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- Data on educational needs and outcomes in X&Y variations are limited in scope and out of date.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

Early Childhood (ages 0-5)

- 0-2 years (N=58)
  - Early childhood special education
  - Speech/Language therapy
  - Occupational therapy
  - Physical therapy
  - Behavior/Mental Health

- Preschool (N=33)
  - Preschool Special education
  - Speech/Language therapy
  - Occupational therapy
  - Physical therapy
  - Behavior/Social skills support

School Aged (grades K-12)

- Delayed Start & Grade Retention
  - Within grades: did your child repeat?
  - School Support Plans

Post-Secondary (ages 18-21)

- High School Completion Rates (N=35)
- Post-secondary Status (N=35)

Implications

- Continue to collect survey data especially in underrepresented X&Y variation populations (XXX, XYY, XXXY, 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

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