

Informing Inclusive Alzheimer’s Research in Down Syndrome: Input from Community-Serving Organizations

#12911

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Organizations highlighted the importance of results-sharing with actionable steps, focus on improving life quality, person-centered designs, translatable results, & more investment in families & organizations.

INTRODUCTION	METHODS	RESULTS (THEMES)	CONCLUSIONS	REFERENCES
Lifetime prevalence of Alzheimer’s dementia among people with Down syndrome (DS) is 90%. Half of adults with DS develop dementia symptoms by their late 50s. Black & Latino Americans with DS <u>are understudied</u>; an <u>external validity issue</u>. Aim: To identify barriers and facilitators to the research participation of understudied populations with DS, as reported by community-serving organizations.	Design: Cross-sectional online survey (n=17). Sample: Non-probabilistic sample of organizations from the US & Puerto Rico. Eligibility: ≥18 years old; working for organizations serving people with Down syndrome from understudied backgrounds. Main assessments: Open-ended questions including research needs, barriers, facilitators, and organizational goals. Analyses: Descriptive statistics and qualitative description.	1. Information, knowledge, resources & programming (e.g., building/ funding/ connecting to resources) 2. Inclusion, representation & collaboration (e.g., person-centered design) 3. Barriers (e.g., over-protective attitudes, non-meaningful studies, changes in government priorities) 4. Dissemination, interpretation & application (e.g., actionable results sharing) 5. Investment (e.g., strengthening cross-organizational referrals & service promotion)	Organizations report <u>high interest in research</u> for their populations. <u>The themes elicited can be leveraged to increase inclusion of understudied groups.</u> Limitations: Small sample & limited generalizability. Future research should address limitations & test strategies that leverage these themes.	References: 1. Kyprianou, Nichole, et al. "Caregivers' perception of adults with Down syndrome willingness to participate in research." <i>Journal of Intellectual Disability Research</i> 67.4 (2023): 352-361. 2. NDSS. "The DS-AD Connection: Clinical Trial Awareness and Participation." (2026). Financial Disclosure: NIH: U19AG068054; P30 AG072973
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