

Early Therapies, School Supports, and Educational Outcomes for Students with Sex Chromosome Variations: Preliminary Results from an International Survey

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Background

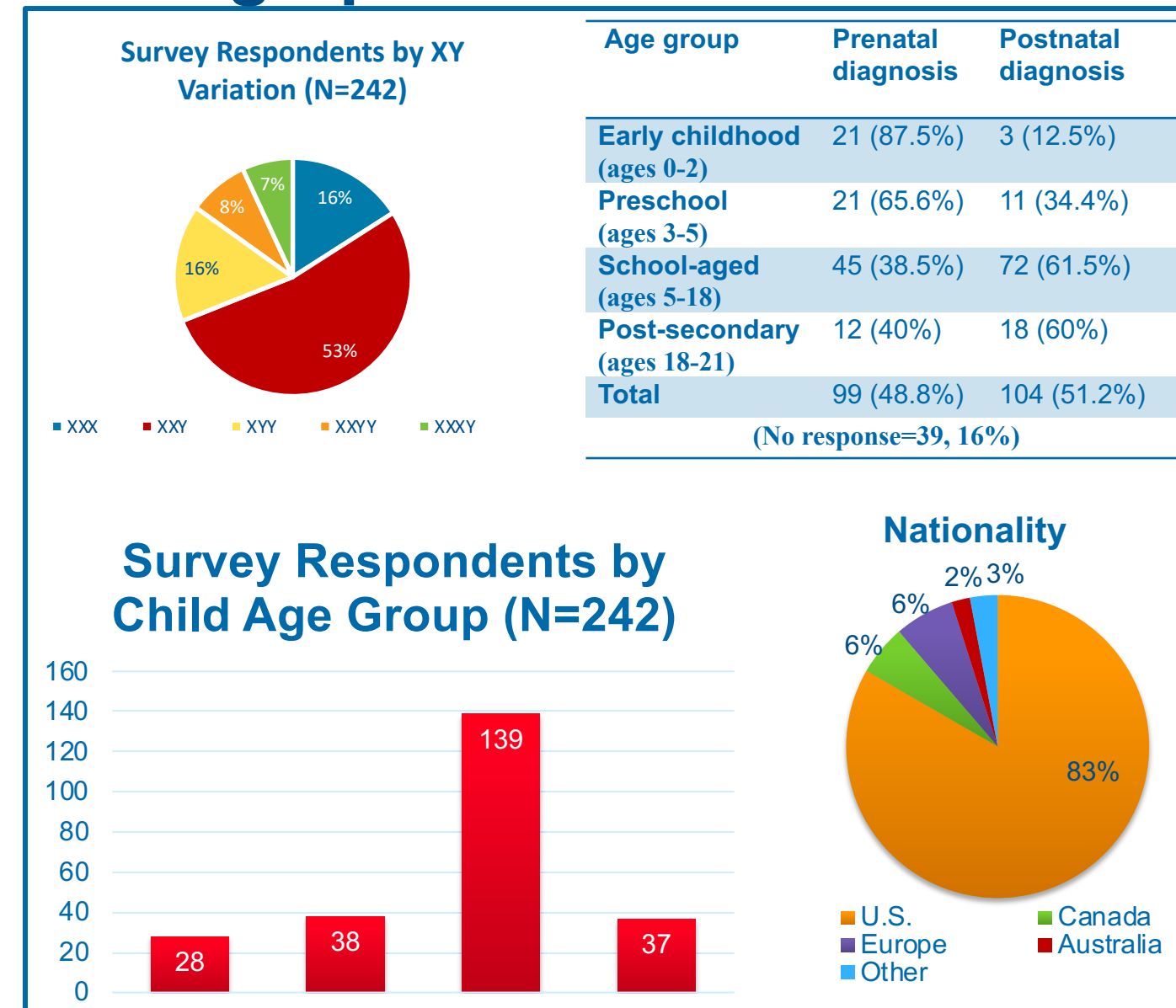
- There are well-documented risks in X&Y variations that result in a need for community interventions, therapies, and school supports including risk for:
 - Developmental delays
 - Speech-language disorders
 - Learning disabilities / Dyslexia
 - ADHD, executive functioning difficulties, anxiety disorders, autism
- Data on educational needs and outcomes in X&Y variations are limited in scope and out of date
- This international survey aims to update our understanding of public supports, therapies, and educational outcomes for students with X&Y variations

Methods

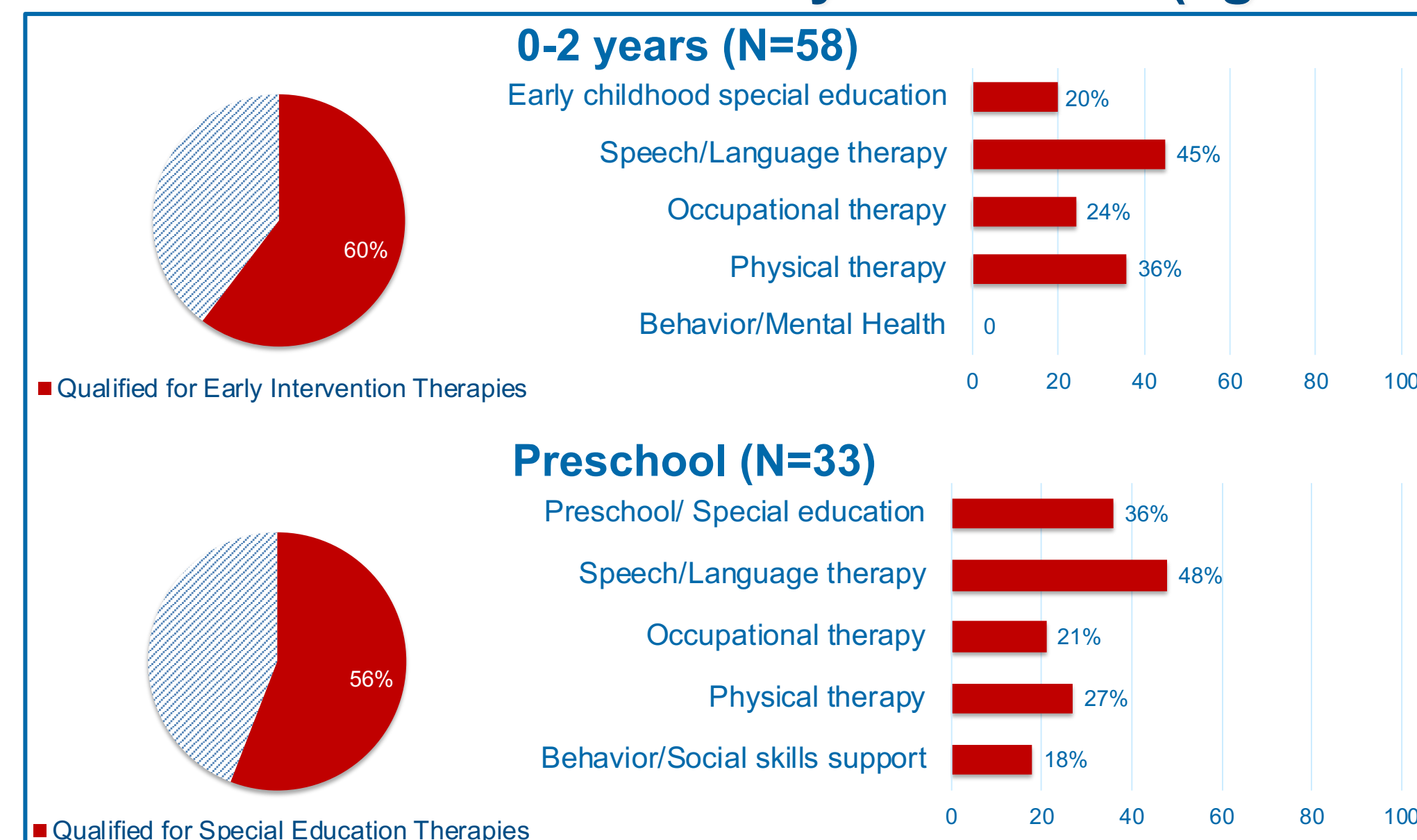
- International, electronic survey of parents of children ages 0-21 with diagnosed X&Y variations
 - 5-20 minute survey
 - Mixture of true/false, multiple choice, and short answer questions
- Disseminated through AXYS and eXtraordinary Kids Clinic email lists and social media websites
- Ongoing data collection; data was pulled on 5/30/2019 for this analysis
- Data collected and stored in REDCap database at the University of Colorado
- Descriptive statistics conducted in Microsoft Excel

Results

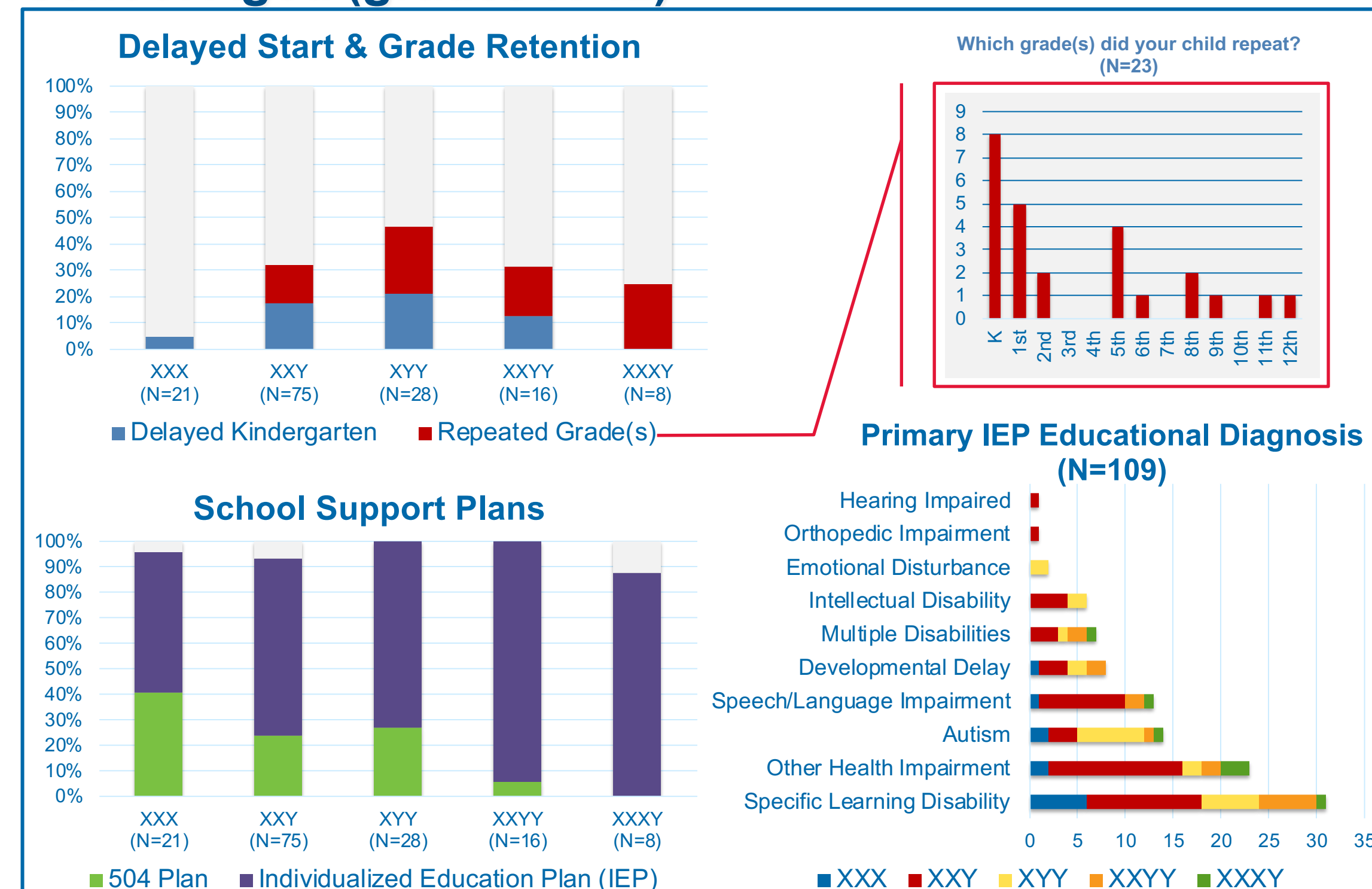
Demographics



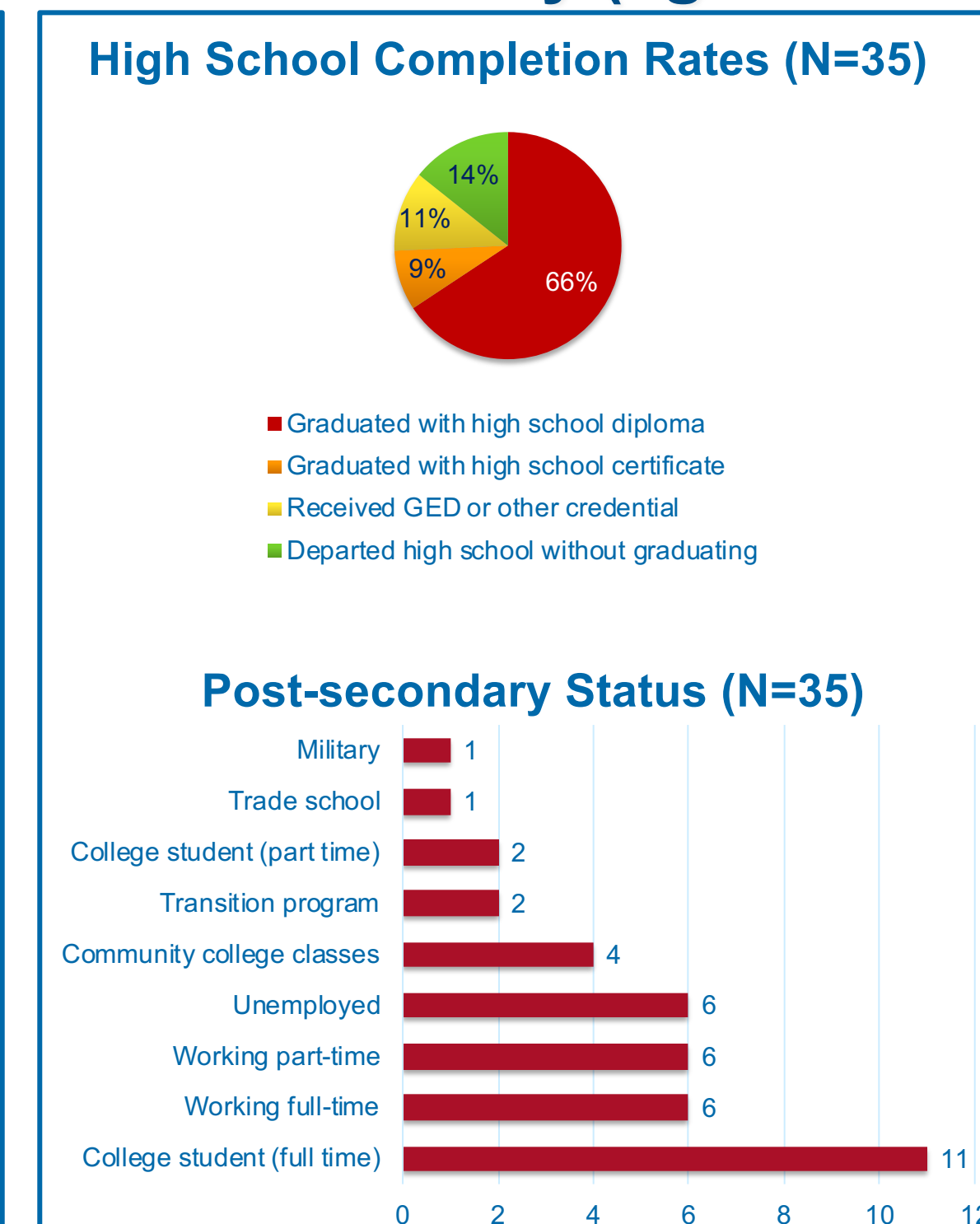
Early Childhood (ages 0-5)



School Aged (grades K-12)



Post-Secondary (ages 18-21)



Conclusions

- Over half qualify for early intervention services or special education preschool
- Speech therapy is the most common intervention for birth to five population
- Over 90% of school aged children surveyed receive some type of educational support plan (either specialized instruction through an IEP or classroom accommodations through a 504 Plan)
- Specific Learning Disability is the most common reported primary educational diagnosis for special education, followed by Other Health Impairment, Autism, & Speech Language Impairment
- There appears to be some variation in educational diagnosis by X/Y condition
- The majority graduate high school & pursue some type of post-secondary education

Implications

- Continue to collect survey data- especially in underrepresented X&Y variation populations (XXX, XYY, XXYY, XXXY)
- Inform the creation of educational guidelines for students with X&Y variations
- Inform genetic counselors, pediatricians, educators, and ECE service providers:
 - Common need for early therapies & educational supports across lifespan
 - Possibility for positive educational outcomes

Disclosures

- The authors claim no conflicts of interest