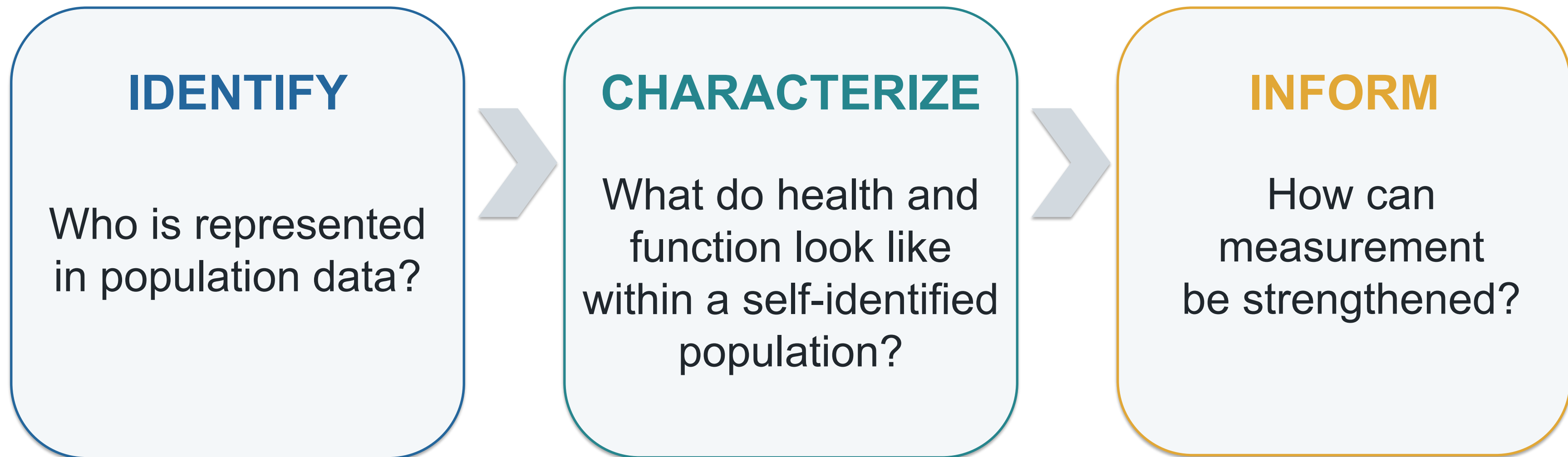


Special Olympics' Contributions to IDD Survey Data and Measurement

Alicia Dixon-Ibarra, PhD, MPH
Director, Fitness and Health Research
Special Olympics International

Strengthening IDD Health Data Through Special Olympics



Complementary efforts that reinforce one another

IDENTIFY

Strengthen identification of people with IDD in population-based data

Rosemary Collaborative

Advocate

- Promote inclusion of IDD indicators in U.S. and global population-based surveys

Analyze

- Examine identification approaches and health disparities
- Use National Health Interview Survey (NHIS) and National Core Indicators data

CHARACTERIZE

Study health, functioning, and measurement within a self-identified IDD population

Healthy Athletes + Public Health Surveillance

- Embed population-based surveillance questions within Healthy Athletes
- Pair survey indicators with Healthy Athletes screening data
- Compare health outcomes with general-population surveillance benchmarks



Washington Short Set Analyses

- Examine functional limitations among Special Olympics athletes
- Understand how athletes and proxies respond to WG-SS measures
- Compare response patterns with NHIS



Dixon-Ibarra et al. (2026)
Scan for the full article.

INFORM

Generate evidence to strengthen future IDD measurement

PCOR Point of Care Project

- Contribute evidence and lived-experience perspectives
- Supported recruitment into multiple phases of the project



Testing Learning and Support Questions

- Examine supplemental questions designed to better represent ID/DD-specific disability domains
- Assess how questions are interpreted and how well response options reflect athletes' experiences

What can Special Olympics contribute?

1 A known, self-identified
IDD population

2 A bridge to
population data

3 A testing ground for
better measurement

THANK YOU.

Special Olympics Health activities are supported by many sources, including in the United States, by Grant Number NU27DD000021 from the Centers for Disease Control and Prevention of the U.S. Department of Health and Human Services (HHS), with \$18.1 M (64%) financed with U.S. federal funds and \$10.2 M (36%) supported by non-federal sources. The contents of this resource is solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.

Supplemental Material: Rosemary Collaboratory American Public Health Association Conference Presentation 2025



Leveraging data to make health systems more inclusive of people with IDD: A Special Olympics analysis of health and healthcare disparities

American Public Health Association Conference 2025

Jae Kennedy, WSU Professor of Health Policy

Lindsay DuBois, HSRI Research Associate

Alicia Dixon-Ibarra, Special Olympics International, Director, Research & Evaluation

Leah Shaffner, Special Olympics International, Senior Manager, Inclusive Health

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Special Olympics
Health

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Special Olympics Health



Rosemary Collaboratory

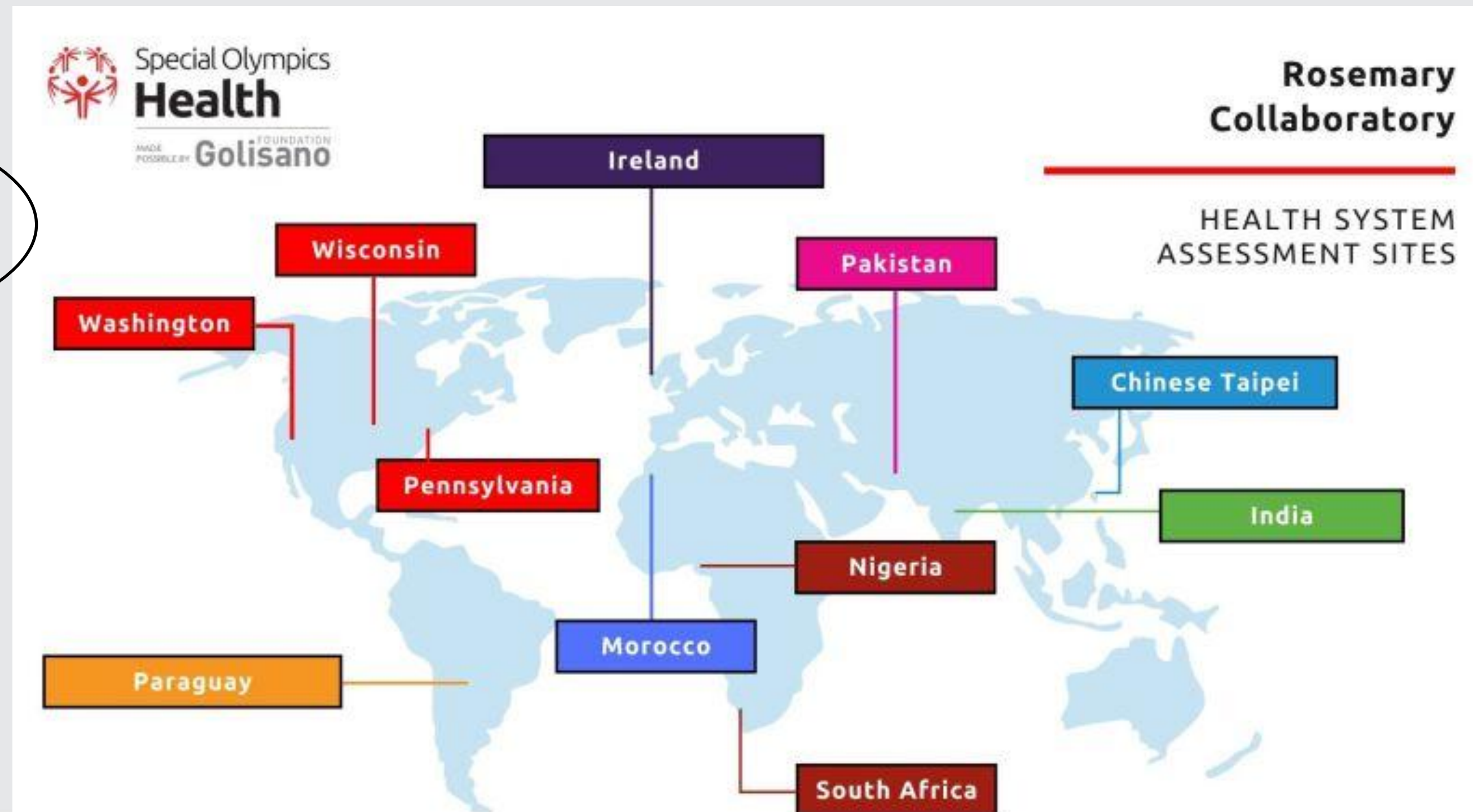


Vision: Create policy, systems, and environmental changes that improve the health of people with intellectual and developmental disabilities.

Rosemary Collaboratory - Approach



1. Partner with Missing Billion Initiative to add an IDD-specific module to their System Level Assessment
2. Engage global sites to evaluate IDD inclusion in health systems. Gather data for action.
3. Guide local action plans for policy and systems change
4. Publish a global report highlighting trends, best practices, and recommendations



National Estimates of IDD Disparities using the NHIS

Jae Kennedy, WSU Professor of Health Policy



Special Olympics
Health

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The National Health Interview Survey (**NHIS**)



- Annual national survey by **the Centers for Disease Control and Prevention (CDC)**.
- Used data from **83,949 adults** (2021–2023 NHIS)
- Compared: population attributes, employment, program participation, insurance, mental/physical health, and healthcare access

The National Health Interview Survey (NHIS)



Definition: Adults with IDD

- Reported being **severely limited** (a lot of difficulty or unable to perform) in **one or more** of the following tasks:
 - Remembering or concentrating
 - Washing all over or dressing
 - Understanding others or being understood
- Reported that the limitation **began before age 22**

National comparisons – income, employment, health insurance and food security



Has IDD

- **19.9%** of adults have family incomes below the federal policy level
- **67.9%** have work limitations
- **38.3%** worked for pay in past week
- **29.5%** have private insurance through an employer or ACA exchange
- **62.3%** have public insurance (Medicaid and/or Medicare)
- **9.8%** have low food security, and **16.4%** have very low food security

No functional limitations

- **7.4%** of adults have family incomes below the federal policy level
- **7.1%** have work limitations
- **69.1%** worked for pay in past week
- **29.5%** have private insurance through an employer or ACA exchange
- **26.5%** have public insurance (Medicaid and/or Medicare)
- **2.9%** have low food security, and **1.5%** have very low food security

National comparisons – health, pain, weight, difficulty doing errands or participating in social activities



Has IDD

- **41.2%** of adults describe their health as fair or poor
- **25.5%** have persistent pain
- **42.6%** are obese
- **58.0%** have difficulty doing errands alone
- **70.1%** have difficulty participating in social activities

No functional limitations

- **5.3%** of adults describe their health as fair or poor
- **5.3%** have persistent pain
- **29.3%** are obese
- **1.1%** have difficulty doing errands alone
- **2.0%** have difficulty participating in social activities

National comparisons – chronic health conditions



Has IDD

- **23.4%** of adults have arthritis
- **20.6%** have prediabetes
- **11.1%** have diabetes
- **31.4%** have high blood pressure
- **4.1%** have heart disease
- **29.3%** have asthma

No functional limitations

- **10.9%** of adults have arthritis
- **10.4%** have prediabetes
- **5.9%** have diabetes
- **24.3%** have high blood pressure
- **2.2%** have heart disease
- **11.4%** have asthma

National comparisons – mental health



Has IDD

- **56.8%** of adults have anxiety disorder
- **40.3%** take prescription medication for anxiety
- **56.9%** have depression/mood disorder
- **37.3%** take prescription medication for depression
- **40.2%** received mental health counseling or therapy in past year

No functional limitations

- **10.6%** of adults have anxiety disorder
- **8.4%** take prescription medication for anxiety
- **9.9%** have depression/mood disorder
- **5.8%** take prescription medication for depression
- **8.8%** received mental health counseling or therapy in past year

National comparisons – affordability of medical, dental and mental health care



Has IDD

- **27.5%** of adults said they were very worried about paying medical bills if they got sick or had an accident
- **14.8%** said they did not get needed medical care due to cost, and **16.9%** delayed getting care
- **18.6%** said they did not get needed dental care due to cost, and **22.2%** delayed getting care
- **18.6%** said they did not get needed counseling or therapy due to cost, and **17.4%** delayed getting care

No functional limitations

- **11.7%** of adults said they were very worried about paying medical bills if they got sick or had an accident
- **4.2%** said they did not get needed medical care due to cost, and **5.0%** delayed getting care
- **7.8%** said they did not get needed dental care due to cost, and **10.0%** delayed getting care
- **3.2%** said they did not get needed counseling or therapy due to cost, and **3.4%** delayed getting care

A profile of Medicaid Recipients with IDD: data from the NCI-IDD

Lindsay DuBois, HSRI Research Associate



Special Olympics
Health

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The National Core Indicators – Intellectual and Developmental Disabilities (NCI-IDD) Survey



Inclusion criteria:

- Person receives at least one service in addition to case management

Consent: Surveyors follow state specific consent requirements

- Those who are surveyed are informed that their services will not be impacted directly by their responses

Surveyor training: All surveyors complete standardized training. IPS uses peer-surveyors as well.

Survey features:

- May be conducted in-person or remotely
- Includes detailed Background Information section that primarily comes from existing records
- Surveys are available in multiple languages

Housing – Medicaid recipients with IDD 2021-2023



Residence type	National sample (N=33,908)	PA (N=1,306)	WI (N=798)	WA* (N=389)
Institutional setting	4.8%	7.3%	3.0%	n/a
Group home	33.6%	43.0%	22.6%	14.2%
Own home or apartment	14.9%	10.7%	31.9%	33.8%
Parent or relatives' home	40.4%	34.5%	41.3%	47.3%
Foster care/Host home	6.3%	4.5%	1.3%	4.6%

*WA data only available from 2018-2019

Health and healthcare – Medicaid recipients with IDD



Health conditions (from respondent records)	National sample (N=33,908)	PA (N=1,306)	WI (N=798)	WA* (N=389)
Diabetes	18.4%	17.3%	16.8%	12.4%
Dementia	2.7%	4.0%	5.9%	1.6%
CVD	7.3%	10.0%	13.1%	7.0%
Hypertension	28.4%	27.8%	28.6%	17.1%
Obesity	37.5%	34.8%	43.4%	36.7%
Health services utilization in past 12 months				
Primary care visit	85.0%	91.3%	84.5%	84.5%
Dental screening/exam	75.8%	82.9%	63.5%	74.4%
ER visit	24.4%	26.7%	30.7%	n/a

*WA data only available from 2018-2019

Mental health – Medicaid recipients with IDD



	National sample (N=33,908)	PA (N=1,306)	WI (N=798)	WA* (N=389)
Anxiety disorder ^a	21.2%	31.5%	43.2%	29.9%
Mood disorder ^a	25.4%	38.8%	44.0%	30.3%
Medications taken for anxiety, depression, and/or psychotic disorders				
None	46.3%	40.9%	51.9%	50.1%
1-2	36.0%	35.4%	33.7%	39.9%
3 or more	17.7%	23.7%	14.4%	10.0%

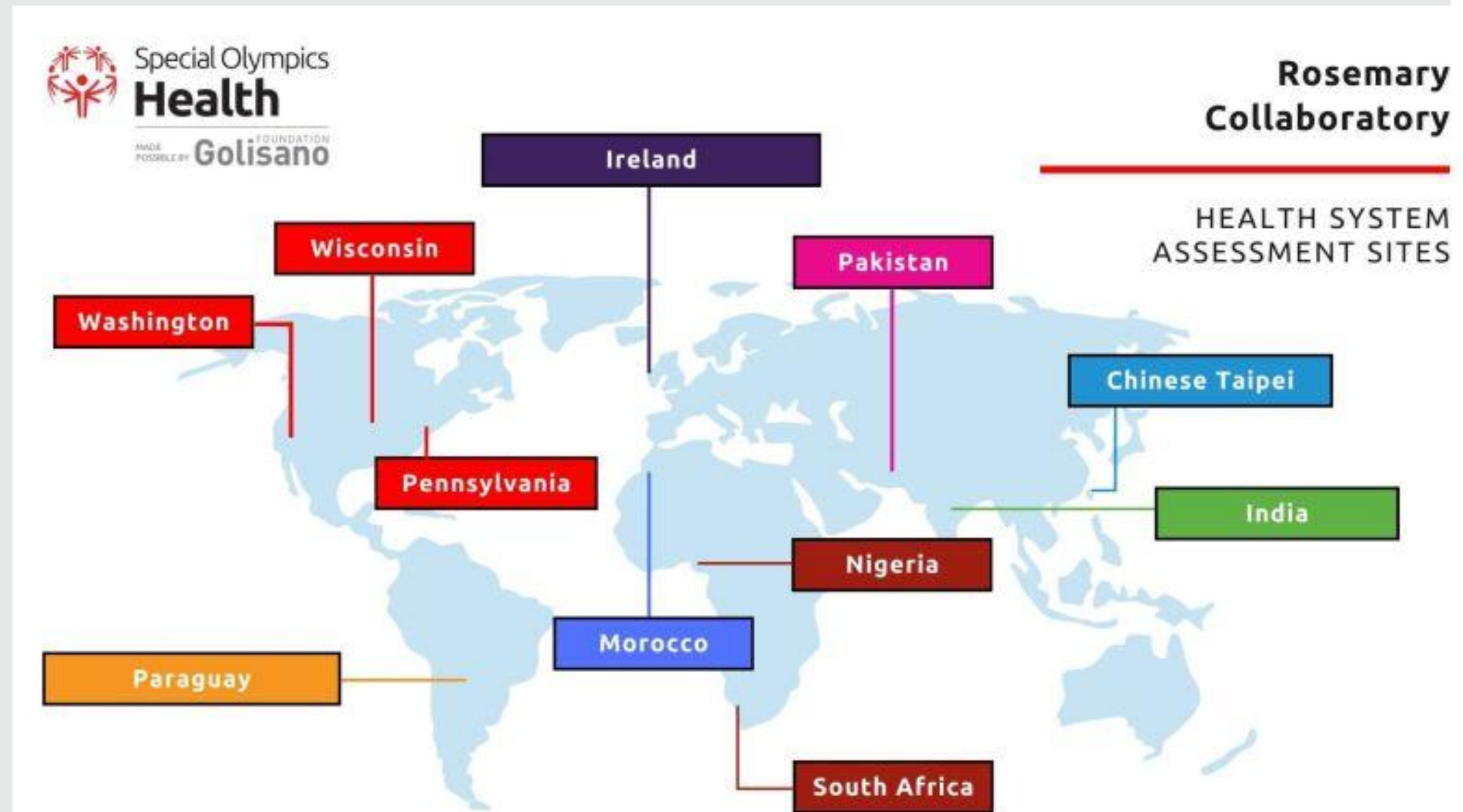
a. Information obtained from administrative records

*WA data only available from 2018-2019

Rosemary Collaboratory- Approach



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4. Publish a global report highlighting trends, best practices, and recommendations



Questions?

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Focusing on the Invisible:

The Overlooked Needs of People with Intellectual
and Developmental Disabilities and Actions to
Strengthen Health Systems for Inclusion





Supplemental Material:

WG-SS Publication



Functional Limitations Reported Among U.S. Adults With Intellectual Disability Participating in Special Olympics: A Comparative Analysis to the General Population

Alicia M. Dixon-Ibarra^a, John P. Hanley^a, Andrew E. Lincoln^a, Julie D. Weeks^b, Jon Baio^b, Joseph Holbrook^b, and Catherine E. Rice^b

^aSpecial Olympics International, Washington, DC; ^bCenters for Disease Control and Prevention, Atlanta, GA

ABSTRACT

The Washington Group Short Set on Functioning (WG-SS) allows for the identification of functional limitations across severity levels. Incorporating the WG-SS into Special Olympics (SO) surveys serves to understand functional support needs and inform SO programming for people with intellectual disability. This study examined functioning using both a restrictive and a broad definition of limitation among 525 U.S. SO athletes who completed an online survey in 2022. Self- and proxy-reported outcomes were compared to National Health Interview Survey (NHIS) estimates. Nearly a quarter of SO athletes (24.2%) reported any functional limitation under the restricted definition, while over three quarters (82.1%) reported limitations under the broad definition. Differences emerged between self- and proxy-reported data. Compared with NHIS age-adjusted estimates, SO athletes had higher prevalence ratios across all six domains, including self-care (PR = 12.93) and communication (PR = 11.21). These findings underscore functional diversity among SO athletes and inform programming and disability surveillance.

ARTICLE HISTORY

Received 16 April 2025
Accepted 8 February 2026

KEYWORDS

Washington Group Short Set; Intellectual disability; surveillance; adults; Special Olympics; functional limitations

Introduction

The inclusion of people with disabilities in public health population data is critical to track prevalence of health conditions, identify health disparities, and aid in policy planning and monitoring (Havercamp & Krahn, 2019; Havercamp et al., 2019; Krahn, 2019; Krahn & Havercamp, 2019). In the United States, the *Patient Protection and Affordable Care Act* mandated that all federally funded population health surveys include the collection of data to assess disability in the general population (*Patient Protection and Affordable*



Dixon-Ibarra et al. (2026)
Scan for the full article.



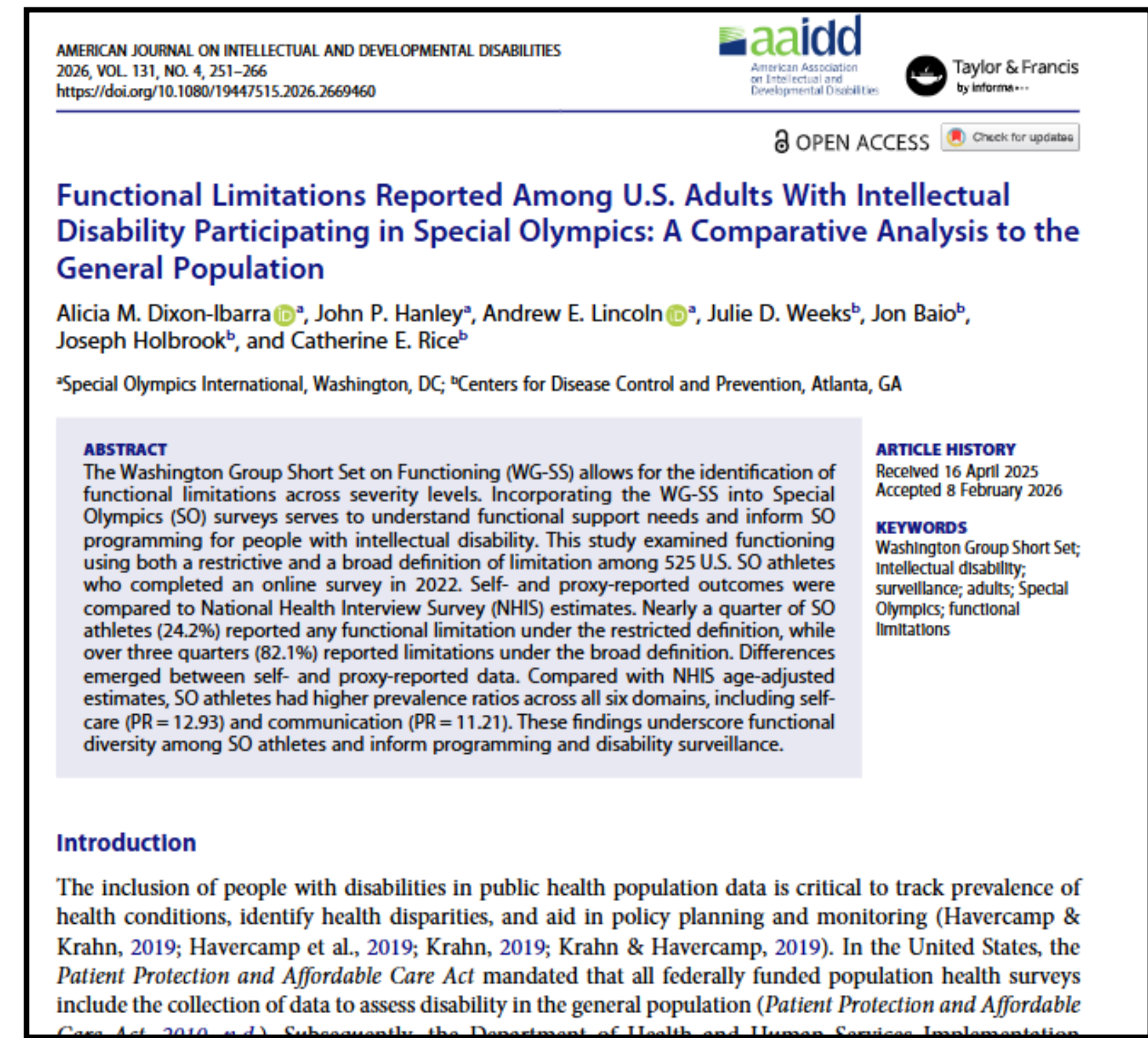
Supplemental Material:

USA Games 2026- Testing Learning and Support Questions



Why this Project?

- Special Olympics Health–CDC collaboration to strengthen IDD surveillance
- Prior work identified limitations in existing surveillance measures
- Evaluate a new functional limitation checklist for surveillance and administrative use



Dixon-Ibarra et al. (2026)
Scan for the full article.



Athlete Investigators

Training

- Completion of Re4all Training
- Evaluation onboarding

USA Games Participation

- Supported recruitment
- Consent with easy read print out
- Incentive distribution

Welcome to Research Ethics for All!

Accessible Research Ethics Education for
Community Research Partners



Methods



- Recruitment and Consenting
- Data integration
- Survey and audio administration on tablets

 REDCap Mobile App Connected tab7 (v5.30.1)

Do you have difficulty seeing, even if wearing glasses?
Would you say... [Read response categories]
* must provide value

☐ No difficulty

☐ Some difficulty

☒ A lot of difficulty

☐ Cannot do at all

☐ I don't know

☐ No response

Did this vision difficulty begin before age 22?
* must provide value

☐ Yes

☐ No

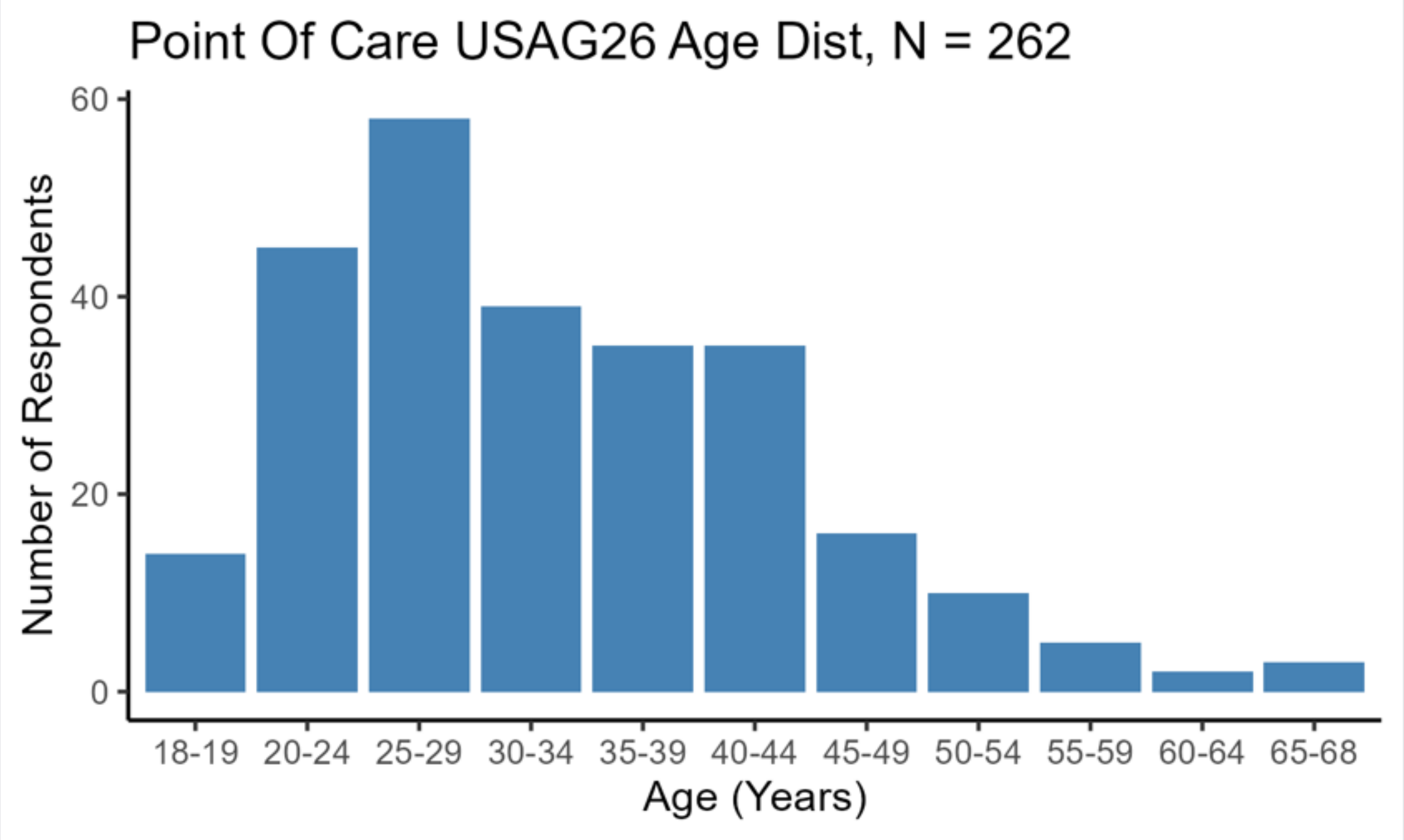
☐ I don't know

Do you have difficulty hearing, even if using a hearing

Demographics, N = 262 Participants



Gender	n	Percent
Female	96	37%
Male	165	63%
Race/Ethnicity		
White	183	69.8%
Black or African-American	53	20.2%
Hispanic/Latino	13	5.0%
Asian	11	4.2%
American Indian	8	3.1%
Other Pacific Islander	2	0.8%
Some Other Race	2	0.8%
Alaska Native	1	0.4%
I don't know	9	3.4%



Data Linkage & Delegations

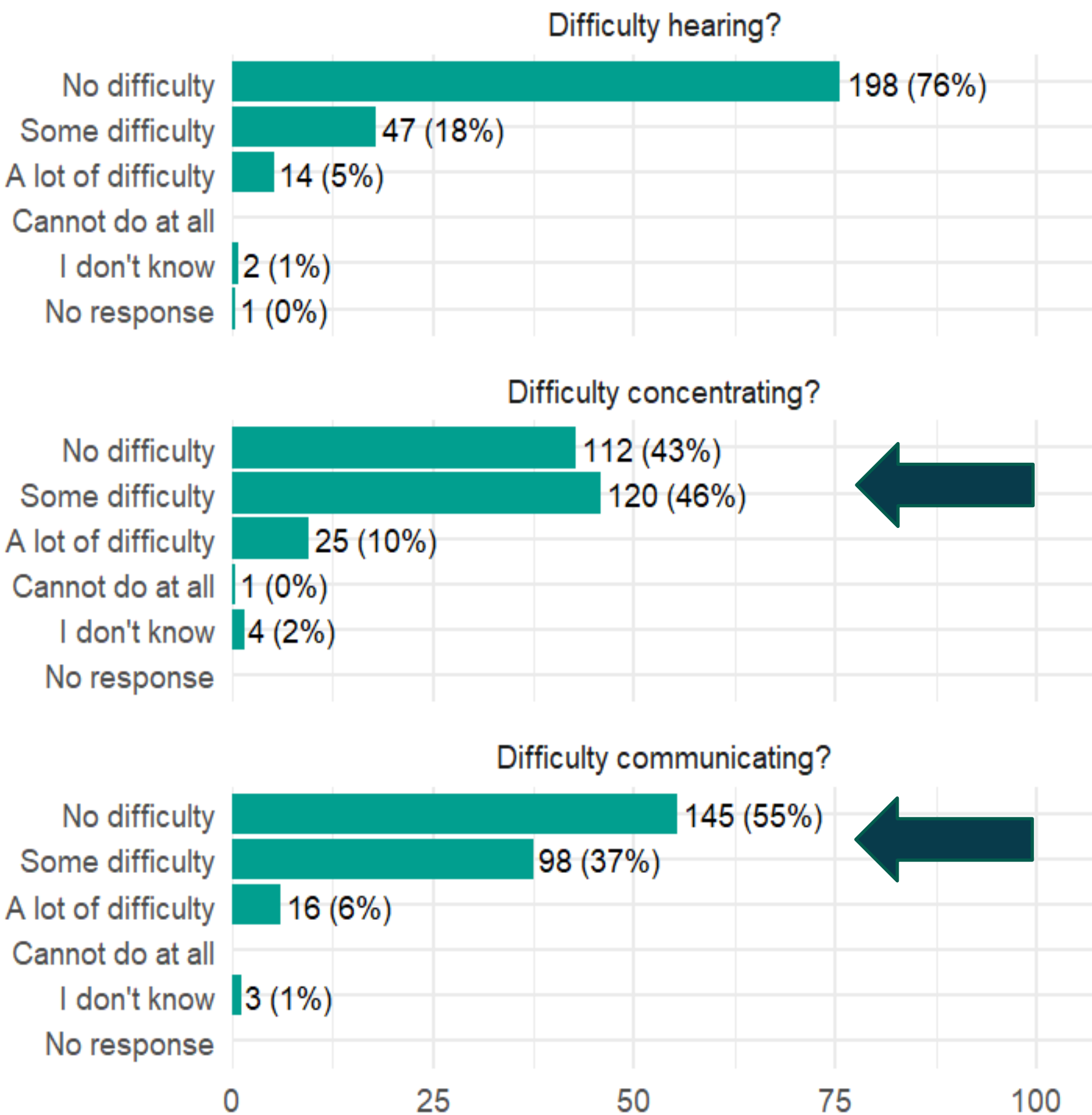
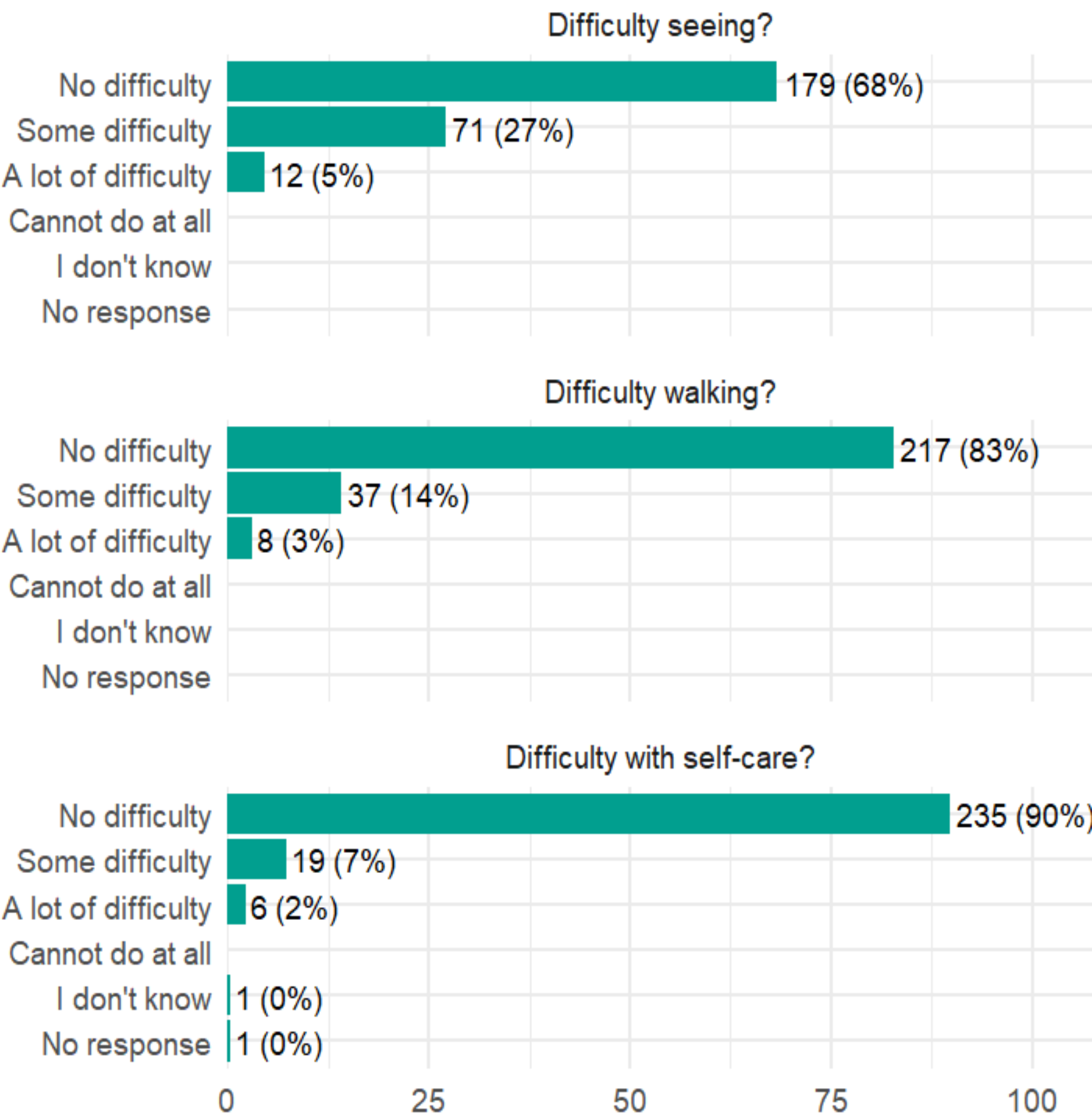


- 254 Participants (97%) approved data linkage with USA Games registration and HAS data
- 252 Participants (96%) recorded audio files



Top Delegations	n	Percent
Wisconsin	29	11.1
Arkansas	27	10.3
Minnesota	20	7.6
Illinois	16	6.1
Florida	12	4.6
Missouri	12	4.6
Pennsylvania	12	4.6
Colorado	11	4.2
New Jersey	11	4.2

Functional Limitations

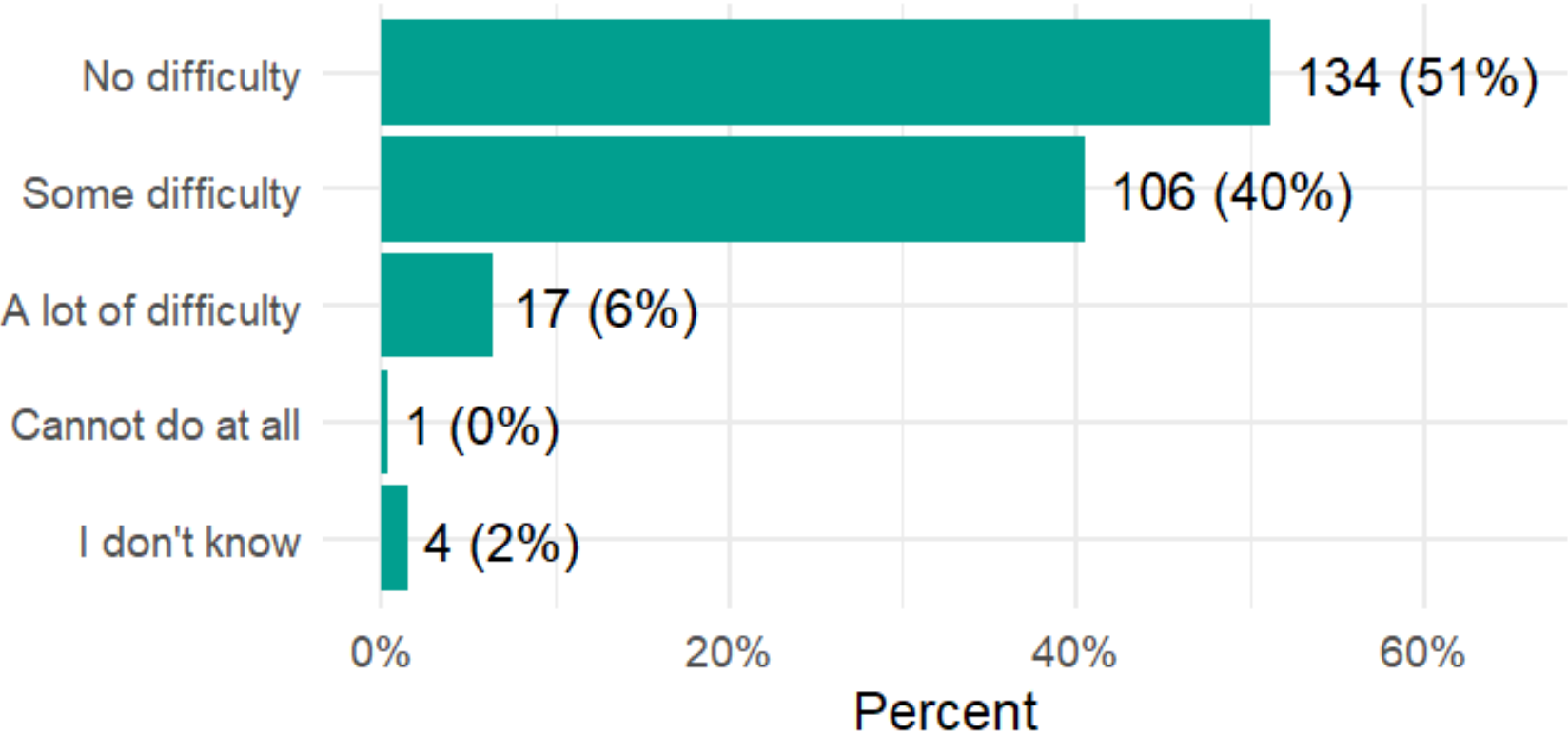


Percent

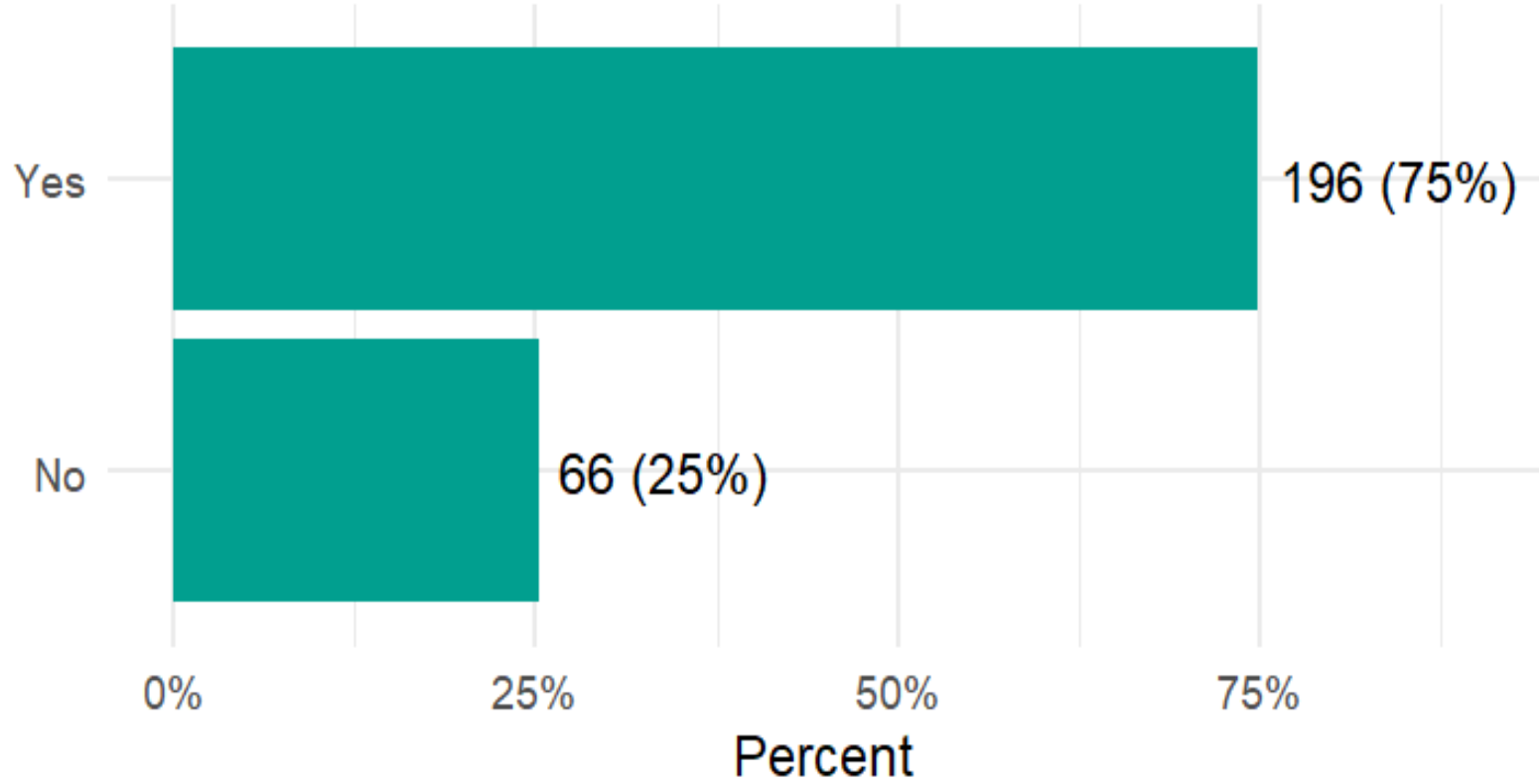
Challenges with Learning, Help with Everyday Tasks



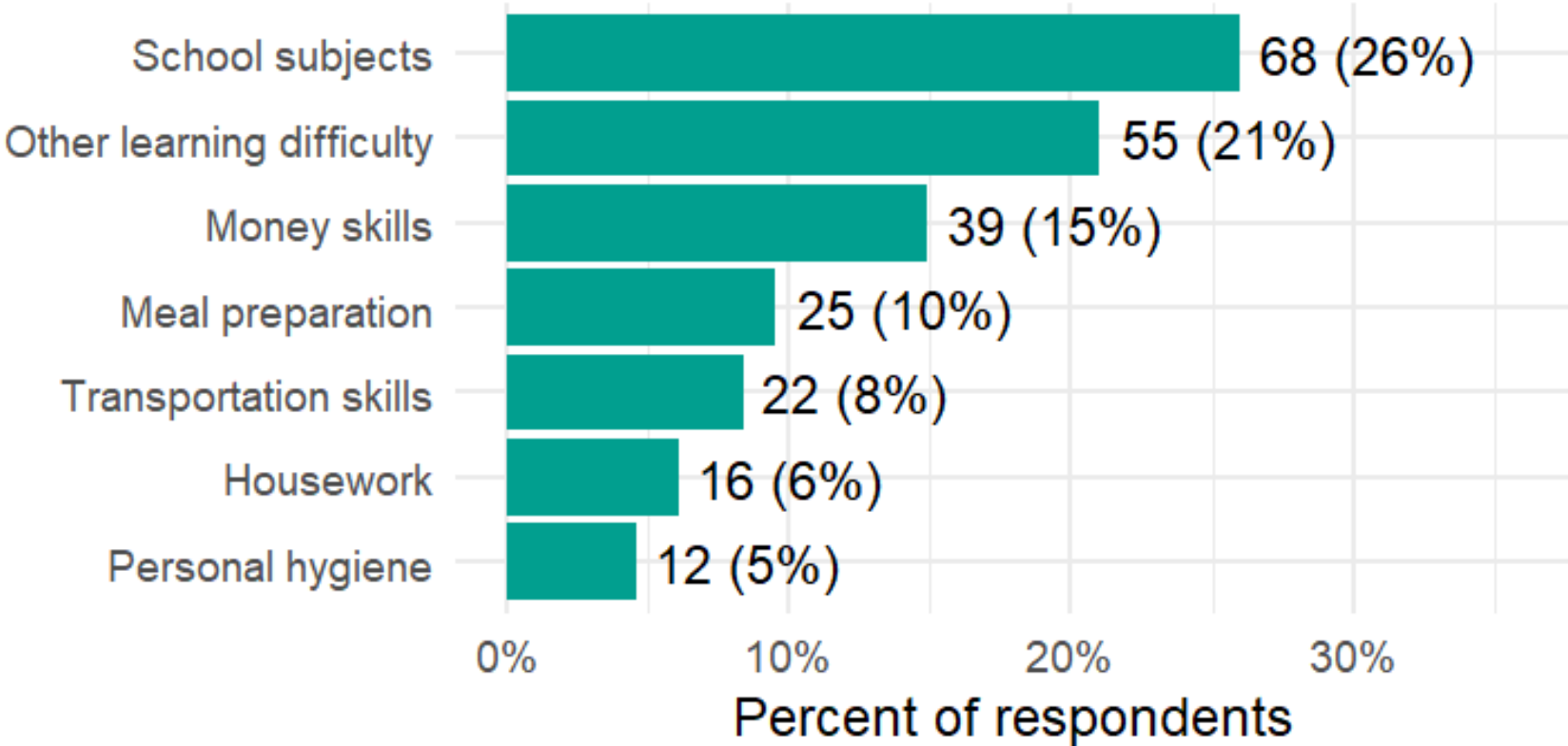
Do you have difficulty learning new things?



Does someone help you with everyday tasks?



What things are difficult to learn?



What kind of help?

