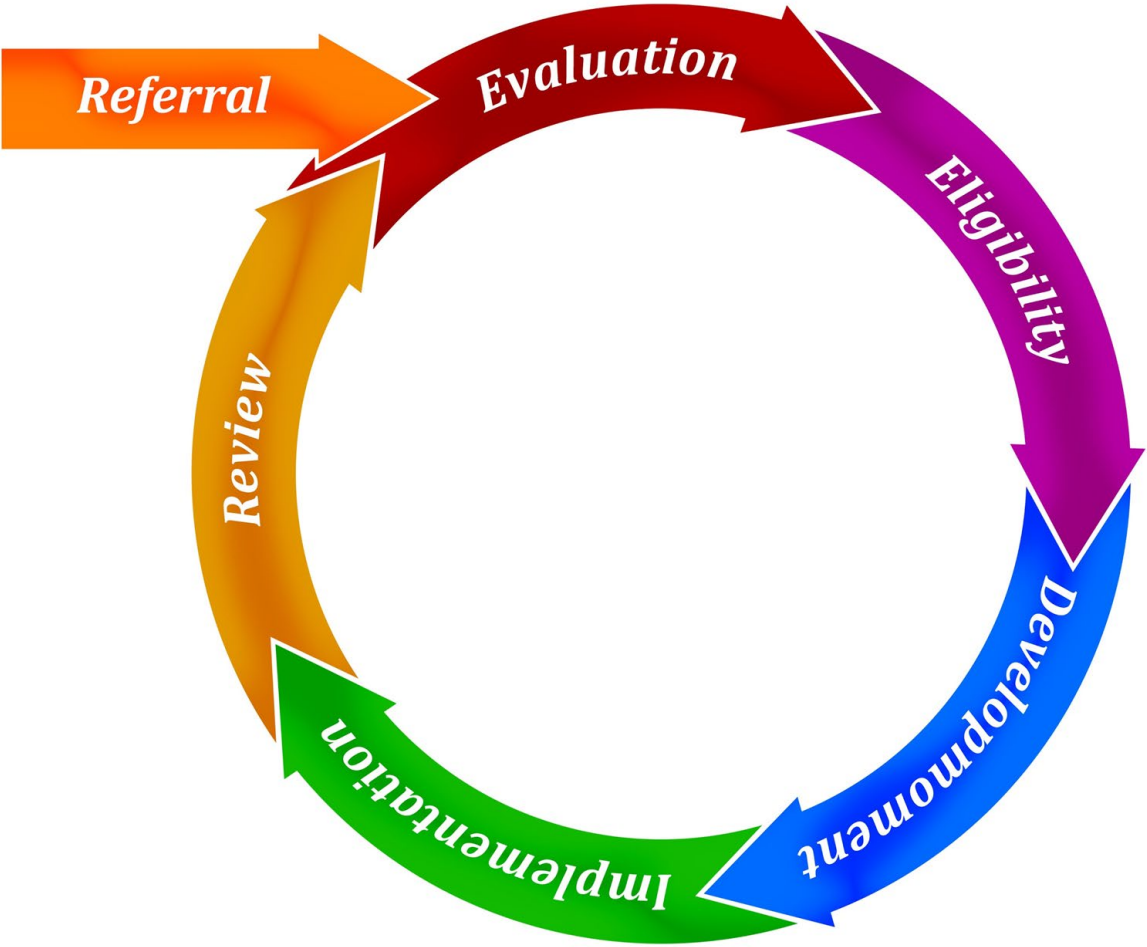


Navigating the IEP Process and Beyond

An overview for newcomers to testing,
accommodations and the IEP/504 process

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Role of Parents during the IEP Process

- Equal partners on a team - by law
- Part of the decision making process
 - No unilateral decision making
- Expert on your child
 - Provide invaluable feedback on your child's strengths and weaknesses
 - Person with the "whole picture" of your child's development - continuity
- Expert on sex chromosome aneuploidies
- The IEP cannot be changed, developed, implemented or ended without your consent

Reasons to Request a Referral

- Pediatrician evaluation suggests child is not meeting developmental milestones
 - Communication
 - Gross motor skills
 - Social interaction
- Child has an identified learning or physical disability
- Child is struggling with
 - Schoolwork (math, reading, writing)
 - Making friends
 - Paying attention
 - Motor skills - coloring, writing, cutting

Referral

- You do not need a referral from a pediatrician to request an evaluation
 - However, pediatrician feedback can be valuable
- You can make the referral yourself
 - Birth - 3 - Contact state early intervention office
 - 3-18 - Contact local public school system
 - Can go through school directly if your child is already enrolled
- Referral requests should be made in writing
 - Deadlines vary by state, but each state must respond within a certain number of days
 - Include specific concerns

Evaluation Birth - 5

Multidisciplinary Developmental Assessment:

- Physical/ Motor
- Cognitive
- Communication
- Social/Emotional
- Adaptive

Special Areas of Concern for X&Y Variations - Birth to 5



Motor Development

- Low muscle tone
- Delayed motor milestones (sitting up, crawling, walking)
- Asymmetry in motor movements



Language Development

- Delayed or limited expressive language
- Lack of response to name
- Poor understanding of frequently used words (mama, dada, milk, bottle)



Cognitive Development

- Fleeting attention span
- Difficulty learning early academic concepts (shapes, colors, letters, counting)



Social-Emotional Development

- Poor self-regulation
- Lack of social reciprocity
- Sensory seeking or avoiding behaviors
- Anxiety

Areas of Evaluation - School Age

- Cognitive (Verbal and non-verbal)
- Language (receptive and expressive language)
(Several expressive language things)
- Fine and gross motor skills
- Social and Emotional Adjustment
- Functional Behavior Assessment
- Academic Skills/Achievement
- Social and educational history
- “Comprehensive educational assessment”

Special Areas of Concern for X&Y Variations School Age Years

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Academic

- Reading decoding
- Reading comprehension
- Writing



Social-Emotional & Behavior

- Social skills
- Anxiety
- Mood/Depression



Executive Function

- Inattention
- Organization & Time management
- Transitioning/ Cognitive Shifting



Communication

- Expressive language
- Pragmatic language

Eligibility Meeting

- What happens
- Who's involved
- Possible results
 - No eligibility, IFSP, IEP or 504
- Common issues with eligibility
- Not “behind enough compared to peers”
 - This is an individual plan designed to help your child reach their full potential

Special Education Categories

- Autism*
- Blindness
- Deafness
- Emotional Disturbance*
- Hearing Impairment
- Intellectual Disability*
- Multiple Disabilities*
- Orthopedic Impairment
- Other Health Impaired*
- Specific Learning Disability*
- Speech or Language Impairment*
- Traumatic Brain Injury
- Visual Impairment

**Categories most often used to qualify students with X&Y Variations. No specific category for this type of chromosomal variation.*

If Eligible for Special Education (IEP or IFSP)

Developing an IEP/Parts of an IEP

- Present levels
 - Results of testing
 - Parental input
- Individualized instruction and/or services
 - Separate from goals
 - Typically extra services (OT, PT, reading/math intervention, speech, etc)
- Goals - specific, measurable.
 - Can have as many as needed
 - Can include social/emotional/behavior goals
- Supports (accommodations)

Sample IFSP

9 month old with an SCA - Reflects only portions of IFSP

- Present Levels (areas of concern)
 - Communication - 7 months
 - Communication, receptive - 7 months
 - Gross motor - 6 months
- Eligibility
 - Chromosomal disorder (“diagnosed mental or physical condition with high probability of developmental delay”)
- Needs Summary *
 - Tongue protruding out at times
 - Does not meet expectations in associating words with actions

* Strengths would also be included in an IEP

Sample IFSP (continued)

■ Outcomes (Goals)

- Developmental skills to progress at the appropriate place particularly with walking and communicating wants and needs

Strategies - Play strategies will be provided to help foster gross motor and communication developmental skills. Consultation between physical and speech therapists.

Measurable Criteria - Child will associate 10 sounds and words with an action label. Child will crawl and/or walk as a means to move about the house

■ Type of Service

Physical Therapy, 4 sessions monthly, 45 minutes per session, individual therapy, at home

Speech Therapy - 2 sessions monthly, 45 minutes per session, individual therapy, at home

If Eligible for 504

- An “individual with handicaps” is any person that (i) has a physical or mental impairment which substantially limits one or more major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment.
- A 504 Plan
 - Recognizes a student with disabilities needs for support
 - Does not provide individualized instruction

Sample IEP

7 year old with an SCA - Reflects only portions of IEP

- Present Levels (Areas of Concern)

 - Expressive and receptive language including:

 - Articulation

 - Expressing wants and needs

 - Reading comprehension

 - Following directions

- Eligibility

 - Other health impairment

- Needs Summary *

 - Actively participates in speech therapy. Transitions well. Increased attention to tasks. Making progress with all speech and language goals.

*Strengths would also be included in an IEP

Sample IEP, Continued

■ Outcomes/Goals

- Given visual and verbal cues, child will use complete sentences to retell a verbally presented short story with 80% accuracy in 4 out of 5 sessions

Child will utilize irregular past tense verbs while formulating sentences with 80% accuracy in 4 out of 5 sessions

Child will follow multi-step auditory directions with with 80% accuracy in 4 out of 5 sessions

■ Services/Accommodations/Modifications

Assessments spread over several days with frequent breaks, specialized instruction in writing skills (daily in class,) oral presentation of directions (daily in class) speech therapy (60 minutes weekly,) physical therapy consult, occupational therapy (30 minutes weekly)

Development of a 504 Plan

- Areas of discussion:
 - Documentation of disability
Student needs
- Things included in a 504 plan
 - Areas of need
 - Accommodations, modifications, services and support - covering all areas of need
 - Classroom
 - Transitions
 - Therapies
 - Special events (like assemblies, fire drills, etc.)
- Things to be wary of
 - Standardized 504 plan based on a specific disability

Sample 504 Plan

13 year old with an SCA

- Eligibility

 - Generalized anxiety disorder

- Areas of Need

 - Sensory, anxiety management

- Accommodations

 - Frequent breaks (outside of the classroom)

 - Quiet space available when needed

 - Noise cancelling headphones available

 - Preferential seating if needed

Main difference between IEP and 504

	IEP	504
What it does	Provides individualized special education and related services to meet a child's unique needs.	Provides services and changes to the learning environment to enable students to learn alongside their peers.

Private Schools and IEPs

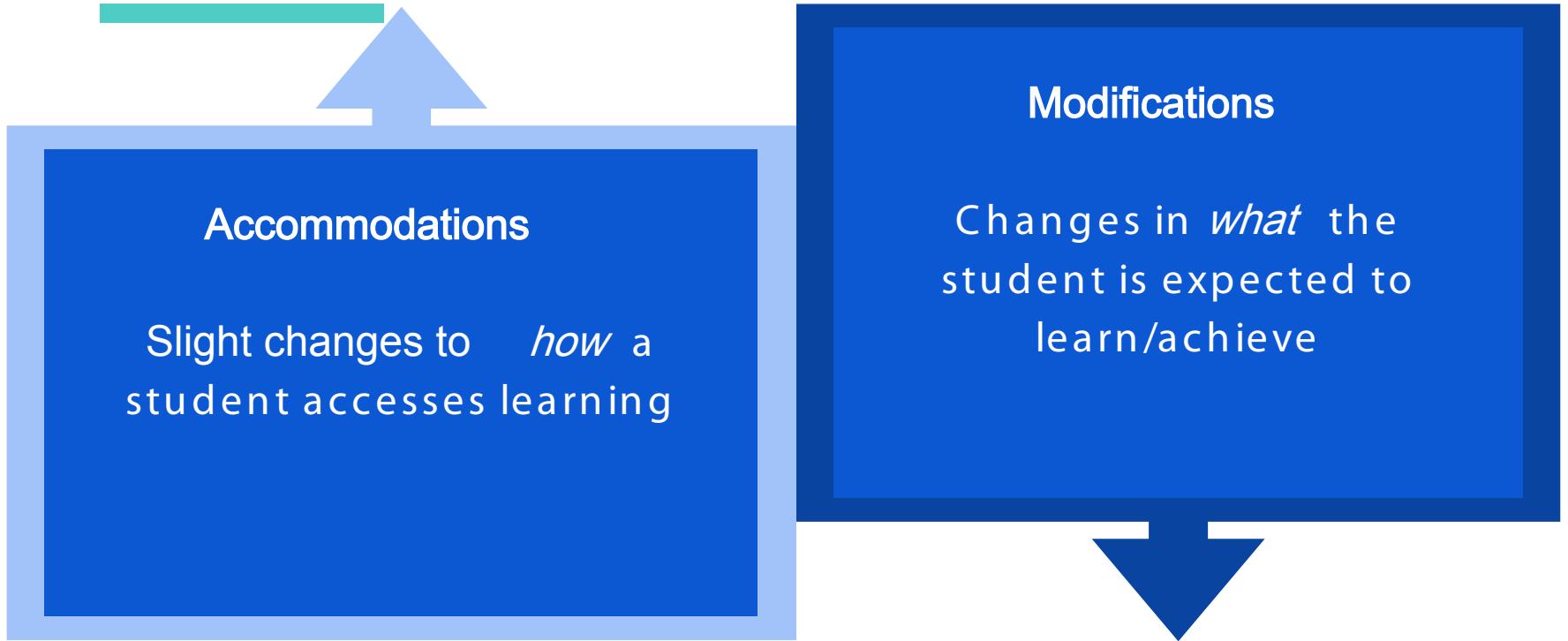
- Private schools *can* - but are not legally obligated to - provide special education services
- School systems may decline to evaluate students enrolled in a private school
 - Should a public school system evaluate a student, they may develop a “service plan”
 - “Equitable services” - designed to supplement the services already provided by the private school

Examples of Accommodations



Area of concern	Behavior	Possible accommodation or service
Sensory issues	Avoidance or distress at loud noises or bright lights	Provide special lighting or acoustics
Attention	Can't sustain focus to task, fidgety	Provide on -task focusing prompts, allow frequent moving breaks, allow use of fidget toys
Delayed expressive language	Infrequent or difficult to understand speech	Evaluation and support from speech therapist
Fine motor skills	Physical difficulty with writing - takes a long time, is hard for child to write	Allow answers to be dictated to a scribe, allow answers to be typed

Accommodations versus Modifications



Implementation

- IEP, with all accommodations, modifications, and supports/services are put into action
- Teachers, support, and outside therapists/instructors are provided a copy of the IEP
- Data collected during interventions, classroom work samples, etc. as it relates to showing progress towards goals
- Documentation
 - Regular updates from intervention or special instruction
 - Work samples
 - Birth - 5 typically relies on reports from therapies and what was done each time
 - Accommodation logs

Review

- How well has the plan worked in helping the child/student achieve success?
- Deletions or additions
- Need for further testing
- Return to evaluation or implementation, depending on need/year (most plans require full evaluations after a certain number of years to determine if student still qualifies for special education)

Post -Secondary Education

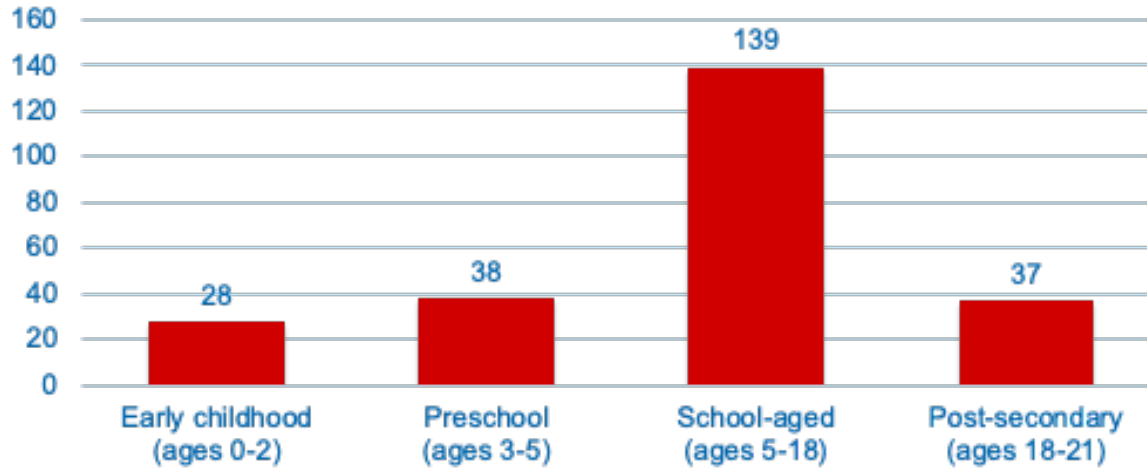
- Colleges do not have the same legal obligations as public school systems
- You can get accommodations!
 - Extended time on tests and assignments
 - Use of scribe
 - Text/voice software
 - Audio textbooks
- Campus resources such as writing centers, tutoring programs, academic coaches
- Apply through a school's disability services office
 - Not allowed to be a consideration

Educational Supports Survey

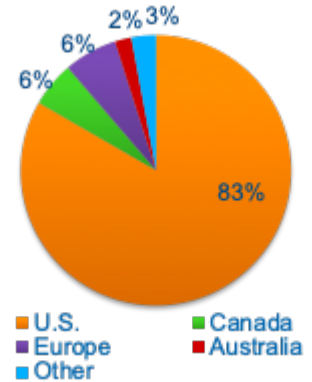
- International survey from the eXtraordinary Kids Clinic, Children's Hospital Colorado, University of Colorado School of Medicine
- Parents of children ages 0 -21 with X&Y variations
- Updating our understanding of educational needs and outcomes for students with X&Y variations
- N=242 (We are still collecting data!)
- Well distributed sample across the U.S.
- Canada, Europe, Australia also represented

Demographics

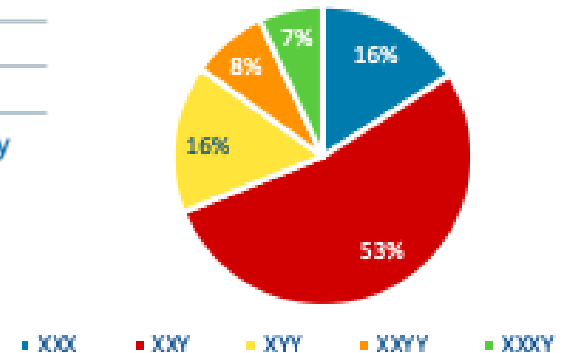
Survey Respondents by Age Group (N=242)



Nationality

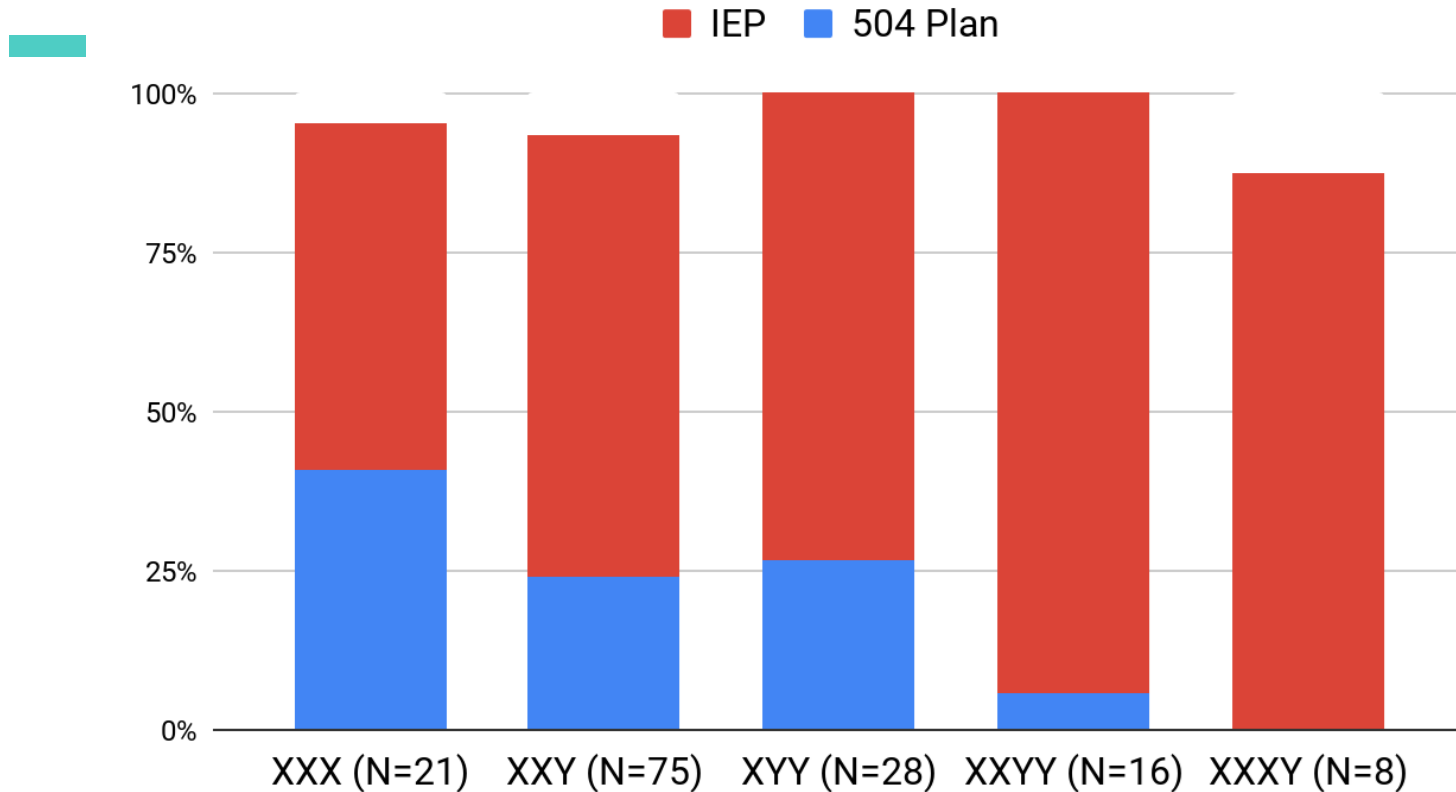


Survey Respondents by XY Variation (N=242)

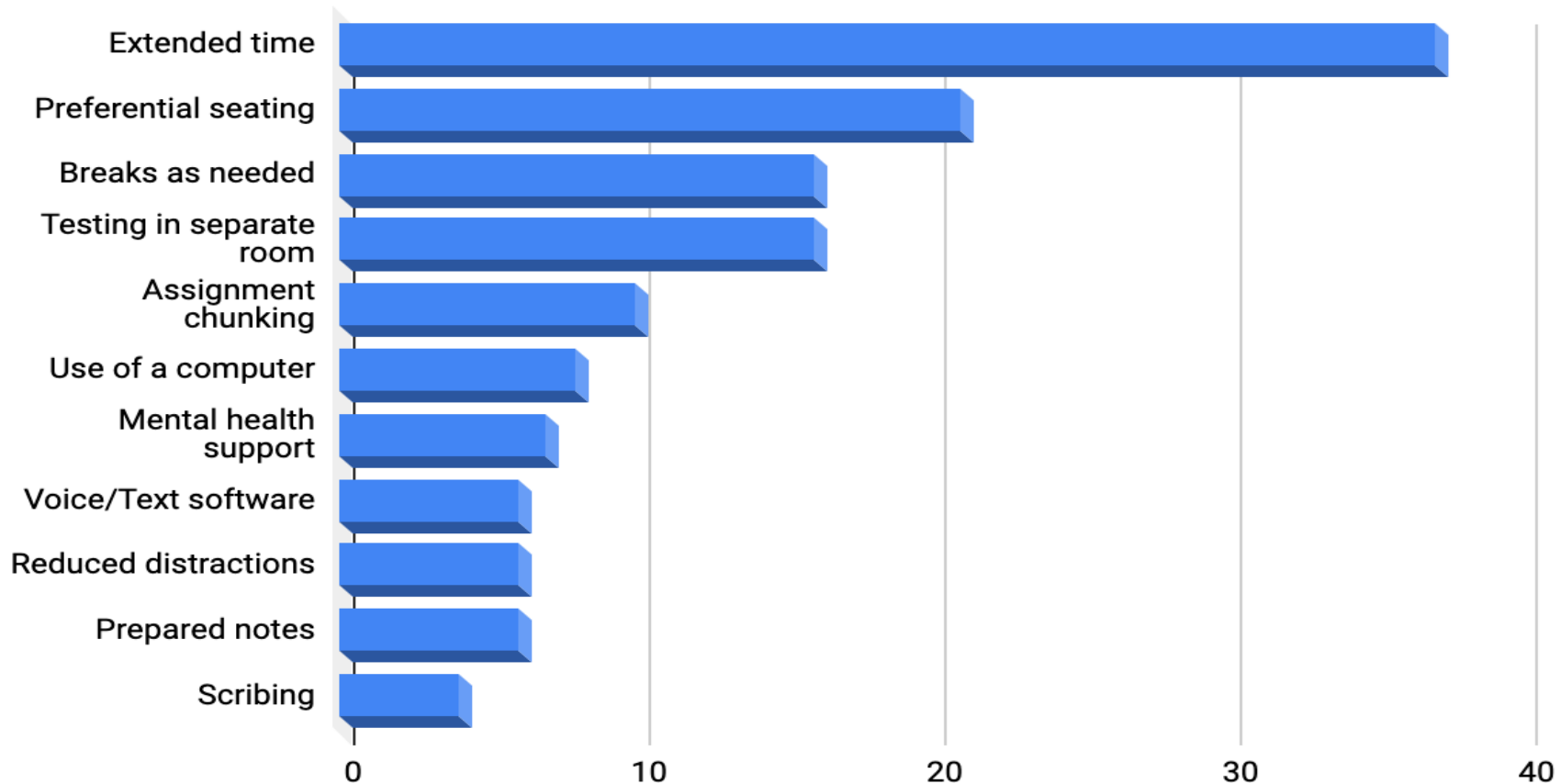


Preliminary Results: School Support Plans

(N=148)



504 Plan Accommodations (N=38)



IEP Primary Educational Diagnosis (N=109)

