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An Exploration of the Genetic Counselor's Role in The Individualized Education Program

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AN EXPLORATION OF THE GENETIC COUNSELOR'S ROLE IN THE
INDIVIDUALIZED EDUCATION PROGRAM

by

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ABSTRACT

Purpose: This exploratory study aimed to assess the knowledge of school psychologists and special education teachers regarding genetic conditions and the resources used in the development of individualized education programs (IEP) for students with genetic disorders. While the IEP process has been described for children with disabilities, literature explicitly focusing on children with genetic conditions is lacking. The rarity of genetic conditions often leaves school personnel with limited information. **Methods:** School psychologists (N=29) and special education teachers (N =14) throughout the United States participated in an online questionnaire. School psychologists were recruited from research committee listservs of state associations, and special education teachers were identified through the Council for Exceptional Children. The questionnaire included demographic questions, Likert-scale questions regarding perceptions, and open-ended responses. The questionnaire assessed current practices of school psychologists and special education teachers when developing and implementing IEPs for students with genetic conditions. **Results:** Overall, school psychologists and special education teachers felt that they had an adequate understanding of the services and expectations, as well as adequate knowledge to discuss IEP objectives about a genetic condition diagnosed in a child. Participants felt that additional information regarding the impact of symptoms on educational abilities, diagnosis, and future associated concerns could help set more realistic goals for students with genetic conditions. Providing information early in the IEP process (early childhood, at time of diagnosis, during background preparation, and during evaluations of IEPs) would

be most beneficial. Conclusions: These results suggest a desire for more information by the IEP team regarding genetic conditions. The participants reported that specific genetic information and the timing of the information would improve the development and implementation of IEPs for children with genetic conditions. While respondents identified little professional experience with a genetic counselor, they recognized that the role of a genetic counselor included expertise in the education of genetic information, as well as the counseling and support of patients and families. Collaboration with a genetic counselor could enhance the knowledge of IEP team members to improve decision-making during the IEP process for children with genetic conditions and identify additional resources available for team members.

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LIST OF ABBREVIATIONS

ASD	Autism Spectrum Disorder
AASEP.....	American Academy of Special Education Professionals
DSM-5	Diagnostic and Statistical Manual-Fifth Edition
ESSA	Every Student Succeeds Act
FAPE	Free and Appropriate Public Education
GEMSS	Genetics Education Materials for School Success
ICF.....	The International Classification of Functioning, Disability, and Health
IDEA.....	Individuals with Disabilities Education Act
IEP	Individualized Education Plan
LRE	Least Restrictive Environment
MCA	Multiple Congenital Abnormalities
NASET	National Association of Special Education Teachers
NASP	National Association of School Psychologists
NSGC	National Society of Genetic Counselors
WHO.....	World Health Organization

CHAPTER 1

BACKGROUND

1.1 Genetic Disorders

Genetic disorders are a group of heterogeneous medical conditions caused by damage to genetic material that can be inherited or occur by chance (de novo) during cell division. While the alteration most often presents in every cell of the body, only certain tissue types or body systems may be impacted. The clinical features can develop from Mendelian disorders or chromosomal abnormalities, including large and small DNA deletions or duplications, gene variants, and mitochondrial conditions. The presenting symptoms can vary among individuals, even with the same diagnosis. Age of onset ranges from a prenatal presentation to adulthood.

Many recognizable genetic conditions in pediatric populations include conditions with visible defects, notably severe symptoms, or life-shortening consequences. Many genetic diagnoses result in physical abnormalities and/or neurobehavioral disorders affecting intellectual abilities, movement, behavior, socialization, and communication. Genetic testing is standard practice for patients presenting with unexplained developmental delay, intellectual disability, autism spectrum disorder (ASD), and multiple congenital abnormalities (MCA) (Bowling et al., 2017; Miller et al., 2010). Up to 3% of the general population are diagnosed with developmental delay and intellectual disability, and around 1% of children in Western populations are affected by ASD (Genovese & Butler, 2020; Mefford et al., 2012). In individuals with severe intellectual disabilities, genetic mutations

cause 62% of cases. Around 40% of individuals with ASD are diagnosed with single-gene conditions, genetic syndromes, chromosomal abnormalities, or mitochondrial disruptions (Genovese & Butler, 2020; Gilissen et al., 2014). Identifying a genetic etiology can direct management, provide therapies, offer new treatments and clinical research opportunities, connect support systems, and improve the quality of care for affected individuals and their caregivers. The clinical features of genetic conditions have physical, emotional, psychological, and functional impacts on the lives of those affected. The manifestations of genetic conditions and the additional supports to accommodate the presenting clinical features can categorize individuals with genetic conditions as having a disability.

1.2 Definition of Disability

Disability is not a medical condition itself but rather an assigned societal label describing the perception of one's functional capacities. The International Classification of Functioning, Disability, and Health (ICF) defines disability as an umbrella term describing impairments, activity limitations, and participation restrictions. However, the World Health Organization (WHO) extends the definition to incorporate the negative aspects of interactions between individuals with health conditions (World Health Organization, 2011). The definition of disability is influenced by societal acceptance and public policy, thus shaping the laws and rights afforded to affected individuals. The consequences of cultural acceptance and laws form the support networks established within communities. Historically, individuals with disabilities have faced stigmatization and discrimination in a society, which negatively impacts their quality of life (Francis & Silvers, 2016).

1.3 Individualized Education Program (IEP)

1.3.1 History

Before the 1970s, children with disabilities were often excluded and denied public education in the United States. In 1975, the Individuals with Disabilities Education Act (IDEA) became federal law and established that children with disabilities receive free and appropriate public education (FAPE) alongside their peers. FAPE ensures that the education for students with disabilities is provided at no cost to families and offers services that meet the specific needs of each child, ranging from accommodations, modifications, therapies, counseling, and transportation. Additionally, the law requires that education be provided in the least restrictive environment (LRE) to promote academic success (Individuals with Disabilities Education Act [IDEA], 20 USC § 1400, 2004). The outcomes shifted the general education classroom towards inclusivity and changed how educational services were established for children with disabilities. The IDEA has been updated to accommodate changes. Still, it has not had a full reauthorization since 2004, and only minor changes have been made to the regulations (Office of Special Education and Rehabilitative Services, 2019a). In 2015, Every Student Succeeds Act (ESSA) passed to update No Child Left Behind, thus returning significant power to state and local jurisdictions when determining the design of performance assessments and the accountability systems used to measure the progress of students with learning disabilities (Darrow, 2016).

Under Part B of IDEA, the Individualized Education Program (IEP) is defined as the legal document between the family and the school district that determines the supports and services the student will receive to increase opportunities for academic, social, or developmental progress. The IEP is established within 30 days after an initial evaluation,

tailored to the specific needs of each child, and reviewed annually or upon parental request (IDEA, 2004).

1.3.2 Eligibility

While the IDEA requires public schools to provide free appropriate public education, it does not imply that every student who struggles in school will qualify for special education services. The eligibility for an IEP requires the child to have a disability that adversely affects academic success (Ball et al., 2018). In total, 13 categories are covered by IDEA: autism, deaf-blindness, developmental delay, emotional disturbance, hearing impairments, intellectual disabilities, multiple disabilities, orthopedic impairments, other health impairments, specific learning disabilities, speech or language impairments, traumatic brain injury, and visual impairments (IDEA, 2004). In 2018-2019, IDEA Part B served 6,315,228 students ages 6 through 21 years old. The four main categories of disabilities were specific learning disabilities (33%), speech or language impairments (19%), other health impairments (15%), and autism (11%) (Office of Special Education and Rehabilitative Services, 2019b). Genetic conditions do not have a specific category because they often cause various symptoms ranging from physical abnormalities to learning disabilities. Genetic disorders can fall into several categories that qualify students for IEP evaluations, and the category is specific to the presenting features in the child.

1.3.2.1 Specific Learning Disability. A specific learning disability is a disorder that affects the basic psychological processes involved in listening, thinking, speaking, reading, writing, spelling, or performing mathematical calculations (National Center for Education Statistics [NCES], 2020). A genetic condition called Turner syndrome is

diagnosed when individuals have a karyotype including monosomy X cells. Studies show that there is an increased prevalence of math learning disabilities in girls with Turner syndrome compared to the general population, and up to 75% of women with Turner syndrome will have some degree of difficulty with math (Hutaff-Lee et al., 2019). The cognitive phenotype of affected individuals can vary greatly. However specific deficits in visuospatial and executive skills, visual working memory, mathematics, and response fluency are well documented for individuals with Turner syndrome (Mazzocco, 2006).

1.3.2.2 Speech and Language Impairments. Speech and language impairments include disorders that affect the understanding or use of spoken or written language. Angelman syndrome is a rare neuro-genetic imprinting disorder that can cause developmental delays, hyperactivity, seizures, and the absence of speech (Margolis et al., 2015). While research describes a dissociation between receptive language and speech for individuals with Angelman syndrome, they can have non-verbal communication behaviors that would be supported with tailored services (Pearson et al., 2019).

1.3.2.3 Other Health Impairments. Other health impairments include disorders that impact physical strength, energy, and alertness due to chronic or acute health problems. Conditions for this category vary but include heart conditions, tuberculosis, rheumatic fever, nephritis, asthma, sickle cell anemia, hemophilia, epilepsy, lead poisoning, leukemia, or diabetes (NCES, 2020). A chromosome condition called 22q11.2 deletion syndrome, also known as DiGeorge syndrome or Velocardiofacial syndrome, can affect a wide variety of body systems with findings including dysmorphic facial features, congenital heart defects, immune deficiencies, kidney abnormalities, eye anomalies, hearing loss, skeletal differences, and developmental delays (McDonald-McGinn &

Sullivan, 2011). The special care needed to manage the variety of complications from 22q11.2 deletion syndrome can fall under other health impairments when determining the needs and services for an IEP.

1.3.2.4 Autism Spectrum Disorder. Autism Spectrum Disorder is described as individuals “having a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3, that adversely affects educational performance” (NCES, 2020). Phelan-McDermid syndrome is a condition caused by a chromosome deletion that results in dysmorphic features, as well as severely delayed or absent speech and autistic features (Phelan & McDermid, 2012). A study by Oberman et al. (2015) found that when assessing individuals with Phelan-McDermid syndrome for autism specific symptoms, the majority of the individuals displayed persistent deficits in social communication and variable features of restricted, repetitive patterns of behaviors or interests fitting within the criteria for autism based on the Diagnostic and Statistical Manual-Fifth Edition (DSM-5). Those with Phelan-McDermid syndrome can have IEPs targeting autistic behaviors to manage the impacts on their educational abilities.

1.3.2.5 Intellectual Impairment. NCES (2020) defines intellectual disability as “having significantly subaverage general intellectual functioning, existing concurrently with defects in adaptive behavior and manifested during the developmental period, which adversely affects the child’s educational performance.” Students with autism, developmental delays, learning and intellectual disabilities, and emotional disturbances account for 5-11% of the students served under IDEA (NCES, 2020). Fragile X is a repeat expansion genetic disorder that presents with intellectual disability, autism, hyperactivity,

and dysmorphic features. Fragile X is the most common inherited cause of intellectual disability and the second most prevalent cause after Down syndrome. Males with Fragile X will have mental impairment, and up to 25% of women with Fragile X will have intellectual disability (Salarriaga et al., 2014).

1.3.3 Components

The IEP records the present performance level of the child, short-term and long-term outcome goals, the established provisions for accommodations, and evaluation criteria. The document describes current abilities and challenges, social skills and behavior, and functional and quantifiable objectives for the year. The No Child Left Behind Act of 2001 states that students with cognitive disabilities, who cannot participate in general educational assessments, should participate in alternate assessments. This requirement creates a necessity for evaluation through measurable, timely, and attainable goals. The IEP must allow the child to make progress in the general education curriculum and fulfill the needs that result from the child's disability (IDEA, 2004). Furthermore, authorization of ESSA extends goal-setting to include measurable progress toward "ambitious long-term goals". The measurements are based on a student's progress and proficiency on state assessments, overall school quality, and state-determined accountability measures (Darrow, 2016).

The focus on goal setting increases the need for effective collaboration between members involved with the IEP team. Not only is the IEP a legal document, but the IEP is also a process that establishes a multidisciplinary team working in collaboration to support the academic goals of the child (Lee-Tarver, 2006). The IEP team can include the student, parent(s), regular education teacher, special education teacher, school system

representative, transition services agency representative, related service providers knowledgeable about the child, and individuals who can interpret evaluation results (US Department of Education, 2000). The obligation of collaboration promotes goal attainment and meaningful involvement for the student and ensures parents are equal partners in the IEP process (Cavendish & Connor, 2018). Student participation encourages self-advocacy and provides a platform to voice his or her own educational needs. Parents offer insight into specific interests of their child and verify the progress seen at home. The IDEA requires that the parents and children are central in the decision-making and planning, and additional personnel will depend on the needs of the student.

Other roles within the IEP process also contribute to the outcomes of the final IEP document. The general education teacher strategizes amendments to the general curriculum and supports behavior management. The special education teacher contributes information regarding curriculum modifications, supplementary aids, alternative assessments, and individualized instruction for the child (US Department of Education, 2000). Together, the general education teacher oversees the general implementation of classroom goals, and the special education teacher monitors the child's progress (Clayton et al., 2006; Rotter, 2014). Furthermore, the school administrators represent the school district, provide knowledge of the available services offered to the child, and make funding decisions (Beck & DeSutter, 2020). The transition services representative helps arrange and coordinate any needed transition planning between schools and health providers (US Department of Education, 2000).

Individuals with knowledge or unique expertise about the child can be invited to participate on the IEP team by parents or school staff. These individuals often include

occupational or physical therapists, adaptive physical education providers, psychologists, and speech-language pathologists. These professionals advocate for the child with the disability and share expertise on the individualized needs of the child. Furthermore, school psychologists are often involved in assessing the child and interpreting evaluation results (Beck & DeSutter, 2020).

1.4 Limitations of Collaboration

Although educators and specialists in child development are involved with the IEP process, challenges arise when determining the short-term and long-term goals for the student with disabilities. While school administrators are knowledgeable about the resources of a district, they are not experts on the needs of students with disabilities. Families and students attempt to be engaged during IEP meetings, but variability in their participation can lead to inconsistencies in the development of the IEP (King et al., 2018). Studies report parents feeling overwhelmed, alienated, and confused by the process (Cavendish & Connor, 2018; Fish, 2008; Goepel, 2009; Zeitlin & Curcic, 2013). Not only is navigating an IEP difficult for families, but Fish (2008) also supports that the dissatisfaction of parents and their reduced involvement in the process results in the lack of knowledge about their child's disability. Similar challenges arise for educators participating in the IEP process. Previous research argues that teachers also feel underprepared in their training to determine the reasonable and attainable goals for children with special needs (Goepel, 2009; Rotter, 2014).

1.5 Special Education Training

Special education teachers are trained following standards set by the Council of Exceptional Children and certified by the American Academy of Special Education

Professionals (AASEP) and the National Association of Special Education Teachers (NASET). The AASEP states that special educators are “highly trained professionals who provide specifically designed instruction and services to children with disabilities” (*Your Career in Special Education*, 2005). The material provided to individuals with disabilities must be adapted and developed to match the special needs of each student while using a variety of teaching strategies to allow the student to reach their learning potential. The Council for Exceptional Children outlines that special education professionals need to understand child development, use knowledge in generalized and specialized curricula, make educational decisions based on data sources and multiple methods of assessment, use evidence-based instructional strategies, and uphold ethical principles and practice standards while collaborating with families and other providers (Council for Exceptional Children, 2015). Despite the well-defined practice standards and ethics principles, the specific training for special educators regarding genetic conditions is vague. The limited training about genetic conditions has been previously identified by the NASET and supplemented with a monthly e-publication covering 38 rare genetic conditions within their *Genetics in Special Education Series* (National Association of Special Education Teachers [NASET], n.d.). While NASET aimed to improve the knowledge of special education teachers regarding genetic conditions, there is a clear desire for supplemental material about genetic disorders.

1.6 School Psychologist Training

The lack of information from other participants in the IEP process often leaves school psychologists as the primary source of information about the prognosis and capabilities of students with special needs. School psychologists often facilitate IEP

meetings and collect pertinent background information about the child's condition by applying their training in psychology, education, and family-school collaboration. While school psychologists are trained in special education, gaps in knowledge arise when supporting children with genetic conditions because there is limited training on genetic disorders (Ross et al., 2002).

In May 2020, the National Association of School Psychologists (NASP) created the School Psychologist Profession Standards, including the NASP Practice Model, Standards for Graduate Preparation of School Psychologists, Standards for the Credentialing of School Psychologists, and Principles for Professional Ethics. These guidelines state that school psychologists “receive specialized advanced graduate preparation that includes coursework and field experiences relevant to both psychology and education” (National Association of School Psychologists Leadership Assembly, 2020). Across the guiding documentation of graduate preparation, credentialing, and the professional practice of school psychologists, there are no specific training or advocacy principles designed to address the complexities of children with genetic conditions. School psychologists are instead trained in the following:

School psychologists support children, youth, families, and schools through the identification of appropriate evidence-based educational and mental and behavioral health services for all children and youth; implementation of professional practices that are data-driven and culturally responsive; delivery of a continuum of services for children, youth, families, and schools from prevention to intervention and evaluation; and advocacy for

the value of school psychological services. (National Association of School Psychologists Leadership Assembly, 2020)

While school psychologists are trained in research and evidence-based practice, data-based decision-making, family and system collaboration, and advocacy and support resources, there is a lack of training that requires education in the nuances of medical genetics. It is arguable that without thorough training in genetic conditions, school psychologists are ill-equipped to fully anticipate other areas of developmental concerns and future prognosis for children with genetic conditions.

1.7 The Rarity of Genetic Conditions

Genetic evaluations are pursued in pediatric populations to identify an underlying explanation for physical symptoms or neurodevelopmental delays in children. The impact of the genetic findings can guide management for that child. Some of the needs that result from the genetic condition can require various assistance or modifications, and individualized education programs help provide the support and specialized care the student may need in a school setting. With over 6 million students receiving services under the IDEA, representing 9.1% of school children ages 6 through 21 years old, an even smaller proportion are children with rare genetic conditions (Ball et al., 2018). Due to the rarity of many of these disorders, little information is available regarding the prognosis and future concerns of children with genetic disorders. The limited knowledge of genetic conditions puts affected students at a disadvantage because parents and educators struggle to define attainable and realistic goals. Information gaps about pediatric genetic conditions affect the quality of education these students receive throughout the IEP process. Improving the understanding of these disorders, developing appropriate interventions, and

improving knowledge of educational professionals about the genetic basis for these disabilities and the genetic testing mechanisms can improve advocacy for students with genetic conditions.

1.8 The Genetic Counseling Profession

The National Society of Genetic Counselors (NSGC) was established in 1979 to support, promote, and advance genetic counseling as a profession (National Society of Genetic Counselors, 2019). The NSGC defines genetic counseling as:

The process of helping people understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease.

This process integrates the following:

- Interpretation of family and medical histories to assess the chance of disease occurrence or recurrence.
- Education about inheritance, testing, management, prevention, resources, and research.
- Counseling to promote informed choices and adaption to the risk or condition. (Resta et al., 2006)

Genetic counselors are trained in medical genetics and counseling to interpret genetic testing results, as well as guide and support patients seeking additional information regarding genetic diseases, risk assessments, and decision-making. The NSGC Code of Ethics further clarifies the goals and values of the genetic counseling profession, in addition to guiding genetic counselors' interactions with their clients, their colleagues, and society. Genetic counselors promote patient advocacy by encouraging patient autonomy, preventing genetic discrimination, acting as a source of reliable information on genetic

conditions, and educating the public on genetics (National Society of Genetic Counselors, 2017).

Incorporating these practices into IEP meetings would protect the rights of students with genetic conditions in the public-school system. The IDEA states that special education, the related services, and the aids provided should be based on peer-reviewed research (34. CFR § 300.320). Genetic counselors are trained in current medical genetics research, so they have the ability to advocate for pediatric patients to provide the most up-to-date information about genetic conditions to IEP teams. The quality of care patients receive as a result of their genetic diagnosis can be supported by utilizing a genetic counselor by the IEP team.

CHAPTER 2

AN EXPLORATION OF THE GENETIC COUNSELOR'S ROLE IN THE INDIVIDUALIZED EDUCATION PROGRAM¹

¹ Barker, N., Hill, C.R., Ferrante, R., Fletcher, R. To be submitted to *Journal of Exceptional Children*

2.1 Abstract

Purpose: This exploratory study aimed to assess the knowledge of school psychologists and special education teachers regarding genetic conditions and the resources used in the development of individualized education programs (IEP) for students with genetic disorders. While the IEP process has been described for children with disabilities, literature explicitly focusing on children with genetic conditions is lacking. The rarity of genetic conditions often leaves school personnel with limited information.

Methods: School psychologists (N=29) and special education teachers (N =14) throughout the United States participated in an online questionnaire. School psychologists were recruited from research committee listservs of state associations, and special education teachers were identified through the Council for Exceptional Children. The questionnaire included demographic questions, Likert-scale questions regarding perceptions, and open-ended responses. The questionnaire assessed current practices of school psychologists and special education teachers when developing and implementing IEPs for students with genetic conditions.

Results: Overall, school psychologists and special education teachers felt that they had an adequate understanding of the services and expectations, as well as adequate knowledge to discuss IEP objectives about a genetic condition diagnosed in a child. Participants felt that additional information regarding the impact of symptoms on educational abilities, diagnosis, and future associated concerns could help set more realistic goals for students with genetic conditions. Providing information early in the IEP process (early childhood, at time of diagnosis, during background preparation, and during evaluations of IEPs) would be most beneficial.

Conclusions: These results suggest a desire for more information by the IEP team regarding genetic conditions. The participants

reported that specific genetic information and the timing of the information would improve the development and implementation of IEPs for children with genetic conditions. While respondents identified little professional experience with a genetic counselor, they recognized that the role of a genetic counselor included expertise in the education of genetic information, as well as the counseling and support of patients and families. Collaboration with a genetic counselor could enhance the knowledge of IEP team members to improve decision-making during the IEP process for children with genetic conditions and identify additional resources available for team members.

2.2 Introduction

Genetic disorders are a group of heterogeneous medical conditions caused by damage to genetic material that can be inherited or occur by chance (de novo) during cell division. While the alteration most often presents in every cell of the body, only certain tissue types or body systems may be impacted. The clinical features can develop from Mendelian disorders or chromosomal abnormalities, including large and small DNA deletions or duplications, gene variants, and mitochondrial conditions. The presenting symptoms can vary among individuals, even with the same diagnosis. Age of onset ranges from a prenatal presentation to adulthood.

Many recognizable genetic conditions in pediatric populations include conditions with visible defects, notably severe symptoms, or life-shortening consequences. Many genetic diagnoses result in physical abnormalities and/or neurobehavioral disorders affecting intellectual abilities, movement, behavior, socialization, and communication. Genetic testing is standard practice for patients presenting with unexplained developmental delay, intellectual disability, autism spectrum disorder (ASD), and multiple congenital

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Before the 1970s, children with disabilities were often excluded and denied public education in the United States. In 1975, the Individuals with Disabilities Education Act (IDEA) became federal law and established that children with disabilities receive free and appropriate public education (FAPE) alongside their peers. FAPE ensures that the education for students with disabilities is provided at no cost to families and offers services that meet the specific needs of each child, ranging from accommodations, modifications, therapies, counseling, and transportation. Additionally, the law requires that education be provided in the least restrictive environment (LRE) to promote academic success (Individuals with Disabilities Education Act [IDEA], 20 USC § 1400, 2004). The outcomes shifted the general education classroom towards inclusivity and changed how educational

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Under Part B of IDEA, the Individualized Education Program (IEP) is defined as the legal document between the family and the school district that determines the supports and services the student will receive to increase opportunities for academic, social, or developmental progress. The IEP is established within 30 days after an initial evaluation, tailored to the specific needs of each child, and reviewed annually or upon parental request (IDEA, 2004).

While the IDEA requires public schools to provide free appropriate public education, it does not imply that every student who struggles in school will qualify for special education services. The eligibility for an IEP requires the child to have a disability that adversely affects academic success (Ball et al., 2018). In total, 13 categories are covered by IDEA: autism, deaf-blindness, developmental delay, emotional disturbance, hearing impairments, intellectual disabilities, multiple disabilities, orthopedic impairments, other health impairments, specific learning disabilities, speech or language impairments, traumatic brain injury, and visual impairments (IDEA, 2004). In 2018-2019, IDEA Part B served 6,315,228 students ages 6 through 21 years old. The four main categories of disabilities were specific learning disabilities (33%), speech or language

impairments (19%), other health impairments (15%), and autism (11%) (Office of Special Education and Rehabilitative Services, 2019b). Genetic conditions do not have a specific category because they often cause various symptoms ranging from physical abnormalities to learning disabilities. Genetic disorders can fall into several categories that qualify students for IEP evaluations, and the category is specific to the presenting features in the child.

The IEP records the present performance level of the child, short-term and long-term outcome goals, the established provisions for accommodations, and evaluation criteria. The document describes current abilities and challenges, social skills and behavior, and functional and quantifiable objectives for the year. The No Child Left Behind Act of 2001 states that students with cognitive disabilities, who cannot participate in general educational assessments, should participate in alternate assessments. This requirement creates a necessity for evaluation through measurable, timely, and attainable goals. The IEP must allow the child to make progress in the general education curriculum and fulfill the needs that result from the child's disability (IDEA, 2004). Furthermore, authorization of ESSA extends goal-setting to include measurable progress toward "ambitious long-term goals". The measurements are based on a student's progress and proficiency on state assessments, overall school quality, and state-determined accountability measures (Darrow, 2016).

The focus on goal setting increases the need for effective collaboration between members involved with the IEP team. Not only is the IEP a legal document, but the IEP is also a process that establishes a multidisciplinary team working in collaboration to support the academic goals of the child (Lee-Tarver, 2006). The IEP team can include the student,

parent(s), regular education teacher, special education teacher, school system representative, transition services agency representative, related service providers knowledgeable about the child, and individuals who can interpret evaluation results (US Department of Education, 2000). The obligation of collaboration promotes goal attainment and meaningful involvement for the student and ensures parents are equal partners in the IEP process (Cavendish & Connor, 2018). Student participation encourages self-advocacy and provides a platform to voice his or her own educational needs. Parents offer insight into specific interests of their child and verify the progress seen at home. The IDEA requires that the parents and children are central in the decision-making and planning, and additional personnel will depend on the needs of the student.

Other roles within the IEP process also contribute to the outcomes of the final IEP document. The general education teacher strategizes amendments to the general curriculum and supports behavior management. The special education teacher contributes information regarding curriculum modifications, supplementary aids, alternative assessments, and individualized instruction for the child (US Department of Education, 2000). Together, the general education teacher oversees the general implementation of classroom goals, and the special education teacher monitors the progress of the child (Clayton et al., 2006; Rotter, 2014). Furthermore, the school administrators represent the school district, provide knowledge of the available services offered to the child, and make funding decisions (Beck & DeSutter, 2020). The transition services representative helps arrange and coordinate any needed transition planning between schools and health providers (US Department of Education, 2000).

Although educators and specialists in child development are involved with the IEP process, challenges arise when determining the short-term and long-term goals for the student with disabilities. While school administrators are knowledgeable about the resources of a district, they are not experts on the needs of students with disabilities. Families and students attempt to be engaged during IEP meetings, but variability in their participation can lead to inconsistencies in the development of the IEP (King et al., 2018). Studies report parents feeling overwhelmed, alienated, and confused by the process (Cavendish & Connor, 2018; Fish, 2008; Goepel, 2009; Zeitlin & Curcic, 2013). Not only is navigating an IEP difficult for families, but Fish (2008) also supports that the dissatisfaction of parents and their reduced involvement in the process results in the lack of knowledge about their child's disability. Similar challenges arise for educators participating in the IEP process. Previous research argues that teachers also feel underprepared in their training to determine the reasonable and attainable goals for children with special needs (Goepel, 2009; Rotter, 2014).

The lack of information from other participants in the IEP process often leaves school psychologists as the primary source of information about the prognosis and capabilities of students with special needs. School psychologists often facilitate IEP meetings and collect pertinent background information about the child's condition by applying their training in psychology, education, and family-school collaboration. While school psychologists are trained in special education, gaps in knowledge arise when supporting children with genetic conditions because there is limited training on genetic disorders (Ross et al., 2002).

Genetic evaluations are pursued in pediatric populations to identify an underlying explanation for physical symptoms or neurodevelopmental delays in children. The impact of the genetic findings can guide management for that child. Some of the needs that result from the genetic condition can require various assistance or modifications, and individualized education programs help provide the support and specialized care the student may need in a school setting. With over 6 million students receiving services under the IDEA, representing 9.1% of school children ages 6 through 21 years old, an even smaller proportion are children with rare genetic conditions (Ball et al., 2018). Due to the rarity of many of these disorders, little information is available regarding the prognosis and future concerns of children with genetic disorders. The limited knowledge of genetic conditions puts affected students at a disadvantage because parents and educators struggle to define attainable and realistic goals. Information gaps about pediatric genetic conditions affect the quality of education these students receive throughout the IEP process. Improving the understanding of these disorders, developing appropriate interventions, and improving knowledge of educational professionals about the genetic basis for these disabilities and the genetic testing mechanisms can improve advocacy for students with genetic conditions.

Recognizing that each role on the IEP team provides a specific skill set contributing to successful outcomes, the increasing presence of students with genetic conditions adds to the complexity of the IEP process. The new frontier of genetic information challenges the collaboration between professionals and family (Bricker et al., 2020). With the current implementation of the IEP process, school psychologists are strained to advocate and educate about rare genetic conditions outside of their training. Historically, adding services

to meet the demands of needed interventions has been successful. Speech-language-hearing specialists, occupational therapists, and physical therapists have entered the educational system to offer services as necessitated by the conditions defined by IEPs (Bricker et al., 2020). As genetic conditions become more common diagnoses in IEP discussions, the education and advocacy for children with genetic conditions is essential. Genetic counselors are trained in the specifics of genetic conditions and patient education and advocacy (Cohen, 2020). Introducing genetic counselors to the IEP process can address the specialized knowledge needed to understand rare genetic conditions and clarify attainable goals for these students. By surveying the most central personnel involved with the writing and implementation of the IEP, this study can determine the necessary information and means to provide said information about rare genetic conditions to professionals involved in the IEP team.

This exploratory study aimed to assess the knowledge of school psychologists and special education teachers regarding genetic conditions and the resources used by school personnel to develop and implement IEPs for students with genetic disorders. While the IEP process has been previously described for children with disabilities, literature explicitly focusing on the education of children with genetic conditions is lacking. The rarity of genetic conditions can leave school personnel with limited information, making it difficult to determine appropriate and realistic goals in the individualized education program (Goepel, 2009; King et al., 2018). The data from this study could identify interventions and additional resources available for members of the IEP team.

2.3 Materials and Methods

2.3.1 Participants

2.3.1.1 School Psychologist Recruitment. School psychologists, across geographical regions of the United States, were emailed an invitation letter to participate in an online questionnaire. Email addresses of school psychologists were assembled through listservs from research committees of state associations.

2.3.1.2 Special Education Recruitment. Special education teachers were identified through the Council for Exceptional Children across geographic regions of the United States. Questionnaires were distributed by email.

The participants identified by these organizations were sent an invitation to participate with a link to an online questionnaire, allowing participants to complete the questionnaire on their own time. The selection process of participants was based on those who identified as a school psychologist or special education teacher. Although other personnel participate on the IEP team, they were excluded from the study. Parents were excluded to protect the privacy of their children's health information, school administrators were excluded because they play a more peripheral role in defining the capabilities of students during goal development in the IEP process, and general education teachers were excluded because their perspective has been previously researched (Cavendish & Connor, 2018; Clayton et al., 2006; Goepel, 2009; King et al., 2018; Lee-Traver, 2006; Warren, 2014).

Inclusion criteria:

- Currently practicing as a school psychologist or special education teacher;
- Certified or licensed to practice in a state or territory of the United States;

- Practiced in schools 70% or more of the time;
- And involved with the IEP process.

Exclusion criteria:

- Professionals other than school psychologists and special education teachers;
- Not certified or licensed to practice;
- Do not practice in a state or territory of the United States;
- And does not practice in schools or with pediatric populations.

2.3.2 Research Methods

The questionnaires were emailed with an invitation to participate and choosing to participate served as the consent of the individual. The questionnaire assessed current practices of school psychologists and special education teachers when developing and implementing IEPs for students with genetic conditions. Authors of this study hoped to recognize themes among school personnel to identify gaps in knowledge about rare genetic conditions. Additionally, the authors expected to determine how resources could be amended to provide better information about genetic conditions during the IEP process. The questionnaire collected demographic information but refrained from including personal identifying information to allow participants to remain anonymous. Other items on the questionnaire consisted of Likert scale questions, multiple-choice questions, and open-ended questions. The authors aimed to sample a population of school psychologists and special education teachers across the United States regions. Upon completion of the questionnaire, participants had the option to enter a raffle for a \$25 gift card to Amazon. Each professional group had two recipients of the \$25 gift cards, totaling four \$25 gift cards

across all participants. The contact information for the raffle was collected on a separate form from the questionnaire to maintain participant anonymity.

2.3.3 Statistical Analysis and Methods

School psychologists and special education teachers were grouped by their profession when assessing the responses to the questionnaire. Descriptive statistical analysis was utilized using Microsoft Office Excel software, and quantitative data was analyzed using the Statistical Package for Social Sciences Version 25 (SPSS). Percentages and frequencies measured categorical information, the Chi-square test for Independence was used to analyze associations between categorical variables, Spearman's Rho was used to determine associations between ordinal variables, and Pearson Correlation Coefficient was used to determine associations between interval-scale variables. Responses to open-ended questions were coded into themes, and frequencies were reported.

2.4 Results

2.4.1 Demographics and Training

A total of 136 individuals responded to the study and 102 of these individuals finished the questionnaire. However, only 43 participants met the inclusion requirements for the study. Participants had the option to skip questions, therefore there was variance in the completion of the online questionnaire.

Demographic characteristics are summarized in Table C.1. The sample population consisted of almost all female (N = 39, 90.7%) and Caucasian (N= 41, 95.3%) individuals. There were 29 school psychologists (67.5%) and 14 special education teachers (32.6%) in the study group. Eighteen participants served Early Education (Preschool/Kindergarten), 30 participants served Elementary School (Grades 1-5), 20 participants served Middle

School (Grades 6-8), and 20 participants served High School (Grades 9-12). Respondents could select multiple grade levels in which they served. Therefore, the frequencies exceed the total number of respondents. Across the study group, an average of two different grade levels were served by participants. Most special education teachers team-taught in a classroom with a general education teacher (N=12, 86%) and specialized in Grade K-12 (N=8, 57%). Two participants selected “other” and recorded a specialization in Mild/Moderate Disabilities and Reading Endorsement.

On average, participants practiced in a school setting for 14 years and participated in the IEP process for 13 years. School psychologists practiced in the school setting and participated in the IEP process on average longer than special education teachers (Table 2.1). Special education teachers reported more semester hours of university training about genetic conditions than school psychologists. In comparison, school psychologists received more hours of professional development about genetic conditions once in their respective profession. The study group averaged 9.4 hours researching information about each genetic condition seen in the IEP process. School psychologists researched each genetic condition an average of 10.9 hours, whereas special education teachers averaged 6.2 research hours for each genetic condition.

2.4.2 Genetic Conditions

The most common conditions seen across both professions include autism spectrum disorder (N=42), seizure disorders (N=37), vision loss (N=37), Down syndrome (N=36), and hearing loss (N=35). The least common conditions seen by both professions were Mucopolysaccharidoses (N=0), Thalassemia (N=0), Bloom syndrome (N=0), and Usher syndrome (N=0). The other conditions reported by participants include Cerebral Palsy

Table 2.1 *Mean of the professional training of School Psychologists and Special Education Teachers within their specialties*

	N	School Psychologists	Special Education Teachers	Total
Years practicing in a school setting	43	15.4	10.9	13.95
Years participating in the IEP process	43	14.2	10.9	13.1
Semester hours (credits) of training about genetic conditions received during university education	40	6.5	8.4	7.2
Total hours of professional development training related to genetic conditions	42	16.7	5.4	12.9
Total hours spent researching medical information about each genetic condition	39	10.9	6.2	9.4

(N=3), Dyslexia (N=1), and Mitochondrial disorders (N=1) (Table 2.2). Figure C.1 shows that the distribution of genetic conditions seen in South Carolina was similar to other states in the United States. The most common genetic condition seen, when comparing the specialization and classroom-type of special education teachers, was autism spectrum disorder in grades K-12 within the team teach setting along with a general education teacher (Table C.2; Table C.3).

2.4.3 Resource Utilization

Generally, school psychologists and special education teachers agreed on the available resources and the usefulness of these resources consulted during the research of genetic conditions in preparation for IEP meetings. Both professions sometimes used general internet search and professional websites when consulting resources for genetic conditions. Most participants never used social media as a resource and found that social

Table 2.2 *Occurrence of genetic conditions reported by School Psychologists and Special Education Teachers*

Conditions	School Psychologists	Special Education Teachers	Total (N)
Autism	29	13	42
Seizure Disorders	27	10	37
Vision Loss	27	10	37
Down Syndrome	29	7	36
Hearing Loss	26	9	35
Fragile X	19	3	22
Sickle Cell Disease	16	5	21
Muscular Dystrophy	18	3	21
Cystic Fibrosis	16	4	20
Prader-Willi Syndrome	14	2	16
Turner Syndrome	10	2	12
Angelman Syndrome	11	1	12
Williams Syndrome	10	1	11
Rett Syndrome	8	1	9
Klinefelter Syndrome	9	0	9
Albinism	8	0	8
Cardiomyopathy	6	1	7
Neurofibromatosis	6	0	6
Tay-Sachs	6	0	6
22q/ DiGeorge/ VCF	6	0	6
Achondroplasia			
Dwarfism	6	0	6
Other	2	3	5
Noonan Syndrome	4	1	5
Marfan Syndrome	5	0	5
Phenylketonuria	4	0	4
Sotos Syndrome	4	0	4
Retinitis Pigmentosa	0	1	1
Progeroid Syndromes	1	0	1
Bardet- Biedl	1	0	1
Charcot-Marie-Tooth	1	0	1
Long QT Syndrome	1	0	1
Mucopolysaccharidoses	0	0	0
Thalassemia	0	0	0
Bloom Syndrome	0	0	0
Usher Syndrome	0	0	0

media was somewhat not useful or never useful (Table 2.3; Table 2.4). School psychologists used the child's medical providers more than special education teachers (Pr $X^2 = 0.005$; Figure 2.1), despite both professional groups agreeing that the child's medical providers were useful as a resource. School psychologists used advocacy and support groups more than special education teachers (Pr $X^2 = 0.053$; Figure C.2), and school psychologists reported advocacy and support groups were more valuable than special education teachers (Pr $X^2 = 0.055$; Figure C.3). One individual also reported using "medical reports from private providers (SLP, OT, PT, ABA, Counselors/Therapists)". On average, respondents routinely used 4.35 resources, 2.81 text sources and 1.53 interpersonal resources. There was a slight decrease in the number of resources used by professionals as the number of genetic conditions seen increased ($R^2 = 0.0069$).

Table 2.3 *Usage of resources, by profession*

Resource	Usage	School Psychologists	Special Education Teachers	Chi-squared (X^2)
General Internet Search	Always	19	9	0.937
	Sometimes	10	5	
	Never	0	0	
Professional Websites	Always	20	8	0.446
	Sometimes	9	6	
	Never	0	0	
Genetics Websites	Always	8	2	0.079
	Sometimes	16	5	
	Never	5	7	
News Articles	Always	2	4	0.158
	Sometimes	16	6	
	Never	11	4	
Condition-Specific Foundations	Always	13	5	0.772
	Sometimes	15	8	
	Never	1	1	

Advocacy/ Support Groups	Always	1	3	0.053
	Sometimes	23	6	
	Never	5	6	
Textbooks	Always	5	0	0.163
	Sometimes	14	6	
	Never	10	8	
Academic Literature	Always	11	3	0.256
	Sometimes	15	7	
	Never	3	4	
Professional Associations	Always	9	3	0.307
	Sometimes	17	7	
	Never	3	4	
Conferences	Always	3	2	0.145
	Sometimes	21	6	
	Never	5	6	
Talks/ Speakers	Always	5	3	0.128
	Sometimes	20	5	
	Never	4	5	
Child's Medical Providers	Always	15	3	0.005
	Sometimes	14	6	
	Never	0	4	
Parents as Advocates	Always	16	7	0.314
	Sometimes	13	5	
	Never	0	1	
Coworkers	Always	5	3	0.277
	Sometimes	19	10	
	Never	5	0	
Social Media	Always	1	0	0.624
	Sometimes	7	2	
	Never	21	11	
Other	Always	1	0	
	Sometimes	0	0	
	Never	5	0	

Table 2.4 *Usefulness of resources, by profession*

Resource	Usefulness	School Psychologists	Special Education Teachers	Chi-squared (X ²)
General Internet Search	Never Useful	0	0	0.683
	Somewhat Not Useful	1	0	
	Somewhat Useful	22	9	
	Always Useful	5	1	
Professional Websites	Never Useful	0	0	0.713
	Somewhat Not Useful	1	0	
	Somewhat Useful	13	6	
	Always Useful	13	4	
Genetics Websites	Never Useful	4	1	0.262
	Somewhat Not Useful	0	1	
	Somewhat Useful	14	4	
	Always Useful	7	1	
News Articles	Never Useful	7	1	0.265
	Somewhat Not Useful	6	1	
	Somewhat Useful	9	6	
	Always Useful	3	0	
Condition-Specific Foundations	Never Useful	1	0	0.698
	Somewhat Not Useful	0	0	
	Somewhat Useful	20	6	
	Always Useful	6	3	
Advocacy/Support Groups	Never Useful	1	3	0.055
	Somewhat Not Useful	3	0	
	Somewhat Useful	20	4	
	Always Useful	2	1	
Textbooks	Never Useful	5	2	0.212
	Somewhat Not Useful	4	0	
	Somewhat Useful	10	5	
	Always Useful	7	0	
Academic Literature	Never Useful	1	1	0.355
	Somewhat Not Useful	1	1	

	Somewhat Useful	14	4	
	Always Useful	11	1	
Professional Associations	Never Useful	0	1	0.159
	Somewhat Not Useful	2	0	
	Somewhat Useful	15	5	
	Always Useful	9	1	
Conferences	Never Useful	1	1	0.721
	Somewhat Not Useful	2	1	
	Somewhat Useful	13	3	
	Always Useful	9	2	
Talks/ Speakers	Never Useful	1	1	0.77
	Somewhat Not Useful	2	1	
	Somewhat Useful	14	4	
	Always Useful	9	2	
Child's Medical Providers	Never Useful	0	0	0.253
	Somewhat Not Useful	3	0	
	Somewhat Useful	14	6	
	Always Useful	10	1	
Parents as Advocates	Never Useful	0	0	0.894
	Somewhat Not Useful	3	1	
	Somewhat Useful	16	4	
	Always Useful	8	3	
Coworkers	Never Useful	3	0	0.571
	Somewhat Not Useful	5	1	
	Somewhat Useful	18	7	
	Always Useful	1	1	
Social Media	Never Useful	13	3	0.763
	Somewhat Not Useful	6	2	
	Somewhat Useful	3	0	
	Always Useful	1	0	

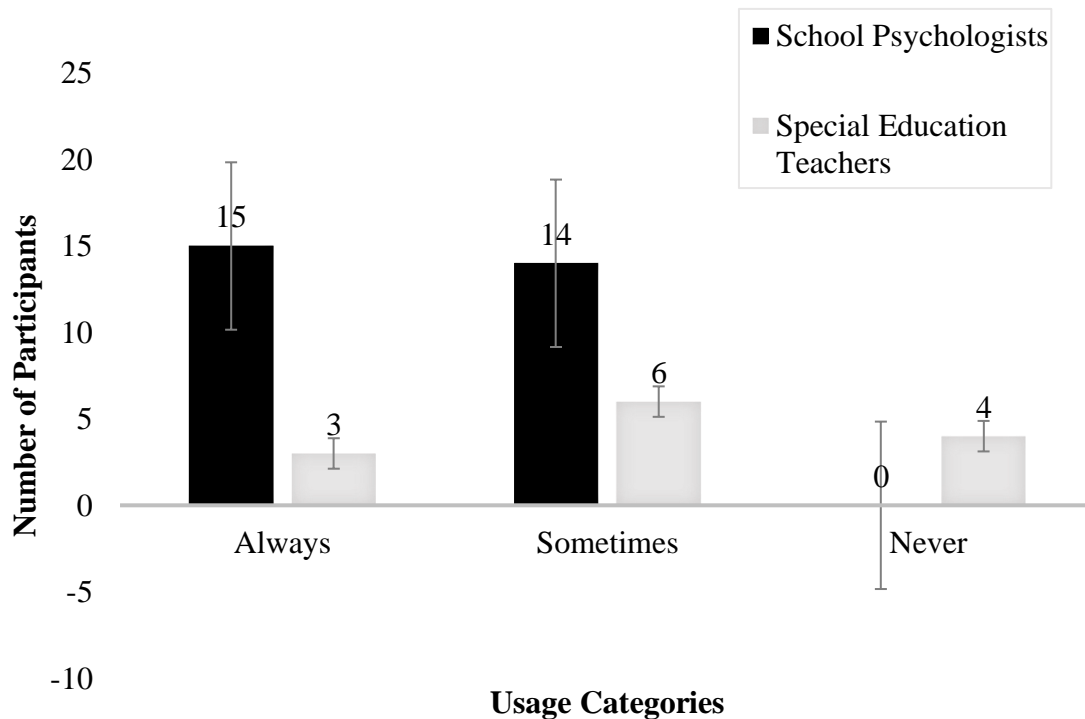


Figure 2.1 *Usage Count of Child's Medical Providers, by profession.* $\text{Pr } \chi^2 = 0.005$. Error bars show standard errors.

2.4.4 Perceptions of IEP Team

When asked about their IEP experience with families of students with genetic conditions, four-fifths of participants believed that they clearly understood the child's needed services ($N = 35$, 81.4%; Figure C.4) and could set realistic expectations ($N = 37$, 86%; Figure C.5). Over two-thirds of the study group felt that they could anticipate other areas of developmental concern ($N = 30$, 69%; Figure C.6). Three-fourths of the study population believed parents were knowledgeable about their child's genetic condition(s) ($N = 33$, 76.7%; Figure C.7), and over half of the participants agreed or strongly agreed they could provide sufficient knowledge to families ($N = 25$, 58%; Figure C.8).

Both special education teachers and school psychologists felt they could thoroughly discuss IEP objectives about their students' genetic conditions ($N = 26$, 60.5%; Figure C.9).

Still, they thought that other educators were not knowledgeable about the genetic conditions (N= 38, 88.4%; Figure 2.2). The majority of the participants desired more information about genetic conditions (N= 42, 97.7%; Figure 2.3). Participants reported that they would develop more realistic goals for students affected by genetic conditions with additional information about the child's specific genetic condition(s) (N= 41, 95.4%; Figure C.10). Furthermore, they would recommend additional services for students with genetic conditions with additional information about the child's specific genetic condition(s) (N=40, 93%; Figure C.11).

2.4.5 Information Regarding Genetic Conditions

The participants ranked the most beneficial information to know about genetic conditions during the IEP process for children with genetic conditions. They ranked the impact of symptoms on educational abilities, diagnosis and condition name, and future associated concerns as the most pertinent information (Table 2.5). The recurrence risk, incidence, basic genetic information, inheritance patterns, and medical terminology were the least beneficial information. Across the IEP team, 'diagnosis/ condition name' was the most likely to be ranked as the most important information to know (N=19), followed by symptoms (N=9) and impact on educational abilities (N=9) (Figure C.12). The second most beneficial information was impact on academic skills (N=10), symptoms (N=7), and prognosis (N=6) (Figure C.13). The second least beneficial information to know was basic genetic information (N=13), followed by medical terminology (N=9) and life expectancy (N=6) (Figure C.14). Medical terminology was the least beneficial information that could be provided (N=19), followed by inheritance patterns (N=9) (Figure C.15).

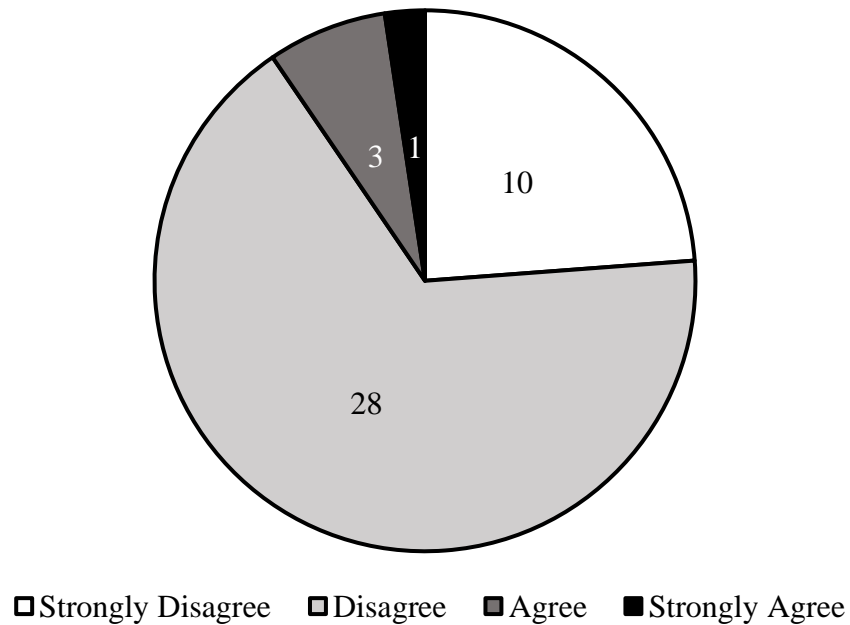


Figure 2.2 *Participant perceptions that other educators are knowledgeable about genetic conditions*

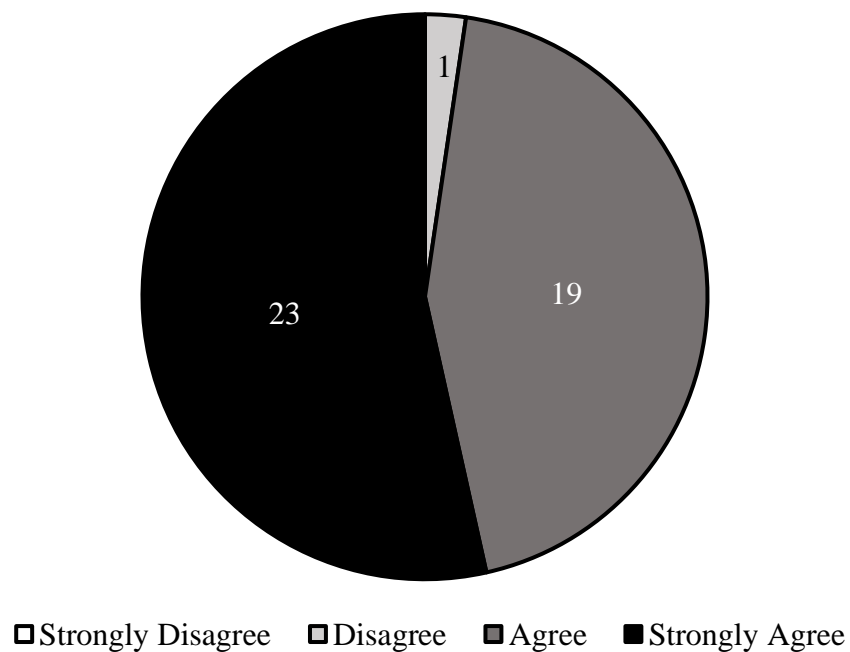


Figure 2.3 *Participants desire for more information about students with genetic conditions*

Table 2.5 *Average ranking of desired information regarding students with genetic conditions by School Psychologists and Special Education Teachers (1 = most desired, 14= least desired)*

Beneficial Information	Mean
Symptoms	3.15
Impact on educational abilities	3.75
Diagnosis/ Condition name	3.83
Future associated concerns	4.93
Common treatment plans	5.20
Prognosis	5.23
Criteria for diagnosis	6.83
Cause	6.98
Life expectancy	9.85
Recurrence risks	10.33
Incidence	10.80
Basic genetics information	10.85
Inheritance patterns	11.18
Medical terminology	12.15

2.4.6 Timing of Information

Across the study population, middle school and high school were the least preferred times to receive information about genetic conditions. School psychologists and special education teachers agreed information about the genetic conditions would be helpful across any stage of the IEP process. However, school psychologists felt providing information early in the IEP process (early childhood, at time of diagnosis, during background preparation, and during evaluations of IEPs) was the most beneficial to receive information about genetic conditions (Figure 2.4). Special education teachers felt that transitional periods (at time of diagnosis, transitions between schools, transitions between educators, and transition to adulthood) and background preparation for the IEP meetings would be beneficial as the optimal time to receive information about genetic conditions.

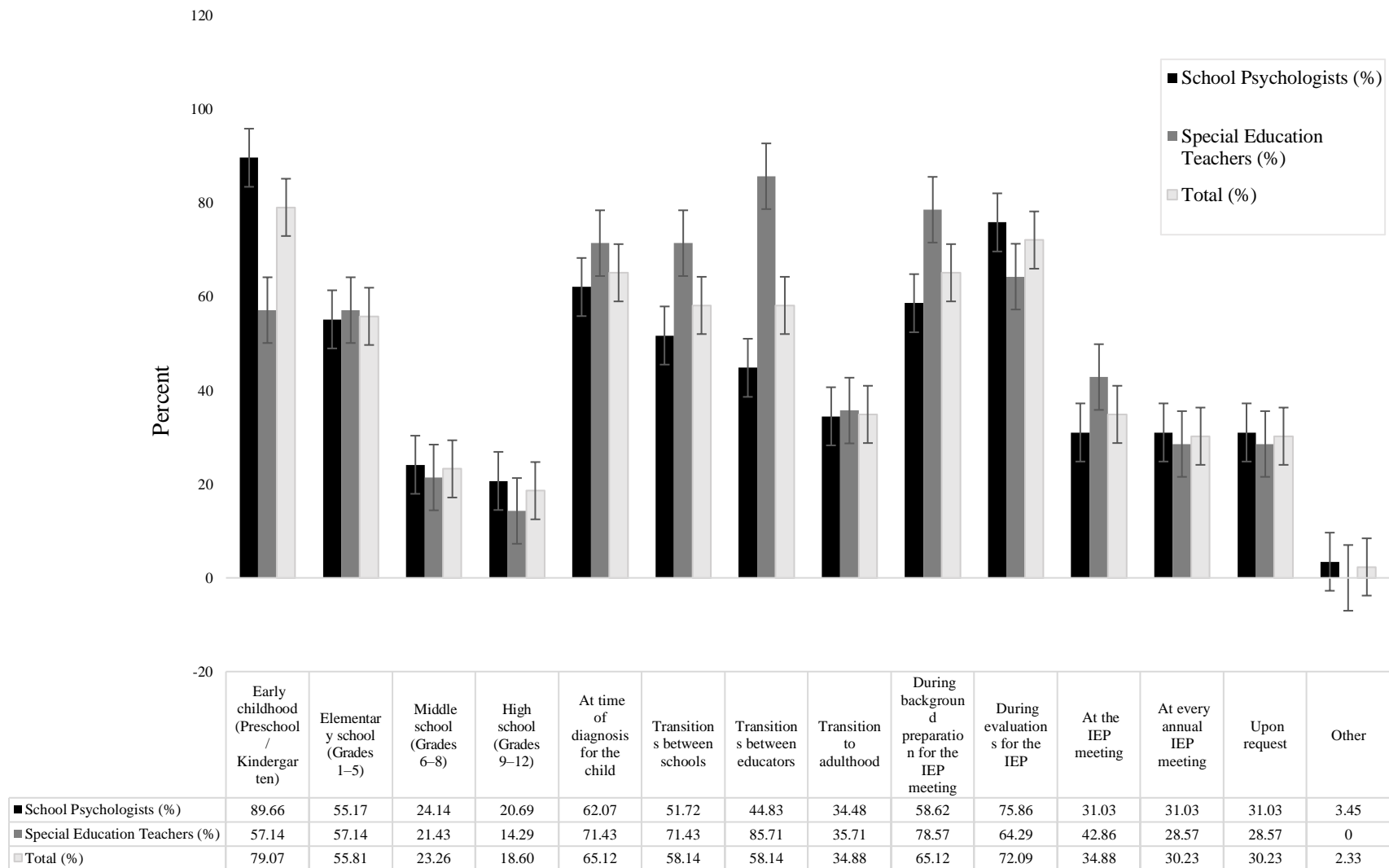


Figure 2.4 Percentage of study participants reporting when genetic information would be most beneficial, by profession

2.4.7 Perception of Genetic Counseling Profession

The majority of the study participants have not worked professionally with a genetic counselor (N=37, 86.05%; Figure C.16) or interacted personally with a genetic counselor (N=30, 69.77%; Figure C.17). When asked to describe a genetic counselor's role, 29 participants provided an open-ended response (67.44%). Over half of the participants reported that a genetic counselor was involved with education/ providing information (N=16, 55.17%). One-fifth of the respondents did not know the role of a genetic counselor (N=6). One-fifth of the respondents reported themes of expertise and professional training (N=6), counseling and support of patients and families (N=6), and discussions of risks, impacts, and prognosis (N=6). Other themes reported by participants included: providing recommendations, acting as a resource, assisting in decision-making, treatment planning and management, evaluating and interpreting genetic testing results, and problem-solving (Table 2.6).

Table 2.6 *Thematic analysis of responses by participants describing the role of a genetic counselor*

Describe the role of a genetic counselor	
Themes	N
Education/ providing information	16
Do not know	6
Acknowledged training/ professional/ expertise/ knowledge	6
Counseling/ supporting patients and families	6
Discuss risks/ impacts/ prognosis	6
Providing recommendations	3
Acting as a resource for others	3
Assist in decision making	2
Management and treatment planning	2
Evaluate/ Interpret genetic testing results	2
Referenced personal experience	1
Problem solving	1

Note. N = 29.

2.5 Discussion

2.5.1 Need for Additional Information

The study population felt that they were prepared to serve children with genetic conditions during the IEP process and reported that they clearly understood the needed services for children with genetic conditions. Both school psychologists and special education teachers felt that they could set realistic expectations, anticipate other developmental concerns, and thoroughly discuss IEP objectives about the child's genetic condition(s). These results suggest that the participants felt they met their duties as members of the IEP team. They reported they could sufficiently evaluate children with genetic conditions to determine if the child meets criteria for disability, assess the educational needs of the child as well as the present level of academic achievement based on the evaluation of data-based research, assessments, and observations (IDEA, 2004). This study revealed that school psychologists and special education teachers generally feel that they can adequately serve children with genetic conditions during the IEP process. However, they agreed that additional information about genetic conditions would be desirable.

There was a consensus that further information could develop more realistic goals and identify additional services for children with genetic conditions. This finding demonstrates that while there is satisfactory service for children with genetic conditions, there is room for improvement and modification surrounding the advocacy of individuals with rare genetic conditions.

The rarity of genetic conditions presents a clear need for additional information when establishing the goals and services of the IEP. The National Association of Special

Education Teachers (NASET) supplemented genetic education through a monthly e-publication covering 38 rare genetic conditions within their *Genetics in Special Education Series* (NASET, n.d). The publication attempts to address a basic genetic overview, but it has limited information accessible to the public and it is not updated as new information arises regarding genetic conditions, educational implications, or developing treatments. Therefore, the material can only be accessed by members of NASET and the content is not current. Additionally, the New England Regional Genetics Network identified the limited information surrounding genetic conditions in the educational system and developed condition-specific genetics education materials for school success (GEMSS). The information pages aim to promote awareness of genetic conditions and educate those involved in the care of children with genetic conditions to assist in IEP development, provide supplementary documentation for meetings, and support children with challenges that are genetic, metabolic, or undiagnosed (New England Regional Genetics Network [NERGN], 2017). While the information provided by GEMSS offers an overview of genetic conditions, it is not extensive across all genetic conditions, nor is it personalized to the specific clinical presentation or phenotype of the affected individual. Genotype-phenotype correlations are ever-growing in genetic research and case studies on genetic conditions can further describe the effective treatments and services for affected individuals. Genetic information changes rapidly and it may be difficult for a webpage to stay up to date, so while this website can serve as a preliminary resource, a genetic counselor will have the most accurate, current, and relevant information regarding a specific genetic condition.

A notable result was that, while participants felt that they could provide sufficient information to families and the parents were knowledgeable about their child's genetic condition, other educators were not knowledgeable about genetic disorders. These results support the hypothesis that there is a lack of knowledge about genetic conditions among the qualified professionals on the IEP team. Not only do the members most informed about genetic conditions desire supporting information and resources, but there is also an awareness that other providers on the IEP team are not well- equipped to provide information about genetic conditions. The limited knowledge of genetic conditions confounds the ability of educators to determine the child's additional developmental needs, related services, and any modifications to the special education to enable the child to meet the measurable goals defined in their annual IEP plans (IDEA, 2004).

2.5.2 Beneficial Information

Another important conclusion obtained from this study was the information that the IEP team members deem beneficial regarding genetic conditions. The most desired information included the symptoms, educational abilities, diagnosis and condition name, future associated concerns, management guidelines, and prognosis. Each of these topics would provide additional information about further medical concerns that can impact the child's educational abilities and mitigate future detrimental and adverse educational outcomes caused by the genetic condition. It was concluded that additional information about genetic conditions could help IEP team members better individualize educational plans for children with genetic conditions.

This study has explored the current perceptions of members on the IEP team and highlighted the desired information about genetic conditions requested by the IEP members

who primarily develop the individualized education plans for children with genetic conditions. This study aimed to recognize themes among school personnel to identify gaps in knowledge about rare genetic conditions. We determined that while there is adequate information to formulate beneficial education plans for children with genetic conditions, obtaining additional information about the genetic conditions could contribute to the decision-making process during IEP meetings that factor in potential future concerns for affected children.

Under ESSA, states and local educational agencies have jurisdiction to determine the design of student assessments and the systems used for accountability when measuring student growth and success (Camera et al., 2019). The shift in the enforcement of accountability systems from Federal to State authorities increases the need for a clear understanding of student abilities. The focus on “ambitious long-term goals” introduces a requirement for states to track the proficiency and engagement of a student. With the complexity and rarity of genetic conditions, limited information is known on the prognosis and future concerns by the IEP team. Thus, unrealistic expectations or measurements could be used when assessing the student with genetic conditions.

2.5.3 Sources of Information

Little difference was noted between the resources used and the perceived usefulness of the resources by profession. We identified that the majority of individuals use general internet searches and professional websites. Social media was limited as a resource both in terms of use and usefulness. Interestingly, significant difference was observed between school psychologists and special education teachers regarding the child’s medical providers. The information provided by the child’s medical providers is used more by

school psychologists than special education teachers to an extent, despite both professions deeming the child's medical providers as useful. This difference may arise because school psychologists are specifically trained to use evidence-based practice and consult the medical records in their background research when establishing the evidence of an IEP case (National Association of School Psychologists Leadership Assembly, 2020).

Similar patterning arose regarding the use and usefulness of advocacy and support groups. Overall, school psychologists utilize advocacy and support groups as a resource more often than special education teachers, and subsequently, school psychologists report a higher significance of usefulness. This finding could be supported by the fact that school psychologists receive training in collaboration and support resources (National Association of School Psychologists Leadership Assembly, 2020).

Beyond the specific sources, a universal preference was identified favoring text-based resources over interpersonal interactions. Text resources, like web-based searches and professional websites, are fast and easy to access. Interpersonal resources, such as conferences, talks or speakers, as well as professional organizations, may restrain access to information by requiring costly participation fees and controlling content availability. It is arguable that print materials are easier to consult than people. However, there is a risk that print materials are not the most accurate and up to date for genetic material. The rate of genetic research and gene discovery is rapid. In 2010, 456 genetic skeletal disorders were described, and pathogenic variants for these conditions were known in 226 different genes. Within nine years, research discovered five new skeletal conditions and pathogenic mutations in 211 new genes (McInerney-Leo & Duncan, 2021). Beyond the growing research in molecular genetics, management guidelines for specific conditions are regularly

revised, and new treatments are available. In 2019, the management guidelines for the health supervision of children with Neurofibromatosis Type 1 were updated, and the first gene therapy was released by the Food and Drug Administration for Spinal Muscular Atrophy (Miller et al., 2019; U.S. Food and Drug Administration, 2019). In the study, participants averaged more than 13 years practicing in the field. Therefore, it is not certain that most accurate information regarding genetic conditions would be known by educators who are not routinely trained in genetic conditions. It could be imperative to consult a genetic counselor who is trained in the nuances of genetic research and information in order to receive the most accurate and personalized data regarding genetic conditions for the development of IEPs.

2.5.4 Timing of Information

The majority of the participants report that information about genetic conditions would be helpful at any stage during the IEP process: referral, identification, determining eligibility, development of the IEP, implementation, and evaluation and review. However, when participants were asked when the information about genetic conditions would be the most beneficial, differences appeared to between the professions. School psychologists believe the information about genetic conditions would be most beneficial early in the IEP process- early in childhood, at the time of diagnosis, and during the background and evaluations for the IEP. This pattern paralleled the current trends of the conditions seen in the IEP process. As we found, the most common condition seen was autism spectrum disorder in grades K-12 (Table C.2). Therefore, the information would help during the establishment of the student in the IEP system, when assessments are made to determine the disability of the child, as well as the identification of developmental needs and

additional services. Conversely, special education teachers felt that information about genetic conditions could be most beneficial during periods of transition (at diagnosis, between schools, between educators, into adulthood). This pattern suggests that the additional information about genetic conditions could benefit the IEP as new team members join or as the students' measurable goals shift.

2.5.6 Role of the Genetic Counselor

The IEP team typically includes the child, the parent(s), general education teacher(s), special education teacher(s), representative of the local education agency, and an individual who can interpret the evaluation results—often a school psychologist. The definition of an IEP team extends to include “other individuals who have the knowledge or special expertise regarding the child” (IDEA, 2004). Historically, service providers, like speech-language pathologists and occupational/ physical therapists, have entered the IEP process as the need for their expertise arose in the educational system. As the population of children diagnosed with rare and unique genetic conditions increases, there will be an increased need for knowledge about the diagnosis and treatment of genetic disorders.

GEMSS aims to fill the need for genetic information geared toward the school setting; however, it states explicitly that the information provided on their website is not to replace professionals trained in the diagnosis and treatment of children with genetic conditions (NERGN, 2017). As observed in the study, the current literature and websites designed for specific genetic information are not routinely used by IEP team participants (Table 2.4). Improved resources may be indicated regarding genetic conditions in the pediatric population.

Genetic counselors are trained in the education, advocacy, and counseling individuals and families impacted by complex and rare genetic conditions (Resta et al., 2006). A notable result from the study was that genetic counseling was an unfamiliar profession to IEP team members. Some study participants appropriately identified that genetic counselors are trained professionals with skills in education and counseling related to genetic conditions and the associated risks. With an uncertain skillset to the IEP team members, it is understandable that genetic counselors are not routinely consulted during the IEP process for children with genetic conditions. IEP requirements distinctly note that individuals with special expertise relating to the child can join at the discretion of local education agency or parents. For a genetic counselor to enter the IEP process, they have to be invited by the other existing participants of the IEP team.

2.5.7 Limitations and Further Investigation

The conclusions drawn from the study are limited since the responses were from special education teachers and school psychologists and exclude the experiences of other IEP members, parents, and affected children. The study population is biased because most participants were selected based on their professional roles. Future studies should explore the perspectives of the entire IEP team to obtain responses from all the individuals involved in the care for children with genetic conditions.

The sample size was small, and the study population was primarily composed of Caucasian females; therefore, the findings may not be generalizable to other populations. People of different sexes, races, and regions may have unique training or experiences that could shift their perceptions and knowledge of genetic conditions. Obtaining a more extensive and more diverse population may be achieved by recruiting through various

organizations and during a different period of the year. Increasing the sample size can determine if the observed patterns remain, and the evidence could strengthen the support for a genetic counselor consultant within school districts.

Recall bias is inherent to the study because the participants were asked to reflect on the entirety of their careers and professional training. Specific questions asked the participants to round to the nearest number, which could cause inaccurate calculations in the reported statistics. The categorization of the disability is often based on the impacts on education and the limitations to learning for the child, rather than the root cause for the challenges. Often, genetic conditions have symptoms that present early in the individual but are not diagnosed until later after a consistent pattern of issues arises. Many children with IEPs have not been evaluated by genetics, and thus their true “genetic-status” is unknown. The determinations made by participants may not reflect the official diagnosis within the child's private health records.

CHAPTER 3

CONCLUSIONS

The prevalence of genetic conditions within the IEP process will steadily increase as the global population grows, the diagnostic yield of genetic testing improves with technology and research, and genetic conditions are better described. In turn, the knowledge of how genetic conditions affect pediatric populations will require IEP team members to have a deeper understanding about the educational and developmental impacts of genetic conditions. Currently, school psychologists and special education teachers are uniquely burdened to represent rare genetic conditions during IEP meetings with little formal training specifically in genetics. This study aimed to assess the current state of research regarding genetic conditions conducted by educators during the IEP process, and to describe the perception of the genetic information obtained. A majority of participants believed they clearly understood the child's needed services and could thoroughly discuss IEP objectives surrounding their students' genetic conditions. However, the participants thought that other educators are not knowledgeable about the genetic conditions. They believed more realistic goals could be set and additional services could be recommended for students affected by genetic disorders with additional information about the child's specific genetic condition(s). We hope that this study highlights the desire for additional resources by IEP team members and lack of information in current practice that is otherwise needed to properly support children with genetic conditions. Additionally, we hope to support the idea that pediatric genetic

counselors can act as consultants to provide the missing information needed by team members during the IEP meetings for children with genetic disorders.

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APPENDIX A

PARTICIPANT QUESTIONNAIRE

Thank you for your interest in participating in my research project. Prior to completing the questionnaire, please review the study details below.

PURPOSE AND BACKGROUND:

You are being asked to participate in an exploratory research study conducted by Naomi Barker, a Genetic Counseling student pursuing a Master of Science at University of South Carolina. This study aims to assess the school psychologists and special education teachers' knowledge about genetic conditions and the resources used by school personnel in the development and implementation of Individualized Education Programs (IEPs) for students with genetic conditions.

DURATION:

Participation in this questionnaire will take under 15 minutes.

PARTICIPATION:

Participation in the study is voluntary and you may choose to exit the survey at any time. Questions requiring an answer are to evaluate if participants meet inclusion criteria for the study. You may skip the questions in the questionnaire that you are uncomfortable answering. All answers collected are kept anonymous and confidential and the data will be securely stored. Only the primary investigator can view the answers collected on the questionnaire. In the event that you withdraw participation in this study, any information provided will be kept confidential and discarded at the conclusion of the study.

PAYMENT:

We thank you for your interest, time, and participation in this questionnaire. Upon completion, there will be an optional final question where you can be entered into a raffle for a **\$25.00 gift card to Amazon**. If you select "Yes" at the end of the questionnaire, then it will redirect you to a new questionnaire to enter your name, professional group and email. Each professional group will have 2 chances to win a \$25.00 gift card to Amazon. This information will **not** be linked back to your questionnaire response.

CONSENT:

By completing this questionnaire, you are consenting for your data to be used in this study and any future research, presentations, or publications related to this project.

If you have any questions, please contact Naomi Barker, by email (Naomi.Barker@uscmec.sc.edu) or phone (614-746-8780).

By clicking the arrow below you agree to participate in this study.

(*) Are you a school psychologist or special education teacher?

- ☐ Yes, a school psychologist
- ☐ Yes, a special education teacher
- ☐ No

What type/ form of special education classroom do you teach?

- ☐ Itinerant and Resource Teacher
- ☐ Self-Contained Teacher
- ☐ Team Teach with General Education Teacher
- ☐ Provide Home-Based Services
- ☐ Specialist
- ☐ Consultant
- ☐ Other

In what area have you specialized in?

- ☐ Early Childhood Education (Preschool)
- ☐ Grade K-12
- ☐ High-Incidence Disabilities
- ☐ Low-Incidence Disabilities
- ☐ Emotional or Behavioral Disorders
- ☐ Autism Spectrum Disorders
- ☐ No Specialization
- ☐ Other

(*) What year did you graduate with your highest level of degree (enter as yyyy)?

(*) Are you certified/ licensed to practice in your profession?

- ☐ Yes
☐ No

(*) Do you serve more than 70% of your time directly working with students?

- ☐ Yes
☐ No

What is your gender?

- ☐ Male
☐ Female
☐ Non-binary
☐ Prefer not to answer

What is your ethnicity?

- ☐ Caucasian/ White
☐ African American
☐ Native American/Alaskan Native
☐ Pacific Islander
☐ Asian
☐ Hispanic
☐ Prefer not to answer

In what state do you practice?

Alabama	▲
Alaska	
Arizona	
Arkansas	
California	
Colorado	
Connecticut	
Delaware	
Florida	
Georgia	▼

What student grade level(s) do you serve?

- ☐ Early childhood (Preschool/ Kindergarten)
- ☐ Elementary school (Grades 1–5)
- ☐ Middle school (Grades 6–8)
- ☐ High school (Grades 9–12)
- ☐ Other

Do you participate in the development of Individualized Education Programs/Plans (IEPs)?

- ☐ Yes
- ☐ No

Describe your role with the IEP team.

How many years have you been practicing in a school setting (round to nearest number)?

Please slide to
select number of
years



How many years have you been participating in the IEP process (round to nearest number)?

Please slide to
select number of
years




What genetic conditions have you seen while working with students during the IEP process?

- ☐ Turner Syndrome
- ☐ Fragile X
- ☐ Williams Syndrome
- ☐ Noonan Syndrome
- ☐ Neurofibromatosis
- ☐ Sickle Cell Disease
- ☐ Down Syndrome
- ☐ Klinefelter Syndrome
- ☐ Rett Syndrome
- ☐ Phenylketonuria
- ☐ Seizure Disorders
- ☐ Prader-Willi Syndrome
- ☐ Angelman Syndrome
- ☐ Mucopolysaccharidoses
- ☐ Progeroid Syndromes
- ☐ Cystic Fibrosis
- ☐ Muscular Dystrophy
- ☐ Thalassemia
- ☐ Bloom's Syndrome
- ☐ Tay-Sach's Disease
- ☐ 22q/ DiGeorge/ VCF
- ☐ Albinism
- ☐ Achondroplasia dwarfism
- ☐ Sotos Syndrome
- ☐ Marfan Syndrome
- ☐ Autism
- ☐ Usher Syndrome
- ☐ Bardet-Biedl
- ☐ Retinitis Pigmentosa
- ☐ Charcot-Marie-Tooth
- ☐ Cardiomyopathy
- ☐ Long QT Syndrome
- ☐ Hearing Loss
- ☐ Vision Loss
- ☐ Other

How many semester hours (credits) of training about genetic conditions did you receive in your university education?

0 5 10 15 20 25 30 35 40 45 50

Please slide, write if over 50



What training did you receive regarding genetic conditions?

How many clock hours of professional development training related to genetic conditions have you received since you started working full time?

0 10 20 30 40 50 60 70 80 90 100

Please slide, write if over 100

Based on your IEP experience with families of students with genetic conditions, do you feel that...

	Strongly disagree	Disagree	Agree	Strongly Agree
You have a clear understanding of their needed services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You can set realistic expectations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You can provide sufficient knowledge to families	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You can anticipate other areas of developmental concern	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You can thoroughly discuss IEP objectives pertaining to their genetic conditions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other educators are knowledgeable about genetic conditions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parents are knowledgeable about their child's genetic condition(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You desire more information about genetic conditions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You would develop more realistic goals for students with genetic conditions with additional information about their specific conditions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

You would recommend additional services for students with genetic conditions with additional information about their specific conditions



How many clock hours do you spend researching medical information about each genetic condition?



What information would be beneficial to know about genetic conditions during the IEP process?
Please rank all in order of importance to you.

- Diagnosis/ Condition Name
- Cause
- Symptoms
- Prognosis
- Future associated concerns
- Criteria for Diagnosis
- Common treatment plans
- Inheritance patterns
- Recurrence risk
- Life expectancy
- Incidence
- Basic genetics information
- Medical Terminology
- Impact on educational abilities

Considering the resources you use to find information about genetic conditions:

	Do you use this resource?			How useful is it?			
	Always	Sometimes	Never	Never Useful	Somewhat not useful	Somewhat useful	Always Useful
General Internet Search (i.e. Google)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Professional Websites (i.e. Informational Hospital Web pages)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Genetics Websites (i.e. OMIM, Genetics Home Reference)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
News Articles	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Condition-specific Foundations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Advocacy/ Support Groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Textbooks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Academic Literature	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Professional Associations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Conferences	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Talks/ Speakers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child's medical providers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parents as advocates	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Coworkers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social Media	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other <input type="text"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

At what stage(s) in the IEP process would information about genetic conditions be helpful?

- ☐ Referral
- ☐ Identification
- ☐ Determining eligibility
- ☐ Development of the IEP
- ☐ Implementation
- ☐ Evaluation and review

When thinking of the children with genetic conditions that you serve, at what age do you think information about their genetic conditions provided by a genetic counselor would be most beneficial to you?

- ☐ Early childhood (Preschool/ Kindergarten)
- ☐ Elementary school (Grades 1–5)
- ☐ Middle school (Grades 6–8)
- ☐ High school (Grades 9–12)
- ☐ At time of diagnosis for the child
- ☐ Transitions between schools
- ☐ Transitions between educators
- ☐ Transition to adulthood
- ☐ During background preparation for the IEP meeting
- ☐ During evaluations for the IEP
- ☐ At the IEP meeting
- ☐ At every annual IEP meeting
- ☐ Upon request
- ☐ Other

Have you ever worked professionally with a genetic counselor?

- ☐ Yes
- ☐ No

Have you ever interacted personally with a genetic counselor?

- ☐ Yes
- ☐ No

Please describe the role of a genetic counselor.

Thank you for completing the survey. Your responses have been recorded. If you would like to be redirected to the survey to enter your email for the Amazon raffle, please select "Yes".

- ☐ Yes
- ☐ No

Please follow the link to continue to the raffle

entry: https://uofsc.co1.qualtrics.com/jfe/form/SV_4Z2Uiu7GQh9DLc9

APPENDIX B

PARTICIPANT RAFFLE

What is your profession?

- ☐ School Psychologist
- ☐ Special Education Teacher

Please enter your email address if you would like to be entered for the \$25 Amazon gift card raffle.

APPENDIX C

SUPPLEMENTAL TABLES AND FIGURES

Table C.1 *Demographic characteristics of study participants meeting the inclusion criteria for an online survey aimed to assess the knowledge of school psychologists and special education teachers regarding genetic conditions*

Characteristic	Total	
	N	%
Gender (N=43)		
Male	4	9.3
Female	39	90.7
Ethnicity (N=43)		
Caucasian/ White	41	95.3
African American	1	2.3
Native American/ Alaskan Native	0	0
Pacific Islander	0	0
Asian	0	0
Hispanic	1	2.3
Prefer not to answer	0	0
Profession (N=43)		
School Psychologist	29	67.5
Special Education Teacher	14	32.6
Special Education Classroom Type (N=14)		
Itinerant and Resource Teacher	5	35.7
Self-Contained Teacher	6	42.8
Team Teach with General Education Teacher	12	85.7
Provide Home-Based Services	0	0
Specialist	0	0
Consultant	0	0
Other	1	7.1
Special Education Specialization (N=14)		
Early Childhood Education (Preschool)	1	7.1
Grade K-12	8	57.1
High- Incidence Disabilities	1	7.1
Low-Incidence Disabilities	3	21.4
Emotional or Behavioral Disorders	3	21.4
Autism Spectrum Disorders	2	14.3
No Specialization	2	14.3
Other	2	14.3

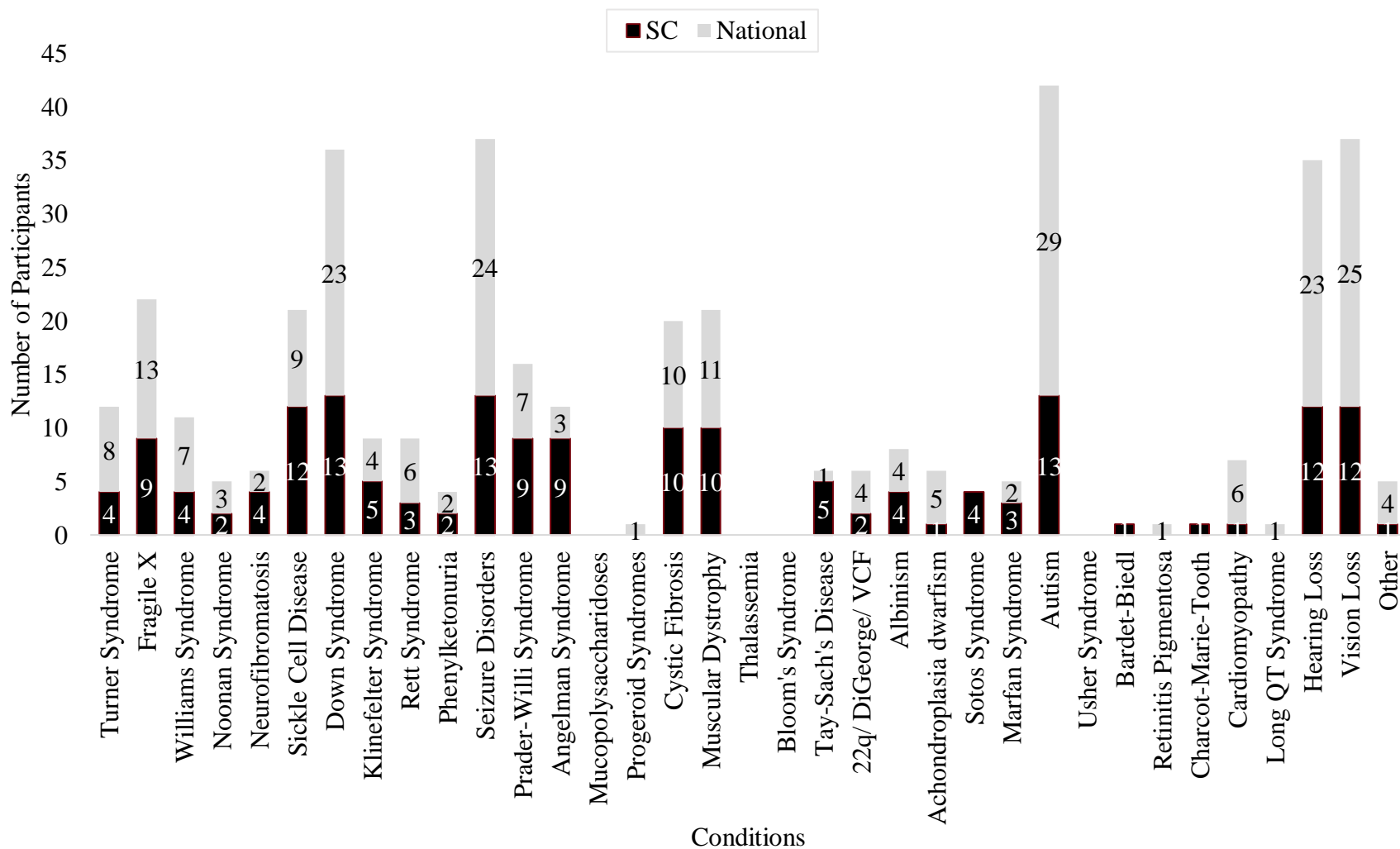


Figure C.1 Occurrence of genetic conditions reported by School Psychologists and Special Education Teachers, comparing South Carolina to all other states in the United States

Table C.2 *Exposure to genetic conditions, by type of special education teacher*

Conditions	Itinerant and Resource Teacher	Self-Contained Teacher	Team Teach with General Education Teacher	Other
Autism	4	6	11	1
Seizure Disorders	2	6	8	1
Vision Loss	2	5	8	1
Hearing Loss	3	3	7	1
Down Syndrome	2	3	5	1
Sickle Cell Disease	2	2	4	0
Cystic Fibrosis	1	3	2	0
Fragile X	1	1	2	1
Muscular Dystrophy	2	0	3	1
Other	1	1	3	0
Prader-Willi Syndrome	0	1	2	1
Turner Syndrome	1	1	2	0
Angelman Syndrome	0	0	1	1
Williams Syndrome	0	1	1	0
Rett Syndrome	0	0	1	1
Cardiomyopathy	0	1	0	0
Noonan Syndrome	0	0	1	0
Retinitis Pigmentosa	0	0	1	1
Klinefelter Syndrome	0	0	0	0
Albinism	0	0	0	0
Neurofibromatosis	0	0	0	0
Tay-Sachs	0	0	0	0
22q/ DiGeorge/ VCF	0	0	0	0
Achondroplasia Dwarfism	0	0	0	0
Marfan Syndrome	0	0	0	0
Phenylketonuria	0	0	0	0
Sotos Syndrome	0	0	0	0
Progeroid Syndromes	0	0	0	0
Bardet- Biedl	0	0	0	0
Charcot-Marie-Tooth	0	0	0	0
Long QT Syndrome	0	0	0	0
Mucopolysaccharidoses	0	0	0	0

Note. The specializations of home-based services, specialist, and consultant were removed because no participants identified within these specializations.

Table C.3 *Exposure to genetic conditions reported by the specialization of Special Education Teachers*

	Early Childhood Education (Preschool)	Grade K-12	High- Incidence Disabilities	Low- Incidence Disabilities	Emotional or Behavioral Disorders	Autism Spectrum Disorders	No Specialization	Other
Autism	1	7	0	2	3	1	2	0
Seizure Disorders	1	5	1	3	3	2	1	1
Vision Loss	1	6	1	2	3	1	1	2
Hearing Loss	0	6	1	2	2	2	1	1
Down Syndrome	1	4	1	2	3	1	1	0
Sickle Cell Disease	0	3	0	1	1	1	1	1
Cystic Fibrosis	0	3	0	1	3	0	0	0
Fragile X	0	3	0	0	1	0	0	0
Muscular Dystrophy	0	2	0	0	0	0	1	0
Other	1	1	0	0	0	0	0	2
Prader-Willi Syndrome	0	2	0	1	1	0	0	0
Turner Syndrome	0	2	0	1	1	0	0	1
Angelman Syndrome	0	1	0	0	0	0	0	0
Williams Syndrome	0	0	0	1	0	1	0	0
Rett Syndrome	0	1	0	0	0	0	0	0
Cardiomyopathy	0	1	0	0	1	0	0	0
Noonan Syndrome	1	0	0	0	0	0	0	0
Retinitis Pigmentosa	0	1	0	0	0	0	0	0
Klinefelter Syndrome	0	0	0	0	0	0	0	0
Albinism	0	0	0	0	0	0	0	0
Neurofibromatosis	0	0	0	0	0	0	0	0

Tay-Sachs	0	0	0	0	0	0	0	0
22q/ DiGeorge/ VCF	0	0	0	0	0	0	0	0
Achondroplasia								
Dwarfism	0	0	0	0	0	0	0	0
Marfan Syndrome	0	0	0	0	0	0	0	0
Phenylketonuria	0	0	0	0	0	0	0	0
Sotos Syndrome	0	0	0	0	0	0	0	0
Progeroid Syndromes	0	0	0	0	0	0	0	0
Bardet- Biedl	0	0	0	0	0	0	0	0
Charcot-Marie-Tooth	0	0	0	0	0	0	0	0
Long QT Syndrome	0	0	0	0	0	0	0	0
Mucopolysaccharidoses	0	0	0	0	0	0	0	0

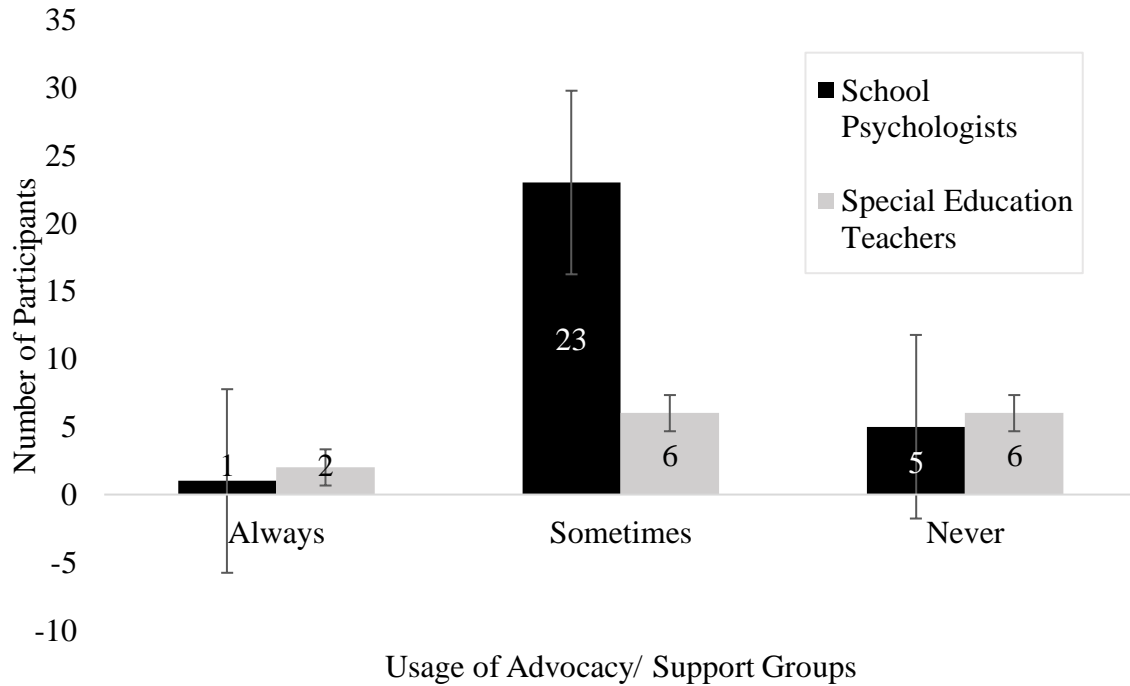


Figure C.2 *Use of Advocacy and Support Groups, by profession.* $Pr X^2=0.053$. Error bars show standard errors.

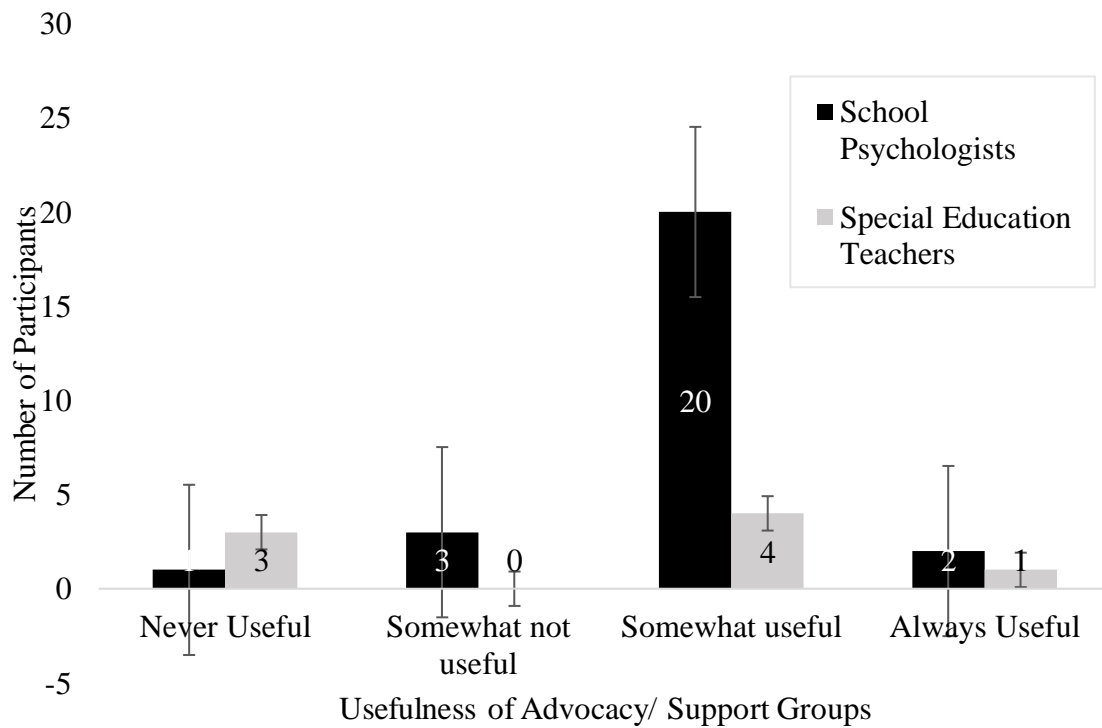


Figure C.3 *Usefulness of Advocacy and Support Groups, by profession.* $Pr X^2=0.055$. Error bars show standard errors.

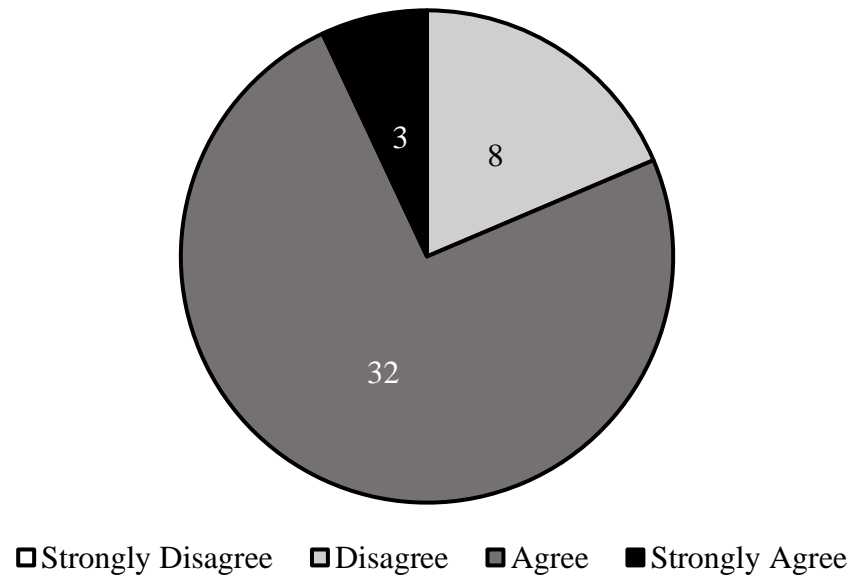


Figure C.4 Participant perceptions regarding their understanding of the needed services for students with genetic condition

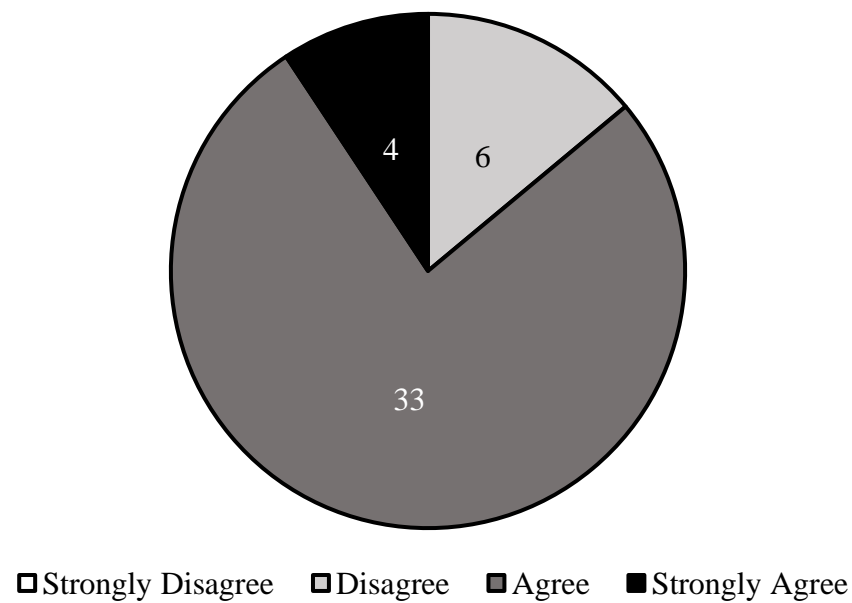
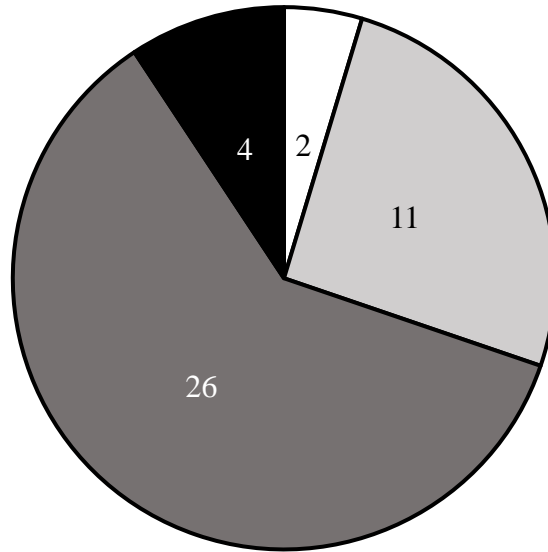
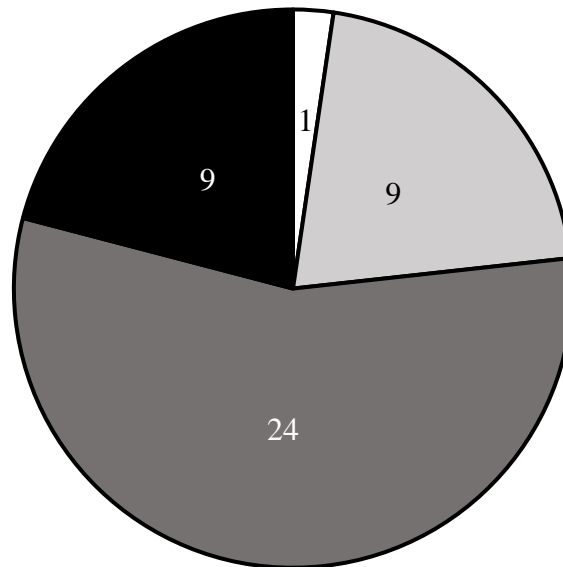


Figure C.5 Participant perceptions regarding their ability to set realistic expectations for students with genetic conditions



☐ Strongly Disagree
 ☐ Disagree
 ☐ Agree
 ☐ Strongly Agree

Figure C.6 Participant perceptions regarding their abilities to anticipate other areas of developmental concern for students with genetic condition(s)



☐ Strongly Disagree
 ☐ Disagree
 ☐ Agree
 ☐ Strongly Agree

Figure C.7 Participant perceptions that parents are knowledgeable about their child's genetic condition(s)

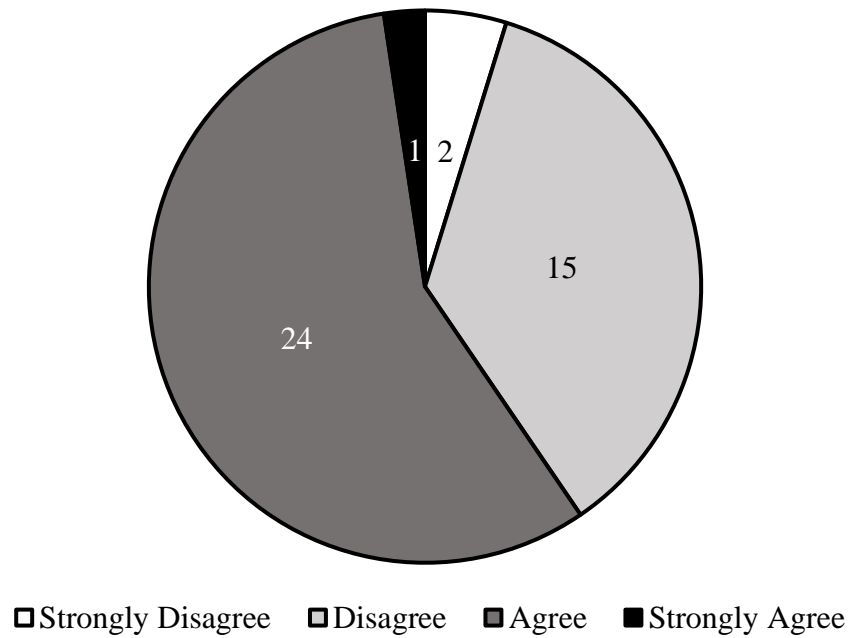


Figure C.8 Participant perceptions regarding their ability to provide sufficient knowledge to families of students with genetic condition(s)

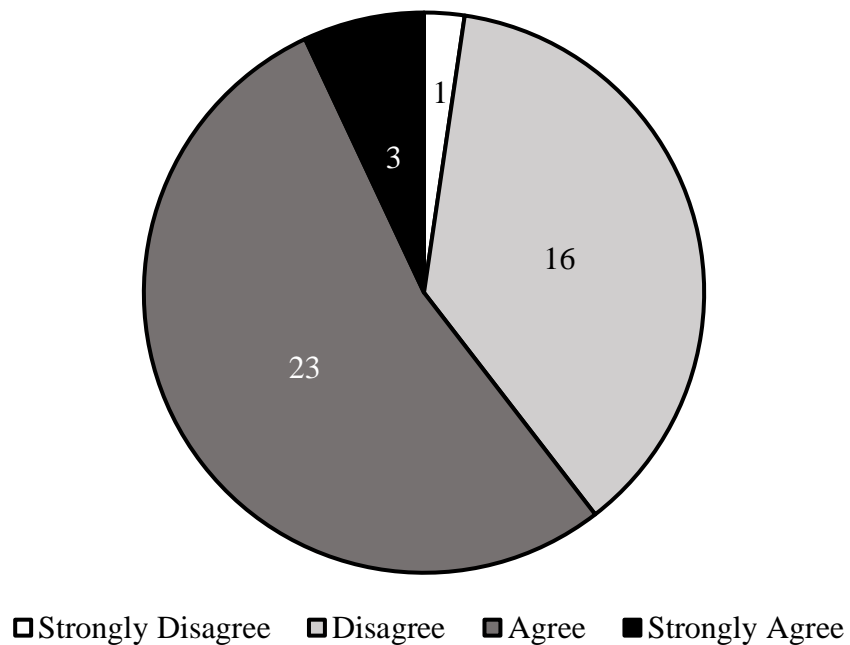


Figure C.9 Participant perceptions regarding their ability to discuss IEP objectives pertaining to the student's genetic condition(s)

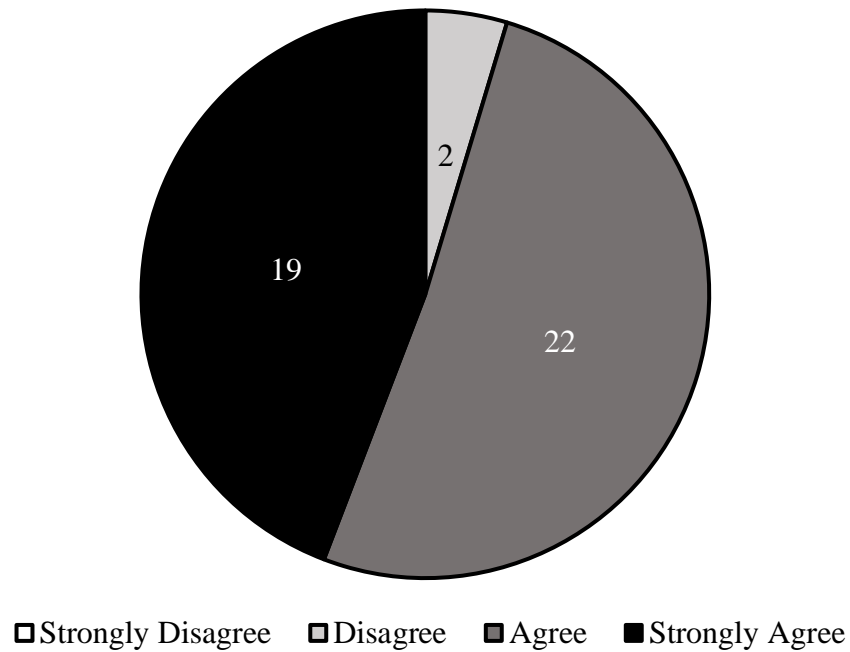


Figure C.10 Participant perceptions that they could develop more realistic goals for students with genetic conditions with additional information about their specific conditions

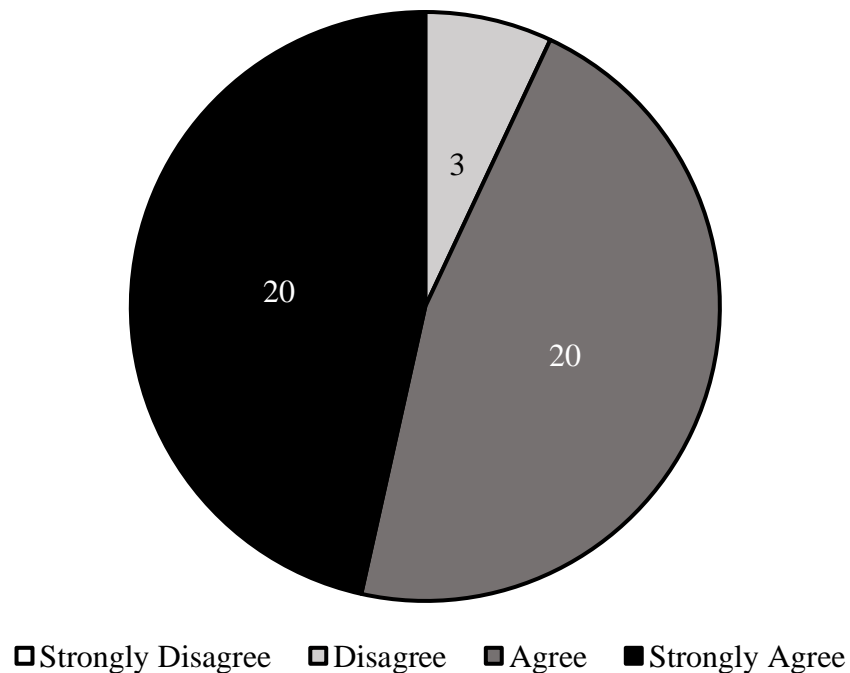


Figure C.11 Participant perceptions that they would recommend additional services for students with genetic conditions with additional information about their specific conditions

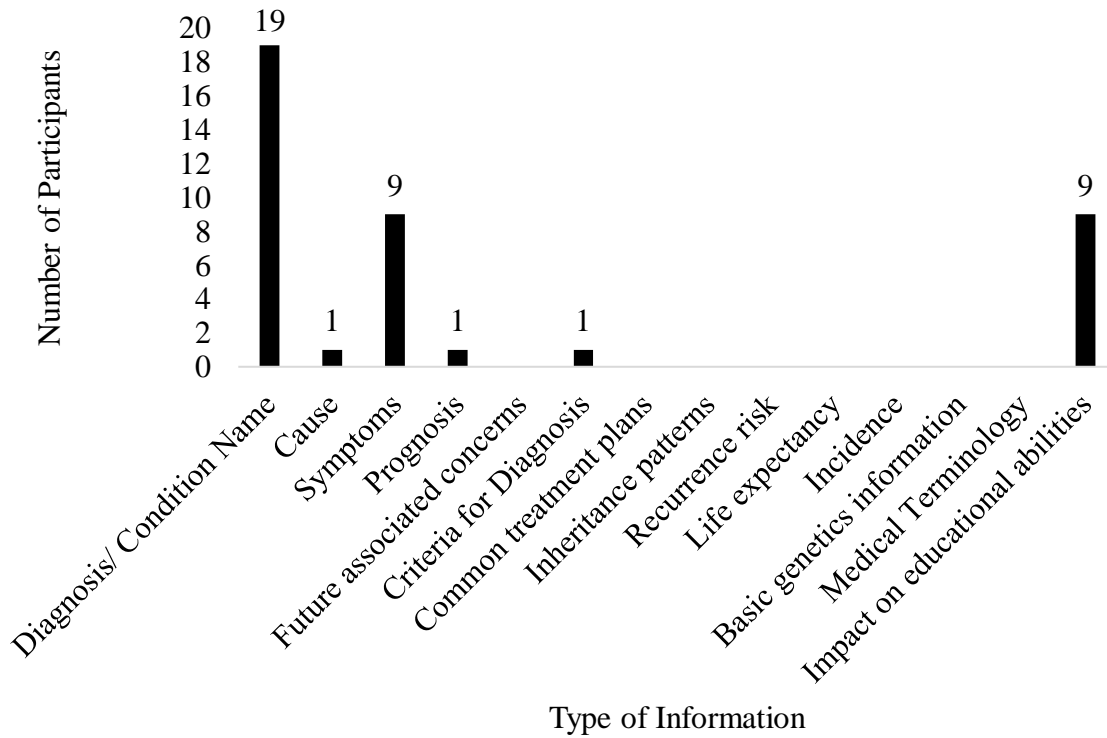


Figure C.12 Frequency the most beneficial information (rank 1) to be provided to School Psychologists and Special Education Teachers about students with genetic conditions

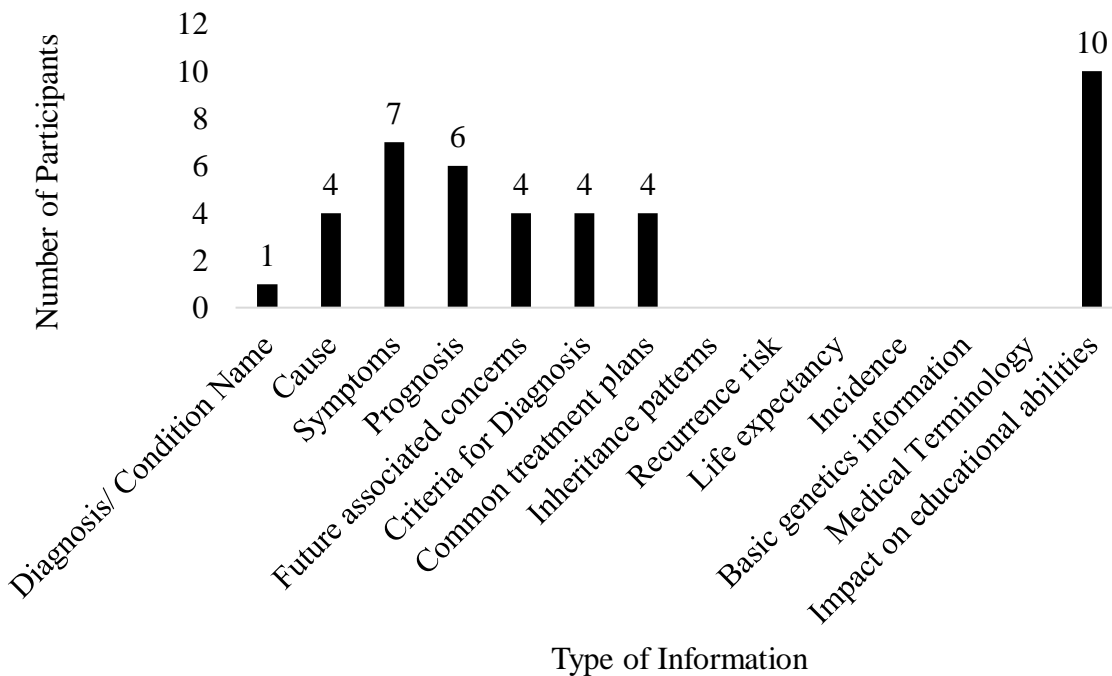


Figure C.13 Frequency of beneficial information (rank 2) to be provided to School Psychologists and Special Education Teachers regarding students with genetic conditions

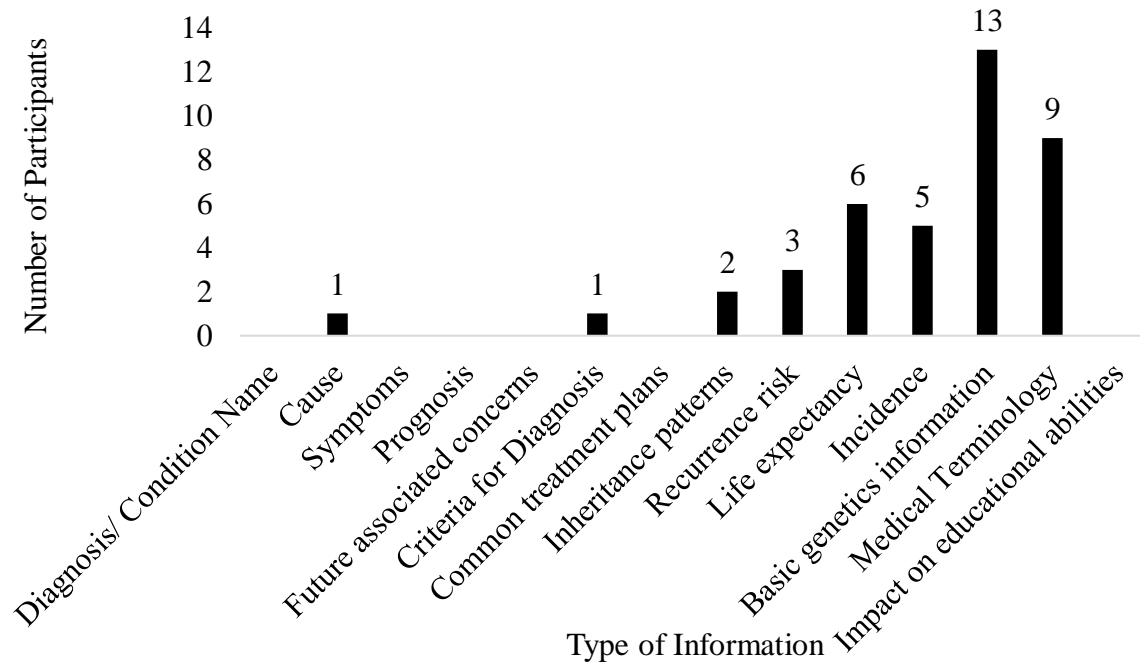


Figure C.14 Frequency of the second least beneficial information (rank 13) to be provided regarding students with genetic conditions

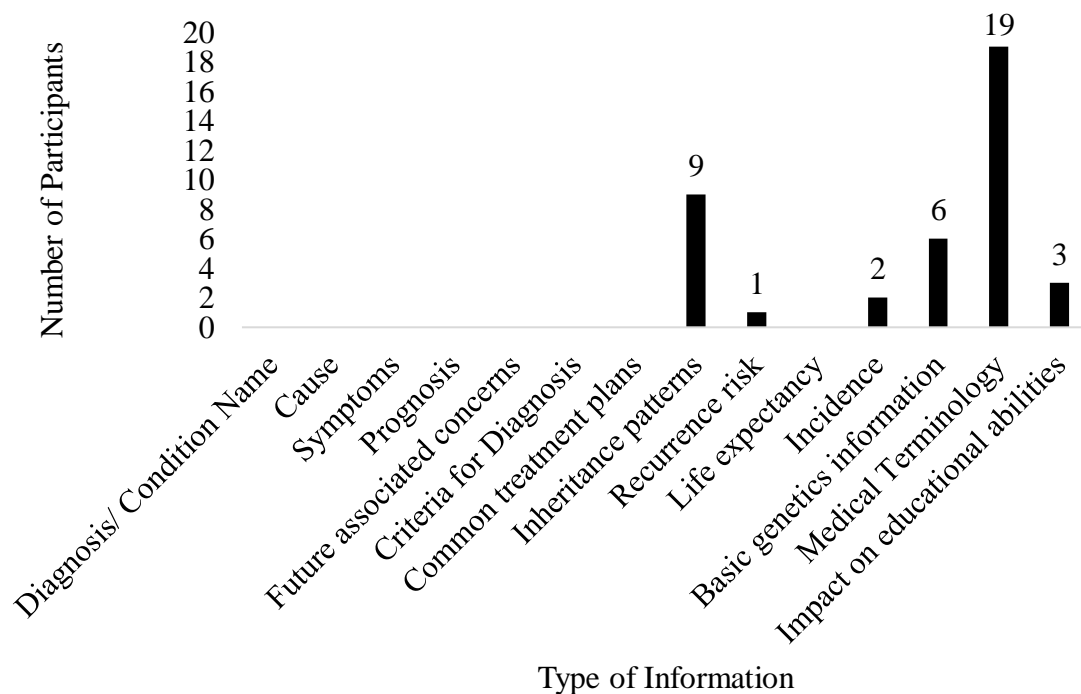


Figure C.15 Frequency of the least beneficial information (rank 14) to be provided regarding students with genetic conditions

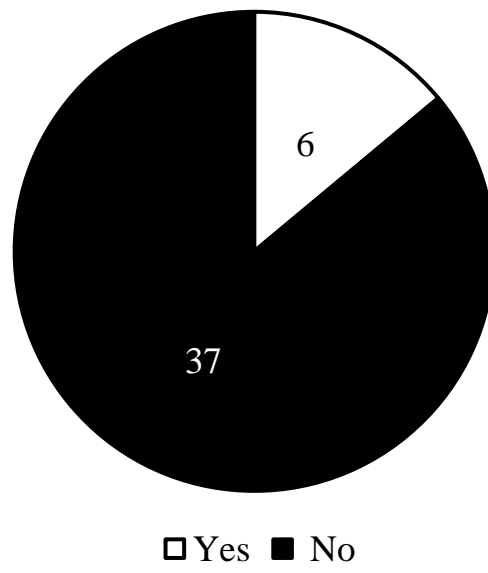


Figure C.16 *Number of School Psychologists and Special Education Teachers that have professionally interacted with a genetic counselor*

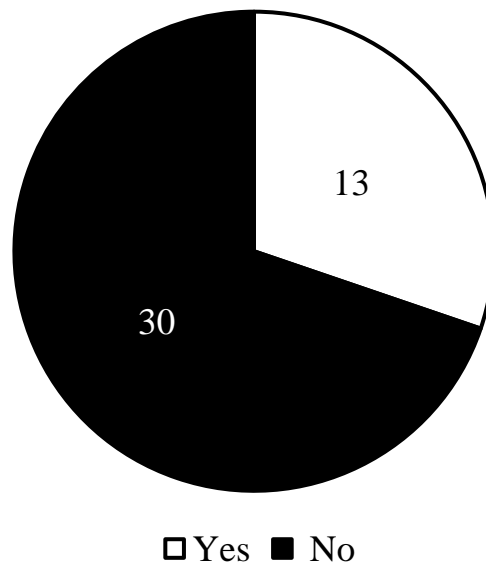


Figure C.17 *Number of School Psychologists and Special Education Teachers that have personally interacted with a genetic counselor*