8-2024

Quality of Life Domains for Students Living With a Severe Disability and Their Families

Eden Withers

Recommended Citation

Withers, Eden, "Quality of Life Domains for Students Living With a Severe Disability and Their Families" (2024). *All Graduate Reports and Creative Projects, Fall 2023 to Present*. 46.
https://digitalcommons.usu.edu/gradreports2023/46

Quality of Life Domains for Students Living with a Severe Disability and Their Families

Eden Withers

Utah State University

Master of Special Education

Table of Contents

Definitions of Terms Used

Autism Spectrum Disorder (ASD): A developmental disorder that is characterized by atypical behavioral patterns that can be seen as repetitive or restrictive. Challenges with social interaction, sensory processing, and emotional regulation are typical with ASD.

Center-Based School: My work setting: a school tailored specifically for students with severe disabilities, where they are offered an adapted Common Core curriculum through essential elements to meet the diverse learning needs of each student, as well as other disability-related services.

Division of Services for People with Disabilities (DSPD): Utah's division of state and federal funding for individuals with disabilities. Services include respite care, behavior support, day programs, supported living, and support coordination.

Family Quality of Life (FQOL): Overall quality of life in relation to a family context or unit. The quality can be measured by scales and modalities rating satisfaction in a variety of different life domains, such as a family's physical satisfaction, emotional satisfaction, social satisfaction, community satisfaction, and, in the context of this project, disability support satisfaction.

Head Teacher: Licensed special educator, my current position. This is what we call the team leader of multiple paraprofessionals in my setting.

Intellectual and Developmental Disability (IDD): Usually used when referring to an individual who has an intellectual disability, along with other comorbid disabilities that can affect neurological functioning and adaptive behaviors; typically, an IDD is present throughout the individual's lifespan.

Itinerant Service Provider: Licensed professionals who rotate through their caseload throughout the day to provide services in my center-based school. These professionals include occupational therapists, speech- language pathologists, physical therapists, a behavioral team, adaptive PE teachers, and a music therapist.

Neurodiverse Affirming: The idea that individuals have differences in their abilities and how their brain interacts with the world around them; encouraging acceptance to those experiencing neurodiversity and embracing those differences, rather than attempting to change them.

Neurodiverse: Atypical brain development that can influence differences in behavioral patterns, communication, and cognition, compared to those considered neurotypical.

Online Practical Teacher Training Program (OPTT): Utah State University's online educational program for teaching licensure, created for individuals who are already employed in an educational setting as a paraprofessional or another related special education position.

Professional Parent: An individual serving in an alternative parental role for a child with a disability; they typically will host the child in their home and take on the caregiving role. The parent is formally trained and compensated through a disability service provider.

Sensory Stimming: Repetitive sensory seeking behaviors or actions that provide input when an individual is feeling under-stimulated or overstimulated. This could be exemplified by flapping an item over and over, chewing an object, or being fixated on a particular texture through any of the senses.

Shop: Classroom in my center-based school dedicated to occupational therapy modalities in completing prevocational tasks to improve fine-motor skills and workplace abilities. This is a service included in the student's IEP.

Purpose of Project

Career History

I started my career working alongside the population of those with intellectual and developmental disabilities in 2017, when I took a job as a supported living staff member in a group home. These experiences opened my eyes to the vast need for quality support and services for people with severe disabilities. After graduating in Sociology at Utah State University (USU), I went to work as a paraprofessional in a separate, center-based school, exclusively for students with severe disabilities and profound support/learning needs. I then joined the USU Online Practical Teacher Preparation Program (OPTT) program and accepted a head teaching position at the school where I continued to recognize the disconnect many parents/caregivers feel when it comes to receiving quality support for their child, especially outside of the school setting. I have continued to work as a licensed special education teacher for the last 3 years in this center-based school, and the experiences I highlighted above have only become increasingly clear over the years. From anecdotal experiences, I have heard people share about the lack of available resources for their student(s) with a severe disability and how to procure these critical resources. These stories are what guided the rationale behind choosing my master's creative project.

Center-based School

To further understand the intention behind my project, it is beneficial to explain the setting in which it occurred. This setting is considered a "center-based school," meaning the entire school is tailored specifically for students with severe disabilities, where they are offered an adapted Common Core curriculum through essential elements to meet the diverse learning needs of each student. Within this setting, there is also a plethora of itinerant service providers that provide further, tailored support to meet the needs of students. These services include licensed professionals in occupational therapy (OT), physical therapy (PT), speech therapy, music therapy, and vision/audiology. This integrated approach, among specialized educators and itinerant service providers, fosters a multidisciplinary collaboration among professionals, enhancing the overall learning and development outcomes for the students.

Career Vision

My vision for my career would be informing the public and education system of the need to create more neurodiverse-affirming learning environments. The more people that understand the way we teach and approach individuals experiencing life through this lens, the better to embrace the uniqueness and inherent worth of each individual and that they are not something to be fixed but rather celebrated in their unique way of navigating the world. Accommodating the needs of an increasing number of students, who fall under the neurodiverse umbrella, will in turn increase the capacity of their ability to function and learn in a system that was not originally designed or catered to their learning desires and needs.

Introduction

From the latter half of the 20th century to now, the United States has undertaken concerted scientific and medical efforts to dramatically increase life longevity and quality of life for people with intellectual and/or developmental disabilities (IDD; Fisher et al., 2009). Along with scientific and medical advancements, the United States has also enacted civil law protection efforts to fight prejudice against people with disabilities. The Rehabilitation Act of 1973 was instituted to prohibit employment related discrimination from programs in the federal sector. Given the limitations of the Rehabilitation Act, which provided protections only in locations that received federal funding, there was a need for additional protections. Amending and broadening the protections of the Rehabilitation Act, the United States Congress passed the Americans with Disabilities Act of 1990 and guaranteed access for people with disabilities in public and private spaces.

Along with societal protections outside of the school system, the U.S. Congress has passed a series of legislation focused on promoting a free appropriate public education, starting with the Education for All Handicapped Children Act (EAHCA) of 1975. The EAHCA evolved and was renamed the Individuals with Disabilities Education Act (IDEA) of 1990, which initially mandated transition services and connections to community-related opportunities and supports. Ensuring access to tailored educational opportunities to meet student needs, IDEA was amended again in 1997 and yet again in 2004. Renamed and amended in 2004, the Individuals with Disabilities Education Improvement Act provided students with disabilities, including students with intellectual and developmental disabilities (IDDs), further protection in receiving a free appropriate public education, focused on access to the general curriculum, leading to successful postschool outcomes.

Even with these federal protections, life can still be extremely challenging and isolating for people living with an IDD when navigating an often ableist and unaccommodating public society (Gardiner & Iarocci 2012). Through the 1960s, people with disabilities were often institutionalized in the United States. It was not until the deinstitutionalization movement that, as a society, we focused on moving people with disabilities out of isolated institutional and clinical living settings and into equitable community-based living arrangements (Fisher et al., 2009).

As a society, we have evolved in our attitudes towards people with disabilities. These attitudinal changes may be attributed to pivotal federal legislation, such as the Americans with Disabilities Act and societal movements like the deinstitutionalization movement of the 1960s. Even with the changing tides of the public opinion on disability, as well as an influx of antidiscrimination attitudes towards marginalized populations, people with disabilities are still often at a disadvantage or bias when it comes to access to equivalent standards of living compared to those without disabilities. According to the National Center for Education Evaluation and Regional assistance, during the National Longitudinal Transition Study (2012), when students with disabilities were compared to those without, they were statistically more economically disadvantaged and at risk for lack of preparation when entering their postsecondary life in terms of employment, independent living, and more (Lipscomb et al., 2017a). The study also found that educational gaps were greater for students with IEPs as well. Students reported struggling academically but receiving less access to resources and help for their support needs.

Due to these expressed inequitable differences throughout environments to which those experiencing disability are subjected, as well as the mental and physical implications of the disability itself, discontentment with the quality of one’s life is all too common amongst this population (Fisher et al. 2009). Given these considerations, it is critical to purposefully examine and understand the quality of life for people with disabilities. Quality of life (QOL) encompasses several domains that can be assessed. These domains often address physical, material, social, emotional, and vocational domains of well-being (Wang & Brown, 2009). Typically, these domains are assessed in terms of the individual, but the past 20 years have brought upon broadening research of quality of life as an entire family unit. Often marginalized families, such as those containing individual(s) with IDD are assessed for family quality of life (FQOL) domains due to the increase of support needs and caretaking demands due to disability (Brown et al., 2006). The reason why families or caretakers are more likely to be considered in the equation of QOL with people with disabilities is often because more support with daily functioning is needed for the individual(s) and their respective family members who help maintain these supports (Hsaio 2018).

As a special educator, fortunate enough to work alongside this population daily, I believe it is pivotal to assess quality of life domains amongst students with IDDs and their families/caregivers to offer them greater equitable access to their community, as well as the most effective educational opportunities. It is essential as an educational practitioner to assess our best practices and make improvements to them for the betterment of the system and the students' lives within it. I have examined literature below that I believe pertains to the purpose of my creative project requirements, as well as shining light on the importance of quality-of-life domains throughout all areas of specialized educational practices.

Literature Review

I chose to conduct a search for literature through the Utah State University library's website, where I navigated to a link for EBSCOhost. My search query was to find peer-reviewed research that pertained to quality of life for people with intellectual and developmental disabilities, as well as the quality of life for the entire family unit. I used the search terms, *quality of life for people with disabilities AND family quality of life AND/OR domains to assess quality of life for people with disabilities.* Although narrowed down a bit, these search phrases returned over five pages and 300 articles. I refined my search procedures to ensure each article was peer reviewed and from North America. This refined search yielded 39 articles. After reviewing each article's title and abstract, I chose three pieces that highlight assessing quality of life for people with disabilities. These studies used and began validating various instruments to assess quality of life for people with intellectual and developmental disabilities (Brown et al., 2006; Hsiao 2018; Samuel et al., 2012).

First, Brown et al. (2006) expressed the importance of measuring family quality of life domains. This study looked at two prominent developmental disabilities: autism spectrum disorder (autism) and Down syndrome. Three groups of families from British Columbia were chosen for this study: one group of families was classified with autism, another group of families was classified as Down syndrome, and the third group was classified as having no disability present in their families. The rationale stated behind these three identified groups was to examine if there were potential differences in quality of life across disabilities, as well as using the control group with no disability to examine potential differences when a developmental disability is present within a family system. The authors claimed that although the effect of disability is not always negative in nature, the societal structure and response can leave families lacking balance and fulfillment in accessing proper care and autonomy for their loved one with an IDD.

Brown et al. (2006) assessed family structure through nine quality of life domains that were (1) Health; (2) Financial wellbeing; (3) Family relations; (4) Support from other people; (5)

Support from disability-related services; (6) Spiritual and cultural beliefs; (7) Careers and preparation for careers; (8) Leisure and enjoyment of life; and (9) and Community and civic involvement. The main instrument used was the *Family Quality of Life Survey.* After surveying all three groups, a total of 51 responses were collected for families with autism (*n* = 18) and Down syndrome (*n* = 33), and 18 families without a disability responded. Results indicated for respondents from families with autism reported lower than 50% satisfaction with six of the nine domains. The families classified with Down syndrome reported less than 50% satisfaction with four out of the nine domains, with families with both disabilities claiming that respite related services were a primary deficit. Disability related services were reported at 44% satisfaction across families with autism, and 48% satisfaction was reported from families with Down syndrome. In families with both autism and Down syndrome, leisure and enjoyment of life also fell quite below 50% satisfaction. The domain identified as support from other people returned significantly low rates across both the Down Syndrome and autism families. The family classified with no disability present was assessed on only 8 domain measures due to the absence of disability support needed. Of these eight domains, only one was identified as less than satisfactory, which was community and civic involvement. The authors discussed that the families without a child with a disability showed higher levels of satisfaction in all domains, this indicates that future related studies should be conducted with families without disabilities in contrast to those with disabilities to examine the effects across populations and the implications of living with a disability in society on a greater scale. Limitations stated were that it was a rather small sample size, which could have been biased from the beginning due to their voluntary willingness to participate in the study, largely mothers were the primary respondents as well, who often tend to be the primary caregivers as well. Severity of disability may correlate to FQOL, which may be assessed further.

The implications of this study apply to my specific purposes of utilizing family quality of life assessment tools to identify support needs and life satisfaction across families in my center-based special school setting. Ultimately, this will lead to actionable steps my colleagues and I can take to improve quality of life for my students and their families.

Second in the literature review, Samuel et al. (2012) suggested evidence points towards finding services through a family-based lens can increase the likelihood of positive outcomes. In this study, Samuel and colleagues screened eligible families from an urban hospital setting and surrounding areas in Michigan, USA. Families recruited were those living with an individual in their family with an intellectual or developmental disability. From a pool of 300 willing families, 149 families were selected as eligible for this study and would be further interviewed and assessed for QOL purposes. Eligibility was determined if respondents fit the criteria of (a) be the parent/caregiver of at least one individual with a disability; (b) have an income of less than $40,000 or be a part of a racial/ethnic minority group; (c) be a resident of the state of Michigan; and (d) speak English as a first language, due to survey instrument language availability. Primary caregivers were the respondents for the questionnaire, survey, and scale, where the main survey instrument being used was FQOLS-2006. This survey is the same as stated in the Brown et al. (2006) review above, which analyzes 9 different domains relating to family quality of life. For this study, formal support services and support from other people were the primary domains being assessed. To qualitatively assess perceptions of disability-related services, caregivers were given a secondary questionnaire, which entailed 27 differing disability-related services that were available to families, where they were asked on a binary yes/no scale if they knew if the service was (1) available to them and (2) if they were utilizing that service. If a caregiver stated they were not aware of or using a service, they were further prompted to write a short reasoning for the absence of that service in their family. Lastly, to further gauge families' perceptions of service supports, researchers prompted families to also fill out a Likert-type scale of six different dimensions of service supports. These dimensions analyzed the quality and perceptions of the disability services available and their applicability in relation to family quality of life. A measure of family sociodemographic data was also considered by asking respondents information regarding income, racial identity, number of parents in the household, and the survey respondents' relationship to the individual with an IDD.

Given these criteria, Samuel et al. (2012), analyzed responses given by primary caregivers and compiled them to be further coded and assessed. Nearly 73% of respondents belonged to an ethnic minority, and less than 50% lived within a two-parent household setting. Findings categorized under *availability and utilization of disability related services* expressed some gaps between awareness of a particular service and the family utilizing said service. Transition and employment services were the least known service at 42%, and an astonishing 3% of families were utilizing this service. In terms of respite service, 25% of families were using this service, and 62% of families said they had heard this service was available.

Survey and data findings coded under *need for services* reported that 58% of families said they need more disability-related service support. The most pressing support needed was therapy, such as speech, occupational, and physical therapy for their child with an IDD. Within the open-ended responses as to why certain service supports were not being used, caregivers displayed frustrations with insurance not covering further therapy, as well as discontentment with the quality and quantity of school-based services. Participants' second most stated support needed for their child was further educational services such as after school programs, social skill training, and transition planning. The third most stated support needed was mental health support (22%) for the individual with an IDD, as well adequate mental health services for other siblings and caregivers. Ten percent of families also stated that they needed further professional medical support for things like dental care for their child with a developmental disability.

Further, Samuel and colleagues' (2012) findings in this study titled under *barriers to accessing services* found that 86 of the 149 families participating (57%) stated that the largest barrier was a lack of awareness or knowledge of how to obtain certain support services. The next greatest barriers were 18% of families stating issues with being on varying waiting lists for these services, as well as financial barriers to funding the needed services for their child(ren). Also, 16% of families reported that they were unsatisfied with the quality of the support services they received. *Dimensions of service support* was reported in the study with 89% of families stating that service support played a vital piece in satisfaction relating to their FQOL, but only 40% reported feeling they have access to "many" disability services. Amongst those who had support, 69% said they had to take great initiative and effort to secure said services, and only half (50%) were satisfied with the disability services they were already receiving. Correlation analysis was utilized to find commonalities between the dimensions assessed, it was found that opportunities, attainment, and stability of support led to greater positive outcomes for families.

Authors concluded that the purpose was to use the FQOL framework to help underserved families access services and support. The most common barrier was awareness of how to access the services, especially amongst families with lower income. Samuel and colleagues discussed that their findings echo previous literature relating to FQOL and the domains that influence them such as demographic factors and perceived parental stress; decreasing parent stress may in turn improve FQOL. It was concluded that parental stress may be reduced by factors, such as formal support services for their child with an IDD, like respite or mental health resources, for the entire family. Limitations of this study were that several white families above the income threshold were excluded for purposes of examining minority populations; however, it could be useful to include them in the future for comparison purposes of demographics. The authors also indicated that FQOLS-2006 should be used for future family research support projects.

The implications of this study apply to existing needs of students and families in my center-based school. Specifically, this study applies to my need to assess dimensions of support, as well as perceived parental stress to greater support students with significant developmental disabilities and their families to achieve lifelong positive outcomes.

Last, in review, Hsiao (2018) examined a potential causal relationship among family demographic characteristics, parental stress, and overall FQOL. This study recruited parents of children diagnosed with autism spectrum disorder (ASD) across four different ASD service providers. This study took place in an unidentified state in southwestern US, where 236 parents voluntarily selected to participate. Three different measures were given: the parental stress scale, the Beach Center FQOL scale, and parental demographic information. The demographic dimensions assessed across parents were gender, educational attainment, marital status, income, and the number of children with ASD. To maintain confidentiality, the researcher enlisted the ASD service providers to send out the three instruments in an email to their respective clients.

Hsaio (2018) compiled responses from the surveys and analyzed their relationship to FQOL. The parental stress scale survey ranks five domains by level of satisfaction. These domains are (1) physical and material wellbeing, (2) family interaction, (3) parenting, (4) disability-related support, and (5) emotional well-being. Results were expressed by the mean (average) domain indicated by parents. The lowest reported level of satisfaction across respondents was emotional well-being, with disability-related support being the next lowest indicator of satisfaction reported. Followed in rank by parenting, family interaction, and finally, the greatest satisfaction was expressed in the physical and material well-being domain.

Next the researcher examined results between individual demographic characteristics and FQOL using regression analysis, which is a data evaluation method that analyzes the relationship between a dependent variable and various independent variables. In this study, the three variables were family demographics, parental stress, and family quality of life. Results indicated that (24.1%) variance was attributed to parental stress, suggesting that parents who expressed higher levels of stress were more likely to express lower levels of FQOL. When comparing income demographics, those who were more financially affluent expressed greater FQOL at (14.2%) variance. Parents who lived with a partner or spouse were identified as a two-parent household also showed higher levels of FQOL at (4.2%). Education showed (3.2%) variance amongst the group, and families who had an individual with a bachelor's degree or higher perceived greater FQOL.

Further analyzing results, Hsaio completed a four-way analysis of variance (ANOVA). In this case, Hsaio examined if family demographic variables could be an indicator of FQOL amongst families with children with ASD. Results showed that all demographic variables considered together are predictors of FQOL. Among the group of parents responding, having a higher income was associated with higher levels of FQOL. When considering parental stress and family demographics together, outcomes conveyed statistical significance in predicting FQOL. In the discussion section, the author stated that each individual parental demographic could predict FQOL when considering parental stress in conjunction with their demographics; these findings highlight the importance of understanding the impact of these variables. Hsaio also concluded that these findings are consistent with other existing literature around FQOL. Another interesting conclusion the author stated from the ANOVA was that once families reach a certain income threshold, other demographics may not be as serious of indicators of FQOL, showing that income is the most statistically significant indicator of quality of life. Limitations expressed were that 65% of respondents were white, and 50% had received a bachelor's degree or higher educationally. Thus, further research could diversify the pool of candidates and respondents. Furthermore, research also may examine the relationship of what barriers are causing higher levels of stress in parents of families with ASD.

The implications of this study are applicable to my purposes in that demographics may play a role in satisfaction amongst families in my current setting. It should be noted that certain characteristics such as race, income, and levels of stress may implicate low FQOL among students with IDDs and their families.

Key Takeaway and Purpose of Project

The chosen literature highlighted an intertwined relationship between family life satisfaction and intentional access to resources that help navigate those gaps in satisfaction. Whether it be through direct disability-related support or community-based resources, the entire family unit can take advantage of resources to reach their goals. Assessing and understanding the state of families navigating life with a disability can help professionals, such as special educators, improve upon evidence-based decisions to implement practices for positive lifelong outcomes in the future.

Due to the level of needs amongst the students at my center-based school, relationships with families are necessary to provide the student with the most appropriate level of support. It is imperative as professionals to adequately meet the needs of students and families. Because of this, the purpose of my project is to assess FQOL, specifically disability support domains across families, and in turn use the assessment to compile and collaborate meaningful resources for those families. Throughout both reports, I will be using language unique to my setting. My rationale for this decision is because the purpose of my project is to support change within my school setting.

Assessment Report - Survey

Description and Creation of Assessment

The rationale behind my first report was to identify the satisfaction and needs of families in my center-based school setting in relation to quality-of-life support, specifically in relation to the FQOL domain of disability support services. I used a survey to assess familial perceptions. The survey was created, formatted, and results compiled by me; the questions written stemmed from previous FQOL surveys such as the Brown Family Quality of Life Survey (2006), as well as the Beach Center Family Quality of life Scale (2015). Considering the literature reviewed above and focusing on my specific setting and previous anecdotal complaints from several families of insufficient disability support, I selected eight questions mirroring those complaints to include in the assessment. These questions are aimed to pinpoint the FQOL domain of disability support in terms of importance, access, and satisfaction among families in the center-based school. To comply with IRB exemption requirements, the survey needed to remain entirely anonymous and optional for families that chose to participate, and the content, as well as the application of results, fell under IRB exemption guidelines 1 and 2. The purpose and intent of this survey are purely to cater for and assess needs from the direct population that I serve. Once I determined the most important questions for this project, I sent the potential survey to my school district research committee with an explanation of the project to receive approval of the content. From there, I worked with my head principal to ensure wording and instructions were clear and pertinent to the purpose of my project. It was originally intended to be a digital survey, but, after collaborating with my principal, I learned there was greater response rate in the past with physical surveys. Taking that suggestion and the questions, I formatted a paper survey (Appendix A) through the Canva designer application to be printed off and put in envelopes to go home in backpacks with students. I copied, folded, and put 252 surveys into envelopes distributed to classroom teachers at my center-based school.

Administration of the Assessment

Collaborating with my head principal, again, to distribute and explain the administration of the assessment, it was decided that a separate letter would be sent home in the envelope along with an email blast to all the families, letting them know that they had been invited to participate in a survey relating to support services and FQOL. I made an announcement at a staff meeting surrounding the purpose of the survey and to request my colleagues please bring all responses into the main office in the envelopes provided. The message and email sent off to parents are displayed in Appendices B and C.

Results

In total, I received 72 completed responses. Results of each survey were then input into a Google form to categorically separate answers and find trends across survey answers and participants. Of the respondents, 62 (86.1%) identified themselves as the mother of the child with an IDD; seven (9.7%) identified as the father of the child; one (1.4%) identified as the grandfather, one (1.4%) as the grandmother, and one (1.4.%) as a professional parent. As far as satisfaction with the relationship of families within-house special education providers (teachers, OT, SLPs, etc.), 50 respondents, (69.4%) expressed they were “very satisfied” with this support relationship, and 22 respondents (30.6%) reported to be “satisfied” with the relationship with SPED providers. However, in terms of the level of satisfaction of disability-related support outside of school, results told a different story. Seventeen respondents (23.6%) indicated to be "very satisfied" with these supports; 29 (40.3%), indicated they were "satisfied;" 11 (15.3%) claimed to be "neither;" 11 (15.3%) were "dissatisfied;" and 4 respondents (5.6%) were "very dissatisfied" with outside-of-school disability supports.

The next question of the survey asked families to select what percentage of their overall income, without financial support, was spent specifically towards disability-related needs for their student with an IDD. Thirty-four (47.2%) families stated that "10-25%" of their income went towards their child(s) disability related needs; 22 (30.6%) indicated they spent "less than 10%;" 8 (11.1%) said they spent "26-50%" of their monthly income; 6 (8.3%) spent "51% or more;" and 2 (2.8%) of families indicated they spend "none."

When asked to what degree families were able to include their child with an IDD in recreation and leisure activities, 16 (22.2%) of respondents indicated that the child was included "always;" 24 (33.3%) said the child was included "frequently;" 23 (31.9%) was able to include their child '"occasionally;" and 9 (12.2%) of respondents were able to include their child "rarely." Those that indicated "rarely" were prompted to provide a brief explanation as to what barriers were inhibiting their child's participation. Appendix D contains those barriers that were stated.

When asked about the importance of receiving disability support to their family's quality of life, responses returned depicted that 64 families (87.7%) considered it to be "very important." Also, 8 (11%) feel it to be "a little important," and 1 family considered it to be "hardly important at all".

After considering the responses, the final question in my survey acted as a guiding tool for the second report of my creative project. To cater directly to the needs of my center-based school, it was imperative to include a survey question pertaining to what resources families felt were the most needed and important to them. The top three resources that families could use extra support in were identified, they were the Utah Division of Services for People with Disabilities (DSPD), respite care, and communication. Refer to Appendix E.

Reflection

Conducting this survey was a major undertaking considering the process that it took to create the survey and then collaborate with my administrator. Because the survey would reflect the school, the questions needed to be digestible and readable for the families we serve. Because there are so many school-related situations occurring, and my administrator has many responsibilities, it created an extra barrier of stress to have to wait extended periods of time to sit down and have a meeting discussing the survey. Looking back, this is something that I should have considered more when trying to meet deadlines and relying on another person for their approval. Considering their busy schedule, it made this a lot more challenging than I had hoped to execute. However, once the long process of finalizing the survey and allowing it to be distributed was completed, the results returned very insightful and useful information for our school. With these results, we were able to get a perspective into families’ quality of life, especially in relation to the domain of disability support. Considering the level of needs of the population at my school, support from others, formally and informally, is of importance to their quality of life and functionality as a family unit, as 98.7% of families reported. The insights from the survey can be utilized for future development of catered resources for the needs of families at this center-based school, as well as a signifier into the ways we can influence families' access to the community and the things that will enhance their quality of life in those ways. It also helps put into perspective the professionals in the building to better understand the satisfaction of families we are serving and their perception of support. I was able to share a brief rundown of the results in a staff-wide meeting, and the head principal asked for the results to be kept for future reference. This helped me feel like the work that I did was useful and impactful for the school.

As far as analyzing the direct results from the families that participated, it is important to discuss what the implications of the outcomes of this survey may mean for them, and what can be deduced from their responses. It could be concluded that since 75% of families still indicate needing further assistance with formal services from DSPD, there could be a structural lack of funding for the number of needed services across applicants, as well as a lack of awareness of how to procure the benefits of this resource. In addition, barriers could be related to the navigation required to access support through state-level processes that are often not provided to families in a way that is accessible for them. This means that we, as a school, should broaden our understanding of what is available to the students and families we serve to bridge the gap between this lack of outside disability support. This survey indicated that there are several families who need support outside of the scope of school and, as a professional in the field of special education, we can encourage a more holistic approach to understanding the population of our school and their respective wellbeing.

Collaboration Report - Resource Collection

Purpose of Collaboration

The guiding principle behind this collaboration report was to discuss the results of the survey with school personnel and to contemplate ways we can provide more access to resources and targeted needs. Below, I overview results from this survey question: ***Please check below what resources your family would benefit from having extra support/education for your student(s) with a severe disability***. This question was considered for the main goal of the collaboration meeting, and the results were averaged in the following rank of the highest to lowest reported need:

1) **DSPD (Department of Services for People with Disabilities) - 54 families**
2) **Respite Care - 49 families**
3) **Communication - 44 families**
4) OT/ fine motor - 37 families
5) Life skills - 34 families
6) Behavior - 34 families
7) Medical - 28 families
8) Mobility/PT - 27 families
9) Transition - 21 families
10) Maturation - 19 families
11) Supported living - 18 families

Taken from this list, I decided to frame the collaboration meeting, along with the product, around the top three identified needs from the above stated survey question. Those needs were

DSPD, respite care, and communication. Taking into consideration those needs, I then selected who I would include in this collaboration meeting. The itinerant service providers I selected from my center-based school to participate in this collaboration effort included a member of the school administration; a speech-language pathologist; and myself, a licensed special educator.

The administrator involved in this effort has been working at this school for 7 years and is involved in the transition services for the students. I selected her to help with ideas surrounding respite and DSPD. The speech-language pathologist in the meeting has been working with students at this school for the past 12 years and is particularly interested in learning about gestalt language processing, which is a prevalent natural language process among students with ASD and echolalic speech patterns, who comprise a large percentage of the students that speak or vocalize at our school. I selected her to help address families' indications in the survey of need for communication support. Prior to the meeting, I gave a brief explanation of the collaboration purpose, including why they were particularly chosen for this collaboration due to the indicated support needs from my first report and parent survey. I thanked them for being willing to work alongside me to enhance the awareness of resources and support for our families at the school. I communicated with both participants about their availability and coordinated a time where we could get together after school. Once a day was chosen, I asked them to please bring their laptops and to get thinking about some resources or information from their specific background.

Collaboration Meeting

The meeting took place after school in the conference room where I had provided both participants with a copy of the survey results. I enlisted the administrator to focus on respite and DSPD information, and the speech language pathologist homed in on communication-related supports. We began by reviewing responses in the survey, and discussions ensued throughout each question. They were quite shocked and saddened by some of the discrepancies related to the respondent FQOL in relation to the domain of disability support. After conversing, I steered the collaborative effort towards the product that I would like to create, which was to collect resources and information regarding each respective collaborator's field of expertise. Both participants were given a piece of paper and a pen to write some resources of what might be useful and accessible from their field, especially any local entities. After offering them both a period to ponder, I brought the collaboration back together and prompted them to discuss what they selected to contribute.

Process Discussion and Creation of Product

The administrator that oversaw compiling resources for DSPD and respite care shared first in the meeting. She elaborated on the fact that there is an extremely long wait list for DSPD services. In her experience, she has had families on the waiting list for over 12 years. She recently discovered that if you call and inform them of families with situations similar to the families in our school, such as the high support needs of their child, your position on the waitlist can improve. This may be indicative of the high volume of people trying to be enlisted in disability support services. The best that we can do is inform families about the process as early as possible; ensure, as a school, we are helping families understand the process; and support families being placed on the list from a young age. It was also mentioned to add a note to the DSPD resource that if families need any assistance in applying to contact an administrator to support their efforts in applying for services. She also shared that we will be inviting a DSPD representative to the school transition fair at the end of April, so we could make a note to inform families about their participation in the fair in advance. Our discussion also led to the likelihood that some families may not qualify for services if they are of undocumented immigrant status, so she shared a resource for undocumented families, who need disability support.

As far as respite care, it was noted that we could inform families if they are looking for respite to let the school know, and we could see if anyone at the school was interested in and able to provide respite care for the family. She also shared the name of four programs that offer respite hours outside of needing to be enlisted in DSPD services, which is important to note, given the highest need stated by families was DSPD. If a family is not receiving funding through DSPD, it can be difficult to enroll in many disability-related supports, and sharing a resource that offers respite without this stipulation would be helpful for several students at the school. She ended by sharing a link on the Utah Parent Center that specifies how families can go about finding care specific to their child's level of need and disability classification. This concluded her contribution for this project, but our collaboration will be ongoing to finish developing the manual of resources for the center-based school.

Next, the speech-language pathologist shared her insight with resources regarding communication for our students. She was ecstatic to share that she has been in touch with a Utah Assistive Technology coordinator and that a website has just been created and launched for public use regarding augmentative and alternative communication (AAC), including Utah-specific support. This will be a huge asset to share with families. She then shared a blog specifically for families of gestalt language processors, which is a common natural language acquisition process that students in our setting are perceived to align with. It is highly prevalent in those diagnosed with ASD and echolalic speech patterns. She then shared two different websites that families could access to browse and select a quality AAC device and how to receive help with funding the device, such as insurance. Her final contributions were to incorporate our school low tech AAC core board in the resource manual for families to print and access. Additionally, she recommended adding in a link to her preferred application for AAC users which can be purchased for a lifetime use called Cough Drop, she stated it is highly customizable and feels it is user friendly for families.

After completing the discussion about communication related resources, I thanked both the administrator and the speech-language pathologist for participating in this meaningful project and informed them that I would compile their contributions from the collaboration meeting into a resource document that will be formatted to set the stage for the creation of an entire resource manual that parents would be able to utilize through the school’s website. Refer to Appendix F for the resource manual.

Current Resource Outreach Practices in Place

After conducting the meeting, I wanted to take inventory of the ways we already approach sharing resources with families before piecing together the sections of the manual. As far as DSPD is concerned, our school administrators typically take initiative with families at a young age encouraging them during meetings such as IEPs to get started early on and quickly in registering for qualifying services through DSPD to get on the list as soon as possible. The typical process at my center-based school for providing respite care information consists of the parent informing the teacher or administrator of the need for a caretaker, where we then offer to make an announcement with a brief explanation of the student and family in need along with their contact information. This happens during staff meetings or through a staff-wide email announcement. In terms of shared resources for speech and communication, there is no formal process and is a case-by-case basis depending on the speech-language pathologist that is assigned to that student and the way they go about sharing their resources with families. The teacher and SLP collaborate to inform the parents of what may benefit their child related to communication.

As expressed in the paragraph above, there is no formal system in place where parents can easily access and learn about resources available to them and their child, especially from home. There have been a few scattered parent nights throughout the years, but no formalized committee or practice dedicated towards students and family resource outreach. This reality helped me recognize the value of something formal and approachable for my setting, which highlights the usefulness of something like the parent manual I am creating.

Occupational Therapist Collaboration

After completing my collaboration meeting and beginning to compile the resources, I determined that it would be useful for the vision of my project and the overall vision of the manual to further collaborate with another itinerant service provider. The fourth stated need in the guiding survey question was additional support in occupational therapy and fine motor. As we have occupational therapists at the school, I found it meaningful to collaborate with another professional, given their background knowledge of what may benefit families. The occupational therapist that I selected has been working with this population for the past 16 years. At the school, we have a class called “shop.” This is where students go to complete tasks that are specifically designed to increase their fine-motor skills. Along with being well versed in fine motor abilities and interventions, her other area of expertise is guided towards offering students access to sensory-related needs, as well as teaching students with mobility deficits how to use adaptive tools in daily life for skills such as eating, drinking, and dressing themselves. Our collaboration was a bit less formal but nonetheless very beneficial. I approached her in her office and showed her the results of the survey and explained that families identified a need for additional education and resources in occupational therapy and fine motor. She was a bit surprised to hear it was number four on the list. Our conversation led into the curiosity of how families understand occupational therapy. She said she gets many questions during IEPs and parents asking for videos about how they perform their pre-vocational task in “shop.” We discussed the possibilities of further collaboration in the future and finding a way to allow families to replicate the tasks at home, with a concerted focus on increasing independence with fine motor-skills and emotional and sensory regulation. Students who receive services at the school not only participate in “shop,” but they also utilize products occupational therapy provides for varying sensory processing difficulties, such as weighted blankets, compression vests, noise canceling headphones, as well as items for sensory stimming, such as chewable necklaces. This is not an exhaustive list, and our conversation exemplified how broad the scope of occupational therapy truly is. I enlisted her to get back to me within the next couple of days with some resources that she feels would encompass what families may benefit from in terms of occupational therapy.

Once she had gathered her resources, she shared them with me in person at my desk. She felt it would be helpful to give families the names of a few websites she utilizes to buy the sensory products that students frequently use that could be implemented in the home as well. She also felt it important to include a resource specifically geared towards products that families could buy to address eating and feeding mobility difficulties their students may experience by offering a link to adaptive silverware. As far as in-person occupational therapy services in the Valley, she said there is a high demand, and, sometimes, the severity of the student’s disability can inhibit them from being accepted into certain programs. This was very disheartening. However, she still shared two clinics that students have previously attended. From which, families may be able to receive services. Part of one resource is a life skills clinic at the University of Utah that parents could attend this summer. This led her to the resource she was most excited to share because she had recently been contacted to spread the word about a new adaptive sports arena in the area that will be opening on April 20th. This is an opportunity for students to participate in their community and increase their fine-motor skills. This concluded our collaboration, and I thanked her for her willingness to take the time to think about ways we, as a school and team of professionals, can begin reaching families outside of our typical job scope in a meaningful way. Pictured below is a compilation of the resources that were produced from my collaboration meetings. This is a beginning section to a complete resource manual.

Future Direction of Resource Manual

After the completion of the manual section, I wanted to ponder upon what the next steps could be to go about sharing it effectively with families, as well as informing staff of its existence, purpose, and presence. There are a few different avenues and possibilities that come to mind when executing this approach. One of the first would be to enact an official announcement to families through an email from the school administration linking the manual on the school's website, along with a simple video elaborating how to access and navigate through the manual and its main proponents. This would be done to reach the widest audience and offer an attainable and accessible product to assist them in finding the best available resources applicable for their student's needs. It would be practical to not only let this be a one-time announcement as the school student body fluctuated throughout the year and new families will enroll; therefore, a scheduled announcement could be implemented annually every fall at the beginning of the school year to ensure all families are aware of its existence and are reminded as well.

Another important aspect to address in the matter of next steps is to ensure feedback from families and parents who will be utilizing this manual. It would be an intentional insight to share the manual with members of the school advisory committee (SAC) to gain feedback. This committee consists of a school administrator, a licensed special educator, and a few guardians of students from varying grade levels, along with a wide spectrum of abilities and needs; this year there were 4 guardians, who participated in this committee. Sharing the manual with the SAC committee would provide useful feedback to gain a better understanding of how parents may approach the manual, its accessibility, and its comprehensiveness for families, as that is the intended audience for which the manual may be an asset and provide benefit. Finally, it is concluded that implementing a system of encouraging teachers and professionals to become informed of the agencies and resources within the manual and potentially look into providing information that may benefit a particular family during their annual IEP meetings or re-evaluations. This manual can serve as a resource guiding tool for teachers and families year-round.

Reflection

Reflecting on this collaboration, I was able to practice taking leadership in my role and create a meaningful product with other professionals in my workplace. This gave me insight into ways this can be expanded towards creating an entire resource manual addressing varying supports. As disability support from outside agencies was identified as important to the families' quality of life from the survey, collaboration into compiling the available resources of those supports, as well as any barriers to receiving them, are essential in bridging the gap in awareness and accessibility. Taking what I learned from this experience, it is important to intentionally create collaboration opportunities emphasizing differing backgrounds of expertise to sufficiently address the high support needs of the students and families in my setting. Reflecting on the process of creating the resource manual section itself, I felt that it was difficult to imagine what would be easy for families to navigate through as they each come from different backgrounds as far as education and awareness of their child's disability. I wanted to add a short description with each linked resource to give clarification about what that resource entails for ease of sifting through quite a bit of information and to steer them in a clear direction to what they might be looking for.

In a finalized manual, I think it would be wise to include definitions of things that families may not be fully aware of such as AAC, gestalt language processing, what the full scope of OT is, and so on. It would be beneficial to further collaborate with more itinerants in my setting to address the other highlighted needs that were identified from the survey question guiding this report. I also think that collaborating further and expanding the manual with other professionals such as the music therapist, adaptive PE teacher, and a physical therapist could create a more diverse and expansive product for families. Further, it would be helpful to have families themselves navigate through the manual and provide feedback as to its usefulness and accessibility. In the discussion with the professionals I collaborated with, it was said that it could be a rich resource for families if we took it a step further and create specific videos modeling what happens at school and how families could implicate the practices at home and during summer to further provide evidence-based intervention strategies in a variety of settings.

References

Americans With Disabilities Act of 1990, 42 U.S.C. § 12101 et seq. (1990). https://www.ada.gov/pubs/adastatute08.htm

Brown, R. I., MacAdam-Chrisp, J., Wang, M., & Iarocci, G. (2006). Family quality of life when there is a child with a developmental disability. *Journal of Policy and Practice in Intellectual Disabilities*, *3*(4), 238-245. https://doi.org/10.1111/j.1741-1130.2006.00085.x

Education for All Handicapped Children Act of 1975, 20 U.S.C. 1411 § 1400 et seq. (1975). https://www.govinfo.gov/content/pkg/STATUTE-89/pdf/STATUTE-89-Pg773.pdf

Fisher, K. M., Green, M. J., Orkin, F. K., & Chinchilli, V. M. (2009). A content analysis from a US statewide survey of memorable healthcare decisions for individuals with intellectual disability. *Journal of Intellectual & Developmental Disability*, *34*(3), 258–265. https://doi.org/10.1080/13668250903083332.

Gardiner, E., & Iarocci, G. (2012). Unhappy (and happy) in their own way: A developmental psychopathology perspective on quality of life for families living with developmental disability with and without autism. *Research in Developmental Disabilities*, *33*, 2177-2192. http://dx.doi.org/10.1016/j.ridd.2012.06.014

Hsaio, Y. J. (2018). Autism spectrum disorders: Family demographics, parental stress, and family quality of life. *Journal of Policy and Practice in Intellectual Disabilities*, *15*(1), 71-79. https://doi.org/10.1111/jppi.12232

Individuals with Disabilities Education Act of 1997, 20 U.S.C. § 1400 et seq. (1997). https://www2.ed.gov/policy/speced/leg/idea/idea.pdf

Individuals with Disabilities Education Improvement Act of 2004, 20 U.S.C. § 1400 et seq. (2004). https://www.govinfo.gov/content/pkg/STATUTE-118/pdf/STATUTE-118-Pg2647.pdf

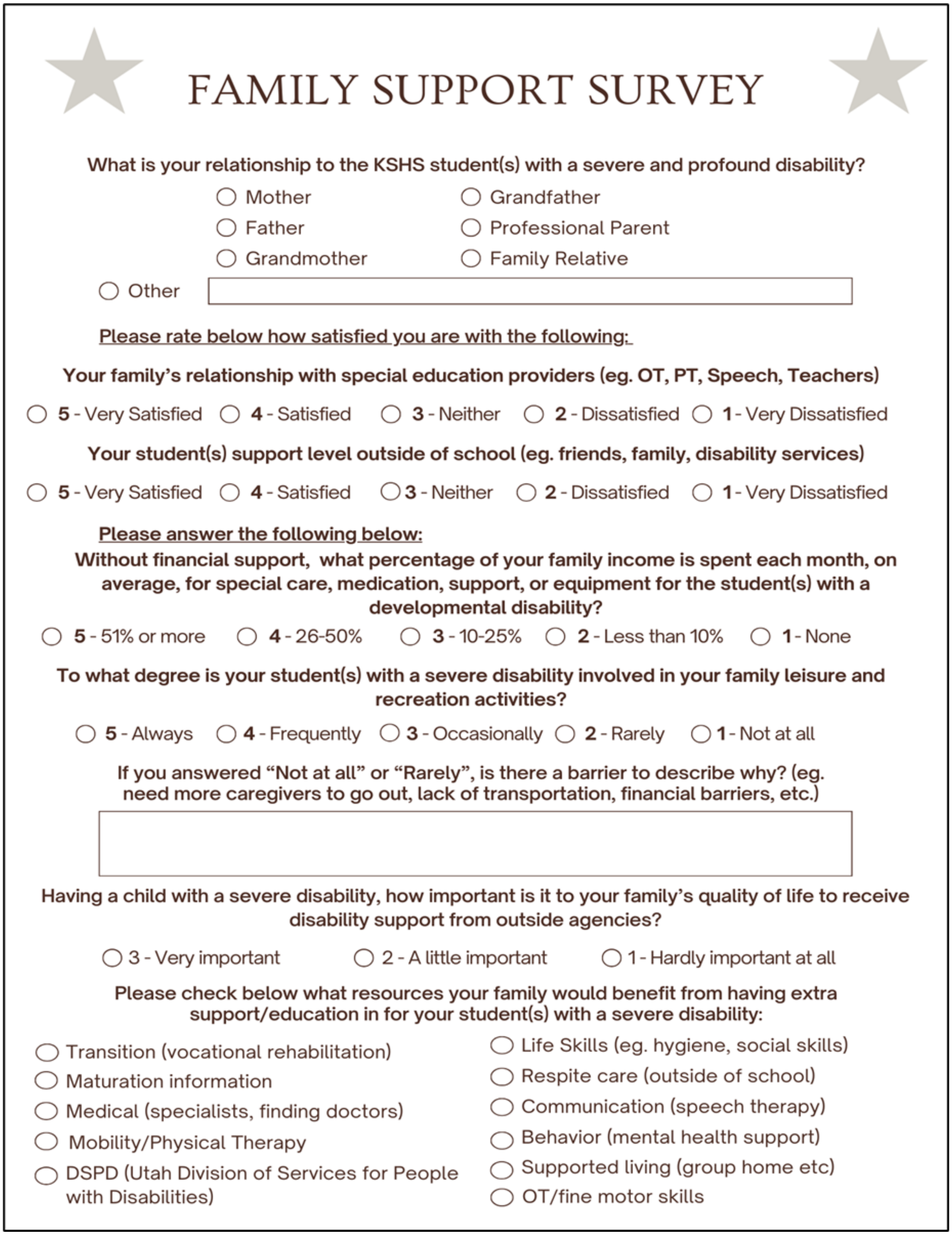
Lipscomb, S., Haimson, J., Liu, A. Y., Burghardt, J., Johnson, D. R., & Thurlow, M. L. (2017a). *Preparing for life after high school: The characteristics and experiences of youth in special education. Findings from the National Longitudinal Transition Study 2012. Volume 1: Comparisons with other youth: Full report* (NCEE 2017-4016). U.S. Department of Education, Institute of Education Sciences, National Center for Education Evaluation and Regional Assistance. https://ies.ed.gov/ncee/projects/evaluation/Disabilities_nlts2012.asp.

Rehabilitation Act Amendments of 1992, 20 USC 701 et seq. (1992). https://www.govinfo.gov/content/pkg/STATUTE-106/pdf/STATUTE-106-Pg4344.pdf

Samuel, P. S., Hobden, K. L., Leroy, B. W., & Lacey, K. K. (2012). Analysing family service needs of typically underserved families in the USA. *Journal of Intellectual Disability Research*, *Volume 56*(1). https://doi.org/10.1111/j.1365-2788.2011.01481.x

Wang, M., & Brown, R. (2009). Family Quality of Life: A framework for policy and social service provisions to support families of children with disabilities. *Journal of Family Social Work*, *12*(2), 144–167. https://doi.org/10.1080/10522150902874842.

Appendix A: Assessment



FAMILY SUPPORT SURVEY

What is your relationship to the KSHS student(s) with a severe and profound disability?

○ Mother ○ Grandfather
○ Father ○ Professional Parent
○ Grandmother ○ Family Relative
○ Other ☐

Please rate below how satisfied you are with the following:

Your family's relationship with special education providers (eg. OT, PT, Speech, Teachers)

○ **5** - Very Satisfied ○ **4** - Satisfied ○ **3** - Neither ○ **2** - Dissatisfied ○ **1** - Very Dissatisfied

Your student(s) support level outside of school (eg. friends, family, disability services)

○ **5** - Very Satisfied ○ **4** - Satisfied ○ **3** - Neither ○ **2** - Dissatisfied ○ **1** - Very Dissatisfied

Please answer the following below:

Without financial support, what percentage of your family income is spent each month, on average, for special care, medication, support, or equipment for the student(s) with a developmental disability?

○ **5** - 51% or more ○ **4** - 26-50% ○ **3** - 10-25% ○ **2** - Less than 10% ○ **1** - None

To what degree is your student(s) with a severe disability involved in your family leisure and recreation activities?

○ **5** - Always ○ **4** - Frequently ○ **3** - Occasionally ○ **2** - Rarely ○ **1** - Not at all

If you answered "Not at all" or "Rarely", is there a barrier to describe why? (eg. need more caregivers to go out, lack of transportation, financial barriers, etc.)

☐

Having a child with a severe disability, how important is it to your family's quality of life to receive disability support from outside agencies?

○ 3 - Very important ○ 2 - A little important ○ 1 - Hardly important at all

Please check below what resources your family would benefit from having extra support/education in for your student(s) with a severe disability:

○ Transition (vocational rehabilitation)
○ Maturation information
○ Medical (specialists, finding doctors)
○ Mobility/Physical Therapy
○ DSPD (Utah Division of Services for People with Disabilities)

○ Life Skills (eg. hygiene, social skills)
○ Respite care (outside of school)
○ Communication (speech therapy)
○ Behavior (mental health support)
○ Supported living (group home etc)
○ OT/fine motor skills

Appendix B: Survey Attachment

Dear Parents/Caregivers,

The Research Review Committee for [School District] has reviewed a research project in which the [School] has been asked to participate.

Project Title: Quality of Life Domains for Students Living with a Severe Disability and Their Families

Enclosed is a short, anonymous survey to gather information to improve support for students with disabilities and their families. Your feedback will give insight and helpful information to give to those who can help direct resources and services to you to enhance the quality of life for your student(s).

While we value your feedback, participation is optional. The survey aims to enhance our understanding of our students' quality of life and how we can better serve our families.

Please return the survey in your students backpack with the provided envelope by Friday, March 15, 2024.

Thank you for your time and support.

Appendix C: Schoolwide Email

Dear Parents/Caregivers,

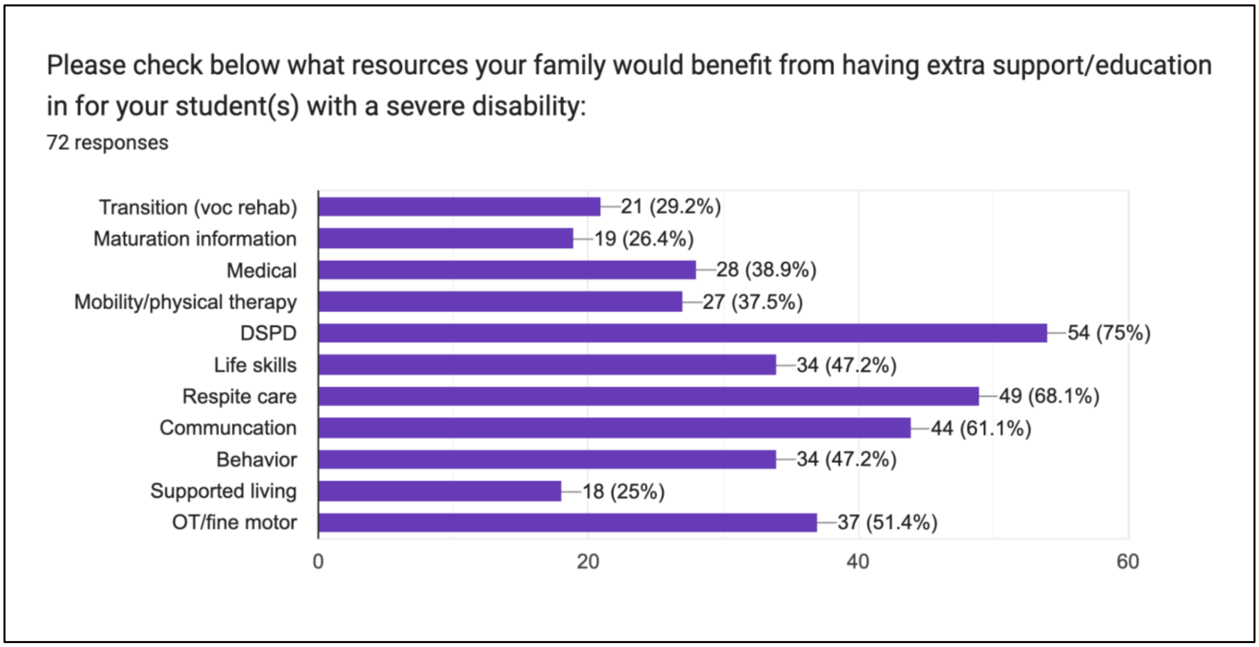
Your student is bringing home an envelope in their backpack today, enclosed is a short survey our school has been asked to participate in. A graduate student from Utah State University is collecting this information to improve support for students with disabilities and their families. Participation is optional. If you want to participate in the survey, please fill it out and return it in your students' backpack by Friday, March 15th.

Appendix D: Written Responses to Recreational and Leisurely Activity Barriers

	Survey Question: To what degree is your student(s) with a severe disability involved in your family leisure and recreation activities? **If answered "Not at all" or "Rarely" is there a barrier to describe why? (e.g. Not enough caregivers, transportation, financial barriers, etc.)*
Respondent 1	"Very short attention span, unable to sit, anxiety in social and public situations."
Respondent 2	"Doesn't like to socialize, especially when small children are present. Can't tolerate commotion and loud noises. Is physically unable to participate."
Respondent 3	"The family intentionally plans and caters leisure and recreation activities to accommodate our disabled student. There are many activities we don't do."
Respondent 4	"Doesn't do well in heat or cold and can only tolerate short excursions. We don't feel safe leaving him with alternate caregivers for long so we don't go either."
Respondent 5	"The family intentionally plans and caters leisure and recreation activities to accommodate our disabled student. There are many activities we don't do."
Respondent 6	"Financial barriers, lack of equipment, stroller, carry backpack etc."
Respondent 7	"Requires full attention 1:1"
Respondent 8	"Our student is too hard to contain/control while outside the home."
Respondent 9	"We only do things she can do and we aren't a very outdoorsy family"
Respondent 10	"Mostly due to her not liking noises."
Respondent 11	"Lack of transportation, respiratory therapist, legal issues."

Respondent 12	“Need more caregiver and financial support”
Respondent 13	“The student is always included with immediate family, but extended family and grandparents rarely. To them, our child is considered ‘too difficult’ and puts too many restrictions on ‘fun’. It breaks our heart because they are missing out on a great kid.”

Appendix E: Survey Responses for Resource Needs



Please check below what resources your family would benefit from having extra support/education in for your student(s) with a severe disability:

72 responses

Appendix F: Resource Manual

Resource Support Manual

2024

Welcome Message

Dear Parents and Caregivers,

At our school, we want to ensure we provide your child an equitable educational experience, and we also hope to serve as a bridge to the often-overwhelming world of navigating disability support and resources that are available to your child. This manual aims to increase awareness and opportunities to access resources that will cater to the unique needs of your child and will hopefully, in turn, increase the overall quality of life for your child and their support system.

Thank you,
The School Team

RESOURCES

If your child is **already** a recipient of funding through DSPD, please get in touch with your support coordinator before looking into the resource sections categorized by this star symbol. ★

DSPD (Division of Services for People with Disabilities)

DSPD is Utah’s branch of formal government funding for services related to your child’s disability. You must apply to enroll in these resources. To qualify for the funding, your child must be a citizen of the United States. We encourage you to apply right away.

DSPD APPLICATION

On this website, you can access information and apply for funding. The services you may receive include respite care, behavior support, day services, supported living, and support coordination. For assistance in applying, please contact a member from our school administration.

DSPD NEEDS ASSESSMENT

If you are on the waiting list, please note that we encourage you to call and check your spot frequently and inform DSPD of your situation and the nature of your child’s disability by highlighting your critical needs in this linked assessment.

FUNDING FOR UNDOCUMENTED FAMILIES

Information to get government funding for your child, such as Medicaid and SNAP benefits. This resource is for families who have immigrated here without official citizenship status.

Respite Care

Respite care is emergency or planned temporary relief for caregivers and their duties in relation to the individual they are caring for. In this case, respite would be given to watch your child. It can take place in or outside your home.

As a school, we offer out information to employees looking for respite hours for extra work. If interested, please contact [School Phone number] and let us know a general idea of the hours you need filled. Then, we can pass you and your child‘s information along to our staff.

OPPO

Person-centered home care and support services offering respite.

BEAR-O CARE

Nonprofit organization providing day-to-day/respite care for individuals with multiple disabilities, including those who need intensive nursing supervision for support, such as G tubes.

UTAH PARENT CENTER

This link specifically highlights ideas on how to procure sufficient and trustworthy respite care for your child.

TURN SERVICES

Disability support services: This specific link takes you to their contact page to identify the need for family support/respite care.

KIDS ON THE MOVE

Weekday and weekend programs providing temporary care in their facility to children with disabilities.

Communication

This section offers purposefully selected communication-based resources for your child and their abilities whether speaking or non speaking. For extra guidance catered to your child's particular needs, please reach out to your child's speech language pathologist.

THE UTAH CENTER FOR AAC EXCELLENCE

Various resources for every stage of augmentative and alternative communication (AAC) use to help you navigate AAC with your child.

MEANINGFUL SPEECH BLOG

If your child has autism or engages in echolalia (repetitive or echoed speech/sounds), they most likely are a gestalt language processor. This link provides interventions and education for families encouraging communication.

TOBII DYNAVOX

Assistive technology and devices for communication and speech generation through eye gaze and other methods.

PRC

AAC and speech devices can be funded through Medicaid or insurance methods.

AAC FOR BILINGUAL FAMILIES (SPANISH)

What AAC is and how to get started for those who are Spanish speaking.

COUGH DROP

Adaptive user friendly Augmentative and Alternative Communication (AAC) software that can be accessed on any device, such as cellphones and tablets.

SCHOOLWIDE 66 CORE BOARD

The low tech printable core board the speech language pathologists at our school use and introduce to students.

Occupational Therapy - Fine Motor

Occupational therapy (OT) happens at our school through progressive fine motor tasks, adaptive life skills training, and addressing/meeting childs sensory-based needs. The focus is to increase independence and enhance quality of life. These resources vary across their utilization but focus on OT products you can implement at home, as well as some site-based services to enroll in and attend.

FUN AND FUNCTION

Many disability-friendly products for sensory-seeking behaviors and stimming, such as weighted vests, fidgets, manipulatives and more.

U OF U LIFE SKILLS CLINIC

Occupational interventions for your child and their ability level. There are clinics taking place annually during the summer months.

ADAPTIVE SPORTS FLYER

New local sports arena focused on adaptive sports and players with disabilities.

OT JUST FOR KIDS

Pediatric occupational therapists encouraging growth through play-based interventions. Child must be under 18.

E SPECIAL NEEDS ADAPTIVE UTENSILS

Specialized utensils to help those with disabilities dine more independently.