INCLUSIVE RESEARCH: "NOTHING WITHOUT US!"

Community Engagement Initiative Report



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ABOUT INCLUSIVE RESEARCH

DOES

Embrace and model the "Nothing Without Us!" demand for equitable inclusion

Ensure a participatory and emancipatory approach

further the interests of PWD, remain collaborative, and produce accessible outputs

DOES NOT

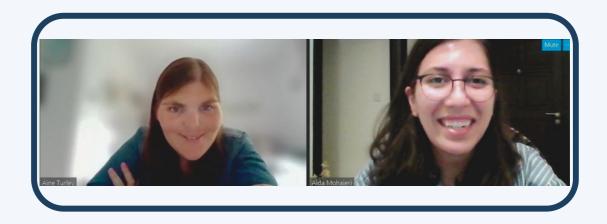
Exclude lived experiences and first-hand demands of largest global minority

Speak for PWD

Harm the community

Remove agency

Perpetuate Ableism



IMPLEMENTATION

May

SCSC Fellow Mohajeri and Athlete Leader and individual with intellectual disabilities Turley connected via Zoom

Research practices adapted to empower participation

Shared lived experiences and conducted research

Sep

Literature Review:

Turley read and summarized Easy Read documents*.

Where Easy Read documents were unavailable,

Mohajeri chose key sections.



*Easy Read documents state information in clear, easy to read and understand language and display relevant images alongside words.

IMPLEMENTATION



Quanitative Research

- Turley took part in survey research, design, and dissemination
- Mohajeri created a template, and Turley reached out to participants
- Turley co-created an Easy Read output with Mohajeri
- Turley drew from her experiences to create relevant recommendations

IMPACT OF INCLUSIVE RESEARCH

- Centered "Nothing Without Us!" demand
- Exemplified how research, policies, and programming can implement inclusive practices:
 - Include PWD in each phase of the process
 - Ask questions and build a connection
 - Adapt practices to empower participation
 - Offer support
- Modeled that inclusion results in accurate, relevant, and accessible questions, results, and discussions for both communities with and without disabilities.
- Provided further evidence prioritize opportunities for social connectedness for families of PWD in the new phase of COVID-19. Additionally, the results and recommendations can prepare relevant entities for future public health emergencies, when PWD and their families face ancillary challenges.

Without inclusion, people tell us what's important without asking us. They presume things about us. They don't give us a chance to speak, so we don't feel heard and may be scared to talk. With inclusion, we can tell the community what we need, we can be involved, we can work on projects, and we can earn money.

We want people to talk to us. Anyone can be inclusive. For example, I go to my dentist because she talks to ME first, and she trusts me to know about myself. With this inclusive research project, I learned a lot of skills. I gained confidence about working on a team and researching.

-Margaret Turley