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## BACKGROUND

- Family-centered care for individuals with Down syndrome requires clinicians to understand and prioritize issues most important to families to personalize recommendations and demonstrate an investment in the family-clinician partnership.
- Caregivers were prompted to list three strengths and three concerns about their child as part of a standardized clinical intake form prior to their clinic visit at the Boston Children's Hospital Down Syndrome Program.

## OBJECTIVES

- To characterize the most common caregiver-reported strengths and concerns by thematic domain for children aged 0 - <3 and 3 - <5 years old.

## PARTICIPANTS + METHODS

- Data were collected from caregiver completed intake forms between 2018-2023.
- Two cohorts were analyzed using forms from the most recent visit. Each cohort included unique patients; 84 children were included in both cohorts as they had a visit in each age range.
  - 0 - <3 (N=261, mean [SD] = 1.58 [0.82])
  - 3 - <5 (N=160, mean [SD] = 4.15 [0.51])
- An inductive codebook was created based on the Vineland-3<sup>1</sup> framework of developmental skills and behaviors and the Infant Toddler Temperament Tool (IT-3)<sup>3</sup>. The codebook consisted of 25 nodes, 13 of which had sub-nodes, and 64 sub-nodes (represented as **Node/Sub-node**, if applicable)
- Data were analyzed qualitatively by two coders for themes. Inter-coder reliability was calculated (Cohen's kappa, κ). Kappa values ranged from good to very good (0.70-0.97).<sup>2</sup>

## CODING SCHEME

Figure 1. Example of Caregiver-reported Response: 3 - <5 Cohort Strength



## KEY THEMES: STRENGTHS + CONCERNS

Table 1. Strengths and Concerns: 10 Most Common Themes\*

0-3 Strengths			3-5 Strengths		
Node	Sub-node	References**	Node	Sub-node	References**
Socialization	Interpersonal	146	Socialization	Interpersonal	132
Motor	Gross Motor	83	Socialization	Play & Leisure	80
Socialization	Play & Leisure	73	Temperament	Persistence	65
Socialization	Coping Skills	72	Socialization	Coping Skills	58
Temperament	Persistence	69	School	Academic Skills & Cognition	51
Daily Living	Personal	52	Temperament	Sensitivity	40
Communication	Receptive	47	Socialization	General	38
Communication	Expressive	46	Communication	Expressive	34
Socialization	General	46	Motor	Gross Motor	27
Temperament	Activity Level	43	Communication	Receptive	23

  

0-3 Concerns			3-5 Concerns		
Node	Sub-node	References**	Node	Sub-node	References**
Daily Living ***	Personal	115	Daily Living ***	Personal	72
Feeding & Eating ***	N/A****	82	Communication	Expressive	48
Communication	Expressive	68	Toileting ***	N/A	39
Non-specified	N/A	54	Feeding & Eating ***	N/A	27
Motor	Gross Motor	52	Sleeping ***	N/A	27
Services & Supports	N/A	39	Non-specified	N/A	22
Medical (Physical)	Gastroenterology	32	Not Answered	N/A	20
Medical (Physical)	Feeding	27	School	Other	16
Toileting ***	N/A	26	Medical (Physical)	Pulmonology	16
Sleeping ***	N/A	24	Medical (Physical)	Otolaryngology	15

\*Each node is represented by a color and sub-nodes are represented by different shades of their respective node color

\*\*To address discrepancies between coders, the average number of references between coders is represented.

\*\*\*Caregiver responses were double-coded across nodes when relevant (ex. "potty training" coded as both **Daily Living**/Personal and Toileting, "feeding themselves" coded as both **Daily Living**/Personal and Feeding & Eating).

\*\*\*\*N/A is used if the respective node did not have a sub-node

## CONCLUSIONS

- Caregiver-reported strengths and concerns referenced medical, behavioral, and psychosocial factors related to their child's profile and family system.
- Knowledge of strengths and concerns may help guide clinicians to improve recommendations and to help tailor their clinical visits to better serve unique families.
- Caregivers can be provided with knowledge about common themes across age groups.
- In the future, we hope to analyze additional age groups in order to maximize clinical expectations and provide additional information to families.

## REFERENCES

- Sparrow SS, Cicchetti DV & Saulnier CA 2016. *Vineland Adaptive Behavior Scales*, Third Edition, San Antonio, TX, Pearson.
- Altman, D. G. (1990). *Practical statistics for medical research*. Chapman and Hall/CRC.
- Georgetown University. (n.d.). Infant Toddler Temperament Tool (IT3). Center for Early Childhood Mental Health Consultation. Georgetown University Center for Child and Human Development.