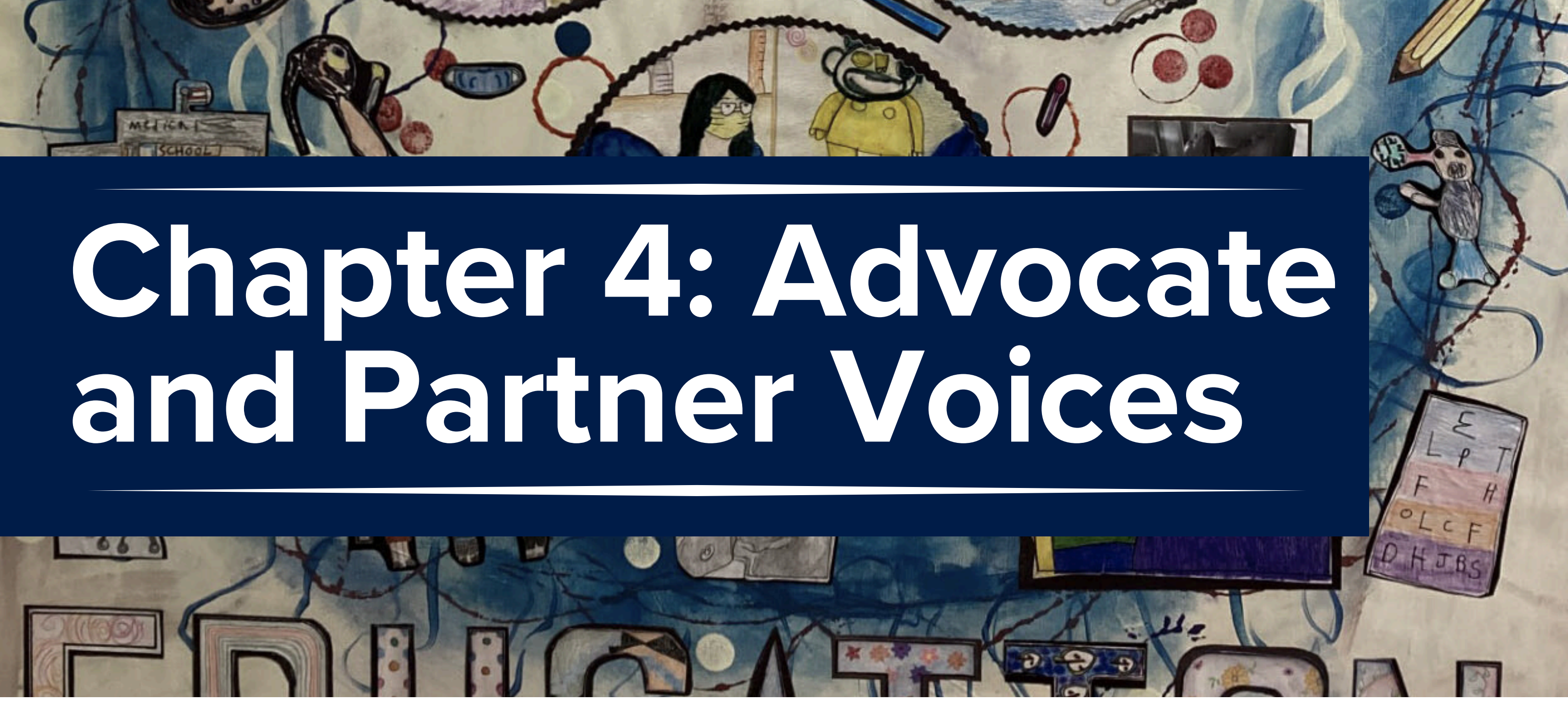
Self-Advocate

I joined AIDD2Health because I wanted to know what opportunities existed in the community that would help people. Moreover, I wanted to participate in creating a better future. I worked on creating the guidebook logo. My favorite cookie is chocolate chip. To stay healthy, I try to watch my sugar intake, and I try to eat healthier.

Dr. Lynne Tomasa, PhD, MSW

Researcher

My background is in education and social work. I enjoy this project because I learn something from every person on the team. We share our life experiences with each other. This helps the team understand how to improve research for different communities and our own health. For this project, I review materials and provide ideas on what might be useful. To stay healthy, I play tennis, spend time with my dogs, and listen to music. I like oatmeal raisin cookies.



Chapter 4: Advocate and Partner Voices

Lessons Learned from the AIDD2Health Project

Why Was it Important to Include Advocate and Partner Voices in Our Project?

To incorporate lived experiences into research and **to**:

- Humanize experiences and foster understanding through real stories.
- Move beyond labels.
- Recognize the skills, professional experiences, expertise, and personal insights of disabled individuals and their allies.
- Highlight the diversity of disabilities and experiences to recognize individuality.
- Identify gaps in current knowledge and practices.

Why Was it Important to Have a Diverse Team?

Diverse voices foster **culturally responsive research** by:

- Providing opportunities to reflect on researchers' actions, attitudes, activities, and approaches (e.g., information sharing) to create opportunities for all.

Culturally responsive research recognizes that individuals and communities have complex and/or different identities that affect experiences; acknowledges that research has a culture as well.

- Creating a sense of belonging where all members (researchers, advocates, and participants) are valued and welcomed to share their ideas and expertise.
- Fostering inclusive practices by improving access to health care services for everyone.
- Conducting quality research that leads to meaningful and practical applications.

Diverse voices lead to shared learning and innovation by:

- Gaining insights from varied backgrounds and disciplines that work toward common goals to improve health.
- Building a supportive community through shared experiences.
- Collaborating effectively towards common goals.
- Challenging assumptions about disabilities.
- Reflecting upon current practices and how we can improve and grow.
- Recognizing what we do not know.
- Understanding that our approach may not be the best or only solution.

What is Inclusive Research?

"Inclusive Research" is a term that includes different ways of doing research with common threads of **mutual respect, co-learning, and co-creation of knowledge**.

- **Researchers work together with or for the people they're studying**,[16] instead of just studying them from the outside.
- It recognizes that researchers and participants can have different relationships in a project. For example, researchers or the participants can lead the work.
- **There isn't just one way** to do inclusive research - there are many different methods.
- **Common methods** include participatory action research, community-based participatory research, and constructive research.

Illustrations by Jamelle

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[16] *Nind, M. (2017). The practical wisdom of inclusive research. Qualitative Research, 17(3), 278-288.* *https://doi.org/10.1177/1468794117708123*

Key Considerations for Making Research Accessible to People with IDD

The AIDD2Health Project Team consulted with inclusive research experts in the disability field to identify key considerations for making research projects more accessible and inclusive for people with IDD.

We summarize the **essential points relevant to health researchers who typically do not work with the IDD population.** The aim is to expand their research projects to include people with IDD:

- **Shared Goals and Mutual Benefits**: Ensure that the research project goals align with what is most important to the study participants by clearly stating the research end goals and roles of participants. Re-visiting ideas over time through discussion will make ideas clearer for all participants.
- **Involvement and Representation of People with Disabilities**: Include them throughout the research process—from formulating questions to recruitment, data collection, and information dissemination. They can serve as advisors, consultants, and/or research team members (co-researchers) where feasible and appropriate.
- **Relationship Building**: Listening to each other fosters trust and reciprocity (mutual benefits) with advocates, participants, and researchers.
- **Empowerment**: Encourage participants to speak up, provide feedback and insights, and ask questions in ways that suit their learning styles. This provides opportunities to express their own wants and needs (with support from another person if necessary).
- **Adaptability**: Recognize that equitable access does not mean having the same tasks or expectations for everyone. Meet people with IDD where they are—small adaptations and flexibility can encourage participation. Consider the amount of time needed or other accommodations that will increase access to materials and participation (e.g., offering alternative options: screen reader, transportation, remote participation, extra and/or flexible time).
- **Accessibility**: Adapt and test measures and tools, simplify options, and develop learning modules (e.g., how to answer multiple-choice questions) to make the research process more accessible.
- **Clear Communication and Plain Language**: Use plain language, visuals, and illustrations to enhance accessibility and accommodate different ways of understanding.
- **Enjoyment**: Make the research process fun and enjoyable for participants.

- **Practical Considerations**: Be aware that individuals may need to limit their income to maintain their insurance status and benefits. Find participants from different places and groups. Provide extra time to plan for transportation, activities, and appointment times.
- **Ethical Considerations**: Use accessible consent forms (use plain language and teach-back question methods to assess understanding) and advocate for the use of adapted forms with Institutional Review Boards (IRBs). Recognize that IRBs may not be experts in consent and assent for your participants-of-interest. Advocating for adapted forms may be necessary. See additional information in the *Informed Consent Considerations* section.
- **Plan Ahead**: Plan grant proposals that include a budget for advocates in paid roles, accessibility tools, and article processing charges (e.g., APCs). Strive to include people with disabilities as meaningful, compensated members of the research team.

Informed Consent Considerations

How to Adapt an Informed Consent Form into Plain Language

- Individual Institutional Review Boards (IRBs) often provide guidance to researchers about informed consent forms. However, everyone must follow U.S. Department of Health and Human Services Guidance for the "elements of consent".[17] Researchers can use plain language approaches to modify consent forms.
- There may be institution-specific language for consent forms. Your IRB will tell you which language is required when they provide feedback on your modified consent form.
    - We modified our institution's informed consent template to use plain language and to include teach-back questions. Teach-back questions enable the researcher to confirm participant understanding rather than making assumptions about capacity to consent.[18]

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[17] U.S. Department of Health and Human Services, Office for Human Research Protections, Informed Consent Checklist, Nind, M. (2017). The practical wisdom of inclusive research. Qualitative Research, 17(3), 278-288. https://doi.org/10.1177/1468794117708123, Accessed 12/18/24

[18] National Institutes of Health. Research Involving Individuals with Questionable Capacity to Consent, https://grants.nih.gov/policy-and-compliance/policy-topics/human-subjects/policies-and-regulations/vulnerable-populations/questionable-capacity, Accessed 12/18/24

Guardianship and Consent

It is important to know that only some people with IDD have a guardian who must provide consent.

- Many states are moving to an alternative to guardianship for people with IDD called “supported decision-making.” This means that a person with IDD may have a person with power-of-attorney to make certain decisions (for example, financial decisions), and have a support network to help them make decisions about other aspects of their life (for example, health).
- Ask the potential participant when you start the consent process, “Do you have a guardian? Can you decide to participate in this research yourself or does someone else make those decisions? Do you need to do some research or talk to someone else about your participation?”
- If someone does have a guardian to provide consent, it is important to have an Assent process for the adult participant with IDD. Participants who have a guardian may be able to understand the research, and they should assent to their participation.
    - Consent and **assent** may be in the same document.

Assent is a process for explaining the purpose and activities of a research study to people who cannot legally provide consent to participate. Assent may include a question about whether the participant agrees to join the study, which is not “consent” but promotes autonomy and agency. Stanford University’s Research Compliance Office has a nice assent model for adults who have a guardian: https://researchcompliance.stanford.edu/panels/hs/for-all-researchers/consent/assent-process

Regulatory Considerations

IRBs outline special considerations for people with cognitive disabilities. You may use documents that support people with cognitive disabilities. It can help everyone who participates. You should not need to submit special paperwork to enroll people with cognitive disabilities who can consent for themselves or who have a guardian who provides consent, if they are part of a general population of participants with/without cognitive disabilities. Talk to your IRB for guidance.

What Does an Inclusive Project Look Like?

AIDD2Health Project: Team Building and Training

The AIDD2Health Team included diverse members, including self-advocates, family advocates, and professionals with various training. Team building began by clarifying the purpose of the project, member's roles, and training about research practices and ethics.

1) **Clarifying Shared Goals and Each Member's Role in the Project:**

- Developed Project Mission, Vision, and Objectives through conversations with team members. We started with the original project description and listened to all members. We facilitated:
  - A safe environment for expression.
    - Start conversations with a short ice breaker to get to know each other as individuals each time.
    - Acknowledge different ideas and opinions without judgement (e.g., self advocates, parent advocate, vs. researchers).
    - Encourage questions and honest feedback.
  - Questions that encouraged deeper and clearer thinking.
  - Discussions about individual motivations for their project participation.
- Revisited the Shared Goals often throughout the project process as a reminder, re-evaluation, and confirmation.
- Developed Project Logo and Video.

To Watch the Project Video, Go to AIDD2Health Webpage

2) Trainings:

- Invited **READI**[19] (**R**esearch **E**ngagement and **A**dvocacy for **D**iverse **I**ndividuals) team, another inclusive research team, as our mentors. The AIDD2Health Team then:
  - Completed the READI research training, which covered health research basics, health story creation, and research process and steps.

READI: The Ausderau Lab at Waisman Center, University of Wisconsin-Madison: https://ausderau.waisman.wisc.edu/hret/readi/

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[19] Ausderau, K. K. & Health Research Engagement Development Team. (n.d.). Research Engagement and Advocacy for Diverse Individuals (READI) Curriculum. A product of the 'Research Engagement with People with Intellectual and Developmental Disabilities' project (PCORI Eugene Washington Engagement Award #10029). https://ausderau.waisman.wisc.edu/hret/readi/, Accessed 12/18/24

    - Learned how to facilitate an inclusive research project team with diverse backgrounds and expertise by observing the READI mentor team.
    - Learned the value of health stories in training advocates and researchers.
- Formed a small group of AIDD2Health team members (a researcher, a self-advocate, and a student researcher) who led the adaptation and facilitation of an **Ethical Conduct of Research training.**
    - Adapted training materials with relatable examples specific for the AIDD2Health team (e.g., case studies involved video game characters Super Mario and Dr. Mushroom conducting a study).
    - Facilitated the training for all team members.

AIDD2Health Project: Health Priority Survey

Overview

To start including people with IDD in health research, our team first identified important health topics for the IDD community:

- Through discussions with local self-advocates, family advocates, and IDD professionals, our team designed an accessible and comprehensive survey on health priorities.
- Our team then implemented the survey nationally with self-advocates and families.

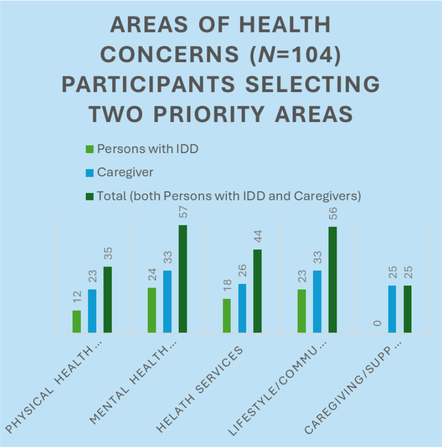


Figure 5. Areas of Health Concern

Listening Session Preparation

Through weekly project meetings, the AIDD2Health team collaborated to develop the following components for hosting listening sessions with self- and family-advocates:

- Structure of the sessions:
    - Meeting Day 1: Project overview, Q&A (with pauses to clarify questions), and consent process with a PowerPoint presentation with key points and illustrations.

UDL
Separating activities into two sessions allows participants to fully understand the project purpose and their role, and provides enough time for Q&A to make informed decisions about study participation.

    - Meeting Day 2: Listening session with key questions/topics provided in the prior session

UDL
Providing enough time to process ideas to increase access to participate.

- Consent-related documents:
    - Written consent form
    - Plain language explanation of our project, including the purpose of the listening sessions and consent process, presented in slides with visuals and key points

UDL
Presenting information in plain language and through multiple formats and methods.

- Semi-structured questions to guide the listening session
    - Key questions were developed by the project team prior to the sessions
- Facilitation plan with role assignments, clarifying questions, and practice sessions
    - Each session was facilitated by a lead researcher and an advocate team member who had existing connections with the listening session's organizing partner or participants

UDL
Hosting listening sessions with advocates who have lived experience of disability to first develop trusting relationship, safe space for sharing, and make the sharing space accessible.

- Recruitment materials and strategies

UDL
Co-creating recruitment materials and strategies with advocates who have lived experiences. Connections with their peers was necessary to recruit participants.

Survey Development

AIDD2Health Team:

1. Hosted six listening sessions with self-advocates (*n*=15), family-advocates (*n*=12), and IDD professionals (*n*=8)
2. Based on the listening sessions,
    - Identified five broad **health categories:**
        - Physical Health
        - Emotional and Mental Health
        - Care Coordination
        - Community Living
        - Caregiver Concerns
    - Created accessible and comprehensive health priority area survey using **plain language**

UDL
Health Categories: These were identified through hosting and reviewing listening sessions with three groups of participant groups (self-advocates, family-advocates and IDD professionals) who shared a common goal of supporting the wellbeing of individuals with IDD. Each group shared different perspectives.

UDL
Plain Language: Wording questions to capture listening session participants' intentions was challenging. Input from advocate team members with lived experience of disability was essential to achieve the right expression.

    - Pilot tested the survey questions and format with listening session participants

UDL

We received valuable feedback from listening session participants regarding the categorization and wording of questions (including commonly used research terms) that could be offensive or misleading based on participants' lived experiences.

Implementation

The AIDD2Health Team:

- Made survey promotion materials

  UDL

  Our project video, created collaboratively by the entire AIDD2Health team, described our project's mission, values, and objectives, along with our advocate members' motivations for joining. This proved highly effective for both community engagement and survey participant recruitment.

- Made accessible survey with screen reader and video instruction on REDCap platform

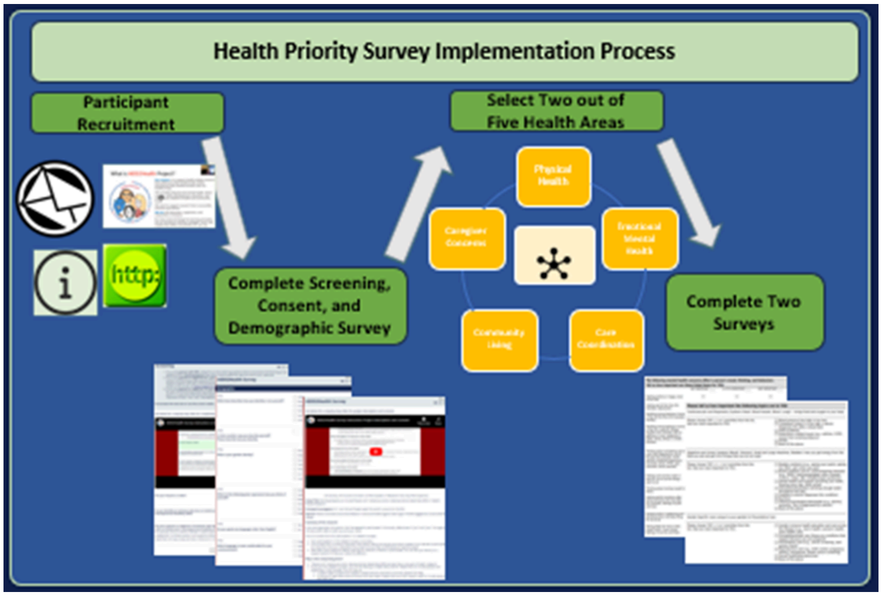
  UDL

  The process was quick and enjoyable for our team members.

- Developed survey implementation structure where participants chose two out of five priority areas for responding

  We wanted to be as comprehensive as possible without burdening the participants.

- Distributed and collected the survey responses (n=104)
- Summarized survey results to identify key health areas that are important to the IDD community



Health Priority Survey Implementation Process

Participant Recruitment

Select Two out of Five Health Areas

Physical Health

Caregiver Concerns

Emotional Mental Health

Community Living

Care Coordination

Complete Screening, Consent, and Demographic Survey

Complete Two Surveys

Figure 6. Health Priority Survey Implementation Process

Health Priority Areas Needing Further Investigation

Our Project Core Team members identified several key areas needing further investigation:

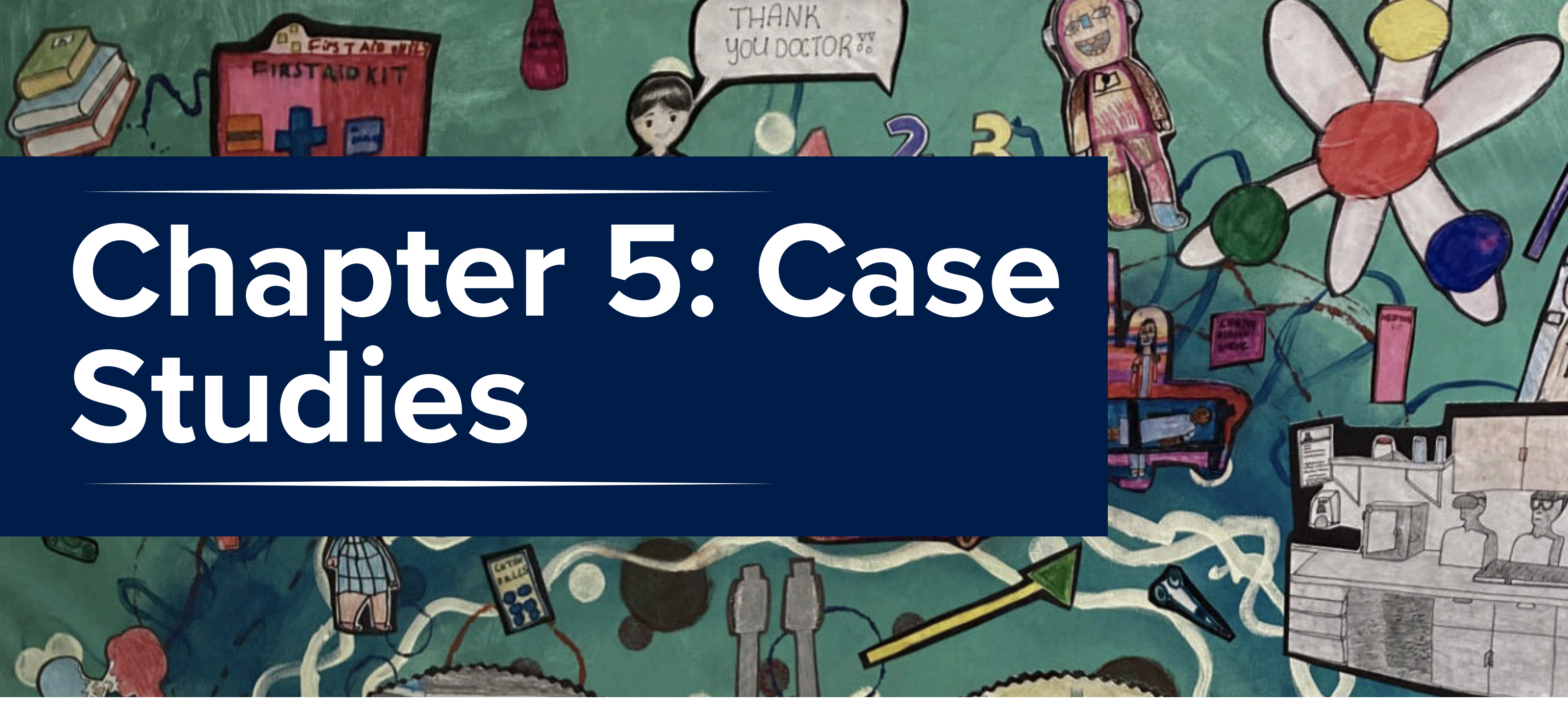
1. Friends and social connections for: Identity, self-awareness, preferences, decision-making skills, and relationship development, as well as peer support. Include opportunities for sharing with others who have similar life journeys, exchanging information and resources, listening to life experiences, and encouraging self-expression
2. Vocation: Identity development and financial stability
3. Respect for individuality: Honoring each person's unique goals, dreams, and lifestyle choices
4. Importance of routines: Establishing and maintaining regular daily schedules and activities
5. Celebrations: Acknowledging and celebrating daily achievements whether small or big
6. Challenges: Working with healthcare providers and addressing complicated health conditions together
7. Health issues: Related to adult transitions and aging
8. Planning for the future: Person and family centered goals/wishes
9. Family caregiver health: Addressing physical, mental, emotional health

Visit the AIDD2Health webpage to access the complete health priority survey, which contains detailed topics discussed during our listening sessions with self-advocates and family advocates.

Next Steps

Based on the health survey results and listening sessions, the AIDD2Health team identified two research projects that had not previously worked closely with people with IDD. One was a local project focused on community living and the other was a national project focused on collecting biological and behavioral data. Both research teams expressed interest in collaborating with our team to make their projects more accessible and inclusive for people with IDD.

For detailed examples of these collaborations, please see our case studies in the next chapter.

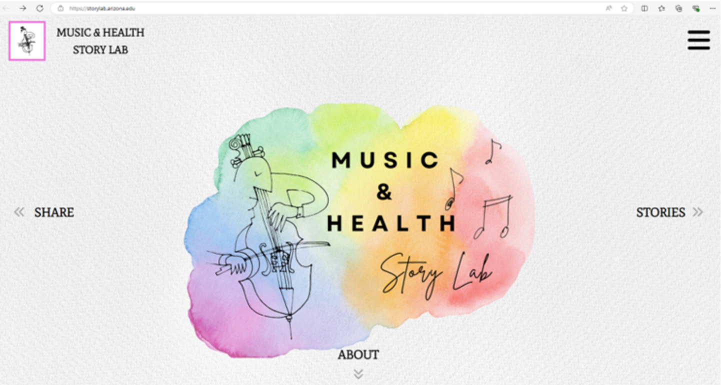


Chapter 5: Case Studies

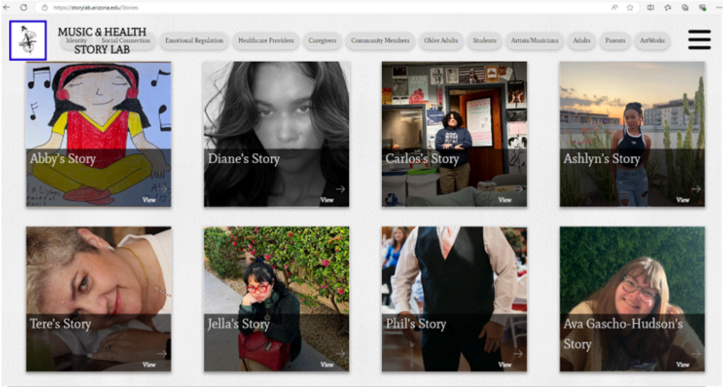
Digital Music Story

What is Music and Health Story Lab?

The Music & Health Story Lab is an ongoing public-facing, community-engaged, research initiative created by Dr. Gubner at the University of Arizona. It features stories about relationships between music, health and wellness made by undergraduate and graduate students in Gubner's courses.



Drawing on multi-modal and ethnographic storytelling techniques, the online platform wants to diversify conversations about how music and the arts can help people live healthier lives and create healthier, more inclusive, and age-friendly communities.



The Music & Health Story Lab (arizona.edu): https://storylab.arizona.edu

What is ArtWorks?

ArtWorks is housed in the Sonoran Center for Excellence in Disabilities, within the University of Arizona, Department of Family & Community Medicine. It promotes community and mutual learning through creative and expressive arts interactions between adults with intellectual and developmental disabilities and University of Arizona students. ArtWorks fosters a safe space for expression, connection, and growth.

Programs

MARY T PAULIN GALLERY

SISTER JEANNE ART STUDIO

UA STUDENT FIELD LAB

A★R★T WORKS Hearts to Hands

AIDD2Health Team Works to Make Projects Accessible

The AIDD2Health Team provided ongoing consultation and technical support before, during, and after the project.

Project preparation and implementation included:
- Adapting consent strategies and documents
- Planning and engagement strategy adaptation
- Facilitating students and artists work together
- Making stories

Process and outcome evaluation included:
- Documenting meetings, activities, and reflections from all participating groups throughout the project
- Reviewing and evaluating documented materials and checking them with UDL guidelines
- Sharing summarized processes and outcomes with the ArtWorks and the Music & Health Story Lab teams for additional notes and reflections

Key Processes for Successful Collaboration

Process Evaluation Results:

1. **Preparation**:
    a. Get to know each organization, space, and culture
    b. Share information about how students can work effectively with artists with IDD to prepare initial **questions** and activities
    c. Make project material accessible through plain language and other **means of representation** (such as bringing a memorable objects, drawings, pictures, videos)
    d. Understand the essence of the **inclusive arts practice** framework.
2. **Build relationship** through get-to-know-you activities where all team members share personal connections to music
3. **Find common threads** by expanding connections through music and story sharing
4. Co-create and share **digital story products:**
    a. Support and validate nuanced expressions (“I am comfortable” “giggling and rocking” “physical expression, noticing a presence”)
    b. Capture authentic individual stories
    c. Post videos as Artworks group, as well as integrated on the digital platform (i.e., individual videos are tagged as Artworks)
5. Celebrate with participants, including video screening

UDL

Preparation: UDL engagement improves significantly with thorough preparation and input from all project stakeholders. This comprehensive planning can accelerate implementation, reduce participant dropout, minimize stress, and enhance data quality by ensuring everyone understands the project's purpose, process, and their specific roles.

UDL

Questions: Helpful for participant engagement through model learning. Staff members demonstrate how to ask and clarify questions. Examples include repeating questions, allowing pauses, understanding the meaning of pauses, and interpreting various expressions and responses.

UDL

Means of Representation: Multiple methods of presenting and sharing information through diverse formats that fit each person's learning style and interests.

Inclusive Arts Practice: A framework that provides key processes and examples to promote mutually beneficial creative arts collaboration between people with and without disabilities.[20]

UDL

Relationship Building: UDL Engagement can be enhanced through **relationship building** and finding **common threads.**

UDL

Digital Story Products: Be open-minded about different expressions and processes for co-producing the final product. The green art studio found that music and dance were common threads among the group, so they created a story together rather than separate individual stories. The red studio was intrigued by the connection between music and emotion, so they built individual stories based on that theme. The pink studio brought objects that reminded them of music to build their conversations and stories.

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[20] *Fox, A. & Macpherson, H. (2015). Inclusive Arts Practice and Research: A Critical Manifesto. London: Routledge Taylor & Francis Group*

Researchers' Reflections:
To optimize collaboration, it is best to work on projects with researchers who value community engagement, co-production of knowledge, and the voices of self-advocates and partners.

"I have learned a lot and my research has changed in terms of more aggressively leaning into thinking about participants as co-researchers. This was an important frame shift that you helped me articulate in this new iteration that I will now keep moving forward no matter who we work with" (Dr. Gubner, personal communication, September 2024).

This approach not only enhances access for people with IDD but also improves general community-engaged programs.

All of Us Research Program

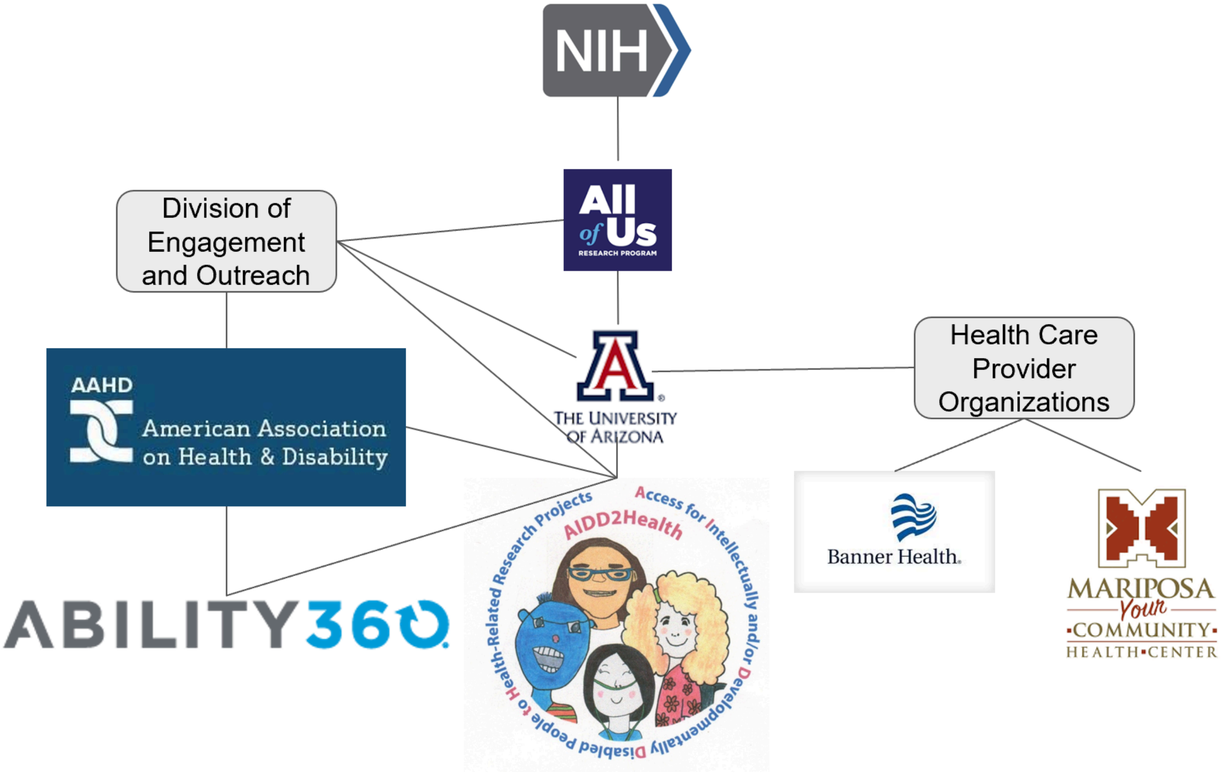


Diagram adpated from National Institutes of Healh, All of Us Research Program. Division of Engagement and Outreach Annual Report, 2022. https://allofus.nih.gov/sites/default/files/AoU_DEO_2022_Annual_Report.pdf

What is the *All of Us* Research Program?

The *All of Us* is a research program overseen by the National Institutes of Health (NIH), which is the biggest medical research agency in the United States. The NIH gives billions of dollars each year to health researchers for their projects.

The All of Us program started when President Barack Obama asked the NIH to start a Precision Medicine Initiative. “Precision Medicine” means that researchers and doctors look at different factors of health, including biology (e.g. genetics), environment, and behavior to create personalized prevention and treatments for patients.

Researchers believe that knowing a person’s biology, environment, and lifestyle can help them understand what makes that person healthy or not. People can join the *All of US* research program and share their personal health information. Their information will be kept in a dataset that is available to help researchers learn more about health of diverse communities.

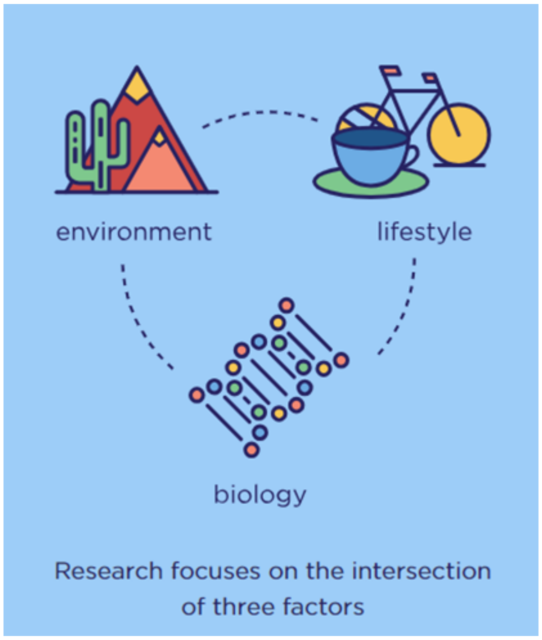


Image from: https://allofus.nih.gov

AIDD2Health Team's Collaboration with All of US

Why did AIDD2Health Want to Collaborate with *All of Us* *(AoU)*?

- *AoU* has sites around the United States, and The University of Arizona is one site.
- *AoU* worked with the American Association on Health and Disability to recruit people with disabilities. Locally, in Arizona, Ability 360, a Center for Independent Living, worked with *AoU* to promote the program to people with disabilities.
- Our team heard about *AoU* and wanted to learn more.

Process and Outcomes

- Meetings were held with:
    - Local/national *All of Us* (AoU) research administrators, researchers, outreach team
    - National/regional disability organizations (AAHD & Ability 360)
- The agenda for each meeting was developed beforehand and included a list of questions.
- During the meeting the AIDD2Health team:
    - Shared information about their project goals.
    - Asked questions about *AoU* partners' work with disability communities and about the process for study enrollment for people with disabilities.
    - Discussed ways to collaborate with *AoU* that included
        - Recommendations on how to increase accessibility for people with disabilities
        - Emails with follow-up notes from each meeting
- After the meeting:
    - AIDD2Health team members debriefed, reflected, and considered next steps.

UDL
Meetings are communicated in plain language for increased understanding and the next steps are clarified among the AIDD2Health and AoU teams.

Key Recommendations from AIDD2Health Team

- Develop shared goals and trust through conversations with disability communities about *AoU*.
    - Identify which health issues are important to people with IDD.
    - Involve people with disabilities in guiding the research.
- Develop processes and practices to include people with IDD.
    - Understand supported decision-making and that adults with IDD may or may not have a guardian.
    - Develop accessible enrollment procedures that include providing support so individual can participate and a budget for accommodations (e.g. ASL interpreters).
    - Ensure that people with IDD are given the choice to participate. Don't assume they cannot or will not.
    - Establish a process for gaining assent/consent for people who are non-verbal.
    - Ensure all staff are trained in disability etiquette and are aware of resources to support participants with IDD.

- Ensure knowledge developed from *AoU* is beneficial for/to the disability communities in the U.S.
    - Make it possible to identify IDD in the data.

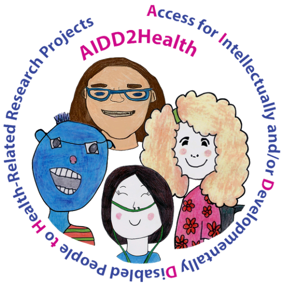
UDL
The action plan is created based on the team's understanding and access to the content and purpose of the *AoU* project.

Reflections on our *All of Us* Engagement

In order to understand *AoU*, we interacted with all levels of partners, from field workers on up to senior leaders.

- Ongoing interaction with AoU team is necessary.
- People with a personal connection to disability may be strong advocates.
- For researchers without a connection to disability, it is helpful to have a growth-mindset and willingness to learn.
- It is helpful to have team members who interact with *AoU* as participants.

UDL
This reflection reminds our audience of why this is important in text that is accessible and written in plain language. Furthermore, next steps are suggested in the recommendations based on advocates' input.



> ***"Nothing about Us Without Us!!"***
>
> **.. means NO research without us!**

Chapter 6: Researcher Tools

Adapted Informed Consent Form with Clear Communication and Plain Language

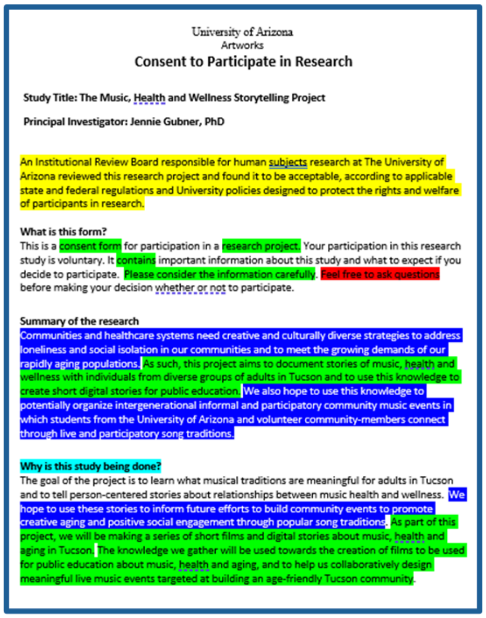
Strategies and tips for clear communication and plain language are listed in Chapter 2. Here, we highlight a few quick tips for adapting informed consent forms, with an example.

Selected Tips with Color Codes:
Yellow – Shorten sentence and paragraph length to focus on one subject per sentence and one topic per paragraph
Green – Use common words or define necessary jargon - Not everyone knows every word, so using common words avoids confusion
Red – Communicate expectations clearly - Not everyone picks up on indirect statements
Blue – Exclude or move less-important information - Too much information can confuse the wrong audience and distract them from the important information
Turquoise – Avoid passive voice and use active voice - Passive voice can be vague and confusing
Dark Red – Use **talk-back (teach-back)** and comprehension checks - Ask open-ended questions and have participants repeat and rephrase information to check for understanding. Provide instructions for the research team on how to explain information differently if someone is not able to answer the teach-back questions.

Talk-back (teach-back) question examples:

1. What will you do if you are part of this study?
2. What are the risks of this study?
3. What do you get for participating in this study?
4. What does it mean that the study is "voluntary?"
5. What can you do if you want to stop or don't want to participate anymore?

You can use these questions after each relevant section or all at once before asking consent. Your decision will depend on the study's complexity and participants' level of understanding. These questions can help the research team to develop possible participant answers that can help to assess participant comprehension.



University of Arizona
Artworks
Consent to Participate in Research

Study Title: The Music, Health and Wellness Storytelling Project

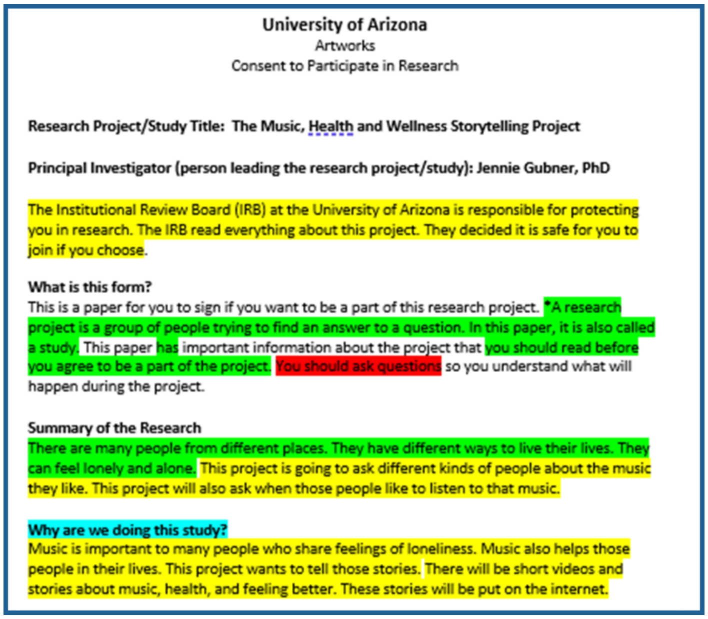
Principal Investigator: Jennie Gubner, PhD

An Institutional Review Board responsible for human subjects research at The University of Arizona reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

What is this form?
This is a consent form for participation in a research project. Your participation in this research study is voluntary. It contains important information about this study and what to expect if you decide to participate. Please consider the information carefully. Feel free to ask questions before making your decision whether or not to participate.

Summary of the research
Communities and healthcare systems need creative and culturally diverse strategies to address loneliness and social isolation in our communities and to meet the growing demands of our rapidly aging populations. As such, this project aims to document stories of music, health and wellness with individuals from diverse groups of adults in Tucson and to use this knowledge to create short digital stories for public education. We also hope to use this knowledge to potentially organize intergenerational informal and participatory community music events in which students from the University of Arizona and volunteer community-members connect through live and participatory song traditions.

Why is this study being done?
The goal of the project is to learn what musical traditions are meaningful for adults in Tucson and to tell person-centered stories about relationships between music health and wellness. We hope to use these stories to inform future efforts to build community events to promote creative aging and positive social engagement through popular song traditions. As part of this project, we will be making a series of short films and digital stories about music, health and aging in Tucson. The knowledge we gather will be used towards the creation of films to be used for public education about music, health and aging, and to help us collaboratively design meaningful live music events targeted at building an age-friendly Tucson community.



University of Arizona
Artworks
Consent to Participate in Research

Research Project/Study Title: The Music, Health and Wellness Storytelling Project

Principal Investigator (person leading the research project/study): Jennie Gubner, PhD

The Institutional Review Board (IRB) at the University of Arizona is responsible for protecting you in research. The IRB read everything about this project. They decided it is safe for you to join if you choose.

What is this form?
This is a paper for you to sign if you want to be a part of this research project. *A research project is a group of people trying to find an answer to a question. In this paper, it is also called a study. This paper has important information about the project that you should read before you agree to be a part of the project. You should ask questions so you understand what will happen during the project.

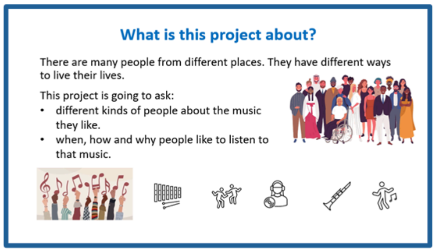
Summary of the Research
There are many people from different places. They have different ways to live their lives. They can feel lonely and alone. This project is going to ask different kinds of people about the music they like. This project will also ask when those people like to listen to that music.

Why are we doing this study?
Music is important to many people who share feelings of loneliness. Music also helps those people in their lives. This project wants to tell those stories. There will be short videos and stories about music, health, and feeling better. These stories will be put on the internet.

You can access:
1) the color coded, side-by-side, example documents
2) the power point presentation
at the AIDD2Health Homepage.

Key Points of the Informed Consent Document with Illustrations

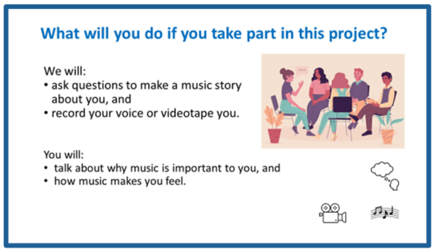
During the consent process, it is also helpful to present key points of the informed consent document with illustrations in PowerPoint.



What is this project about?

There are many people from different places. They have different ways to live their lives.

This project is going to ask:
- different kinds of people about the music they like.
- when, how and why people like to listen to that music.



What will you do if you take part in this project?

We will:
- ask questions to make a music story about you, and
- record your voice or videotape you.

You will:
- talk about why music is important to you, and
- how music makes you feel.

What can you do if you want to start this project, but do not want to finish?

You are a volunteer, so you can quit when you want!

Validated Health Outcome Measures Used with Adults with and without IDD

To include people with IDD in your research programs, we gathered participant self-reported health outcome measures, validated for people with IDD. These measures can serve as more inclusive measurement tools for everyone in your research project or as parallel measurement tools specifically for participants with IDD. Additionally, these measures may inspire you to adapt your program to be more accessible for participants, with effective data gathering strategies that capture what you're trying to study.

A link to a Google spreadsheet containing these measures is available on our project webpage in the "Resources" section. The form will be updated as we identify additional tools.

Why are validated health outcome measures important?

Health Researcher:
Validated standardized health outcome measures that work for all participants, including people with IDD, are important because these:

1. Allow researchers to compare results across different samples and populations.
2. Ensure appropriateness, equity, and usability of research results.
3. Enhance health outcomes across diverse populations.

Plain Language:

1. Health researchers often use tested tools to measure health outcomes in their studies. These tools are called **validated tools.** They help researchers:
    - Get accurate information.
    - Get data about health issues that impact people with and without disabilities (like depression or quality of life).
    - Compare results of different studies.
    - Learn more as a research community.
    - Understand health issues better.
2. It is important to have validated tools that work for all participants, including people with IDD. This makes studies fair and unbiased. With these measures, inclusive study data and results can be used to help different groups of people become healthier.

What steps did we take to gather these measures?

Health Researcher:
To identify health outcome measures validated with people with IDD, we conducted a systematic narrative review with a medical librarian:

1. Used a double-pronged search strategy of using a range of terms for the following concepts: IDD + Measures + Validated + Patient Reported Outcomes + Health
2. Identified 2,871 studies (duplicates removed) via databases (i.e., PubMed, EBSCOhost, CINAHL Plus with Full-Text, PsycINFO, and Scopus)
3. Reviewed abstracts and full articles based on inclusion criteria:
   - Validated health measures by people with IDD
   - Published in the last 10 years, in English, and about adults

Plain Language:
A narrative review is a review of current research on a topic. Working with a librarian, our narrative review:

- Found 2,871 studies by searching research databases, using key words
- Reviewed summaries and full articles that met these rules:
  - Health measures that were used and tested with people with IDD
  - Written in the last 10 years, in English, and about adults

What types of health outcome measures are included?

Health Researcher:

- Our health outcome measure list includes:
  - Common health measures used in general research that have been adapted and validated for people with IDD.
  - Health measures created specifically for the IDD community that may be useful for general health researchers.
- We categorized the measures into five health areas identified by self and family advocates through our project listening sessions.

Plain Language:
Our health tests/surveys list includes:

- Common health tests and surveys adapted to be easier for people with IDD.
- Health tests and surveys originally developed for people with IDD that may help with other health studies.

We categorized these tests into five health areas. These areas were chosen based on what people with IDD and their families told us was important.

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A Guide to Using Universal Design for Learning (UDL) to Enhance Inclusive Health Research

AIDD2Health:
Access for Intellectually and/or Developmentally Disabled People to Health-Related Research Projects

Research often excludes people with disabilities. Yet, people with disabilities may experience poor health outcomes, often the result of unequal practices, programs, and policies that discriminate.

Health equity and justice means everyone should have opportunities to be as healthy as they can be, no matter who they are or what their circumstances. To achieve this, we need to:

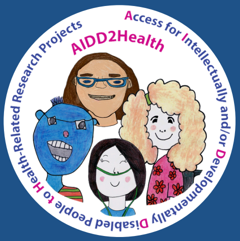
- Challenge our ideas about health and who is at the center in health research
- Bring new perspectives about health into healthcare research
- Make research and care more inclusive to serve a more diverse population, including people with disabilities

The research process should be clear and accessible to engage people from diverse communities so researchers can better understand their health needs and ultimately improve health outcomes for all people.

This guidebook is designed for researchers seeking knowledge, skills, and resources for inclusive research practices. While it specifically focuses on working with people with intellectual and/or developmental disabilities (IDD), the information is applicable to all people through the use of Universal Design for Learning (UDL) as a framework.

"Nothing about Us Without Us!!"

.. means NO research without us!



THE UNIVERSITY OF ARIZONA
COLLEGE OF MEDICINE TUCSON
Sonoran Center for
Excellence in Disabilities