Editorial

Welcome to the Conference Proceedings of the 39th Annual Pacific Rim International Conference on Disability & Diversity 2024

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Abstract

This is a welcome message for the Conference Proceedings of the 39th Annual Pacific Rim International Conference on Disability & Diversity 2024 organized by the Center on Disability Studies, College of Education, University of Hawai'i at Mānoa.

Keywords: Pacific Rim, disability, conference

Welcome to the Conference Proceedings of the 39th Annual Pacific Rim International Conference on Disability & Diversity 2024

We are pleased to share the Conference Proceedings for the 39th Annual Pacific Rim International Conference on Disability and Diversity 2024. This collection documents some of the diversity of work presented at the conference in Spring 2024. Since 1988, the Pacific Rim Conference has served as an important international forum celebrating efforts by those with disabilities and their allies to create more inclusive spaces. In the decades since the conference's inception, it has emerged as the premier global gathering on disability. The conference draws people with disabilities, educators, researchers, practitioners, entrepreneurs, policymakers, advocates, and others from across the globe to come together and consider ways we may help make our communities more inclusive and equitable places.

As such, this collection represents some of the many diverse voices present at the Pacific Rim Conference 2024. Drawn together by the conference's theme, *Beyond Access: Building a Culture of Belonging*, participants were invited to consider the ways in which we can help create a culture of belonging, where each of us can fully contribute to the communities we are part of while receiving the support and accommodations we need to flourish.

Presentations and events at the conference were organized within seven broad strands:

1. Public Health & Healthcare—Health and Healthcare Inequities; Flexible Public Health and Healthcare; Community-Designed Practices; and Culturally-Grounded Practices.
2. Inclusive Physical Activity, Recreation, and Sport—Accessible and Inclusive Physical Activities; Recreational Activities; Sports; Physical Activity Across the Lifespan
3. Neurodiversity—Neurodivergent Identities and Perspectives; Neurodiversity and Education; Neurodiversity and Culture; Self-Advocacy and Empowerment; Intersectionality
4. Built Environments: Digital, Physical, and Social—Digital Environments; Physical Infrastructure; Social Inclusion; Climate Resilience and Disasters; Digital Accessibility; and Transportation.
5. Employment—Employment First; Culture of Belonging through Equity, Diversity, and Inclusion; Disability Benefits; Transitioning from High School to Post-Secondary Education to the Workforce; Technology for Inclusive Workforce
6. Inclusive Practices in Education

   Strand Topic: Instructional Design & Technology—Accessibility; Assistive Technology; Universal Design for Learning; Collaboration and Communication; Professional Development

Strand Topic: Higher Education—Diversity, Equity, and Inclusion; Belonging and Social Justice; Higher Education Research in Public Policy

7. Low Incidence Disabilities/Extensive Support Needs—Advocacy; Communication Access; Curriculum Access; Vocation; Language and Culture; Independent Living; Legal Rights and Issues; Inclusion and Intersectionality; Family Support

Within these strands, the contributions reflect a broad, cross-section of work in the field. In "Navigating Uncertainty: The Family Perspective of Preparing for Crisis with a Disability," Stjernholm discusses the importance of including individuals with disabilities in family disaster planning. Based on interviews, the study explores gaps in information and support, emphasizing the need for proactive and inclusive planning to enhance resilience. Schmid, Heil, Yoshida, Ching, Kalua, and Sentell outline a study to evaluate the physical activity benefits and metabolic equivalents of outrigger canoe paddling, a culturally relevant means for promoting physical activity for those with and without spinal cord injuries. Park, Nip, and Feliciano discuss the Hōkūlani program that helps Native Hawaiian high school students explore careers in science, technology, engineering, and math (STEM) through a culturally supportive, strengths-based approach. Kashihara, Hasegawa, Takahashi, Ogura, Haraguchi, and Sasaki explore how chatbots and professionals can provide helpful information for neurodiverse people through text-based chats. They analyzed data from a chatbot developed in Japan to clarify the roles of the chatbot and professionals in improving support for those facing daily challenges.

For all contributions to this volume, plain language versions of abstracts may be accessed at: https://rdsjournal.org/index.php/journal/2024CP proceedings.

We wish to thank all the attendees and presenters attending the event. The Center on Disability Studies at the University of Hawaiʻi at Mānoa is honored to host this important yearly event for our global community. At the time of writing, we are eagerly anticipating the 40th Pacific Rim Conference taking place at the Hawaiʻi Convention Center to be held in person in Honolulu, Hawaiʻi, April 15 to April 16, 2025. The conference theme is *By Us and For Us: Legacy and Future of Our Movement*, and it invites us to think about how we may collectively both honor the past and consider the future of the movement we create together. We hope to see many of you there and thank you for all your continued efforts toward these shared goals.

Research Articles and Essays

Neuroscience for Neurodiverse Learners:

Lessons Learned about Engaging All Students

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Abstract

The *Neuroscience for Neurodiverse Learners* program provides hands-on experiences and resources to high school and early postsecondary students identified as neurodivergent learners. This article shares lessons learned that can benefit educators seeking to engage neurodivergent learners in the classroom and includes summary results from the NNL summer program.

Keywords: neurodivergent, disability, STEM

Neuroscience for Neurodiverse Learners:

Lessons Learned about Engaging All Students

The University of Washington (UW) received funding from the National Science Foundation (NSF) Innovative Technology Experiences for Students and Teachers (ITEST) program for a project called *Neuroscience for Neurodiverse Learners (NNL). NNL* provides hands-on experiences in the field of neuroscience, networking opportunities, and resources to high school and early postsecondary students identified as "neurodivergent" learners—those with academic challenges related to conditions such as dyspraxia, dyslexia, attention deficit hyperactivity disorder, dyscalculia, autism spectrum disorder, and Tourette syndrome. The project also disseminates findings to teachers of neuroscience and related courses, and, more broadly, to science, technology, engineering, and mathematics (STEM) teachers.

The project is led through a collaborative effort between the UW Disabilities, Opportunities, Internetworking, and Technology (DO-IT) Center and the UW Center for Neurotechnology (CNT). DO-IT has a 30-year history of helping empower students with disabilities to pursue challenging academics and careers. The CNT is one of several Engineering Research Centers across the country, originally funded by the National Science

Foundation. This article shares lessons learned through the continuing DO-IT and CNT partnership, building on previous work (Bellman, et al., 2018).

Grounded in theory and research, the *NNL* project takes a student-centered approach that embraces cutting-edge neuroscience, the social model of disability, social justice education, disability as a diversity issue, universal design, and a multi-faceted view of student engagement and retention. The project seeks to achieve the following two goals:

1. College-capable neurodivergent students, through engagement in neuroscience experiences, will gain knowledge about and interest in challenging STEM fields. They will practice communication skills (e.g., for scientific presentations, communication with faculty about disability-related accommodations, and job interviews) that will prepare them for college and careers.
2. Educators and other stakeholders will develop or enhance strategies for teaching neurodivergent learners (e.g., universal design, academic accommodations) and engage in activities designed to encourage neurodivergent learners to participate in STEM fields.

Project strategies include hands-on and technology-rich activities, team-building, problem-solving, communities of engagement, and mentoring activities for neurodivergent students; professional development for educators; and resources for multiple stakeholders. *NNL* applies lessons learned in earlier DO-IT efforts to develop and implement engaging, intrinsically motivating, potentially transformative content that will increase the knowledge and skills of neurodivergent students and ultimately build capacity within formal and informal academic settings to motivate these students to pursue neuroscience and, more broadly, STEM fields. This article focuses on lessons learned from working with neurodivergent students and shares preliminary evaluation outcomes regarding students. These data were presented previously at the 2024 Pacific Rim International Conference on Disability and Diversity.

Frameworks

Traditional efforts to assist individuals with disabilities embrace a “medical model” of disability that focus on the “deficit” of the individual and how the person can be rehabilitated or accommodated so that he or she can fit into an established environment (Loewen & Pollard, 2010; Moriarty, 2007). In contrast, the “social model” of disability and other integrated approaches within the field of disability studies (DePoy & Gibson, 2008a, b; Gabel & Peters, 2010), consider variations in abilities—like those with respect to gender, race, and ethnicity—to be a natural part of the human experience and suggest that products and environments should be designed in ways that make them welcoming and accessible to everyone. The *NNL* project creates, tests, and disseminates activities and products that are aligned with the social justice model of disability, social justice education, disability as a diversity issue, the characteristics and needs of neurodivergent learners, and universal design. Universal design (UD)—defined as “the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design”—is an approach that is consistent with the social justice model of disability and has the potential to reduce the need for individual accommodations (Center for Universal Design, 1997; Burgstahler, 2011, 2015). UD challenges society to construct a world where everyone can participate with maximum independence (Loewen & Pollard, 2010). Social justice education is an educational philosophy committed to equity and social change, with its goals clustering around social responsibility, student empowerment, and equitable distribution of resources (Loewen & Pollard, 2010).

Identified Needs

To fill increasing numbers of positions in STEM fields and develop a more robust STEM workforce (CEOSE, 2011; Hecher, 2005; Office of Science and Technology Policy, 2006), the US must draw from a talent pool that includes all demographic groups, including those with disabilities(AAAS, 2001; Congressional Commission…, 2000). Although increasing numbers of individuals with disabilities are attending college, at times they experience less academic and career success than other students (National Council…, 2000; NSF, 2023b; Office of Disability Employment Policy, 2001).

High-tech careers are possible for individuals with disabilities, including neurodivergent learners, due in part to advancements in assistive technologies that provide access to information technology (IT). The success stories of the relatively few individuals with disabilities who are in STEM fields demonstrate the potential that these individuals have to contribute significantly to STEM disciplines (Bellman & Burgstahler, 2016; Dreyfus, 2009; Helft, 2009; Misner, et al., 1995). Diversity in STEM fields is beneficial not only to specific underrepresented groups, but to the fields themselves. Teams of professionals composed of individuals with diverse skills, experiences, and perspectives are better able to identify multiple ways to solve problems (Beck & Andres, 2005; Hazzan & Dubinsky, 2006; Taylor & Ladner, 2011), thus promoting NSF’s mandate to support “the best ideas from the most capable researchers and educators, now and in the future” (Congressional

Commission…, 2000). Efforts should be made to increase participation in STEM by citizens with disabilities since, according to NSF, underrepresentation causes a loss of opportunity for individuals, a loss of talent to the workforce, and a loss of diverse perspectives and creativity that are needed to shape the future of technology (NSF, 2023a). Technology companies have recognized the capacity of neurodivergent individuals, especially those with autism spectrum disorder, to contribute to their mission, yet report difficulties in recruiting work-ready job applicants with neurodiversity (Ladner, 2016). Many companies, including Microsoft (n.d.), SAP (n.d.), SAS (n.d.), DXC Technology (n.d.), have undertaken programs to recruit neurodivergent employees.

Additionally, there is a need for science curriculum that is exciting for a diverse audience. Some students do not pursue STEM disciplines because they have not been encouraged to do so, they are not motivated by the content, they are unaware of the broad range of careers in STEM fields, they lack role models and mentors in these fields, or they expect careers in these areas to be boring and/or unrewarding (Gupta & Houtz, 2000; Jacobs & Simpkins, 2006; Kerry, 2013; Kiernan, 2000; Thomas, 2004; Yardi & Bruckman, 2007). For example, a significant disconnect has been observed between the perceptions of precollege students (who perceive computing careers as "boring, solitary, and lacking real-world context") and those of graduate students in computing (who consider their research "exciting, social, and having a direct and meaningful impact on the world around them;" Yardi & Bruckman, 2007), Students who experience intrinsic motivation in academic areas tend to be more interested in pursuing them (Amabile, 2002). To draw women into STEM fields, it has been recommended that they be shown how work in these fields improves the lives of others (Cohoon, 2007). Leaders in the DO-IT Center have made observations that suggest this is true of neurodivergent students as well.

Researchers at the CNT are leaders in fields of neural engineering, computational analysis, brain-computer interfaces, implantable technology, wireless power, and other exciting innovations that have the potential to improve the lives of individuals who have been injured through accidents, stroke, or disease. Experiences engaging with educators and students have led the *NNL* leadership team to believe that projects, activities, and opportunities that include exposure to these exciting research areas are highly motivating for students, including those with disabilities.

Methods: Key Interventions for Students

During the NNL program, student participants engage in a multi-day Neuroscience Summer Study program. In 2020 and 2021, activities were conducted online due to the COVID-19 pandemic. In 2022 and 2023, activities took place both online and on the UW campus. Activities included hands-on, inquiry-based activities and cooperative learning. Students participated in neuroscience activities as well as activities designed to practice skill building related to challenges faced by neurodivergent students. More advanced neurodivergent college students acted as mentors, providing support and encouragement to younger students as they progress in academics and toward careers.

Throughout the year, neurodivergent students participated in online and on-campus sessions designed to further promote STEM interest and college readiness. Sessions provided opportunities to practice skills and share strategies for managing challenges. They participated in electronic mentoring, where they learned about neuroscience, informal science learning opportunities, college preparation, and related topics.

All students were offered 1-to-1 mentoring opportunities designed to help them address challenges related to attention, organization, time management, listening skills, and sensory perception. Many sessions included the involvement of a neurodivergent peer-mentor.

Lessons Learned About Engaging Neurodivergent Students

Through conversations with students, observations during *NNL* activities, and engagement with other professionals serving neurodivergent students, project staff identified ten promising practices for engaging students [Table 1] which were presented at the 2024 Pacific Rim International Conference on Disability and Diversity. The lessons will be shared in two new publications of the DO-IT Center called *Tips for Engaging Neurodivergent Students in K-12 Classrooms* and *Tips for Engaging Neurodivergent Students on Postsecondary Campuses* (in press-a, -b) The practices fall broadly within three categories: preparing students, student engagement, and flexibility.

Table 1

Lessons Learned about Engaging Neurodivergent Students

	Lesson Learned	**Category**
1	Share “what we’re doing and why it’s important”	Student Engagement
2	Find ways to incorporate humor	Student Engagement

3	Be genuine and be vulnerable at times	Student Engagement
4	Build and share social narratives	Preparing Students
5	Allow for hands-on learning	Student Engagement
6	Encourage student teaching of others	Student Engagement
7	Offer options to students	Flexibility
8	Allow for student-driven content	Flexibility
9	Utilize near-peer leaders	Student Engagement
10	Be aware of assistive technology	Preparing Students
11	Focus on student strengths	Preparing Students
12	Explore coaching for executive functioning skills	Student Engagement

Share “What We’re Doing and Why It’s Important”

At the beginning of each classroom session, *NNL* instructors make efforts to share the reasons they selected the content and the method of instruction, tying the content to broader goals of the course. This practice was adopted from emerging concepts within the Transparency in Learning and Teaching (TILT) model of academic engagement. The TILT model employs a set of teaching strategies that focuses on making transparent to students how and why they are learning content in particular ways. TILT's goal is to provide more concrete support for student success, and encourages faculty to be transparent about their course and assignment design choices to provide answers to questions students might have about their coursework such as: 1) *Why am I learning this information – how will it help me achieve course goals in this course, future courses, or future careers?* 2) *What is the specific task I'm being asked to do? What steps should I follow?* 3) *How will this doing this activity help me learn or understand course content better?* 4) *What criteria will the instructor use to evaluate my work?* (Indiana University Bloomington, n.d.)

Find Ways to Incorporate Humor

While it is often said that neurodivergent students, especially those on the autism spectrum, have difficulty understanding humor, NNL staff observed that the use of humor is particularly engaging to students. Project staff have observed that nearly all neurodivergent students in the program appreciated the use of humor in the classroom, even when such experiences were challenging to them. When staff asked students for advice about using humor, three themes emerged. First, students said it is helpful for an individual to explicitly state they are joking and explain the joke after telling it. Those with longer processing times or a more concrete style of thinking said this practice helps them follow the humor and decreases confusion. Second, students said it helps to check in with them about the various humor being utilized in the classroom. The most common concern heard from students was "Sometimes I just want to know people aren't laughing at me." Third, it was observed by staff that using humor over email or other text-based platforms is more challenging as compared to in person. Over text-based platforms, jokes are more difficult to explain, checking in with students is more difficult, and contextual cues such as body language and facial expression are absent.

Be Genuine and Be Vulnerable at Times

Project staff have observed that neurodivergent students in the program appreciate it when instructors and staff share their “authentic selves” and show vulnerability. On the first day of class, for example, one instructor shared “I am over 50 years old, and it’s still a challenge for me to meet new people and make new friends. I’ve learned some strategies along the way but it’s still hard for me. If you have a hard time with these things, just know that there are others here with similar challenges.” When one student talked about outside noises making it hard for them to learn, a mentor in the program shared “Yes! Me too. There is so much distraction outside today and I’m having a hard time staying focused. I think I understand what you’re saying.”

Build and Share Social Narratives

A social narrative, also known as a social story, is a “specially written story that explains a social situation to a student. The emphasis is on describing the situation so that the student can better understanding events as well as the potential thoughts, feelings and actions of other people. Most social narratives also provide the student with information about what they can do in the situation” (Queensland Government, 2022) Project staff provide an online orientation to the campus and classroom activities, including the types of activities to be engaged in, images of buildings and spaces to be visited, anticipated sensory experiences (e.g., the odor in the brain dissection lab, things you can see and hear from the main classroom). For educators interested in more detailed examples of social narratives, the Museum, Arts, and Culture Access Consortium (MAC) maintains a collection of examples on their website (n.d.).

Allow for Hands-On Learning

NNL project staff observed that students were especially engaged during hands-on learning activities, such as the dissection of a sheep brain, the construction of a brain model "brain hat," neuroscience demonstrations with graduate students, the creation of sound-makers from everyday objects, and creating neuron models. The project employed a large number of hands-on learning activities, believing that hands-on learning is highly engaging. By using multiple styles of learning, the brain creates better connections and can store more relevant information. Brain scans also indicate increased activity in motor-related and sensory parts of the brain when thinking about concepts they learned through hands-on experience (Arnholz, 2019).

Encourage Student Teaching of Others

To enhance student learning, one student was offered an opportunity to teach one of the neuroscience classes at *NNL's* Summer Study. Through the development and teaching of a course called "The Neuroscience of Facial Recognition," the student gained confidence in their speaking skills, reinforced their own learning, and acted as a peer mentor to others. Observations from project staff included increased attention from the student group, lively questions, and excitement for the hands-on portion of the class, where students explored the campus in search of items that looked like human faces.

Offer Options to Students

Throughout the *NNL* program, students were offered different options to engage content. For example, prior to the sheep brain dissection activity, students were given the option of a small group learning session outside of the lab, to learn about brain structure on a laptop instead of dissecting a real brain. Students were offered options on where they wanted to sit in the room, how they might want to respond to questions, and how they might want to control their setting (e.g., a quiet space was close by for students who felt overstimulated and items for fidgeting were placed on tables for students).

Allow for Student-Driven Content

Throughout the *NNL* program, students were offered the opportunity to suggest topics of interest to them. Project staff intentionally left time in the course to build new content based on student suggestions. For example, students said they wanted to learn how meditation impacts the brain, and requested a session exploring how different kinds of music and experiences with music can impact the brain. The most popular class was one suggested by students: the exploration of how neuroscience is portrayed in movies, with an analysis of a movie's accuracy and plausibility.

Utilize Near-Peer Leaders

The NNL program utilizes "near-peer" mentors, defined as mentors who are slightly older than mentees. After completion of a summer study session, for example, students can apply to return as mentors. Undergraduate students who identify as neurodiverse also participate in the program to engage with high school students on college-preparation activities as panelists, provide assistance with lab work, and other skill building. Educators at all levels are encouraged to seek opportunities for near-peer mentoring with their neurodivergent students.

Be aware of Assistive Technology

Educators are encouraged to explore assistive technology (AT) commonly used by neurodivergent learners, especially in the areas of note taking, organizing ideas, reading, writing, and calendaring (Exceptional Individuals, n.d.). Project staff offered opportunities for students to learn about and try AT in the classroom. For example, three of the four students who tried using smart pens for the first time during the summer study program stated they would continue using the technology during their academic year. A smart pen, in combination with specialized notebook paper, allows the user to record a lecture and synchronize the audio recording to their written notes. Later, when the user is reviewing their written notes, they can easily locate and play back the related audio content.

Focus on Student Strengths

Project staff are encouraged to invest time with students to ask them about their academic and social strengths, and actively encourage students to build on and utilize their strengths in the classroom. *NNL* students learn about “strengths-based” models of viewing disability, which means focusing on what the person can do well, not what they cannot do because of their disability. Students are encouraged to recognize traits related to their disability that make them unique, helping them see that these traits can contribute positively to their identity. Common strengths reported by students in the program included the following:

- Does well in online learning
- Creative thinking and problem solving

- Persistence and dedication
- Empathy skills and kindness
- Strong or detailed memory
- Spatial memory and three-dimensional thinking
- Music and artistic skills
- Honest and direct communication
- Strength in mathematics

Students in the program also learned about historical models of disability such as the “medical model,” which has viewed disability as a defect within the individual. In this model, disability is viewed as an unfortunate trait that needs to be “fixed.” They are encouraged to consider how various models might impact their identity and experiences.

Explore Coaching for Executive Functioning Skills

Educators are encouraged to explore how they might support the development of executive functioning skills in their disabled students, especially neurodivergent learners (Bellman, et al., 2015). Executive functioning skills typically develop quickly in childhood and during the teen years but keep developing into the mid 20s. Trained “academic coaches” can help students build skills in the areas of paying attention; organizing, planning, and prioritizing; starting tasks and staying focused on them to completion; understanding different points of view; regulating emotions; and self-monitoring (keeping track of what you’re doing).

Results

The application process for the *NNL* program was competitive, and applicants had to meet the following criteria to be eligible for consideration:

- Identify as a neurodiverse learner (defined as those with academic challenges related to conditions such as dyspraxia, dyslexia, attention deficit hyperactivity disorder, dyscalculia, autism spectrum disorder, and Tourette syndrome).
- Have aptitude and interest in attending college.
- Currently be a high school sophomore, junior, or senior, or in their first year of college.
- Have access to a computer and internet connection to use video conferencing tools.

The COVID-19 pandemic had a significant impact on the student activities. Due to the pandemic, project staff were forced to pivot many activities that were planned to be on-site to virtual environments. As the pandemic and the resulting guidelines regarding in-person events changed every year of the project, the data collected each year cannot be compared directly. No two years were conducted in exactly the same way. Below is a brief summary of each summer program including the number of students who attended and the results from feedback collected from the participants at the end of each summer study program.

The first summer study program was originally planned to be a 10-day in-person event. Due to the pandemic, the program shifted to a virtual environment composed of a 5-day online summer program and fourteen online events during the academic year. The program included seven educational sessions about neuroscience and ten sessions related to communication, college preparation, mentoring, and leadership. Twenty-one students participated in the first summer study program experience. Ten of these students went on to engage in additional year-round activities, along with students new to the program.

At the end of the first summer study program in 2020, students were asked to choose from a list of skills they felt more confident and/or increased competency in as a result of the camp experience. The results were as follows:

- 41.18% chose Initiating or participating in conversations
- 52.94% chose Interacting with other people appropriately
- 52.94% chose Requesting modifications to the environment/class
- 70.59% chose Managing my time and my schedule
- 47.06% chose Focusing attention and listening to others
- 58.82% chose Requesting disability-related accommodations
- 52.94% chose Using technology
- 82.35% chose Talking about my challenges

Due to the continued pandemic, the second summer program was composed of a ten-day online program. Seventeen students participated, along with five returning mentors from the first summer study. The summer program included fourteen educational sessions about neuroscience and eighteen sessions related to communication, college preparation, mentoring, social skill-building, and leadership. Seven of these students went on to engage in additional year-round activities. At the end of the second summer study program students were asked to choose from a list of skills all those they felt more confident and/or increased competency in as a result of the experience. Results:

- 38.46% chose Initiating or participating in conversations
- 30.77% chose Interacting with other people appropriately

- 61.54% chose Requesting modifications to the environment/class
- 76.92% chose Managing my time and my schedule
- 61.54% chose Focusing attention and listening to others
- 69.23% chose Requesting disability-related accommodations
- 61.54% chose Using technology
- 69.23% chose Talking about my challenges

As concerns regarding the pandemic continued to persist, the third summer study program was held in a hybrid format composed of six days of online activities and four days of activities on campus. Eighteen students participated, along with three returning mentors from previous summer camps and activities. The summer program included twelve educational sessions about neuroscience and twelve sessions related to communication, college preparation, mentoring, social skill-building, and leadership. Fifteen of these students went on to engage in additional year-round activities. At the end of the third summer study program students were asked to choose from a list of skills all those they felt more confident and/or increased competency in as a result of the camp experience. Results:

- 53.8% chose Initiating or participating in conversations
- 46.2% chose Interacting with other people appropriately
- 69.2% chose Requesting modifications to the environment/class
- 61.5% chose Managing my time and my schedule
- 46.2% chose Focusing attention and listening to others
- 38.5% chose Requesting disability-related accommodations
- 69.2% chose Using technology

- 53.8% chose Talking about my challenges

The fourth summer study program was composed of five days of online activities and five days of on-campus activities. Twenty-six students participated in this summer study program along with one returning mentor from previous summer camps and activities. The summer program included eleven educational sessions about neuroscience and seven sessions related to communication, college preparation, mentoring, social skill-building, and leadership. Thirteen summer study program students engaged in additional year-round activities. At the end of the fourth summer study program students were asked to choose from a list of skills all those they felt more confident and/or increased competency in as a result of the camp experience. Results:

- 66.7% chose Initiating or participating in conversations
- 66.7% chose Interacting with other people appropriately
- 75% chose Requesting modifications to the environment/class
- 50% chose Managing my time and my schedule
- 41.7% chose Focusing attention and listening to others
- 66.7% chose Requesting disability-related accommodations
- 50% chose Using technology
- 41.7% chose Talking about my challenges

Discussion

Educators seeking to effectively engage neurodivergent students can benefit from the lessons learned during the *NNL* project implementation. Most of the lessons came about as the result of direct conversations and interactions with students, helping ensure that their voices are centered in the larger conversation about serving neurodivergent students. The data shared in this article are limited to a sample that project staff have been collecting. With the small sample size for each cohort, it was decided that evaluators would need several full years of data prior to engaging in a larger complex analysis. Over the next year, the project will analyze these data as well as data collected from student interviews and the repeated surveys that focus on interest in neuroscience and STEM education and career, participation in *NNL* activities, growth in skills to manage challenges typical of neurodiverse individuals, and confidence in ability to succeed in a STEM career to explore the relationships between independent variables, outcome variables, and mediating variables.

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Research Articles and Essays

Navigating Uncertainty: The Family Perspective of Preparing for Crisis with a Disability

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Abstract

Family disaster planning and preparation demands proactive acknowledgment and accommodation of individuals with disabilities. This study, based on interviews with families including members with disabilities, uncovers insights on information gaps, adaptive strategies, technology use, and support networks. Contributing to disaster and disability studies, resilience, and crisis planning, it highlights the effect of crises on family dynamics and the crucial role of early engagement of individuals with disabilities in disaster planning

Keywords: crisis preparation, disasters, disability-inclusive disaster risk reduction

Navigating Uncertainty: The Family Perspective of Preparing for Crisis with a Disability

The pandemic years and the war in Ukraine have left many of us with an increased awareness of the fragility of personal safety and national security. Even with the advancement of science and technology, there are things that can endanger most of us. For people with disabilities, this became acutely apparent when access to care, vaccinations, and in some cases, shelters were not equally accessible for all. For people living at home, in a family situation, a preparation plan could very well be missing (Barton-Hulsey et al., 2024).

Deinstitutionalization and community living mean that many people with disabilities live at home, with families or in single households. Some have personal assistance, and some have none. Some have family carers, and some have other arrangements (Orru et al., 2023). In the event of an emergency or disaster, a relatively independent person can become more at risk by the impact of unfamiliar hazards or difficulties. Activities that could be easily navigated in everyday life may suddenly present an obstacle impossible to mitigate.

Lindsay and Hsu (2023) describe how families with technology-dependent children confront distinct hurdles in disaster preparedness. They rely on different kinds of technology, such as medical devices or tools, to manage their health and daily lives. However, sustaining continuity of care and safety during crises can be very difficult for these families (Hamann et al., 2016). According to Lindsay and Hsu (2023), many families with technology-dependent children are unprepared for emergencies and have significant unmet preparedness needs. Certain people need hospitalization because of disaster-related power outages that impact the supporting technology they need to survive, emphasizing their vulnerability during times of emergency. Other findings revealed that nearly half of the families queried had taken their child to the hospital because of previous power outages or planned to do so if power outages lasted for an extended period.

In times of crisis, relying on household members for assistance becomes even more important, particularly for people with disabilities. A study by Chang et al. (2023), highlights how a majority of respondents expect to seek support from their household members during emergencies. The disproportionate impact of disasters on people with disabilities reveals a social aspect of vulnerability where gaps in disaster risk reduction creates vulnerabilities for certain populations (Alexander et al., 2012 and Chadwick et al., 2022). To mitigate this, this study aims to find methods of capturing the lived experiences of people with disabilities in their home environment and identify areas of interest in collaboration with the families. With the pandemic as a backdrop and heightened awareness of preparedness issues, interviews with families with one or more disabled members can help improve knowledge about how different emergencies may impact the safety of such families. This study is part of a larger research project which investigates the use of structured ways to integrate people with disabilities into disaster risk reduction (DRR) activities. It uses interviews to investigate techniques for inclusive crisis preparation. The goal is to capture questions and problem areas, with individuals with disabilities and their families serving as active resources from the outset.

Methods

The current study used qualitative analysis to delve into the viewpoints on crisis planning and preparation within households where one or more members have a disability. It has an ethics approval and uses informed consent in all interviews.

Four semi-structured interviews were conducted with individuals with a disability in a family or those in a family-setting with experience of disability. This approach was chosen for its versatility in obtaining rich, nuanced observations. Participants were recruited from informal and professional networks within the disability community. Two male and two female respondents between the ages of 30 and 65 participated, all from different families. This study used in-depth interviews that lasted 45–60 minutes and were conducted online via Zoom. The participants were asked a variety of questions about disaster planning and how their families prepare and think about emergencies. An interview guide was used, and the sessions were recorded and transcribed using the software Whisperer. Braun and Clarke's (2013, 2021) six-phase process of reflexive thematic analysis was used: the transcribed material was analyzed by coding and interpreting patterns of meaning. Themes around these patterns were developed and used as a framework. The resulting themes were Awareness, Accessibility, Information, Technology and Strengths.

Results

Five broad themes were developed from the analysis. The findings include awareness of the need for crisis planning, information shortages, adaptive methods, technology utilization, and informal support networks for people with disabilities and their families in crisis preparation.

Awareness

The participants demonstrated an awareness of the importance of planning for crisis or emergency, especially considering the recent global events such as the pandemic and large-scale conflicts. This theme highlights how families were proactive in recognizing the need to prepare for potential disasters, but also encountered the difficulties in planning:

> So, we got our son almost eight years ago. Everything turned upside down then, and I stopped even thinking along these lines of crisis preparedness. The crisis was just to make life work. He has some disabilities and other things.

Participants further demonstrated an awareness of the importance of crisis preparedness, having discussed it within the family unit: "There is a barbecue area in the yard. There are probably people who have charcoal somewhere. The first meals can probably be heated in some way." Other potential strategies were considered: “I started looking a bit, because I'm out for a walk with my daughter. So, I started in the nearby area. Looking around—where are the places that might have electricity? IKEA uses solar panels" or "I have a small safe with about a thousand kronas in it. It's my reserve in case there's something. It's not much, a thousand kronas. But in such a situation, cash is king.”

There was a notable absence of specific plans. This suggests a gap between theoretical acknowledgment of preparedness and practical implementation. However, it is noteworthy that some participants exhibited proactive behaviors, such as mental strategizing around essential resources like food and shelter: “Yes, that's something we have considered to some extent. Firstly, we have thought about where our nearest shelter is located. And how do we find our way there?" They also contemplated the acquisition of necessary supplies, such as water containers and battery-powered radios. One participant stated:

> We've always tried to be a bit prepared at home. We always buy the next size up in winter clothes or shoes for the kids. There are always things at home. We have an extra supply of water at home; it was something I thought was important when I built that house. We've always had food prepared. When you say you're going to manage for a week, we've had that for several years, and we've probably never really thought about it. We just have it."

Additionally, participants demonstrated an understanding of the potential challenges in accessing assistance during emergencies, highlighting the need for self-reliance and tailored municipal support.

Accessibility

The study reveals significant challenges in accessibility for individuals with disabilities during crises. The family members expressed uncertainty regarding wheelchair accessibility to shelters, highlighting a potential barrier to seeking refuge as in this participants case:

> I have found out that there are shelters and that they are quite close from here. However, I don't know if there is a chance to get down there with a heavy and clumsy wheelchair. There are usually stairs and all.

Additionally, evacuation is seen as complicated by a lack of suitable transportation, emphasizing the need for tailored evacuation plans and accessible transportation options for vulnerable populations, especially for the families with children who have multiple disabilities. One family expressed worries about heavy and necessary equipment:

> But then one would think that evacuation might be necessary. Like if they come with buses, then you would probably have to help carry him onto the bus. But how do you bring his equipment? He needs to have a wheelchair. Maybe you can bring some things in a backpack. You may not be able to bring everything with you.

One person expressed difficulty as a blind person in navigating new places in an emergency: “There must actually be someone on site; there must be staff who can give us information. What's happening? Where should we go? And show us, physically guide us there. Offer an arm so that we find the right place.” The need for practice finding shelter beforehand also was mentioned:

> One can't really go around the entire shelter or potential evacuation apartments beforehand and check. It's on-site. Someone needs to take the time on-site to describe what it looks like and perhaps show us around a bit. That's probably it.

Information

When the participants were asked about preparations already taken, all commented on the need for more information and the barriers to accessing information on their situation:

> I don't know who to contact to go to the shelter and check. That can, of course, be found out. But we haven't received any information about this either; I have found out by myself. One has to go in and look at the shelter map and such.

Another said: "I would like clear information about shelters. I would like there to be an emergency function regarding medication. That there was an emergency stockpile." Two of the participants had been in contact with the local municipality to find out more and a majority indicated that they had planned with extended family to help in an emergency: "When it comes to crisis and planning specifically, I feel that the crisis information available is very general and targets a very broad audience. For such special groups that we belong to because of (name), we have no clue." Several participants mentioned online networks and communities disseminating information that could be useful in a disaster: "I have a Facebook group with other parents. From there, I get almost all useful information, I would say. It's usually the beginning of something, turning to other parents, because so very few have the same problem." And another observed: "We are entirely dependent on each other in these groups, I would say. There are some parents who have almost dedicated their lives to helping others." One parent shared positive experiences with the municipality’s information service:

> So, she needs to have it on paper. I must say that the disability services were fantastic during the pandemic times. They actually sent letters with information, and it was in easy-to-read Swedish. There were even pictures. So, it was like, yes, they understood here. It was excellent information regardless of whether you can speak Swedish or not. Image and text simplicity, the brochure should be distributed to all residents of (City). I am completely convinced it would have been understood differently.

Technology

Several challenges related to technology and healthcare preparedness during crises are highlighted in the material. One of the participants cited this example:

> Where do you turn to get electricity? And someone said you have to buy one of these small crank radios. So that you have power. I can't charge her C-PAP, for example. The breathing machine. It requires much more than a hand-crank generator to work.

Restrictions prevent stockpiling medicine and medical equipment, leaving individuals vulnerable in emergencies. Reliance on medical equipment increases vulnerability in a power outage, made worse by supply chain issues and medicine shortages. One participant described this situation:

> She has medical equipment that requires electricity to function. She has a bed with a mattress that is ... yes, exactly. It must have electricity all the time, otherwise it freezes. What do we put her on then? Is it pressure-relieving, like ... yes, and then there's the breathing machine and inhalation that ... It wasn't the phone charging that was the primary concern. But it was like, what the heck do we do with all the stuff?

Communication can be affected when assistive technology fails during power outages. There is a need for safe evacuation spaces equipped with essential medical equipment like breathing aids and tracheotomy suction devices. Some of the families in the study had also bought things like a generator, a stock of food or adult diapers to make sure there were enough in a crisis. The families demonstrated an awareness of the gaps in availability of support systems for the technology and equipment they need:

> I know that healthcare is decentralized in such a way that there should be more healthcare at home. And that includes everything from dialysis to other treatments. And that requires electricity. So, the regions must start thinking, okay, what do we do if it doesn't work?

One parent described how medical equipment is necessary for eating:

> He can sometimes eat through his mouth, but most of the time, we administer through a button on his stomach. How are we doing with syringes, tubes, and these buttons? Every three months, we receive a shipment, and we can order what we need. What happens if we can't get hold of them? We've thought about that. There has always been a delivery truck. You go into an app, order, and it gets delivered home.
>
> We can mash food and inject it. It's a backup, but we need syringes, tubes, and this special valve that needs to be changed every three months. You can only get one at a time. On occasion, we've requested an extra one if we're traveling or away somewhere. It's a small balloon filled with water inside the stomach, and if it bursts, you have to give a new one.

Strengths

The importance of a close network was emphasized several times. Family, varied communities, and local cooperation are recognized as essential components of disaster preparedness for people with disabilities and their families:

> We have thought about it in a way, you know, we don't know. Now my husband and I live alone. We are both blind. Depending on how easy it is to move around and how easy it is for our relatives to perhaps pick us up or so, it may be that we might gather.

Some other strengths observed includes the development of a family plan for sheltering in place, indicating proactive preparedness measures in the family setting. Informal networks created by parents of children with multiple disabilities emerged as valuable resources for both knowledge and support during crises. These networks, along with social media platforms and communities, facilitated the rapid acquisition of specialized equipment during emergencies, outpacing the efficiency of official channels. One parent stated:

> Yes, because I've heard very specific topics and combinations ... perhaps not a large group, but internationally, it becomes a bunch of people who know things. Yes, exactly. Some diagnoses I can imagine, there you probably have worldwide contacts. To get new and the latest research and aids and such that are specifically for that unique diagnosis.

Another participant told of a resource they have used:

> For example, there is a Facebook group called "The Button Thread." There, they only discuss matters related to tube feeding and how the button works. There are other groups where they talk about all of life's concerns in general when you have children with disabilities.

These findings show the importance of leveraging informal networks and digital platforms as effective means of support and resource dissemination during emergency situations.

Discussion

In this section, a discussion on the findings is presented. This study focuses on crisis planning among families with disabilities, analyzing their specific obstacles and preparedness requirements.

Awareness

Similar to Chang et al., (2023), the majority of families interviewed for this study had thoughts on how to seek support or be the supporter of their family members during emergencies. This also extended to relatives outside the immediate family unit. The complexity of crisis preparedness attitudes and behaviors within the population that was interviewed showed a recognition of the need to prepare for emergencies, but the difference between acknowledgment and acting was apparent. Participants seem to engage in what could be termed as "passive preparedness" — they had contemplated the idea of readiness, discussed it within their families, and even considered some specific measures such as acquiring water containers and battery-powered radios.

The interview study revealed a variety of attitudes about preparedness within the population. In line with research by Hipper et al. (2018) and Orru et al. (2023), the families prepared for crisis at varied levels. Some individuals or families are proactive, strategizing about essential resources and thinking about practical steps to enhance their readiness. On the other hand, there are those who may be less proactive, only thinking about preparedness when prompted by external factors or discussions within their social circles. This variance underscores the importance of understanding the factors influencing individual preparedness behaviors, which can range from personal beliefs and experiences to socioeconomic status and access to proper information. Importantly, participants expressed awareness of the challenges they may face during emergencies, such as difficulty in accessing assistance and the need for tailored support from municipal authorities. This awareness reflects a critical aspect of preparedness: understanding one's vulnerabilities and the resources available for mitigation. However, there is also a recognition that individual efforts alone may not be enough, highlighting what Hipper et al. (2018) describes as the need for collaboration between communities and local government agencies to develop comprehensive preparedness plans. While the interviewed families demonstrate varying levels of preparedness engagement, there is a clear need for more focused efforts to bridge the gap between awareness and action. By addressing these gaps, communities could better equip themselves to effectively respond to crises and mitigate the impact of emergencies on both individuals and localities.

Accessibility

The findings highlight the critical issue of accessibility for individuals with disabilities during crisis situations. Participants expressed genuine concerns about whether their wheelchairs would be able to navigate shelters effectively. This uncertainty not only raises questions about the physical infrastructure of shelters but also points to a broader issue of inclusivity and accommodation for diverse needs within emergency preparedness plans. The study by Crawford et al. (2023) mirrors this with experience of family carers expressing concerns about the difficulties to evacuate in a crisis and experiences of inaccessible shelters during actual disaster scenarios. The study reveals the significant challenges faced by individuals with multiple disabilities when it comes to evacuation. Without suitable transportation options, evacuating becomes a daunting task, potentially leaving individuals stranded and exposed to heightened risks during emergencies. This highlights a systemic failure in emergency planning that inadequately considers the needs of those with mobility limitations and multiple disabilities.

These findings can prompt a critical discussion on the need for inclusive emergency preparedness strategies. It is not enough for shelters to merely exist, they must be designed and equipped to accommodate individuals with diverse mobility needs. This includes ensuring wheelchair accessibility, providing accessible transportation options for evacuation, and offering support services tailored to the needs of individuals with disabilities. While these challenges faced by individuals with disabilities during crises highlight broader issues of equity and social justice, access to safe shelter and reliable transportation during emergencies is a basic human right. Yet these findings reveal systemic barriers that prevent individuals with disabilities from exercising that right fully.

Information

Families may need to create channels of communication with healthcare providers and local emergency agencies to ensure rapid assistance during a crisis. The study findings highlight significant gaps in information and clarity regarding emergency preparedness resources and procedures. Chadwick et al. (2022) discuss the lack of accessible COVID-19 information during the pandemic. Participants also reported a lack of information on nearby shelters, hindering their ability to make informed decisions during emergencies. The absence of clear instructions resulted in a lack of practical planning, leaving individuals uncertain about where to seek assistance and what responsibilities fall on which level of government, whether local, regional, or national. This uncertainty made finding answers and solutions to specific questions more difficult, indicating a systemic failure in providing accessible and comprehensive guidance for emergency preparedness. Addressing these gaps is essential to ensuring that individuals can effectively navigate emergencies and access the support they need in times of crisis.

Technology

The intersection of technology and family preparedness for crises shows several critical challenges. First, restrictions on stockpiling medicine and medical equipment impose significant vulnerabilities, leaving individuals reliant on external supply chains during emergencies. As reflected in the research by Lindsay and Hsu (2023), technology and dependance on medical equipment were a significant area of concern. This dependence can become precarious during power outages, when the reliance on medical equipment becomes a problem. Compounding this issue are supply chain disruptions and shortages of essential medications, exacerbating the risks faced by those with medical needs. This issue is also discussed by Crawford et al. (2023); carers closest to the individual with a disability have critical knowledge about the situation and can provide useful solutions to address problems.

The reliance on assistive technology introduces additional complexities. During power outages, communication channels can falter, further isolating individuals and hindering access to essential services and support networks. This insight, shared by Barton-Hulsey et al. (2024) highlights the necessity for robust backup systems and contingency plans to maintain connectivity and communication channels during emergencies. Also important is the need for safe evacuation spaces equipped with specialized medical equipment. Individuals requiring breathing aids or tracheotomy suction devices face heightened risks during evacuations if adequate provisions are not in place. Ensuring the availability of such equipment in evacuation centers is essential to safeguarding the health and well-being of vulnerable populations during crises.

The urgent need for comprehensive emergency planning that addresses technological vulnerabilities in family preparedness is highlighted in this study. Strategies to mitigate the risks include enhancing local stockpiles of medical supplies, implementing backup power systems for critical medical equipment, and establishing communication protocols to support individuals reliant on assistive technologies during emergencies. By prioritizing these measures, communities can better protect the safety of individuals with medical needs during emergencies.

Strengths

As described in the study by Hamann et al. (2016), the importance of a close network has been emphasized by the participants. Family, varied communities, and local cooperation are recognized as essential components of disaster preparedness for people with disabilities and their families. Informal networks, as discussed by Crawford et al. (2023), are also a resource for carers such as relatives and spouses who may have experience with previous crisis and have knowledge about what worked and what needs improvement. Two of the interviewees who have experience with online networks observe that these share common interests around a specific disability. The virtual communities serve as knowledge-sharing resources and channels of communication that can help with practical issues in a crisis.

Conclusion

The study adds to the body of knowledge around crisis planning and the significance of personalized emergency preparedness and support processes in ensuring the security, health, and well-being of people with disabilities during crises or disasters. Addressing these specific needs and problems can help communities build resilience and respond more effectively to emergencies affecting people with disabilities.

The study's main outcome underscores the importance of representation—ensuring the active participation of people with disabilities in planning processes. Initial investigations reveal a lack of coordination in crisis planning, necessitating a platform or arena for information exchange and practical preparation. The findings also highlight the need for customized readiness exercises and disaster scenarios for effective engagement. The insights further emphasize a shift from knowledge transmission to actionable readiness and adaptive materials, as well as inclusive involvement.

With a focus on the importance of early engagement in planning, this research can help policymakers, emergency planners, and support organizations identify areas of improvement in crisis preparedness for people with disabilities and their families.

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Research Articles and Essays

Parent Involvement in Promoting Social Integration in Elementary Schools in Canada – A Preliminary Teachers' Report

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Abstract

Parent involvement in children's education is crucial to their education. It may also facilitate the social integration of children with disabilities which has been advocated but which has been lacking. To effectively involve parents in promoting social integration, information is needed. Of interest would be knowledge of parents' support of social integration and the role they play in promoting it. These questions were investigated based on teachers reports. Using a qualitative inquiry method, the research found only partial parent support and participation. Implications for advancing practice and research are suggested.

Keywords: parent involvement, social integration, children with disabilities, education

Parent Involvement in Promoting Social Integration in Elementary Schools in Canada – A Preliminary Teachers' Report

Parent involvement in children's education is crucial to children's development and education and has indeed long been promoted. Research has shown a significant association between parent involvement and a child's academic performance beyond the impact of the child's intelligence (Topor et al., 2010). Literature reviews have concluded that students with strong parent involvement are more likely to attend school regularly and stay in school longer, earn high grades, show appropriate behavior, and graduate to enter higher education (Henderson & Mapp, 2002; Jeynes, 2005). Parent involvement in special education, such as in Individualized Education Program (IEP) meetings, is mandated in the U.S. (Goldman & Burke, 2017).

Parent involvement is broadly defined as various types of parent engagements (Zhang et al., 2011). Grossly, parent involvement is classified into home-based activities engaged between the parent and the child such as outside of school. Parent involvement also includes school-based activities, which include child-focused activities typically conducted at school (Fishman & Nickerson, 2015). Despite its influence on children's education and development, parent involvement is less studied in special education (Zhang et al., 2011). Even less, if any, research has examined parent involvement within the school in the broader context such as promoting social integration for children with disabilities or other special needs.

Inclusion of children with disabilities in the regular class has been ardently called for since 1990s (Stainback & Stainback, 1990). Inclusion has long been legislated in the United States such as in the Individuals with Disabilities Education Act (IDEA) (Goldman & Burke, 2017). Inclusion is considered to benefit all aspects of child development for children with disabilities (Stainback & Stainback, 1990). A major purpose of inclusion is to cultivate social inclusion. "Social inclusion matters in K-12 school," according to Juvonen et al. (2019, p. 251). Based on research, social inclusion is defined as "the presence of reciprocal friendships, interactions between special education needs (SEN) and non-special needs (non-SEN) students, the social status of SEN students as perceived by non-SEN students, and the acceptance of SEN students by their classmates" (Vyrastekova, 2021, p. 1).

Researchers and educators have advanced the term "social inclusion" to "social integration." Social integration is specifically applied to people with disabilities (McCay & Keyes, 2001). A main goal of inclusion, also commonly referred to as mainstreaming, is the social integration of children with disabilities or other special needs. However, social integration is far from being achieved in the U.S. or Canada even today. A lack of social inclusion for children with disabilities has persistently been reported. Earlier studies found that preschool students with disabilities experienced rejection and low acceptance from peers (Odom et al., 2002). Children with disabilities were found to be less popular and had fewer friends than their nondisabled peers (Avramidis, 2013). More recent studies found that a child with Down syndrome would be less socially accepted than a child without disability (Schwab et al., 2016). Adolescents with autism were reported to be lonely and lacking friendship in an inclusive school setting (Locke et al., 2010). In a study, students with hearing impairment reported feeling less socially integrated and less accepted by their peers. They interacted more with other students with special needs. Social inclusion for children with disabilities continues to be an elusive and difficult goal (Koller & Stoddart, 2021).

There is a clear need for promoting social integration in schools and communities. Given the potential influence parents possess in children's lives and education, they have a role to play in contributing to the fulfillment of social integration. Of beginning interest are whether parent involvement takes place and what type of involvement they assume in promoting social integration. No studies have examined parental involvement in this regard.

The ecology of human development proposes that the child is surrounded by a set of overlapping layers of sub-ecological environments which would impact their development (Bronfenbrenner, 1979). The most intimate sub-ecological environment is the home, which is normally headed by parents. Parents' participation in their children's education would have a crucial impact on their children's development. Because parents are inherently supportive of their children's education as literature has shown, parents would be expected to support an important school activity such as promoting social integration. With various parenting skills, parents could also employ methods to help promote the social integration of children with disabilities. These assumptions were tested in the present study.

Legislation such as the IDEA advises that educators form partnerships with parents**,** specifically in the field of special education**.** It also requires schools to allow parents to participate in all phases of educational assessment and planning for students who receive special education services. Parent collaboration is thus important especially in the field of education. For optimal collaboration, teachers' opinions become pivotal. Teachers' perspective and experience with parent involvement in the promotion of social integration would provide a good start toward actions to plan and generate effective parent involvement in such a movement. Teachers' reports have been published to inform various aspects of education concerning disabilities (Laia & Gil, 2014). This study thus examined parent involvement in promoting social integration based on the perception and experience of elementary school teachers in Canada. As a pilot study, certain beginning questions have arisen which are: (a) what is the state of parent involvement in the form of support for social integration; and (b) What kinds of parent involvement are taking place? The answer would help planning and programs to promote the social integration of children with disabilities.

Method

Participants

The participants were 54 Canadian elementary school teachers, all but one of whom taught regular classes. The one exception taught special classes. The schools are located in a metropolitan city with a population of 360,000 in the Pacific-West region of Canada. The Canadian teachers taught kindergarten through Grade 7. The schools had a student population ranging from 200 to 650. The teachers had varying degrees of teaching experience, from 2 to over 30 years. Privacy prevented the collection of information on the teachers' ages. There were 15 males and 39 females.

Procedure

With the approval of the university research ethics committee and the initial approval by the school principal, the researcher verbally presented a written description of the project to the teachers as a group or individually. Teachers took part in the study voluntarily with a verbal and written consent.

The teachers were interviewed by the researcher. Each interview was facilitated by a questionnaire devised to examine issues surrounding social integration. Interviews were tape-recorded and later transcribed.

Instrument

This study is part of a larger study which applied a set of questions concerning various aspects of social integration. The questions related to the present study were: (1) How much parent support is there in your school for social integration of children with disabilities; (2) What role do parents play in facilitating social integration?

Data Analysis

The transcribed interview data were analyzed according to the questions, using the content analysis method (Johnson & LaMontagne, 1993). Each word, phrase, or sentence related to the topic being asked constituted a unit of analysis. Major categories were first identified after comparisons were made for similarities and differences between each smaller category or concept. Major categories were subsequently used for coding the rest of the data. New themes were added as they emerged. The coding reliability was further examined by comparing between the two coders. The reliabilities for the entire data were 78% to 90%**,** with an average of 81%.

Results

Results are presented by the research questions as follows:

Degree of Parental Support

Table 1 below presents themes and frequency of teachers' responses to the question: "In your class, how much parent support is there for the social integration of children with special needs/disabilities?"

Table 1

Degree to Which Parents Supported Social Integration Based on Teacher Responses

Theme	Statistics	
	n	%
1. Parents are supportive (Teachers: They've been outstanding)	11	50.0
2. Parents are not very supportive (Teachers: Did nothing that I was aware of, outside of school, to encourage friendships)	8	36.4
3. Miscellaneous (Teachers: I think they have some concerns but I don't think they know how to go about doing it; parent support is crucial)	3	13.6
Total	22	100.0

As seen in Table 1, only 40% of the teachers responded to the question. Of the responses, half of them reported that parents were supportive of social integration while 36% of the teacher gave a negative response. As one teacher remarked, “Parents did nothing that I was aware of, outside of school, to encourage friendships.” Another 14% had mixed reaction. One reason for the mixed response was that, despite support for social integration, some parents lacked the ability to promote it. Another reason for the non-supportive response was the teacher’s lack of knowledge of the parents’ stance and views regarding social integration.

Type of Parental Support

Table 2 presents themes and frequency of teachers' responses to the question: “What role have parents been taking in facilitating social integration?”

Table 2

Type of Parental Support for Social Integration

Theme	Statistics	
	n	%
1. Very supportive/helpful in classroom (Teachers: Parents help on field trips, organizing class activities, fund-raising)	30	25.9
2. Little or no involvement/not supportive/rely on teacher (Teachers: None of the parents of the children I'm working with this year have come into to drive on a school trip or accompany the students)	30	25.9

3. Parents supportive outside of classroom/support from home (Teachers: Special needs child is in a loving, caring foster home and the parents are very aware of his difficulties socially and they try to find playmates for him)	20	17.2
4. Parents supportive through communication (Teachers: I phone them and they phone me a lot)	14	12.1
5. Involved/deciding role (Teachers: Very heavy involvement for better or worse – we have a really supportive parent groups ... the parents are fairly powerful professional people; very strong advocates)	9	7.8
6. General care/concerned attitude (Teachers: Very concerned and wanting as much extra help for their child as we can provide)	3	2.6
7. Parent is having difficulty coping (Teachers: I think she's trying to juggle the needs of two kids and working)	3	2.6
8. Parents have unrealistic expectations (Teachers: I think they often have expectations that I think at times are very optimistic and unrealistic in what they expect us to within the regular classroom)	1	0.9
9. Miscellaneous (Teachers: You see, by having extra special contact, all I do	6	5.3

is single him out. He's better as part of the crowd if he can be; all kids primarily learn their attitudes and beliefs from their home and the culture of their home and the view of the world)		
Total	116	100

Various levels of parent involvement were revealed from the teachers' responses to the question of "What role have parents been taking in facilitating social integration?" The responses ranged from very positive to non-supportive. The same percentage (26%) of presence of parental support and absence of parental support was also reported. Parental support was provided through various means of involvement in the school such as help on field trips, organizing class activities, and fund-raising. A significant percentage (17%) was reported to have provided support outside the classroom and at home. Inviting classmates to the child's house was a major form of parental support. Another common form of parental support was through communication between school and parents of children with disabilities (12%). Still another common means of parental support (7%) appeared in parents serving as "very strong advocates."

On the other hand, there were parents who lacked the skill to provide support for the social integration of children with disabilities (3%). The lack of parental support was also attributed to the teachers' view that the children's home and culture, not the parent alone, were responsible for the promotion of social integration.

Discussion

This study examined parent involvement in promoting social integration of children with disabilities. The study was prompted by the lack of social integration of such children and the importance of parent involvement in children's education which may serve as a potential source for increasing social integration. Based on the teacher's reports, the results failed to confirm the expectations as would be predicted by the ecological model of human development (Bronfenbrenner, 1979) and by research. The research found instead that only half of the parents were in support of social integration philosophically and were providing the actual support. Moreover, where parent support was delivered, the activities were limited to participating in regular school activities such as driving for field trips, participating in some classroom activities, and fundraising. Occasional support involved inviting playmates to the home of children with disabilities.

The study thus found parent involvement has yet to be enhanced. It is unknown why parents do not support social integration aside from the fact that some parents lacked the resources or knowledge for providing support for social integration.

The results suggest that despite the potential for parents to help educate their children and promote their social development, parents have been underutilized in promoting social integration. There is therefore the need to increase parent involvement in promoting social integration. As the study shows that parents may not have the knowledge or the skill for such an undertaking, short-term workshops or information sessions may be helpful to educate parents in promoting social integration. Schools, with government funding, may facilitate such a program.

Moreover, a child with disabilities poses challenges for parents (Ludlow et al., 2012). In comparison to parents of nondisabled students, parents of students in special education encounter greater barriers to involvement and are less involved (Dyson, 1997; Fishman & Nickerson, 2015). To promote social integration, it may be helpful to enlist the help of parents of children with disabilities with special support such as transportation, information sessions for promoting social integration or baby-sitting to facilitate their participation.

Alarmingly, the study found that only a small number of teachers reported whether there was parent support for social integration. This observation does not imply the lack of parental support. Rather, it suggests that there may be a lack of knowledge among the teachers about parents’ participation in promoting social integration. The phenomenon speaks to the possible lack of teacher-parent cooperation in social integration. Schools may consider increasing efforts or developing programs to encourage more teacher-parent cooperation for the promotion of social integration.

This study pilots the research and provides preliminary information on parent involvement in promoting social integration. Further research may extend the present findings and begin a more systematic examination and exploration of parent involvement for the promotion of social integration for children with disabilities. Many issues regarding parent involvement remain to be addressed in research. One may well be the definition of social integration, which has to date not been clearly defined. The definition with its main components would serve as a starting point for activities and programs for a systematic approach to promoting social integration or social inclusion. Only through systematic research, planning, and program delivery can society in general and schools in particular improve the social integration and inclusion of children and adults with disabilities. A clear definition would also provide a guide for systematic research of social integration: in theory and in practice.

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Research Articles and Essays

Who are Twice-Exceptional Students?

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Abstract

This paper explores twice-exceptional (2e) students, emphasizing neurodiversity. It discusses the concept, under-identification reasons, strengths, and needs of 2e individuals. Practical tips and resources are provided for educators and stakeholders interacting with 2e students, including students from diverse backgrounds (3e).

Keywords: twice-exceptional; neurodiversity; gifted and talented education

What is a 'Twice-Exceptional' Gifted Child?

Twice exceptional (2e) students are those who exhibit exceptional ability and disability, which results in a unique set of circumstances. Their exceptional ability may dominate, hiding their disability; their disability may dominate, hiding their exceptional ability; each may mask the other so that neither is recognized nor addressed. Additionally, twice-exceptional individuals come from — and are impacted by — socio-economic, individual, and cultural diversity (Council for Exceptional Children, 2020).

The Individuals with Disabilities in Education Act (IDEA) disability categories encompass a range of conditions, including autism, deaf-blindness, deafness, developmental delays, emotional disturbed, hearing impairments, intellectual disabilities, multiple disabilities, orthopedic impairments, other health impairments, traumatic brain injuries, specific learning disabilities, speech language impairments, and visual impairments (a Department of Education, 2018).

Neurodivergence, a term coined by Judy Singer in 1998, and can be found under autism, specific learning disabilities, and other health impairment in the IDEA disability categories. Singer (2017) defines neurodivergence as when someone's brain processes, learns, and/or behaves differently from that considered “typical.” This means neurodivergent people may have different strengths and challenges from people whose brains don’t have those differences. The possible differences include medical disorders, learning disabilities, and other conditions. The possible strengths include better memory, mentally picturing three-dimensional objects easily, solving complex mathematical calculations in their heads, and many more skills.

Why Focus on Neurodivergence?

Neurodivergence affects 15%-20% of the global population (Goulet, 2022), and it encompasses the most prevalent and most promising disability types 2e students possess. Notably, neurodivergent traits can offer distinct advantages, such as heightened pattern recognition and analytical skills. For instance, dyslexic individuals excel in roles requiring big picture thinking and pattern recognition, as evident in their success in espionage and other fields (Griggs, 2021). However, despite their potential, many neurodivergent individuals face societal misconceptions and barriers to being recognized for their exceptional traits.

Why are They Under-Identified?

Some reasons for under-identification include that their exceptional characteristics often mask each other. Teachers often target areas that need support rather than focus on 2e students’ need for advanced lessons. Below grade-level performance criteria may be too low to catch high-ability learners with disabilities. Misunderstanding by adults may lead to assumptions that students lack motivation or are lazy (Josephson et al., 2018; Pate & Betz, 2021).

What are 2e Individuals’ Traits?

The 2e individuals exhibit a diverse array of traits and abilities, encompassing strengths and challenges across various domains. Key needs for 2e students include support in areas such as mathematics, reading, writing, concentration, and sensory processing (Differently Wired, 2017). Despite their disabilities, 2e students possess numerous strengths, including creativity, problem-solving, perseverance, and empathy (Baum et al., 2017). For example, gifted autistic individuals display strengths in sequencing, concentration, visual thinking, diverse imagination, and logical reasoning. Gifted students with attention deficit hyperactivity disorder (ADHD) often exhibit strong intuition, quick-wit, high-energy levels, empathy, and strong verbal skills. Gifted dyslexic students demonstrate strengths in spatial thinking, visual creativity, and non-linear thinking. Leveraging these strengths can form the foundation for a strengths-based approach to education, emphasizing individualized support and nurturing students' unique abilities.

What Can Teachers Do for Diverse 2e & 3e students?

Educators play a vital role in supporting the diverse needs of 2e and 3e (i.e., 2e students from culturally and linguistically diverse backgrounds) students. Strategies include adopting a strengths-based approach, addressing social-emotional learning, and individualizing instruction to accommodate students' unique learning styles and preferences. Providing opportunities for student choice and autonomy, integrating technology, intentional grouping, providing counseling, and fostering inclusive classroom environments are also essential (Mulvahill, 2022; Skolnick, 2021). Additionally, educators should consider cultural preferences in teaching and assessment methods and provide flexibility in learning pace and assessments to effectively meet the needs of diverse learners (Bevan-Brown, 2005).

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Research Articles and Essays

A Promising Intervention Model to Promote Postsecondary Transition and Career Development

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Abstract

The Hōkūlani program is a strengths-based, work-based, and culturally responsive intervention designed to support Native Hawaiian high school students entering science, technology, engineering, and mathematics pathways. Among the five program components, this article will provide an overview of the work-based learning component of the Hōkūlani model intervention.

Keywords: work-based learning, STEM education, culturally responsive

A Promising Intervention Model to Promote Postsecondary Transition and Career Development

Science, technology, engineering, and mathematics (STEM) play a major role in solving problems in today's world. Recruiting talented people from diverse backgrounds into STEM fields is essential to ensure high-quality research and practice (DO-IT, 2013). Working together with people from different backgrounds, experiences, and disciplines in STEM fields and having varying cognitive abilities brings about a creative advantage (Packard, 2016). To diversify the STEM workforce, there is a need for high-quality STEM education for all Americans, particularly those who are underserved and underrepresented in STEM fields (National Science & Technology Council, 2018).

Although there is an obligation to draw on new talent sources to make the STEM workforce as strong and diverse as possible (Hossain & Robinson, 2012), Native Hawaiians are significantly underrepresented in STEM fields (Kerr et al., 2018). According to the 2011 U.S. Census, the combined population of Native Hawaiian, Pacific Islanders, and "Other Race" accounted for 4.6% of the overall U.S. workforce but only 1.4% of the STEM workforce (Nguyen et al., 2016). Meanwhile, the STEM workforce will grow faster than any other sector (U.S. Bureau of Labor Statistics, 2017). In Hawaiʻi, STEM jobs will increase by an average of 11% from 2018 to 2028 (The Alliance for Science & Technology Research in America, 2019).

To improve Native Hawaiian youth matriculation into STEM pathways, we developed and are evaluating the effectiveness of a strengths-based, work-based, and culturally responsive intervention for indigenous high school students called the Hōkūlani model program. Our intervention consists of five components: (a) academic enrichment in science, (b) mentoring STEM interests and connection to Native Hawaiian cultural practices, (c) college transition supports, (d) family engagement, and (e) work-based learning. To date, our program has served 92 high school students across four major Hawaiian islands with the majority of students identifying as Native Hawaiian and first-generation college students (defined as those whose parents/guardians have not completed a four-year postsecondary degree program). In this article, we highlight the work-based learning component of our program.

Work-based learning allows students to acquire real-world research experience and further develop their career interests (Scott, 2012). It is an effective strategy to enhance students' learning experiences in STEM fields and shape commitment to a STEM career pathway (Salto et al., 2014), especially for underrepresented students (Pender et al., 2010). For instance, the Meyerhoff Scholar Program at the University of Maryland, which pairs each student with a professional in the STEM field and provides summer internships to gain hands-on experience, is nationally renowned as a model for successfully supporting students from underrepresented groups into the fields of science and engineering (Pender et al., 2010).

In our work-based learning program, students complete summer internships at a local STEM worksite, individually or in small groups, while guided by a working STEM professional. Our STEM internship sites represent a wide range of STEM fields, including conservation and restoration, marine, health, computer and agricultural sciences, biology, and engineering. By providing a range of options, students can select an internship site based on their individual STEM interests.

Prior to the summer, students complete a series of lessons designed to prepare them for their internship experience. During the preparation process, students meet and observe the STEM professional(s) who will mentor them throughout their internship and learn more about their responsibilities and the tasks they will complete at their work site. Students take inventory of prerequisite knowledge and skills that may be required to complete their assigned tasks and are supported to employ self-advocacy skills to share concerns or request workplace accommodations from their internship mentor.

At the culmination of their summer internship, students reflect on the tasks they accomplished—connecting their internship work to community improvement, as well as towards reaching their academic and career STEM goals. In their reflections, 92% of students surveyed (*n* = 85) felt their summer internship influenced their intention to enter a postsecondary STEM field. Parent/guardian perspectives mirrored the students' views. Most of the parents/guardians surveyed (*n* = 30) agreed that the summer internship helped their child or children become more interested in enrolling in STEM-related courses or activities, participating in early college or dual enrollment programs, matriculating to a postsecondary institution, and pursuing a STEM-related career. These preliminary findings suggest that

Hawaiʻi high school students are receptive to guided work-based learning opportunities and these experiences may further foster their STEM interests and intention to pursue STEM career fields after high school.

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Research Articles and Essays

The Lived Experiences of People with Disabilities During COVID-19

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The Lived Experiences of People with Disabilities During COVID-19

Societal crises—whether natural disasters, deadly viruses, or mass shootings publicly reveal the deeply embedded attitudinal, interpersonal, and structural forms of oppression that plague our communities living with identities or backgrounds maltreated by society. COVID-19 laid bare the deleterious and dehumanizing effects of ableism on our disabled communities (Pulrang, 2020). While not unexpected by disabled people, the devaluation of our disabled communities during COVID-19 is profoundly disturbing, reflecting persistent and intractable ableist policies, practices, and norms (Andrews et al., 2019; Lund & Ayers, 2020; Lund et al., 2020). To be clear, ableism is the social devaluation of disabled people and its coinciding forms of oppressions (Jampet, 2018). Within the context of COVID-19, ableism spotlighted, most broadly, (a) eugenics—or the more palatable terms, “care rationing” or “ventilator-rationing" (Andrews et al., 2019 Lund & Ayers, 2020), (b) inequitable emergency response policies and practices (International Disability Alliance, 2020), and (c) negative attitudes regarding the overall health status and quality of life of people with disabilities, namely, that disabled people have poor health and low quality of life (Scully, 2020). Moreover, disability often intersects with other oppressed identities and positions with many disabled people experiencing multiple, intersecting forms of oppressions (e.g., ableism, ageism, racism, and classism). Specifically, people with disabilities are more likely to be older adults, African Americans or Native Americans, females, living in poverty, unemployed or underemployed, and less likely to attend or have graduated from college (National Disability Institute, 2019). While the preponderance of disability and COVID-19-related articles highlight the deleterious impacts of structural ableism and other intersecting forms of oppression on our disabled communities during the pandemic, fewer studies seek to understand the COVID-19 experience through the lens of disabled people. Aligned with the disability justice framework, or the social movement to end ableism in conjunction with ending other systems of oppression (Sins Invalid, 2018), the experiences of disabled communities within any context must be understood through the voices of those most impacted (Sins Invalid, 2018). Moreover, sources of change, access, and collective liberation among our disabled communities is rooted not the provision of care through non-hierarchal and non-capitalistic webs of care and support. According to d-Samarasinha (2018), mutual aid and exchanges of care among precolonial brown, Black, and Indigenous communities occurred long before social work and charity models were in place. Using the disability justice framework as a guide, our study sought to describe the lived experiences of disabled people during the COVID-19 pandemic. Specifically, we asked participants to describe in their own words their experiences with COVID-19. Our study sought to deepen counselor and allied professionals' understanding of the experiences of our disabled communities during the pandemic to learn from their lived experiences and guide present-day preparedness for future crises and disasters.

Method

Participants

Participants had a mean age of 28.7 (*SD* = 10.2). More than half the sample were assigned female sex at birth (68.1%), were cis women (those whose gender identity matches the sex they were assigned at birth) (54%), and identified as heterosexual (54.9%). Regarding race, 71.5% reported one racial background and 16.7% reported two or more racial backgrounds

(12.5% had two racial backgrounds and 4.2% had three or more racial backgrounds). Of the 71.5% with one racial background, 45.1% were White, 13.9% Hispanic or Latinx (7.6% Hispanic, 6.3% Latinx), 9.8% Asian (4.9% East Asian, 2.8% South Asian, 2.1% Southeast Asian), 9% Black or African American (5.5% Black, 3.5% African American), 0.7% Indigenous, 0.7% Middle Eastern, and 0.7% Native Hawaiian or Pacific Islander. Participants had a mean of 16.2 (*SD* = 2.3) years of education and annual income of $30,770 (*SD* = 42,809). Nearly half of our participants (48.5%) had fixed incomes (i.e., SSI, SSDI, GA, or unemployment), 47.9% received employment income, and 27.9% were supported by family. Most of our participants rend on the West Coast (74.6%) in urban (51.8%) or suburban areas (46.1%). Except for one participant, all participants (94.4%) who responded reported having a disability as defined by the World Health Organization (2023). Most of our participants reported experiencing disability in the social realm (80.6%), workplace (77.6%), school (77.6%), and community participation (55%). On average, participants had 2.1 (*SD* = 1.2) health or mental health conditions and had lived with their condition(s) for an average of 16.2 (*SD* = 13.1) years. Participants reported living with psychiatric conditions (56.5%), physical conditions (39.7%), neurodevelopmental conditions (34.7%), neurological conditions (16.1%), autoimmune conditions (10.5%), and visual or hearing impairments (4%). During COVID-19, 40.7% were employed full-time or part-time and 39.3% were unemployed. Prior to COVID-19, 56.2% were employed full-time or part-time and 25.2% were unemployed. Our sample included 27.3% participants who were essential workers. Almost half of our sample owned a home or an apartment (47.5%) and 29.8% were renting a home or apartment. Most participants lived with family (50.3%), 22.6% lived with a spouse or partner, 15.8%

lived with friends or a roommate, and 11.5% lived alone. Participants lived with an average of 3.4 (*SD* = 1.7) people and 28.1% needed in-home care support. A majority of our sample reported being a member of one or more historically marginalized communities (76.2%).

Table 1

Participant Characteristics (*n* = 168)

Variable	***M***	***SD***	***n***	**%**
Age	28.7	10.2		
Sex or Gender*				
Assigned Female at Birth				68.1%
Cis female				54%
Heterosexual				54.9%
Race/Ethnicity				
One Racial Background				71.5%
Black or African American				9%
Asian or Pacific Islander				9.8%
Hispanic or Latino/a				13.9%
Native American				.7%
White				45.1%
Multiracial				16.7%
Two races				12.5%
Three or more races				4.2%
Education	16.2	2.3		
Annual Income	$30,770	42,809		
Fixed Income				48.5%

Employment Income			47.9%
Supported by family			27.9%
Place of Residence			
West Coast			74.6%
Urban			51.8%
Suburban			46.1%
Disability			94.4%
Social disability			80.6%
Workplace disability			77.6%
School			77.6%
Community Participation			55%
Number of health or mental health conditions	2.1	1.2	
Number of years living with condition(s)	16.2	3.1	
Psychiatric conditions			56.5%
Physical conditions			39.7%
Neurodevelopmental conditions			34.9%
Autoimmune conditions			10.5%
Visual or hearing impairments			4%
Employment Status During Covid			
Full time			40.7%
Part time			39.3%
Employment Status Prior to Covid			56.2%
Full time			56.2%
Part Time			25.1%
Essential workers			27.3%

Living Arrangement	
Owned home or apartment	47.5%
Renting a home or apartment	29.8%
Living with family	50.3%
Living with spouse	22.6%
Living with friend or roommate	15.8%
Living alone	11.5%
Needed in home care support	28.5%

Procedure

The study was approved by the authors' academic institution's Institutional Review Board. The research team consisted of two professors and two graduate students. The professors developed the research survey, recruited study participants, and collected and input data into SPSS and Excel. Participant recruitment and data collection occurred from April 5–May 18, 2021. The survey was closed once the researchers reached their compensation limit of $4,500. Participants were recruited via email invitation disseminated by Independent Living Centers in California and Disability Programs and Services at California State University settings. The body of the email invitation included: (a) brief description of the study, (b) eligibility criteria, (c) $25 compensation statement, (d) disability access statement, (e) researchers' names, roles, and emails; and (f) the Institutional Review Board's study protocol and phone number. Eligibility criteria included: (a) being age 18 or older, (b) living with a disabling health or behavioral health condition, and (c) being able to read, understand, and write in English. Persons consenting to participate in the study clicked the option "I consent to participate in this research study." Upon consent, participants were then moved to the survey questions. Captcha questions were sprinkled throughout the survey to ensure human participation. Participants were able to complete the survey at their leisure, stopping and re-starting as needed. The average survey completion time was 42 minutes, with completion times ranging from 20 minutes to four hours.

Upon survey completion, participants clicked “submit,” allowing the survey data to record into the first author’s Qualtrics XM software folder. All data was transferred from Qualtrics into an Excel file. The quantitative data was then input into SPSS and the qualitative data was input into a separate Excel file for coding. The Qualtrics, SPSS, and Excel files are secured by a two-factor authentication password process managed by the authors’ university. In addition, the Qualtrics survey was further secured by allowing access to only those receiving the invitation, providing an anonymous survey link, anonymizing responses (e.g., no record of IP address, location data, and contact information), and disabling the multiple submission and indexing features. Once the survey was submitted by a participant, a post-survey message occurred thanking the individual for their participation and providing specific directions for requesting the $25 compensation. To receive compensation and ensure participant responses were decoupled from the compensation request, participants were asked to send an email to the first author with “SURVCOM21” in the subject line. Upon receipt of the email, a $25 Amazon gift card was sent electronically to the participant within 24 hours of receipt of compensation request email. All emails received from participants were stored in a two-factor authenticated password protected email file in Outlook until an email from Amazon was received by the first author noting the gift card was delivered and received. Once received, the email was deleted from the researcher’s computer.

Measures

Our primary measure used to investigate the lived experiences of participants during COVID-19 was a qualitative inquiry that asked participants to respond to the following question: "Please describe in your own words your experience with COVID-19." Participants typed their responses directly into the survey. In addition, participants were asked to respond to 25 demographic, disability-related, and healthcare access/quality questions. Participants were also asked to rate their level of daily stress in general, level of stress as it relates to COVID-19, and level of stress as it relates to specific areas including: (a) basic living stress (e.g., food, shelter, clothing), (b) health/symptom management stress, (c) financial stress, (d) transportation stress, (e) isolation stress, (f) healthcare stress, and (g) parenting and relationship stress. Participants were also asked to rate the impact of COVID-19 on their life and their level of preparedness. Participants rated these areas on a 10-point ratio scale with possible scores ranging from 0 (not stressed at all) to 10 (extremely stressed).

Data Analysis

Quantitative data was analyzed using descriptive statistics to analyze our sample and to describe the level of stress and preparedness. Qualitative data was analyzed using the content analysis method of Krippendorff (2004). Content analysis is systematic and replicable, and distills written, verbal, or visual communication into content categories with explicit procedures for coding raw data (Stemler, 2001). Researchers can derive captured meanings, intentions, consequences, and contexts of communications (i.e., images, videotapes, and text) using an inductive or deductive content analysis, depending on the purpose of the study (Elo & Kyngas, 2008). For this study, we employed an inductive content analysis (i.e., emergent coding) due to the lack of previous information on the topic of interest. An inductive content analysis moves from a specific to a general analysis, and individual responses are coded and then combined into a larger statement (Chinn & Kramer, 2014). The inductive content analysis involves five steps to organize and code the data, including (a) open coding, (b) the development of coding sheets (i.e., coding protocol), (c) grouping, (d) categorization, and (e) abstraction (Elo & Kyngas, 2008). In this study, we developed our coding sheets or coding protocol after initial groupings and categorization had occurred. We approached our study in the following order: (a) open coding, (b) grouping, (c) categorization, (d) coding sheets/protocol, and (e) abstraction. Microsoft Excel was used to organize and code the participant responses to the open-ended question using the five-step process for content analysis.

In the first step, the open coding process allowed the researchers to freely explore meanings and actions found in the text by coding each word, sentence, or segment of the data (Charmaz, 2006). Two coauthors, who are well trained in qualitative research, and two graduate students individually analyzed the text responses by coding the text line by line, and categories were freely generated at this stage. Second, the researchers met multiple times to discuss meanings and patterns in the text and group the data. Third, similar categories were collapsed into higher-order categories to eliminate any outliers or irrelevant categories. The researchers continued to meet to discuss interpretations of the data and compared relationships between categories until consensus was reached. The grouping and categorization process occurred over several meetings and included consultation with an external auditor to reconcile any overlap or differences in the categories coded. Fourth, the researchers developed a coding protocol and used this protocol (i.e., consolidated coding checklist) to independently apply the coding to the text responses. The researchers checked the reliability of the coding and repeated the previous steps until reliability was reached and then applied the coding protocol to the entire data set. Fifth, during the abstraction process, several broad themes and mutually exclusive subcategories were generated from the coding protocol. The researchers continued to follow an exhaustive process of meeting regularly to compare categories and relationship between categories and themes.

Credibility

Credibility establishes that the interpretation of the meaning of the data is accurate and believable (Creswell & Creswell, 2017). To confirm credibility, data collection, analysis and findings are systematically described in the research process (Creswell & Creswell, 2017). In this study, peer debriefings and an external audit, which are commonly used by qualitative researchers, were conducted. A question-and-answer process between the external auditor and researchers was used to evaluate the research process and findings. For peer debriefing, a qualitative researcher was invited to review and provide critical feedback on data collection and analysis, findings, and interpretations. While reviewing the methodology of the study, our peer asked several questions about coding procedures (e.g., What is your coding protocol?) and findings (e.g., How can you identify patterns and relationships among your findings?). The peer confirmed that coding procedures and findings were systematically grounded in this study. The external auditor, a professor with no connection to the study, was invited to examine whether findings and interpretations are supported by the data. The external auditor requested to observe the coding process. While reviewing the coding process, the auditor had several questions about data analysis (e.g., What do the data say to you?) and interpretation (e.g., What does it mean to you?). Our auditor confirmed that findings and interpretations were believable in this study.

Results

Findings revealed the following nine themes: a) social isolation, b) social responsibility, c) returning home, d) barriers to resources, e) job loss, f) positive impacts, g) academic impacts, h) emotional and physical impacts, and i) adjustment and coping.

Social Isolation

Social isolation was described as losing contact, feeling alienated and being disconnected from people, places and support networks, and was accompanied by negative emotions. For example, one participant noted, “the isolation from friends and family is my worst part. Second-worst is the amount of alienation I feel at school (I'm a teacher) and disconnect from my students.” Another participant stated, “I did not have any real time contact with friends or family as most of them drifted away and lost contact with me and my family.” A participant also described the negative emotions, or subjective experience of social isolation, stating:

> “Because of the lack of socializing, I have become very depressed not being able to even sit at a coffee shop and do homework has been really hard…as humans we crave human interaction and without it, life doesn't feel as meaningful.”

Similarly, a participant described the negative impact of social isolation on their sense of being cared for, their ability to trust others, and becoming less comfortable opening up to others, stating:

> "It has been really difficult to not have more of an external support system. None of my friends checked in on me . . . . Covid has made me a bit more introverted than I used to be because it's hard to talk about my health and trust people."

Isolation was also described to include periods of sensory deprivation whereby participants described the loss of sensorial connection to others—through sight, hearing, smell or touch—reduced the scope of information taken in to make sense of oneself and the world. For example, one participant stated, "being isolated has led me to being in my head even more than before," and another noted how "the mask can keep you from life interaction." Finally, isolation was also described to include physical confinement or being restricted to a physical space or specific people, that contributes to emotional and physical discomfort. For example, several participants described being confined to small spaces, stating "because of Covid-19, I am stuck in my small room" and "I never leave my room since our house is small and is basically an office." Others described being trapped or stuck in their homes, with specific family members, in traumatic spaces, or restricted to a particular geographical area. For example, several participants described being confined to specific family members, stating "it is very isolating being here with family, not being able to go anywhere much," and "I am an in-home care provider for my 83-year-old mother-in-law who lives with me and my spouse. I have income but I feel trapped here and can't get a break." Participants described being trapped in their home and in traumatic spaces. For example, one participant stated, "I stayed home for most of 2020 without really going out," and another noted "now I have no separation…it feels like I'm stuck in a physically negative space (literally sleeping in the room my childhood traumas took place in)." Finally, a participant described "being confined to my urban neighborhood and not being able to be in nature was hard on both my body and mental state."

Social Responsibility

Social responsibility was defined by participants as being accountable for taking COVID-19 safety precautions for the welfare of themselves and others. Specifically, participants described social responsibility to include practicing social distancing, masking, and accepting— versus denying—the seriousness of COVID-19. For example, one participant stated, "it's the burden involving what is essential, how to get groceries, what is safe for myself, what can I do to increase safety for others." Participants also shared that social responsibility was particularly critical to themselves and/or their families because of pre-existing health conditions. For example, one participant noted "because of my and my family's health issues, we have been extremely cautious to only leave the house for necessary food and groceries, to always send the healthiest person, and to double-mask." Another participant stated, "I have a family of five, three of which are immunocompromised. Like almost everyone, extended family is practicing social distancing." Participants described experiencing worry, frustration, discomfort, and a sense of aloneness in response to the lack of social responsibility by others who denied the existence or trivialized the severity of COVID-19, resisted public health orders, and/or may have scapegoated Asian

American and Pacific Islander communities for COVID-19. For example, participants shared feelings of “discomfort and frustration aboard public transit due to forgetful and resistant passengers who board without mask,” being “worried caregivers are not taking illness seriously,” and “it has been terrifying to see people deny Covid, not take precautions, blame AAPI people etc.” Participants also described how others did not take COVID-19 seriously, and/or did not follow public health orders. For example, one participant noted “no one enforces the rules, so we're pretty much on our own to keep ourselves safe,” and another participant shared “before, when people wore their masks without complaint, I could at least continue at work. But then that change[d], people stopped taking things as seriously, putting me at risk, so I had to stop working because it wasn't safe anymore.” Finally, a participant described how the impact of COVID-19 was easier on those with resources, reducing its seriousness:

> “She’s [roommate] now home all the time. She has access to resources I don't that have made her experience of the pandemic easier and more comfortable. This has given her the impression that it isn't as serious as it is—which has meant problems with encountering her and workers she's hired unmasked & not distancing.”

Returning Home

Returning home during the pandemic was a common theme for many participants. Specifically, participants described returning home as a sudden, psychologically impactful transition. For example, many participants described the unexpected, negative experience of moving home, including such statements as: “When the pandemic first hit, I moved back in with my family, which was/is not good because they are toxic”; “With the shelter in place, it affected my mental health a lot with me having to move home so suddenly”; “The stress of living with my immediate family has made it increasingly hard to manage my depression and anxiety and hence, productive in my daily life”; “Then I moved back home with my family. However, it was a small apartment, and my family was overly critical of me which really hurt my mental health”; “It has been awful. I had to move back in with my parents, and they both work from home. I never leave my room . . . ”; and “Now I have no separation it feels like I'm stuck in a physically negative space (literally sleeping in the room my childhood traumas took place in)." Notably, most participants described returning home as an abrupt, negative experience.

Barriers to Resources

Barriers to resources was another theme described by study participants. Specifically, participants described the significant impact of COVID-19 on accessing essential services including in-home care, medical care not related COVID-19, mental healthcare, dental care, prescriptions, transportation, and health insurance. Several participants described how the dire nature of COVID-19 impacted their health and functioning. For example, one participant described the potentially life-threatening impact of COVID-19 on their in-home care:

> “I rely on eight caregivers seven days a week, 24 hours a day. I use a ventilator 24 hours a day. Covid created barriers on my access to my

> health care workers. Many were exposed to covid. I had to juggle all my workers constantly."

Another participant described the significant impact of COVID-19 on timely access to essential vision care stating,

> "Instead of being able to see a doctor in a week, or two I have had to wait up to three months. In those three months, I almost went blind and had to have emergency surgery to be able to keep my sight."

Similarly, a participant described the impact of COVID-19 on timely access to healthcare for epilepsy, stating "it's difficult to get access to my healthcare workers that deal with my Epilepsy Seizures. It takes more time to actually get an appointment, because COVID has become the main focus that my doctors are treating." Other participants described difficulties accessing quality, in-person health and dental care. For example, one participant stated "it's been difficult for me to receive full and accessible health and dental care, which has had me going through many trials and tribulations to find what works best for me." Another participant noted "my quality of healthcare has decreased due to the limited access to in-person health services." Yet another shared "it was really difficult to make in person appointment with my healthcare provider as offices were closed in the beginning." Finally, participants described difficulty accessing mental health care with one participant stating, "I have not been able to get a therapy session since all the therapists in my county are not accepting new clients." Another shared:

> "My mental health took a drastic toll on me. It's been 2 years now since I've had a therapist because I rely on Medi-Cal as my insurance and COVID-19 has made it difficult to get a hold of government offices."

Job Loss

Job loss and income instability was another common theme among study participants. Participants described unexpected job loss and its negative impacts on paying bills, housing stability, mental health, and healthcare access. For example, one participant noted:

> "It has been hard being able to take care of myself. I've lost my job, which gave me the access to healthcare, and I couldn't seek the help I need since health insurance takes a while to kick it. Paying for bills also took a toll on me. I had to miss multiple payments because of not having enough funds to pay for it."

Other participants described the negative impacts of job loss, for example, participants stated, "It's terrible, I lost most of my job, and I almost lost my place." Another said, "I am barely making ends meet." A third said "with unemployment, I couldn't really afford these services anymore." Finally, one participant noted the impact of job loss on finances and mental health stating, "when I lost my teaching job finances became very tight. Not working for months took a large toll on my mental health." Participants also described job loss as a primary consequence of COVID-19 stating, "the main effect COVID-19 has had on me is my loss of a job in theatre," and "work life is very affected." Another participant described the depth to which COVID-19 had on their career, stating, "I lost a lot from Covid. I lost my fashion brand. I lost my job." Most participants described job loss because of layoffs from their place of employment. For example, one participant noted, "I planned to teach, and teachers are being laid off in droves." Another stated "because I have intermittent mental illness, under the influence of covid, the company had to lay me off to reduce the pressure of the company." Still another reported, "I was doing pet care to supplement my social security and that work evaporated."

Positive Impacts

Participants defined the positive impacts of the pandemic as salutogenic (staying well doing periods of stress) or described resources and benefits that occurred in the face of the pandemic. Participants described pandemic-related resources to include occupational, financial, personal, psychological and disability-related assets, and strengths and motivations. For example, several participants described the occupational benefits that emerged during the pandemic. One participant stated, "I quit that job ASAP and started my own company." One participant described an opportunity: "I was furloughed due to the COVID-19 pandemic but took the opportunity to attend grad school."

Others described a healthier work experience. For example, participants stated: "Covid-19 has helped my work life balance" and "I also work alone more often these days which I sometimes get bored of, but it is also a lot less stressful than when I worked with my bosses nearby. And I feel just as productive." Financial resources were also noted, with participants sharing "the stimulus was used for investments have given me a high return. Working from home had saved me a lot of money." Another shared: "When I gained unemployment benefits, I was making a lot more than I did before." Participants also described the personal and psychological benefits that emerged during the pandemic, including establishing boundaries, self-awareness, self-care, asking for help, and increased self-efficacy. One participant shared, “I love that I have learned to take care of myself and learn to say no to people,” and another participant noted, “It helped me reconnect with myself and learn how to better take care of myself." One participant poignantly described the personal and psychological salutogenic effects of the pandemic stating:

> “I've grown and at times thrived. but it's also taught me how precious life is, and how being alone in life doesn't mean that there isn't value and light to be found. I've started to learn how to live for myself and why that's important, and I've also learned that asking for and needing support isn't something to be ashamed of. All in all, this has been one of the hardest years of my life, but I have found the light in the darkness, and I've found confidence in my ability to get through things that seem impossible.”

Participants also described how pandemic-related stressors had positive impacts on living with a disability. For example, one participant noted: “In some ways it made it better for some of us with disabilities because everything moved to Zoom, I didn’t need to deal with events where people use fragrance and was spending less time getting to events.” Similarly, another participant shared:

> “In some ways, it has been a lot easier to manage my sensory processing issues during the pandemic. I can be home a lot more where I can better control the environment to my needs (temperature control,

> being able to change my clothes easily when needed, ability to snack throughout the day)."

Other participants described how the easing of pandemic-related stressors allowed for a healthier pace and energy conservation, stating "mostly, it has decreased stress around having enough energy to go places and get things done" and "COVID-19 aided me in better understanding my conditions and how I need slower paced learning." Finally, participants described how the pandemic fostered participants' ability to pursue interests and goals and gain self-efficacy. For example, several participants described pursuing personal goals/interests: "On the brighter side, I learned how to drive and got my driver's license and a car." Another noted, "I'm exercising way more and getting out in nature more." Other participants described a sense of self-efficacy and pride in pursuing personally meaningful goals/activities. For example, one participant shared, "I've done well in school due to online classes," and another noted, "it has been both a great opportunity to refocus my energy on my academics and improving my marketability for internships and the future labor force by taking on more leadership positions/projects as well."

Academic Impacts

Participants described academic impacts as physical, psychological, and cognitive difficulties occurred during the pandemic as well as environmental and disability-related academic stressors. Specifically, participants described a loss of motivation towards school, a sense of isolation related to remote learning, anger and sadness linked to the loss of the expected college experience, feeling misunderstood by faculty, and having reduced attention, concentration and task completion. For example, participants described difficulty with focus and motivation stating, “in terms of school, my ability to focus was negligible and my motivation was nonexistent,” “learning online has been a struggle to stay focused, and “ . . . I have had to delay my master's program a little, it is really hard to concentrate.” One participant described how difficult it was to complete homework tasks stating, “It has been brutally difficult to write or finish homework.” Participants also described negative feelings related to remote learning and the loss of the college experience. For example, one participant described feeling isolated, stating “the isolating factor took some getting used to and it showed itself most with the inability to adapt well to online schooling.” Another participant described sadness and anger towards the loss of their college experience, sharing “my last year of undergrad were stolen away from me. When I heard we would not be having an in-person graduation, I was so sad. I also felt robbed of my experiences during my last year.” Participants also described how academic impacts intersected with disability. For example, one participant shared that “being forced to take classes online was stressful. I'm dyslexic, so in-person instruction is important, I tried waiting this out, but unfortunately, it went on too long and I'm just struggling now to keep my head above water.” Similarly, participants shared “because of my learning disability, I normally ask a lot of questions to my professors to understand a new material. But because of Covid-19, it has been very challenging to do so” and “my ADHD did not mesh well here.” One participant described the physical consequences of online learning stating: “It was stressful because school was online making it difficult for me to learn as it caused more migraines.” Participants also described academic impacts linked to such environmental factors as online learning and physical space. Participants also described feeling both misunderstood and a lack of support from their course instructors. For example, one participant noted, “The workload has been insane, and sometimes I wonder if some of my professors do not understand what we as students are going through.” Another participant shared, “It’s very hard to be able to be in contact with professors as some do not reply at all.” A third participant shared:

> “School, though, was the worst. Many faculty said they were understanding but heavily penalized me for late work even when flexible due dates was part of my accommodation. Between the illness and lack of understanding & compassion from a faculty member, I felt stressed and wondered why I was even in school.”

Finally, participants described the academic impacts of loss of space and being in community. For example, one participant noted, “COVID-19 has been challenging for some students who don't have extra space and quiet places to do work and due to the Pandemic.” Another shared “not being able to even sit at a coffee shop and do homework has been really hard.”

Health and Mental Health Impacts

Participants described health and mental health impacts as part of another theme. Mental health impacts were described as negative thoughts, feelings, and behaviors that occurred or worsened because of pandemic-related phenomena. For example, one participant described how COVID-19 contributed to behavior changes, worsening of mood, and having an overall deleterious impact on their life.

> “I reverted back to more dependent behavior, and I experienced an increase in depression because I no longer had to keep myself active;

> overall COVID has caused significant environmental trauma for me that heavily affected my mental health and irrevocably changed my life."1

Other participants described a similar experience of declining mental health. For example, participants shared "it has really taken a toll on my mental health. It increased my anxiety which in turn made my depression worse. It made me overthink everything"; "my mental health has been on a steady decline"; and "the experience has made my quality of life worse than it was already." Participants also described a sense of hopelessness and loss of energy, noting "there is no future anymore"; "I am losing my will to keep going"; and "I struggle to find focus and vigor to complete important tasks." Mental health impacts also included feelings of frustration and regret. One participant shared, "It has been awful, I am frustrated on a daily basis, I also feel a lot of feelings of regret." Others described trauma-related responses including fear, nightmares, avoidance, and negative thoughts and imagery. For example, one stated: "It's a very high level of stress and scared of dying if I contracted COVID-19." Another participant described avoidance and nightmares:

> "I try to avoid social media and news programs as I often feel triggered and experience grief for the suffering and life lost. I have nightmares of forgetting to wear a mask in public. I often avoid going to bed probably because when I try to sleep that's when my mind becomes overactive with worry."

Other participants described fears associated with leaving the house and negative imagery. For example, one participant shared:

> "I struggle with leaving the house. My anxiety hits me harder than ever to even run to the grocery store. I never leave, only for walks to get my son out of the house. I have bad thoughts any time I leave the house because I fear something bad will happen."

Similarly, another participant noted:

> "It has just been a disaster. Every time I left the house to ride the bus to buy groceries, I felt I was taking my life in my hands. I kept seeing images of people on ventilators dying alone in hospital. People were and are dropping like flies."

Participants also described how the pandemic negatively impacted their body image, eating patterns, weight, and sleep. For example, one participant shared, "It has also taken a toll on my body image as now I'm inside and like most people have gained weight, and being on social media more I compare myself more and more to people." Other participants shared, "I either didn't eat or overate depending on the day" and "I gained a lot of weight that worsened my other health problems." Participants described the impact on their sleeping patterns as well stating, "I lost a family member before lock-down, this affected my sleeping habits, my eating patterns." Another stated, "My insomnia and sleep apnea had gotten really bad during the pandemic, I am also always exhausted as a result."

Participants described the physical or health impacts of the pandemic. For example, one participant shared, "I have asthma and have had a lot of fear and anxiety about the possibility of getting Covid, my health fell apart." Other participants stated, "I went from getting sick two days a month to more than every two weeks," and the "stress I am under has triggered more symptoms with my mental health and has begun to take a toll on my physical health." One participant described pandemic-related fatigue and its impact on their mental and physical health stating:

> "Mentally I am exhausted. Everything has to be meticulously planned…I get anxious. When I get stressed, I usually fall into a depression, and I have a fibromyalgia flare up. That leads to not being able to take care of things."

Finally, participants described the impact of pandemic-related isolation and loneliness in their social functioning. For example, one participant stated, "My interactions with others became awkward." Another participant shared:

> "I am scared to go back to normal now because I don't know how I'm going to be interacting with friends. I feel very lonely but am struggling with talking with friends as I only now know how to be around my family."

Adjustment and Coping

Participants described coping with and adjusting to the pandemic. Specifically, participants described employing behaviors and emotions to minimize or buffer the negative impact of pandemic-related stressors. For example, participants described behavioral coping stating, "I found ways to sort of relieve myself of the stress by walking with my dog," "to combat this, I go for long walks to give my legs some sensory input and to let my mind wander," and "I got a job, transportation, continued therapy." In addition, participants described coping through positive emotions. For example, participants described coping by having faith and hope, stating, “I had faith everything would be okay,” and “somedays I had to rely purely on the slight hope that it might get better.” Participants also described relying on persistence or grit; for example, participants shared, “ . . . just push through with any energy I could find left in my system,” “just kept going, even when it felt like there was no reason to go on,” and “I have to force myself to adjust everything around me.” In addition, participants described coping with pandemic-related stress by allaying their fears and those around them. For example, a participant stated, “I have to ease my fears and the fears of others around me in order to function.” Participants also described a pandemic adjustment process characterized by an initial phase of abrupt adversity that over time shifted to adaptive, resilient responses. For example, “Covid-19 was very scary in the first few months of 2020 but then I did my best to adapt and live a quality life in accordance with the guidelines”; “my experience with covid was rough at first and now I'm flourishing, at first it was an adjustment but now I'm doing well”; “it was extremely hard getting used to staying inside all day, in the summer, it was routine”; and “it completely changed the way and where I had to live, work and go to school. My world slammed to a halt and changed direction.” One participant described a slow, arduous adjustment process and the benefits of seeking help, stating:

> “When COVID first began I was uprooted from my life. The first 4 months I just got worse and worse until I reached out for help. Getting healthy again was hard and slow and over the next few months I went from low functioning to functioning but still less capable than before COVID.”

Discussion

Our findings revealed nine themes: a) social isolation, b) social responsibility, c) returning home, d) barriers to resources, e) job loss, f) positive impacts, g) academic impacts, h) emotional and physical impacts, and i) adjustment and coping.

Social Isolation

Participants described social isolation as physical confinement, sensory loss, and losing contact with and connection to people, places, and support networks. Participants also described the affective experience of social isolation, namely, loneliness, sense of alienation, and emotional abandonment (i.e., not being cared about). Our findings are aligned with existing models of social isolation that include both an objective dimension, or the amount or degree of social contact, and the subjective or affective dimension (Findlay & Cartwright 2002; Fine & Spencer, 2009). While forced isolation impacted society-at-large during COVID-19 and the negative impacts were pervasive, the impact of mandatory isolation on those affected by pre-existing social isolation and other intersecting social harms (e.g., ableism, racism, and poverty) is particularly deleterious (Cornwell & Waite, 2009). The pandemic response highlighted, and likely exacerbated, the pre-existing social isolation experienced by our disability communities (Macdonald et al., 2018). Indeed, it is well documented that people with disabilities are more socially isolated, have fewer friends, experience higher levels of loneliness, and have less social support than the general population (Gilmore & Cuskelly, 2014; Krahn et al., 2015; Mithen et al., 2015). The protective factors associated with social integration and its allied constructs (e.g., social support) have long been empirically documented (Lakey & Cohen, 2000), and include such outcomes as longevity, lower rates of mortality, and other positive outcomes (Cohen, 2017). For people with disabilities, social contact and integration may also be vital to daily living and tangible benefits. In addition, casual and regular encounters with neighbors and other community members may serve to protect against the harmful impacts of isolation and ableism. In fact, studies show that secondary sources of support (e.g., neighbor, coffee shop barista, grocery clerk, and UPS delivery person) may provide those who are most at risk for isolation with sources of positive social exchange (Thoits, 1985, 2021). While the academic scholarship suggests that disabled communities have smaller social networks and are more isolated than their nondisabled peers, what is not captured by the academy is that many disabled people maybe isolated because of lack of access and resources. Moreover, the breaking of relationships and isolation experienced by disabled people is also shaped by capitalism, oppression, fear, criminalization, and violence (Mingus, 2016). According to Goulden and colleagues, disabled people have relied on each other “through non-hierarchal and non-capitalistic webs of care and support for centuries” (Goulden et al., 2023, p. 3). Mutual aid and interdependency amongst the disability community are bedrocks of survival for many disabled people. Mingus (2016) proposed reconceptualizing communities of support through a transformative justice lens whereby “pods” are specifically built to include people who can turn to each other for on-going safety, accountability, and support directly related to harm and violence. Simply put, pods are focused on individual and collective healing and resiliency (Mingus, 2016) and have the potential to counteract the isolation inherent within, and a consequence of, the capitalist and oppressive structures that keep people isolated (Mingus, 2016).

Social Responsibility

Participants identified social responsibility as a collective practice of social distancing, masking, and accepting–versus denying–the seriousness of COVID-19 to mitigate the risk of contracting COVID. Broadly speaking, social responsibility is about cooperating with others for the benefit of the community, or a commitment to civic responsibilities that may benefit both the individual and their community (Alliance, 2021). In the context of COVID-19, social responsibility is most aligned with adherence to public health policies and practices, such as social distancing, masking, and sheltering-in-place (Lim et al., 2021). Our participants described being vigilant agents of social responsibility during COVID-19, adhering to public health policies for their own protection and for the protection of others. These findings are well aligned with prior studies showing that social responsibility was one of the most frequently described motivations for social distancing, greater disinfecting, and fewer hoarding behaviors during COVID-19 (Oosterhoff & Palmer, 2020; Oosterhoff et al., 2020). At the same time, participants perceived others as not being socially responsible during COVID-19. For example, participants experienced a lack of COVID-19-related social responsibility by others on public transportation, with in-home care providers, and among co-workers, which in turn, contributed to anxiety, discomfort, and a sense of being alone. Thus, while participants were not burdened by abiding by COVID-19 policies, they did experience negative emotions associated with relying on these policies (and others to uphold these policies) to protect against sickness and death. This experience is aligned with prior studies showing that while those who practiced social distancing to prevent getting sick were less burdened by upholding COVID-19 protections (as compared to those not motivated by the fear of getting sick), they were more likely to experience greater anxiety (Oosterhoff et al., 2020).

The factors underlying why a person engages in socially responsible behavior, particularly during a global pandemic, are related to multiple personal and environmental factors (Oosterhoff & Palmer, 2020; Harper et al., 2020). For example, several studies noted factors that likely influence adhering to public health policies such as political orientation (Harper et al., 2020; Kushner et al., 2020), social responsibility, social trust, self-interest (Oosterhoff & Palmer, 2020), and attitudes about COVID-19 severity or fear of the virus (Oosterhoff & Palmer, 2020; Harper et al., 2020). While all people faced some degree of COVID-19-related external "rules" or norms, it may be that for many, particularly nondisabled people, the externally imposed policies and practices held less personal meaning and impact than for disabled people. For our participants, having a disabling health condition(s) coupled with an already unreliable, and for some, harmful healthcare context that was becoming even less accessible, being socially responsible was perhaps not a choice, but a way of survival. As such, it is not surprising that while social responsibility is generally a prosocial act, for our participants, being socially responsible was not only a prosocial act, but an act fueled by the anxiety, discomfort, and a sense of loneliness associated with not feeling protected by society from COVID-19. Moreover, our participants described COVID-19-related social responsibility to worsen overtime. The latter made sense; as COVID-19 progressed, the public health messages became more politicized and were often mixed with false information and mistrust of our public health system. In addition, some of the COVID-19-related safety precautions such as masking may not have been physically possible for some disabled people due to respiratory or other physiological impairments. These likely also contributed to additional worries about not being protected from the virus and being judged by others as not taking appropriate precautions. Disabled people were also receiving harmful ableist messages (i.e., threats of care rationing) and actions (i.e., not prioritizing early vaccines for disabled people) from our healthcare system, which likely further exacerbated their worries, discomfort, and sense of loneliness in protecting themselves and their communities. Indeed, the perceived lack of COVID-19-related social responsibility by others was likely a painful reminder of the pervasive and longstanding devaluing, ableist attitudes that plague society and our disability communities.

Returning Home

Participants described returning home as an abrupt, negative transition from not living with family to living with family. Returning home not only involved isolation from society but isolation within the family home, with many participants describing being confined to a childhood bedroom or small space. Participants also described the negative impact of returning home on their mental health, describing their environments as toxic and contributing to increased depression and anxiety. For some, returning home was re-traumatizing. Our findings are aligned with prior research indicating increased mental health difficulties within families who have a member with a disability (Bougeard et al., 2021; Rydzewska et al., 2021) and poorer family functioning (Desquenne Godfrey et al. 2024). In addition, our findings are aligned with contemporary COVID-19 research that reveals an increase in abuse, neglect, domestic violence, and aggression in the home during the pandemic (Jesus et al., 2021; Khan et al., 2021).

For people with disabilities, returning home during the pandemic may have been particularly upending and tenuous given the historical and present-day harms experienced by many disabled people in spaces they consider their “home.” While most adults have some control over decisions regarding their living situation (Murray, 2018), life decisions for people with disabilities, including those related to housing, have historically been partially, if not entirely, made by others (Murray, 2018). Moreover, “home” for disabled communities has been corrupted by historical and present-day sociopolitical harms and injustices. The abrupt, forced return home for disabled people may have reignited the pains of existing in a space where choice, personal decision-making, dignity, and identity are lost or compromised and a stark reminder of the contextual nature of self-determination. For some people with disabilities–particularly those from western cultures–moving out of the home into the community may have offered a space where autonomy and self-determination could develop and power and control by others lessened. According to Blunt (2005), “intimate and personal spaces of home are inextricably linked to wider power relations” (p. 4). Research also confirms this hypothesis; for example, one study found that persons with intellectual disabilities who moved into their own place of residence reported greater control and choice in their lives, more community engagement, and increased personal relationships (McConkey et al., 2016).

Barriers to Resources

Participants experienced difficulties accessing in-home care, health, mental health and dental care, medications, and transportation. Accessing resources was an abrupt barrier for many people, however, our disabled communities that already experience significant access barriers rooted in ableism, were particularly harmed. During COVID-19, public transportation, paratransit, accessible taxi, and rideshare services were disrupted and not reliable. Public transportation is typically the most frequent form of transportation for disabled people (, & Chowdhury, 2018) and is a particularly salient requirement for community participation, social connectedness, employment, and access to a wide range of basic needs (Jansuwan et al., 2013; Park & Chowdhury, 2018). However, public transportation has been, and continues to be, a significant barrier to community participation, social connectedness and accessing basic needs for disabled people (Bezyak et al., 2020; Sabella & Beyzak, 2019). Our findings are well aligned with prior studies revealing public transportation barriers experienced by disabled people (e.g., Taylor et al., 2010; Bezyak et al., 2020; Sabella & Beyzak, 2019). For example, one study found that 34% of disabled people (as compared to 16% nondisabled people) have problems with inadequate transportation (Taylor et al., 2010); more recent studies have found that two-thirds of a community sample of people with disabilities reported experiencing problems with public transportation (Beyzak et al., 2020), and nearly 90% reported at least one barrier to using public transportation, and on average, experienced at least three barriers to transportation (Sabella & Bezyak, 2019). Notably, disabled people with other intersecting positions, including being Hispanic/Latino/a/x, low income, and/or female increased transportation barriers (Sabella & Bezyak, 2019).

Access to healthcare including mental and dental health care was also impeded. Ableism in our health and mental healthcare systems is the norm, not the exception, and, like other societal injustices experienced by people with disabilities daily, were highlighted during the pandemic. The attitudinal barriers were rampant, with disabled people experiencing medical rationing (Goggin & Ellis, 2020), or the fear of medical rationing. While considered most "at risk," disabled people were often the last to get access to vaccinations and quality care. At the same time, many disabled people live with multiple or co-occurring health conditions that require ongoing healthcare and medication access. Our findings are well aligned with prior studies showing that disabled communities experienced significant barriers to healthcare during COVID-19, including insufficient ambulance and transportation resources to go to the hospital, difficulty finding medications, abrupt changes to usual care, and lack of available outpatient appointments (Lebrasseur et al., 2021; Jumreornvong et al., 2020). Importantly, in some ways, disabled people may have been more psychologically prepared than nondisabled people, given environmental barriers rooted in ableism (Mingus, 2016). Indeed, access barriers to healthcare, transportation, and other resources existed long before the pandemic, and disabled people have relied on their disabled communities and those from other historically marginalized groups to break through ableist and other oppressive resource barriers. Nonetheless, barriers to resources significantly intensified during COVID, while at the same time support amongst disability communities was compromised due to quarantine policies and reduced transportation options (Jumreornvong et al., 2020).

Job Loss

Participants described job loss as an unexpected and destabilizing disappearance of paid employment. Job loss was described as having destabilizing impacts on personal and familial finances, housing, mental health, and healthcare access. Participants shared that job loss was linked to business closures, suspension of operations, furloughs, and forced self-termination due to lack of enforced safety protocols at the workplace. Others pivoted to opportunities to return to school or make a career change. Our findings are not surprising given the historically high rates of unemployment and underemployment among people with disabilities. Specifically, prior to the pandemic, less than one in three (30.9%) working-aged people with disabilities were employed, as compared to three-fourths (74.6%) of their nondisabled peers (Bureau of Labor Statistics [BLS], 2020). People with disabilities are also historically underrepresented in white-collar jobs and overrepresented in service and blue-collar jobs (BLS, 2020; Schur et al., 2023) and, compared to nondisabled people, exit the workforce during economically challenging times at higher rates (Livermore & Honeycutt, 2015). Regarding job loss among people with disabilities during COVID-19, the research is more complicated and fluid. For example, some research indicates that a significant percentage of people with disabilities lost their job during the pandemic (Bishop & Rumrill, 2021) and employment dropped more among workers with disabilities as compared to those without disabilities (Schur, Van der Meulen & Rogers, 2021). Other studies, however, suggest that early in the pandemic, there was an equal number of disabled and nondisabled workers who lost employment or exited the workforce and later in the pandemic, the employment rate grew quicker for people with disabilities than for people without disabilities (Ne’eman & Maestras, 2023).

The complexities associated with understanding job loss for people with disabilities during COVID-19 is likely linked to other factors such as living with multiple intersecting positions/identities and the type of occupation and industry to which the disabled person was employed. For example, studies suggest that employment loss during COVID-19 was more severe for Hispanic, Latinx, Black, African Americans, and females (Bishop & Rumrill 2021; Schur et al., 2023). Studies also showed that workers with disabilities were more likely to be employed in occupations and industries that had larger employment declines during COVID-19 (e.g., building and grounds cleaning, food preparation and serving, and transportation and material moving) whereas disabled workers using telework who were essential, and were non-frontline workers, made gains in employment (Ne'eman & Maestras, 2023). For disabled workers, the ability to pivot to telework or having the support of employers to work from home experienced much less economic uncertainty and destabilization. Part-time workers, non-union disabled, and public-facing disabled workers faced the greatest economic uncertainty (Maroto et al., 2021).

Irrespective of the nuances during the pandemic, for our participants, job loss was harmful and abrupt, and impacted their ability to support themselves and their families. These findings are well-aligned with studies indicating that people with disabilities experienced more financial difficulties than nondisabled people during COVID-19. Specifically, people with disabilities were nearly three times more likely to experience financial hardship during the pandemic than nondisabled people, and 52% of people with disabilities had difficulty paying usual household expenses (Friedman, 2022). Financial hardship can have long lasting impacts on people with disabilities, including on their physical and mental health, well-being, and overall quality of life (Friedman, 2022). The global pandemic changed the way people work for both disabled and nondisabled workers, with working from home or using technology to engage in virtual work commonplace. This sudden shift to virtual and work from home had both advantages and disadvantaged for all people, including disabled workers. For disabled people, the flexibility that comes with remote work coupled with less reliance on unpredictable transportation and coping with ableist work environments may at times outweigh the potential costs of being isolated in one's home and less connected with people. At the same time, remote connection may increase opportunities for social connection for those who are physically isolated.

Positive Impacts

Positive impacts included occupational, financial, personal, psychological and disability-related assets, strengths and motivations. For example, participants shared being able to leave unhealthy work environments, gain financial stability due to unemployment benefits and stimulus funds, and leverage technology and outdoor spaces (i.e., nature) to improve access, reduce stress, and address health-related issues in creative ways. Participants also described that, during COVID-19, they were able to conserve energy and better control their daily environment (i.e., temperature, access to food, and clothes). Participants reported taking risks they would not have taken prior to COVID-19, establishing and achieving personally meaningful goals, developing a better work-life balance, and gaining confidence and self-efficacy in such spaces as school and work. In addition, participants reported that classes, events, and many other forms of social participation were immediately accessible through Zoom and other forms of live, online platforms. While our findings suggest that remote platforms increased access for our participants, it is important to note the digital divide between people with disabilities and those without disabilities during the pandemic (Cho & Kim, 2022). Specifically, internet use during the pandemic increased among those without disabilities yet remained the same for those with disabilities, with the most significant discrepancy seen in social network use. Further, people without disabilities were more likely to be aware of, utilize, and perceive the usefulness of digital services during COVID-19, including application, information, delivery, and subscription services (Cho & Kim, 2022). While online platforms may have increased access for some people with disabilities, it is likely that many of the available digital services that emerged during COVID-19 were not fully accessible for marginalized groups, including people with disabilities (Cho & Kim, 2022). According to Cabero-Almenada et al. (2022), digital competency among people with disabilities must also be met with digital services that are designed to meet the needs of people with all types of disabilities.

Participants also described improved boundary setting, increased self-awareness regarding their values, interests, and life goals, better self-care, and being more comfortable asking for help. These findings stand in stark contrast to the overarching body of COVID-19 and disability research, which has predominantly revealed the COVID-19-related harms inflicted on people with disabilities (Negrini et al., 2020). At the same time, our findings are aligned with the literature that suggests trauma is also grounds for personal growth, deeper connections, appreciation of life, and spiritual change (Sidener, 2019; Splevins et al., 2010; Calhoun & Tedschi, 2008). While there are numerous studies investigating post-traumatic growth related to disability onset, few studies have investigated it within the context of a universal or societal-wide trauma such as COVID-19 experienced by cultural groups. According to Jayawickreme et al. (2021), post-traumatic growth research is not generalizable to people from marginalized groups, particularly those who have been systematically excluded from mainstream, social, economic, cultural, or political life because of power inequalities. Jayawickreme et al. (2021) posit that post-traumatic growth and response to adversity should be defined within a given “bounded group-community" (Fuller & Garcia Coll, 2010), or defined within the social context, time, and space (Jayawickreme et al., 2021). Many social contexts, including the United States, rely upon social position variables—like race, ethnicity, gender, sexuality, ability, citizenship, and social class—to stratify individuals into existing social hierarchies. Thus, these social positions both help to define bounded group-communities, to influence the types of exposures those communities have (e.g., to adversity and different traumas), and to shape their desired competencies (e.g., character strengths). Members of any given bounded group-community are constantly adapting to the opportunities and challenges they encounter across contexts and settings (White et al., 2018). In this way, the types of adversities encountered, the notions of competence, and the mechanisms of growth—all key features of post-traumatic growth—may depend on the specific bounded group-community under investigation, and extending post-traumatic growth research to more diverse populations and settings will depend upon definitions of adversity, trauma, character, and growth in those bounded group-communities. Our findings address this gap in the research by shedding light on how people with disabilities both respond to adversity and experience post-traumatic growth.

Academic Impacts

Participants described difficulties abruptly transitioning to the online learning environment. Access to learning and to the college experience was impacted in several ways. While some of the impacts were likely common to any college student (e.g., being isolated and disconnected from peers, mourning the loss of the college experience, and losing motivation to engage in learning), other impacts were specific to being disabled. Aligned with prior studies showing that the transition to online learning was more difficult for disabled college students than nondisabled students (Scott & Aquino, 2020), our participants described COVID-19 as having mostly negative academic impacts. Indeed, like the pre-existing inequities and access barriers in healthcare, employment and other societal structures that worsened during COVID-19, the education realm was no different. Participants described isolation, disconnection, low mood, lack of support from instructors and overall difficulty accessing the online learning environment. Particularly, engaging in discussions, asking questions for clarity and understanding, and completing homework were academic consequences that were likely linked to the interaction between reduced attention, concentration, physical symptoms (e.g., migraines) and the online learning context. It may be that disabled college students' pre-existing accommodations were less effective in an online context or new accommodations needed to be instituted, a hypothesis aligned with prior studies finding that transition to online education created barriers to accessing and receiving appropriate accommodations (Scott & Aquino, 2020). For example, students with learning or attention-related disabilities–which comprised a large proportion of our sample–may have benefited from access to recorded and/or pre-recorded classes, extended time to complete assignments, frequent in-class breaks, a structured plan for turning on/off their video, and learning options that include both asynchronous and synchronous platforms. While the chat function is now a standard option for participating in an online environment, using chat was novel at the time, and may have worsened classroom engagement and increased isolation for those with attentional or learning impairments. These findings are aligned with prior research finding that college students with disabilities experienced difficulties accessing equipment, Wi-Fi, technological support, examinations and libraries, using online platforms, and communicating with instructors and peers (Scott & Aquino, 2020).

Participants also described difficulty communicating with, and getting support from, course instructors. These findings likely reflect the chaotic structural response to the impact of quarantine orders on educational institutions generally and instructors more specifically. Guidance on how higher education institutions responded to COVID-19 was limited to recommendations that these institutions consult with public health officials and comply with federal nondiscrimination laws (U.S. Department of Education, Office for Civil Rights, 2020). Simply put, limited concrete guidance on protecting the rights of college students with disabilities was available, reflecting the lack of consensus on how to adhere to public health recommendations and nondiscrimination laws (Chugani & Houtrow, 2020). Moreover, for most traditional 2- and 4- year educational institutions, remote/online learning options prior to COVID-19 were, by far, the exception not the norm. As such, institutions and instructors were ill-prepared to transition to online learning in general and, more particularly, to ensure disability access and accommodations occurred within these contexts. Indeed, educators learned that providing instruction in a classroom setting and providing instruction in an online setting is not only different but challenging (Young & Donovan, 2020), and those who lacked technology training and resources faced many barriers when teaching students with disabilities in an online environment. According to Hamilton et al. (2022), 42% of teachers reported difficulty in receiving adequate support and guidance for working with students with disabilities. In addition, campus ADA coordinators reported encountering difficulties more frequently than other professionals. At the same time, the transition to online platforms forced instructors and institutions to teach creatively and adopt practices that are fundamentally more accessible to our disabled students. The academic impacts of COVID-19, while reported as mostly negative by our participants, may eventually improve educational access through institutional acceptance and de-stigmatization of accessible online teaching platforms, disability services that utilize more accessible and justice-oriented registration, better documentation and accommodation protocols, and establishing an educational structure that is accessible and sustainable irrespective of abrupt environmental changes.

Emotional and Physical Impacts

Participants described substantial emotional health and physical health impacts during the pandemic. Many described worsening of existing mental health symptoms, declining emotional health, and increased depressive and anxiety symptoms. Anxiety was attributed to worries about leaving the home, as a response to the news, and of catching COVID-19 and of dying. Changes to sleeping and eating patterns were reported, such as disturbed sleep, oversleeping, lack of quality sleep, and lack of appetite or overeating as a response to the pandemic. Others reported decreased quality of life, difficulty concentrating, and trauma responses such as persistent fear and recurrent nightmares. Increased daily stressors triggered mental health and physical health issues, such as those that exacerbate with stress, autoimmune conditions, and other health problems. For participants who experienced weight gain, the physical changes contributed to negative body image and increased health issues. Participants with asthma, preexisting respiratory conditions, or other health conditions feared catching COVID and experienced pandemic fatigue. The fatigue was attributed to the need to meticulously plan to get groceries and leave the house for work or errands. Lastly, participants reported that long periods of social isolation created barriers to reconnecting with friends and the larger community, increased social awkwardness, and other difficulties with social functioning.

Among people with chronic health conditions and disability, unique traumas and stressors were experienced during the pandemic, leading to worsening of mental health and physical health conditions. Stressors and worries about access to medical treatment, supplies, or medications as well as risk for severe illness from COVID-19, led to worsening mental health and health outcomes for disabled communities (Okoro et al., 2022). Many experienced health care rationing, ableism in health care, social isolation, and were grieving significant losses in their community due to COVID-related deaths (Lund et al., 2020). Sleep quality was worse for people with disabilities, including people with blindness and visual impairments, compared to those without disabilities. However, over the span of the pandemic, nondisabled communities experienced worsening of their sleep quality compared to disabled individuals (Heinze et al., 2021). Adults living with disabilities reported significantly more depressive symptoms, mental distress, suicidal ideations, and substance use as during the pandemic compared to adults without disabilities (Okoro et al., 2021). The health conditions and disability were compounded by the impact of stress and worry about being infected with COVID-19. Along with social isolation, this led to increased vulnerability to negative health and mental health impacts for the disabled community. A literature review on the effects of lockdown measures on disabled communities during the early phase of the pandemic (up to

September 2020) found that disabled communities experienced many mental health and physical impacts, including disrupted access to essential healthcare, reduced physical activity leading to health decline, social isolation, and loneliness due to physical distancing. Further, negative effects included psychological impacts from the loss of routine and support, disruptions in personal assistance and support networks, experienced increased risk for maltreatment, vulnerability to violence, and self-harm (Jesus et al., 2021).

Calls for a more responsive policy at the state, federal, and local levels related to inclusive emergency preparedness and response plans are warranted to reduce negative impacts to the overall health of disabled communities during a pandemic and other emergencies. Aligned with disability justice principles, the establishment of mutual aid pods among disabled and nondisabled communities with pre-arranged response plans during emergencies that identify needed resources, caregivers, and support by the pod community members is a viable solution. Pod-mapping is a concept developed by disability activist, Mia Mingus (2016), which offers a tool to map out the mutual aid sources of support, resources, and access for disabled communities developed in response to community violence and harm. These tools can be used to help mitigate the impact of any future disaster, health, and climate response which may not be reliable and can reduce overreliance on response by public health officials to mitigate the negative impacts unique to disabled communities and aligns with the disability justice principle of mutual aid provided by disabled communities and their allies.

Adjustment and Coping

Participants employed coping strategies to minimize the emotional and negative pandemic-related stressors on their overall well-being. Participants found going for walks outside to be helpful in releasing physical and mental stress. Others held on to hope and faith that things were going to get better with time, pushed through difficult times, and found the grit within themselves to persevere through the challenges. Some worked through fears and found ways to function despite starting off not functioning well and discovered ways to respond with more resilient and adaptive responses. Many described debilitating responses initially to the pandemic and then adjusting to the protocols, staying inside for long periods of time and adhering to the social requirements to isolate. Others reported that through adjustments, they continued to find a way to live their lives, go to work, and continue with therapy and other treatments. Some participants reached out for help when they exhausted their personal coping resources.

Our findings align with some of the coping strategies deployed by people with disabilities. A study found a correlation between perceived stress and active coping mechanisms, such as distractions, venting to others, use of emotional support, religion (faith), and humor for people living with disabilities and chronic health during the pandemic (Umucu & Lee, 2020). A study of Canadian college students found that students with mental health disabilities experienced more difficulties adjusting and coping with the pandemic compared to nondisabled students; females living in urban areas with a disability were particularly vulnerable to increased stressors from the pandemic (Larose et al., 2024). In a study of youth and young adults with disabilities, helpful coping strategies during the pandemic included social support, financial support, keeping busy (establishing routines), and work-life balance. Particularly helpful for young adults and the youth were assistance with creating routines that helped them to get outdoors and exercise and allowed their minds to wander as a distraction from the pandemic and to reflect on life's purpose (Lindsay et al., 2021). As our study included many young adults with disabilities, these recommendations are particularly pertinent; those who adjusted well may have received some help or found ways to create healthy routines to better cope with the pandemic restrictions. Younger age, chronic pain, higher disability-related stigma, and more worries about contracting the COVID-19 were among the predictors of a lack of adjustment and coping strategies and higher prevalence of anxiety and depression among the disabled during the pandemic (Wang et al., 2022). These predictors are important in identifying elevated risk for mental health concerns and needed coping strategies for people with disabilities during a pandemic or other crisis.

Limitations

First, our research is a qualitative study; therefore, the findings cannot be generalized to a larger representative population. Second, most of our participants were White, heterosexual, educated cis women from urban or suburban areas residing on the West Coast who lived with their disability for an average of 16 years. In addition, most of our participants lived with psychiatric, neurodevelopmental, or physical disabilities. These lived experiences likely influenced our findings and should be considered within that context. Third, while our study focused on the lived experiences of disabled people during COVID-19, none of the research team members were disabled at the time that the study idea was conceived or executed. As such, our study was constrained by not having input by disabled people—an important disability justice principle. Our study is also limited by data collection methods. Specifically, our data was textual and collected via online survey. Consequently, we did not capture the voices of those without online access nor those who experience barriers related to typing out responses. In addition, we could not control for other factors that may have influenced participant response. Finally, we were unable to conduct member checks—a method for increase credibility—given the anonymized data gathered through our online survey.

Conclusions

Our findings highlight the multiple ways in which disabled people's lives were impacted by COVID-19, including social isolation, experiencing barriers to resources, job loss, academic difficulties, and mental health impacts. At the same time, our participants experienced positive impacts and effectively coped with the crisis. While these impacts likely affected society at large, our disabled communities were placed at higher risk given the significant changes in access to transportation, healthcare, and vital support services—services that are vital for those with disabilities. At the same time, it may be that many people with disabilities were more prepared than nondisabled people for the pandemic given the creative and ingenious ways that disabled people have managed ableism long before COVID-19. Specifically, lack of access to reliable transportation, services, and resources are a common daily experience for disabled people. The drastic change that nondisabled people felt at the onset of the pandemic may have been incremental or even slight for disabled people. Unfortunately, the voices of disabled people in disaster preparedness continue to be omitted, which is a particular flaw given their lifelong experiences of coping with access issues and managing limited supports and resources.

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Research Articles and Essays

Inclusion or Segregation?

The Specialist Subsidiary System for Accessibility in Japanese Workplaces

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Abstract

In Japan, companies are encouraged by the government to create specialist subsidiaries which focus solely on the employment and inclusion of disabled people. This paper examines one such subsidiary, NTT Claruty, to discuss whether this system represents meaningful inclusion or is further segregating disabled people.

Keywords: disability, employment, Japan

Inclusion or Segregation?

The Specialist Subsidiary System for Accessibility in Japanese Workplaces

According to the Ministry of Health Labor and Welfare (2023d), 642,178 disabled people are currently working in Japan, out of over 9 million people who have some kind of disability (MHLW 2016), which equates to roughly 7%. In other words, for the other 93% of disabled people, the workplace is inaccessible, for any number of reasons. One solution endorsed by the Japanese government is the specialist subsidiary system; in it, companies create a subsidiary which focuses solely on the employment of disabled people. But how effective are these companies at promoting accessibility for disabled workers? Are these subsidiaries truly accessible? And does this constitute a step towards inclusion or further segregation of disabled people? To answer these questions, this paper will discuss one example of such subsidiaries as a case study, NTT Claruty, and analyze its usage of assistive technologies and techniques for workplace inclusion. As every company's approach is very different, it is hard to generalize and say whether all specialist subsidiaries are inclusive of or segregating disabled workers. Additionally, it goes without saying that all disabled people are different, and disabled people's support requirements are constantly changing. What is inclusive for one person might be seen as segregation by another. However, this paper will argue that having a variety of options available for disabled people in the workplace is positive, and that companies should utilize these subsidiaries to learn from disabled people, including how to make the whole company accessible as well as about what needs to change.

Employment of Disabled People in Japan

First, it is important to highlight that the working landscape in Japan has changed a great deal in the past few decades; the main example of this being that there are a lot more people working in nonregular employment. Nonregular employment, such as part-time work or contract jobs, have a lot less security, lower pay, less benefits, and so on. This category of ‘nonregular employees’ is where a large proportion of marginalized workers, including disabled workers, is situated. On average, roughly 51% of disabled workers are nonregular employees (MHLW 2019), compared to roughly 36% of the overall workforce in Japan (MHLW 2023a).

The Japanese government has a policy, introduced in 2013 (Japan Labor Issues 2018), to promote disabled employment which states the minimum employment ratio of disabled people. Currently, the minimum percentage of the workforce that must be disabled employees is 2.3% for private companies, although this is being raised in the next 5 years to 2.7% (MHLW 2023b). The current average actual employment rates show that there is an upwards trend in the number of disabled people in the workplace. The 2023 average was 2.33% (MHLW 2023d), which was a record high in terms of the proportion of disabled people in the workplace, and in terms of the actual number of disabled people in employment.

Although this paints a positive picture, the continuous employment rate paints a very different one. In a study in 2017, the National Institute of Vocational Rehabilitation found that between 20-40% of disabled people quit their job within a year. In Japan, this is uncommon mostly due to the lingering expectation that you will be loyal to your company, a holdover from the days of lifetime employment during the post-war economic boom (cf.

Tanaka 1981). The closest equivalent survey that currently exists is a report by the Japanese Nursing Association (2023) which states that in 2021, the percentage of newly hired nurses who left their roles in their first year was 10.3%, the highest it had been since 2005, a statistic the Japanese Nursing Association attribute in large part to the coronavirus pandemic. Although the yearly staff turnover percentage will certainly vary between industries, this demonstrates how extraordinarily high the turnover of disabled staff is.

A study by the Ministry for Health Labor and Welfare in 2017, the same year as the NIVR study, reported that the most common reasons disabled people cited for leaving their jobs were the atmosphere at work, relationships with their co-workers and/or their boss, dissatisfaction with their wages and/or their working conditions, dissatisfaction with the content of their work, their illness got worse, they tired too easily, and insufficient consideration from their company.

Specialist Subsidiaries

To address some of these issues and to promote better inclusion for disabled employees, the government incentivizes the creation of ‘specialist child companies,’ or ‘special subsidiaries.’ This system was first created in 1975 and fully put into place in 1988 (MHLW 2023c). Any company can make one of these subsidiaries, but they need to meet the following requirements to receive official certification from the Ministry of Health Labor and Welfare (n.d.):

1. There must be a close personnel relationship between parent company and subsidiary.
2. There must be more than 5 disabled employees, or a total proportion of disabled employees of over 20%.

3. A minimum of 30% of disabled employees must have what are classified as "severe disabilities."
4. There must be appropriate adjustments available to make the workplace accessible to disabled workers, such as adaptations to the physical environment or assigning full-time support staff.
5. It must be possible for disabled employees to be promoted, and they must also have job security.

As of 2023, there are 598 such specialist child companies, situated across Japan in 46 of the 47 prefectures, with the majority being in proximity to large cities such as Tokyo, Kanagawa, and Osaka (MHLW 2023c). There are a wide range of industries represented here, with everything from 7 Eleven to Sony, to banking and finance, to power companies and more. For this paper, I will introduce one of the specialist subsidiaries I visited to discuss their self-described purpose and goals, what the workplace was like, and the experiences of the disabled people who worked there. By the end of this paper, I will pose the question as to whether companies like these constitute steps towards inclusion, or whether this is just a different form of segregation.

NTT Claruty

NTT Claruty is a specialist subsidiary company whose parent company is NTT, or Nippon Telegraph and Telephone, a telecommunications company. NTT Claruty's headquarters is in Musashino, Tokyo, an hour from Tokyo Station by public transport.

Their webpage greets you with a big message which says, roughly translated "through the advancement of normalization and the expansion of universal design, towards the realization of a society which is friendly to all" (NTT Claruty n.d.). Their aims are to promote the active participation of disabled people in the workplace, beyond a mere 'compliance' approach. This is reflected in NTT Claruty's vision, which states they are "working to contribute to the realization of a prosperous society without barriers, through the work satisfaction and brilliance of every individual employee" (ibid.). In other words, NTT Claruty looks at every individual employee's strengths and goals, and works to help each individual realize those goals whilst assisting with the removal of barriers they encounter.

To achieve this vision, NTT Claruty (n.d.) has 3 pillars to their approach:

1. Providing a reliable service to their customers.
2. Creating a society where disabled people can work comfortably.
3. Building relationships between employees who accommodate each other's disabilities.

Workplace

When I visited NTT Claruty's headquarters, I was greeted very warmly by the staff, and the building itself was very inviting as well. The entire premises seems to have been built with accessibility in mind; for example, the elevators and corridors were very wide, making it easy for mobility aid users to navigate. All signage was in high contrast colors and was written in Japanese in a large and easily readable font, and in Braille.

The main offices were standard cubicles, but with wide spaces in between, instead of the typical layout, with plenty of room. At the corners of any intersecting paths, there were domed mirrors on the ceilings so that wheelchair users and shorter people could easily see around corners without bumping into anyone. Additionally, the flooring was different at the doorways and corners so that blind and visually impaired people could feel where the doorway is more easily; for example, most of the flooring was smooth, but there would be slightly varied or raised textures at doorways to indicate their location. Most desks had electronic adjustable heights, so that wheelchair users can work at desks comfortably with the height which matches their own wheelchair, as this varies. There was a range of chairs available to staff, some with wheels and some without; the reason for this is that some wheelchair users find it easier to safely transfer into chairs with wheels, but others, alongside those with balance issues, may need a chair without wheels for stability. This office in itself reflects the goals of the company and would be an excellent template for other office-based companies to follow.

Inside the building, there is an in-house massage service staffed by 14 physical therapists who are disabled, the majority of whom are blind and visually impaired. On another floor, there is a cafeteria which is, of course, accessible, and there is a clear menu and organization system on a board outside of the cafeteria for employees to check, in high contrast colors and with braille.

Staff at NTT Claruty broadly work on web accessibility training for outside companies; supporting the recruitment of disabled people; on office work, planning, and inside a call center on behalf of other subsidiaries in the NTT Group; digitizing documents; and providing training on understanding disability, led by disabled people. They also run a webpage called *YuYuYu*, which publishes articles relating to every part of disabled life, including work and support for entering the workplace, whether the latest attractions and exhibitions are accessible, detailed recipes with descriptions of how the recipes' disabled authors used different assistive technology or techniques to suit their own impairments, and information about where to sign up to a parasport. This portal is extremely useful for disabled people living in Japan, and with the adapted recipes, internationally, and it is exciting to see a platform which is created and maintained by disabled people, with disabled authors writing articles full of useful information and tips for disabled peers.

Technology

I interviewed the management staff at NTT Claruty who shared their system for furthering inclusion in the workplace. It is very simple at its core: they listen to their disabled employees. They have regular meetings with each individual disabled employee, to discuss their experiences working there, and what would make the workplace even more accessible for them. As a result, they have a spreadsheet full of different technologies which have been requested by employees, which they then work on implementing.

Some of these technologies are simple, like those previously mentioned: adjustable height desks, different types of chairs, carpet and flooring changes, etc. Another example of a simple adjustment is whiteboards. Having notebooks and whiteboards in meetings is a cheap and easy way to aid communication, for Deaf and hard of hearing folks, but also for neurodiverse people and others who struggle with speech and listening who find writing easier. Another option here is communication cards, which are also very easy to make or cheap to purchase, but these allow people to communicate using flashcards or by pointing to a board.

Some are more involved and specific, such as braille keyboards, bone conduction speakers, a loop system which converts voices into subtitles, and a portable device called See-Through

Captions, which has a clear screen so that you can look at the person talking while subtitles appear in front of them, allowing the user to look at both, among many others.

Most of these ‘technologies’ are things which would be useful to everyone, disabled and nondisabled, and whilst some are more specific to certain types of impairments, implementing these technologies as NTT Claruty has been an excellent way to make the workplace more inclusive for everyone.

Inclusion or Segregation?

This leaves us with a question I raised at the beginning of this paper; how effective is this? And by extension, is this inclusion, or does this constitute another kind of segregation?

In the case of NTT specifically, Claruty’s management stated that they believe it would be better not to have specialist subsidiaries at all, i.e., that in an ideal world, they would no longer be necessary because everywhere would be accessible. They themselves feel that such subsidiaries create a ‘difference’ between the main company employees and them, which could work to further ‘other’ disabled folks.

On the other hand, it might be a form of inclusion for disabled folks who are nervous about entering or re-entering the workplace. Knowing that the company you are interviewing for or being hired at is a specialist subsidiary specifically focusing on accessibility, and that you will be surrounded by disabled peers, might be exactly what some disabled people need. In this case, the specialist subsidiary becomes a kind of safe space to work in, as free from ableist discrimination as possible.

Ultimately, it is difficult to say whether the concept of specialist subsidiaries itself represents inclusion or exclusion, as every company’s approach internally is different. Not all specialist subsidiaries operate in the way that NTT Claruty does, promoting a culture of inclusion and mutual respect and understanding. Additionally, every disabled person has different and constantly changing needs. And like anyone else, disabled people have the right to choose their profession, so not all roles will be suitable for everyone. Overall, companies need to reflect the needs of disabled staff, and specialist subsidiaries need to model this and act as a blueprint for their parent company to learn from, so that all companies can become more accessible over time.

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Research Articles and Essays

Overcoming Barriers in Job Coaching for Adults with Intellectual Disability in Supported Employment

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Abstract

This case study explored the barriers associated with job coaching for adults with intellectual disabilities (ID) in supported employment. Through field notes, interviews, and real-time observations, two main barriers were identified: task analyses and communication and continued presence and support within the workplace. These findings highlight the complexities of providing effective job coaching for individuals with intellectual disabilities.

Keywords: intellectual disabilities, supported employment, job coaching

Overcoming Barriers in Job Coaching for Adults with Intellectual Disability in Supported Employment

Job coaches assist individuals with intellectual disabilities in carrying out their job functions. Careful planning and specific strategies must be employed to keep these individuals on task. Since job coaches may work with individuals who have varying conditions such as autism, psychiatric issues, and other cognitive impairments, coaching must be personalized for the individual to attain the best work experience within their own capabilities. Job coaching is informal and involves the application of evidence-based “supported employment” (Frederick & VanderWeele, 2019; Probyn et al., 2021; Sundermann et al., 2022). In other words, job coaches work with employers in building disability awareness and problem-solving skills that will assist the job coach in slowly phasing out direct involvement.

In addition, the notion of supported employment ties in with the two roles of a job coach regarding client interaction: the individual with the disability and the employer who will hire the job seeker. It is important that the job coach represent the job seeker or client and vouch to the employer that the client will not be a liability while maintaining the support the individuals with ID will need to become successful employees (Probyn et al., 2021; Virginia Commonwealth University Rehabilitation Research and Training Center, 2022). Since a job coach works as a liaison between the client and the employer, there are certain barriers that can prevent successful supported employment.

One barrier is disability awareness. Individuals with intellectual disability may not be aware of the impact of their actions (e.g., acquiring items owned by others) and the outcome may make a difference in how they will be held accountable for such actions. If they are unaware of the consequences of their actions, how will they be reprimanded? The job coach may eventually defend such actions given the individual's disability. However, the employer must enforce company policies.

A second barrier is the lack of problem-solving skills. An individual with intellectual disability will initially be trained in using equipment they will handle and other specific skills pertaining to their assigned task. But individuals with intellectual disabilities may have unpredictable mood swings, which can cause an inability to solve issues relating to their task. For instance, a job may entail some sorting, counting, or transferring items from one place to another. The job coach will devise strategies to assist crew members in finding solutions, i.e., by counting how many items will fill up any container. Nevertheless, individuals with intellectual disabilities must be encouraged to complete their assigned tasks, despite their mood swings. If there is refusal to work, they still are held accountable, and the employer will have to enforce company policies.

Scholarly Significance of the Study

Job coaches work with remarkable resilience alongside individuals with intellectual disability. Within the workplace, job coaches apply evidence-based supported employment practices and work with employers in building disability awareness and problem-solving skills. There are barriers implementing supported employment due to the disability surrounding individuals with intellectual disability. To ensure that supported employment is implemented successfully, additional insights are needed in the field to improve ways in which these barriers are explored, analyzed, and solved so the job coach can eventually and successfully phase out direct involvement. Furthermore, there is a gap in understanding or implementing the “phasing out’ portion of job coaching that needs to be addressed. In this study, the job coach’s intention is to follow the “phasing out.” However, on most occasions, the job coach regularly works with different clients, which requires a constant presence in the workplace. While some individuals with disabilities may function better compared to other individuals with cognitive and functional disabilities, some employers may be reluctant to work with such clients because of the amount of effort that it takes to supervise individuals with prominent disabilities. The job coach needs to uphold work efficiency and provide the emotional support that individuals with ID and their families need. Clients may not simply learn when job coaches tell them what to do in a job, finding ways to model those instructions. Thus, job coaches provide more than just workplace encouragement but also emphasize team success over individual success and set goals for their clients (Tyson & Nelson, 2023).

This study is potentially significant to employers who will engage with individuals with intellectual disability. Job coaches plan, find strategies, and assist individuals with intellectual disabilities in successfully carrying out their work tasks. Most often, job coaches to individuals and groups with multiple disabilities are hired in the same work location. Job coaches can assist individuals in diverse job tasks and support other hires in their first few days of acclimatization at the workplace. In some cases, employers and clients are trained to work with job coaches.

Based on the experiences of a job coach, he or she can work as a liaison between the individuals with intellectual abilities and the employer. The job coach can make the employer aware that individuals with intellectual disabilities can function productively in society if they are trained and given the proper tools to become successful in their assigned tasks. With the onset of the Americans with Disabilities Act (ADA), employers cannot deny employment based on someone's age, sex, gender, sexual orientation, and disability. The workforce should be inclusive and that means employing individuals with disabilities. To comply with these provisions, a state agency can provide a job coach to train individuals with disabilities. Because of this setup, employers are gaining valuable support from a job coach who can train and guide individuals with disabilities, which at the same time greatly benefits the employer. In fact, there are appropriate contingency plans (e.g., contact with family or state agency) regarding stressful situations that a job coach can have in place and ready to execute anytime (Poses Family Foundation Workplace Initiative, n.d.).

Additionally, employees with disabilities should be treated no differently than other regular employees. They will still experience a regular review process to accomplish their tasks and responsibilities. If any conflicts arise, some employers may not even have to directly reprimand the client but rather direct any issues to the job coach as the liaison. The job coach must also be included in the review process and any feedback must be communicated by the job coach directly to the client.

Furthermore, the existence of a job coach can mitigate issues in the workplace and compliance from the clients. Job coaches can fill gaps such as problem-solving and communication that can create confusion in the workplace. Through this study, agencies and organizations who wish to employ individuals with disabilities, in compliance with state or federal regulations, can benefit from knowing about various barriers and how to overcome them through supported employment and using a job coach in the workplace. Although job coaching is a temporary situation that will phase out as clients acclimatize in their job, it is a necessary resource for training. While not overburdening clients, job coaches can review client work quality that could lead to productivity and other gains for the employer. Hence, there is a need to advocate for job coaches to remain in this field.

Definition of Terms

The following terms were utilized in the study and are defined as:

1. Client—refers to the individual or employee with intellectual disability.
2. Disability—refers to a person's physical or mental condition that can limit their everyday activities. The term may cover physical impairments, learning disabilities, developmental disabilities, and intellectual disabilities.
3. Disability awareness—refers to the notion that an employer is aware an individual with intellectual disability will have unpredictable mood swings and may create a barrier in fulfilling job duties.
4. Intellectual Disability or ID—refers to a condition in which an individual has a below average intellectual function. This term was a shift from the mental retardation terminology.

5. Job coach—refers to an individual who plans and uses strategies to assist individuals with intellectual disability within the workplace environment.
6. Problem-solving skills—refers to strategies used by a job coach to assist individuals in completing their assigned tasks.
7. Supported employment—refers to a situation in which a job coach works alongside employers in building disability awareness and problem-solving skills followed by a slow phaseout of the coach's direct involvement.

Perspectives

The notion of "identity" in the field of disability studies has come into focus in recent discussions about inclusion. We know that the concept of self (one's essential being) has a large part in forming identity. As Shahnasarian (2001) wrote, this "self" concept, and the reality that confronts people with disabilities, has led many individuals with disabilities to certain "underachievement and inadequate fulfillment" (p. 276). Shahnasarian's (2001) work in the integration of vocational and career development investigates this concept of self and the broad reality confronting individuals with disabilities related to their education, personal growth, career, and community engagement. The implication of underachievement and inadequacy could equate to low self-esteem and negative self-image. However, they need to be given opportunities to work and engage with other members of the community. For instance, individuals with intellectual disabilities live a very structured life. They have family members caring and making decisions for them around the clock. Most often, family members are very active participants in their daily activities, even as grow into adults. Family members are also very disposed to allowing their relative with a disability, to stay engaged, regardless of their age, if they are willing to work.

Although we have been promoting equality regarding opportunities for individuals with disabilities through various regulatory boards and provisions, cultural and societal prejudices still abound. Even with the existence of laws, it does not mean that work discrimination ceases to exist. Shahnasarian (2001) noted that individuals with disabilities are not immune to bias by employers. Some employers are sometimes not willing to extend accommodations regardless of their obligations to the ADA. Accordingly, a career counselor could dispel any baseless notions about extending accommodations. Similar, a job coach could step in and work as a go-between the client and employer. He or she could be cognizant of a client's potential functional changes in abilities, remediate any problems in the workplace, plan to recognize other work options, and make decisions to enable transitions into flexible situations. Putting aside society's discouraging views and raising awareness that both client and employers could receive needed support, the bottom line is there is still a critical economic need to harness the capabilities of individuals with disabilities so they can effectively contribute to society (Shahnasarian, 2001).

This paper presupposes that an individual with a disability has the potential to develop a self-identity (Watson, 2002) regardless of their disability. Shahnasarian (2001) defines "disability" as a diminished function based on a physiological or mental impairment that decreases an individual's ability to engage in meaningful activities. Arneil (2009), in reference to Charles Taylor's essay (2021) entitled "Politics of Recognition," even highlights how the notion of individuals-with-disabilities-not-incapable-of-realizing-their-potentials or using words such as “handicap” or “disabled” have been subjected to negative language. In history, the term disability was associated with an affliction that someone was born with. Thus, any discussion must begin with acknowledging the language we use and the way it is construed.

As for identity, we derive its meaning from the works of psychologist Erik Erikson from the 1950s. Identity is a purported individual trait, expected behaviors, or a socially distinctive attribute in which a person takes unique pride. Moreover, in terms of self, identity, and disability, Murugami (2009) posits that individuals with disabilities try to negotiate their lives as normally as possible, calling the process normalization or assimilation, because they strive hard to live a life like a person with no disability. They ascribe normalcy in every aspect of their lives and even challenge the biological part of themselves (or the part that has the impairment) so to partake in the same activities as their counterparts (Murugumi, 2009). Thus, when it comes to the concept of self and identity for persons who have disabilities, it is vital that we analyze these concepts through a lens of empowering them while also considering society’s repressive and changing views. Furthermore, as Nick Watson (2002) writes, "Well, I know this is going to sound very strange to you, but I do not see myself as a disabled person" (p. 509). He explains that the individual with a disability can put aside his or her disability or impairment and express their self-identity based on their abilities. If the individual with a disability is unable to complete their tasks even if they are capable to do so with proper mentoring, training, or supervision, the logical explanation is ascribed to societal barriers rather than the disability (Murugami, 2009; Watson, 2002). A person with the disability is willing to accept their own disability or impairment, and even do more than their counterpart, if limitations or restrictions are removed.

Indeed, there are certain challenges in the job coaching process. The job coach has two main roles: one is providing ongoing support to individuals with intellectual disabilities in the workplace and, second, as a liaison between the individual and the employer. Within the process of liaising, job coaches may encounter barriers that will keep the supported employment endeavor from being successful. A more thorough review of these challenges and the results found is warranted in this case.

Review of ADA, Supported Employment, and Related Literature

The following text will clarify provisions regarding the employment of individuals with disabilities under the Americans with Disabilities Act. The premise behind supported employment will also be reviewed as it is implemented in the workplace. A literature review will also examine the common barriers in the job coaching process, as well as identify the general support provided in job coaching.

Job Coaches and Provisions Under the Americans with Disabilities Act

There are requirements that employers need to comply with when employing individuals with disabilities. Employers are required to determine effective accommodations, while considering individual limitations, to meet provisions under the ADA. Employers are required to consider reasonable accommodations by adjusting a job to enable an individual with disability to enjoy equal employment opportunities and personalized job coaching. With personalized job coaching, tasks that are necessary include: assisting an individual with a disability to carry out specific job functions; conducting intensive monitoring; developing strategies for communication and social skills; and providing individual assessments.

Since accommodations may differ for each client, there are a few considerations to utilize job coaches:

1. What physical or mental limitation is the client undergoing?
2. How do these limitations impact the client's job performance?
3. What accommodations are available to reduce such problems?

By considering these questions, a job coach can plan strategies accordingly to meet the needs of his or her clients. A job coach can also work with employers and find out if they are complying with the proposed reasonable accommodations.

Supported Employment in the Workforce for Clients with Intellectual Disabilities

Reynolds et al. (2016) explain that supported employment is an evidence-based practice that supports the effectiveness of a job rehabilitation program. Its three features include competitive employment that refers to equal compensation between disabled and non-disabled workers; integrated work sites so individuals with disabilities work alongside those without disabilities; and workers are provided ongoing support (i.e., a job coach) (Reynolds et al., 2016). Sundermann et al. (2022) noted "having employment and a supporting employer makes it easier to resume a job, which is important for self-image" (p. 673).

The support discussed in this context is considered bi-directional (Reynolds et al, 2016). For instance, a job coach works with individuals with ID and the employer in building a partnership. While the job coach works directly with the individual worker, the job coach also works with employers to ensure reasonable accommodations are implemented as stipulated from the ADA. One example is discussing with managers how to talk and work alongside workers without disabilities, particularly in giving instructions. Overall, the best strategy is offering training on the job skills using “instructional techniques, adding assistive technology, [and] implementing training to help teach appropriate social skills on the job” (Virginia Commonwealth University Rehabilitation Research and Training Center, 2022, para. 9).

Barriers Faced by Job Coaches in Supported Employment

Job coaches are advocates for individuals with disabilities, particularly encouraging employers to become aware of disability issues in general. There are workplace situations such as encouraging a manager to be patient while giving instructions or articulating a request to the individual with ID to avoid non-compliant behavior. Hollins (2002) explains that depression occurs and is often overlooked in individuals with intellectual disabilities. Clients may suddenly refuse to work without reason anytime, walk out from their job station or even wander around a building. If an employer is unaware of their condition or behavior, the client will likely be reprimanded without exception and be held accountable for their actions. If an employer insists that company policies will have to be followed regardless of a disability, the job coach must assuage the employer, discuss the underlying disability, and then explore options to alleviate the foregoing situation. In fact, the client may be unaware of the infraction and its consequences. Hollins (2002) writes that depression is easily missed in people with social and communication disabilities, and common in people with intellectual disabilities and autism. If employers do not understand this occurrence, the job coach will automatically step up and defend the client. As Sundermann et al. (2022) explain:

> “That an organizational culture characterized by discrimination, unfair treatment of workers by supervisors, or job insecurity can determine an individual’s stress reaction that leads them to quit the organization. These results were supported by other studies, which provided evidence that workplace culture and client inclusion in the team are important in job tenure.” (p. 673)

It is vital to understand that organizational culture is related to employer and colleague attitudes, awareness of client needs, and whether coworkers stigmatize or support such challenges among individuals with intellectual disabilities. Moreover, Probyn et al. (2021) found in a systematic review on the effects of supported employment interventions that supported employment is more beneficial to people with conditions other than mental illness alone and competitive employment is possible given the opportunity (Sundermann et al., 2022).

Another barrier to job coaching pertains to problem-solving skills. For instance, a job coach can demonstrate strategies to help individuals solve common problems, socialize, and develop approachable relationships with supervisors and co-workers. The job coach can demonstrate how clients are able to track their working hours, count, sort items, and purchase food at the building canteen. But clients are prone to challenges such as mood swings anytime of the day.

In a study on mood disorders in intellectual disability, Hurley (2006) explains that individuals with mood disorders have more behavioral problems, including aggression, because of their inability to sometimes verbalize symptoms. It is vital to comprehend the intensity of these mood swings to track the disorder, as well as not “take what a person does in a manic or depressive state personally” (McHugh, n.d., para. 21). The job coach will teach the client how to manage their anger and frustration towards others (Reynolds et al., 2016).

But foremost, the job coach will have to ensure that these individuals stay on task since they receive compensation for the hours they work and can affect production time for the company. If they refuse, there are consequences, such as losing compensation. In the worst-case scenario, the client will be forced to “clock out” and the job coach will need to arrange for pickup service as soon as possible by the job coach. The job coach will need to stay with the individual until he or she is picked up by a family member or contracted public transportation service.

Decreasing Support for Job Coaching in Supported Employment

Job coaches commonly help solve practical problems in the workplace, as well as demonstrate proper workplace social skills (Reynolds et al, 2016). As clients master the job skills, job coaches can eventually decrease support. But this does not mean the job of a coach will entirely disappear. They are still available for consultation and may reactivate the increased support whenever needed or as the situation arises. According to Community Living Toronto (n.d.), it is in the best interest of the client to gain as much independence as possible. Phasing out does not necessarily mean leaving the client to fend for themselves. It means when the client is showing confidence in taking on a task, then the job coach can gradually step back and restrict the usual hands-on approach they once provided. Community

Living Toronto (n.d.) advises that it is vital to acknowledge when to step back in supporting an individual with ID.

Due to on-site and off-site models that are often employed for supported clients with various disabilities, some required assistance can lessen over time. In their study, Parsons et al. (2001; 1999) offered job assistance/coaching for three adults with severe multiple disabilities in a part-time community job. They assessed an off-site/on-site program for decreasing job coach assistance following evaluations of job performance. In lieu of the rigid coaching, the three individuals received more traditional day services when not at work. In essence, the program involved reviewing the total and category of assistance offered for each process in a worker's job assignments and then decreasing the assistance through environmental adaptations and instruction (Parsons et al., 2001; 1999). Following implementation of the services in the nonwork setting the adaptations and instruction were extended to the work site and the amount of assistance provided by job coaches was reduced:

> “No adverse effects on productivity were observed. These results suggest that an off-site/on-site approach to reducing work assistance represents a viable alternative to current supported work models. Social validity observations in 10 job sites highlighted the need to demonstrate ways to reduce work assistance provided for workers with severe multiple disabilities.” (Parsons et al., 2001, p. 162)

Case Study Overview and Method

This qualitative study is guided by the following research questions:

1. In what ways can job coaching implement supported employment between employers and individuals with intellectual disabilities?

2. What barriers arise in the liaison between the job coach and potential employers?
3. How does job coaching overcome these barriers?

To address these questions, a qualitative case study approach was used to observe a job coach and her clients with intellectual disabilities. Both the job coach and clients were employed by a nonprofit organization located in West Texas. The organization had over 200 employees and employed individuals who have varying physical and mental/psychological disabilities. When the study was conducted, the job coach was overseeing four clients with intellectual disabilities, four clients with physical disabilities, and one client with a mental disability. For this study, only the job coach and her interaction with her clients who have intellectual disability, were included and directly observed during their work schedule (including interactions with co-employees and completing tasks) and during their 15-minute break time. The study purposely investigated a single job coach. Erlandson et al. (1993) explain that case studies were developed from “data derived from key human sources in various social settings….” (p. 17). As in this case, names were changed and given pseudonyms, locations disguised. and other steps taken to preserve the anonymity of the participants (Erlandson et al., 1993).

An initial interview and a follow-up interview were arranged as part of this study. Field notes and reflections were jotted down in a journal and were triangulated.

To ensure trustworthiness, the first criterion employed was the credibility criteria of prolonged engagement. During the preliminary conversation with the job coach, the researcher was informed that clients with intellectual disabilities (including others with different disabilities) only worked 20 hours or less in a week. Hence, field observations were conducted only on certain days of the week when the clients were scheduled to work. The observations were conducted in three sessions for at least half an hour per observation. Erlandson et al. (1993) assert that "enough time" is considered the amount that enables the researcher to "understand daily events in the way individuals who are part of that culture interpret them" (p. 30).

The second criterion used was transferability by employing purposive sampling. Erlandson et al. (1993) explain that purposive sampling "seeks to maximize the range of specific information that can be obtained from and about that context" (p. 33). It was vital to the study that participants recruited were relevant to the study.

The third criterion was the confirmability audit to ascertain dependability by "enabling an external reviewer to make judgments about the products of the study" (Erlandson et al., 1993, p. 35). The researcher was referred by a colleague to the job coach who was employed by the workforce development division of the nonprofit organization. The job coach had a combined number of over 28 years as an educator and job coach.

Data Sources

Using field notes, interviews, and three on-site observations, the following tables are examples of interactions observed between the coach and her clients. Note that as the researcher, I used the noun "I" to refer to my own reflections and descriptions of events as they happen at the time of observation. Refer to Appendix A for Tables 1.1, 1.2, and 1.3 for description of events and reflections of site visits numbered one to three. After each table, an explanation of events follows.

Thematic Data Analysis

Below is a description of the data sources utilized to answer each research question, as well as the evidence of themes during the coding process.

Research Question 1: In what ways can job coaching implement supported employment between employers and individuals with intellectual disabilities?

The data sources used for this research question are field notes and interviews. Open coding was utilized while perusing data several times and important events were summarized based on the meaning derived from the data. A table with headers was developed and includes fields such as open code, properties, and examples of participants' words. Based on the open coding, six insights were gained from the experiences of the job coach: (a) providing support and assistance, (b) providing accommodations, (c) fulfilling required documentation, (d) monitoring job engagement, (e) assisting in decision making, and (e) liaising. By providing support and assistance, a job coach ascertained that client had opportunities to experience job tasks. According to an interview with the job coach, maintaining workstations for her clients was important and, if possible, she recommended it to management. A job coach also provided needed accommodations to maintain employment and maximize productivity. In one of the field observations, the job coach managed to create pictures of various hangers so one of the clients could sort hangers by type and not by color. Documentation was also a large part of a job coach's daily routine. Case notes must be sent regularly to supporting agencies. This was an avenue to evaluate the progress or job performance of clients. Monitoring job engagement was another aspect of a job coach's work. This aligned with maximizing productivity and allowed the job coach to model the correct execution of a task, i.e., sorting hangers in appropriate bins. When decisions had to be made about sorting books, the job coach assisted and guided the client in implementing decisions—whether to accept or reject books that the computer system was not able to scan from a barcode. Most of all, conducting liaison work required external support for acquisition of certain equipment or securing necessary modification. Ultimately, the job coach must make recommendations to management, so clients are able to work efficiently despite their disability.

Research Question 2: What barriers arise in the liaison between the job coach and potential employers?

The data sources used were field notes and interviews. Open coding was utilized to derive meaning from data. One barrier that the job coach identified was task analyses. It was important to identify which aspect of work was manageable and difficult for the client. In one session, it was evident that Bob (pseudonym) could not read, and pictures were drawn. The pictures became substitutes for text so Bob could sort hangers, not by color, but by type. Annie and John (pseudonyms), who have a mental and physical disability respectively, read, used a machine (barcode scanner), and identified the ISBN (International Standard Book Number) in books. Clients were placed in certain workstations based on their level of abilities. According to the job coach, the client's employer was aware of their disabilities and the necessary accommodations. The employer has been supportive of her recommendations. She hopes the employer will always accept and act on all her requests.

Another barrier mentioned by the job coach was communication difficulties. According to the job coach, an individual with autism was unable to immediately interact or respond to work instructions. A nonverbal client with autism may also react differently when approached, like tapping his or her chin, banging his or her head or hurting themselves overall. An incident involved Bob, and the job coach was worried. Although Bob's disability did not allow him to consciously consider his actions, management might sanction him for his own misbehavior. The job coach's opinions may be communicated to the employer, but it is not guaranteed that the employer will be understanding of the job coach's clients. Employee policies will have to be enforced per the policies established by an organization.

Research Question 3: How does job coaching overcome these barriers?

Data sources for this research question are field notes and interviews. As mentioned previously, there were two barriers: task analyses and communication. In task analyses, it was vital to identify which aspect of work was manageable and difficult for the client. These aspects are crucial in planning tasks. To overcome this barrier, work must be broken into smaller components and must focus on areas that are within the client's level of capabilities. This way, planning can be done appropriately, and the employer can be informed of any work modifications for each client. As for Bob, if sanctions were enforced to make him understand the consequences of his conduct, the job coach would comply with the employer's wishes and then communicate the reprimand to Bob's family. As for communication difficulties, the job coach realized it was more effective to communicate through writing or hand signals if a client is nonverbal and not engaging otherwise. Bob, for instance, has a low retention rate. He mumbled a lot and was not coherent. So, instructions must be repeated regularly for him.

Implications

Job coaching for individuals with disabilities is a very challenging job. There must be consistent support to maximize productivity of clients within the workplace by providing accommodation and modifications, assisting with decision-making, and communicating with supporting agencies. Liaison work becomes crucial because the job coach serves as the bridge between the employers and the clients, between the clients and the supporting external agencies, and between the employers and external agencies.

Barriers to liaison work must be addressed in two ways: task analyses and communication. Tasks must be broken down to ascertain that tasks are being performed within the individual’s level of capabilities. Any recommendations made by the job coach are open to scrutiny by the employer. There is no guarantee the employer will be fully on board with any requests, although by law employers must comply with the Americans with Disabilities Act. Communication is an issue with individuals who are not engaging. The employer will always rely on the job coach to communicate with clients. The employer will look at any infraction in the workplace, regardless of disability. The job coach may be able to present an argument on behalf of the client, but a job coach would have no control of any decisions made by the employer.

Job coaches generally help clients with intellectual, physical, and mental disabilities in carrying out work-related responsibilities. Clients may only be able to work for 20 hours or less to comply with Social Security regulations regarding weekly earnings. Clients may also have limited mental functions and skill sets to carry out their jobs (Reynolds et al., 2016). The job coach must provide ongoing and consistent support to guarantee workplace success. The goal is to train clients for their major job functions and eventually allow them to work independently. A job coach may be able to forego direct involvement in the future. Individuals with intellectual disabilities, and those with other disabilities, usually continue to rely on the traditional support of Supplemental Security Income (SSI) checks and health insurance in the form of Medicaid (Blanchett et al., 2009). However, giving clients opportunities to work will also give them a sense of accomplishment. Despite their disability, they can become competent and productive. To bring them along a path of productivity, the presence of a job coach is a crucial aspect of this success.

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Research Articles and Essays

Recent Trends in Supporting Students with Developmental Disabilities in Japanese Institutions of Higher Education

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Abstract

The existence and role of assessors for students with developmental disabilities remain debated in Japan. This study examines the skills and competencies needed for professionals supporting such students in higher education institutions, including universities, junior colleges, vocational schools, and technical colleges. Assessors in Japan must act as generalists, adapting their roles to assess functional disabilities, coordinate casework, and engage with students. They also need to understand the educational philosophy and organizational structure of their institutions.

With the increasing number of students with developmental disabilities, training programs for assessors are critical. We propose three core skill categories: understanding students and institutions, collaborating with internal and external organizations, and conducting and interpreting standardized psychological assessments. Additionally, two learning processes are outlined: foundational education through universities or graduate programs and post-employment professional development. Future training initiatives should emphasize the latter to prepare assessors for diverse institutional environments and ensure effective support for students with disabilities.

Keywords: assessment, developmental disabilities, Japan, higher education, teacher training

Recent Trends in Supporting Students with Developmental Disabilities in Japanese Institutions of Higher Education

According to statistics from the Japan Student Services Organization (2022), the number of students with disabilities enrolled in Japanese institutions of higher education has been increasing in recent years, with a particularly high percentage related to developmental, mental, and internal disabilities. Assessment is important for such students to confirm the evidence for support provided in their applications and to better understand their characteristics. However, some university faculty and staff members may find it difficult to decide on the content of the requested support and provide reasonable accommodation at universities and other institutions of higher education.

To clarify the relationship between the functional impairment caused by a developmental disability and the content of the application for consideration, it is important to procure an assessment and evidence showing the degree of the disability. However, there are also cases in which there are no easily available resources that can be used to provide academic support, or where those in charge of academic support do not necessarily have any expertise in relation to disabilities. In addition, discussions on how to ensure study opportunities for students with developmental disabilities and how assessment can contribute to this process, taking the curriculum policies of faculties and departments into account, are still in their infancy in Japan. Developmental disabilities are commonly considered to be Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), and Specific Learning Disorder (SLD).

A breakdown of the numbers of students with developmental disabilities reveals that the United States has the largest percentage of SLD students (National Center for Education Statistics, 2011), while Japan has the largest percentage of ASD students (Japan Student Services Organization, 2022; Kondo, Takahashi, & Shirasawa, 2015). In addition, in 2016, the Law for the Elimination of Discrimination against Persons with Disabilities was enacted in Japan, and as a result of an amendment to the law in 2021, the provision of reasonable accommodation for students with disabilities becomes a legal obligation from April 2024 and will require the compliance of all higher education institutions, including private universities. For further information on the current status and issues concerning support for students with disabilities in Japan, please see Nakano et al. (2024).

Discussion of the Importance of Assessors in Japanese Higher Education Institutions

The role and position of assessors in other countries appears to be very clear compared with the case in Japan. For example, the determination of Specific Learning Difficulties (SpLD), which accounts for about half of the students with disabilities in the United Kingdom, is performed by psychologists or specialized faculty members with SpLD assessment qualifications (Ryder & Norwich, 2018). In addition, at higher education institutions in the United States, psycho-educational assessments of developmental disabilities are conducted by, for example, qualified school or clinical psychologists (Eurich, Krause, Cigularov, and Thornton, 2009).

In Japan, Tsukuba University (Nakano et al., 2024) and Osaka University (Suwa et al., 2017) have appointed professional assessors and have established a systematic approach for the academic support of developmentally disabled students based on assessments. As mentioned, the number of students with a diagnosis of or tendency toward developmental disabilities enrolled in Japanese higher education institutions is increasing, and opportunities to adjust the learning environment based on the study support needs of students with developmental disabilities and their appropriateness are expected to increase. Moreover, assessors, who may be responsible for making such decisions based on their professional knowledge will become indispensable professionals in Japanese institutions of higher education.

We have been examining the skills and competencies needed by professionals who, among other things, are responsible for supporting students with developmental disabilities. The first difference between Japan and other countries in this regard is the difference between specialists and generalists. In Japan, the roles of academic support staff vary widely, depending on the legal background and the economic situation of each institution of higher education, as well as on environmental factors such as the human and material resources available for the academic support system for students with disabilities. Administrative staff may be in charge of interviewing and coaching students with disabilities or may conduct informal assessments of the study environment and other factors necessary for the provision of reasonable accommodation.

In some higher education institutions, it is difficult to conduct formal assessments based on objective indicators, and it is not always clear where and from how to request, for example, that psychological and intelligence tests be conducted, or there are no such resources easily available. Therefore, it was confirmed that it is necessary to establish a reasonable assessment implementation system and a study support system that is compatible with the environment of each institution of higher education. It was also inferred that in Japan, there is a need to develop human resources while taking into account the training and placement of generalists.

In addition, the University of Tsukuba, to which many of the present authors belong, has been accredited since 2018 as an "institution for the systematic training of university staff" as part of the Ministry of Education, Culture, Sports, Science and Technology's system of education-related inter-use centers. In partnership with this initiative, several training sessions related to assessors and assessment at the higher education level and symposiums have been conducted. The discussions held at these training sessions gave rise to the following important points as regards assessment in higher education institutions:

・The importance of working as a team to support each student by identifying each student's functional disabilities and needs from a multifaceted and ongoing perspective, and by sharing ideas for the best possible study support in the current study environment.

・The importance of having at least one person with experience as a psychologist on the team, who comprehensively and appropriately utilizes approaches including psychological tests, and maintains ongoing involvement with the intention of promoting self-understanding that matches the target student's situation.

With respect to multidisciplinary cooperation, it is important for experienced psychologists to provide clear explanations of the student's functional disability and social barriers in the study environment, to share information as a team, and to plan support that can be provided in the student's current study environment.

In addition, there have been discussions on the importance of skills and competencies that faculty and staff involved in supporting diverse students should acquire, such as knowledge of developmental disabilities and a positive attitude such as that of a coach who can empower students. Previous studies that informed the discussion were also thought-provoking. The details are provided below.

Harrison et al. (2022) sent cases of fictitious students to 50 universities to investigate the reasonable accommodation review process. They reported that many universities made decisions to provide reasonable accommodation even though there was no clear diagnosis of ADHD or functional impairment supporting the need for extended testing time. As this study suggests, it is important to remember that an unreasonable one-size-fits-all response may not only undermine educational equity for students with disabilities, but also deprive those students of the opportunity to learn and be legitimately evaluated. Again, since the number of students with disabilities, especially developmentally disabled students, is increasing in Japanese institutions of higher education, we believe that we should try to train Japanese assessors to support students with disabilities in Japan.

What skills and competencies are considered necessary for assessors in Japan?

As mentioned, unlike assessors in Europe and the U.S. who work as specialists, assessors in Japan are expected to work as generalists. In addition, although it is desirable for an assessor to be a licensed psychologist working as a specialist who handles evidence and psychological/intelligence testing, considering the reality of dual employment in the field, nurses, public health nurses, social workers, etc. assessors are not the only professionals who are expected to be involved in the support of students with developmental disabilities. They are also involved in the actual support of students with disabilities. In this way, many staff members work together as a team to support individual students with disabilities. Supporters are required to have the skills to conduct assessments using psychological and intelligence tests and to be able to propose appropriate support based on the results of those assessments. (It is assumed that not all supporters need to be proficient in testing.)

Based on the discussions reported in the previous section, we have developed three major categories of skills and competencies ("understanding students and universities," "cooperation and collaboration with related organizations inside and outside the university," and "assessment of dysfunction") as requirements for a Japanese assessor. The details are as follows.

In relation to understanding students, universities, etc.:

- The ability to identify various difficulties related to study associated with the student's main complaint.
- The ability to deal with necessary and desired information according to the main complaint and findings.
- The ability to understand the context (climate, atmosphere, educational goals, etc.) and social barriers of the university or other institution to which the student belongs.

In relation to coordination and collaboration:

- The ability to understand the situation and roles of support coordinators, medical, health, welfare, and other related parties inside and outside the university.
- The ability to work and collaborate with support coordinators, medical care, health, and welfare personnel, and other related parties inside and outside the university, and share information appropriately and communicate it to non-specialists in an easy-to-understand manner.
- The ability to confirm whether and to what extent information can be shared while taking personal information into consideration.

In relation to the assessment of functional impairment:

- The ability to understand what tests can be used to determine functional impairment (and to refer to specialists as needed).
- The ability to handle and administer standardized psychological and other tests appropriately, and to interpret assessment results in the context of the university and other institutions to derive and suggest necessary support.
- The ability to make cross-diagnostic observations (assessments), taking into account the non-specificity of symptoms and non-cognitive factors (e.g., students' own thoughts and experiences), such as various difficulties (Lagacé-Leblanc et al., 2022) that are not limited to functional disabilities (e.g., the research domain criteria; RDoC) (Pacheco et al., 2022).
- To provide appropriate feedback and encouragement, mediated by assessment tools, with the intention of promoting students' self-understanding and guiding them to appropriate career choices.

- To monitor the support status and student situation and derive support that suits the situation.
- To use assessment results obtained from outside medical institutions as evidence for assessing the student's condition and employ them to formulate and test various hypotheses.
- To be able to incorporate new knowledge (examination and symptom mechanisms) and skills.

In addition, based on the opinions that "there is insufficient time to learn widely and deeply enough solely in training programs for psychologists," "it is necessary to continue and learn further after entering the field," and "there may be things that can only be learned after entering the field," we assumed that there are two major stages of learning, namely in educational programs at universities or graduate schools, and during employment. In the future, when planning assessor training at an institution of higher education, it may be necessary to consider a program based on the latter stage of learning.

Summary and Future Prospects

To secure professional human resources (≈assessors) to support students with developmental disabilities, it will be necessary to create and secure opportunities for learning after graduation from the program, as well as to describe the content, learning process, and skills and competencies to be acquired, and design a program with the required content. In Japan, the term "assessor" is still unfamiliar, and its definition has not yet been established. In addition, it bears repeating that staff members involved in the support of students with disabilities are considered to be generalists rather than clerical staff, assessors, etc., and that their job descriptions and the scope of work they can handle are more important than their job titles. They are required to implement psychological tests such as intelligence tests and questionnaires (e.g., autism spectrum quotient (AQ) (Wakabayashi et al., 2004), CAARS Japanese version (Nakamura et al., 2012), AASP Japanese version (Hagiwara et al., 2015), and reading and writing fluency (RaWF) (Takahashi et al., 2022)) Of course skills are important, but in addition, as a coordinated and collaborative team, skills related to obtaining and interpreting materials on which rational considerations are to be based are currently important in support of study at Japanese higher education institutions. For example, it is important to develop and understand the process and routes that must be followed to obtain the evidence for reasonable accommodation by asking where the accommodation is and by whom is it provided, to relate the test results to the student's functional disability and needs, and to develop support plans based on the results, as a team of faculty members involved with the student with the disability. The team will be able to develop a plan to support the student with disabilities based on the results of the test. In the medium to long term, however, it would be ideal if assessors were recognized as highly specialized and indispensable personnel for supporting students with developmental disabilities in Japan, as they are in Western countries, and if budgets for such professionals were secured and they were positioned within many higher education institutions.

Future practical issues facing Japan are the need to examine programs for training professionals involved in supporting students with developmental disabilities, and to discuss programs that focus on what students learn after graduation from educational programs undertaken after employment. It is also necessary to discuss the three types of skills and competencies required for Japanese assessors in the context of the actual conditions found in Japanese institutions of higher education.

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Research Articles and Essays

The Fatigue in Educational Contexts Survey (FEC): Elevating, Empowering, and Engaging Deaf and Hard of Hearing Students

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Abstract

This research addresses the lack of inclusive fatigue measures for Deaf or hard of hearing (DHH) students in educational settings. It introduces the Fatigue in Educational Contexts (FEC) survey, designed to assess and interpret fatigue in DHH students, enabling better understanding, advocacy, and mitigation of fatigue-related challenges in the classroom.

Keywords: Deaf, hard of hearing, fatigue assessment, inclusive educational tools

The Fatigue in Educational Contexts Survey (FEC): Elevating, Empowering and Engaging DHH Students

Classrooms comprise an ongoing array of cognitive, visual, auditory, and attentional demands. Students who are Deaf or hard of hearing (DHH) must navigate these demands with degraded hearing amidst competing auditory sounds (e.g., teacher's voice, chair movements, and hallway conversations) for up to six hours a day, five days a week. The increased effort and exertion needed to learn contributes to greater levels of fatigue that is compounded when students are denied resources known to minimize fatigue. Fatigue in educational settings for students who are DHH is poorly understood by both students and educators. Students often disregard fatigue symptoms or internalize the causes, have limited or maladaptive coping strategies, and minimize the serious consequences these actions have on their learning and academic success. Teachers frequently misconstrue ineffective coping behaviors as a lack of motivation, and those who liken hearing devices to jewelry fail to recognize the importance of educational supports moderating cognitive, auditory, and visual exertion. Thus, our goal is to provide a means for DHH students and their educational team to understand the impact of fatigue, to advocate for appropriate supports (strategies and programs) and to moderate fatigue in educational contexts. Thus, we designed the Fatigue in Educational Contexts (FEC) survey. The purpose of the survey is to accurately identify, describe, and interpret the presence and intensity of fatigue, and inform alleviation approaches.

What is Fatigue?

Fatigue is a complex and multifaceted construct to define. Fatigue is often misconstrued as synonymous with being tired. Although tiredness may be a symptom of fatigue, fatigue cannot be resolved with rest. Fatigue results when cognitive, emotional, or physical attentiveness is required for prolonged periods of time. When an individual is tired, sleep can help to alleviate feelings of tiredness. Current definitions vary, based on whether fatigue is defined subjectively or objectively. Subjectively, fatigue is defined as a decline in the efficiency of an individual's focus, concentration, and alertness and objectively defined as a decline in an individual's performance due to sustained or prolonged demands (Hornsby et al., 2017; Hornsby, 2013).

Three types of fatigue have been identified in the literature: cognitive or mental fatigue, social-emotional fatigue, and physical fatigue. Cognitive fatigue refers to a decline in an individual's focus, concentration, and alertness due to prolonged demands (Bess & Hornsby, 2014a; Bess & Hornsby, 2014b). For DHH students this could look like cognitive energy spent on localizing a teacher's voice in a noisy classroom, trying to simultaneously watch the teacher and signed language interpreter to comprehend instruction, or understanding a signed (e.g. ASL) message and translating it to create academic notes in written English. Social-Emotional Fatigue occurs when interpersonal effort results in feeling emotionally worn out and feeling drained (Michielsen et al., 2004). For example, feeling a lack of motivation, frustration, or sadness, and a need to push oneself to complete schoolwork or socialize. Finally, physical fatigue stems from physical effort creating muscle strain or injury (Bourland Hicks et al., 2002). For example, eye strain from hours of watching an ASL interpreter or attempting to speechread/lipread and decipher a teacher’s facial expressions.

More likely, a combination of these three types of fatigue will impact students. However, it is important to differentiate between them as they will impact different aspects of the students’ school life and social life. Separating these aspects of fatigue into categories helps to identify the difficulty students are presenting with, to better support students with their fatigue.

Auditory Effort and Visual Effort

There are two factors that may contribute to higher levels of physical, social-emotional, and mental fatigue for DHH students: auditory effort and visual effort. Auditory effort refers to the cognitive exertion required to attend to, and understand, a spoken message (McGarrigle et al. 2014). Spoken messages in classrooms must often be processed and understood in the presence of noise (e.g., classmate chatter, squeaking of moving chairs, ventilation systems, or hallway noise). Notably, Goldberg and Richburg (2004) reported that younger students in general perform more poorly in noisy classrooms than adolescents regardless of hearing ability. Thus, students with compromised auditory systems will need to work much harder to attend to and understand spoken messages than students with adequate hearing abilities (Bess et al., 2020; Hornsby et al., 2021; Hornsby et al., 2014). Even the seemingly simple act of localizing sound sources in a classroom may be inordinately challenging for students who are Deaf, particularly when there are competing noises or when speaker utterances overlap (Tharpe, 2008).

Visual effort refers to the physical and mental exertion required to visually attend to and comprehend a message (Rohatyn-Martin & Hayward, 2016). Classroom examples include looking at the person communicating a spoken message, reading a textbook, or watching a video. Fatigue can result due to the auditory signal in amplification devices, which is rarely equivalent to normal hearing, resulting in students attempting to use visual information to supplement and compensate for the diminished auditory signal (Bess & Hornsby, 2014a). For students who communicate or learn through a signed language, greater levels of fatigue related to visual effort may also arise as students attempt to attend simultaneously or alternatively to their teacher and an interpreter to comprehend classroom instruction or conversation.

Few studies have investigated student fatigue within the classroom despite the negative effects of fatigue on student's education being widely acknowledged in research (Bess et al., 2020; Bess & Hornsby, 2014b; Davis & Hornsby, 2023; Hornsby et al., 2014). Additionally, students have seldom been placed in the role of primary informant regarding their educational experiences. Authentic student voices provide the opportunity to uncover beneficial or potentially disadvantageous educational practices within classrooms, which can help to mitigate the compounding effects of fatigue. The social, academic, vocational, and economic outcomes of students are significantly compromised when student voices are absent or ignored. Furthermore, investigating students' experience of fatigue within inclusive education is valuable for educators and policy makers. Students' perspectives can inform and enhance decisions on educators' pedagogy with respect to fatigue to support increased student engagement, motivation, and achievement within the classroom.

Development of the FEC

The objective of our program of research is to establish a framework for DHH students and their educational team to understand the implications of fatigue, advocate for suitable supports (including strategies and programs), and moderate fatigue within educational environments. The first phase of the research involved the development of the Fatigue in Educational Contexts (FEC) survey. This phase aimed to construct a survey instrument to accurately identify, describe, and interpret the presence and intensity of fatigue, and inform alleviation approaches.

The development of the FEC survey encompassed a systematic progression of measures, including the conduct of focus group interviews with DHH experts (i.e., DHH post-secondary students; parents of DHH students; and DHH professionals—teachers and clinicians). These expert groups provided complementary perspectives, experiences, and knowledge related to fatigue.

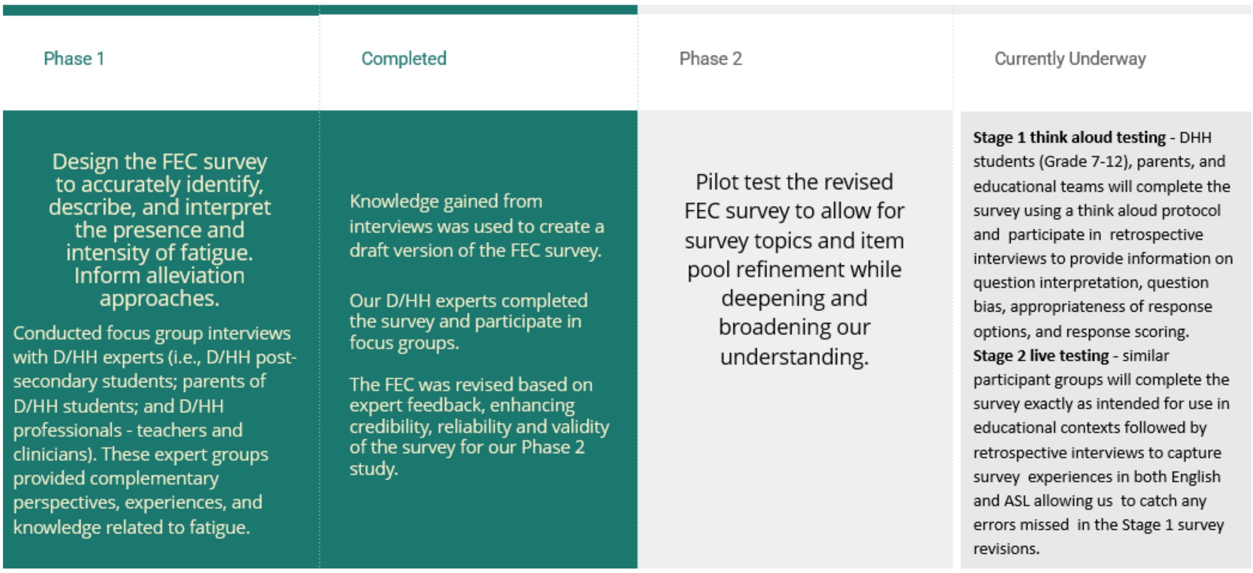
Understanding the perspectives of DHH students is essential as they give first-hand experience of how they are affected by fatigue in their educational and home settings. Student voices have traditionally not been considered credible sources in instrument development, yet students themselves possess unique insights that enhance instrument credibility and applicability (Hayward et al., 2013).

Perspectives of parents/caregivers of students who are DHH are also essential as they provide first-hand accounts of the effect of fatigue for their child at home, enact key advocacy roles throughout their child's education, and tend to consider education beyond academic outcomes, which include social, emotional, and vocational values. Like student voices, parent voices have traditionally not been considered credible sources in instrument development, yet parents possess unique insights that enhance instrument credibility and applicability (Hayward et al., 2013).

Professionals included teachers, speech-language pathologists, and audiologists who have a minimum of 5 years' experience supporting students who are DHH in educational settings. Teachers can speak to their classroom experiences, successes and challenges encountered in employing fatigue-mitigation strategies, and professional training received to support diverse student needs. Speech-language pathologists and audiologists can provide assessment, intervention, and consultation support in educational settings for students who are DHH. Their professional training and focus on individual students rather than an entire classroom of students offers a complementary lens to that of teacher experts. Knowledge gained from interviews was used to create a draft version of the FEC survey, and two parallel versions for parents/caregivers and teaching/professional teams. The FEC was then revised based on expert feedback, enhancing credibility, reliability, and validity of the survey for Phase 2.

Figure 1

The Fatigue in Educational Contexts Survey Timeline

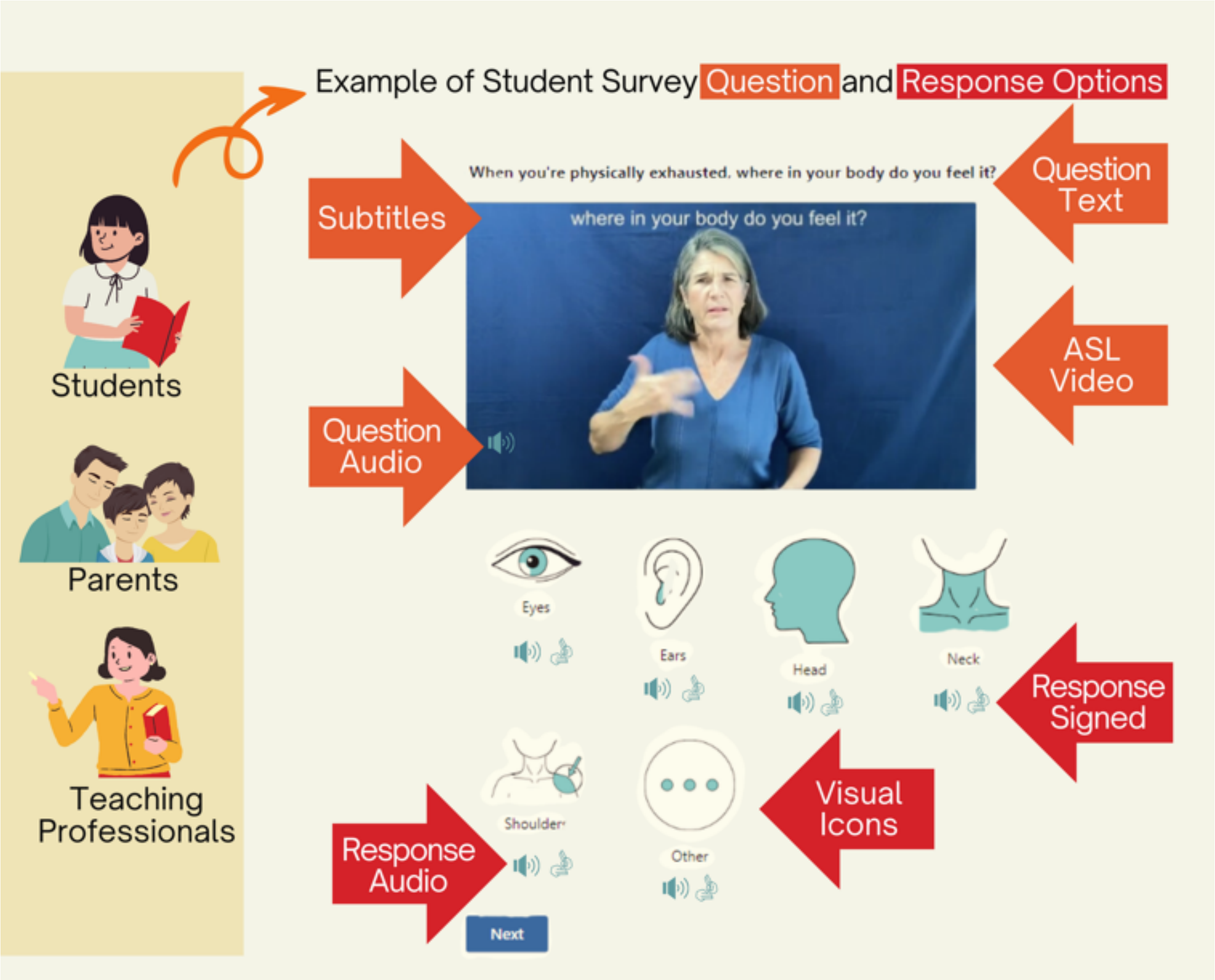


Phase 1	Completed	Phase 2	Currently Underway
Design the FEC survey to accurately identify, describe, and interpret the presence and intensity of fatigue. Inform alleviation approaches. Conducted focus group interviews with D/HH experts (i.e., D/HH post-secondary students; parents of D/HH students; and D/HH professionals - teachers and clinicians). These expert groups provided complementary perspectives, experiences, and knowledge related to fatigue.	Knowledge gained from interviews was used to create a draft version of the FEC survey. Our D/HH experts completed the survey and participate in focus groups. The FEC was revised based on expert feedback, enhancing credibility, reliability and validity of the survey for our Phase 2 study.	Pilot test the revised FEC survey to allow for survey topics and item pool refinement while deepening and broadening our understanding.	**Stage 1 think aloud testing** - DHH students (Grade 7-12), parents, and educational teams will complete the survey using a think aloud protocol and participate in retrospective interviews to provide information on question interpretation, question bias, appropriateness of response options, and response scoring. **Stage 2 live testing** - similar participant groups will complete the survey exactly as intended for use in educational contexts followed by retrospective interviews to capture survey experiences in both English and ASL allowing us to catch any errors missed in the Stage 1 survey revisions.

Through the revision process, we received feedback to incorporate additional visual components to the FEC survey. We have worked to ensure various accessibility features are present in the survey to be inclusive of all DHH individuals. As illustrated in Figure 2, each survey question will present individuals with options to view the question as text, listen to an audio recording of the question, and watch a video of the question signed in ASL with subtitles. Additionally, individuals will be presented with each of the response options as visual icons, signed in ASL, and spoken language audio recordings. These features will cater to the heterogeneity of students who are DHH—spoken language users, signed language users, and dual language (spoken and signed) users who may be monolingual, bilingual or multilingual.

Figure 2

Accessibility Features on the Fatigue in Educational Contexts Survey



When you're physically exhausted, where in your body do you feel it?

where in your body do you feel it?

The second phase of development of the FEC is currently underway and is dedicated to the pilot testing of the refined Phase 1 FEC survey. This stage facilitates the refinement of survey themes and item pool, thereby fostering a deeper and more comprehensive understanding of fatigue within educational settings. The pilot testing will unfold in two stages, each designed to address specific facets of refinement and expansion.

The first stage of Phase 2 involves facilitating think aloud testing. Secondary DHH students (Grade 7-12), their parents/caregivers, and educational teams will complete the survey using a think aloud protocol and participate in retrospective interviews to provide information on question interpretation, question bias, appropriateness of response options, and response scoring. The second stage will involve live testing of the survey. Similar participant groups will complete the survey exactly as intended for use in educational contexts followed by retrospective interviews to capture survey experiences in both English and ASL, providing opportunities to catch any errors that may have been missed during stage 1 (think aloud testing) survey revisions.

The ongoing pilot testing of the FEC survey marks a significant step towards refining our understanding of fatigue and implementing effective strategies to support students in managing and mitigating its effects. By acknowledging and addressing fatigue, educators, policymakers, and stakeholders can foster more inclusive and supportive learning environments that promote student engagement, motivation, and achievement. Furthermore, it is imperative to highlight the accessibility features embedded within the FEC survey and underscore their importance. Recognizing the diverse needs of students, including those who are DHH, we have intentionally worked to ensure that the FEC survey is accessible to all participants. To that end, incorporating visual design alongside accessibility features such as screen reader compatibility and language representation in spoken, written, and signed modes enhances the usability and inclusivity of the survey. This commitment to accessibility is essential in ensuring all students are empowered, regardless of their abilities or communication preferences, to actively engage in the survey process. Intentionally prioritizing accessibility, we not only defend principles of equity and inclusion but also ensure that the voices and experiences of all participants are heard and valued. Thus, the FEC survey, designed to elevate, empower, and engage DHH students will serve as a cornerstone in promoting genuine understanding and meaningful insights into the experiences of DHH students regarding fatigue in educational contexts.

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Research Articles and Essays

Where is Adapted Physical Education Heading?

Is it the Right Direction?

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Abstract

Over the past two decades, Adapted Physical Education (APE) has advanced, yet access to physical activities for people with disabilities persists. Stakeholders were mixed into groups and discussed barriers such as limited access, funding, and misconceptions about disabilities. Emphasis was placed on interdisciplinary cooperation and understanding for progress in this field.

Keywords: Adapted physical education, physical activity, inclusion

Where is Adapted Physical Education Heading?

Is it the Right Direction?

Adapted physical education (APE) is physical education (PE) designed to provide access to the general PE curriculum for disabled students who cannot participate successfully in the curriculum even with modifications or accommodations (Auxter et al. , 2010; Sherrill, 2004). Historically, APE followed a medical model, meaning that disability was a result of a condition that doctors were trained to address and attempted to cure when possible. It wasn't until the 1990s with the passage of key legislation that participation in PE for students with disabilities began to change and more appropriate options for students with disabilities were made available. This article will summarize conversations and outcomes from a facilitated discussion at the 39th Annual Pacific Rim International Conference on Disability and Diversity on February 28, 2024 in Honolulu, Hawai'i.

Initial Background

The following background information was provided by the presenters so that participants had a shared framework and discussion language. Participants travelled to the conference from various states, including California, Georgia, New Jersey, Virginia, and others, with varied knowledge of APE and PE. No participants were current APE teachers or receiving APE services at the time of this presentation.

Legislation

Adapted physical education began with the implementation of P.L. 94-142, Education for all Handicapped Children Act of 1975. P.L. 94-142 mandated a free and appropriate public education (FAPE) for all students with disabilities ages 3-21(20 U.S.C. §1401). Physical education was viewed as a direct educational service (20 U.S.C. §1401). The law also introduced the Individualized Education Plan (IEP) which is specifically designed instruction for students with disabilities (20 U.S.C. §1401). Along with the IEP, least restrictive environment (LRE) was introduced and refers to the environment where students with disabilities can participate to their fullest potential (20 U.S.C. §1401). Multiple placement options can be considered to adhere to LRE for the students with disabilities, including: (1) placement in a general PE setting; (2) placement in a general PE setting with instructional modifications implemented; (3) placement in a general PE setting with assistance from a paraeducator or APE specialist; and (4) placement in a separate APE class with other peers with disabilities and additional staff for assistance. Education for all Handicapped Children Act of 1975. P.L. 94-142 is now known as P.L.101-476 - Individuals with Disabilities Education Act (IDEA) of 1990 and has continued the concepts of FAPE, IEP, LRE, and PE as a direct educational service (20 U.S.C. § 1400 2004).

The implementation of P.L.101-336 - Americans with Disabilities Act (ADA) of 1990 expanded civil rights protections for individuals with disabilities in the public and private sectors which included public and private schools (42 U.S.C. § 12101 *et seq*., 1990). Americans with Disabilities Act of 1990 was reauthorized in 1997 and 2003. Even though the laws were meant to increase opportunities for students with disabilities to participate in general PE with their peers to the maximum extent possible, there have been positive and negative trends that have influenced this.

Current Positive Trends in Physical Education

The aforementioned laws have allowed for improved access to the PE curriculum which has led to increased inclusion of students with disabilities in general PE. Physical education teacher candidates learn about disability awareness in their coursework and learn how to adapt and modify skills and include those modifications in their lesson plans for all students regardless of ability level. The growth of both high and low technology and enhanced equipment has allowed for greater inclusion of students with disabilities in PE. For example, equipment that provides sounds for those with visual impairments to locate equipment and their body in space or equipment that is more tactile in nature for those with sensory needs. In the past decade, there has also been continued funding available in higher education for APE personnel preparation grants. When awarded, these grants provide direct financial support to help prepare APE teachers or those going into doctoral programs to work with students with low incidence disabilities.

Current Negative Trends in Physical Education

Despite some positive developments in APE, numerous negative trends persist. Often, uncertified teachers from other disciplines are hired as PE and APE teachers, undermining their importance and potentially leading to inadequate instruction. This shortage of qualified personnel, including paraeducators, exacerbates the issue, creating a detrimental cycle that deprives students, especially those with disabilities, of the full benefits of PE and APE participation. Additionally, support staff and paraeducators are not trained to understand how to appropriately instruct in PE classes, and often fall back on outdated “roll the ball out” models that have persisted for decades and provide little support to students with disabilities.

This lack of support can lead to frustration on the part of the student and prevent them from engaging in physical activities outside of the mandatory classroom instruction. This further widens health disparities and health outcomes for those who are disabled.

Barriers to Progress

While people do understand the importance of physical activities for those who are disabled to enhance over all well-being and quality of life, the connection often is not made with the confines of school-based settings such as PE and APE. Students should be given the opportunity in schools to learn the skills necessary to engage in lifetime activities outside of school that will result in healthier lifestyles and should be provided the accommodations needed to do this successfully. This often does not happen due to a lack of understanding of the importance of PE and APE among state legislators, educational leaders as well as educator and administrators in the schools.

There is a lack of awareness of the competencies needed of PE teachers to deliver APE which is demonstrated by school administrators not filling the positions with certified educators. When teachers are placed in positions with a lack of training in that subject area, professional development is needed and lack of funding at schools does not offer those important opportunities for teachers to learn. At universities and colleges, the pre-service curriculum for many Physical Education Teacher Education programs only includes one class in APE, which often is not sufficient for teachers to teach APE. Therefore, professional development opportunities are needed to supplement their knowledge base but may not be readily available. Collectively, these factors minimize and create barriers for progress within the APE field.

Discussion and Guiding Questions

After background information was provided through lecture format by the presenters, the presentation shifted to include general discussion. Prior to discussion, the presenters asked the background of attendees and found that participants ranged across the lifespan and a variety of educational and professional backgrounds. An informal poll was gathered and, based on responses, the presenters loosely categorized attendees into the following groups: high school students who attended a segregated deaf high school; adults with disabilities; special education teachers; K-12 service providers; higher education faculty; and doctoral students. The participants were then prompted to mix into three discussion groups so that participants were represented across all stakeholder types in each group. After this process, two of the discussion groups included various professionals and several deaf high school students, whereas one group was primarily made up of professionals and adults. Three questions were created and used as initial conversation starters for the discussion groups:

1. What advancements have been made in the broader disability field in the last 10 years? Are those trends the same in APE?
2. What issues still need to be addressed in the disability field? Who is being left out of the conversation? Is this the same for APE?
3. How can we work collaboratively to move the field forward? How can APE be a part of this?

Themes and Take-Aways from Audience Discussion

Conversations in groups centered around the general topics, but not all groups discussed all questions in the given time. The following are general themes that emerged from the conversations: 1) desire for engagement; 2) lack of awareness and professional training; and 3) need for advocacy. These themes are further discussed below.

Those Who Are Disabled Want to Engage

Across the discussion groups, disabled students made clear their interest in and desire to engage in PE, physical activity, recreation, and sport. This desire was echoed by professionals actively working with disabled students and individuals. Within the discussion, several deaf students shared their love for sport. One student provided several examples of his love for basketball, sharing stories of various opportunities he had to play and develop his skill and passion for the sport.

In one discussion group, conversations of love for sport and physical activity prompted further questions of specific barriers or negative experiences within these spaces. While students agreed on their desire to engage, varied experiences were shared regarding whether or not disability contributed to any exclusion in sport. One student described that he did not experience specific barriers due to disability or deafness, and instead minimized his playing when his skill level did not match the teams he was trying out for. Other students described specific experiences in which they were interested in engaging in activities, but differences in communication between them and hearing individuals presented challenges.

Lack of Awareness and Professional Training

The faculty and doctoral students felt that there has been a shift in the focus of inclusion. In particular, based on their observations, they discussed a potential increase in focus on academic inclusion in the classroom and a decrease on inclusion in APE. The focus recently seems to be more on academics, while the importance of physical activities to enhance academics is being overlooked. Additional discussions uncovered that attendees felt there has been a positive change in person-first versus identity-first language, and that more people with disabilities are being included in important conversations and decision-making processes.

Across all groups, there was an overall thread that many teachers were not adequately prepared to teach PE/APE and it was an “afterthought” assignment to their workloads. For example, special education teachers shared that they were often responsible for the PE programming of the students when they have little to no training in that area. One educator also shared frustrations she held toward other professionals that did not actively engage or make accommodations for her disabled students. These discussions appear to align with challenges documented with the literature and compliment previous calls for improved capacity for APE training among various professionals.

Need for Advocacy

Many stakeholders shared the need for improved advocacy at all levels- K-12, administrators in schools, higher education PE teacher education and APE programs, legislators, and educational representatives in order for effective change to take place. Parents, students with disabilities, and their families are a critical component of this communication. Education regarding the purpose of APE and how it can enhance academics and overlap needs to occur. There seems to be a lack of understanding of APE outside of the field, and there is a responsibility among those in the APE field to educate and communicate with others on the importance of the field.

Some students in the audience mentioned that in their own school, they felt like they had good support and were given several opportunities to engage in those interests. Many specifically shared that they did not have experiences with exclusion and that was never an issue or even a conversation. However, some students described that outside of their school, they weren't always given those same opportunities. In fact, those with experiences in general schools shared stories of not being included or acknowledged in the same way purely due to communication differences, similar to experiences of not being included in sport. A Deaf teacher shared that when she was a student, she had to learn to advocate for herself due to the lack of opportunities that included her and limited awareness among professionals that she could participate with her non-disabled peers.

Conclusion

This session aimed to increase understanding of PE/APE for disabled individuals among a diverse audience, provide an opportunity for shared conversation between stakeholders to understand varied perspectives, and hear what problems and solutions attendees had with understanding and implementation of PE and APE for disabled population. The guiding questions prompted engaging and meaningful conversations that highlighted several key themes that are also apparent in recent literature. One prominent theme that emerged from the discussions was the strong desire among disabled population to be included and engage in physical activity and sport. The enthusiasm for engagement was echoed by both disabled students and various professionals in the audience, emphasizing the importance of providing accessible opportunities for individuals to enjoy the benefits of physical activities.

Moving forward, improving advocacy and understanding around PE/APE across the disability field, as well as encouraging professionals from within the field to engage and collaborate in other disability adjacent professions could contribute to important progress in the field. In addition, the conversations in this session underscored the importance and value of collaborative efforts, especially those including and highlighting the voices of members of the disability community. Future sessions that provide opportunities for such collaborations will be advantageous to our overall goals of creating inclusive and supportive PE/APE environments.

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Research Articles and Essays

The Exploratory Survey of Usage Data with Chatbot for Neurodiverse Individuals

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Abstract

In Japan, people facing daily challenges without a medical diagnosis have difficulty receiving public support services. We aimed to improve their accessibility to support information through text-based chat communications using chatbots and professionals. This study discusses the roles of chatbots and professionals based on our developed chatbot usage data.

Keywords: neurodiversity, chatbot, online support system

The Exploratory Survey of Usage Data with Chatbot for Neurodiverse Individuals

In Japan, public services, such as economic or life support, are provided to neurodiverse individuals based on medical diagnoses. Thus, people who have the characteristics of developmental disabilities without medical diagnosis cannot receive any public services in Japan. The characteristics of autism are included under the broad category of autism spectrum disorder (ASD) (Centers for Disease Control and Prevention, 2022). There is a related idea called “neurodiversity,” which means that the nature of the human brain and nervous system is diverse, not just for individuals with autism but generally (Singer, n.d.). From these perspectives, a medical diagnosis may exclude an individual, even if the characteristics of a developmental disability are present. In the Japanese public support system based on medical diagnosis, there is a problem whereby people without a medical diagnosis who experience daily challenges due to the characteristics of developmental disabilities have difficulty receiving public support or outreach from support organizations. From this background, it is necessary to establish a society and system in which everyone, regardless of a medical diagnosis, can achieve self-actualization. This is possible by individuals demonstrating their abilities in their studies and work and by society ensuring access to support resources, according to the difficulties that such individuals face. Through this chatbot implementation, we aim to build a culture of belonging in which all people are accepted, included, and able to establish their identities.

Even if they have not been diagnosed with developmental disabilities, people with the characteristics of ASD, attention-deficit/hyperactivity disorder (ADHD), or specific learning disorders (SLD), and who have difficulties in their daily lives due to the characteristics of developmental disabilities may have various challenges, such as difficulty in face-to-face conversations, frequent nighttime activities because of a lack of rhythm in their lives, and difficulty in verbalizing their problems. We focused on a chatbot that can provide support information and outreach in an interactive format via smartphones, which are used by 97.1% of Japanese citizens (Institute for Information and Communications Policy, 2023). Since digital technology can best meet individuals' needs, chatbots can provide a ready source of support. The technology, automatic response systems that use artificial intelligence (AI), can respond without face-to-face communication, regardless of the location or time of day. Therefore, chatbots can effectively support people facing difficulties in their daily lives owing to the characteristics of developmental disabilities.

However, although chatbots have advanced, they come with technical limitations in providing human services. According to OpenAI, which developed ChatGPT, a chatbot that uses generative AI and has been advancing rapidly in recent years, may provide incorrect information, even if it presents users with plausible answers (OpenAI, 2022). In addition, chatbots that run on artificial intelligence, including generative AI, are based on machine-learning algorithms, which are subject to the constraints of learned language models and other limitations. Therefore, it is difficult for chatbots to respond to unlearned inputs as flexibly as humans do. It is also difficult for them to obtain background information on users to respond appropriately and provide information accordingly. These are serious problems in the context of human services, which must appropriately identify users' support needs and provide evidence-based or correct support resources based on these needs. Solving this technical limitation involves a long process and considerable time.

Considering the background presented above, we proposed a "dabot network," where not only professionals, such as psychologists, and users who face daily challenges but also people with solutions to daily challenges arising from developmental disabilities can give and benefit from support resources. These resources can include support information and coping strategies, provided through cooperation between humans and digital technology using chatbots. By providing this network, we aim to achieve two things for users who face daily challenges owing to the characteristics of developmental disabilities: provide appropriate, well-founded, and correct information through chatbots, regardless of time and place, and provide support that appropriately identifies the support needs of the user.

The dabot network consists of four elements: (a) users, (b) dabot supporters, (c) human operators, and (d) support organizations. Users seek solutions to their daily challenges based on their characteristics of developmental disabilities. Dabot supporters are volunteers who suggest coping strategies for daily challenges to the human operators. Human operators are professionals, such as psychologists, who provide appropriate coping strategies in interactions with users, and they review and register all coping strategies for dabot. Support organizations include medical facilities and developmental disability service centers that provide support resources, such as coping strategies and support information. In this network, each element plays a role in the system to support the user. Human operators provide support information by corroborating, selecting, and editing evidence from the practical coping strategies that dabot supporters suggest for achieving the goal of providing appropriate, well-founded, and correct information through chatbots, regardless of time and place. Users obtain coping strategies by interacting with dabot. Some of these coping strategies involve public or private support facilities that allow user access. To address dabot's technical limitation, which is difficult to overcome, the network has human operators who help provide support that appropriately identifies the needs of the user by suggesting appropriate coping strategies through text-based chats with users. In addition, human operators can provide outreach to users when follow-up is necessary by chatting with users.

In a trial version, we provided dabot without human operators since there is a need to clarify the roles of operators and the dabot network when providing human intervention.

Several studies have been conducted to ensure access to information and resources by individuals with developmental disabilities. Bradford et al. (2020) provided resources through a chatbot as one way to make support more accessible to higher education students on the autism spectrum and those with related conditions. Grové (2021) is also working with young people, its intended users, to design a chatbot that can communicate evidence-based resources, mental health information, and other coping strategies through artificial intelligence and rule-based AI. The aim is to help young people who struggle to cope appropriately with stressors, such as school stress and feelings of depression and anxiety. However, these projects aim to develop and design appropriate chatbot content and conversations that support people in higher education and other youth through the collaborative efforts of key stakeholders. As such, no actual implementation of chatbots has been undertaken to determine the support needs of users or to survey their use of chatbots.

Research has been conducted to identify the usage needs for mental health chatbots by having those who self-identify as having ASD use a mental health conversational agent and then analyzing the messages between the user and agent (Aghakhani et al., 2023). However, this study focused only on the need for chatbot use and did not examine the division of roles by focusing on the relationships between supporters and chatbots. Therefore, the purpose of this study was to clarify the roles played by dabot and human operators based on the analysis of usage data to provide dabot users with access to appropriate support resources.

Method

Participants

We provided a trial version of dabot through our cooperating facilities, including medical facilities, developmental disability support centers, and higher educational institutions. We recruited 527 dabot users registered from January 23 to August 31, 2023 for this retrospective study. Twelve users declined to participate. The total number of participants was 515. Of the 515 participants, 166 were from a higher educational institution, 139 were from medical facilities, 111 were the dabot supporters, 48 were from welfare facilities, 16 were from government offices, 13 were from parents' associations, and 22 were unknown. "Unknown" means that dabot could not record their referrer due to a system malfunction or a method that does not record the source of the inflow.

Materials

Our developed chatbot called "dabot" automatically suggests coping strategies to users facing daily challenges. The use of dabot by university students has been shown to reduce the feelings of difficulties related to developmental disabilities, regardless of the presence or absence of a medical diagnosis or tendency of developmental disabilities (Sasaki et al., 2022). The dabot has two main user functions to access appropriate coping strategies: coping strategies suggestion and support needs assessment.

Figure 1

Overview of dabot

スケジュール管理・整理整頓について教えて

スケジュール管理・整理整頓・忘れ物防止についてですね

下から選んでタップしてね

どちらを知りたいか、選択してください。

●ものをなくさないための工夫
●ものを忘れないための工夫

知りたい内容を選んでタップしてね！（選択肢を横にスクロールしてね）

メールの仕方がわからない

メールの管理に関する工夫や、電話応対のコツをご紹介します。
どんなことが知りたいですか？

●メールの見逃し防止
●効率的なメールの探し方
●複数のアカウントを一括管理する
●上手なメールの書き方
●電話応対のコツ

「コミュニケーションについてもっと質問する」を選択すると、恋愛や友人関係、先生との関係づくりやグループワークのコツなどの工夫をお伝えできます。

知りたい内容を選んでタップしてね！（選択肢を横にスクロールしてね）

メールの書き方

困りごと評価ページ

このウェブページでは、あなたの困りごとが、ほかの人と比べて、どの程度強いのかということを定量評価します。
質問項目は全部で33項目あります。

1. 持ち物の中で捨てられないものが多くて、困る
○ そう思わない
○ あまりそう思わない
● ややそう思う
○ そう思う

2. 時間はあるのに課題や作業にすぐに取りかかれなくて、困る
○ そう思わない
○ あまりそう思わない
○ ややそう思う
● そう思う

3. 忘れ物や物をなくすことが多く

1. 「対人関係」に関する困りごと
非常に高い

「対人関係」の困りごとへのアイデアを知りたいときは、ダボットに「コミュニケーションについて教えて」と聞いてください。

2. 「注意・記憶」に関する困りごと
非常に高い

Note. These figures are screenshots of dabot providing some support information and support needs assessment to users. The dabot indicates support information according to menu selection (left) and typing (the second from left) by the user. The second image from the right is a screenshot of the support needs assessment input form. The right image is an example of the result of support needs assessment.

Coping Strategies Suggestion

Coping strategies suggestion has two kinds of interfaces: “Menu selection” and “Typing.” Menu selection allows users who have difficulty verbalizing their daily challenges to access appropriate coping strategies by selecting an item displayed by dabot (left in Figure 1). The main menu that is shown on the left in Figure 1 has five items related to daily challenges, such as “Daily Challenge Categories,” and one item that is a link to support needs assessment. The “Daily Challenge Categories” are: “What Can I Do Here?,” “Schedule Control, Tidy Up, Keep Your Stuff,” “Communication, Reading and Writing,” “Daily Rhythm, Physically and Mentally Drained, Stressed,” and “University Life, Job Seeking.” However, users can readily access coping strategies by typing if they can verbalize their daily challenges.

Support Needs Assessment

The support needs assessment allows the user to determine the tendencies of their support needs related to developmental disabilities by answering 33 questions with “Disagree,” “Disagree a little,” “Agree a little,” and “Agree” (the second from left in Figure 1). These questions have a significant correlation with the characteristics of ASD and ADHD as measured by the Autism Spectrum Quotient (AQ) and Conners’ Adult ADHD Rating Scales (CAARS) (Nakano et al., 2021). After the assessment, cute characters inform the user of the assessment results. In addition, a flow line allows users to ask dabot about the coping strategy in which they are interested by clicking the link on the results page.

Data Extraction

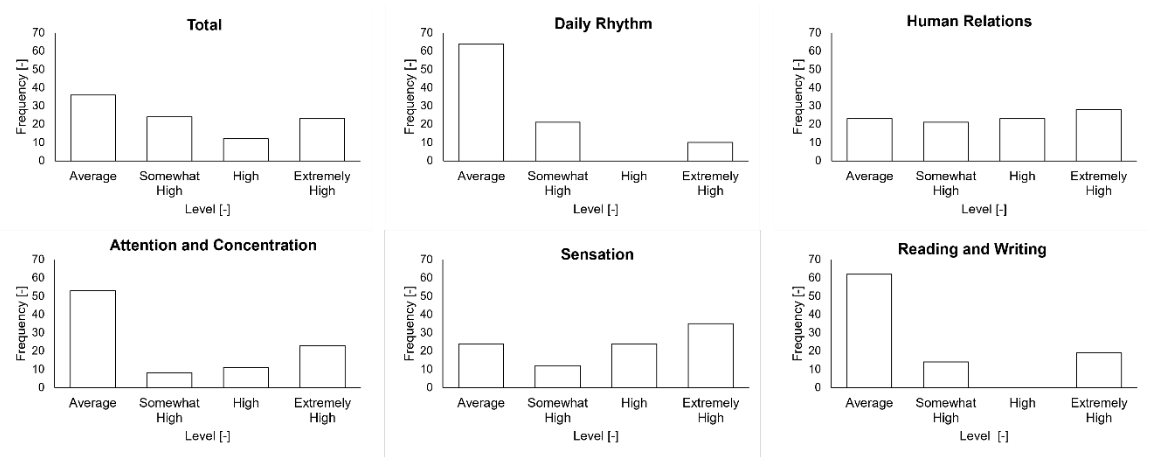
We can obtain two types of data: input to dabot using menu selection or typing and input to support needs assessment. All input data to dabot was textual and was linked to the input date and time. We processed them using natural language processing (NLP) in the analysis. The input into dabot was categorized as either menu selection or typing and was classified into one of five daily challenge categories. The input into the support needs assessment is numerical and calculated at the level of each daily challenge category based on the percentile value as calculated following Sasaki et al. (2018). The levels of each daily challenge category are “Average,” “Somewhat High,” “High,” and “Extremely High.”

Results and Discussion

Tendencies of Support Needs

Figure 2

Tendencies of support needs among dabot network users



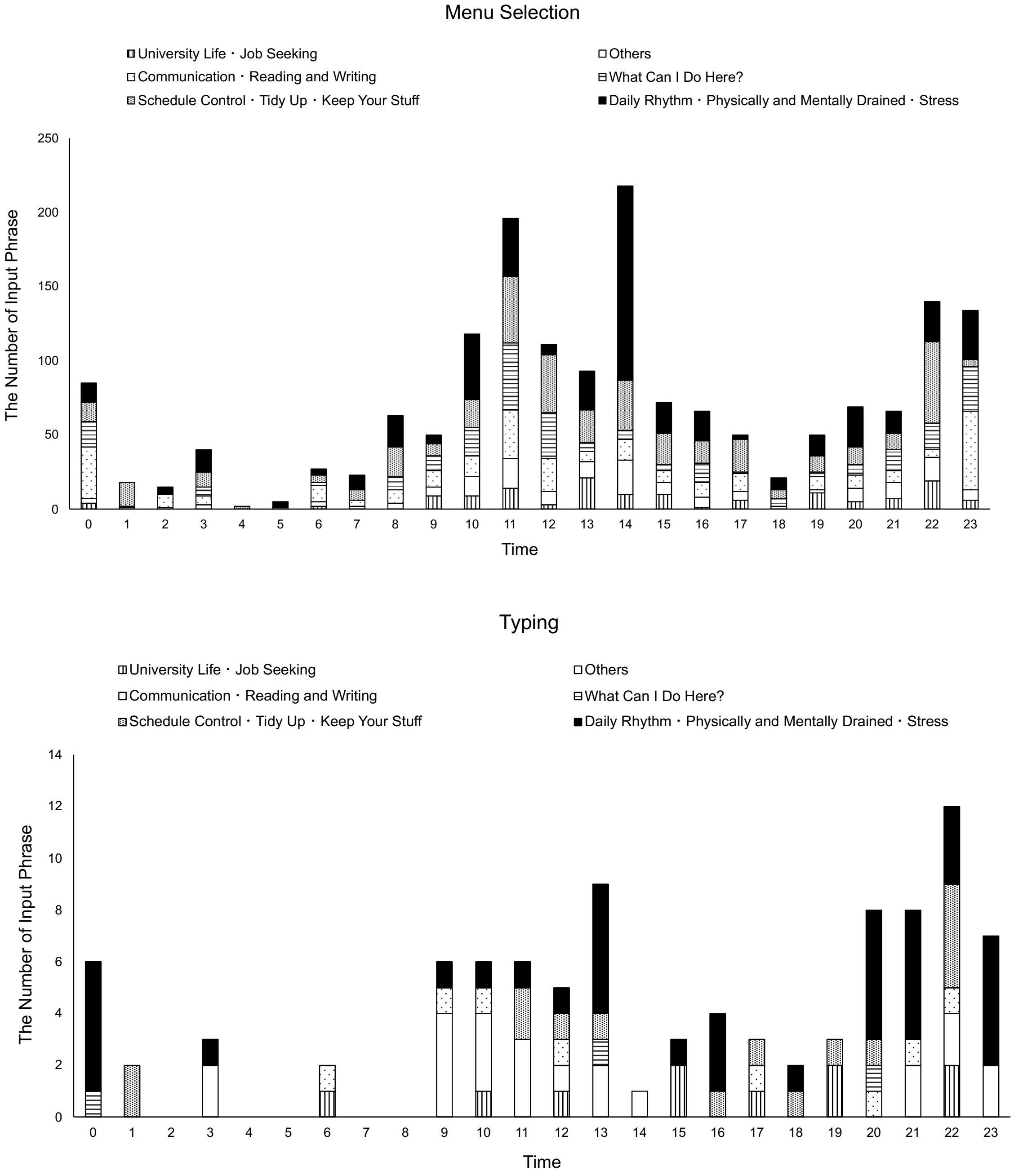
Note. We obtained 95 uses by 81 people and calculated the level of support needs based on the percentile value calculated by Sasaki et al. (2018).

The support needs assessment was used 95 times by 81 participants. Percentile values are standardized by the data based on Sasaki et al. (2018) and should be monotonically decreasing in the following order: “Average,” “Somewhat High,” “High,” and “Extremely High.” However, the results presented in Figure 2 were unexpected. In particular, the ratio of “Extremely High” was the highest in Human Relations and Sensation, indicating that the participants of this survey who used the support needs assessment tended to have these two types of support needs.

Hours of Use and Input Daily Challenges Categories

Figure 3

Timeline of accessing the dabot network and the categories the participants searched



Note. The top graph was generated from the menu selection input. The bottom graph was generated from the typing input.

The input into dabot was categorized into an appropriate daily challenges category. The dabot obtained 1,720 inputs through the Menu Selection interface. They were classified as follows: 487 inputs (28.3%) into “Daily Rhythm, Physically and Mentally Drained, Stressed,” 394 inputs (22.9%) into “Schedule Control, Tidy Up, Keep Your Stuff,” 289 inputs (22.9%) into “Communication, Reading and Writing,” 247 inputs (14.4%) into “What Can I Do Here?,” 166 inputs (9.7%) into “Others,” and 137 inputs (8.0%) into “University Life, Job Seeking.” The dabot obtained 96 typing inputs in total. They were classified as follows: 38 inputs (39.6%) into “Daily Rhythm, Physically and Mentally Drained, Stressed,” 22 inputs (22.9%) into “Others,” 15 inputs (15.6%) into “Schedule Control, Tidy Up, Keep Your Stuff,” 10 inputs (10.4%) into “University Life, Job Seeking,” 8 inputs (8.3%) into “Communication, Reading and Writing,” and 3 inputs (3.1%) into “What Can I Do Here?” Among the typing inputs, those classified as “Others” were inputs that had nothing to do with the coping strategies, such as “greetings” and “self-talk,” and inputs that did not fit into any of the categories of daily challenges we set, such as “childcare” and “tantrum.” In addition, inputs from the results page of the support needs assessment totaled 38. They were classified as follows: 14 inputs (36.8%) into “Daily Rhythm, Physically and Mentally Drained, Stressed,” 13 inputs (34.2%) into “Communication, Reading and Writing,” and 11 inputs (28.9%) into “Schedule Control, Tidy Up, Keep Your Stuff.”

Figure 2 indicates that the support needs of the user who used the support needs assessment are high in “Human Relations” and “Sensation.” However, in the coping strategies suggestion, many inputs related to “Daily Rhythm, Physically and Mentally Drained, Stressed” and “Schedule Control, Tidy Up, Keep Your Stuff’ were included, except for “Others.” According to Nakano et al. (2021), “Human Relations” is highly correlated with many characteristics of AQ, and “Sensation” has a correlation with the overall score of AQ and the subscale “interest in details.” Therefore, it can be inferred that many users who used the support needs assessment had characteristics of autism. However, this point needs to be carefully discussed in the future using scales of developmental disability characteristics such as the AQ and CAARS, as in the study conducted by Nakano et al. (2021). Furthermore, the large number of inputs of “Daily Rhythm, Physically and Mentally Drained, Stressed” and “Schedule Control, Tidy Up, Keep Your Stuff” is probably because the users had these characteristics. However, not all users of dabot used the support needs assessment, and the results of the support needs assessment did not link the input to dabot with each user. Thus, it is necessary to implement information-gathering systems in the dabot network to validate this possibility.

The number of users using the flow line from the support needs assessment results page to the coping strategies suggestion in dabot was 38, which represents 40% of the 95 users of the support needs assessment. This indicates that the flow line may help users develop coping strategies.

Figure 3 shows the inputs received by dabot from users and their categories plotted in a time series. This graph shows that dabot usage was relatively high around noon and late at night (around 10 p.m.). Menu selection tended to be performed around noon, whereas typing tended to be performed late at night. The most common late-night input in the typing category tended to be “Daily Rhythm, Physically and Mentally Drained, Stressed.” However, there was only one input related to sleep in the typing category during the night, between 6 p.m. and 8 a.m., and there was only one input related to the description of a time factor, such as not being able to sleep at night. In particular, the sample size of the typing category was small, and it is necessary to continue collecting data on the relationship between time and input categories to investigate and verify the relationship periodically, but “Daily Rhythm, Physically and Mentally Drained, and Stressed” tends to be common at midnight. In addition, when looking at the individual user inputs for typing, we found that many required repeated dialogue to gather the user’s background information. There were cases in which dabot could not provide a suitable response to the user in a single turn. For example, the coping strategies sought are not clear if the input is only “tantrum.” It is unclear if the user feels difficulty because they are having a tantrum or there are people around them who are having tantrums. Therefore, it is possible that the information provided by dabot was not in line with users’ needs. In addition, owing to the limitations of current technology, there is a possibility that chatbots may provide inappropriate answers. Therefore, in cases where the reliability and appropriateness of the presented information are required, a manned response by an expert is necessary. Looking at typing usage in Figure 3, it was found that this occurred was mostly at night. Considering the social background of Japan, where there is a shortage of volunteers for telephone counseling (The Hokkaido Shimbun Press, 2023; TOWNNEWS-SHA CO., LTD., 2024), it is preferable that dabot responds during nighttime hours. Thus, it may be necessary for dabot to gather the users’ basic information at night because dabot can smoothly pass the baton to human operators to provide appropriate coping strategies the next day if the suggested information from dabot is not the information the user was seeking.

Limitations

We used NLP to categorize the user text chat inputs so the classification accuracy might be less than 100%. However, we attempted to decrease the number of incorrect classifications through visual checks. Further, we were unable to collect personal information or link it to any data, such as support need tendencies.

Conclusion

People facing daily challenges without a medical diagnosis have difficulty receiving public support services in Japan. We developed a chatbot called dabot to provide support resources, including support information and coping strategies for people's daily challenges regardless of a medical diagnosis. However, chatbots have technical limitations during conversations with people. Thus, it is necessary for professional human operators, such as psychologists, to converse with users if dabot cannot respond appropriately. To realize this cooperative relationship between chatbots and professionals, we aimed to clarify the reasonable roles of dabot and professionals based on data-driven analysis to supplement the technical limitations of chatbots, where they cannot appropriately converse with users. We recruited participants from the users of the trial version of dabot and analyzed the text chat data and input for the support needs assessment. We confirmed the helpfulness of a flow line from the results page of the support needs assessment to a coping strategies suggestion. In addition, we clarified the needs of dabot users at noon and at night. In future studies, we aim to clarify the needs of users linked to personal information to analyze the association between input into dabot and the support needs tendencies. Additionally, we will gather users' basic information related to their daily challenges on dabot; the chatbot should be able to gather users' basic information to pass to human operators who can provide appropriate support information based on the users' background. The most important contributions of this study are in obtaining suggestions about the division of roles between professionals and dabot and in clarifying the frequency of time usage by analyzing dabot's data. In doing so, dabot may help people who face daily challenges in developing coping strategies, regardless of whether they have a medical diagnosis.

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Research Articles and Essays

Metabolic Equivalents of Outrigger Canoe Paddling for Health Equity: Methods of an Inclusive AccessMETs Study

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Abstract

People with disabilities have relatively low reported physical activity rates, increasing risk for chronic diseases and early mortality. This paper proposes a study design for evaluating the metabolic equivalents of outrigger canoe paddling, a culturally relevant means for promoting physical activity, for those with and without spinal cord injuries.

Keywords: Energy Expenditure, NHPI, METs

Metabolic Equivalents of Outrigger Canoe Paddling for Health Equity: Methods of an Inclusive AccessMETs Study

Physical Activity, Health, and the Burden of Chronic Disease Risk

Habitual physical activity (PA) is indispensable to the maintenance and improvement of physical and psychological health, and can be defined as *"a bodily movement produced by skeletal muscles that requires energy expenditure – including activities undertaken while working, playing, carrying out household chores, travelling, and engaging in recreational pursuits"* (WHO, 2023). More than a quarter of adults and over 80% of adolescents globally are insufficiently physically active according to standard guidelines - defined as engaging in at least 150 minutes of moderate intensity PA per week. Sedentary lifestyles causing physical inactivity (i.e., being insufficiently or not active at all) are common, especially in the United States (US). Physical inactivity is a risk factor for noncommunicable diseases, including obesity, diabetes, and cancer; it is the fourth-leading risk factor for mortality worldwide, decreasing life expectancy (United Health Foundation, 2021). Habitual PA reduces the noncommunicable diseases health burden and its risk factors by improving physiological and psychological well-being, as well as quality of life in the adult population (WHO, 2008).

Both the Center of Disease Control and Prevention and the World Health Organization emphasizes that guidelines for habitual PA are for everyone, across all communities, including people with disabilities (PWD) (CDC, 2021; WHO, 2023). While the health benefits of habitual PA are well established by research and widely accepted by health practitioners throughout the world, the actual health risks from a chronic lack of PA are not evenly distributed across populations. People with disabilities (PWD) have disproportionately high noncommunicable diseases rates and lower PA. Globally, more than 15% of the population has a health condition resulting in disability (WHO, 2011). Within the US, more than 60 million adults experience disabilities (Okoro et al., 2018). In 2018, the prevalence of people of all ages with disabilities in the US was 10.4% (Erickson et al., 2020). PWD have three times greater risk of developing noncommunicable diseases than people without disabilities (CDC, 2021). While PA research often excludes PWD (Rios et al., 2016), consistent PA is critically important for PWD who meet PA guidelines less frequently than people without disabilities. Almost half of people with Spinal Cord Injury (SCI), for example, reported no PA at all (Rochi et al., 2017).

Some groups are at higher risk for disability. Native Hawaiian (NH) and Pacific Islanders (PI) have a higher risk for disability compared to many other racial/ethnic groups (Seto et al., 2018; Taira, 2022). NH and PI also have a relatively high noncommunicable diseases burden when compared to the U.S. population average (HDOH, 2022a; Mau et al., 2009). While PA promotion shows promise to reduce this burden (Mau et al., 2009), only one quarter of adults meet the PA guidelines in Hawaiʻi (An et al., 2016; HDOH, 2022b). In existing population-level surveillance instruments, NHPI are reported to have lower rates of PA than other racial/ethnic groups (HDOH, 2022b). National samples also find that NHPI have lower rates of PA than other racial/ethnic groups (Kruger et al., 2004).

Culturally Relevant Physical Activities

“Culturally relevant physical activity is exercise that is based on a population’s cultural customs and is a promising field for chronic disease prevention and management”

(Sentell, Wu, et al., 2023). Culturally relevant PA also promotes health from a “strengths-based” perspective, which is an alternative to a deficit-focused approach to improve health, focusing on community strengths, inclusion, and prevention rather than poor health outcomes and stigmatization (Tones, 2019). Though good examples do exist, more evidence is needed about culturally relevant PAs and their potential to influence positive health outcomes and reduce disease risk. Hula dance (culturally relevant practice of dance in Hawaiian culture), for instance, has been shown to reduce disease risk and provide strong health benefits (Kaholokula et al., 2021; Usagawa et al., 2013). Additionally, land-based practices in the outdoors also show considerable promise for health (Ahmed et al., 2021). “Green exercise” (exercise done outdoors), and “bluespaces” (activities in bodies of water in nature) provide positive outcomes (Barton & Pretty, 2010; Liu, 2021). PWD are significantly understudied in this literature. There is a strong need to build the evidence base for culturally relevant PA, especially for PWD, and to consider these for health interventions, as well as for public health promotion to reduce health inequities. Health professionals call for the establishment of culturally relevant PA interventions when working with minority populations (Look et al., 2012).

Outrigger Canoe Paddling

Outrigger canoe (OC) paddling (or “paddling”) may hold deep promise for health promotion generally, as well as assist with the reduction of health inequities for NHPI specifically, but research is scarce (Canyon & Sealey, 2016). Paddling is a popular, culturally relevant activity in Hawaiʻi and beyond (*Hawaiian Outrigger Canoeing | It’s History & Revival To Date*, n.d.). A recent study found that in flagship state-level public health surveillance, 19.8% of the Hawai‘i population had participated in paddling in their lifetime with paddling participation much higher for NH (41.5%) and PI (31.1%) (Sentell, Wu, et al., 2023). There were also high levels of lifetime engagement in paddling across gender. Notably, few statistically significant differences were seen for NHPI on engagement across demographic or health factors (Sentell, Wu, et al., 2023). Ongoing research-in-progress by our study team to explore this engagement in more detail through mixed methods also strongly supports the promise of paddling as a health intervention. Our quantitative research-in-progress has found that paddling engagement is highest during earlier periods of life and tended to decrease over age, but meaningful engagement is still seen in older ages, including over 65, showing relevance over the lifespan (Sentell, Thompson, Mika, et al., 2023).

An especially important characteristic of paddling is that paddling can be adaptive and thus inclusive for PWD. Paddling could be beneficial not only to health from a strengths-based, cultural perspective, but also specifically for PWD. Other community-based aquatic activities for PWD among US adults have shown to increase quality of life and adaptive paddling has been developed to expand aquatic PA opportunities to PWD (AccesSurf Hawai‘i, 2023; Lopes et al., 2018).

Paddling METs

Outrigger canoe paddling shows enormous promise as a health promotion tool, but the physiological consequences of OC paddling on the ocean are unknown. While it could be assumed that OC paddling will influence the human body like that already described for many other well-studied aerobic PAs (e.g., running, cycling, cross country skiing), the lack of information still represents a critical barrier to both health promotion and scientific efforts.

Clinicians, health promotion specialists, and exercise scientists, for instance, are less likely to include or focus on PAs that are not definable and referenceable in the research literature.

One of the most common starting points for studying PAs, is to characterize the typical metabolic intensity, or metabolic equivalent (MET), experienced by the body during standardized measurement conditions. As a reference, a 1.0 MET value is equivalent to the energy cost of sitting quietly at rest, which is generally assumed to be 3.5 mls/kg/min (rate of oxygen uptake per kg per minute) (Jetté et al., 1990), which is also an assumed population average for resting metabolic rate for people without physical impairments (*ACSM's Guidelines for Exercise Testing and Prescription.*, 2006). MET values are commonly classified by intensity, where values from 1.0-1.5 METs are considered "sedentary," 1.6-2.9 METs are "light" intensity, 3.0-5.9 are "moderate" intensity, while ≥6.0 METs are classified as vigorous intensity PA (Jetté et al., 1990). Hence, when a person is engaged in moderate intensity PA, one is expending 3.0 to 5.9 times more metabolic energy than when sitting at rest. The practice of determining MET values for different human activities has been occurring for many decades. So many MET values have been reported in research literature, in fact, that an all-inclusive list of values has been compiled into a compendium. The most recent addition of this compendium – The 2024 Compendium of Physical Activities (February 2024) – has been subdivided into three separate compendiums by population – the Adult Compendium (18-59 years old; 1,114 PAs), the Adult Wheelchair Compendium (124 PAs), and the Older Adult (60+ years old) Compendium (427 PAs) (Conger et al., 2024; Herrmann et al., 2024; Willis et al., 2024). Even though the 2024 Compendium of Physical Activities has summarized the MET values for 1665 individual PAs (which is nearly double the number of PAs reported for the 2011 Compendium), OC paddling is not included as one of evaluated PAs for any population of adults. Further, with notable exceptions (e.g., hula), most METs are calculated for "Western" activities (e.g., jogging).

Additionally, most METs are for activities on land, but water sports are also popular, and the ocean has important cultural value and healing attributes (Amrhein et al., 2016; Huffer, 2017). Some water activities, such as canoeing and rowing are represented in the Compendium (Ainsworth, et al. 2011; Ainsworth, et al., 2011) However, these MET values are based on caneoing (i.e., without an outrigger arm) and rowing rather than OC paddling. A paddler in an outrigger canoe paddles with one paddle with a "T-top" and alternates paddling sides (left and right). A truly unique characteristic of the outrigger canoe itself is the stabilizing outrigger float called "ama" to the left of the boat. The ama is attached to the canoe with two connectors called "iako" (Haley & Nichols, 2009) and collectively – the ama and iako – have a stabilizing effect on the canoe during rough water conditions. There are options for 1-, 2-, 4-,6- and 12-person outrigger canoes for recreational usage, as well as for short (regatta) and long-distance OC races. While METs for other sports do provide plausible benchmark values, they are dramatically different sports. A rower, for example, uses two paddles, sits backwards, and is "attached" to the boat. Without an outrigger, a canoe can go backward more easily and canoeists are usually solo or in pairs in fresh water, less commonly in open ocean. OC paddling, in contrast, is designed for the open ocean and the paddler faces forward while always going in one direction. The complete lack of MET information for OC paddling in the 2024 Compendium represents a clear foundational gap in the research literature.

Establishing the METs for OC paddling would lay an important foundation to expanding the knowledge of the effectiveness of paddling as a health intervention and for public health promotion. Establishing METs also allows a direct comparison of metabolic intensity to other well-studied sports and builds critical knowledge for future research, including potential benefits, plausible effect sizes, necessary “doses,” and adaptations for different clinical groups. This also builds the evidence base in research to resolve health inequities for NHPI from a strengths-based perspective. It also addresses other important scientific knowledge gaps. Few METs are calculated for PWD, a large and important research gap for PA generally. Emerging research has found that established METs for people without disabilities are often not appropriate to use for PWD, such as paraplegia (CDC & ACSM; Collins et al., 2010; Lee et al., 2010). Thus, a study that could focus on establishing OC paddling MET values for several populations simultaneously could be highly beneficial.

Study Purpose and Aims

The primary objective for this study is to measure and characterize the range of typical metabolic intensities (i.e., METs) experienced when outrigger canoeing for people with and without disabilities. We did so in the state of Hawai‘i. OC paddling is not only a culturally relevant and popular PA in the state of Hawai‘i, it’s a popular PA with NHPIs and has a proven history to be adaptive and thus inclusive for PWD. Further, the state of Hawai‘i has the largest population of NH in the United States, as well as a higher relative prevalence of people of all ages with disabilities than that reported in the US (10.9% in in Hawai‘i versus

10.4%) (Erickson et al., 2020).

The study has two specific aims:

Aim #1: *Establish Paddling METs for people without SCI*. This aim will be accomplished using standard 6-person outrigger canoes (i.e., OC6, which includes 5 paddles and 1 steersperson) in open ocean water. During each canoe run, multiple paddlers will be wearing instrumentation for the direct measurement of metabolic intensity and heart rate.

Aim #2: *Establish Paddling METs for PWD*. Using the same methods as described for Aim #1, but for paddlers with Spinal Cord Injuries (SCI).

For both paddlers with and without SCI, recreational and competitive paddlers will be recruited and we hypothesized that the energy expenditure for paddling, even at the lowest intensity evaluated, will meet, or exceed, the MET level defined as moderate intensity (≥3 METs), while the highest paddling intensities tested will also meet or exceed the MET level defined as vigorous intensity (≥6 METs).

Community-based

This study is a community-participatory research (CBPR) study (Briss et al., 2004; Fong et al., 2003). This study is a collaboration across universities, non-profit organizations, canoe clubs and paddlers with the motto of “from paddlers, with paddler, for paddlers.” This study is led by a post-doctoral researcher and paddler who has a bridge position across the Department of Health (DOH), Chronic Disease Prevention and Health Promotion Division, Surveillance, Evaluation and Epidemiology Office, and the University of Hawaiʻi (UHM), Office of Public Health Studies. Additional DOH and UH staff are on the research team, as a Co-Investigator and Mentor. Our community partner, AccesSurf Hawaii ("AccesSurf"), founded in 2006, has been a leader in adaptive ocean sports, including swimming, surfing and paddling (AccesSurf Hawai`i, 2023) and adapting equipment to allow people with all abilities to participate. For an adaptive paddler with SCI, for example, this includes attaching a backrest and straps to help the paddler sit in the wa‘a or va‘a (canoe; wa‘a used in this paper) and an adaptive paddle if needed. One of the investigators in our study team is the Training and Innovation Director at AccesSurf, is an international ranked competitive adaptive paddler who is NH with a SCI, an expert of adapting ocean sports and a well-respected mentor with deep lived experience of the holistic benefits of paddling (Outrigger Duke Kahanamoku Foundation, 2023). The main partnering canoe club is Honolulu Pearl Canoe Club, with the representative, Penny Kalua being the community liaison for this study. She and a partner were also the founder of the Hawai'i Adaptive Paddling Association in 2012, which was "merged" with AccesSurf Hawai‘i's adaptive paddling program in 2019. This study also included cultural practitioners. We established a scientific advisory committee and a community hui, who with the community liaison are helping to plan and execute the study.

Proposed Study Methodology

Study Design. The study will be a cross-sectional, correlational, quantitative analysis of data to evaluate the METs of OC paddling. This study is currently planned for the Spring of 2024.

Participants. Criterion sampling (Patton, 1990) will be used to recruit up to 60 experienced adult OC padders with and without SCI, and one to two experienced steersperson. To successfully volunteer for this study (i.e., inclusion criteria), study participants must be experienced paddlers who are safe and confident in the open ocean and comfortable wearing the testing equipment during data collection for 45 minutes. Exclusion criteria include any of the following: Being <18 years of age; Not reporting female or male gender; inexperienced or beginner paddlers (<30 times total); Currently pregnant; Anyone at higher risk for an adverse exercise-related cardiac event. Health screening will be performed using the ACSM Health Screening Algorithm, unless appropriate medical clearance is provided (Riebe et al., 2015). In addition, all participants will complete an Informed Consent Document that has been reviewed and approved by the Internal Review Board (IRB) from the University of Hawai'i (Honolulu, HI USA).

Measurement Procedures. After screening, eligible study participants will be invited to meet with the study team for testing during the Spring of 2024 at Mauliola Keʻehi (on the South Shore of Oʻahu) (Honolulu, HI USA). This location is not only the home for many local canoe clubs, and a popular location for local OC competitive events, but also a meaningful place for health for Kanaka ʻŌiwi (Kaholokula, J.K, n.d.; *Mauliola Keʻehi* 2023). Participants will be invited to participate as part of a group – i.e., five paddlers and one steersperson – where four paddlers would wear measurement equipment, and the steersperson and paddler would call and relay commands for operating the canoe on the water. Prior to getting in the canoe, several demographic measures were collected for the setup of the metabolic testing equipment: Age (date of birth), body weight, and body height. For paddlers without SCI, we will record body weight and collect self-reported height, paddlers with SCI were asked to report their last documented weight and height from their medical provider. Participants will also complete a survey requesting information about paddling history and exercise routine. For those with SCI, questions about each person's SCI injury (level and length of injury) are included. Additionally, once accepted into the study, the paddlers with SCI will meet with a certified physical therapist to perform tests relevant to the functioning of the paddler (Collins et al., 2010) (sitting/standing balance, core, length/leg, shoulder hand grip strength) (Gorman et al., 2014; Wadhwa & Aikat, 2016; Westrick et al., 2012). These additional tests will provide the functional range for these SCI paddlers which, we hope, can be used to help explain their metabolic and cardiovascular responses during OC paddling.

Next, with the canoe already in the water and paddlers in their designated seats, each of the four paddlers will be fitted with the measurement equipment: 1) Telemetry-based chest strap for the measurement of heart rate; 2) Face mask and headcap for wearing the portable metabolic measurement. After the equipment is fitted, the canoe will leave shore under the verbal guidance of the steersperson and the unmasked paddler. Each paddling session will begin with about 15 minutes of warmup at a range of self-selected intensities and then a 2-minutes break. Next, the paddlers will be instructed to paddle at an "easy" intensity for 5 consecutive minutes with the goal of being as consistent with their paddling stroke and effort level as possible. This 5-minutes "easy" effort was followed by another 2-minute break, and then another 5-minutes "moderate" or "intermediate" intensity for another 5 minutes. Following another 2-minutes break, the canoers then paddled 5 more minutes at a "high" intensity. The goal with this strategy was to measure both metabolic and cardiovascular intensities at three discretely different levels (i.e., for the assessment of Aims #1 and #2). Following the last 5-minute piece, there will be a 1-minute break before the paddlers are instructed to paddle at the highest intensity possible for 2-minutes, followed by another 1-minutes break, and then a final 2-minutes maximal effort again.

From the portable metabolic measurement systems we will collect direct measures of absolute oxygen consumption (AVO_2, L/min), which are then converted to a measure relative to body mass (RVO_2, ml/kg/min). This RVO_2 measure is then divided by 3.5 ml/kg/min – a standardized, or population value, of resting metabolic rate – to derive a measure of metabolic equivalents, or METs: METs = RVO_2/METs. The mean MET value from the last 2-minutes of each 5-minutes paddling bout will be used to represent the metabolic intensity of paddling at the three steady-state conditions. Finally, both HR and HR% for each paddler will be computed from the same 2-minutes of each 5-minutes bout as described for METs. The %HR will be computed as a percentage of age-predicted maximal HR (APMHR=220-Age), where HR%= (HR / APMHR)x100.

Data analyses. Statistical analysis Intraclass reliability (ICC) for internal consistency will be computed between the last two minutes for each metabolic and cardiovascular variable. The transformed metabolic (RVO2, METs) and cardiovascular (HR, %HR) variables will then be summarized (Mean ± SD) for descriptive purposes. To satisfy the study objectives, mean MET values at intensity (“easy,” “moderate,” “high”) for both paddlers with and without SCI will be statistically compared to both 3.0 and 6.0 MET threshold cut-points (CP), respectively, using two-sided T-tests at a 0.05 alpha level. Effect sizes (ES) for comparisons will also be calculated using Cohen’s d (10): $d = (EE_{METs} – CP) / SD_{METs}$, where EE_{METs} and SD_{METs} are the sample mean and SD for each paddling condition, and CP is either 3.0 or 6.0 and corresponds with the moderate and vigorous intensity CPs, respectively.

Study Limitations. While the study team is well prepared to address both expected and the unexpected challenges certain to present themselves with this study, there are several limitations worth addressing apriori. First, sample size will likely be relatively small for the SCI paddling group. There is usually a relatively low number of PWD, e.g. SCI in any given community (Craven et al., 2014; Martin Ginis & Hicks, 2005). Comparable research that analyzed METs of aquatic exercise included either 9 or 14 participants. Research of METs and energy expenditure within populations with SCI used between 31 and 100 participants; however, they were performing 10 and 27 activities, hence only a few participants per activity (Collins et al., 2010; Lee et al., 2010). Low participant numbers can be common in MET studies, such as MET evaluation for hula (Usagawa et al., 2013). Regardless, our partner – AccessSurf - has strong reach into communities of PWD who paddle, mitigating this concern. Second, the generalizability to the general adaptive paddler population might be limited due to the exclusion of people with various additional diseases/symptoms (common in the population with physical impairment). While this is a legitimate concern, it is simply not possible to focus on every possible population of adults within the context of a single study. Third, MET measurements may vary with the ocean and weather conditions both within and between days of testing. Ideally, all measurements (i.e., OC paddling) should be done in relatively calm ocean and weather conditions so that metabolic and cardiovascular measurements between test groups are most comparable. Our study team does have some degree of flexibility with the window of measurement. As such, some testing may be rescheduled for another day if cancellation is needed. Regardless, data collection will not occur on days where the ocean conditions are determined to be too rough or dangerous.

Dissemination plan. To report back to all paddlers, we plan to visit regattas and communicate them to canoe clubs, as well as at the world sprints event by the International Va‘a Federation (IVF). The results of this study will be disseminated first to the participant paddlers with and without Spinal Cord Injuries (at regattas, email), then the rest of the AccesSurf community (Board of Director meeting, events, social media), Honolulu Pearl Canoe Club, and the paddling community in Hawai‘i (through the racing associations). The Hawai‘i Department of Health (HDOH) will help disseminate these findings from a practice perspective. Next, a summary of select findings will be reported at select public health and sports medicine conference and results manuscripts will be submitted to peer-reviewed scientific journals.

Expected Findings and Future Research.

This study has clear implications for health disparities research for strengths-based health promotion with cultural relevance for NHPI. Additionally, if it can be shown that adaptive paddling reaches the moderate-to-vigorous PA thresholds, it can help promote (adaptive) paddling as a PA option for people with physical impairment (and other aquatic activities) in places where water sports are possible. If adaptive paddling can be quantified as a moderate-to-vigorous PA option then PWD might be encouraged to engage in more (adaptive) paddling, helping to meet the PA recommendations (Haskell et al., 2007). Hence it can help prevent noncommunicable diseases and lower future health care costs in this population.

This work is highly relevant for populations with known health inequities and considerable community strengths that should be leveraged for health promotion. Notably, this PWD inclusive study with a strong transdisciplinary research team with deep community engagement, will provide foundational METs data to reduce health inequities for NHPI and for PWD, an important research gap, and addresses other limitations in the health and research literature. (This study is funded by OlaHAWAII [NIH/NIMHD U54MD007601]).

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Research Articles and Essays

Health Profile, Primary Care and Preventive Care Utilization in Adults with Intellectual and Developmental Disabilities in Hawai‘i

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Abstract

Adults with intellectual and developmental disabilities (IDD) have poorer health outcomes compared to adults without intellectual and developmental disabilities. In describing the health profile, primary and preventive care utilization in adults with IDD, we found high primary care utilization and low preventive care utilization in a population with significant medical problems. We describe strategies to improve preventive care utilization for this population.

Keywords: intellectual and developmental disability, primary care, preventive care

Health Profile, Primary Care and Preventive Care Utilization in Adults with Intellectual and Developmental Disabilities in Hawai‘i

Adults with intellectual and developmental disabilities (IDD) are known to have poorer health outcomes than adults without IDD. As we work to improve the health and well-being of the IDD population, it is imperative that we study and understand the drivers of their health disparities.

Importantly, adults with IDD have greater medical complexity and a denser disease burden than adults without IDD. This population has a higher prevalence of a multitude of medical conditions, including asthma, arthritis, diabetes, cardiac disease, high cholesterol, high blood pressure, stroke (Reichard & Stolzle, 2011), hypothyroidism (Ptomey et al., 2020), and dementia (Ptomey et al., 2020; Takenoshita et al., 2020). A higher rate of polypharmacy (O'Dwyer et al., 2016) accompanies these conditions, adding to their overall complexity.

The dense burden of medical disease in this population is, not surprisingly, associated with disparities in health outcomes. In the United States, their life expectancy is 12 years shorter on average than their counterparts without IDD (Landes et al., 2021a). Like those without IDD, heart disease is the leading cause of death in people with IDD (Landes et al., 2021c), but that is where the similarities end. Diabetes mellitus causes disproportionately more deaths in those with mild to moderate IDD (Landes et al., 2021b) and those with IDD also have poorer cancer outcomes (McCarthy et al., 2007).

Health outcomes are influenced by many factors, including social and economic drivers, physical environments, and healthcare itself. People with IDD often have difficulty with and differences in communication, making symptom identification and investigation challenging for healthcare providers. Therefore, for this population, primary care, and preventive care can have an outsized influence on outcomes, and we must ensure both access to and quality of care.

Preventive care is important to maintain good health and for early detection of problems. From a dental standpoint, oral hygiene and health in the IDD population is significantly poorer than that of the general adult population, with higher rates of periodontal disease and untreated caries (Anders & Davis, 2010; Morgan et al., 2012). Poor dental health is known to lead to respiratory and cardiovascular disease (Stephens et al., 2018). Similarly, with vision care, many adults with IDD have untreated needs for distance, near vision, and cataracts (Warburg, 2001). It is easy to understand how poor vision can directly lead to poorer health outcomes—lowering medication compliance and limiting communication, mobility, and overall function. An additional critical aspect of preventive care is cancer screening, which is important for early detection and improved survival. People with IDD face multiple barriers to cancer screening (Steele et al., 2017) and women with IDD have lower rates of undergoing pap smears and mammograms (Horner-Johnson et al., 2014).

The importance of primary care and preventive care cannot be overstated in the IDD population. In this study, we sought to describe the medical complexity and primary and preventive care utilization of adults with IDD in the state of Hawaiʻi, investigating whether demographic or clinical factors were associated with utilization. In addition, because the state of Hawai‘i requires an annual visit to a primary care provider (PCP) to access benefits for home and community-based services (HCBS) (State of Hawai‘i, 2022), we hypothesized that there would be a high rate of primary care utilization and that preventive care utilization would be lower since it is not required to receive HCBS.

Method

Adults, 21 years and older, with IDD engaged in HCBS across six programs on four Hawaiian Islands (Hawai‘i, Kaua‘i, Maui, and O‘ahu) were included in this study. A cross-sectional retrospective chart review of all Individualized Service Plans (ISPs) created during the 12-month period from August 2022 to July 2023 was performed.

Data collected included demographics (sex, age, race, insurance, and living arrangement), presence and severity of intellectual and developmental disability (IDD), medical conditions (ICD-10 codes, the International Classification of Diseases, Tenth Revision, for classifying diseases and conditions), body mass index (BMI), number of scheduled medications, and times since last PCP visit, dentist visit, and vision screening. In accordance with current national screening guideline recommendations, time since last Pap smear was collected for women aged 21 to 65 (*American College of Obstetricians and Gynecologists* [ACOG], 2021), and time since last mammogram was collected for women aged 50 to 74 (Siu & Force, 2016). Descriptive statistics were used to describe the study population’s demographics, health status, and overall primary and preventive care utilization.

We used non-parametric statistics with a significance level set at $p > .05$ to compare primary and preventive care utilization by sex, race, presence/absence of Down Syndrome

(DS), and autism spectrum disorder (ASD), severity of IDD, medical complexity, number of medications, and obesity class (Class 1 = BMI 30 to <35, Class 2 = BMI 35 to <40, Class 3 = BMI >=40).

Statistical analysis was performed using SPSS Version 28.0. Institutional Review Board approval was obtained for this study.

Results

Our study included the records of 158 adults with IDD. The characteristics of the study population are shown in Table 1.

Table 1

Study population characteristics

Characteristic	Overall, N=158 n (%)	DS, n=30 n (%)	ASD, n=39 n (%)
Sex			
Female	73 (46.2)	12 (40.0)	14 (35.9)
Male	85 (53.8)	18 (60.0)	25 (64.1)

Age (years)			
Median	36.5	35.5	32.0
Interquartile range	30.0 to 43.0	30.0 to 40.8	28.0 to 39.0
Race			
Asian	71 (44.9)	11 (36.7)	16 (41.)
Multiracial	36 (22.7)	7 (23.3)	6 (15.4)
White	27 (17.1)	9 (30.0)	8 (20.5)
Native Hawaiian/Pacific Islander	18 ((11.4)	2 (6.7)	4 (10.3)
All others	6 (3.8)	1 (3.3)	5 (12.8)
Medicaid insurance	156 (98.7)	30 (100.0)	39 (100.0)

IDD severity			
Mild	27 (17.1)	0 (0)	5 (12.8)
Moderate	80 (50.6)	21 (70.0)	15 (38.5)
Severe	14 (8.9)	4 (13.3)	3 (7.7)
Profound	10 (6.3)	1 (3.3)	2 (5.1)
Unspecified	27 (17.1)	4 (13.3)	14 (35.9)
Living arrangement			
Family home	136 (85.4)	29 (96.7)	37 (94.9)
Adult foster home	11 (7.0)	-	-
Independent	8 (5.1)	-	2 (5.1)
Group home	3 (1.9)	1 (3.3)	-

A slight majority of the study population was male (53.8%) and the median age was 36.5 years (IQR 30.0 to 43.0 years). Asian (44.9%), Multiracial (22.7%) and White (17.1%)

were the three most common races. All but two individuals (98.7%) had Medicaid, which is a state and federally funded health insurance. In terms of IDD severity, half of the study population had moderate IDD, and the remainder were distributed approximately equally between less severe and more severe IDD. IDD severity was unspecified or missing in 17.1%. A high proportion of individuals lived at home with family (85.4%) and the rest lived in adult foster homes (7.0%), independently (5.1%), and in group homes (1.3%).

The study population included 30 individuals (19.0%) with DS and 39 individuals (24.7%) with ASD, all of whom had Medicaid insurance. Both groups were also majority male and had similar racial composition to the overall study population. The ASD group was significantly younger with median age 32.0 years (IQR [Interquartile Range] 28.0 to 39.0 years) (p = .005), which was expected given the more recent rise in ASD diagnoses. The vast majority of both the DS (96.7%) and ASD (94.9%) groups lived with family. In both groups, the majority had moderate IDD. However, in the ASD group 35.9% had unspecified or missing data on IDD severity. Due to the retrospective nature of this study, we were unable to discern whether the data was missing because the individual did not have IDD, which is common in ASD, or if IDD was present and the severity was not captured in the ISP.

Health Profile

The study population's health profile is detailed in Table 2.

Table 2

Health Profile

	Overall, N=158	DS, n=30	ASD, n=39

	n (%)	n (%)	n (%)
Number of ICD-10 diagnoses (including primary IDD diagnosis)			
5 or more	49 (31.0)	6 (20.0)	14 (35.9)
4	34 (21.5)	8 (26.7)	7 (17.9)
3	28 (17.7)	6 (20.0)	10 (25.6)
2	26 (16.5)	8 (26.7)	7 (17.9)
1	21 (13.3)	2 (6.7)	1 (2.6)
5 Most Prevalent Comorbidities			
Epilepsy	35 (22.2)	0	11 (28.2)
Hypertension	29 (18.4)	0	4 (10.3)
Lipidemias	29 (18.4)	7 (23.3)	4 (10/3)
Type 2 diabetes mellitus	16 (10.1)	0	7 (17.9)
	13 (8.2)	6 (20)	2 (5.1)

Hypothyroidism			
Obesity*			
Class 1 (BMI 30.0-34.9)	30 (21.1)	6 (20.0)	5 (12.8)
Class 2 (BMI 35.0-39.9)	11 (7.7)	1 (3.3)	5 (12.8)
Class 3 (BMI >40.0)	13 (9.2)	3 (10.0)	2 (5.1)
Number of medications			
5 or more	33 (20.9)	3 (10.0)	13 (33.3)
4	13 (8.2)	2 (6.7)	2 (5.1)
3	20 (12.7)	2 (6.7)	4 (10.3)
2	18 (11.4)	3 (10.0)	4 (10.3)
1	29 (18.4)	8 (26.7)	5 (12.8)
None	45 (28.5)	12 (40.0)	11 (28.2)

*BMI was missing for 16 participants

Medical Complexity

The number of medical conditions, including IDD, per individual ranged from 1 to 10. A majority, 86.7%, had at least one medical comorbidity in addition to their primary IDD diagnosis, with almost one-third (31.0%) having five or more total comorbidities. As a group, those with ASD tended to have more medical conditions than the DS group, but this difference was not statistically significant. Overall, the five most prevalent comorbidities were epilepsy (22.2%), hypertension (18.4%), lipidemias (18.4%), type 2 diabetes mellitus (10.1%) and hypothyroidism (8.2%). These were similar in the ASD group, but the DS group did not have any epilepsy, hypertension, or type 2 diabetes mellitus.

Obesity

The prevalence of obesity was 37.3% (Class 1, 21%; Class 2, 8%; Class 3, 9%). The prevalence of obesity was similar in the DS and ASD groups.

Medications

The number of scheduled medications ranged from 0 to 12. Polypharmacy, defined as being on 5 or more scheduled prescription medications, was present in 21%. Fifty-one percent were on 1 to 4 prescription medications and 29% were not on medication. The finding that polypharmacy was more common in the ASD group (33.3%) than the DS group (10.0%) trended toward statistical significance ($p = .059$).

Primary Care, Dental Care & Vision Screening

Primary care and preventive care utilization are shown in Table 3.

Table 3

Primary Care and Preventive Care Utilization

	Overall, N=158 n (%)	DS, n=30 n (%)	ASD, n=39 n (%)
Primary care	131 (82.9)	25 (83.3)	32 (82.1)
Dental care	101 (63.9)	20 (66.7)	23 (59.0)
Vision screening	48 (30.4)	8 (26.7)	14 (35.9)
Pap smears	11/69 (15.9)	0/12 (0)	1/14 (7.1)
Mammograms	5/14 (35.7)	0/2 (0)	None eligible

In the 12 months prior to ISP creation, 82.9% of individuals had seen their PCP, 63.9% had seen their dentist, and 30.4% had their vision screened. Rates of PCP visits, dental care, and vision screening in the DS and ASD groups were similar. Rates of primary care, dental care, and vision screening were not significantly different when compared by sex and by race.

One might suggest that those with more severe IDD and/or more medical complexity might receive more primary or preventive care than others given their higher risk for poor outcomes. However, the number of medical conditions (1 to 4 vs. 5 or more) and number of medications (none vs. 1 to 4 medications vs. 5 or more medications) were not associated with differences in utilization rate in primary care, dental care, or vision screening.

Rates of primary care and preventive care utilization were also compared across obesity classes. Those with Class 3 obesity had the highest rates of primary care utilization (100% vs. 81.8% in Class 2, 80% in Class 1, and 83.0% in those without obesity) and dental screening (76.9% vs. 45.5% in Class 2, 70.0% in Class 1, and 65.9% in those without obesity). Due to the small subgroup sizes, these differences did not reach statistical significance. Vision screening was around 30% across the groups.

Women’s Preventive Care

Only 11 of 69 (15.9%) women aged 21 to 65 years had undergone cervical cancer screening in compliance with national guidelines (i.e., within the last 36 months), and only 5 of 14 women aged 50 to 74 years had undergone breast cancer screening in compliance with national guidelines (i.e., within last 24 months). In the DS group, none of the 12 women eligible for cervical cancer screening had received a Pap smear in compliance with national guidelines, and neither of the 2 women eligible for breast cancer screening had received a mammogram in compliance with national guidelines. In the ASD group, only 1 of the 14 eligible for cervical cancer screening had undergone a Pap smear. None in the ASD group qualified for breast cancer screening.

While the cervical and breast cancer screening in women in the DS and ASD group was almost non-existent, due to the low overall screening rates and small size of the DS and ASD groups, the difference in screening rates was not statistically significantly different. Owing to small obesity subgroup sizes, we were not able to compare cervical and breast cancer screening rates across obesity classes.

Discussion

Adults with IDD in HCBS have a complex medical disease burden at a young age with significant rates of polypharmacy. While this is reflective of the literature, our study has additional important findings regarding primary and preventive care utilization in adults with IDD.

Primary care and preventive care are medical cornerstones of health outcomes. The IDD population often has difficulty in symptom identification and communication, elevating the importance that primary and preventive care play in their overall health and outcomes. In Hawai‘i, an annual visit to a primary care provider is mandatory to access HCBS (State of Hawai‘i, 2022). Our results show that adults with IDD are largely compliant with this requirement, putting our study population close to par with non-IDD (MedQuest, 2023) adults in the general population (CommonwealthFund, 2022).

Not surprisingly, but importantly, engagement with preventive care, which is not required for HCBS, was lower than primary care engagement. In our study, we found that dental, vision, and female preventive care had lower participation than primary care. It is important to note that while vision screening and female preventive care were covered benefits under Medicaid, preventive dental care did not become a Medicaid benefit in Hawaiʻi until January 1, 2023 (MedQuest, 2023), which was during the study period. Our study is not able to discern the reasons for lower preventive care utilization, but postulate that there may have been issues of geographic access, provider inexperience or unwillingness to provide care to adults with IDD, and provider and/or caregiver beliefs about the necessity of preventive care.

Prioritizing preventive care in this population would be expected to not only improve well-being and health outcomes, but also to reduce overall healthcare costs. A means to improving health outcomes in the IDD population could include requiring preventive care to access benefits such as HCBS. To improve the IDD population's use of preventive care, we need a multi-pronged approach that addresses:

1. Policy and benefit design
2. Healthcare provider readiness
3. Caregiver awareness and perception.

Policy and Benefit Design

Our results demonstrate the effectiveness of mandated primary care participation, which prompts consideration of tools to increase utilization of additional preventive services. While policymakers must contemplate barriers to access, including geographic constraints and patient anxiety, they can harness interest in HCBS to urge increased preventive care participation. For example, HCBS intake procedures can include mandatory discussions about preventive care and service providers can facilitate medical linkages. While HCBS providers hold power as a centralized point of contact with the IDD population, it is vital that they maintain a person-centered approach and guide clients to medical care while respecting individual preferences and needs.

Benefit design is perhaps the most important tool to direct patients to care. Providing comprehensive coverage for all preventive care, including dental and vision care, reduces the likelihood of patients skipping screenings to avoid costs. The inclusion of preventive services in a health plan also signals the importance of these services to patients and families. In Hawaiʻi, preventive dental care was not a covered benefit under Medicaid until January 1, 2023. This could have been a driver of lower dental care utilization in our study population.

Policymakers must also address the unique barriers that impact their communities. Medical student training incentives and interstate licensing compacts can bring additional providers to areas with shortages. Robust telehealth options can alleviate geographic distance strain in rural areas. Transportation coverage mitigates inequities for those who cannot drive or safely navigate public transit. Identifying pain points impacting the local population enables policymakers to craft effective solutions tailored to community need.

Healthcare Provider Readiness

Healthcare providers need to be prepared to care for people with IDD (Smith et al., 2021). Communication with and performing procedures on people with IDD is different and requires skills that are not yet taught in today's mainstream healthcare professional education (Edwards & Hekel, 2021; Lee et al., 2023). As a result, people with IDD have a worse experience with healthcare, reporting poorer quality and quantity of provider interactions compared to the general population (Stone et al., 2023). Education during medical, nursing, and allied health school that includes a curriculum on the nuances of caring for patients with

IDD would begin to close this gap, as would continuing education for those already in practice.

Primary care is highly utilized by adults with IDD, and providers must be knowledgeable about the importance of preventive care in this population. Beyond that, providers must be prepared to discuss preventive services with their IDD patients and their caregivers. Since there is often a high-trust relationship with a PCP, patients may be most comfortable with them. Therefore, PCPs must be facile at performing preventive care procedures within their professional scope, such as Pap smears for cervical cancer screening. Specialty care providers, including dentists, require similar skills to take care of this population.

Geographic availability is also imperative in the effort to improve preventive care utilization. While rural areas quickly come to mind, other geographic constraints are also important to consider. For example, archipelagoes may have overall adequate numbers of primary and specialty physicians and healthcare facilities. However, we often see them geographically concentrated on one island, often the financial and governmental center, making these resources difficult for those living on the other islands to access.

Lastly, it needs to be formally recognized that taking care of patients with IDD is different and necessarily more time-consuming than taking care of patients without IDD. Provider reimbursement should reflect the additional effort that it takes to provide good care to this population.

Caregiver Awareness and Perception

Adults with IDD typically rely on their caregivers to identify their primary and preventative care needs, arrange these visits, serve as their advocate for effective communications with providers, support in decisions regarding care, and ensure that the recommendations made by their providers are followed. These caregivers are often family members of the person with IDD who are balancing the support needs of the person with IDD alongside the needs of other family members, the family unit as a whole, and their own self-care needs. Because of this, caregiver awareness of the importance of the preventative and primary care needs of these persons with IDD is critical to ensuring their ability to appropriately prioritize these needs. For caregivers who are experiencing excessive caregiver burden or stress, additional supports may be necessary to ensure that the caregiver has the necessary resources and capacity to both ensure the necessary preventative and primary care visits occur and to serve as an advocate for the person with IDD.

Addressing existing misconceptions around the need for or effectiveness of primary and preventative care for adults with IDD may also contribute to increased engagement. It is common for an adult with IDD to be actively engaged with providers representing a range of disciplines simultaneously (e.g., neurology, behavioral health, and gastroenterology), which could lead to an assumption by caregivers that their healthcare needs are being adequately addressed. However, preventative and primary care are critical to ensuring that emerging health concerns are identified and that treatment for existing health concerns continues to be effective and positively impacting overall health outcomes.

Another commonly held misconception is that women’s health screenings are only necessary for women who are sexually active. Caregivers of adult women with IDD who hold this belief are likely to determine that these screenings are unnecessary, resulting in missed cervical and breast cancer screenings. A similar misconception related to vision could also impact a caregiver's understanding of this preventative care need in that caregivers of adults with IDD could believe that vision screenings are only necessary for those who have known or suspected vision challenges.

Including the IDD Community

Inclusion of the IDD community in each of these three areas (policy and benefit design, healthcare provider readiness, and caregiver awareness and perception) will ensure the development of the most effective and impactful programs. Where appropriate and when possible, adults with IDD should be brought directly into the conversation in a setting and format where their contributions can be impactful. Caregivers of adults with IDD also represent an important stakeholder group to include as they are intimately aware of barriers to care and are also often a crucial gateway to access for healthcare services.

Study Limitations

This chart review of administrative data in ISPs was not without limitations. A significant constraint lies in the potential for inaccuracies within the administrative records themselves as these documents serve administrative purposes rather than research objectives. Inaccurate codes, misclassifications, and incomplete documentation may introduce biases and compromise the overall accuracy of the extracted data and our analyses. We saw this specifically in the missing data on IDD severity in the ASD group.

Additionally, the inherent selection bias in relying on data from individuals in HCBS may affect the generalizability of our findings to broader populations with IDD, particularly those with less severe IDD who are not engaged in HCBS.

Conclusion

Primary care and preventive care are critical to the health outcomes of people with IDD. Health behaviors are promoted when tied to HCBS access. Engagement in preventive care is suboptimal in the adult IDD population. To improve the health and well-being of this population, consideration should be given to strategies that tie preventive care to HCBS access.

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Notes from the Field

Selected Posters and Recorded Sessions

Sandra S. Oshiro,

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Abstract

This notice provides select listings of posters and recorded sessions presented at the 39th Annual Pacific Rim International Conference on Disability and Diversity in Honolulu, Hawaii.

Keywords: disability, conference, posters, recorded sessions

Selected Posters and Recorded Sessions

The following listed selections represent some of the diversity of posters and recorded sessions shared at the 39th Annual Pacific Rim International Conference on Disability and Diversity in Spring 2024. (Note: not all fields available for all listings.)

Career Advancement Program for Neurodivergent People: A Holistic Lifelong Approach

Type: Poster
Name: Dan Middleton
Affiliation: Catalight Research Institute
Other Contributors: Dr. Lindsey Sneed, Catalight Research Institute
Dr. Vincent Bemmel, Catalight Research Institute

Abstract: The Compass Work Tool is designed to assist neurodivergent individuals in identifying lifelong and meaningful Competitive Integrated Employment (CIE) opportunities that align with their unique strengths, interests, and skills. This person-centered tool offers three different assessments and two employment integrator technologies to help candidates secure a lifetime of employment. The assessments evaluate the candidate's well-being, career skills, and sense of belonging in the job and company.

The Compass Work tool had 7 modules with over 30 training elements like How to write a resume, conduct an interview, ask for accommodations, and accept a job offer. The last

module is designed with a 100 day plan that will ensure career success.

Keywords: Competitive Employment, person-centered, neurodivergent, career skills, lifetime of employment

Technology-Enabled Training in Emergency Preparedness for People With Disabilities: A Literature Review

Type: Poster
Strand: Built Environments: Digital, Physical, and Social

Name: Sandra S. Oshiro
Affiliation: University of Hawai‘i at Mānoa

Abstract: People with disabilities are among those most at risk during and after natural and man-made emergencies (Flanagan et al., 2011). While the literature covers multiple issues in emergency preparedness and response for the general population, research on disaster readiness training specifically for those with disabilities is far from robust. An initial, iterative literature review was undertaken as part of LTEC 750C, a learning design and technology class offered by the University of Hawai’i in the fall of 2023. The review helped determine the sweep of existing research on emergency readiness training for those with disabilities and identified some gaps in the studied area.

The review was conducted using the University of Hawai’i’s Hamilton Library OneSearch tool and Google Scholar, exploring journal article databases covering publication in the past 10 years. The following search keywords and combinations of these keywords were used: disaster preparedness, disabilities, climate change, whole community, emergency training, disaster simulation, virtual reality, and augmented reality. Twenty-four relevant journal articles were identified. One described the impact of a virtual reality storm surge simulation that aimed to increase emergency preparation and action (Bernhardt, J., et al., 2019). The search results support the assertion that little is known about enabling emergency

preparedness within standing health care, disability, and rehabilitation service systems (Subramaniam & Villeneuve, 2020). More research employing new and emerging technologies to train those with disabilities and prepare for emergencies could help address this deficit. Particularly as climate change increases the frequency and severity of life-threatening weather events (Rodell & Li, 2023), research into effective training practices and approaches in transferring critical emergency preparedness knowledge and skills to vulnerable populations and their families takes on more urgency.

This poster presentation argues for more study into disability-inclusive emergency preparations, harnessing technologies both existing and emerging. Such efforts can help ensure those with disabilities are part of a whole community approach to disaster readiness and mitigation (Kruger et al., 2018). Further, the presentation reflects the conference theme, “Beyond Access: Building A Culture of Belonging,” in that it seeks to add to knowledge in a critical area that must be inclusive of people with disabilities. In the planning, implementation, and management of disaster readiness training, those with disabilities have a stake that is indisputably larger than many others. Changing an exclusionist culture to one of belonging can have no more important focus than in ensuring the well-being of the entire community.

Keywords: emergency preparedness, disaster preparedness, disabilities, climate change, whole community, disaster simulation, virtual reality, augmented reality, mixed reality

Students with invisible disabilities and their use of accommodations in Engineering courses

Type: Poster

Name: Isabel Miller
Affiliation: University of Michigan
Other Contributors: Karin Jensen, University of Michigan

Abstract: College students with invisible or non-apparent disabilities, including learning disabilities and mental health challenges, can be reluctant to ask for accommodations or disclose to instructors their disability. Sense of belonging, as partially determined by social contexts and classroom climate, influences help-seeking behavior. Engineering students in particular may be less likely to seek help or self-identify as having a disability because of the tense culture and climates within engineering. Situated in Social Cognitive Theory and Weidman's Model of Undergraduate Socialization, and through a Social Model of Disability lens, this work uses the word "disability" to mean any impediment or limitation a person faces from the physical and social environment at any time. In a higher education context, institutional and programmatic structures and practices, such as attendance policies or unwelcoming climates, create barriers in the environment that impact students with disabilities. The following work investigates how language and attitudes presented by the instructor on the first day of class establish a classroom climate that along with students' attitude towards accommodations influence accommodation utilization. Using a convergent mixed methods approach, surveys containing the Attitudes Towards Requesting Accommodations (ATRA) scale and free response items will be distributed to approximately 7,600 undergraduate engineering students at a large, public, research-intensive institution in the Midwest after the first week of class to assess their initial experiences. The ATRA scale prompted students to respond to items about their views on disability, academic integrity, and the accommodation process. We included 10 additional items on perceived classroom climate that were validated and refined with cognitive interviews. Open-ended questions asked students to share their experiences (positive and negative) with requesting and using accommodations in their engineering courses. In this presentation geared to faculty and staff,

we will identify common attitudes of disabled students towards using accommodations in engineering courses, and specific language and actions instructors can use to build a welcoming classroom climate that improves student comfort in asking for accommodations.

Keywords:
Students with disabilities; engineering; Social cognitive theory; help-seeking

Music Therapy in the Diverse Early Childhood Setting: Two Research Studies

Type: Poster

Name: Andrew Knight, PhD, MT-BC
Affiliation: Able Arts Work and Colorado State University

Centering Voices of People with Multiple Sclerosis to Promote Environments Supporting Community Participation: A Community-engaged Mixed Methods Study

Type: Poster
Strand: Built Environments: Digital, Physical and Social

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Abstract: Multiple Sclerosis (MS) is the most common inflammatory and neurodegenerative disease affecting approximately one million adults in the US. Active, autonomous, and contributive participation in important and meaningful out-of-home activities is a human right. However, people with MS encounter external barriers to community participation and experience feelings of isolation. Most of the MS research focuses on the impact of impairments. MS studies examining external impact, centering stakeholders' needs, and advocating for sociopolitical changes to promote community participation are generally lacking. This study adopted a participatory approach by having a community advisor board involved throughout the study and utilized a mixed methods design that included a secondary analysis of GPS-measured and self-reported data and focus group discussions with mobility aid users and nonusers.

The objectives were to understand the influences of physical, social, and attitudinal environments and to identify individual and desired collective actions to address environmental barriers. Preliminary findings revealed that environmental factors were significantly associated with satisfaction with participation and activity range. Mobility aid users with MS discussed more concerns about the built environment, whereas nonusers shared increased barriers related to other people's lack of understanding and employment. In addition, focus group participants shared how environmental support helped mitigate the negative impact of impairments and enabled their community participation, although quantitative results did not confirm such interactive effects. Improving the ease of access to information, increasing the availability of accessible transportation and MS specialty care across regions, and enforcing regulations to improve physical accessibility were examples of advocacy topics.

Keywords: environmental impact, community participation, multiple sclerosis, participatory research

Embracing universal design for learning (UDL) principles for transforming higher education for students with disability and diverse equity groups.

Type: Poster
Strand: Inclusive Practices in Education

Name: Dr Christine Krol
Affiliation: Western Sydney University
Other Contributors: Josie Galeng, Western Sydney University

Abstract: We welcome conversations about universal design for learning (UDL) principles for transforming higher education experiences for students from diverse equity groups. Equity groups include students with disability, carers, First Nations, mature-aged, first in family to attend university, from lower socio-economic communities and those whose first language is not English. The Center for Applied Special Technology (CAST) defines UDL principles as an approach to teaching aimed at meeting the needs of all students. The three key principles are: ‘1) providing multiple means of engagement (so that students are engaged and motivated to learn in different ways), 2) representation (offering or delivering teaching and learning experiences in more than one format), 3) action and expression (allowing students to express their understanding of the content differently)’. Multiple higher education institutions are successfully implementing these strategies across the globe. UDL strategies go beyond offering affirmative interventions, such as the provision of accommodations, for academic engagement. It promotes equitable participation and fosters building a culture of belonging with accessible curricula and educational environments. Being part of UDL community of practice (CoP) groups is a wonderful way to learn. Likeminded members share their UDL strategies, both successful and in need of improvement. If you are part of a higher education UDL CoP group, we encourage you to share your group’s contact details. If you would like to join a group, we can pass on contacts of established groups. If you would like more information about using UDL principles, we are happy to share some resources.

Keywords: UDL, equitable participation, disability, higher education

Implementing Healthy Living Habits in College with Young Adult with Intellectual Disability

Type: Poster
Strand: Inclusive Physical Activity, Recreation, and Sport
Name: Kelly R. Kelley, Ph.D.
Affiliation: Western Carolina University
Other Contributors: Meredith Morrison, Western Carolina University
Ryan Rockey, Western Carolina University

Abstract: Peers can influence behavioral changes, particularly within inclusive postsecondary education (IPSE) programs. Since the Higher Education Opportunity Act was reauthorized in 2008 to provide Transition Programs for Students with Intellectual Disabilities (TPSIDs) there are now 325 IPSEs across the United States (Think College, 2023). With IPSEs evolving in almost all states and 127 of them offering housing opportunities, peers (natural supports) can play a vital role in teaching important skills beyond academics, employment, social interactions, and healthy lifestyles since young adults with intellectual and developmental disabilities (IDD) are living away from their family members for the first time.

College students with IDD encounter challenges with healthy lifestyles. Implementing healthy lifestyles can improve overall quality of life, life expectancy, and personal fulfillment. Having healthy lifestyle habits is challenging for all individuals and can host additional unique challenges for individuals with IDD. Many college students with IDD indicate a desire and interest in participating in inclusive physical activities, recreation, and sports with other college students. This preliminary study focused on topics including macronutrients, vitamins and minerals, nutrition labels, whole foods, implementing MyPlate recommendations, resistance training, cardiovascular endurance, stress management, and superfoods. The health education curriculum lessons used were modified from the university’s introductory health education courses (e.g., MyPlate, nutrition labels, stress

management, exercise, meal planning, macronutrients). Preliminary data indicated 9 of 10 college students with IDD increased their nutritional knowledge, 10 of 10 increased servings of fruits and vegetables, and 6 of 10 increased cardiovascular endurance.

Keywords: intellectual disability, inclusive postsecondary education, healthy living

Practical report on a short-term paid internship program for high school students with intellectual disabilities.

Type: Poster

Strand: Employment

Name: Ayumi Matsukiyo
Affiliation: Research Center for Advanced Science and Technology, the University of Tokyo
Other Contributors: Takeo Kondo, Research Center for Advanced Science and Technology, the University of Tokyo

Abstract: The purpose of this study was to develop a short-time paid internship program for students of special-needs schools. By engaging only in specific tasks that are determined by the company, students can gain a sense of accomplishment, and the rewarding internship provides them with a different sense of responsibility and a real sense of work experience. To realize this program, it is necessary for schools, local companies, local employment support organizations, and various other related organizations to organically connect and collaborate with each other.

There are several courses offered at Japanese special-needs schools for the intellectually disabled, some of the students enrolled in this course think that they cannot work in a company. However, the problem is not that they really cannot work, but that they cannot match their skills with jobs.

To increase their work opportunities, it is important to adjust the employment environment

and promote a system that allows them to be employed only for specific jobs with short times. The current challenge in Japanese society is that employment opportunities for people with disabilities are not expanding because "a system of employment in specific jobs for a short time" that facilitates work for people with disabilities is not common.

Therefore, this study aims to develop an internship program that leads to post-graduation professional life, focusing on the establishment of an organizational structure to realize a short-time paid internship, clarification of the roles of each organization, and sustainable organizational management through the utilization of social resources.\\\\\\\\\\\\

Keywords: a short-time paid internship program, students of special-needs schools

Mapping Accessibility in the August 8, 2020 Wisconsin Primary Election

Type: Poster

Strand: Built Environments: Digital, Physical and Social

Name: Emmett Lockwood

Affiliation: University of Wisconsin - Madison

Abstract: According to the Centers for Disease Control (CDC), in 2022, 26% of American adults have documented disabilities. This means that there are currently 1,200,000 eligible voters in Wisconsin with documented disabilities. In 2013, the Wisconsin Elections Commission found an average of 6.5 violations of the Americans with Disabilities Act of 1990 in the state of Wisconsin. Any one of these elections can cause disenfranchisement of a voter. In this study, I used a fifty-four point criteria to measure the adherence to the Americans with Disabilities Act of 2010 and the Helping America Vote Act of 2002 in voting sites in the greater Madison area during voting in the Wisconsin Primary Election. Forty polling sites were surveyed during the early voting and day-off voting in Madison, WI. There was an average of 3.73 violations of the Americans with Disabilities Act and the Helping America Vote Act per polling site. There was an average of 3.33 violations per early voting site and 3.93 violations per day-of the polling site. Early voting sites having fewer violations was not surprising because of their positions as the site where absentee ballots are returned.

Two of the leading causes for violations were the lack of free accessible parking in downtown Madison, Wisconsin, and the disconnect in incentives for adherence at polling sites that need to adhere to the Americans with Disabilities Act of 1990 every day until when they are a polling site and need to adhere to the Americans with Disabilities Act of 2010.

Keywords: Americans with Disabilities Act, Helping America Vote Act of 2002, disability studies, accessibility, elections, voting

Enhancing Asynchronous Online Classes in Higher Education for Students through Virtual Learning Environments

Type: Poster
Strand: Built Environments: Digital, Physical and Social
Name: Joseph Peters & Patrick Agullana
Affiliation: UH Manoa
Other Contributors: Patrick Agullana, University of Hawaii at Manoa

Abstract: Virtual reality (VR) technology has emerged as a promising tool for transforming traditional educational practices by offering immersive and interactive learning experiences. VR can offer place-based learning in the form of immersive virtual field trips in a digital virtual learning environment.

For example, at the University of Hawaii at Manoa, I helped make an asynchronous online course in the Sakai learning management system that embedded a window that linked to Mozilla Hubs, a free virtual reality digital environment platform to present 3D coral objects and the concept of coral bleaching for a public health course. This paper presents a proposal for a qualitative research study on the potential for virtual reality to enhance learning by leveraging the capabilities of VR to situate cognition through added digital access to realistic contexts.

Keywords: Digital & Virtual Environments

US-Japan Comparison of the Working Context: Impact on People with Disabilities and Challenges in Japan

Type: Poster
Strand: Employment

Name: Yumi Yuzawa
Affiliation: Department of Advanced Interdisciplinary Studies, Graduate School of Engineering, The University of Tokyo

Abstract: Plans to improve social systems and support methods to empower people with disabilities to work at their full potential must be based on the characteristics of cultural views of work of a particular country or region. Therefore, this study explored the Japan's working environment in comparison with the U.S. Relevant literature was searched on the PsycNet database using the search terms "job stress," "United States," and "Japan," and external factors leading to job stress were compared. A correspondence analysis was conducted, and a text-mining approach, to compare the environmental context descriptions for both countries. The factor "relationships with colleagues" was mentioned more frequently in Japan than in the U.S. The term "support" was used as a variable for factors that buffer job stress in Japan, versus the term "resources" in the U.S. Furthermore, the correspondence analysis shows that the term "organization" was mentioned in the U.S. in response to the frequent mention of "workplace" in Japan.

These results suggest that job stress arises between organizations and individuals in the U.S. versus the "workplace" in Japan. Moreover, relationships with colleagues are closer in Japan than in the U.S. Therefore, in Japan, uncertainty about becoming a harmonious member of the "workplace" can inhibit employment decision-making among people with disabilities. Furthermore, the mindset of workers may be more "support-oriented" than "resource-oriented" in Japan. This context limits the career development of people with disabilities and

might position them as "being supported." Transforming this context is a challenge for Japan.

Keywords: working context, regional characteristics, impact on people with disabilities, challenges in Japan

Practitioner Research on Online Social Skills Training Incorporating Discussion for Adults with Developmental Disabilities or Tendencies

Type: Poster
Strand: Employment

Name: Shoji Sayaka
Affiliation: Counseling and Rehabilitation Center of University of Tsukuba
Other Contributors: Kuagai Keiko, University of Tsukuba

Abstract: It is known that people with developmental disabilities (DD) find it difficult to take turns in a conversation and maintain relationships. Therefore, we provide social skill training (SST) to adults with DD who have difficulty communicating.

The SST we provide involves listening to individual goals and planning the program. The program involves procedures such as instruction, modeling, roleplaying, and positive reinforcement for skill improvement, in addition to discussions among clients. The clients practice their speech for another group of children with DD in the final session. Moreover, discussions among clients increase their experiences, such as through expressing their opinions to others. In the final session, all clients discuss how they can express their opinions in an easy-to-understand manner within the allotted time.

In the SST, six participants were asked to fill out a 24-item questionnaire on communication skills, divided into six categories, both before and after the intervention using a seven-point Likert scale. These seven-point Likert scale results were analyzed using the Wilcoxon signed rank test.

As a result, this online SST program suggested improvements in two categories. The first category was “self-control,” which involved suppressing one’s impulses and desires and managing one’s emotions effectively. The second was “regulation of interpersonal relationships,” which involved prioritizing human relationships in one’s actions and striving to maintain good relationships.

Furthermore, clients supported each other through discussions and experienced mutual growth. Additionally, by giving advice to school-aged children, clients had a positive experience wherein their own past experiences proved to be useful.

Keywords: Social skill training, adults, developmental disabilities, online SST

The Significance of "Experience Narratives" in Career Support for People with Neurodevelopmental Disorders.

Type: Poster
Strand: Employment
Name: Ayaka Sueyoshi
Affiliation: University of Tsukuba, Institute of Human Sciences

Abstract: It continues to be pointed out in Japan that students with Neurodevelopmental Disorders (NDD) enrolled in HEIs face challenges in their career development. It is necessary to propose specific support methods and verify the effectiveness of support for people with NDD in the process of transitioning from higher education institutions and career support offices to the workplace, and for them to work stably in the workplace after the transition. Efforts to provide opportunities to listen to the experiences of others or to talk about one's own experiences have been reported in Japan and abroad as a way to support people with illnesses and disabilities. However, in these practices, especially in Japan, how much attention has been paid to those in a position to "tell others about their own experiences"? It is expected that people with NDD (or students with NDD) would benefit from hearing about the

experiences of their "senior" colleagues. Not only that, for "senior people with NDD who talk about their experiences," it may be inferred that sharing their experiences with others may have some impact on their self-understanding and motivation to work. This presentation will examine how listening to others' experiences with employment and sharing one's own experiences with employment affected people with NDD in terms of their self-understanding and their attitudes toward employment.

Keywords: Neurodevelopmental Disorders, Career Support, Narratives

Accessibility First: Designing an Effective and Proactive Procurement Policy for Digital Products

Type: Recorded Presentation
Strand: Built Environments: Digital, Physical and Social
Name: M. Beth Valentine, PhD
Affiliation: University of North Dakota
Other Contributors: Jessica D. Gilbert Redman, MLIS, University of North Dakota School of Medicine & Health Sciences

Abstract: Software and other digital resources are integral to most built environments. To create a sense of belonging in these environments, organizations must go beyond merely providing access to these resources and instead ensure that they are accessible to all, which requires selecting accessible software and other digital products. Creating a policy governing procurement of digital products can help achieve this goal organization-wide. The associated recording provides resources to help with these tasks by sharing lessons learned from the Digital Accessibility Policy implementation at a flagship state university in the U.S. The presenters define foundational terms, criteria, and documents surrounding digital accessibility before providing guidance for the three key phases of policymaking: (1) pre-policy writing, (2) policy writing, and (3) implementation. Presenters highlight often overlooked logistical issues and ways to generate organizational support which are critical to the first phase. They then identify considerations for the policy-writing stage: which office will have policy ownership, what digital products – if any – will be exempt from the policy, how often digital products should be reviewed, what that review process is, and what review standards will be used. Because these standards are often unfamiliar to those purchasing digital products, education on the review process, the required documentation, and the importance of accessible products is key and should be done prior to implementation as well as at regular intervals post-implementation. Lastly, the presenters will address the ongoing work needed during the implementation and post-implementation phase to promote success.

Keywords: digital procurement, software accessibility, digital accessibility, ACR, VPAT, WCAG

Metabolic Equivalents of Outrigger Canoe Paddling for Health Equity: Methods of an Inclusive AccessMETs Study

Type: Recorded Presentation
Strand: Inclusive Physical Activity, Recreation, and Sport

Name: Simone M. Schmid
Affiliation: University of Hawaiʻi, Office of Public Health Studies and Hawaiʻi Department of Health, Chronic Disease Prevention and Health Promotion Division, Surveillance, Evaluation and Epidemiology Office
Other Contributors: Daniel Heil, Montana State University
Ann Yoshida, AccesSurf Hawaiʻi
Penny Kalua, Honolulu Pearl Canoe Club
Lance Ching, Hawaiʻi Department of Health, Chronic Disease Prevention and Health Promotion Division, Surveillance, Evaluation and Epidemiology Office
Tetine Sentell, University of Hawaiʻi, Office of Public Health Studies

Abstract: People with disabilities, as well as Native Hawaiian and other Pacific Islanders, have relatively low reported physical activity rates that increases risk for chronic diseases, all-cause and early mortality. This paper proposes a study design for evaluating the efficacy of outrigger canoe paddling as a culturally relevant means for promoting physical activity.

Keywords: Energy Expenditure, NHPI, METs

REVIEW OF DISABILITY STUDIES: AN INTERNATIONAL JOURNAL Vol. 20 Issue 1 (2024)

Dissertation & Abstracts v20i1

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Abstract

The following provides a listing of select recent citations of dissertations and theses relevant to disability studies.

Keywords: disability, disability studies, dissertations

Bishop, G. M., Llewellyn, G., Kavanagh, A. M., Badland, H., Bailie, J., Stancliffe, R., ... & Aitken, Z. (2024). Disability-related inequalities in the prevalence of loneliness across the lifespan: Trends from Australia, 2003 to 2020. *BMC Public Health*, *24*(1), 621. https://doi.org/10.1186/s12889-024-17936-w

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Pearson, C. A. (2024). *Self-efficacy of college students with learning disabilities in traditional disability services as compared to students in a specialized tutoring/coaching program* (Doctoral dissertation, Houston Baptist University). https://www.proquest.com/docview/3145314119/E2A1E8A039FC435CPQ/1?sourcetype=Dissertations%20&%20Theses