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OVERVIEW

November 2019 University of Missouri Thompson Center launched the monthly multidisciplinary pediatric Down syndrome clinic.

Team members have included:
Clinic coordinator
Pediatric ophthalmologist
Pediatric endocrinologist and NP
Developmental pediatrician
Speech Language pathologist
Otolaryngology and Audiology
Social work

CLINIC STATS

16 clinic sessions as of May 2021
29 unique patients seen in Down syndrome clinic
46 patient visits
125 arrived visits

8 babies under age two are followed in the infant clinic
51 total individuals seen at our center age 40 to 2 months

FUNDING and LOGISTICS

REDCap database established with \$10,000 Sears grant trust funding.
Children's Miracle Network Funding: \$5,000 grant.

Thompson Center hosts the clinic as it has a mission to support interdisciplinary care for children with neurodevelopmental disabilities. MU Health care and the Thompson center provide the clinical support.

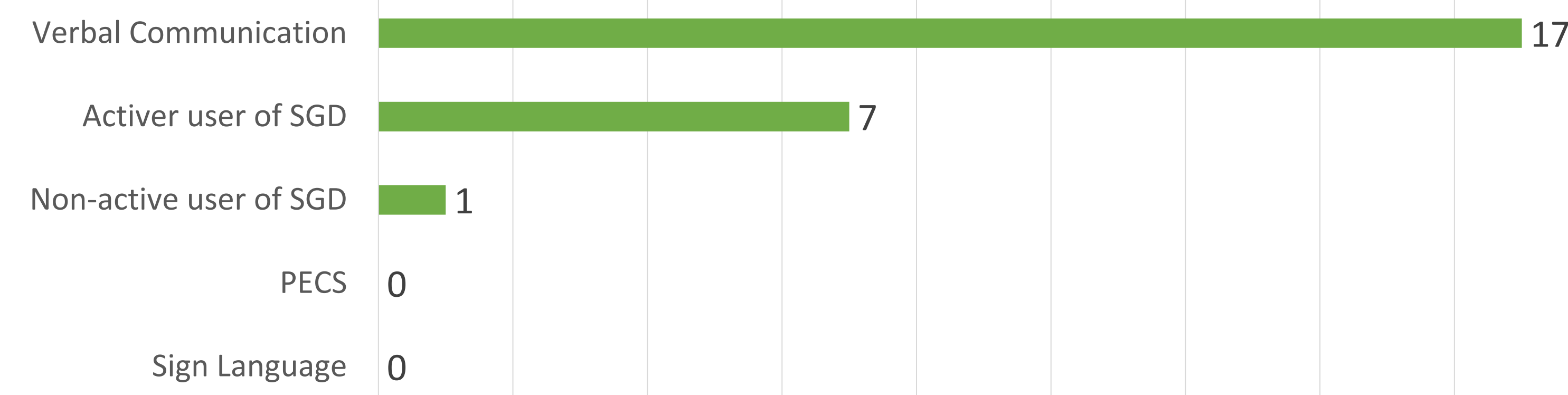
Administrative time is being utilized by endocrinologist and developmental pediatric team members at this time to start this clinic until volumes are more consistent. Speech language department obtains authorization and bills for the speech language evaluation.

Pediatric ophthalmology integrates patients from Down syndrome clinic into a modified existing clinic in order to have expected productivity.

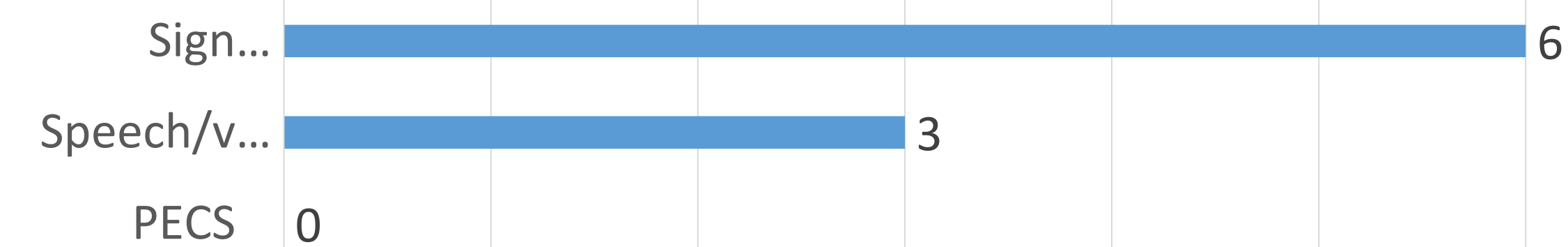
Clinic coordinator has multiple roles and coordinating this clinic was added to her work load.

COMMUNICATION

Primary Expressive Communication



Secondary Expressive Communication



Hearing: 2 children have hearing aids.

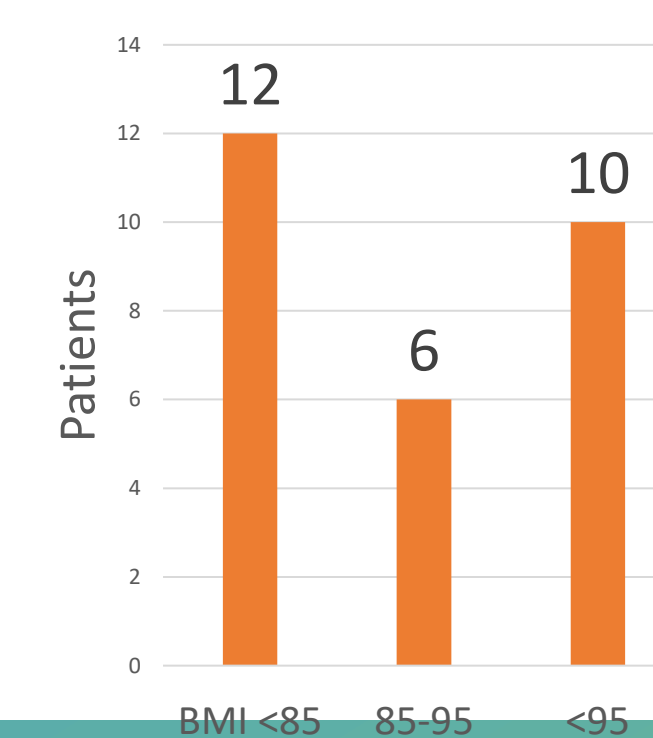
ENDOCRINE

Hypothyroidism 59% 17/29

Average dose levothyroxine is 50 mcg with a range of 25-137

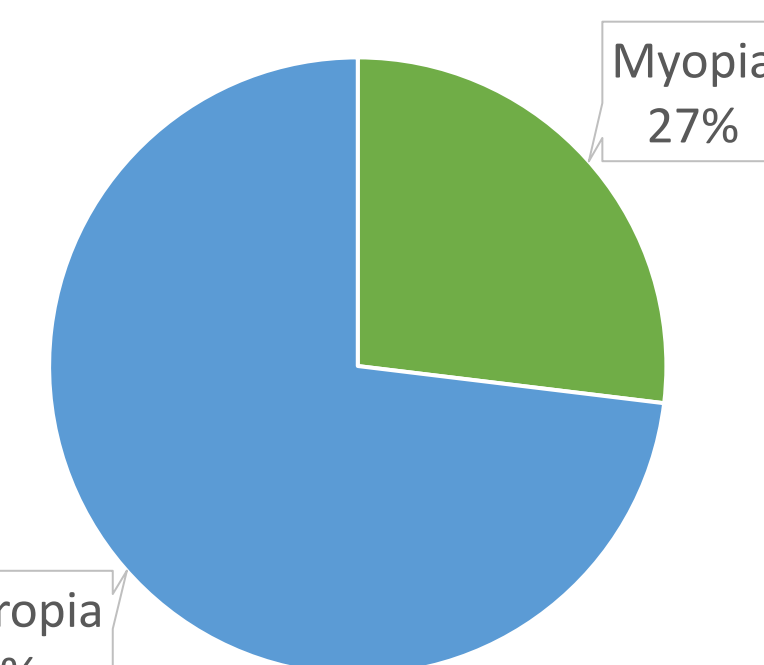
BMI data

Healthy weight 42%
Overweight or obese 57%



OPHTHALMOLOGY

Prescription lenses 79%

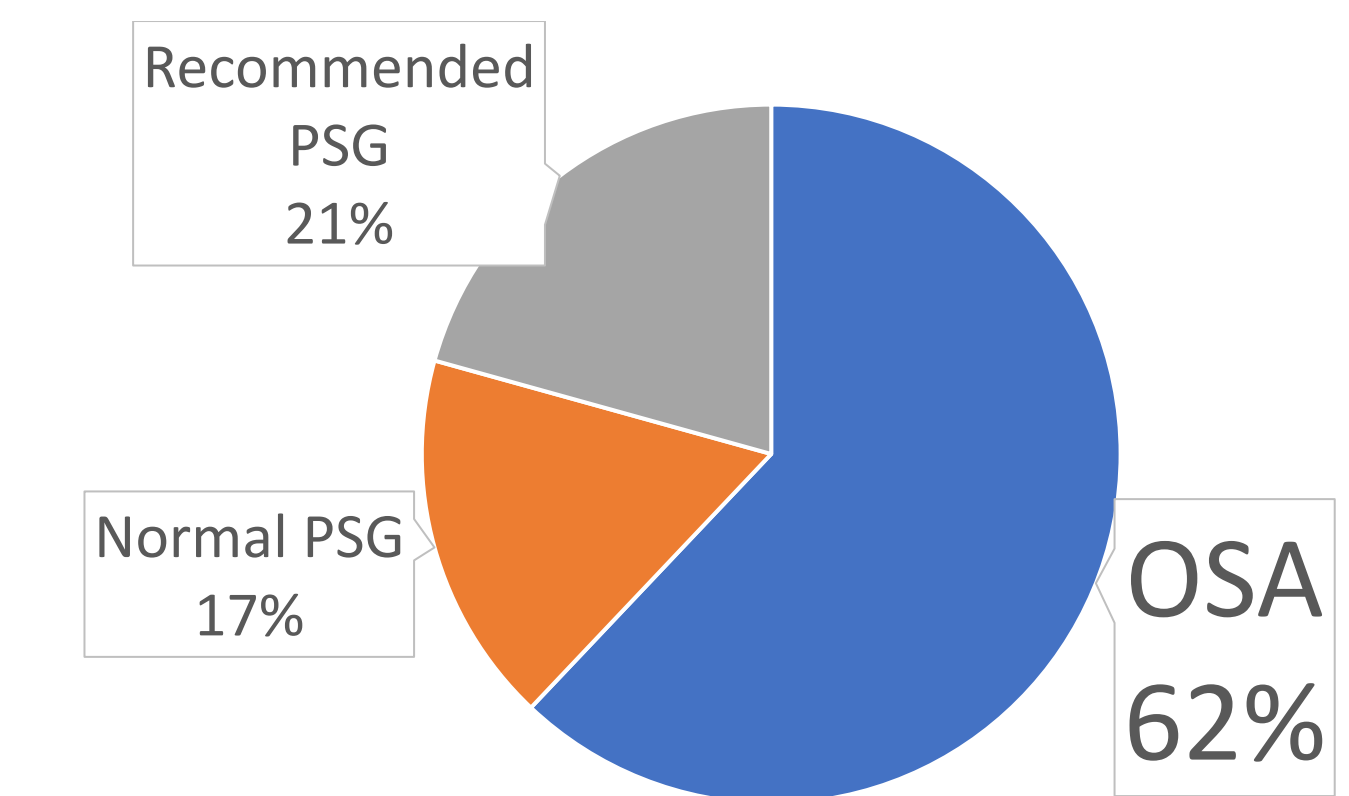


10/27 with strabismus
3 children were observed to have pseudopapilledema

CO-OCCURRING ASD

3 individuals currently have a formal diagnosis of autism with an additional 3 that have a suspected diagnosis and have been referred for formal testing. MCHAT screening, STAT, RITA-T.

OBSTRUCTIVE SLEEP APNEA



Average AHI is 21 with a range of 0.63 to 67
10/29 have had T&A

We have 3 individuals who have been prescribed CPAP. Compliance is 0 hours per night for 2 and one child will tolerate an average of 2 hours per night.

DISCUSSION

Children with Down syndrome have medical needs that require vigilance. Having a dedicated team is important.

Audiology to start coming to the center in August. Pulmonary is the next provider type we anticipate adding.

Having a dedicated clinic has given us the opportunity to increase communication with regional Down syndrome organization Down Syndrome Innovations. We have been able to partner with KUMC to recruit for NIH funded DS Determined study. We have recorded a podcast about the clinic and communication needs of children with Down syndrome. Improved educational materials for families.

Due to our location within an established autism center we have opportunities for partnerships with ABA providers, therapists and psychologists.

A single clinic space with access to the specialized equipment needed by subspecialists is a challenge. Initially we had patients were going to 4 different locations in our health system within 4 hours.

ENT had to bow out of this clinic early on due to high clinical demands and scheduling conflicts.

Due to demand we have expanded the clinic to accommodate a total of 6 children in a half day session.