

Design and pilot of an instrument to survey caregivers of children with special health care needs (including Down syndrome) about quality of self-management supports

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BACKGROUND

- Children with special health care needs (CSHCN) need specialized care and supportive services
- Health care providers can help by providing “self-management support” (SMS) to caregivers
- SMS are informational, social, emotional, and technological tools and services
- Little is known about the extent to which SMS is provided in health care for CSHCN

METHODS

- Collaborated with caregivers, an advisory board, pediatric health care providers, and disabled self-advocates to create a **28-item SMS measure** for families of CSHCN
- Response choices: (1) Strongly disagree (2) Disagree (3) Agree (4) Strongly agree
- Conducted two rounds of user testing and qualitative inquiry
- Piloted a digital survey with **52 caregivers** in **English and Spanish** at two pediatric clinics in **Oakland, CA** (community-based site, survey completed at the clinic) and **San Francisco, CA** (hospital-based site, survey completed at home)
- Analyzed answers for children **with (n=7)** and **without (n=45) Down syndrome (DS)**
- Participants with Down syndrome received care in the context of a **specialized DS clinic**

AFFIRM (Assessing Family Friendly care In Realizing self-Management)



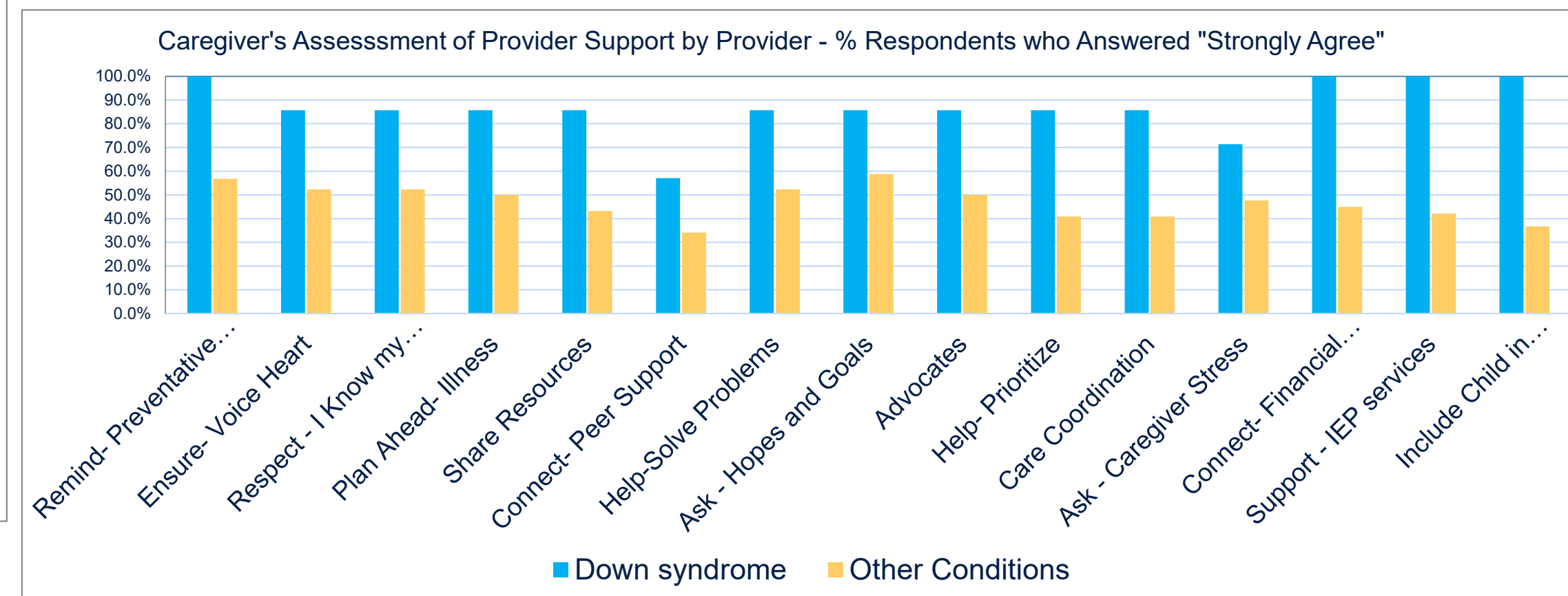
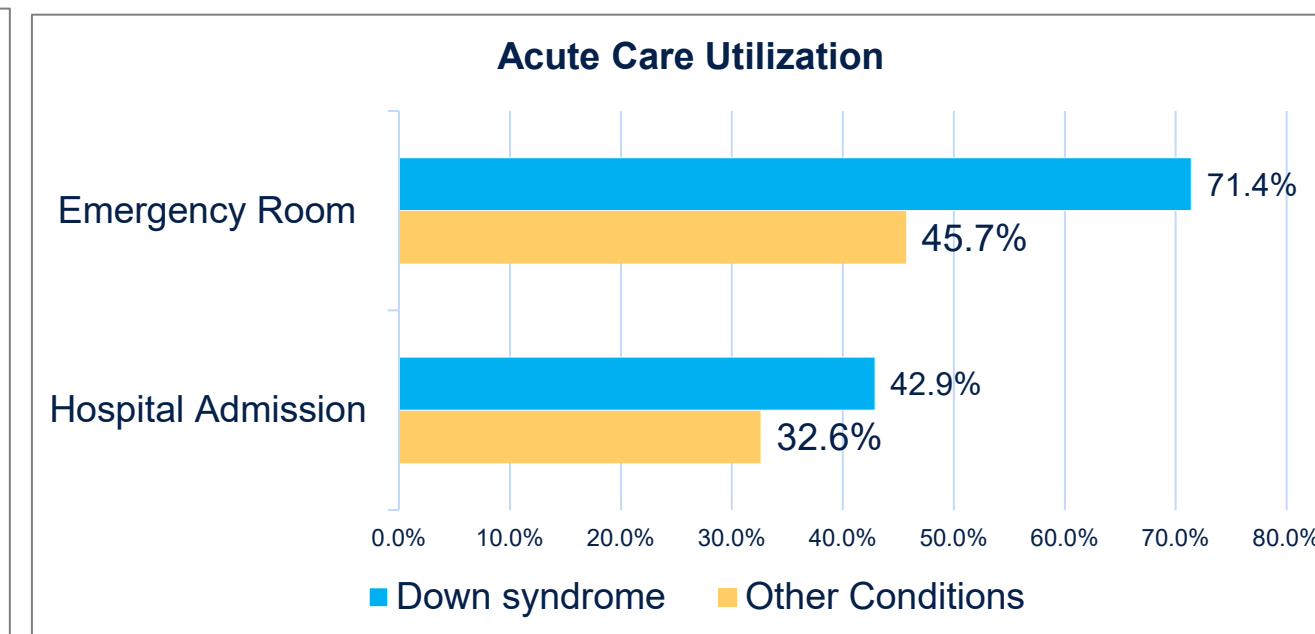
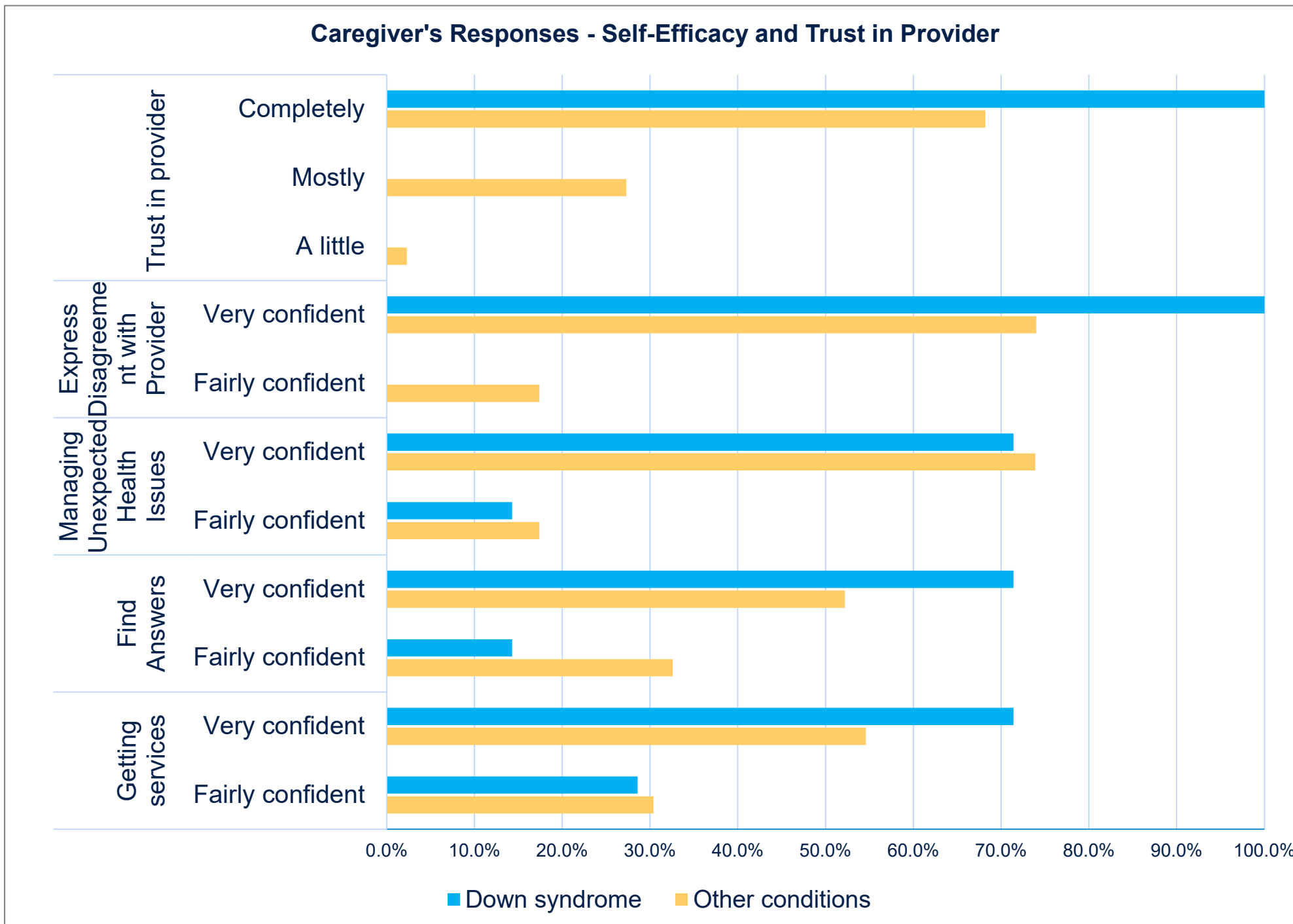
RESULTS

Self-management support Composite SMS score 3.49 (SD=.60)

- Domain 1:** Being available/accessible to patients/caregivers (*Cronbach α = .883*)
- Domain 2:** Providing information on disease management & resources within medical system (*Cronbach α = .918*)
- Domain 3:** Helping access supports outside the medical system (*Cronbach α = .947*)
- Domain 4:** Helping organize, prioritize, and plan (*Cronbach α = .939*)
- Domain 5:** Empowering, strengthening, and emotionally supporting (*Cronbach α = .956*)
- Domain 6:** Preparing caregivers/patients for transitions or big changes in condition/care (*Cronbach α = .915*)

Characteristics of Participants in Pilot (N=52)

- All were low income
 - 52% had income under 100% FPL
 - 40% completed the survey in Spanish
 - 79% had a high school education or less
 - Age of child**
 - 33% 0-5 years old
 - 38% 6-10 years old
 - 29% 11-17 years old
 - Type of condition of child***
 - 87% Physical/developmental disability
 - 57% Other chronic condition
 - 48% Behavioral health
 - Race/Ethnicity of child**
 - 58% Latinx
 - 10% White
 - 5% Black/African American
 - 2% Native American/Alaskan Native
 - 23% Asian/Pacific Islander
 - 2% Middle Eastern/North African
- * More than one category may be selected, so total is more than 100%



DISCUSSION

- Assessment of SMS is a vital step to improve care delivery for CSHCN
- The SMS instrument developed in this study appeared to be accessible to caregivers across health literacy levels, language groups, and educational attainment
- Caregivers of children with DS who receive care within the context of a DS clinic report high levels of satisfaction with SMS and trust in their provider

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