

# Strategies for Increasing Recruitment in Down Syndrome Research:



## A Multifaceted Toolkit

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### BACKGROUND

- Following the 2018 National Institute of Health (NIH) INCLUDE Project, increased research opportunities have emerged for individuals with Down syndrome (DS) and their families, prompting the Boston Children's Hospital DS Program (DSP) to develop a toolkit of tailored recruitment strategies.
- The DSP conducts a variety of research projects including in-person and virtual modalities.
- Projects include single and multi-site studies of neurodevelopment and health outcomes, and clinical trials of behavioral and pharmacological interventions.

### BARRIERS TO RECRUITMENT

- Obtaining a demographically and geographically diverse sample
- Lack of education surrounding the concept of research, leading to misconceptions and preconceived notions
- High team effort may produce a low yield of enrolled participants
- Retaining study participation over the duration of a study

### RECRUITMENT TOOLKIT

#### In-clinic

- self-advocate explanations
- clinician-led conversations
- central, targeted recruitment

#### Social Media

- paid advertising companies
- postings in specific groups
- scheduled postings to page

#### Partnerships

- local and national advocacy/community groups
- targeted mailings, flyers

#### Direct Contact

- different modes of contact
- calling at certain times/days
- newsletter

#### Clinical Database

- eligibility screening
- monthly pulls of newly eligible participants

#### Weekly Team Meetings

- detailed recruitment tracking
- adjustment of strategies based on enrollment

### IN-CLINIC RECRUITMENT VISUALIZATION

#### Eligibility Screening Phase:

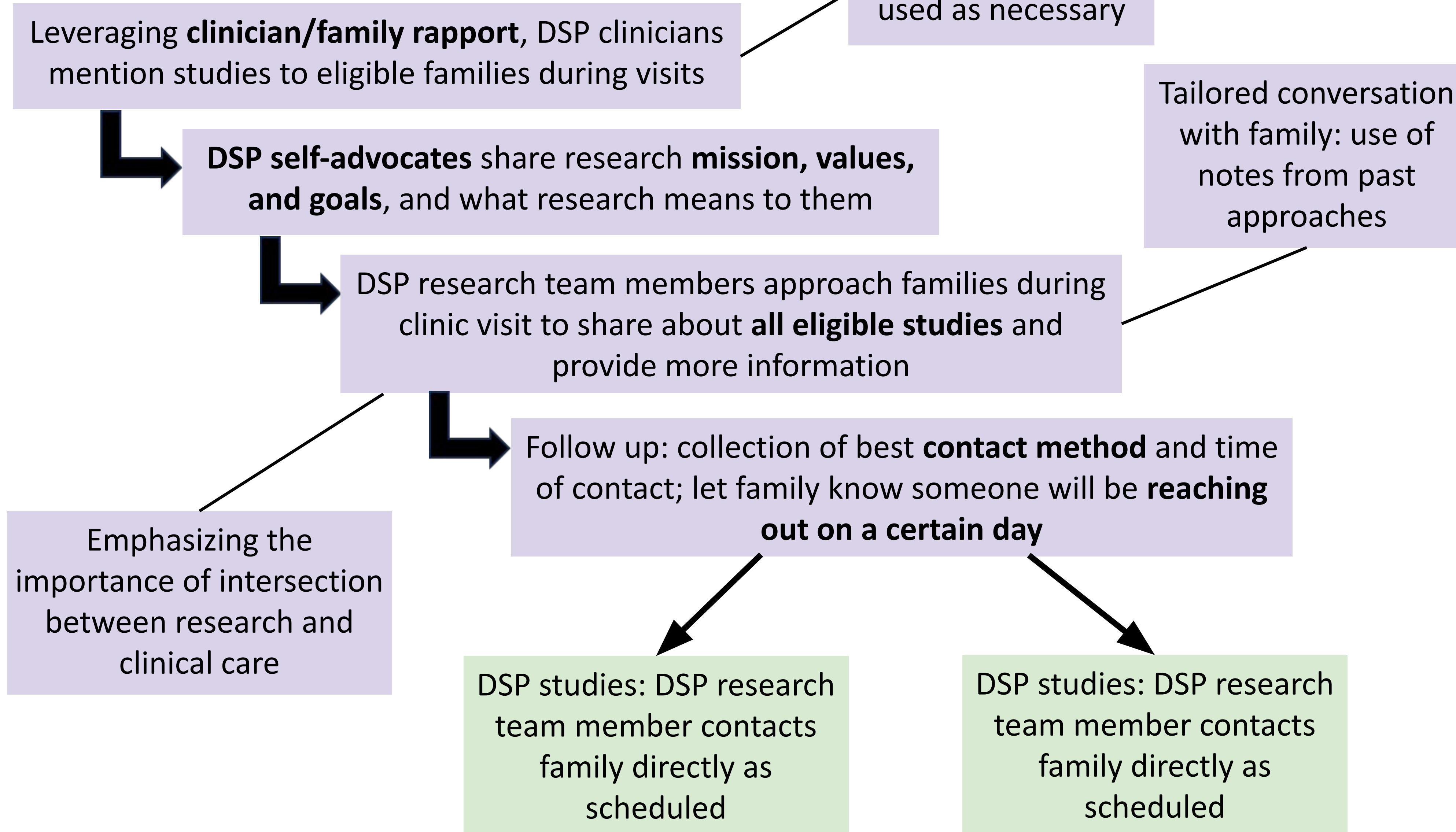
Coordinator reviews **clinical database** for basic eligibility information

- **Self-advocate research assistant** verifies basic eligibility criteria
- Enrollment check: verification that patient isn't being approached for a study that they already participated in

#### Eligibility & Participation Ability Confirmation Phase:

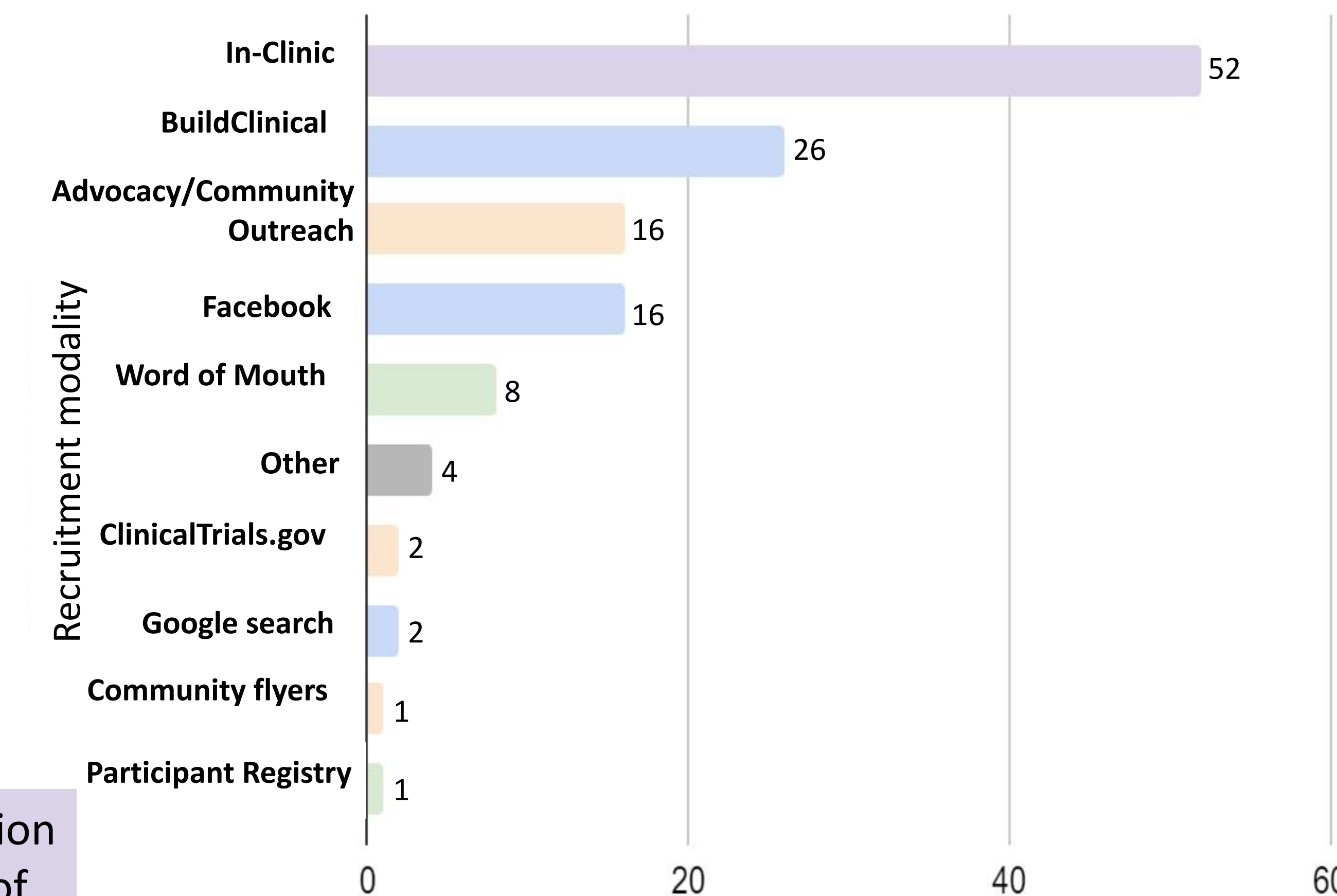
- Likely eligible clinic **patients are reviewed** at a weekly clinical and research team meeting
- DSP clinicians provide **medical clearance** and input on participation ability, potential **family barriers**

#### Coordinated Research Approaches:



### RECRUITMENT EXAMPLE

#### Recruitment Modalities Used in Virtual Study\*



Number of screened participants

\*This specific research study was chosen for this illustration due to the large range of recruitment strategies that were implemented.

### TYPES OF STUDIES REPRESENTED

Type of Study	Participants Screened*	Time actively recruiting
Virtual caregiver curriculum study (20 weeks)	128	15 months
Multi-site observational study (one-time visit)	50	13 months
Multi-cohort longitudinal study (2 visits over 2 years)	76	29 months
At-home/virtual pilot study (15 visits over 6 months)	10	10 months
Longitudinal observational study (3 visits over 3 years)	5	3 months

\*Screening metric was used to illustrate efficacy of recruitment in order to account for studies that may have stricter inclusion/exclusion criteria; refers to documentation of screening, not just interest in study

### BEST PRACTICES

**In-clinic recruitment** builds rapport and allows for connections between research and clinical team

Implementation of a **clinical database** allows for easy access to contact lists for eligible participants

Addition of a **third-party recruitment** company increases diversity profile and size of pool of potential participants

Partnering with **local and national advocacy groups** to help with recruitment and community engagement

### CONCLUSIONS

- Development and execution of research studies necessitates fluid adjustment and implementation of wide-ranging strategies to promote successful recruitment of participants with DS in clinical research.
- This multifaceted toolkit of strategies can be implemented across a wide range of research studies.

Author disclosure. We have no disclosures to report.

\*see In Clinic Recruitment Visualization for additional details