

Spring 4-26-2019

Parental Perspectives on Physical Education Services for Children with CHARGE Syndrome

Kristi Jo Lane
klane5@brockport.edu

Follow this and additional works at: https://digitalcommons.brockport.edu/pes_synthesis

Part of the [Health and Physical Education Commons](#), [Kinesiology Commons](#), and the [Sports Sciences Commons](#)

Repository Citation

Lane, Kristi Jo, "Parental Perspectives on Physical Education Services for Children with CHARGE Syndrome" (2019). *Kinesiology, Sport Studies, and Physical Education Synthesis Projects*. 64.
https://digitalcommons.brockport.edu/pes_synthesis/64

This Synthesis is brought to you for free and open access by the Kinesiology, Sport Studies and Physical Education at Digital Commons @Brockport. It has been accepted for inclusion in Kinesiology, Sport Studies, and Physical Education Synthesis Projects by an authorized administrator of Digital Commons @Brockport. For more information, please contact kmyers@brockport.edu, digitalcommons@brockport.edu.

Parental Perspectives on Physical Education Services for Children with CHARGE Syndrome

by

Kristi Jo Lane

A Thesis

Submitted in Partial Fulfillment of the Requirements

for the Master of Science in Education

Department of Kinesiology, Sport Studies, and Physical Education

State University of New York

College at Brockport

Spring, 2019

Approved:

4/23/19
Date

Laura Lieberman
Thesis Advisor

4/23/19
Date

R. H. B.
Committee Member

4/26/19
Date

Abili Fata
Committee Member

4/12/19
Date

J. C.
Committee Member

4/23/19
Date

Cathy Houston-Wibber
Department Chair

PERMISSION TO COPY

I grant The State University of New York College at Brockport the non-exclusive right to use this work for the University's own purposes and to make single copies of the work available to the public on a not-for-profit basis if copies are not otherwise available.

Kristi Jo Lane

(Your name here)

Abstract

The Individuals with Disability Education Act (IDEA), American's with Disability Act, and Section 504 all provide legislation that supports children with disabilities and their rights to accessing physical education services. Although there are federal laws that require physical education as a direct service to students with disabilities many students are still inactive both in and outside of physical education classes. Approximately 18% of children and adolescents in the United States have a disability and are limited to opportunities where physical activity can take place (Murphy & Carbone, 2008). There is some literature currently that discusses parental perspectives of their child's physical education services (Columna et. al., 2008). However, there is limited research regarding physical education services and children with CHARGE syndrome specifically. To investigate this problem this study aims to look at perspectives of parents with children who have CHARGE syndrome and their experiences in adapted physical education.

Keywords: Adapted Physical Activity, Parental Perspectives, Disability, CHARGE Syndrome, Physical Education

Table of Contents

Chapter 1 – Summary:.....	6
Introduction	6
Hypothesis.	9
Limitations.....	9
Assumptions.	10
Definition of Terms.	10
Chapter 2 - Review of Literature.....	11
Chapter3 - Manuscript: PARENTS PERSPECTIVES FOR CHILDREN WITH CHARGE SYNDROME.....	18
Introduction	20
Methods	23
Findings	26
Discussion.....	43
References	52
List of Figures	
Table 1.1: Sample Questions for Semi-Structured Interviews.....	56
Table 1.2: Participant Name Codes.....	57
Table 1.3: Demographics of Vision	57
Table 1.4: Demographics of Hearing Loss.....	58
Table 1.5: Demographics of Other Impairments.....	59
Table 1.6: General Demographics.....	60
Table 1.7: Demographics of Physical Education	61

Chapter 1 – Summary:

Introduction

The U.S. Department of Health and Human Services (2008) published Physical Activity Guidelines for Americans, which states that children should participate in 60 minutes or more of physical activity daily. In 2015, the American College of Sports Medicine reported 73% of students are currently not satisfying this guideline. Approximately 18% of children and adolescents in the United States have a disability and are limited to opportunities where physical activity can take place (Murphy & Carbone, 2008). When comparing youth with disabilities to their typically developing peers' research shows that children with disabilities are more sedentary (Maher, Williams, Olds, & Lane, 2007). The research stated above shows that there is a sedentary problem for the youth in the United States especially youth with disabilities. This is a problem because according to the World Health Organization sedentary children become adults who live sedentary lifestyles, which increases the risk of mortality, cardiovascular diseases, diabetes, obesity, high blood pressure, cancer, and depression (Praskash, 2002). Although there is legislation currently in place (IDEA, ADA, Section 504 of the Rehabilitation Act of 1973), that all supports physical education for all youth today there are still many barriers to participate in physical education for these children. One theory that helps explain these barriers and how they interact is Newell's (1984) Theory of Constraints. This theory breaks down constraints into three categories (Task, Individual, and the Environment) and explains how they each play a role in how an individual learns skills. This theory will be utilized throughout this paper to assist in organizing and answering the research questions proposed by the primary investigator.

Research has made some of these barriers visible for children with disabilities, but there are still many unknowns when examining children with disabilities experiences in physical education. One key concept when identifying barriers to quality adapted physical education (APE) is investigating the parent's perspectives on these services. Research shows that parental

perspectives have been utilized before to identify themes of success or areas for improvement within an adapted physical education program for many disabilities, such as Spina Bifida (An & Goodwin, 2007), Visual Impairments (Perkins, Columna, Lieberman, & Bailey, 2013), Developmental Disabilities (An & Hodge, 2013), and Deaf-Blindness (Štěřbová & Kudláček, 2014). Although this information is already utilized today there is still a need to investigate the experiences of specific disability populations and physical education services.

Although there is research about parental perceptions in physical education for many disability groups CHARGE Syndrome has not yet been investigated. According to the CHARGE Syndrome Foundation, CHARGE syndrome currently affects one in every 10,000 births and presents itself when a gene mutation occurs during development. CHARGE is an acronym that stands for: coloboma, heart defects, atresia choanae, growth retardation, genital abnormalities, and ear abnormalities. This acronym symbolizes how CHARGE syndrome is a multiple disability condition that typically affects more than one area of the body and usually multiple body systems. Since we know that CHARGE syndrome affects multiple body systems and many sensory input systems it is understood that the educational needs of children with CHARGE syndrome are different than a typically developing student. Students with CHARGE syndrome have lower levels in the performance of balance, flexibility, hand-eye coordination, proprioception, and motor skill than their typically developing peers (Lieberman, Haibach, & Schedlin, 2012). This is why it is so important to have more information about the needs of children with CHARGE syndrome in physical education to ensure that physical education teachers and motor teams are meeting the needs of each student.

Current research on CHARGE syndrome and physical education is very minimal which

displays a need for more research to be done to continue to improve the physical education experiences of this population. Investigating the parental perspectives of current APE services for children with CHARGE can lead to better evidence based practices for this population in physical education. It is known that parents play a critical role in their child's educational programming this includes physical education. Investigating their perspective on services can give professionals insight on what parents believe to be important and better meet their expectations. The aim of this study is to investigate parental perspectives of physical education services for children with CHARGE Syndrome. Through this investigation we hope to reveal facilitators and barriers to quality physical education services for this population from the parent's point of view.

Statement of the Problem.

Individuals with Disability Education Act (IDEA), American's with Disability Act, and Section 504 all provide legislation that supports children with disabilities and their rights to accessing physical education services. Although there are federal laws that require physical education as a direct service to students with disabilities, many students are still sedentary. Approximately 18% of children and adolescents in the United States have a disability and have limited opportunities for physical activity (Murphy & Carbone, 2008). Currently, there is some literature that discusses parental perspectives of their child's physical education services (Columna et al., (2008). However, there is limited research regarding physical education services and children with CHARGE syndrome specifically. It is known that children with CHARGE Syndrome are typically placed in general physical education this develops a case to question if general physical education teachers are meeting the needs of students with CHARGE. One was to investigate this problem this study aims to investigate parental perspectives with children who

have CHARGE syndrome and their experiences in physical education.

Purpose of the Study.

The purpose of this study is to investigate the parental perspectives on physical education services of children with CHARGE Syndrome.

Hypothesis.

1. It is expected that parents will think more communication should be done between the physical education professional and the parents.
2. It is expected that that parents will believe their child is not receiving physical education services as much as their typically developing peers.
3. It is expected that more research will need to be done in the area of children with CHARGE syndrome and physical activity.
4. It is expected that there are many barriers to children with CHARGE syndrome and physical activity opportunities in physical education.

Delimitations.

Some delimitation are that the participant pool is limited to only parents with children with CHARGE Syndrome, who all reached out to the primary investigator to participate. Thus is can be assumed that these are the perspectives of parents who are already proactive in their child's educational programs.

Limitations.

Some limitations are that the parents will answer honestly about their child's experience in physical education, that parents have a understanding of their child's current physical education services, and participant pool is only parents with children with CHARGE and their physical

education services- cannot generalize outside of that population or mode of physical activity.

Assumptions.

I am going to assume that the parents will answer truthfully to the interview questions, and that parents have a general understanding of their child's current physical education experience.

Definition of Terms.

- **Adapted Physical Education:** Adapted physical education is a direct service provided to a child with a disability that is received at school for physical education by law.
- **CHARGE Syndrome:** CHARGE stands for features common in the disorder: coloboma, heart defects, atresia choanae (also known as choanal atresia), growth retardation, genital abnormalities, and ear abnormalities (National Institute of Health (NIH), 2017). Most individuals who have CHARGE Syndrome have several major characteristics, or any combination of major and minor characteristics which makes the way this disorder presents itself unique in each diagnosis (NIH, 2017).
- **Parental Perspectives:** Views that parents have on their child's overall experience with an adapted physical education services including curriculum, professionals, instructions, support, and environments.

Significance of the Study.

Investigating the parental perspectives of current physical education services for children with CHARGE can lead to better evidence based practices for this population in physical education.

Chapter 2 - Review of Literature

CHARGE Syndrome

In 1981 the acronym CHARGE was used to describe the set of unique characteristics that present themselves together to describe the characteristics a child may have with this syndrome. CHARGE syndrome is a genetic disorder that is complex and multifaceted. There is a lack of research about children who have CHARGE Syndrome and their experiences with physical education services. Currently there is only one article examines physical education and children with CHARGE Syndrome, focusing on the experiences and needs in physical education for this population (Lieberman et. al., 2012). Due to the complexity of this disorder and the multiple physical and health issues associated with it children with CHARGE Syndrome often have long hospitalizations leading to additional developmental complications. These complications are due to an absence in socialization and physical activity during these hospitalizations (Lieberman et. al., 2012).

According to the CHARGE Syndrome Foundation, CHARGE Syndrome affects multiple body systems especially the functions of the eye, heart, nasal cavity, delays in growth and development, and ear abnormalities (2017). These physiological effects cause functional implications on the performance of balance skills, flexibility, hand-eye coordination, proprioceptive skills, and motor skill development (Lieberman et. al., 2012). It is known that students with disabilities lack opportunities in physical education when compared to their peers; it is understood that when children with CHARGE Syndrome are given the opportunity for participation in physical activity they have the potential to develop a level of health-enhancing fitness and motor skills (Lieberman et. al., 2012). The findings of Lieberman et. al., (2012)

discusses four needs that need to be addressed when working with children with CHARGE Syndrome in physical education. 1) more work on open and closed skills, 2) need for properly trained support personnel, 3) the need to address skills in top-down and bottom-up approach, and 4) the need for extended time in physical education. It is essential for future research to determine what children with CHARGE Syndrome are currently experiencing in physical education, and one way to investigate that is thorough parent perspectives of these physical education services.

Federal Laws Pertaining to Rights to Physical Education Services

The Individuals with Disabilities Education Act (IDEA) (2004) states that physical education is a direct service to all students and is a necessary component of all students' individualized education plans. This act also proposes that students with disabilities ages 3-21 years old have the right to access a free, appropriate, and public education in their least restrictive environment. Students with disabilities have the same rights to have equal time in physical education as their same aged peers, and access to the general physical education program. IDEA states that the least restrictive environment should serve students in the same environment as their peers as long as they are still finding success. If this placement does not meet the needs of the student, they should be served in the most appropriate environment for their individual success.

The Rehabilitation Act of 1973 is a federal civil rights law that defends individuals with disabilities and sets guidelines for state departments of education, school districts, colleges, and universities. This act states that all public programs that receive federal funding cannot discriminate against individuals with disabilities, and must provide accessible programming.

Although these laws are in place to advocate for students with disabilities and their rights to physical education many students with disabilities are still not active participants in their physical education classes. This means there is a disconnect between the interpretation of the law for what children with and without disabilities are entitled to in terms of physical education, and what school districts and/ or physical education professionals are delivering to students currently.

Barriers in Physical Education for Students with Disabilities

The American Association for Physical Activity and Recreation and the National Association for Sport and Physical Education (2010) advocate that students who score 1.5 standard deviations below the mean on a norm-referenced test, or are two years or more behind their same aged peers on criterion-referenced test or other tests for physical and motor fitness should be considered eligible for adapted physical education services. The same associations argue that students who have additional needs to be successful in physical education regardless of disability should receive accommodations through adapted physical education. Although it is well established that including all students in physical education is not only the law, but also best practice there are still many barriers to physical education for students with disabilities.

Currently, there is a lack of research about barriers in physical education for students with disabilities. One article from Lieberman, Houston-Wilson, and Kozub (2002) discusses barriers to children with visual impairments in general physical education. This article concluded that there are multiple barriers to children with visual impairments in physical education including: lack of professional preparation, lack of equipment, programming/curriculum barriers, time in schedule, deficient communication, scarce qualified teachers/personal, pace of units, teacher over protectiveness, limited expectations, parental over protectiveness, and apathy of the

teacher. Although this article is specific to students with visual impairments these barriers may be related to what other students with other disabilities are experiencing in physical education.

An and Goodwin (2007) concluded other barriers to participation such as safety concerns, equipment and wheelchair accessibility, and instructional support. This articles findings are congruent with Lieberman et. al (2002) even though this study focused on the experience of children with spina bifida.

While there is not a lot of literature discussing barriers in physical education for students with disabilities (Lieberman et. al., 2002) there are many articles that demonstrate the barriers to physical activity in general for this population. Shields and Synnot (2016) suggest that the barriers in general to physical activity are multifaceted. Shields and Synnot state that some barriers to physical activity for individuals with disabilities include: lack of knowledge of skills, child's preferences, fear, parental behavior, negative attitudes towards disability, inadequate facilities, lack of transportation, lack of programming and staff capacity, and cost (2016). Overall, this study found three themes to barriers to physical activity in children with disabilities. Theme one is that there are similarities and differences between children with disability and children with typical development. Theme two was that people make the difference in the experience. The next theme was one size does not fit all, and that there must be an emphasis on choice. The final theme suggested that there must be clear and consistent communication between stakeholders.

Perkins et. al (2013) proposed a few barriers to participation to physical activity including: lack of recreational and sport opportunities, general physical educators' lack of knowledge about modification, lack of appropriate facilities, and lack of parental knowledge of

physical activity resources. Even though this study focused on physical activity in general many of these barriers may be consistent with the barriers found in physical education.

Štěřbová and Kudláček (2014) investigated deaf-blindness and barriers to leisure-time physical activity. This study found many variables both for key barriers and facilitators of physical activity for their children with deaf-blindness. Some themes that emerged for facilitators of physical activity included: providing special schools and care centers that understood the needs of this population, special programming for youth to learn the skills needed to participate in physical activity, adapted equipment to assist with active participation, parent support groups where networking can take place and community could be built, and having trained recreation and adapted sport specialists to work with this population in sport and recreational settings (Štěřbová & Kudláček, 2014). These facilitators then become barriers when not implemented; for example: when equipment is not provided that would help a child be more successful at a task or participate more with their peers such as utilizing a lighter and larger ball that stays in the air longer to allow more reaction time and a larger surface area for contact this would lead to less successful contacts with the ball, less confidence playing, and lead to decreasing rates of participation.

Parental Perspectives of Children's Physical Education Services

Currently, there are no known articles on the parental perspectives of physical education services for children with CHARGE Syndrome. However, there are many research studies done on parental perspectives of physical education and other disability categories which may lead to a trend for students with disabilities in general.

The first theme after reviewing the literature is that most parents found their child had a

sense of belonging, inclusive peer social integration, and active participation within the physical education class (Columna et. al., 2008; An & Hodge, 2013). Perkins et. al. (2013) found that when children were included in physical education they were building confidence in skills. However, Perkins et. al. (2013) and Štěrbová & Kudláček (2014) also suggested that there was a lack of true inclusion for students with visual impairments who were in physical education and other physical activity opportunities with their same aged peers.

Another theme parents had in common was they could see the health benefits of physical education and the importance of teaching children with disabilities how to live active lifestyles (An & Goodwin, 2007; Perkins et. al., 2013).

The third theme that was discovered in the literature from the perspective of parents with children with disabilities was there was a true necessity for having quality adapted physical education professionals who understood their child's disability and how to fully include them in all of the physical education curriculum (An & Goodwin, 2007; Perkins et. al., 2013; Štěrbová & Kudláček, 2014; and Columna et. al., 2008). This included concern of physical education professional's ability to modify and adapt lessons, equipment, and instruction for their child's disability to allow participation in the general physical education curriculum as much as possible, as well as utilizing nontraditional activities within the curriculum (Perkins et. al., 2013; Štěrbová & Kudláček, 2014). Perkins et. al., (2013) suggested that one way to combat this lack of knowledge is to integrate an emphasis on the nature of disabilities into teacher preparation programs.

Finally, the last trend observed in the literature when identifying parent's perspectives of their child's physical education experience was how essential communication is between the

parents, physical education professionals, and the multidisciplinary team (An & Goodwin, 2007; Columna et. al., 2008; An & Hodge, 2013; Štěřbová & Kudláček, 2014; and Perkins et. al., 2013). An and Hodge (2013) also investigated that parents responded how networking was important for them within their multidisciplinary teams including the physical education professional. This aided in the parent's knowledge of rights and services for their child both within the school district, as well as the preparation of transition services from school to adulthood recreation (Columna et. al., 2008).

Conclusion

It is well cited that all students have the right to a free, appropriate, and public education regardless of ability in the United States of America. Children in the United States are also in a health crisis that can be combated with proper doses of moderate to vigorous physical activity. The literature suggests that physical education professionals and multidisciplinary team members are doing students with disabilities a disservice when it comes to providing physical education services. This includes barriers to active participation, poor inclusion implementation, lack of prepared quality adapted physical education professionals, and clear modes of communication for all involved on the children's multidisciplinary team. Although literature has identified barriers to physical activity very little is known about physical education specifically, and hardly anything has focused on children with CHARGE Syndrome which suggests that more research needs to be done in both of these areas.

Running Head: PARENTS PERSPECTIVES FOR CHILDREN WITH CHARGE
SYNDROME

**Parental Perspectives on Physical Education Services for Children with CHARGE
Syndrome**

Kristi Lane¹, Lauren J. Lieberman¹, Pamela Haibach¹, Melanie Perrault¹, and Luis Columna²

¹The College at Brockport and ²University of Wisconsin at Madison

**Submitted to
Journal of Disability and Rehabilitation**

Corresponding Author:

Luis Columna, Ph.D., CAPE
University of Wisconsin at Madison
Department of Kinesiology
School of Education
1021 Gymnasium-Natatorium
2000 Observatory Drive
Madison, WI 53706
608-890-2916
lcolumna@wisc.edu

Parental Perspectives on Physical Education Services for Children with CHARGE

Syndrome

Abstract

Purpose: Although there is literature currently that addresses parental perspectives of their child's physical education services related to specific disabilities (Columna, L., Streete, D., Hodge et. al., 2018; Dillion, S., Dolphin. Et. al. 2017; Perkins, Columna, Lieberman, & Bailey, 2013; Columna et. al., 2008; An & Hodge, 2013; Štěrbová & Kudláček, 2014), there is a lack of research in investigating parental perspectives and CHARGE Syndrome. The aim of this study was designed to explore parental perspectives with children who have CHARGE Syndrome and their experiences in physical education. **Methods:** In this descriptive qualitative study, the participants were 10 mothers of children with CHARGE Syndrome ages 6-23 years old. These parents completed a demographic survey and semi-structured interview discussing their perspectives regarding their child's physical education services. **Results:** Three independent themes were revealed (a) holistic expectations, (b) multifaceted barriers, and (c) facilitators to quality physical education. **Conclusions:** The overall finding from this study that parents do find physical education services as an important part of the educational program; however, these programs currently do not meet their expectations in terms of programming, qualified physical education teachers, and mindfully implementing the general physical education curriculum in an effective means for students with multiple disabilities.

Key Words: deafblind, physical activity, inclusion

Parental Perspectives on Physical Education Services for Children with CHARGE Syndrome

The U.S. Department of Health and Human Services published Physical Activity Guidelines for Americans which states that children should participate in 60 minutes or more of physical activity daily (2008). In 2015, the American College of Sports Medicine reported 73% of students were not satisfying this guideline. These numbers are more alarming among children with disabilities. In the United States (US), approximately 18% of children and adolescents have a disability and have limited physical activity opportunities (Murphy & Carbone, 2008).

Unfortunately, there is a worldwide increase in sedentary lifestyles among youth with disabilities (World Health Organization, WHO 2010). This is problematic and worrisome because according to the WHO, sedentary children become adults who live sedentary lifestyles which increases their risk of mortality, cardiovascular diseases, diabetes, obesity, high blood pressure, cancer, and depression (World Health Organization, WHO 2010). A plausible solution to ameliorate the long terms effects and secondary conditions that might arise because of having a disability, is by teaching children the necessary skills to become physically active adults. Physical education is the place where these skills can be learned (Bailey, et. al., 2009). Despite current legislation (e.g. the Individuals with Disability Education Act (IDEA, 2004), Americans with Disabilities Act (ADA), and Section 504 of the Rehabilitation Act of 1973), that supports physical education for all individuals with disabilities, there are still many barriers that inhibit the participation in physical activities and physical education classes for individuals with

disabilities.

Although there is a plethora of research highlighting the barriers children with disabilities experience while attempting to participate in physical education and physical activity settings, there are still many unknowns in regard to barriers to physical education, particularly, the experiences of low incidence disabilities. One key resource when identifying barriers to physical education for children with disabilities is the parents. Research studies have been conducted in the fields of physical education and physical activity to explore parents' perspectives of children with spina bifida (An & Goodwin, 2007), visual impairments (Columna, Streete, Hodge et. al., 2018; Dillion, Dolphin. et. al., 2017; Perkins, Columna, Lieberman, & Bailey, 2013), developmental disabilities (An & Hodge, 2013), deaf-blindness (Štěrbová & Kudláček, 2014), and autism (Lee, Haegele, & Chang, 2017). These studies identified barriers and facilitators to physical education services from the parent's perspective. Despite the research studies conducted to explore parental perspectives toward physical education programming, there is a need to know more about the perspectives of parents of specific disabilities, such as CHARGE Syndrome.

CHARGE Syndrome currently affects one in every 10,000 births and presents itself when a gene mutation occurs during prenatal development. It is usually diagnosed during early childhood. CHARGE is an acronym that stands for: coloboma, heart defects, atresia choanae, growth retardation, genital abnormalities, and ear abnormalities. This acronym symbolizes how CHARGE Syndrome is a multiple-disability condition that typically affects more than one area of the body and multiple body systems (CHARGE Syndrome Foundation, 2017).

In addition to the medical characteristics, individuals with CHARGE Syndrome often experience motor delays impacting their balance, flexibility, hand-eye coordination, (Hefner &

Davenport, 2006). Due to the multifaceted implications of CHARGE Syndrome, it is critical to have quality physical education for this population to ensure that professionals are addressing these needs.

Constraints Theory

In 1986, Newell created a framework to explain how movement patterns emerge from three interacting constraints including: the learner, the task, and the environment. The interactions of these three types of constraints also provide a foundation which can be used to assist teachers, parents and allied health professionals in modifying the task or environment to design a more effective learning environment. CHARGE syndrome includes a set of unique characteristics that should be accounted for when teaching motor skills. For example, children with CHARGE syndrome have dual sensory deficits and many would benefit with balls with bright colors or bells in them to help them locate the location of the ball. Children with CHARGE may also benefit from pre-teaching which is providing the child additional time to learn a motor skill or set of rules or strategies for a sport or game prior to a physical education class.

Research Questions

Investigating the parental perspectives of current adapted physical education (APE) services for children with CHARGE can lead to better evidence based practices for this population in physical education. Thus, the aim of this study was to investigate parental perspectives of physical education services for children with CHARGE Syndrome. Specifically, this study sought to answer the following research questions:

1. What are parental expectations of the physical education professionals in their child's

- educational program? Switch order
2. How do parents view their child with CHARGE Syndrome's physical education experience?

Methods

This study was a descriptive qualitative methodology using interviews of parents with children with CHARGE Syndrome (Cohen, Manion, & Morrison, 2011). A descriptive-qualitative research design was selected because it provides the basis for understanding a phenomenon with completeness (Creswell, 2016). This includes, but is not limited to, things which cannot be observed, such as past events (e.g. a parent's previous experience in physical activity environments with their children), events occurring outside of the researcher's sphere of observation (e.g. a parent's reflection on and recall of past events), and mental processes (e.g. a parent's beliefs of their child's physical education teacher). We used semi-structured interviews that involved individual telephone-based responses. Interviewing in this manner provided a medium for the participants to reflect on and speak about specific situations related to their experiences with physical education and their views regarding physical activity for their children with CHARGE Syndrome.

Participants.

Purposive sampling was used to identify possible participants for the study (Creswell, 2016). The participant population was recruited from the Northeastern Regional CHARGE Conference, as well as the CHARGE Syndrome Foundation in the Eastern United States, and the CHARGE Syndrome Facebook group. The primary investigator (PI) provided flyers that included a summary of the project and the contact information for the PI. The PI sought parents

of children with CHARGE Syndrome, aged 6–23 years, and were receiving or had received physical or adapted physical education services. The research team chose 23 as the maximum age for children because parents could still reflect upon educational programming for their children. A total of 10 families participated in the study, and it happened to be that all were mothers (See table 1). Interested families emailed the PI who then contacted them by phone or email. The PI described the purpose of the study and the timeline for involvement to the families. Families who choose to participate subsequently completed consent forms and scheduled an interview regarding their child’s physical education services. All participants’ consent forms were approved by the lead author’s university Institutional Review Board along with the study protocol. Also, pseudonyms were used to protect participants’ identities in this study.

Data Collection

Data was collected using a demographic surveys and semi-structured interviews. A demographic survey was collected from each participant and included information such as: child’s current age in years, and information about characteristics of CHARGE Syndrome (visual impairment, hearing loss, heart defects, atresia of choanae, delayed growth/development, and status of semicircular canals) (see table 1). The demographic survey and semi-structured interview questions were reviewed and validated by a panel of nine experts with experience in the fields of adapted physical education, CHARGE Syndrome, general physical education teachers who teach children with CHARGE Syndrome, and parents of children with CHARGE Syndrome. Based on the experts’ recommendations, the lead researcher made changes (e.g. ordering of the questions and time references within questions) and re-submitted the instrument to the panel for final approval.

After reviewing written informed consent, the PI conducted the one-on-one semi-structured phone interviews with the participants. Each interview lasted approximately 45 to 60 minutes and was audio-recorded to ensure accuracy and content validity. The PI made every effort to help the participants feel comfortable, such as asking introductory questions to engage the participants in the topics. Sample questions are included in table 2.

Data Analysis

The 10 interview recordings were audio recorded, transcribed, and analyzed using a thematic line-by-line analysis (Merriam, 1998). The interview data was prepared for analysis by transcribing the audio-taped interviews. The first and second author independently read the transcripts numerous times and analyzed the data independently of one another. Subsequently, the researchers reviewed the document together to reach consensus regarding the themes and subthemes. The extracted and categorized themes from the data were reduced when the researchers found revealing common threads. As the data was reviewed, this process led to the connection of patterns within categories resulting in the emergence of recurring themes and subthemes. Finally, the researchers provided the themes along with supporting quotes retrieved from the transcripts to three investigators from the research team to ensure that they were consistent and to assure the themes reflected the purpose of the study and corresponded with the research questions.

Trustworthiness

To ensure trustworthiness of the data, several strategies were implemented. These included: 1) validating interview protocol, 2) conducting member checking, 3) search for negative cases and 4) utilizing multiple researchers to analyze the data. A committee of

professionals was formed who are familiar with both the field of adapted physical education and CHARGE Syndrome (adapted physical education professors, parents of children with CHARGE Syndrome, and general physical educators). The individuals on this committee are all experts on these topics and did evaluate and revise the interview questions that were utilized to collect data. This process was completed several times to ensure the validity of the questions before the interviews were conducted. Also, the PI conducted member checking to ensure the trustworthiness of the data. Member checking involves sending the interview transcripts back to the participants to improve the trustworthiness of the information (Creswell, 2016). The transcriptions of the interviews were returned to the participating parents for member checking to ensure that the information was accurate, and 5 of the 10 parents completed the process. After hearing back from participants about these checks, the PI either left the transcripts as is when the participant said they were accurate or the PI added their comments. We also conducted a “search for negative cases” by looking for responses that were counter to or did not align well with the established major themes and categories (Creswell, 2016). Two researchers independently reviewed the transcripts for themes, subthemes, and supporting quotes. Then they consulted each other to come to agreement on common findings. Lastly, these were sent to three other researchers from the team to confirm the accuracy of the data.

Findings

Three recurrent and interrelated themes emerged from the data analyses, which were (a) *holistic expectations*, (b) *multifaceted barriers* and (c) *facilitators to quality physical education* (see Figure 1). These themes emerged as parents expressed their voices in terms of their experiences and expectations toward physical education programming for their children with

CHARGE Syndrome. Several subthemes support each theme. An interesting phenomenon in this study is the fact that the findings are somewhat contradictory; meaning that the expectations towards PE programming were mentioned barriers and facilitators depending on the context.

Theme 1: Holistic Expectations

Parent's who participated in this study, were asked if physical education was important to their child's educational programming. Parent's agreed that it was important; however, these parents further explained that their expectations for physical education go beyond the physical domain. This means that participating parents of children with CHARGE Syndrome, value the impact of physical education for the development of fundamental motor skills that might lead to health improvements; yet, they placed a deeper value on other skills that are developed in a physical education class such as self-advocacy, cooperation, and the development of social skills.

Three subthemes emerged under the theme of *holistic expectations*. These subthemes were (1) expected benefits of programming, (2) qualified physical education teachers, and (3) effective communication.

Subtheme 1: Expected benefits of programming. Overwhelmingly, all parents' explained that physical education is an important part of the educational plan for their children. This subtheme is about the expectations of physical education programming that parents discussed in the interviews. Parents mentioned that they believe physical education should include curriculum beyond motor or sport specific skills. They would like for the skills their children learned in the physical education class to be part of their daily life. Melanie commented in this regard,

It's very important for kids to be involved in physical education and learn health and how

to take care of themselves and just getting into a routine of exercise every day. I think sport in general is very important for kids with disabilities. Just to give themselves confidence, that they can do those things that kids without disabilities can do.

For Melanie, giving her son the opportunity to be part of the physical education class provides an outlet for children with Charge Syndrome to learn the skills that will allow them to participate in sports and enjoy similar benefits as their peers without disabilities. Parents in the current study indicated that physical education not only provided an opportunity to learn motor skills, but also facilitated experiences that helped their child work on daily living skills such as social skills.

When asked about benefits that physical education offers her child in terms of social skills, Rachel commented: *“Working with others in a team and having friends,”* and Jasmine mentioned *“Being able to appropriately take turns...and recognizing others [peers] achievements.”*

Physical education often prompts collaborative learning and social skill development through activities that foster interaction between peers and the teacher. Another parent, Jasmine shared a similar opinion to Melanie and Rachel, that by participating in physical education, children can learn social skills and learn how to interact with their peers. However, Jasmine indicated that physical education is the place that the different needs of the child can be addressed such as coordination, upper body strength, and balance. Physical education is also a place where sensory needs can be attended to. She commented,

She [Olivia] needs that sensory input that comes from physical education. It gives her a huge social outlet because there’s always a group in physical education and Olivia is very quirky, but when you get in a class where everyone knows her and they’re all working together to get a basket, or goal...Olivia becomes part of something bigger than herself.

According to Jasmine, in physical education her child can have social interactions and experiences that she normally would not have the opportunity to have in other settings, such as physical therapy. For parents in this study, physical education also provides an opportunity to increase overall stamina, strength, and balance in their children. In this regard, Jackie mentioned,

Definitely increase balance and a lot of range of motion in arms and shoulder areas. Then just stamina, strength to be able to sit without so much stress on the body. A good physical stature overall, well-being, and physical benefits.

This quote supports that not only does physical education work on these skills (of stamina and strength) but that the development of these skills is essential to a child's ability to learn and develop throughout childhood. In general, parents expressed that one of the main benefits of participating in physical education is the fact that the children will learn activities that will guide them to improve their health, and consequently overall quality of life. Jackie shared,

I think having the opportunity to have physical activity in their lives is good. I feel for their health it's better to have opportunities to be active and moving. So I think its beneficial health wise, social wise, and communication wise.

This statement mentioned by Jackie, and the statements presented by other parents suggest that not only is physical education beneficial to their child's educational plan, but a quality program is multidimensional. It has been reported in the literature the impact and the multiple benefits that can be obtained through an active participation in physical education for all children regardless of ability levels (Shields & Synnot, 2016). Physical education develops skills not only in the physical domain, but also in the cognitive, and social-emotional domains.

Parents in this study seemed to be cognizant of the impact physical education can have in

their children as they discussed many of the benefits they felt came directly from physical education. As such, they articulated that physical education gave their children an increased level of independence, confidence, and self advocacy skills. In other words, by participating in physical education, children learned physical skills, gained strength, and consequently, their level of independence was improved. Madelyn indicated, “*The more endurance she builds up through physical activity the better that will help her endurance in just handling everyday life.*” Madelyn and other parents also mentioned that physical education develops related skills to independence such as navigating in a crowd, having the skills and knowledge to stay healthy, and knowing their way around a recreation center. Jasmine stated,

I am hoping that she will walk away from physical education and think I always need to be physically active, it’s important for my mind and body. I am hoping it’s something that because of physical education she’ll want to do.

Parallel to Jasmine, other parents mentioned that they want their child to leave physical education programming with a value for physical activity and the skills to be active for their rest of their lives.

Subtheme 2: Quality physical education teacher. As previously mentioned, parents in this study valued the multiple benefits that can be obtained through physical education. However, they believed that in order for their children to learn the necessary skills to have and engage in an active lifestyle, the professionals providing such services must have the skills and knowledge to guide and teach their children effectively. Parents indicated that they believed they know what characteristics a quality physical education teacher should have, yet most physical education teachers do not meet these expectations.

When asked what qualities a physical education teacher should possess, several parents mentioned that they would like to see a teacher who values a healthy lifestyle themselves. In other words, they would like to see a teacher who is a role model in terms of physical activity. Parents also mentioned that they would like for their children's physical education teacher to be a teaching professional who includes all students regardless of ability or needs to actively participate as a part of the whole class community. Jasmine explained,

I would like to see a PE teacher that looks healthy. I would want one [a physical education teacher] who sees' the challenge of something different in the child to be something to embrace rather than something to deal with. So creatively thinking outside of the box, being willing to look up the syndrome and reading about it. Finding what things have worked before.

Jasmine, like other parents in this study mentioned that they want a physical education teacher who is creative and willing to take the time to actively include their child safely and to the greatest extent possible in class. Another parent, Jackie articulated,

One who looks at each individual child and can somehow incorporate that into their overall plan for the day, the activity, the whatever, so that always they're having an activity that is inclusive regardless of any child's challenges or disabilities.

Jackie wants a teacher who keeps all students' abilities in mind when planning and implanting activities so that all children are active participants and no one is sidelined. Parents also indicated that they would like a physical education teacher who has high expectations for their children. They want a teacher who will treat their children as equal. Melanie commented, "*Just so they would treat him like all the other students and make him do all the work the other kids were*

doing. Not to give him a break.”

Another expectation the parents held for a qualified physical education teacher is that they wanted these professionals to know their children, including the child’s diagnosis, abilities, and their best mode of communication. Rachel shared that she would like for the teacher to not only know about her child’s preferences, but also to be cognizant of her child’s disability. She commented, *“To understand my child and CHARGE Syndrome. To know her limits and behaviors in relation to activities.”* Parents indicated that getting to know the child and the characteristics required a conscious effort from the teacher. For this reason, parents would like for teachers to spend the necessary time to get to know the child. Melanie mentioned, *“Spending time with the kids, understanding their disabilities, not only hearing it from the parents, but asking the kids, “What are your abilities, what do you think you can do.”* The statements presented highlight the fact that parents not only want their physical education teacher to know their child and their disability, but also be willing to communicate and ask the child about instruction and the best way to get them to actively participate in class. This is often overlooked by professionals currently.

Basically, the quotes presented under the *qualified physical education teacher* subtheme, support the notion that parents want a teacher who embraces differences, works hard to have all students in class actively participate regardless of ability, and also holds their children to high standards. Parents also mentioned that physical education teachers should know their children and know how to best communicate with them.

Subtheme 3: Effective communication. Another parental expectation of quality physical education is that teachers should effectively communicate with the parents, the multidisciplinary

team, and the child. By having good communication skills, parents believed that the teacher will be able to better advocate for their children's needs. This includes partnering with parents on how to advocate for their child's needs in regard to physical education and physical activity goals. All parents in one way or another mentioned ways that communication could be improved. Jasmine stated, "...*If she [physical education teacher] comes to a roadblock and can't figure it out that she would contact me and we could do it together.*" Another parent, Ashley, explained the importance of communication. She commented, "*Communication with parents, and educate the parents how they can help.*" This quote takes the above reflections a step further and suggests that not only do parents want the physical education teacher to communicate with the parents, but that the parents also want to know resources and how they can help their child succeed in physical education. Furthermore, more than communicating just with parents, participants also expressed a desire for the physical education teacher to communicate and collaborate with other professionals on the educational team. Katrina suggested "*To communicate with PT/OT [physical and occupational therapist] professionals.*" Participants asserted that if the physical education teacher communicates with other professionals, their children have a higher chance of succeeding. It is the parents' expectation for the teachers to all communicate and be on the same page for instruction and services they are providing the child. Parents believe that when lines of communication are not in place, these can exacerbate barriers to participation in physical education and physical activity.

Theme 2: Multifaceted Barriers

Parents expressed many barriers that challenged their child's means for active participation in physical education. All parents mentioned how their child's abilities negatively

impacted their participation in physical education. According to the participants, it is not the activities themselves that are the sole barrier to participation, but the disability that negatively impacts their child's performance during physical education. Knowing this, according to the parents, physical education teachers should consider the characteristics of CHARGE Syndrome when trying to make helpful modifications to support active participation in their classes. Parents stated that due to their child's medical conditions they had a difficult time with tracking moving objects, hand-eye coordination, balance, holding attention, physical endurance, and understanding instructions. This theme is supported by the following subthemes: (1) learner capabilities, (2) teachers' competence, (3) lack of communication, and (4) physical education not a priority.

Subtheme 1: Learner capabilities. All parents agreed that the nature of their child's disability impacts in some capacity how their children learn, develop skills, and perform in physical education. Madelyn articulated, "*Jumping jacks, coordination are not her strong points. The biggest thing would be endurance. She just doesn't have enough energy. Anything that has to do with endurance or obviously balance- she doesn't have semicircular canals.*" Madelyn, like many parents, mentioned that the physical nature of the disability negatively impacted her daughter's performance in physical education. Parents mentioned that their children struggle with activities that require endurance for long periods of time, skills related to hand-eye coordination, or activities that entailed skills in balance. Each of these delays can be explained by the nature of the disability. Not only does CHARGE Syndrome impact multiple body systems but it can also impact cognitive functioning. Pamela stated,

His reliance on his stroller, his vision, and cognitive delays probably plays a big part of it.

And his cognitive deficits also cause ...I don't know that he understands the concept...he may understand a piece that he's doing at the moment, but I don't know that he knows the whole sequence and how it comes together.

Pamela, like other parents mentioned that their children may understand parts of skills or activities, but have difficulty putting skills together or understanding concepts. According to the parents, knowing this about children with CHARGE Syndrome should give teachers information they need to plan for these students in their physical education classes.

Subtheme 2: Teachers' Competence. All parents agreed that their child's physical education teacher had no knowledge about CHARGE Syndrome, or how to teach children with CHARGE Syndrome. One parent [Madelyn] when asked about how much knowledge her child's physical education teacher had on CHARGE Syndrome and appropriate teaching strategies, *"I doubt any. I doubt any at all, except for the extent that she's learning from meeting my child. And probably talking to the head of special education."* Madelyn mentioned that their child's physical education teacher did not have knowledge about their child's disability or the most appropriate way to teach them in class. Another parent, Elizabeth, further explained, *"Probably not a whole lot. They might know a little bit but I don't think anyone really knows anything. Physicians don't know a lot."* Elizabeth in addition to stating that she does not believe the physical education teacher has any knowledge about CHARGE Syndrome also mentioned that other professionals who work with her son also do not know a lot. Parents in this study believe that overall there is a lot about CHARGE Syndrome that is unknown or not being communicated across services. Ashley articulated, *"...lack of teacher/school knowledge to effectively accommodate him."* Not knowing how to include their children in the physical education class

was a concern voiced by parents.

In any physical education class, it is imperative to teach children how to use equipment safely, utilizing adapted equipment for student success, and making appropriate modifications for all students to actively participate in physical education. If teachers do not know about what disabilities their students have or what their specific learning needs are; how can they possibly include these students in a safe, dynamic, and inclusive learning environment? Jasmine mentioned in this regard, “...*He goes to regular school...so they don't know equipment that they would have in schools that take care of kids with special needs.*” Jasmine, explained that she believes there was a connection between the type of school and the resources they had to accommodate students with unique learning needs. For parents, teachers not having the adequate equipment as part of their physical education class is problematic, but when the equipment is available, parents believe that physical education teachers do not have the skills to teach their students how to use the equipment in a safe manner. Elizabeth indicated, “*A lot of concerns would be to teach him how to use equipment safely.*” For Elizabeth her concerns were with making sure that her son was safe in class and being taught about the equipment, how to use it, and the expectations associated with using the equipment. This was a common barrier where parents thought their physical education teacher was not doing an adequate job addressing safety and use of equipment.

Another parent, Melanie mentioned, “*They [the school and physical education teacher] stopped using the FM system [technology that aids in hearing] in middle school and the PE teacher yelled, and he wouldn't always hear it and missed some of the instructions...our biggest barrier is communication.*” For Melanie, their school had the technology needed to effectively

communicate with her son, but they did not use it in physical education class which lead to him missing instructions and getting a delayed start when compared to his peers. According to Melanie, these situations also threaten the safety of her child during class because he could not hear the teacher. This puts into question the teachers' competence regarding safety throughout facilitating physical activities.

Parents explained that not only did they question the physical education teachers' competence to teach their children and provide a safe environment, but parents also mentioned that the physical education teacher was not advocating for physical activity and recreation to be on the transition plan. Most parents stated that they did not currently have a transition plan in place regarding educational programming or next steps after formal schooling. Thus, without these plans, transition services regarding physical activity and recreation were not being addressed or discussed at the time of this study. This connects to the next barrier *lack of communication* because parents currently are not seeing physical education teachers communicating about services in general or transition planning.

Subtheme 3: Lack of Communication. Communication was a significant barrier that was revealed by the parents who participated in this study. Lack of communication was evident between the teacher and child, child and peers, the teacher and parents, and the teacher and other professionals. However, the main communication barrier was between the teacher and the child. Children with CHARGE Syndrome communicate in a variety of ways including verbal, nonverbal, written, sign language (ASL), tactile sign. For these reasons, it is important that open and multiple sources of communication are available between the teacher and the student. Parents indicated that it's imperative for teachers to communicate in the same mode of

communication as the child communicates. To support this overall subtheme, when parents were asked about what barriers their children faced in regard to accessing physical education programming many said communication first. One parent, Becky stated, *“One is communication, the APE teacher doesn’t have sign skills (ASL), or the GPE either...there is always a delayed start cause of it (hearing loss).”* For Becky the lack of communication is a huge barrier for her son because he was getting a delayed start in class because he doesn’t have access to instructions. When asked the same question, another parent, Ashley articulated, *“Between the teacher and him because I don’t feel that it’s a good connection since he always needs to have somebody who helps him to translate and communicate in class.”* For Ashley, having an interpreter, although helpful, limited the opportunity of the child to communicate directly with the teacher. According to Ashley and other parents, teachers have to be willing to learn and communicate with all of their students in the way that the child communicates best.

Communication was viewed by the parents as a multifaceted barrier. Not only was a lack of communication between the child and the teacher a barrier, but also the lack of communication between the child and their peers. CHARGE Syndrome affects multiple body systems and in turn impacts how each child communicates. Individuals with CHARGE Syndrome may communicate drastically different from one another depending on the extent to what each sense of the body is impacted (Bashinski, 2015). Similar to many of the parent’s worries, Katrina related a concern related to communication between her child and his peers, *“I mean with peers it would be a language barrier because he only knows ASL.”* Parents indicated that communication between their child and their peers was an area that had to be facilitated because depending on the child with CHARGE Syndrome the way they communicate may not be

verbal which is the how the majority of general education students communicate.

Parents also voiced their frustrations with the lack of communication between the physical education educators and parents. Even though this was an expectation voided by parents, almost all of parents, (see theme 1) in this study said there was little to no communication between them and the physical education teacher. However, many stated this was not an issue as long as there were no issues in class, they were getting the services they needed without initiating it, and there was clear communication going through them indirectly via interpreters or support personnel. Fifty percent of the parents stated that the physical education teacher did not attend the IEP meetings at all. The other half of parents shared that the physical education teacher did attend the meetings, yet among these parents, they felt physical education teachers' involvement was adequate or less than adequate in the meetings.

When asked about the nature of communication with the physical education teacher, Madelyn stated, *"Oh, very minimal. Not really at all. I feel like we've talked about it literally just in passing in her IEP. It's [physical education] not a big topic of discussion."* Like Madelyn, other parents agreed that physical education was not considered an important topic of discussion at the IEP meetings. Professionals in the field of physical education have indicated that it is the physical education teachers' job to make sure that parents know the value of physical education (Columna et. al. 2008). Parent's in the current study believed that the reason for the lack of communication between them and the teacher, mainly because the parents utilized the support personnel as an indirect way to communicate with the physical education teacher, Jackie stated, *"Probably minimal. I mean it's the interpreter is there. I would say very minimal direct communication, but indirect via his interpreter."* For Jackie, she utilized the support personnel as

a connection to understand what was going on in physical education. The support personnel were the people who were providing the physical education teacher with information on best practices for their student, and the parents were not present.

Subtheme 4: Physical Education Not a Priority. Through the interviews parents indicated that they valued the benefit of a physical education program. However, it was clear from the interviews that physical education was not a high priority for parents in terms of addressing their child's educational needs. All parents stated that they had little to no involvement in their child's physical education programming. Some reasons parents mentioned included but were not limited to: parents did not know it was an important part of child's education, teachers never took initiative to reach out, physical education was often put on the back burner due to other medical (many hospital visits) or educational focuses. Ashley further expanded, *"I didn't feel that...this was a subject of importance...I didn't focus much about it...It didn't even get my attention to be honest. I didn't realize that it's a subject by itself, who can help my son also."* For Ashley, she like most parents in this study, did not know that physical education was an important part of the educational program or beneficial to her son. For this reason, parents wanted to be educated and convinced on how physical education should be part of their children's IEP. Ashley commented, *"Meetings...maybe educate me about the importance of having that professionally in my son's life."* In other words, parents would like physical education teachers to take the initiative to educate parents about the role physical education plays in the overall programming and what the benefits are of having quality physical education programming in their child's life. These quotes support the important role physical education teachers have on ensuring parents understand the value of physical education and what their

critical role is in their child's programming.

Theme 3: Facilitators to Quality Physical Education

Parents mentioned many strategies that promoted their child's participation in physical education. Many discussed small class sizes, support personnel, equipment or task modifications, and facilitating a community environment where all peers felt accepted in class. Two subthemes support the theme of facilitators to quality physical education. These subthemes were: (1) class size and support personnel and (2) instructional considerations.

Subtheme 1: Class size and support personnel. It is well supported in literature that students with disabilities thrive in smaller class sizes and from the assistance of paraprofessionals or interveners (Lieberman & Houston-Wilson, 2018). About half of parents mentioned that having smaller class sizes helped their child actively participate because there was more hands-on support and more opportunities for skill development. Rachel explained, *"She's in an 8:1:1 class with more 1:1 support. Only about 10 kids per class."* Rachel, indicated that this setting in which her daughter was in an 8:1:1 class meaning there was an eight student to one teacher ratio, as well as 1:1 paraprofessional support in her class. Providing an environment where learning and success can take place especially for students with additional learning needs similar to CHARGE Syndrome. Not only did Rachel mention that her daughter is in a relatively small class (10 students) but that there was also one-to-one support for students. This is critical not only in the classroom but also in physical education where learning predominately takes place through the physical domain. Another parent, Madelyn also supported the small class sizes by stating,

...1:1 teachers are great to guide her and help her do activities and to interact with her

peers. Being part of the regular group [her general education peers] not being pulled out and there with her friends. She doesn't realize that she's different.

Madelyn discussed that she thinks that the 1:1 paraprofessionals are helpful because her daughter was able to actively participate with the rest of her class and was treated as equal.

Half of parents reported that their children do not have a paraprofessional working with them, two parents were unsure, and seven parents reported that their child does not utilize an intervener at school or in physical education. All parents who mentioned their child worked with support personnel also stated that the support personnel were not trained to work with their child nor in the physical education environment.

Subtheme 2: Instructional Considerations. Task and instructional considerations encompass any differentiated instruction (e.g., activity modifications) the teacher made to include a child with CHARGE Syndrome as recalled by the parents. Parents stated that they know or think their physical education teacher does make modifications for their child in class. Modifications included variations to the task, environment, and equipment used during each lesson. Modifications mentioned were related to the types of activities, location of those activities, and types of equipment. Pamela discussed that many modifications were made to accommodate her son in physical education, she stated,

Based on his IEP and the progress report they tend to make lighting accommodations like high contrast equipment. Also, enough time to transition, and repetition. If he knows the equipment, if he's done it before he's more likely to be successful the next time.

Pamela, like other parents, indicated that these modifications made by the physical education teacher made it possible for her son to participate in physical education. Jasmine further

expanded on the topic of activity modification and when asked about modifications that she believed helped her daughter in physical education, Jasmine added, *“Like basketball...maybe instead of five people on the court, there could be three, and we’re not blocking shots. We’ve had a lighter basketball where with her one eye, she does see the ball well then.”* Jasmine added that changes in the activity rules and color contrast equipment helped her daughter participate in general physical education with her peers.

Finally, in addition to the above parent remarks about modifications as a form of task or instructional considerations, another parent [Jackie] articulated, *“Peer supporters, instructions or directions given in his mode of communication, activities that interest him.”* Jackie added that having helpful peer support, class instructions given in his best mode of communication, and having a dynamic curriculum were all extremely helpful to her sons’ success in class. These quotes support that there are many modifications that can be made by teachers to help students with CHARGE Syndrome be successful and actively included in physical education.

Discussion

Research studies exploring parents’ perceptions about physical education services for their children with disabilities are limited (Chaapel et al., 2012; Lee, Haegele, & Chang, 2017; Perkins et al, 2013). Nevertheless, such research exploring this issue among parents of children with CHARGE Syndrome were none existent. Research studies among parents of children with Spina bifida (An & Goodwin, 2007), visual impairments (Perkins et. al., 2013), and other disabilities (Chaapel et al., 2012) have indicated that parents have different views of what physical education should look like for their children. However, we have limited information about the expectations of children with CHARGE Syndrome towards physical education. In the

current study, researchers examined 10 parents of children with CHARGE Syndrome and their perspectives and expectations regarding current or past physical education experiences.

These parental perspectives summarized the absolute need for teachers in the field to be competent working with students with multiple disabilities. One way to do this is by teacher preparation programs including curriculum on how to include students with multiple disabilities and communicating with parents of unique learners about parental involvement in programming. It was also evident that physical education professionals need to advocate for physical education services of children with multiple disabilities in their classes and find resources for physical activity in the community. This section is organized according to the research questions that drove this investigation.

Research Question #1: What Are Parental Expectations of Physical Education Professionals in Their Child's Educational Program?

Both the need for quality physical education programming and qualified professionals teaching aligned with other literature findings about what parents with children with disabilities expected from physical education (An & Hodge, 2007; An & Hodge, 2013; Columna et. al. 2008). Parents also thought that physical education should be taught by qualified individuals who were healthy themselves, good communicators, and implemented a well rounded all inclusive curriculum that met all students learning needs and included disability awareness units. According to Lytle, Lavay, and Rizzo (2010) to be a highly qualified adapted physical education teacher, teachers must a Bachelor's degree in physical education teacher education, hold a state license to teach physical education, at least twelve semester hours of course work addressing the educational needs of students with disabilities, at least nine semester hours of course work

addressing adapted physical education, 150 hours of practicum experience, and professional preparation programs must be based on the state and national standards for adapted physical education.

With this in mind, it is imperative that teachers providing physical education services acknowledge the expectations of their children's parents. One of the goals of physical education programs is for the skills children learned in the gymnasium to be transferable to their home environment and their communities (Columna et. al., 2008). Parents in this study voiced the need for physical education teachers who are role models and have high expectations toward their children. Similar findings have been reported in the literature (Columna et. al., 2018).

Previous studies among children with Spina Bifida (An & Goodwin, 2007) and Visual Impairment (Columna, Streete, Hodge et. al., 2018; Dillion, Dolphin. et. al., 2017; Perkins, Columna, Lieberman, & Bailey, 2013) have indicated the importance of establishing lines of communication between parents and teachers. When these lines of communication are in place, multiple benefits tend to accrue for the children and the family as well (Columna, et. al., 2008). Parents in the current study were concerned with the lack of communication between themselves and the physical education teacher, the physical education teacher and their child, and their child and his/her peers.

Although parents mentioned that physical education was an important part of their child's overall educational program many also stated that physical education often is not a high priority for their educational team or at home. This low priority on physical education may be due in part to not having knowledgeable physical education teachers for there children who should be providing positive and encouraging communication to the parents of children with CHARGE

syndrome. In addition, physical education teachers can share with parents the importance of including physical education as part of their children's IEP, and advocate for physical education services and resources.

Communication is so important that the future of the child is in play. For example, according to IDEA, starting at age 14 years, children should receive a transition plan. Interestingly, all parents said that there was no transition plan in place for their child at the time of the study including the areas of recreation and physical activity plans. This is congruent with what other research (Lieberman, Kirk, & Haegele, 2017), and experiences of parents of children with disabilities regarding accessing community resources and transition planning related to physical activity and recreation (Columna et. al., 2008; An & Hodge, 2007; Lee, Haegele, & Chang, 2017).

One solution would be having quality PETE programs that prepare future physical education teachers to include students with multiple disabilities in the classes. This includes being knowledgeable about student learning needs, adapted equipment, and how to effectively modify tasks to allow for maximum participation. Physical education teachers also need to advocate for physical education for their students both with parents and families, but also administrators.

Parents mentioned that there was a disconnect between the qualities they would expect in an outstanding physical education teacher in comparison to the qualities of their child's physical education teachers. . Parents discussed the main concern was the physical education teachers' competence and ability to teach children with multiple disabilities. This included the teacher's knowledge about CHARGE Syndrome and the child's unique learning needs. Parents questioned

teachers' ability to effectively accommodate children with CHARGE Syndrome in their classes to have active participation from all students. This included their knowledge about adapted equipment, ability to communicate with students, and modifications to utilize in terms of manipulating the task, environment, and equipment for maximum learning to take place. These areas; understanding the learner, manipulating the task and environment are congruent with Newell's Constraints Theory (1984).

Parents suggested that a quality physical education teacher was one who led a healthy lifestyle themselves, was knowledgeable about content and teaching students from diverse backgrounds, and one who was willing to try new things and collaborate with parents, professionals, and the student themselves. This was congruent with current findings on what parental expectations of children with visual impairments regarding quality of physical education teachers (Columa et. al., 2008).

Research Question #1: How Do Parents View Their Child's Physical Education Experience?

Parents overall viewed physical education as an important component of their child's educational programming. Participants indicated that by having an active participation in physical education their children can develop their motor, social, and cognitive skills. These parents believed that physical education can equip them to be successful later in life. These participants also highlighted the health benefits that can be obtained through physical education. These findings are in alignment studies among families of children with disabilities. The findings of this study are also in alignment with those presented by Columa et. al. (2008) among parents of children with visual impairments in Guatemala and with those presented by Columa et. al.

(2018) with parents of children with various disabilities in the US. This means that parental expectations toward physical education may vary according to the disability of the child.

Parental views on physical education was overall positive in this study, however, parents believe that there were multiple barriers that affected their children's participation in physical activity. Some of these barriers were related to the child itself, while others were related to the nature of the activities their children were exposed. Newell's Constraints Theory (1984) provides a frame of reference to this study to better understand how each part of physical education interact. According to this theory, the way in which individuals move emerges from the interaction between learner (e.g. child with CHARGE Syndrome), the task (e.g., games and activities played during physical education), and the environment (e.g., general physical education setting). Parents and teachers can use this model to learn how to modify the environment and the task to encourage more motor skill development in their child with CHARGE syndrome. Children with CHARGE syndrome have unique structural and functional constraints which can delay their motor skill acquisition, however, through additional experiences, they can improve their proficiency in motor skills to perform closer to the level of their typically developing peers. If taught using communication modes that the child with CHARGE Syndrome prefers and given additional time to learn motor skills, they are much more likely to succeed and enjoy participating in physical activities and sports with their peers. This is why it is of particular importance that adapted physical education teachers, paraeducators, and allied health professionals understand each child's unique needs to provide them with a more effective teaching environment.

It is known that more students with disabilities are being served in general physical education with their typically developing peers at higher rates than before. This is following the implementation of guidelines of IDEA and placing students appropriately in their least restrictive environment (LRE) to the greatest extent possible, including physical education services (Winnick, 2011). Ensuring appropriate placement of students with disabilities in physical education is a decision made by the educational team (Columna, et. al., 2013). The current study found that meaningful placement and small class sizes were preferred by parents and facilitated a meaningful learning environment for students with CHARGE Syndrome. These findings are similar to the findings by Lieberman, Haibach, and Schedlin (2012) where the parents stated that they preferred their children be included in general physical education and a self-contained class to gain the skill development (self-contained) and the socialization (general physical education). Parents revealed that they believed that smaller class sizes were safer environments for their children and allowed them to be active participants. These findings are consistent with what An and Goodwin (2007) discovered when investigating parental perspectives of physical education for children with spina bifida. Although parents preferred these classrooms, parents in this study asserted that teachers lack the competencies and skills to include their children in their physical education class.

Another barrier mentioned by parents was that physical education was not a priority. These findings are contrary to those reported by An & Goodwin (2007) and An & Hodge (2013) in which these families were cognizant and engaged in the physical education programming for their children. In fact, the findings of this study are in alignment with those reported by Columna et. al. among Hispanic families (2008). One solution to this is physical education teachers should

advocate for physical education and physical activity opportunities for children on their caseloads. This includes educating both parents and administrators about the meaningful impact physical education has on their child's quality of life.

Future Research

Results from this current study prompt future research areas. It would be interesting to investigate perspectives of teachers who teach children with CHARGE Syndrome as well as children with CHARGE Syndrome on their own perspectives of physical education. It would also be interesting to examine what PETE programs are implementing currently as far as skills they are giving pre-service teachers in these areas discussed above. Currently, parents are not getting the resources they need to ensure their children have lifetime physical activity options necessary for achieving and maintaining a high level of health. It would be interesting to see what options there are currently and what barriers adults with multiple disabilities face in terms of accessing and utilizing these programs.

Limitations of the Study

This study did have a few limitations. First, it is assumed that all participants answered honestly about their child's physical education experiences and that they had a significant level of understanding of those services. Another limitation was that the participant pool was limited to parents of children [ages 6-23 years old] with CHARGE Syndrome. The findings of this study cannot be generalized outside of individuals with multiple disabilities. It should also be known that all parents volunteered to participate in this study which could show that they are already proactive in their child's life and educational programming. This may not represent parents with CHARGE Syndrome as a whole population due to the low sample size and large age range.

Conclusion

Overall, there were multiple components which revealed the impact that physical education programming had upon youth with multiple disabilities. The findings from this study are also similar to other published literature investigating parental perspectives on physical education services for children and adolescents with disabilities other than CHARGE Syndrome. First, physical education teachers must take initiative in communicating with parents about the value and importance of physical education services within the educational program, as well as resources and options in the community for recreation programming. This includes having a partnership with parents so that they are involved in physical education programming. Second, physical education teachers need to show investment into their students with disabilities and seek out information to be knowledgeable about specific disabilities and the impacts this may have on accessing the physical education curriculum. This includes implementing units on disability awareness, Paralympics sport, and opening dialogue in class about disability in general. Next, PETE programs should include curriculum for pre-service teachers that includes how to effectively communicate with parents and students with unique learning needs, as well as how to effectively include students with multiple disabilities into their general physical education classes. For professionals already in the field continuing education on teaching children with CHARGE Syndrome and including them in their classes should be offered as professional development.

References

- About IDEA. (2019). Retrieved from <https://sites.ed.gov/idea/about-idea/>
- American Association for Physical Activity and Recreation/National Association for Sport and Physical Education. (2010). *Eligibility criteria for adapted physical education services* (Position statement). Reston, VA.
- American College of Sports Medicine. (2015). *Physical activity in children and adolescents*. (Brochure). Indianapolis, IN.
- An, J., & Goodwin, D. L. (2007). Physical education for students with spina bifida: Mothers' perspectives. *Adapted Physical Activity Quarterly*, 24(1), 38–58.
- An, J., & Hodge, S. R. (2013). Exploring the meaning of parental involvement in physical education for students with developmental disabilities. *Adapted Physical Activity Quarterly*, 30(2), 147–163.
- Bailey, R., Armour, K., Kirk, D., Jess, M., Pickup, I., Sandford, R., & BERA Physical Education and Sport Pedagogy Special Interest Group. (2009). The educational benefits claimed for physical education and school sport: An academic review. *Research Papers in Education*, (24)1, 1-27.
- Bashinski, S. (2015). Communication programming for learners with CHARGE Syndrome: Augmenting comprehension and expression. *American Speech-Language-Hearing Association*, (24), 86-93.
- CHARGE Syndrome Foundation. (2017). *Overview*. Retrieved from <https://www.chargesyndrome.org/about-charge/overview/>
- Columna, L., Davis, T., Lieberman, L., & Lytle, R. (2013). Determining the most appropriate

- physical education placement for students with disabilities. *Journal of Physical Education, Recreation, & Dance*, 81(7), 30-37.
- Columna, L., Dillon, S., Dolphin, M., Streete, D., Hodge, S.R., Myers, B.A., ... Heffernan, K. (2017). Physical activity among families of children with visual impairments and blindness. *Disability and Rehabilitation*, 41(3), 357-365.
doi.org/10.1080/09638288.2017.1390698
- Columna, L., Pyfer, J., Senne, T., Velez, L., Bridenthall, N., & Canabal, M. Y. (2008). Parental expectations of adapted physical educators: A Hispanic perspective. *Adapted Physical Activity Quarterly*, 25(3), 228–246.
- Columna, L., Streete, D., Hodge, S.R., Dillon, S., Myers, B.A., ... Heffernan, K. (2018). What parents believe about physical activity and their children with visual impairments. Submitted to *Adapted Physical Activity Quarterly*, 35(4), 361-380.
- Haibach-Beach, P.S., Perreault, M., Lieberman, L., Foster, E. Motor skills in children with CHARGE Syndrome. (Under Review).
- Hefner, M., & Davenport, S. (2006). CHARGE: What it stands for. *American Speech-Language-Hearing Association Leader*, 7-8.
- Lieberman, L. J., Haibach, P., & Schedlin, H. (2012). Physical education and children with CHARGE syndrome: Research to practice. *Journal of Visual Impairment & Blindness*, 106(2), 106-119.
- Lieberman, L. J., Houston-Wilson, C., Kozub, F. (2002). Perceived barriers to including students with visual impairments in general physical education. *Adapted Physical Education Quarterly*, 19, 364-377.

- Lytle, R., Lavay, B., & Rizzo, T. (2010). What is a highly qualified adapted physical education teacher?, *Journal of Physical Education, Recreation & Dance*, 81(2), 40-50, DOI: 10.1080/07303084.2010.10598433
- Murphy, N. A., & Carbone, P. S., (2008). Promoting the participation of children with disabilities in sports, recreation, and physical activities. *American Academy of Pediatrics*, 121(5), 1057-1061.
- Newell, K.M. (1986). Constraints on the development of coordination. In *Motor development in children. Aspects of coordination and control*, ed. M.G. Wade and H.T.A. Whiting, 341–60.
- Perkins, K., Columna, L., Lieberman, L., & Bailey, J. (2013) Parents’ perceptions of physical activity for their children with visual impairments. *Journal of Visual Impairment and Blindness*, 35(2), 131-142.
- Prakash, R. (2002, April 4). *Physical inactivity a leading cause of disease and disability, warns WHO*. Retrieved from <http://www.who.int/mediacentre/news/releases/release23/en/>
- Shields, N., & Synnot, A. (2016). Perceived barriers and facilitators to participation in physical activity for children with disability: A qualitative study. *BMC Pediatrics*, 16(1), 9.
- Štěrbová, D., & Kudláček, M. (2014). Deaf-blindness: Voices of mothers concerning leisure-time physical activity and coping with disability. *Acta Gymnica*, 44(4), 193-201.
- U.S. Department of Health and Human Services. (2008). *2008 Physical activity guidelines for Americans*, (Guidelines). Washington, D.C.
- Williamson, C. (2014). Effects of disability awareness educational programs on an inclusive classroom. *Honors Projects*, 1-32.
- World Health Organization. (2010). *Global recommendations on physical activity for health*.

(Guidelines). Geneva, Switzerland.

Winnick, J. P. (2011). *Adapted physical education and sport* (5th ed.).

Champaign, IL: Human Kinetics.

Appendixes

Table 1:1 Sample Questions for Semi-Structured Interviews:

Table 1.1: Sample Questions for Semi-Structured Interviews:
<ol style="list-style-type: none"> 1. What placement is your child currently having physical education in? (GPE, Modified, Small Group, Self-Contained)? 2. How would you describe your child's participation in physical education? 3. How would you describe your child's physical education experience? 4. What is your view on physical education in your child's educational experience? 5. How would you consider the importance of physical education in your child's educational experience? 6. How would you describe the communication between the adapted physical education teacher and yourself? 7. Does the level of communication between you and the adapted physical education teacher meet your expectations? 8. How would you describe your involvement in your child's adapted physical education program? 9. What are your expectations for the professionals providing adapted physical education services for your child? 10. Does your child receive the same amount of physical education services as their same aged peers? 11. In what ways do APE/PE teachers provide opportunities outside of the school day for physical activity for your child?

12. What outcomes tied to physical activity do you hope your child will demonstrate?

- Physical domain:
- Social domain:
- Affective domain:

13. What are your expectations regarding your child's ability to access and enjoy community-based leisure, recreation, and sports programs?

14. Have transition services been discussed in regards to physical education? (School to school or after K-12).

Table 2: Participant Name Codes

Participant #:	Names used for Article:
1	Ashley
2	Rachel
3	Elizabeth
4	Katrina
5	Pamela
6	Melanie
7	Jasmine (name of child to use: Olivia)
8	Madelyn
9	Becky
10	Jackie

Table 3: Demographics of Vision

Code #	Child's Visual Impairment if known	Child's Visual Acuity (Left)	Child's Visual Acuity (Right)	Is Your Child's Vision Loss Progressive? (Y/N)
1		B4	B4	N
2		B4	B4	N

3	Stigmatism / Coloboma	B4- field loss: coloboma top of retinas	B4- field loss: coloboma top of retinas	N
4	None			
5	Optic Nerve Coloboma	B3 (uncorrected) Field loss: central	B3 (uncorrected) Field loss: central	N
6	Coloboma in Left Eye	B3 (coloboma)	B3	N
7		B1	B4	
8	Optical Coloboma, Retinal Coloboma	B4- Field loss: potential in upper right corner and lower center.	B4- Field loss: potential in upper right corner and lower center.	N
9	Microphthalmia: left eye with coloboma detached from retina, right eye is structurally sound	B1- Field loss upper and lower	B4- Field loss upper and lower	N
10	Colobomas of the optic nerve (lateral)	Field Loss 75%	Complete Field Loss	N

Table 4: Demographics of Hearing Loss

Code #	Type of Hearing Impairment if known	Child's Degree of Hearing Loss (dB HL)	Child's Degree of Hearing Loss (If different Left)	Child's Degree of Hearing Loss (If different Right)	Status of Semicircular Canals
1		Profound (91+)			
2	Sensirvere Hearing Impairment		Moderately Severe (56-70)	Severe (71-90)	Both Affected
3			Profound (91+)	Severe (71-90)	No
4			Severe (71-90)	Moderately Severe (56-70)	

5			Moderately Severe (56-70)	Moderate(41-55)	No
6			Moderately Severe (56-70)	Moderate(41-55)	Both Affected, several surgeries and never corrected
7		Profound (91+)			Both Affected
8			No Auditory Nerve	Moderately Severe (56-70)	Both Affected: not present or so deformed they are not recognizable.
9		Profound (91+)			Both Affected: both are missing
10			Severe (71-90)	Moderately Severe (56-70)	Both Affected: both are missing

Table 5: Demographics of Other Impairments

Code #	Status of Heart Defects (Y/N, Explain)	Atresia of Choanae (Nasal Passages)	Status of Delayed Growth and Development	Age of Onset of Walking Independently (in months)
1	Y: Atrial Septal Depect, Patent Ductus Arteriosus (left mitral valve, and bicuspid aortic valve). Fixed in 2009.	Y, 2 surgeries	Y: Sat at 3 years old, and never crawled.	83
2	Y: Ebstiens Anomaly	N	Y: Does not produce growth hormone naturally	36
3	Y: coartation (repaired with surgery), Ventricular septal defects (patched partially with surgery),	N	Y: at 23 years old: 75 lbs and 5 foot 3 inches	36

4	Y: Double outlet Right Ventricle with Residual VSD and Tricuspid Regurgitation (repaired)	Y	Y: born with bilateral choanal atresia. Repaired at 1 week old with surgery.	
5	N	N	Y: significant intellectual impairments	48
6	Y: ventricular septal defects (repaired fully with surgery)	N	Y: growth hormone injections from 3-16 years old, mild learning disability	24
7	N	N	N	48
8	N	N	Y: dropped off growth chart at 4 years old, currently on growth hormone with shots.	28
9	N	N	Y: never been on the chart, significantly delayed, takes growth hormone and testosterone.	42
10	Y: Atrial Septal Depect and Ventricular Septal Defects (both healed on own)	Y: only left side atresia choanae-corrected with surgery (at 11 years old)	Y: delayed due to cranial nerve defects causing feeding difficulties, and development delayed due to sensory loss and impairment.	40+

Table 6: General Demographics

Code #	Child's Age in Years	Number of CHARGE Characteristics Present	Parent Interviewed
1	13	5/5	Mother
2	12	4/5	Mother
3	23	4/5	Mother
4	11	2/5	Mother

5	18	3/5	Mother
6	22	Born with 4/5. Currently 3/5.	Mother
7	17	2/5	Mother
8	7	3/5	Mother
9	16	3/5	Mother
10	21	5/5	Mother

Table 7: Demographics of Physical Education

Code #	APE Teacher, GPE Teacher, Combination	Time of APE Services (Days per week, length of sessions)	GPE with Peers? (Y/N)	IEP Team Members with focus of Motor Skills and who	Same amount of PE as peers? (Y/N)	Level of intensity of PA during PE	Setting where PE/APE Services are Done
1	APE	2X, 45 min each	N	Y: OT,PT, APE	Y	Light	Combination of 1-1 and small group
2	APE, GPE	2-3X, 40 min each	Y	Y: OT, PT, APE to push in to GPE	Y	Moderate/Vigorous (tries very hard with frequent rests, stamina prevents from vigorous ex)	Combination of: full participation with peers with 1-1 assistance (APE), PT also pushes in at times.
3	GPE	N/A	N	Y: OT, PT	Y	Moderate	Participation with a small group of SWD
4					Y	Moderate	Participation with a small

							group of SWD
5	APE	DK	Not an option at Perkins	Y: OT, PT, APE, Classroom paraprofessionals	N/A	Light	Combination of 1-1 with APE, and small group with SWD
6	GPE	N/A	Y	Y: in grade school only: OT.	Y: ES: 2X, 1 hr. MS: 5X, 1hr. HS: 5X, 1 hr.	Vigorous: no modification in PE	Full participation with peers without disabilities
7	GPE	N/A	Y	N	Y: 4X, 60 min.	Moderate	Combination: depends on activity requirements. Typically full participation with peers.
8	GPE	N/A	Y	Y: OT, PT, GPE	Y: 2X time unknown	Light	Full participation with peers without disabilities
9	APE	1X, 20 mins	Y: partner PE	Y: GPE, APE, OT	Y: 5X, 45 mins each	Vigorous	Combination: Partner PE- reverse mainstreaming
10	APE	5X, 90 mins each	Y	Y: PT, OT, APE, O&M	Y: 5X 90 mins each (not all peers have PE, = to those who choose to	Moderate	Combination: 1-1 with APE and push in with GPE with peers

					take it)		
--	--	--	--	--	----------	--	--