

# INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndrome (INCLUDE)

## Building a Diverse Community for Down Syndrome Research

### Listening Session #1—Families

May 17, 2022

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#### Welcome and Overview

- *Sujata Bardhan, Ph.D., Program Director at NIH/NICHD Intellectual and Developmental Disabilities Branch (IDDB)/INCLUDE Leadership Team*
- *Linda Garcia, B.A., Communications and Outreach Coordinator for INCLUDE/INCLUDE Leadership Team*

Dr. Bardhan welcomed attendees and said that the purpose of the workshop was to continue to build a diverse community for Down syndrome research. Ms. Garcia reviewed the agenda and said that the objectives of the meeting were to provide an overview of the INCLUDE project, encourage inclusion and engagement by listening to community stakeholders, and understand the needs of the community in order to engage them in Down syndrome research that benefits them.

#### Overview of INCLUDE and DS-Connect®: The Down Syndrome Registry

*Dr. Bardhan*

Dr. Bardhan presented slides to provide an overview of the INCLUDE project and NIH efforts to fund and conduct clinical research for all health conditions. Two of the goals of the INCLUDE project are to increase both diversity in Down syndrome research and the number of researchers who are studying Down syndrome. In fiscal year 2021, NIH awarded \$65 million for Down syndrome research through the INCLUDE Project. The DS-Connect® registry is a secure, confidential, online survey tool to collect basic health information about people with Down syndrome. It was launched in 2013 and currently has almost 5,500 registrants, but the participant demographics are not diverse when race/ethnicity, socioeconomic status, and education level are considered. Therefore, NIH seeks to support families to encourage more diverse participation in all types of Down syndrome research (e.g., surveys, DS-Connect®, INCLUDE-funded studies, clinical trials). Engaging with diverse communities to learn about positive experiences and identify barriers and challenges can help increase diversity; that is why the INCLUDE team is conducting this listening session and workshops with families on September 20-21, 2022.

#### Listening Session

An outside moderator presented questions to attendees and allowed for open discussion. The questions and responses are outlined below.

## Have you or your loved one with Down syndrome participated in Down syndrome research?

This question was presented as a live poll. The response was 50% yes and 50% no.

## Share any positive experiences you have had when taking part in research studies.

Families reported several positive experiences when participating in research studies, including that researchers shared reports with schools, empowered participants to ask research questions, and made friends with participants who had Down syndrome. Families were pleased when researchers strictly followed safety protocols, provided upfront and direct communications, sent follow-up reminders, and communicated about study findings.

- *An advocate shared that her 11-year-old daughter had participated in cognitive research with a Ph.D. researcher at a children's hospital. The advocate has been able to share the research reports with her daughter's school to positively affect her daughter's individualized education program. To empower the child, the researcher asked her what she would like to research and followed up with her about the research process.*
- *An advocate shared that her adult son participated in a sensory motor exercise program at a university about 10 years ago and had a wonderful experience. He became friends with many of the researchers and attended football games and other activities together.*
- *An advocate shared that her daughter participated in a drug clinical trial that was very impactful. Her daughter enjoyed participating because the researchers were kind to her, addressed her directly, talked with her, and made her feel comfortable. The advocate was happy that her daughter enjoyed the experience. Also, the advocate was impressed with how strictly the protocol was followed and how the researchers made safety paramount.*
- *An advocate shared that her daughter had participated in one DS-Connect® research study at a National Down Syndrome Congress (NDSC) convention. The advocate was impressed with the process, up-front explanations, and communications. She did not remember the specifics of the study but remembered encouraging other families from her community to participate because, despite blood draws and needles, the researchers made it a positive experience for her daughter.*
- *An advocate shared that her daughter has participated in many research studies, including surveys, heart scans, and video speech evaluations. All of the experiences have been positive, including reminders for follow-up and providing the final findings after they have been published.*

## What can help motivate participation in clinical research in your communities?

Families were motivated to participate in clinical research when they heard of opportunities through community education and awareness, had free time to participate, and did not have to travel to a research site. Families appreciated trusted physicians who encouraged participation in research studies and researchers who built rapport and trust by attending events for Down syndrome families. Families said that they were more likely to attend informational meetings that were held near public transportation, provided child care and food, offered a gift card for attending, and demonstrated knowledge and appreciation of attendees' diverse cultural backgrounds.

- *An advocate said that providing food at networking events has been effective for introducing research studies to families.*

- *An advocate said that although she was a leader in her local Down syndrome community for 10 years, she and her 16-year-old daughter had not participated in clinical research, because of a lack of free time. She said that educating the Latino community about why their participation and representation is important could motivate them to join research studies. She agreed that holding celebrations or parties could be a good incentive for participation, because every holiday is important in Latino culture. The advocate also recommended providing education, research materials, and consent forms in a bilingual format and using bilingual staff who understand Latino culture and can provide a personal approach. It is important for researchers to understand the diversity within Latino culture (e.g., the cultural differences between Cubans, Mexicans, and Ecuadorians).*
- *An advocate who shared that she has an adult sister with Down syndrome said that people needed to be made aware of opportunities to participate in research. Although her sister participated in drug trials for dementia, some of the research locations were too far away for traveling. Some experimental studies created too much fear of adverse effects or worsening symptoms.*
- *An advocate shared that time and location were key factors. A centralized location that completed the study quickly motivated her family to participate in one study. Taking time out of a busy day is often difficult for families.*
- *An advocate agreed with the previous comments and said that having a trusted person, such as a pediatrician or physician, encourage participation in research studies could be motivating. She also said that researchers could build rapport and trust by attending events in which families with Down syndrome are participating.*
- *An advocate shared that she provided a bridge between a researcher friend and her Down syndrome group for marginalized communities, because it is important to have someone you trust to make introductions. Holding the informational meeting in a central location that was near public transportation, providing childcare, and giving participants a gift card for attending at the event (not mailed out later) would also create interest in her community.*
- *An advocate said that she agreed about time and location (along with food and money) being important motivating factors. She added that it is helpful to acknowledge past historic problems with research while providing examples of how research findings have helped improve lifespan and quality of life for people with Down syndrome. Although she is involved as the president of a major Down syndrome organization, she still does not hear of many local research opportunities through grassroots efforts. She said that Down syndrome clinics are often not centrally located. Family and church events are important to African Americans, so those can be used for engagement and trust building. Gift cards or the provision of basic needs can help alleviate the high price of insurance deductibles and copayments. Success stories could be motivating.*

## Word cloud: Barriers to participation in Down syndrome research

Attendees inserted words into the Mentimeter website to produce the following word cloud, which graphically describes barriers to participation in Down syndrome research.

***In 1 or 2 words, what do you see as the barriers to participation in Down syndrome research?***



## What are the barriers to participation in Down syndrome research?

When asked about barriers to participation in research, families described travel distance and expenses, fears of adverse effects or worsening symptoms, mistrust of the government, exclusion of special populations in studies, generational barriers, and not knowing how the data will be used.

- *An advocate shared that although her sister participated in drug trials for dementia, some of the research locations were too far away and some experimental studies created too much fear of adverse effects or worsening symptoms.*
- *An advocate said that mistrust in the United States government is a barrier. Additional barriers include not knowing how the research will be used or how it could benefit loved ones. Clarity on what the researchers are hoping to achieve is needed. She also mentioned varied cultural and religious beliefs throughout the diverse Latino community, along with educational and political differences.*
- *An advocate said that the distance from rural towns to the cities in Arizona where research is conducted can be a barrier to participation, especially for Native American families.*
- *An advocate said that many clinical trial exclusions state that children with intellectual or developmental disabilities are not allowed to enroll. Many researchers are unwilling to take extra steps to gain investigational review board approval to include special populations, and many scientists are unaware of the importance of including children with special needs in research. Other researchers have liability concerns. In general, researcher education is needed for designing and conducting inclusive studies.*
- *An advocate who shared that she has an adult brother with Down syndrome said that there are generational barriers to participation in research (e.g., her parents are less inclined to enroll her brother) and that sibling organizations may be able to help improve recruiting and participation.*

- *An advocate who was a previous leader in a Down Syndrome organization in Puerto Rico said that he has an adult daughter with Down syndrome. He agreed with the previous comments about Latino communities and added that no clinical research has been conducted in Puerto Rico since 1995, so new studies on Down syndrome there are welcome, needed, and encouraged.*

## How can we build trust with your community?

To build community trust, families suggested developing long-term partnerships with trustworthy large and small community organizations and diverse Down syndrome groups. Becoming involved in these organizations and groups without asking for anything in return will help to build trust. Families suggested building trust through inclusive practices, mentorship, listening, and cultural competency training. Social media and newsletter stories could also be used to build trust.

- *An advocate said that existing trusted community organizations and partner organizations, large and small, can help link researchers to Latino communities and all communities. As an organization, NIH does not mean anything to many people. She added that the Down syndrome organizations that have diverse leadership have more diverse participation.*
- *An advocate said that good will and trust are developed when people become involved in a community without asking for anything in return. She added that there is not a quick or easy fix—the efforts must be long term and intentional.*
- *An advocate recalled a saying, “People will not trust until you prove that you can be trusted.” She said that NIH must learn how to gain the trust of Hispanic people with inclusive practices, an inclusive mentorship environment, listening to understand priorities and perspectives, and through cultural competency training. The trust of the community leaders must be gained before gaining the trust of the members of a community.*
- *An advocate pointed out that some churches have special needs ministries, so working through this type of trusted entity to gain research trust might help mitigate trust and access issues, such as lack of time, transportation, money, and access to technology. She also suggested using social media to build trust and encourage participation. She said that a TikTok video message shared via social media and email would work well in the African American community. Stories that show how research has benefited individuals with Down syndrome would be effective, especially if they showed racial/ethnic diversity. The key is a short, to-the-point message to the target audience, not a long newsletter.*
- *An advocate said that GiGi’s Playhouse Down syndrome achievement centers use Facebook, Instagram, LinkedIn, and email to connect with families.*
- *An advocate suggested disseminating research opportunities through The Arc to reach both state and local groups. This could be a helpful way to get information to families. The Arc distributes newsletters via emails and on Facebook, as well as mailing print copies to families.*
- *An advocate said that many local Down syndrome groups look to NDSC, DSAIA (Down Syndrome Affiliates in Action), and the Global Down Syndrome Foundation for the most up-to-date information, research, and advocacy, so communicating through these organizations could be helpful.*
- *Another advocate suggested using these organizations to disseminate information about research studies, especially the NDSC. An advocate said that her family recently participated in a clinical trial that they learned about through NDSC. She added that meeting the research presenters at the NDSC congress can be powerful and builds trust.*

- *An advocate agreed and said that a consistent message could be disseminated through those national organizations, as well as the Down Syndrome Diagnosis Network (DSDN). The message should answer the question, “What’s in it for me?”*
- *An advocate suggested inviting researchers to events and having families who have participated in research in the past speak about their support for research and their successes with it. She suggested the National Down Syndrome Society (NDSS) as another organization that could be helpful.*
- *An advocate suggested listening to what families want and providing education on what research is and is not (e.g., it is not a meme on the Internet). Research comes in many forms, including surveys, quantitative, and qualitative. Following up on the outcomes of research—what was done, how they did it, what they learned or did not learn—is important. Results must be explained in plain language that families can understand.*

## How can NIH support your efforts for outreach and advocacy with diverse participants?

Families said that NIH should conduct relevant research, help families understand how the research will help their loved ones with Down syndrome, engage with families during the progress of a study, and return final results to participants. The families also suggested that NIH work through diverse Down syndrome advocacy groups and provide useful social media resources, educational content (e.g., videos, expert speakers), and other resources to these advocacy groups. Suggested communication methods included holding informational meetings at nontraditional days and times, speaking Spanish without interpreters, and printing marketing materials in plain language that a person with Down syndrome can understand.

- *An advocate asked NIH to ensure that research is relevant and that families understand how the research will help their loved ones with Down syndrome.*
- *An advocate suggested reaching out to the Sibling Leadership Network (SLN), a nationwide group for siblings of individuals with disabilities. Many states have their own SLN affiliate groups. The SibNet Facebook group is an online group for adult siblings.*
- *An advocate suggested providing short, succinct content that could be easily shared on Facebook.*
- *An advocate said that clearly describing the intent or the objective of the research is important, followed by providing updates on the research through every possible distribution channel.*
- *An advocate suggested reaching out to Grupo Latino, which meets monthly. NIH could have someone speak directly with groups like this in Spanish about research opportunities.*
- *Dr. Melissa Parisi suggested that NIH inform families of research progress in a way that keeps them engaged, even if publications and conclusions from a study are not yet available.*
- *An advocate agreed and suggested that NIH use shareable resources.*
- *An advocate suggested that NIH researchers consider the people with whom they are engaging. Even this listening session presumes the privilege of being able to join a Zoom call for 90 minutes in the middle of the day. Days and times that would work for different groups should be considered.*
- *Two advocates suggested communicating information in Spanish without using interpreters, because a lot of information is missed through interpretation. One of these added that all marketing materials must be in plain language to ensure that the person with Down syndrome understands the research and can make their own decisions about how they are helping the larger community.*

- *An advocate suggested providing the larger Down syndrome organizations with ready-to-share videos or social media posts to make it easy to reach their members.*
- *An advocate suggested using materials that gain attention (“an appetizer”), such as a modern social media post that links out to more information (“the dinner”). Others agreed with using social media platforms that are popular with younger people, including TikTok, Snapchat, Instagram, and Twitter.*

## Wrap-Up and Closing Thoughts

*Nathaniel Stinson, Jr., Ph.D., M.D., Director of the Division of Community Health and Population Science at NIH/NIMHD*

Dr. Stinson thanked the attendees for their important contributions. He said that NIH plans to continue supporting the Down syndrome community and shared closing thoughts on the value of the listening session comments for improving the health of all individuals.

## Attendance

**15 Advocates**

**9 NIH**

**4 Unknown**