Poster #XXXX

Co-Creation of a Down Syndrome Clinic: Integrating Healthcare Systems and Family Advocacy Organizations

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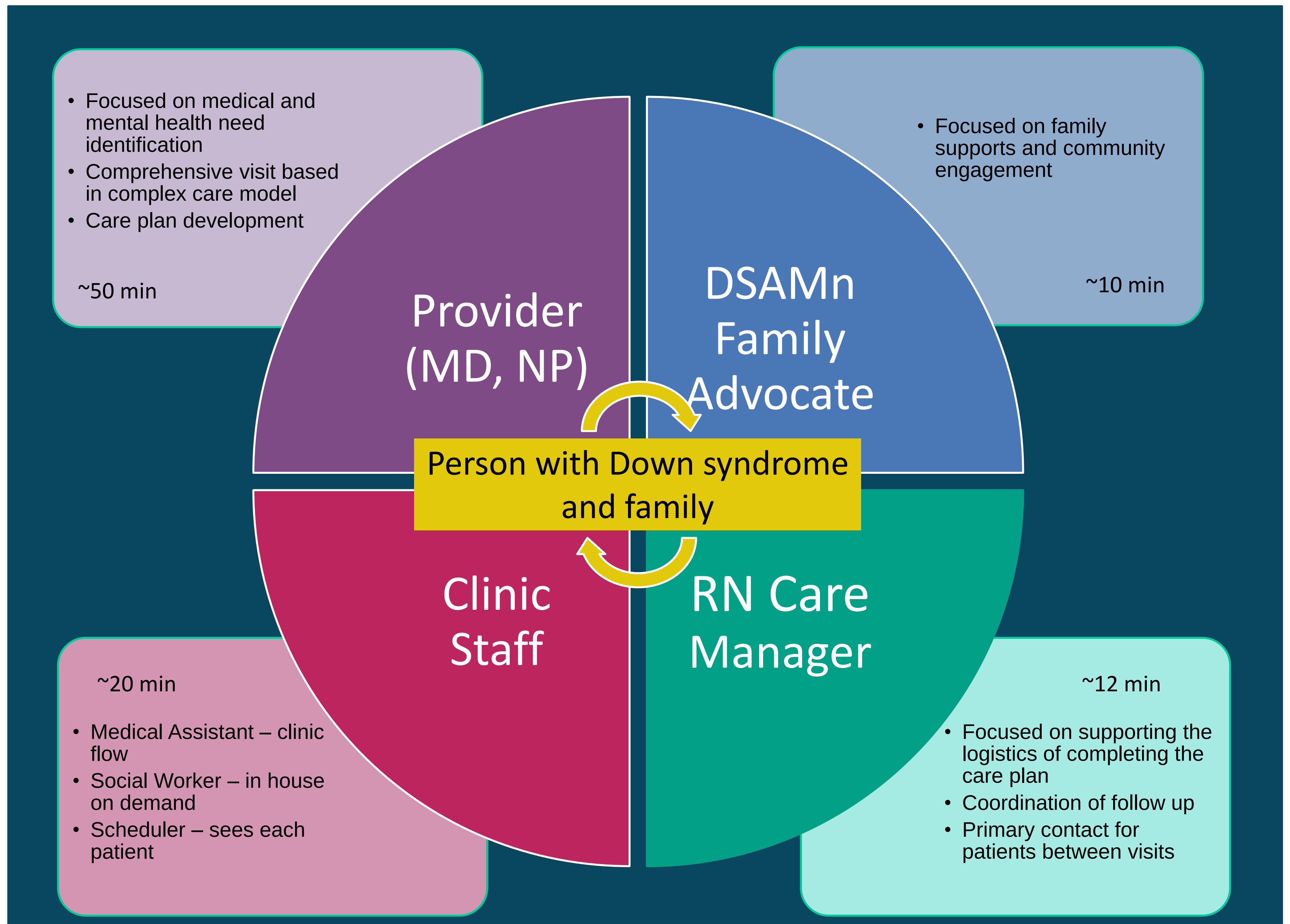
BACKGROUND & OBJECTIVES

- Traditional healthcare models for Pediatric Down syndrome care focus on the guidelines written by the American Academy of Pediatrics (AAP) which includes "offer parent-to-parent or support group information to family"
- Development of the Gillette Children's Down syndrome clinic began in early 2023 with engagement of the Down Syndrome Association of Minnesota (DSAMn).
- Gillette Children's has a robust Complex Care program, serving 1,300 children and young adults with medical complexity. But there was still a gap in caring for persons with Down syndrome.
- This project demonstrates a holistic care model by integrating medical care with social and familial support through a partnership between a healthcare system and a local family support organization starting in November 2024.

METHODS

- The clinic structure and nursing/provider team was modeled after the existing Complex Care and Muscular Dystrophy Association Neuromuscular Clinic at Gillette Children's.
- Incorporation of in-clinic Family Advocates from DSAMn required logistical consideration of contract agreements, staff training, compliance with HIPAA regulations, staff vaccination protocols, and identification of clinic flow with prolonged appointment duration.
- Shared commitment to holistic care required strong communication channels and clearly defined roles foster collaboration between clinicians and support group representatives.
- Using informal Plan-Do-Study-Act (PDSA) cycles, the clinic has evolved to incorporate continuous feedback from families and healthcare providers.
- Patient reported outcomes are collected at baseline and then every 6-12 months thereafter.



Provider (MD, NP)
- Focused on medical and mental health need identification
- Comprehensive visit based in complex care model
- Care plan development

~50 min

DSAMn Family Advocate
- Focused on family supports and community engagement

~10 min

Clinic Staff

~20 min
- Medical Assistant – clinic flow
- Social Worker – in house on demand
- Scheduler – sees each patient

RN Care Manager

~12 min
- Focused on supporting the logistics of completing the care plan
- Coordination of follow up
- Primary contact for patients between visits

Person with Down syndrome and family

Figure 1: Clinic Flow

Above noted times are based on a time study over 4 weeks

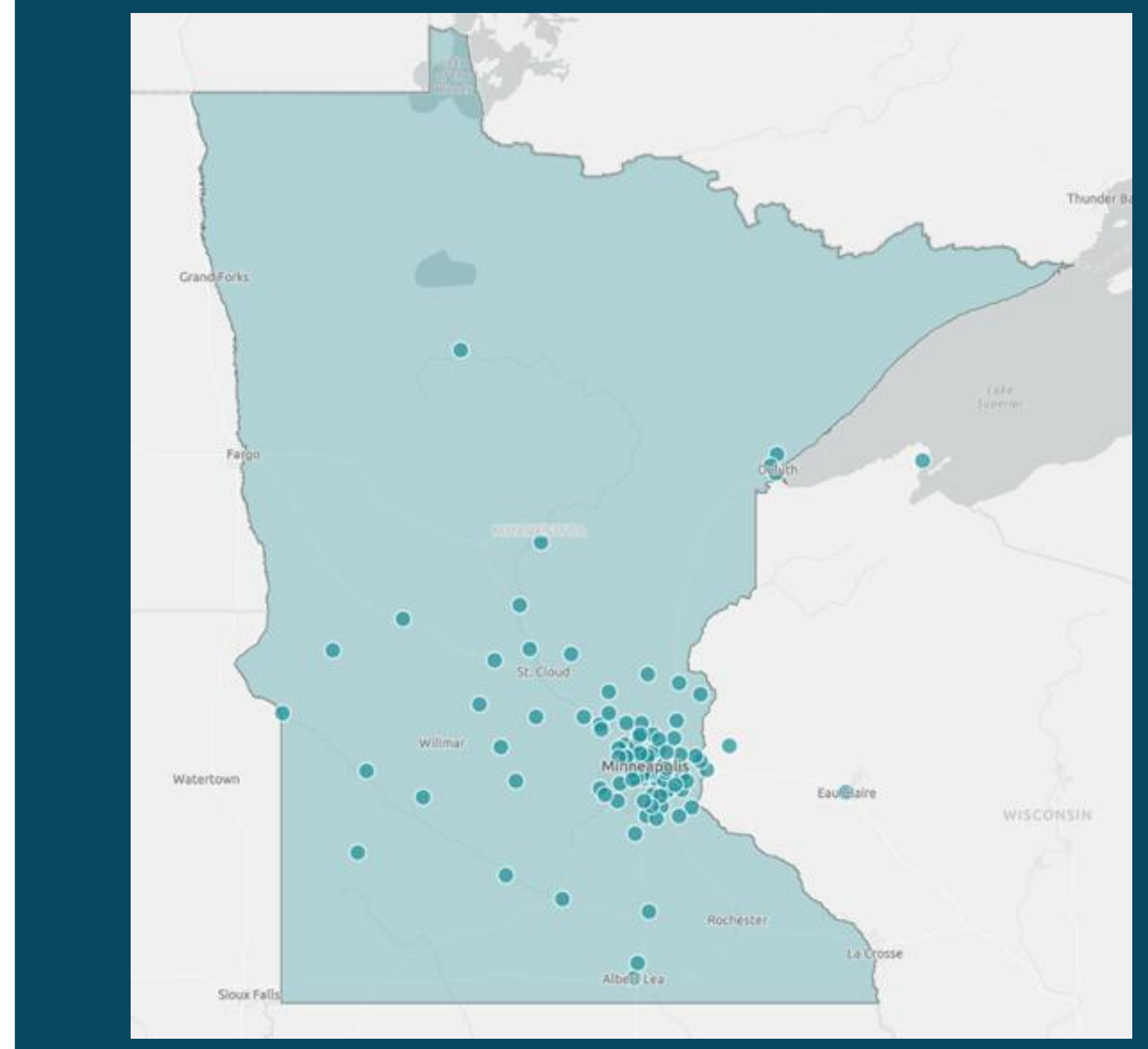
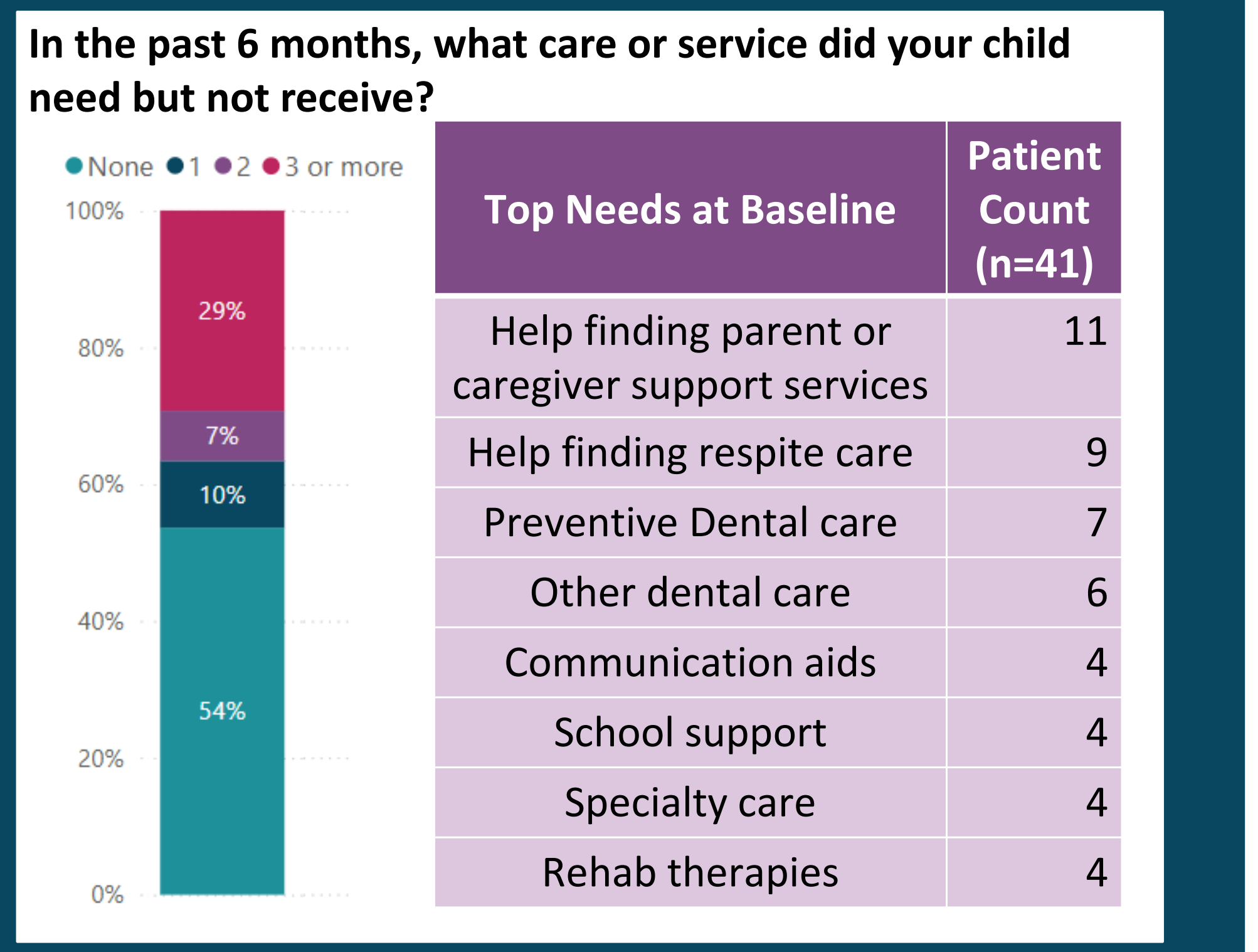


Figure 2: Patient Reach

Locations ranged from twin cities metro to greater MN and western WI



In the past 6 months, what care or service did your child need but not receive?

Top Needs at Baseline	Patient Count (n=41)
Help finding parent or caregiver support services	11
Help finding respite care	9
Preventive Dental care	7
Other dental care	6
Communication aids	4
School support	4
Specialty care	4
Rehab therapies	4

Figure 3: Baseline Patient Reported Outcomes: Unmet needs

Survey adapted from the Family Experience with Care Coordination (FECC) Survey)
Includes some patients followed in complex care clinic previously.

RESULTS

- In the first 7 months of clinic, a total of 111 patients were enrolled with a total of 16 patient appointment slots available every four weeks. Currently there is a 5 month wait for a new patient appointment.

Table 1: Demographics

	Connected to DSAMn Prior	Not Connected Prior
Total (n=111)	73%	27%
Gender		
Male (n=64)	81%	19%
Female (n=47)	62%	38%
Age		
0-5 (n=32)	50%	50%
6-12 (n=27)	85%	15%
13-18 (n=17)	82%	18%
19-25 (n=35)	80%	20%
Race		
White (n=76)	84%	16%
Black (n=16)	31%	69%
Asian (n=5)	40%	60%
Other (n=14)	89%	11%

- 30 families were not connected prior to the visit and 17 identified as BIPOC+. From this, 14 of the 17 families opened a case to address unmet needs at the visit.
- Clinic time studies performed by Performance Management Strategy Office supported clinic workflow efficiencies and more accurate expectation setting for patients and families.
- Monthly DSAMn/Gillette clinic process discussions revealed need for addition of infant slots, refinement of team roles, strategies for raising awareness of the clinic within the community, and direct feedback from Down syndrome community "insiders."

DISCUSSION & FUTURE DIRECTIONS

- Integrating a family support organization within a Down syndrome clinic enhances service delivery, ensuring that care is holistic - addressing both medical and social factors.
- This model provides a replicable framework for integrating family support groups into specialized healthcare settings.
- Future directions: Continuing to grow the clinic to reach more patients with Down syndrome. Integrating more with the Down syndrome community to further connect and provide optimal patient care
- Utilizing the Learning Health System model to incorporate Patient Reported Outcome insights into clinic design and growth.

References

1 .Marilyn J. Bull, Tracy Trotter, Stephanie L. Santoro, Celanie Christensen, Randall W. Grout, THE COUNCIL ON GENETICS; Health Supervision for Children and Adolescents With Down Syndrome. Pediatrics May 2022; 149 (5): e2022057010. 10.1542/peds.2022-057010