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PREPARING THOSE WITH DEVELOPMENTAL DISABILITIES FOR ADULTHOOD AND WORK: PARENT PERSPECTIVES ON SUPPORT SERVICES AVAILABLE IN WASHINGTON STATE

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WASHINGTON STATE

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A Thesis

Presented to

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In Partial Fulfillment

of the Requirements for the Degree

Master of Arts

Individual Studies

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Amy Katherine McAlindon

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CENTRAL WASHINGTON UNIVERSITY

Graduate Studies

We hereby approve the thesis of

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ABSTRACT

PREPARING THOSE WITH DEVELOPMENTAL DISABILITIES FOR

ADULTHOOD AND WORK: PARENT PERSPECTIVES ON

SERVICES AVAILABLE IN

WASHINGTON STATE

by

Amy Katherine McAlindon

June 2018

Services designed to support the transition periods for individuals with special needs from high school to employment vary throughout the state of Washington. There is little information available regarding the opinions of parents and their experiences while navigating supports available in their area, and recommendations for system improvements. This paper derived from an in-depth study regarding these experiences and questions how the Diffusion of Innovation theory could be used to impact public policy, leading to improvements in high school to employment supports for individuals with special needs. This study presents the findings of a survey sent to parents of children with special needs throughout the state of Washington. The results of this survey will reveal parent perspectives regarding high school transition programs, and compare them to those of teachers. The study also discusses what parents value the most in a post-secondary setting, the importance of job coaching and promoting the will to work. The use of change agents as described in the Diffusion of Innovation theory is explored, which discovers that parents view other parents of children with special needs as their most trusted source of information. This implies that the strongest change agents

regarding system improvements in a community should be the parents themselves.

Future research should include a closer look at communication gaps between schools and families and how community engagement can enhance programs already in place. Future research should also include an in depth-study of the differences between rural and urban communities, focusing on culture, resource funding and availability.

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You are braver than you believe, stronger than you seem, smarter than you think, and loved more than you'll ever know.
-A.A. Milne

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made. Thank you to all my fellow Parent to Parent moms, who shared all your stories and advice. Time spent with you has been invaluable!

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CHAPTER 1

INTRODUCTION

Evan was born with a rare chromosome anomaly that was diagnosed at two

months of age. His parents, Don and Stacy, learned that the anomaly would leave Evan

with developmental delays and some disabilities, and that he would likely need supports

throughout his life to work and live independently one day. Don and Stacy were not

entirely sure what this would mean for their family, and tried their best not to worry too

much about the future at such an early age. Their friends and family assured them that

things would be "fine," and they took comfort in believing this advice while trying to

overcome the initial shock and fear of their son's diagnosis.

Evan was soon referred to early intervention, by his pediatrician and qualified for

services that included occupational, physical, speech therapy and specialized instruction.

These services would take place in Evan's home based on the philosophy that children

ages zero to three learn best in their natural environment. This approach worked well

with the family because Stacy stayed at home during the days with Evan while Don

worked to financially support the family. Although Don carried insurance coverage, it

was limited. Fortunately, early intervention services billed his insurance but also covered

additional costs not covered.

Therapy visits in the home took place throughout the week, and Stacy felt

empowered with the amount of advice and strategies designed to help support her son's

growth and development she learned from Evan's therapists. Socially, she felt as if on a

deserted island because she knew no one who shared the same experience of raising a

child with special needs that she could relate to. She was the only parent in her mothers'

group that had a child with special needs, and knew that many of the other parents she ran into did not know how to talk to her, or act around her son. Eventually, Stacy found a small group of women meeting in town through a Parent to Parent group, and all had a child with special needs. Over time, she learned to trust their advice as they all had children older than Evan, and had been through the process of raising a child with special needs in a rural town.

When Evan turned three, he qualified for developmental preschool due to his diagnosis and the likelihood that it would contribute to developmental delays. The school explained that under the Individual with Disabilities Education Act (IDEA), Evan was entitled to special education that would accommodate his educational needs, and could be placed on an Individual Education Plan (IEP). An IEP focused primarily on setting academic and school driven goals as opposed to his IFSP (Individual Family Service Plan), that he was placed on while in early intervention. The IFSP was family centered, which focused on goals the family perceived were important at home and would support Evan and his family during routines and activities throughout the day. All services he would receive at school, such as speech and occupational therapy would be a part of his IEP and at no financial cost to the family.

Every day, Evan was thrilled to ride on the school bus, and seemed to be doing well in his developmental preschool classroom. Evan used some verbal language but was still very hard to understand. The classroom Evan attended was a self-contained classroom, meaning all other children enrolled in the class were also on IEP's. Most of Evan's peers were non-verbal and in need of communication supports. Stacy noticed halfway through the school year that Evan was picking up very few language skills, and

she realized that there was very little peer-modeling available that Evan could learn from because most all the other children were struggling with speech as well. Frustrated, she began seeking private preschools that Evan could attend in addition to the developmental preschool. This search was difficult because of the limited number of preschools that had openings available in her rural town. On top of things, the few preschools that did have openings did not have the resources available to work with Evan or help with potty training. Private preschools required all children to be potty trained, and Evan was still working towards that goal. Fortunately, a former preschool teacher of Evan's older sister reached out and offered to take Evan two afternoons a week in her private preschool. This teacher knew Evan because of his sister's attendance, and felt comfortable with his level of development. Evan loved the additional classroom, and soon thereafter began picking up and using words and gestures after watching and interacting with his new typically developing peers. Stacy was excited to share his successes with a few parents that had younger children with special needs. Soon, her friend who had graciously accepted Evan into her program was flooded with phone calls from town and outer lying areas asking for enrollment opportunities for children with special needs, including children with Autism, Down syndrome and Sensory Processing Disorder. Stacy felt obligated to not discuss anything regarding Evan's enrollment outside her friend's preschool after that because she had made an exception by enrolling Evan, and was flooded with more requests than she could process. Stacy did not want her to feel overwhelmed. This experience made it apparent how difficult it was for families of children with special needs to find quality private daycare or preschool.

Evan received speech and occupational therapy in the preschool classroom, but this model changed once he entered elementary school. In elementary school, Evan would go to a different location to receive these therapy supports. He had a particularly hard time with his fine and gross motor skills, and Stacy worried about his occupational therapy services. Evan's elementary school only had a small space available in the back of the junior orchestra classroom portable. So, Evan received occupational therapy 30 minutes a week amongst music stands that he would occasionally stumble over. Stacy learned that the school district did not have the funding or space available to provide services in an environment conducive to therapy treatments for children receiving such supports.

Don and Stacy continued throughout Evan's first few years of elementary school following his IEP and each teacher's advice regarding all academic instruction. Evan seemed to be keeping up with the other students for the most part through third grade with adaptations to his schoolwork. But social and academic changes took place during Evan's fourth year of school. Compared to the social and academic growth of his peers, the rate and trajectory of Evan's growth began to slow down.

At the age of nine, Evan started realizing he was different than his peers. The school principal suggested moving Evan to a self-contained classroom like his developmental preschool classroom which consisted of students solely on IEP's. The principal explained that he felt drawing from his own experience, other students would soon start treating Evan differently and he would be considered nothing more than a mascot among his peers. Stacy was fearful that, like his preschool days, if he was placed in a self-contained classroom his skills would plateau or fall behind. She insisted he

remain in an integrated setting because she knew the importance of peer modeling.   So, Evan remained in the classroom throughout his elementary years, leaving to attend resource room where he received special instruction in reading, writing and math in a traditional resource room setting. The resource room consisted of five to six students receiving longer periods of one-on-one help from a special education teacher. His assignments were adapted to meet his individual strengths, and monitored to measure his goals set in his IEP to check progress each academic quarter.

Stacy knew that having typically developing peers around him would support Evan developmentally, but he also seemed to be missing out on instruction that enforced adaptive skills. As Evan entered middle school, he still did not know how to tell time, or count even the smallest amount of money. He could read at about a second-grade level, which was an accomplishment, but had a harder time comprehending what he read. His speech was still difficult to understand. He needed to be reminded about his hygiene and more often than not needed assistance with simple tasks like putting his clothes on correctly, washing his hair or clipping his nails. He wasn't keeping up with boys his age socially, and they often dismissed him. Evan played instead, with girls who would "mother" him. He started to ask when he could play football, and baseball. Stacy enrolled him in Special Olympics swimming and softball, which he really enjoyed. Special Olympics allowed Evan to be himself and simply have fun learning and playing new sports, not having to worry about keeping up with typically developing kids his age.

Transitioning into middle school, Evan was assigned to the resource room for longer periods of the day. There, he experienced counting money and cooking first hand with the school's mini catering lunch program for teachers in the school. He responded

well to hands-on learning, as opposed to writing on worksheets. He was able to spend time part of the day in mainstream classrooms, but was not able to participate in many of the electives, like band and foreign languages. Evan could not participate in band because his fine motor skills lacked the strength needed to play the instruments available. His reading comprehension remained at a third-grade level, which made it difficult to understand foreign languages. In their small town, social outlets were limited for teens with special needs except for one small Special Olympics team and the occasional dance a college intern would put together for a school assignment. People would talk about putting some type of social club together, but funding was scarce. Trying to find people to volunteer was difficult. One teacher told her that people in the town were unwilling to volunteer unless it served their own interests. He had been trying to organize social programs for years. Stacy worried about Evan's social emotional development. Not only did he struggle with social cues and communication, he had never been invited to any birthday parties or social events from any of his school peers.

Eventually Evan faced registering for high school. Don and Stacy truly started to worry about Evan's future. Until now, they felt as though they "floated" through school years with some minor bumps in the road. The reality regarding Evan's future into adulthood began to kick in. What would Evan do for work? What kind of opportunities would be available to him? Would he live with them forever, or would he have the ability to live independently? Would he ever find a way to access transportation that could get him to and from work and other places? They had heard other parents talk about a state "waiver" they could apply for that might help him with employment training beyond high school, but did not know how to sign up for one, who to talk to or where to

start. It seemed as though school years and all of the IEP meetings might have better prepared them for the moment Evan would graduate high school, but now it seemed like they were once again, deserted on an island with a lot of unanswered questions. They wondered why discussion and better preparation for this moment was not a more integral part of Evan's IEP planning over the years. Stacy decided to start researching on her own the history of families of children with disabilities in Washington State. She wanted to know their stories and what it took to get their children beyond high school, into employment and living as independently as possible.

Stacey and Don are not alone. Many families of student with developmental disabilities (DD) often find themselves wondering what opportunities will be available after high school that will lead to employment. These students need proper supports in place to experience a smooth transition between high school to post-secondary opportunities and ultimately employment. Parents of children with DD need to know how to help their children navigate these transitions. Available supports and resources vary from county to county in Washington and can be complicated to access.

<div align="center">Purpose of Study</div>

According to a study conducted by Rabren and Evans (2016), it is estimated that in the United States alone, there are over 5.9 million students with disabilities that reside at home with their families. These families must not only advocate for their child with DD, but act as their primary caregiver as well. Although parents are the primary advocates for their child with DD, many feel ill-equipped to navigate a system designed to transition their child from public school, and prepare them for work (Rabren & Evans, 2016).

This study aims to investigate what the parents of children with DD in Washington State have experienced while navigating the system of school to work transition programs, and what their ideals and beliefs are regarding this process. The Diffusion of Innovation theory will identify who is likely to start change within the system of transition programs for students with DD.

Research Question

The purpose of this study is to seek answers to two questions. First, what are parent perceptions regarding transition services provided by their local high school? And second, how well do they know the process of gaining access to services that may assist in providing their child with future employment support? In answering these questions, this study will produce deeper understanding of (a) Washington State parent perspectives of their local high school transition services (b) family attitudes and needs pertaining to local post-secondary education and employment opportunities; and (c) implications for practice that will enhance parent understanding of the transition process and promote parent advocacy for quality post-secondary education and employment for children with developmental disabilities. This study will be used as part of an effort to inform educators and Developmental Disabilities Administration (DDA) professionals of the needs parents express during transition, post-secondary education and employment. This research will also draw on the Diffusion of Innovation theory to identifying change agents that can help guide public policy change and professional growth regarding the needs of families of children with developmental disabilities during the transition process.

CHAPTER 2

LITERATURE REVIEW

Discovering the needs of transition students during and after high school from

concerned parents is the focus of this research. This study also draws on Diffusion of

Innovation theory (Rogers, 1986), to determine what role parents can play in advocating

for change in public policy regarding access to transition and employment supports. To

gain a broader understanding of systems and supports available to individuals with

special needs, it is important to also consider the history of how transition services and

post-secondary opportunities came to be in Washington State.

History of Developmental Disabilities Administration

During the start of the 20th century, children with developmental disabilities in

Washington State were either institutionalized or remained at home full time and were

denied the opportunity to attend school and gain an education. Over time, with parents as

at the forefront of advocacy for their children, Washington passed legislation that would

emphasize care in the community for people with developmental disabilities, rather than

support of institution living only. In 1971, Bill HB 90, commonly known in Washington

as the "Education for All Act" was passed mandating free and appropriate special

education services for all children with disabilities (Code of WA). In part, Bill HB 90

influenced changes at a federal level which introduced the passage of the Education for

All Handicapped Children Act in 1975 (PL 94-142). This Act established that all

children with disabilities would have the right to free and appropriate education in the

least restrictive environment possible. In 1990, the Education for All Handicapped

Children Act evolved into the Individual with Disabilities Education Act (IDEA), which

was re-authorized in 2004 (WSIPP Publication No. ESHB 2687).

History of Developmental Disabilities Administration

House Bill 90, Washington State
Free and appropriate special
education services for all children
with disabilities.

Individuals with Disabilities Education Act (IDEA)
IDEA now derives from the Education for All Handicapped Children Act and is signed into law by President George H. W. Bush

IDEA Amended
IDEA amendments specified that transition planning should begin at age 14. Requires active parent participation

1975

1992

1971

1990

2002

**Federal Act: Education for
All Handicapped Children (PL-94-142)**
Established that all children with disabilities
would have the right to free and appropriate
education in the least restrictive environment.
Use of advocacy

**Developmental Disabilities
Administration WA State (DDA)**
County Guidelines are issued that
continue to support the Department's
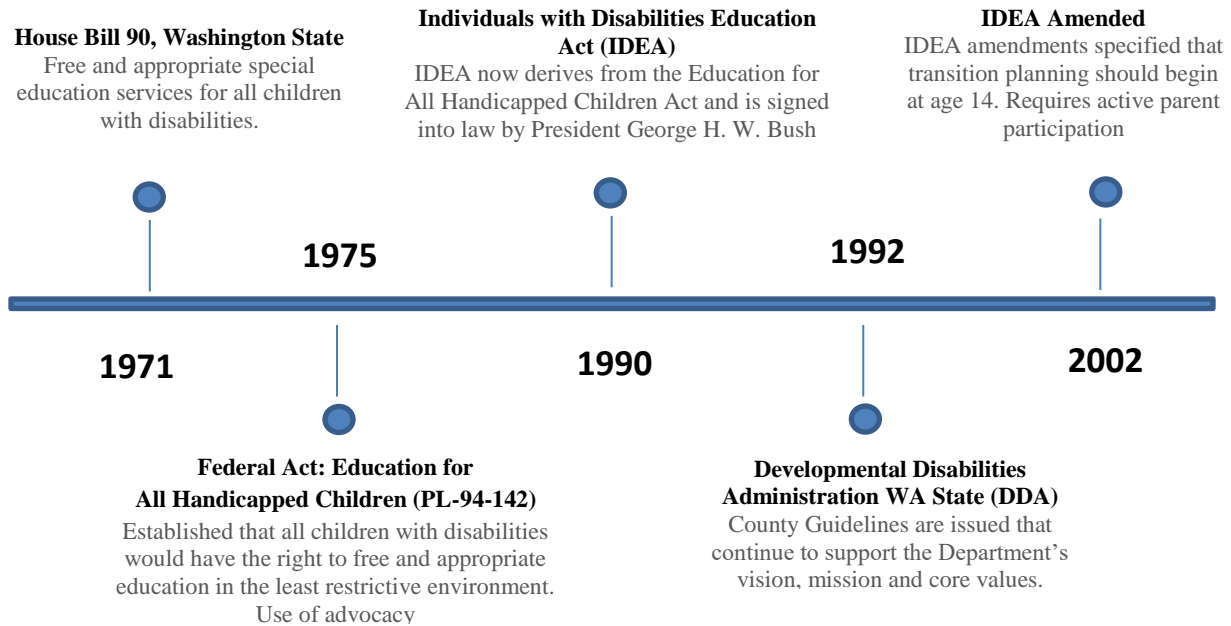vision, mission and core values.

Figure 1: History of Developmental Disabilities Administration

The shift in education practices also spurred the appropriations of federal dollars

from institutional settings for people with developmental disabilities to the support of

community centered care. In 1975, the Developmentally Disabled Assistance and Bill of

Rights Act (PL 94-103) was passed, requiring states to maintain and protect those with

developmental disabilities through advocacy to receive federal funded grant to use for

supports in communities (WSIPP Publication No. ESHB 2687).

Developmental Disabilities Administration (DDA) in Washington State is housed

under the Department of Social and Health Services (DSHS). DDA provides public

funding for support services through distribution of Medicaid as well as state and federal

funding. Support services vary throughout state counties, and consist of birth to three,

education from age three to 21, and lifetime supports. In 1992, DDA created county guidelines to ensure the vision, mission and core values of the administration be carried throughout the state of Washington. The current study focuses on supports available during the period of transition from high school to community-based work settings in Washington State (WSIPP Publication No. ESHB 2687).

In Washington, eligible DDA clients receive support services through special education in the public-school system. At the age of 21, students with developmental disabilities exit special education, and must be assessed to determine if they are eligible for DD funding for supported employment services. If the graduated student is found eligible, there still may be a waiting list to receive the funding and continue with a community-based employment program (DSHS, 2014). The period of transition between high school and employment can be difficult for families of a child with developmental disabilities, due to the lack of knowledge pertaining to the DDA funding process, transition services, post-education opportunities and supports.

Barriers to Attaining Transition Services and Post-Education Supports

Parents' support is critical in the development of their child's self-determination, which assists in strengthening self-advocacy skills. While community policy makers and stakeholders involved in the education of a child with disabilities understand this importance, little research has been conducted in Washington concerning the viewpoints of families and their transition planning and post-school needs. The IDEA Amendment of 2002 states that parent participation pertaining to special education decision making and transition planning is required. According to Defer, Todd-Allen, and Getzel (2014) families perceive their input as undervalued during the transition process. At the same

time, secondary schools report parents of students with developmental disabilities as passively involved (Defer et al., 2014). Some lack of communication between parents, schools and resources available exists in all communities. This miscommunication combined with the presence of cultural or linguistic diversity and a range of socioeconomic status may account for the lack of parent involvement expressed (Defer et al., 2014)

Research has shown that parents' values differ according to the age of the child and severity of the child's disability. However, a survey study conducted by Hamre-Nietupski, Nietupski, and Strathe (1992), found that parents of students with moderate disabilities valued functional life skill instruction most, followed by academic skills and relationship development. The overall attitude of all parents from a different study expressed the need for post-secondary opportunities for their children exiting high school (Grigal & Neubert, 2014). Yet, post-school outcomes related to youth with disabilities exiting school report a lack of skills, attitudes, and experiences needed during transition to post-education employment. This deficit may be due to the lack of vocational and employment training opportunities available to transitioning students (Carter, Trainor, Cakiroglu, & Owens, 2010).

In a study conducted by Carter et al. (2010), high schools reported offering a large variety of vocational opportunities for transitioning students, including but not limited to, career interest assessments, tours of college or technical schools, job shadowing programs and cooperative education programs. Yet participation in these programs was described as generally uneven and limited. The study also described career related professional development opportunities being infrequently available (Carter et al, 2010).

Diffusion of Innovation Theory

Rogers' (1983) Diffusion of Innovation theory explains how an innovation is adopted and diffused within a social system over time. This theory has been used to investigate the adoption of innovations in educational environments, and health care systems throughout the world. Rogers (1983) defines adoption as, a decision to make full use of an innovation as the best course of action available (p. 21). If an innovation is not adopted, it is rejected, and cannot be sustained over a period of time.

The first step to the adoption process is called the knowledge stage. This stage allows individuals to answer the questions, "what," "how," and "why" of the innovation presented, and help them form a favorable or unfavorable opinion regarding the innovation. This step is also referred to as the persuasion step (Sahn, 2006). In the context of transition supports recommended by parents, the more state legislatures recognize there is a valid need for transition supports and become knowledgeable on the subject from people who know students best, the more likely they are to recognize those needs and make changes to state requirements. Rogers (1983) also states that potential adopters of an innovation are more likely to fully adopt when they receive reinforcement from others regarding its expected outcomes. Information on an innovation is available from outside experts, but uncertainties are more likely to be resolved through an individual's circle of peers and their opinions (Sahn, 2006). During the decision stage, an adopter will accept or reject an innovation. This is followed by the implementation stage, or, putting the innovation into practice, and the confirmation stage, when the individual seeks support on their decision (Rogers, 1983).

Rogers (1983) defines the level of adoptees as innovators, early adopters, early majority, late majority and laggards. Innovators are defined as those willing to experience new ideas and are willing to cope with the uncertainties of new innovations. These are most often people with a higher social status and financial resources. They are willing to take risks on an idea because they typically have the financial backing to do so. Early adopters are more limited to the boundaries of the social system, and tend play roles as leaders, such as politicians and lawmakers. Early adopters hold the highest degree of opinion leadership or enough esteem where their opinion is highly valued, within any of the groups of adoptees. They are highly educated and are also have financial liquidity. Early adopters play a key role in the diffusion process in that that their acceptance to an innovation decreases the uncertainties that may exist among others, therefore promoting the diffusion process (Sahn, 2006).

The early majority have interpersonal networks that can help promote adoption among the late majority. These are people who may have some connections with early adopters, but hold little opinion leadership within a larger system. The late majority communicates with the early majority, have little to no financial backing, and have little opinion leadership compared to the early majority. They are skeptical about new innovations, and have below average social status.   Parents of children with DD are predicted to fall within the categories of early or late majority. Laggards are those who hold a more traditional belief system, and are slower to adopt an innovation. Laggards tend to wait until the success of the innovation is determined before adopting it (Sahn, 2006).

Application of Diffusion of Innovation to Transition Needs

The Diffusion of Innovation theory has been used in many school settings to better understand why a program conceived becomes successful or fails. In a study conducted by Dearing (2009) it was discovered that social work programs in higher education lack the ability to design programs that will be adopted by many social service providers, but rather focus on a program's internal validity, or, how well it may work. This action is extended into the field of intervention, where new intervention programs are often deemed undesirable, or not credible, regardless of their potential effectiveness. Dearing found that when a program is developed, it is easily rejected by early adopters because of unknown effectiveness. Programs are often revealed during inception and development, therefore leaving potential users wondering whether the intervention has potential. If parents are unsure how a new system change was created and if it is enacted without their input from their own personal experiences, it is likely they will reject it.

It is also easy for intervention creators to substitute their own perceptions for those of early adopters, by using information gathered from inadequate or poorly performed formative evaluations. Dearing, (2009) recognized that intervention creators are often used as the intervention communicators, which can create a biased report of findings. Dearing (2009) suggests introducing additional variables when presenting an innovation, such as compatibility, cost and simplicity to attract the attention of early adopters. He also suggests introducing a new intervention plan after it has been clearly completed and tested, and comparing other types of evidence-based practices to strengthen the argument for using the new intervention. The use of appropriate formative evaluations will ensure proper information needed to successfully launch a new

intervention, and will identify participants, such as parents, able to fulfill various roles, therefore allowing space for a variety of change agents, or, one who will enable and promote change within a group.

Pickard and Ingersoll (2014) found that research has shown a 20-year gap from the time an intervention program is developed, to when it is effectively integrated into the community. The researchers believe this is partially due to many intervention efficacy trials being run in a nature not typical to the average community setting. Once the intervention is tested and approved, there is little knowledge of who relays program information to parents. The author suggests that social networking theories can assist in dissemination of Autism Spectrum Disorder (ASD) intervention programs. Currently, social network theories have been studies in the field of health policy, HIV and substance abuse. Social networking has been found to influence beliefs through multiple pathways, influence others and provide a broad resource base (Pickard & Ingersoll, 2014). Rogers (1983) contends that communication channels, or, the catalyst to transferring information between one group to another must exist for information to diffuse, and can take time to build.

Pickard and Ingersoll (2014) suggest that social-networking ties are one explanation for the transferring of knowledge in the healthcare field, but different forms of social-networking have different implications for the spread of information. People, who have larger social-networking ties, have greater opportunities to share and receive knowledge. Denser social networks can collaborate and influence others more. The authors suggest that individuals are more likely to adopt ideas when shared among people with similar circumstances (Pickard & Ingersoll, 2014).

Evidence from a survey Pickard and Ingersoll (2014) conducted among 320 parents concluded that parents use a variety of social-networking strategies that influence adoption of ASD interventions. Like social networking in health-related fields, parents searching for advice on innovative ASD programs turned to community members within the social networking arena. Parents were found to be mostly influenced by individuals in their own similar circumstances. The study implies that individuals using social-networking can also be utilized as opinion leaders, disseminating evidence-based ASD intervention techniques among large groups of people. The author also recommends that the dissemination of ASD best practices take place to allow easier access of information for parents, rather than keeping this information limited to research journals and more formal autism resources (Pickard & Ingersoll, 2014).

For a newly introduced intervention to gain success, Dingfelder and Meyer, (2011), found that school administrators must perceive the new intervention as better in relation to the one it replaces. But the program's relative advantage or, the degree to which a program would work compared to others, must work in tandem with values, beliefs and needs of the adopters for diffusion to take place. The complexity of the program must also be suitable to the adopters for change to take place (Dingfelder & Mandell, 2011).

To incorporate Diffusion of Innovation into the research conducted by Dingfelder and Mandell (2011), it is suggested that several refinements from dissemination to implementation occur. The use of change agents to create relationships within the community, and act as communicators within a boundary to ensure a credible foundation for the program is recommended. The authors also suggest conducting target research

directed to public interest which may include parent input, and relaying cost and efficiency as a crucial element for early adopters. A successful program will conduct efficacy trials, utilizing a diverse representation of children with DD and parent input to evaluate and plan for sustainability of the program (Dingfelder & Mandell, 2011). The research in this study will be utilized to further support the belief that parents play a necessary role in transition and post-secondary programs within the state of Washington.

CHAPTER 3

METHODS

Participants

A total of 41 family members of children with developmental disabilities in Washington State participated in this study. Of the 41 respondents, none reported their child as enrolled in early intervention services, 14% reported their child as attending elementary school, 18% as attending Middle School, and 68% reported their child as currently attending High School. None of the responders reported home schooling their child. Of those attending high school, 24% reported as currently enrolled in high school transition services. Most respondents described the community they live in as suburban (62%) while 23% reported living in a rural community, and 4% described their community as metropolitan.

Procedure

A survey was developed and delivered using Qualtrics, a web based survey software through Central Washington University's Human Subject Review Department. A welcome letter was sent to all families on each county Parent to Parent list serve describing the study. The letter also informed respondents that the survey was completely voluntary, and that each response would maintain anonymity of the user. The welcome letter included a website link that would navigate the user directly to the electronic survey. Once the link opened, the survey would guide the respondent through a series of questions, which also allowed the respondent to withdraw at any point or skip questions. Once the survey was complete, the responses were tracked and recorded through Qualtrics.

To reach parents of children with developmental disabilities throughout the state of Washington, this study was introduced to the state Parent to Parent Coordinator who first reviewed and approved all questions to distribute. Parent to Parent is a statewide parent support organization that provides families in need information and education about disabilities, personal support, referrals to resources in local communities and culturally relevant services through ethnic outreach. The Parent to Parent program is established in several counties throughout Washington state, including, Kittitas, Grant/Adams, Chelan/Douglas, Walla Wall/Columbia/Garfield/Asotin, Benton/Franklin, Spokane/Lincoln/Whitman, Pierce, King, Skagit, Whatcom, Snohomish, Island, Kitsap/Jefferson/Clallam, Grays Harbor/Pacific, Thurston/Mason, Lewis, Clark and Cowlitz Counties. The survey was first approved by the state Parent to Parent Coordinator. A welcome letter and a link to the survey were sent electronically to all Parent to Parent Coordinators representing each county. In return, each Parent to Parent coordinator sent the letter and link to all families on their list serve within the county.

Survey Instrument

The survey was comprised of 13 questions. There were a total of seven multiple choice questions, four ranking questions and two open-ended questions. The questions were then placed into four categories: respondent information, current feelings parents have about transition services, what parents know about transition services, and what parents believe should be changed or implemented to improve transition services and the best living and/or employment outcomes for their children with developmental disabilities (Appendix B).

CHAPTER 4

RESULTS

The results of the survey data will be presented in this chapter. The main themes described relate directly to the research question and will explore: (a) parent perspectives of their child's high school transition program, (b) needs for post-secondary school and community opportunities, (c) resources parents would trust the most for information regarding transition, post-secondary opportunities and DDA information.

Regarding high school transition services, the following question was asked; "How well informed are you on high school transition services?" Respondents felt that they knew little to some about transition services in their school. The response to this question is presented in figure 2.
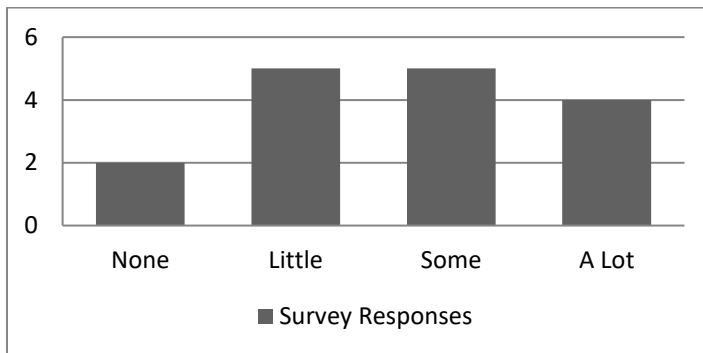

Figure 2: How well are families informed regarding transition services?

Participants of the survey were then asked to respond to what they felt should take priority in high school transition programs. Using a ranking scale, participants were asked to choose career interest assessments, tours of college and technology programs, internships with job shadowing, high school and college education programs, and other, with "1" being their first choice (figure 3). Parents appeared to show interest in internships between high school and college the most.
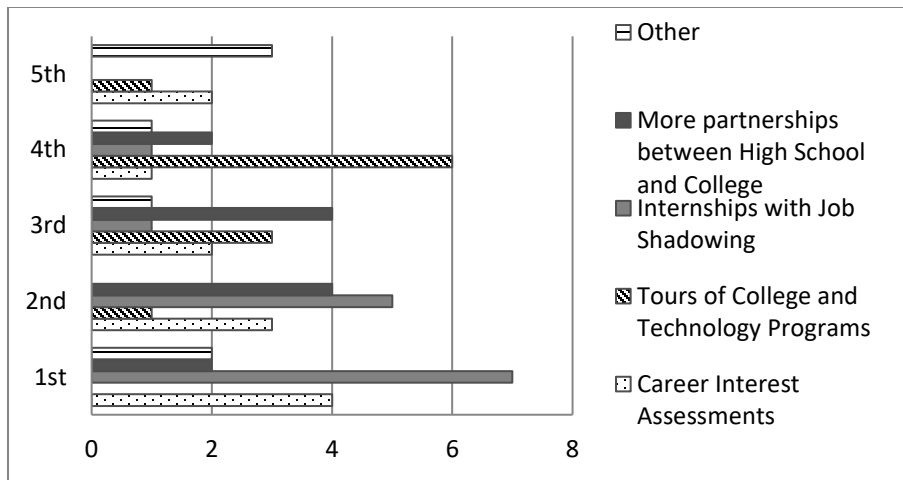
Figure 3: What should take priority in high school transition programs?

Participants were invited to report their ideas in the "other" category, if selected.

Those that chose the "other" category reported:

(1) Each student should work in the summer during high school so that they can figure out what kind of jobs they like and what they are good at and what they need help with and start earlier.
(2) Tour supported employment job sites to envision what's possible.
(3) Providing appropriate transition to those who qualify and need that extra time and help.
(4) Although my son had an IEP for 12 years, he was denied transition services and was expected to attend college. He will be graduating with a BA from UW this year. Without parental support and belief in, this would not have been possible.
(5) More information on what is available
(6) Completion of academic work from high school that was not given time due to special education classes taking priority.

The next question concerning participant's perspectives on their high school transition program asked that if system improvements were needed in the participant's high school transition program, how long would it take for such improvements to become fully implemented and utilized? (Figure 4). Participants of the survey overwhelmingly chose 20 years or more.
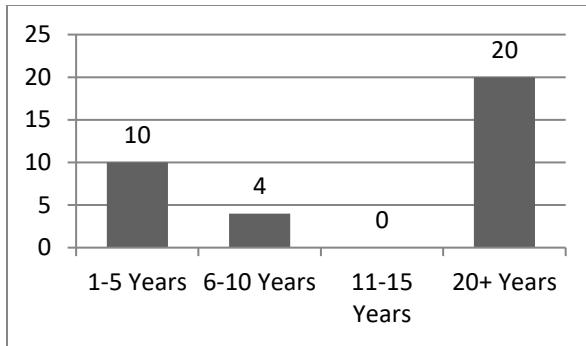
Figure 4: How long would it take for changes to be implemented and utilized?
Participants were asked to answer questions regarding their thoughts on

community needs regarding people with DD. The first question was based on a ranking

scale and asked; "What do you value the most for your child's future employment

training?" Participants were instructed to rate the following categories with "1" as their

highest priority: life skills instruction, academic skills, relationships and social

development and, other (Figure 5). The responses concluded that relationships and social

development are the largest priority needed in employment training programs.

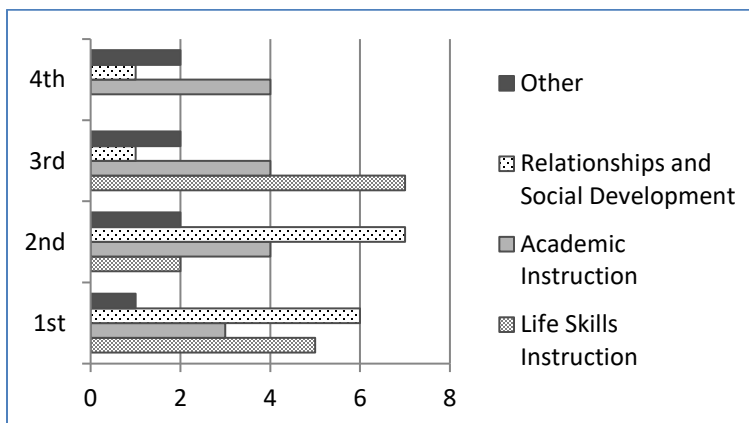*Figure 5*: What do you value the most for your child's future employment training?
Participants who chose "other" reported the following:

(1) The "will to work." Encouragement that is the goal. Everyone needs
to work.
(2) Job coaching on the job
(3) Access to well trained, knowledgeable support personnel and systems
for young adults without intellectual disabilities
(4) Job skills

(5) How to take his fears of unknown away

The second question regarding community opportunities asked, "If your child had the opportunity to attend college or post-secondary schooling, what would your concerns be? "Participants were asked to rate their choices on a ranking scale, with "1" being their favorite choice; cost, your child's compatibility with the program, organizational structure of the program, lack of communication between you and your staff, and other (Figure 6). Participants chose their child's compatibility with a program as their number one concern.
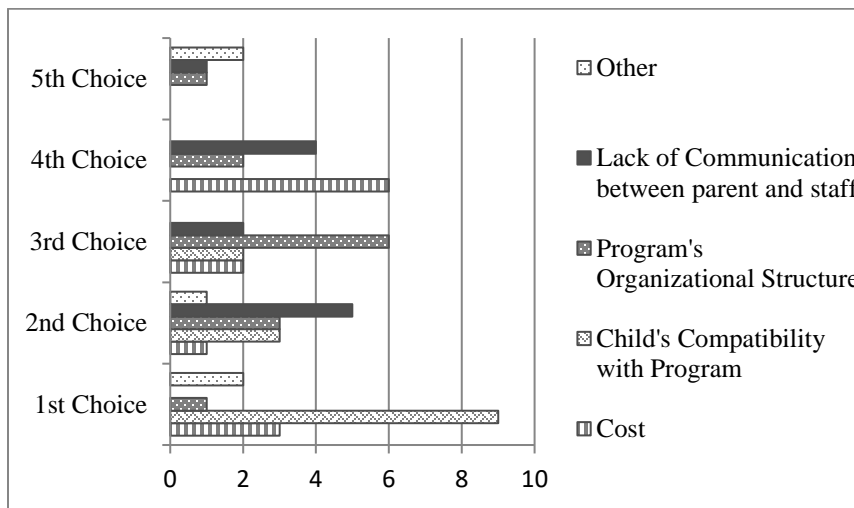

Figure 6: Concerns for college and post-secondary school attendance.

Those that chose "other" responded with:

(1) Having to "test" into the program, where they could take the classes pass fail and still be ok
(2) Availability of 1:1 staff support
(3) We have and are doing this now with my ASD 25-year-old son. There are few effective programs to support his needs. We have to figure out how to provide this service behind the scenes. We have also paid for everything. PSE has always been my passion and for those who are intellectually able, they should have the necessary support and programs to help them finish their degree."

The question, "In general, do you feel there are enough opportunities available in your community that would assist in preparing your child for future employment?"

(Question 10) was asked, and 16 respondents answered. Of those, four answered "yes," and 12 answered, "no."

Participants of the survey responded to open-ended questions regarding needs in the community that respondents felt would better prepare those with developmental disabilities to gain employment, and who they would trust most for information and supports.

Participants were asked, "What do you feel your community needs to better prepare those with developmental disabilities to gain employment?" An open-coding system, as described in Straus and Corbin's book, *Basics of Qualitative Research* (1998), was used to determine distinct concepts from the open-ended questions. Once identified, larger concepts were transformed to themes. The themes were titled; Community Engagement, Post-Secondary Opportunities, Supported Employment, Career Centers, Employer Knowledge of People with DD, Social Emotional and Advocacy Supports and Career Focused Education in Middle and High School. Each theme was assigned a code and all responses from the open-ended question were categorized under each theme that seem to fit best. The codes were tabulated and used to compute the frequency and proportions of all responses combined. The results found that respondents felt that communities need more community engagement. Results of this question are recorded in Table 1.

Table 1:
Open-Ended Question Responses

Themes	Percentage %
Community Engagement	30
Post-secondary Education Opportunities	3
Supported Employment	10
Career Centers	10
Employer Knowledge of People with DD	13
Social-emotional and Advocacy Supports	17
Career Focused Education in Middle/High School	17
TOTAL	100

   Participants in the survey were asked, "Who are the resources you would trust the most to learn about high school transition services?" Using a ranking scale, participants were asked to rank the options of answers using "1" as their first choice and "6" as their last. The choices of answers were listed as, "friends with a similar disability, anyone who has a child with a disability, the Developmental Disabilities Administration, advocacy organizations, social networking and school districts." A total of 15 participants answered the question. They chose friends as their most trusted source of information, and school districts as the least trusted. The results of this question are recorded in figure 7.

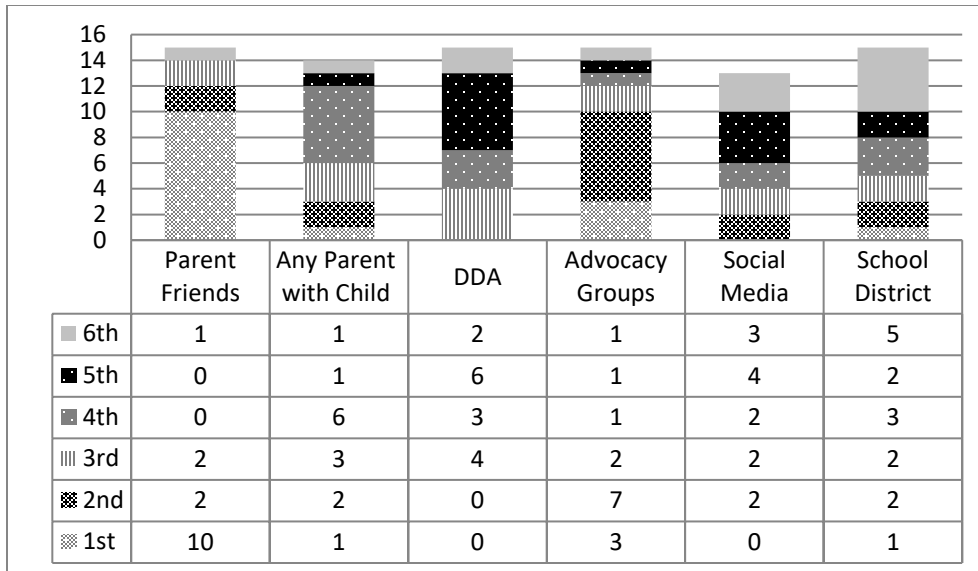|	Parent Friends	Any Parent with Child	DDA	Advocacy Groups	Social Media	School District
6th	1	1	2	1	3	5
5th	0	1	6	1	4	2
4th	0	6	3	1	2	3
3rd	2	3	4	2	2	2
2nd	2	2	0	7	2	2
1st	10	1	0	3	0	1

Figure 7: What are the resources you would trust the most to learn about high school transition services?

CHAPTER 5

DISCUSSION

This study was conducted to seek perspectives from parents of children with developmental disabilities in the state of Washington regarding their experiences with transition and post-secondary school programs. Initially, this research anticipated that the opinions of parents would center strictly on the system of public school supports and services available for students with DD. Surprisingly parents not only voiced their feelings regarding public school supports, but also shared great concerns regarding social emotional support for their child moving into the work field beyond high school. In addition, parents not only indicated changes take place within school districts, but also called for greater community engagement, or, community collaboration, to take place to help create programs designed to support future employment for students with DD. Finally, parent knowledge regarding transition and post-secondary programs draw a clear connection to the adoptee role they play pertaining to the Diffusion of Innovation theory.

On question 8 of the survey, parents reported their biggest priorities in a transition program should include internships and job shadowing, in addition to tours of colleges and technology based vocational programs.   One parent suggested that tours of supported employment job sites would give students an idea of what is even available for work beyond high school and post-secondary schooling. Another parent replied:

> There needs to be more opportunities for young adults to have mentors, job shadowing and exposure to different career ideas.

However, Noel, Oulvey, Drake and Bond (2016) reported through a recent study that a common barrier for transition age students moving into adulthood and looking for work include lack of social skills and cognitive problems on the job.

To reflect this idea, this study found that the number one concern among parents regarding work training as being the quality of relationships among co-workers and the social-emotional feelings towards work. One parent described their child needing the "will to work," while another wanted to know how to take "his fears of the unknown" away. Another parent reported needing access to, "well-trained, knowledgeable support personnel and systems for young adults without job skills." These findings appear to move beyond the realm of system strategies for employment and tap into the human element of emotions and fears of a person with DD as they pertain to being in the workplace. If participation in many vocational programs is found to be limited (Carter et, al., 2010) perhaps the component of social emotional supports within these programs should be further explored. In addition, a study conducted by Papay and Bambara (2011) suggests that most college programs available for students with DD programs tend to admit those who have the motivation to work and be a part of campus life versus those who have a higher level of need for appropriate behavior, mobility or safety issues.

Recent research has found that the transition needs of parents pertaining to their child with DD in high school most often differ greatly from school district professionals' perceptions of what a family needs (Hayfaa & Al-Kandari, 2014). It is imperative that parents have a full understanding of their child's rights under IDEA to relay their needs appropriately to district professionals and to help their child advocate for services and supports. Cobb and Alwell (2009), found that students who were more actively involved

29

in their transition planning and had their voices heard, also had more success of meeting

their goals beyond high school pertaining to school and work. To illustrate this point,

one parent that completed question 2 of the survey reported:

> School just didn't make much sense for him until someone from the transitions program sat down at the table with us and our team. We found that the high school counselors and special education teachers were lacking in their ability to share helpful information regarding our son's transition. I am thankful we did finally have this person come to our meetings. Now, I am insisting these people attend out daughter's meetings.

The IDEA Amendment of 1997 states that parent participation pertaining to

special education decision making and transition planning is required. Yet, question 2 of

the survey indicates that parents, in general, know some or little about transition services

available in their school districts. One respondent of the survey stated:

> We found that high school counselors and special education teachers lacking in their ability to share helpful information regarding our son's transition.

To be more informed of transition programs, it is imperative that parents, school

staff and the student be actively engaged in all phases of transition planning. Question

Cobb and Alwell (2011) suggest including peer advocates, mentors and friends in team

meetings, and that transition meetings are separated from IEP meetings to help parents,

students, and team members clearly delineate the two and their end goals.

In this study parents also expressed fears regarding their child having the

opportunity to attend college and/or post-secondary schooling. Question 7 reported the

main concerns were for their child's compatibility with a program, lack of

communication between school staff and their child and the cost of programs available.

In addition, one parent commented that they feared their child having to test out of a

program, when they could easily be graded as pass/fail and still be ok. In contrast,

child's safety was reported as parent's number one fear in a study conducted by Griffin, McMillan, and Hodapp (2010). This was followed by parents wanting a strong preference for a focus on employment during post-secondary training. The study also found that in general, parent's limited knowledge of transition plans and post-secondary options were a barrier, and that educator's and post-school expectations for students did not seem to align. Again, these findings suggest that parents are indeed in need of better communication between educators, administrators and families.

Question 11 of the survey asked parents what they felt their community needed to better prepare their child for employment beyond high school. An overwhelming response referred to community engagement as being a necessary support. This idea correlates with the Wrap-Around Planning approach being studied in communities across the nation. According to Lechtenberger, Barnard-Brak, Sokolosky, and McCrary (2012), a Wrap-Around Planning process includes a collaborative team approach that designs a strength-based, individualized and community-based service plan that supports a student with DD. This type of plan would support parents needs for community post-secondary school supports, because it would be built around a team of people actively invested in the student's goals and success in life, therefore promoting motivation and social opportunities. One parent responded:

In our county, there is a wide variety of places to work. But it does take some parent initiative also. Looking around your community, places your child could work, talking to people about job opportunities, interviewing job vendors, finding the right person to support your child. Job vendors may get competitive between each other, but that is a great thing.

According to Dingfelder and Mandell (2010), research of the implementation of autism interventions suggest that to link program development and its use there must be

community partnerships to strengthen programs already in existence, followed by the construction of improved systems designed to meet the needs of the community utilizing these programs.

According to question five from this study, parents limit themselves to only fully trust parents of children with a disability like their own child's disability, as well as any parent that has a child with disabilities. Parents valued advocacy groups for information as well. These groups act as communication channels for information dissemination. If administrators and educators are to play the role of early adopters relating to the Diffusion of Innovation theory, parents should be considered as early and/or late majorities regarding new policies and system changes around transition and post-secondary programs. For new transition programs and systems to be adopted into school systems, parents must first trust that what they are being told by administrators and educators what will be put into place, and therefore fully accept changes. Or, parents and advocacy groups should be invited and integrated into the social connections of early adopters, which may include a reserved seat and voice at policy-making council meetings.

Most parents' responses to question 12 indicated that they felt it would take 20 years or more for a new system overhaul regarding transition, college and post-secondary opportunities to be fully accepted, adopted and implemented. This aligns with Pickard and Ingersoll (2014) findings showing a 20-year gap from the time an intervention program is developed, to when it is effectively integrated into the community. Therefore, it is implied that if system additions and improvements are to take place, students with

DD might not have the opportunity to take advantage of them within their high school and post-secondary school years.

Conclusions

The findings of this study revealed that parents have major concerns regarding their child's ability to build healthy relationships among coworkers in the workplace. Parents also report great concern regarding their child's will to work and question the availability of supports that could help increase work motivation. These unexpected concerns show that social emotional supports rank as a high priority in addition to community and academic supports. Community engagement that involves families could help promote motivation and social opportunities with a wrap-around planning approach. For instance, local business owners could be invited to IEP and transition meetings to gain a better understanding of students they hope to hire in the future.

There appears to be a large communication gap between parents, educators and educational institutions regarding transition services. In this study, parents indicated they trust school districts the least for information regarding transition services. This implies that parents lack strong partnerships with school districts in the past, including communication and collaboration opportunities. To create successful transition outcomes and fulfill parent participation requirements set forth in IDEA, it is imperative that parents, school staff and the student remain actively engaged in all phases of transition planning.

The voice of parents and advocacy groups should be introduced to the political arenas of early adopters to educate opinion leaders. There appears to be a missing link between the voice of parents and those in the position to make system changes. Allowing

parent input before decision making takes place will educate opinion leaders, and therefore lend credibility to new system changes. This can also help a new change be accepted soon and disseminate sooner. Parents felt it would take 20 years or more for new and improved transition supports to be implemented and utilized in a community. Unfortunately, this idea suggests that if system addition and improvements are to take place, current students with DD will miss the opportunity to take advantage of them within their lifetime.

Limitations of Study

Due to the sensitive nature of personal information, CWU Human Review Board restricted survey questions regarding disability type, specific age, gender or residential location. The answers to these questions may have been used to better understand the opinions of parent's participating in the survey. Also, some participants completed the survey partially while others completed it in full.

Recommendations for Future Research

This study revealed that the families of children with DD do struggle with navigating transition, post-secondary and employment opportunities at some point in their journey. It is difficult to understand a system of education, funding and policies already put into place. In addition, parents worry about their child's social emotional stability entering into the workforce and community engagement opportunities that seem scarce or unknown.

It may be of benefit to conduct a comparison study of services and parent perspectives in the different regions throughout the state. Gaining a better understanding of what services exist in both rural and suburban areas might answer more specifically

why parent opinions differ greatly regarding services in their area. This research may compare topics including population factors, cultural bias and belief, and economic status.

A theme that appeared to resonate throughout this study and warrants further examination was the lack of communication that exists between parents, school educators and administrators regarding transition and post-secondary opportunities. It appears parent expectations for their child differed greatly from the idea that educators had, which is something other studies have also found. Parents also worry about their child's social emotional well-being including motivation to work and developing healthy work relationships. Further research may focus on communication between transition programs and families, encompassing not only works skill expectations, but social emotional and mental health concerns and expectations in the work force as well.

Future research may also focus more specifically on why some parents have more of an inclination to trust information from their friends and advocacy groups rather than schools and community stakeholders putting programs in place. Researchers may call on the Diffusion of Innovation theory to find if the role of parents fall more into the early or late majority adoptee category. More specifically, if parents can be identified as majorities, what would it take to move parent advocates into early adopter roles, and help them earn the voice of an opinion leader? It can also shed light on the importance of communication channels made up of parents and their most trusted sources of information. This may better predict how well new systems put in place will be responded to, accepted and diffused over time.

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APPENDIX A

Definitions of Terms Used

Anomaly: any congenital defect that results in the interference with the normal growth and differentiation of the fetus ("Mosby's Medical Dictionary, 8th edition, n.d.)

Developmental Preschool: a special preschool designed for children with special needs, whether it is a disability, or a developmental delay, usually after a child has "aged out" of an early intervention program

IDEA: a law ensuring services to children with disabilities throughout the nation. IDEA governs how states and public agencies provide early intervention, special education and related services to more than 6.5 million eligible infants, toddlers, children and youth with disabilities (IDEA, 2004).

Individual Education Plan (IEP): a legal school document that spells out a child with disabilities learning needs, the services the school woll provide and how progress will be measured ("Special Education Guide," 2017).

Individual Family Service Plan (IFSP): a written treatment plan that maps out early intervention services, as well as how well these services will be administered ("Special Education Guide" 2017).

Least Restrictive Environment: school districts are to ensure that the provision of services to each student eligible for special education be provided in a general education environment. Students should only be removed if services are not achieved satisfactorily with the use of aids.

Natural Environment: settings that are natural or typical for a same-aged infant or toddler without a disability and may include the home or community settings (IDEA, 2004).

Post-Secondary Education: programs that exist on college campuses and allow students with developmental disabilities to continue their education alongside typical peers (Griffen, McMillan, et. al., 2010).

Self-contained Classroom: a classroom where a special education teacher is responsible for the instruction of all academic subjects. The classroom is typically separated from general education classroom, but within a neighborhood school (Spencer, 2013).

Self-determination: acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference (Zhang and Stecker, 2001).

Transition Services: are a set of coordinated activities designed to be a results-oriented process that facilitates the successful movement from school to postsecondary living. These activities are based on the student's needs, strengths, preferences, and interests (n.d.)

APPENDIX B

Survey Questions

1. Is your child currently enrolled in:

    a. early intervention

    b. elementary school

    c. middle school

    d. high school

    e. home schooled.

2. How well informed are you on high school transition services?

    a. None

    b. Little

    c. Some

    d. a lot.

3. Is your child currently in high school transition services?

    a. Yes

    b. no

4. Do you feel there could be changes in your child's transition services that might
    result in better future employment outcomes for your child?

    a. Yes

    b. no

5. What are the resources you would trust the most to learn about high school
    transition services? Please rank in order with "1" as your first choice:

    a. Friends with a similar disability to your own child

    b. Anyone who has a child with a disability

    c. The Washington State Developmental Disabilities Administration

    d. Advocacy organizations

    e. Social networking

    f. School districts

(opportunity to name advocacy groups)

6. What do you value the most for your child's future employment training? Please rank in order with "1" as your highest priority:

    a. Life skills instruction

    b. Academic skills

    c. Relationships and social development

    d. Other

7. If your child had the opportunity to attend college or post-secondary schooling, what would your concerns be? Please rank in order with "1" as your greates concern

    a. Cost

    b. Child's compatibility with the program

    c. Organizational structure of the program

    d. Lack of communication between you and the staff

    e. Other

8. What do you feel should take priority in high school transition programs? Please rank in order with "1" as your first choice:

    a. Career interest assessments

b. Tours of colleges and technology programs

c. Internships with job shadowing

d. More partnerships between high school and college programs

e. Other

9. How would you describe the community you live in?

a. Rural

b. Suburban

c. Metropolitan

10. In general, do you feel there are enough opportunities available in your community that would assist in preparing your child for future employment?

a. Yes

b. No

11. What do you feel your community needs to better prepare those with developmental disabilities to gain employment?

12. If changes were required to take place in your high school transition program, how long do you think it would take for them to become fully utilized after implementation?

a. 1-5 years

b. 6-10 years

c. 11-15 years

d. 20+years

13. Please state any additional comments concerning your child's future employment career and high school transition services you would like to add.