

# Understanding Engagement Awards in IDD and How They Can Inform Future Intellectual Development Disability (IDD) Clinical Effectiveness Research (CER) Awards

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## BACKGROUND

The Patient-Centered Outcome Research Institute (PCORI) is the leading funder of patient-centered comparative clinical effectiveness research (CER) in the United States. PCORI funds research and related projects to help people with intellectual and developmental disabilities (IDD) and those who care for them, like their family members and doctors, have more information to make the best healthcare decisions, improve healthcare delivery, and reduce health disparities. The goal is to support projects that will build a community that can better participate in patient-centered comparative clinical effectiveness research (CER) and serve as channels to disseminate study results. My project focused on utilizing and evaluating IDD engagement awards to ensure that CER awards meet the population's research needs and accurately represent IDD participants.

## LEARNING OBJECTIVES

- Portfolio description of IDD Engagement Awards from PCORI (2015-2022)
- Understanding engagement awards and how they inform CER awards
- Exploring trends and understanding what makes engagement/outreach successful for priority populations
- Improve access to research and engagement materials
- Target populations and research topics for future cycles

## POPULATION

IDD can be viewed as a larger community under which multiple specific conditions fall. Some conditions are clearly defined because of distinct genetic or medical findings (eg, Down syndrome and spina bifida), whereas other IDD conditions rely on a constellation of behavioral features or performance on standardized measures (eg, ADHD, autism spectrum disorders, intellectual disability). Furthermore, a person may have more than 1 IDD condition. PCORI's funding decisions fall under these definitions:

- Developmental disabilities are “chronic disabilities that originate at birth or in the developmental period and cause impairment in physical, learning, and/or behavioral areas.”
- Intellectual disability: included under the category of developmental disability, involves “limitations to cognitive function (ie, reasoning, learning, problem-solving) and adaptive behavior.”

## METHODOLGY

- Using Salesforce and a template, I analyzed the engagement awards for IDD from 2015-2022
- Data abstracted from Salesforce from 2015-2022
  - Priority population, age group, research agenda, engagement tools and resources, success and challenges
- Inclusion criteria
  - Had to be a completed engagement award that covered an IDD population
- Then I was able to find common trends, data, and “successes” for the engagement awards
- I did basic data analysis for CER awards for IDD as well

## DELIVERABLES

My first deliverable was to create a dataset of Engagement Awards given at PCORI from 2015 to 2022.

- Examples of what information was compiled can be found in Table 1.
- The dataset allowed for resource management and analysis of Engagement Awards to see what works for researchers and participants.

My second deliverable was an analysis and presentation of the dataset.

- Figure 1-4 just some of data analysis from a created dataset during my time at PCORI.
- These exemplify different populations engagement awards are being awarded too. They answer questions such as how often different populations are being awarded, what types of engagement awards are being given out and how frequently they are being given out. There are some exclusions in the dataset, in 2020, there was a significant decrease in awards awarded to researchers due to COVID-19.
- Engagement and CER is critical to know to inform future Engagement and CER awards. With this quantitative analysis, I was able to do a qualitative analysis to understand the trends found in the Engagement Awards to inform future CER awards.

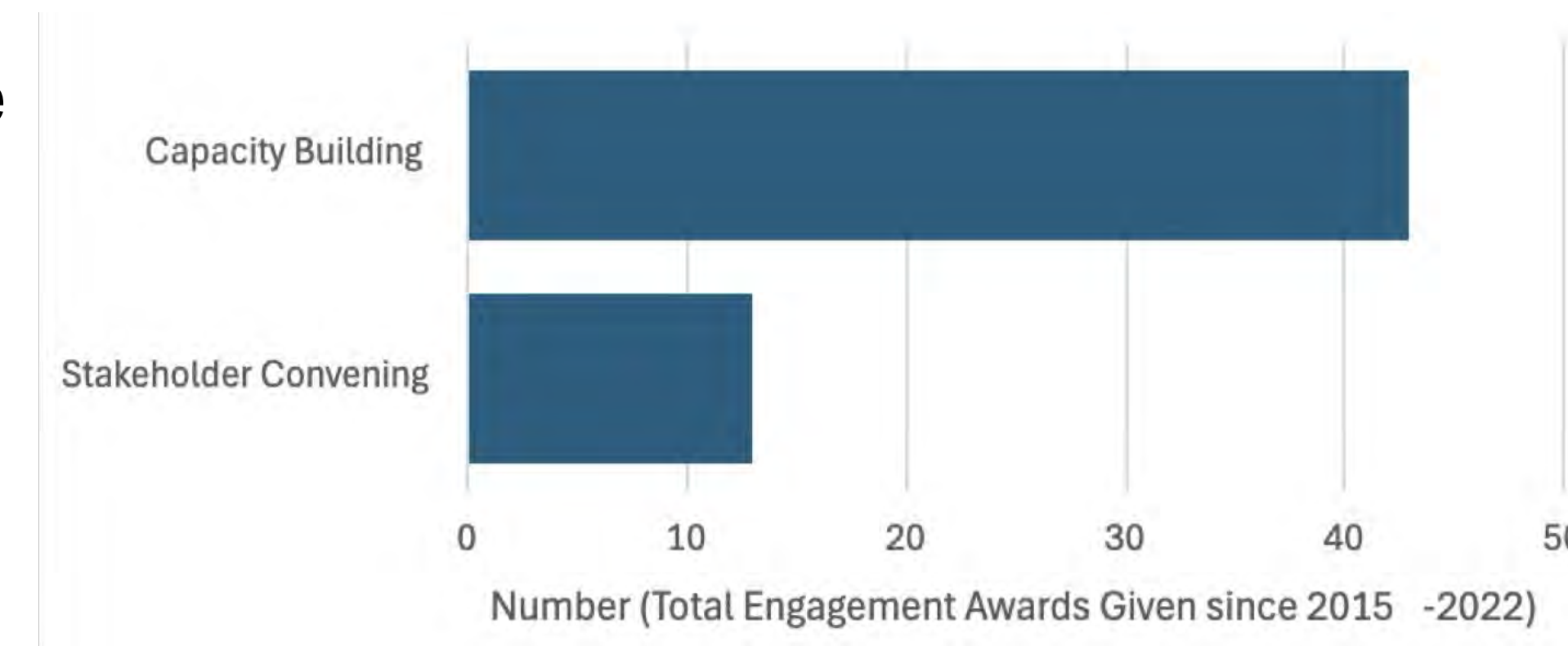


Figure 1. The different types of Engagement Awards awarded from 2015 to 2022 at PCORI

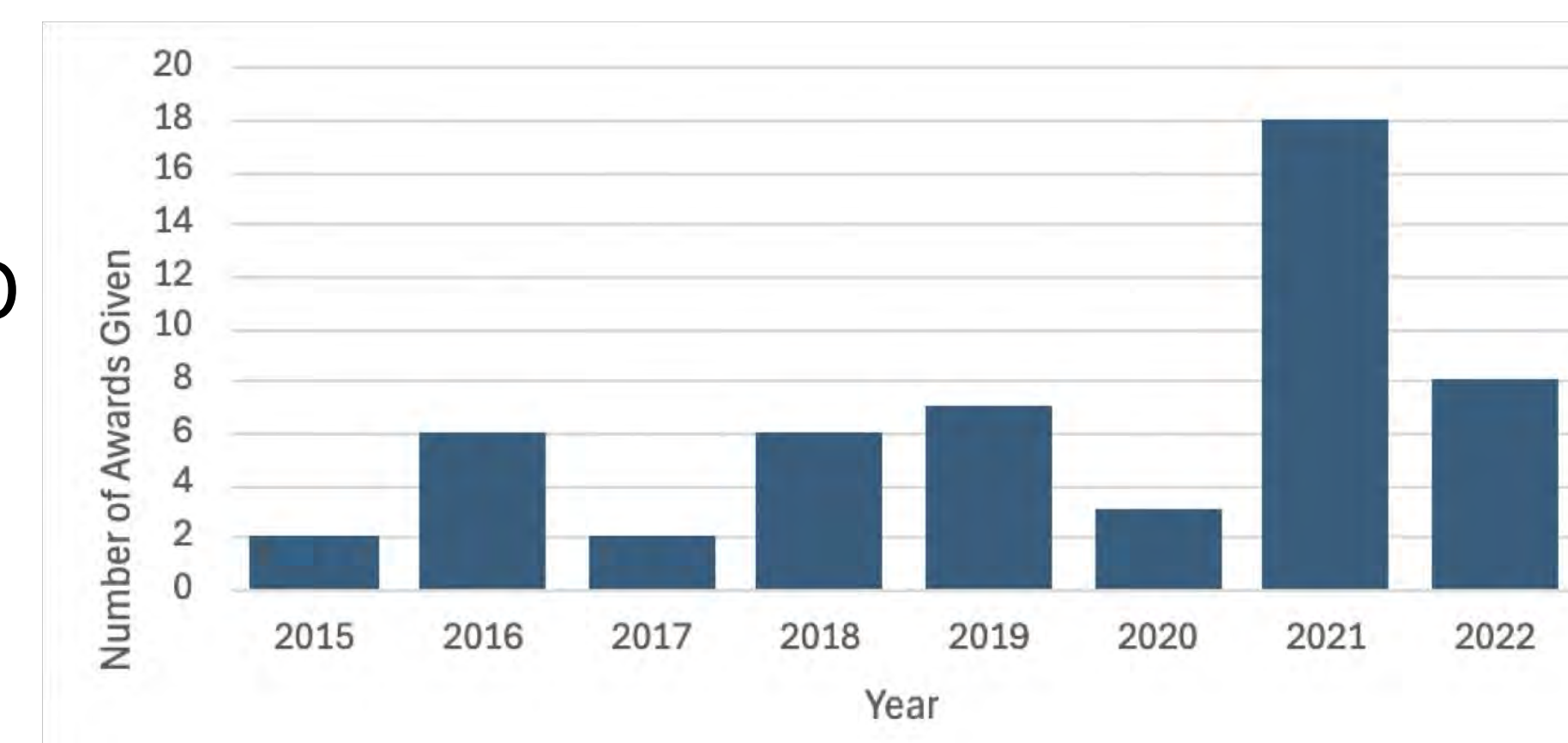


Figure 2. The number of Engagement Awards awarded from 2015 to 2022 at PCORI

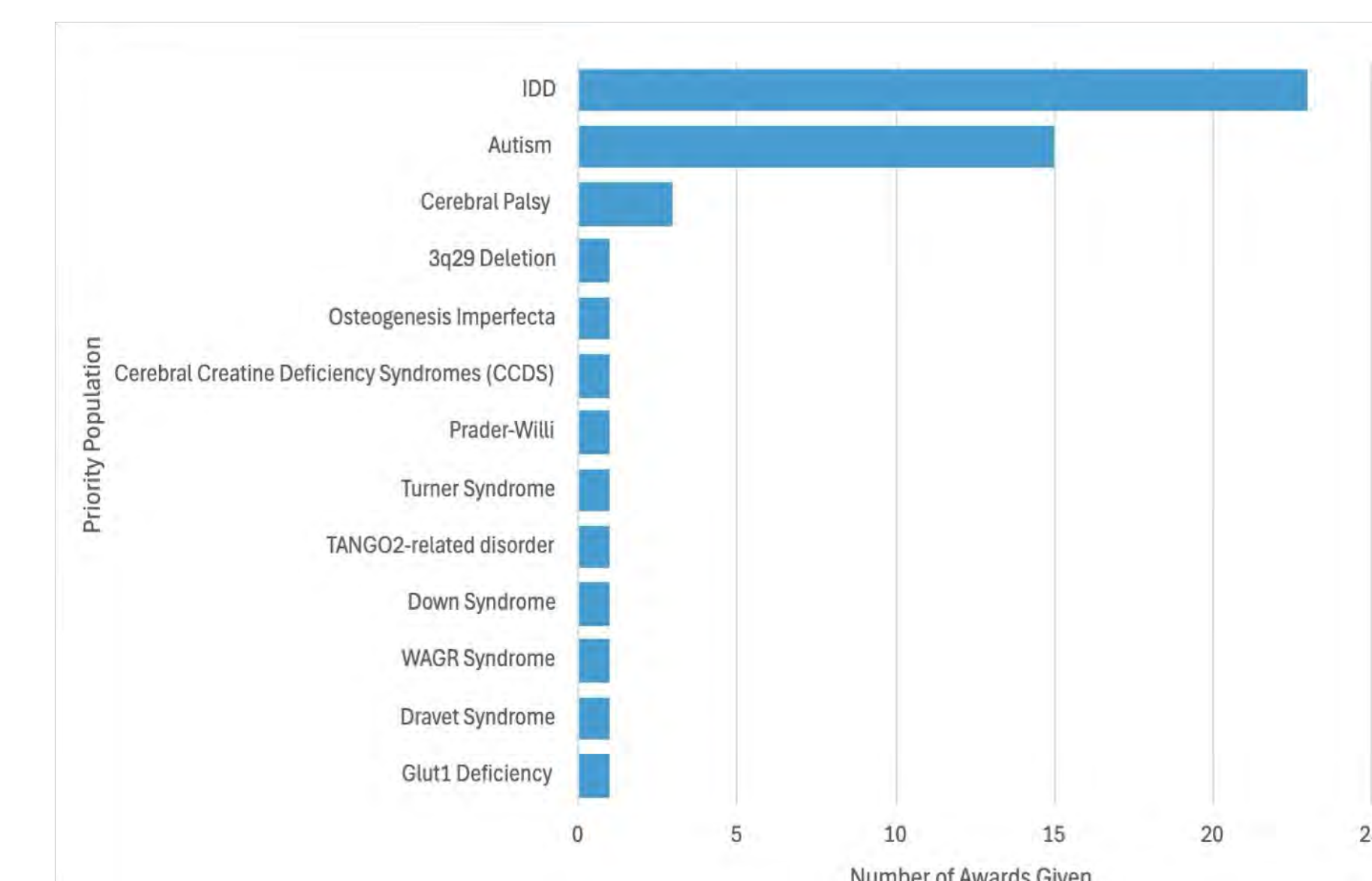


Figure 3. The populations that received Engagement Awards from 2015 to 2022 at PCORI and the frequency.

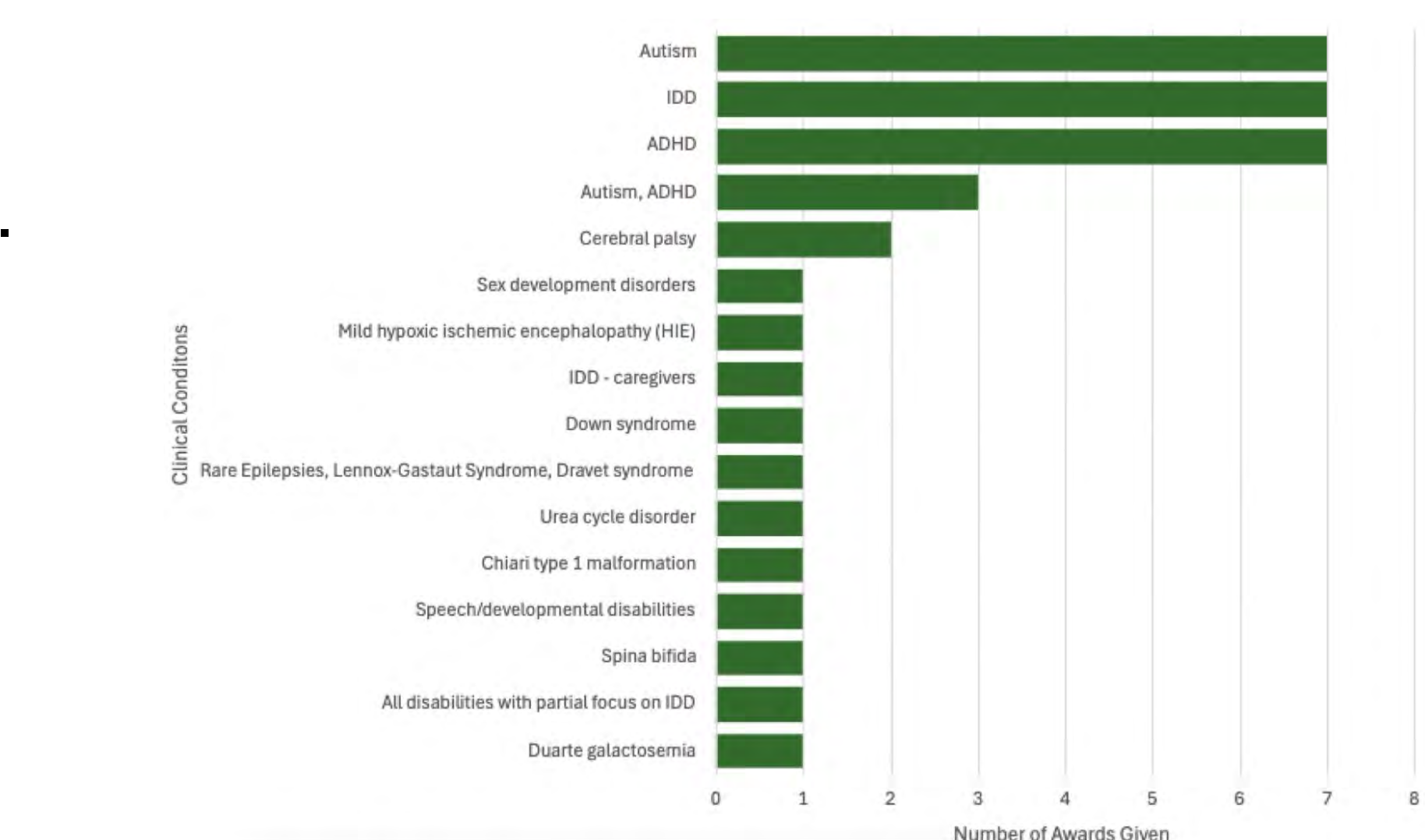


Figure 4. The populations that received CER awards from 2015 to 2022 at PCORI and the frequency.

## LESSONS LEARNED

- How to utilize Salesforce which allows for PCORI to data storage safely, organize data efficiently and manage a large amount of grants.
- Resource management and how to understand awards effectively
- I was able to learn about grants and the process of how PCORI evaluates different research projects.
- I was able to understand how research agendas can center participant outcomes and build to strength CER
- I was also able to evaluate different engagement strategies and what can be successful for engagement in research, especially in under resourced populations.

## PUBLIC HEALTH IMPLICATIONS

Public health seeks to empower populations through health decisions and behaviors, and PCORI wants to facilitate the actionable information needed to make healthy decisions. Engagement awards, further, helps researchers understand their participant population and their desires. Bridging the gap between researchers and participants can ensure respectful relationships and better research outcomes when participants feel safe and secure.

Table 1 Template for the created dataset of Engagement Awards distributed from 2015 to 2022.

Award Type	
Year awarded	
Project status	
Organization/institution	
Contract Number	
Project Title (link to PCORI website)	
PI First and Last name	
State/geographic location	
Contract Amount	
A brief bulleted summary of the project	
Population	
Age Group	
Sex	
Priority population	
Clinical condition	
Inclusion of Individuals with Lived Experiences?	
Outcomes/ Key Findings	
Setting	
Associated research study?	
Is the final summary report available?	
Website	
Research Agenda (if applicable)	
Workshop Summary (if applicable)	
Engagement Resource/Tool/Product	
Successes/Challenges	
Takeaway	

## References

Patient-Centered Outcomes Research Institute. (n.d.). Intellectual and developmental disabilities. PCORI. Retrieved November 12, 2024, from <https://www.pcori.org/topics/intellectual-and-developmental-disabilities>