Editorial

Welcome to the Conference Proceedings of the 38th Annual Pacific Rim International Conference on Disability & Diversity 2023

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Abstract

This is a welcome message for the Conference Proceedings of the 38th Annual Pacific Rim

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Disability Studies, College of Education, University of Hawai'i at Mānoa.

Keywords: Pacific Rim, disability, conference

Welcome to the Conference Proceedings of the 38th Annual Pacific Rim International Conference on Disability & Diversity 2023

We are pleased to share the Conference Proceedings for the 38th Annual Pacific Rim International Conference on Disability and Diversity 2023. This collection documents some of the diversity of papers presented at the conference in Spring 2023. The conference was held in person for the first time in three years following the COVID-19 pandemic. 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 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 2023. Drawn together by the conference's theme, *Coming Together and Moving Forward*, participants were invited to consider the ways in which their work might help invite attendees to take collective action and amplify our power for change. Presentations and events at the conference were organized within six broad, general strands:

> <u>Built Environment: Digital, Physical, and Social</u> – Building and Housing, Climate Resilience and Disasters, Digital Accessibility, and Transportation;

- (2) <u>Deaf Innovations</u>: Policy and Legislation; Qualified Service Professions/Providers; Workplace Barriers and Overcoming Them; Advancement in the Work; Resources (e.g., interpreters, technological services, therapies, etc.); Social Concerns (e.g., life experiences, self-esteem, confidence, self-acceptance, self-advocacy, peer interaction, mentors, and role models); Collaboration Between All Stakeholders (e.g., medical vs. cultural perspective); Family Support and Involvement; Lack of Understanding/Knowledge (from outside and inside deaf communities); Access to Communication and Language Modalities; Access to Technology; Literacy;
- (3) <u>Education:</u> Equitable and Accessible Systems; Pedagogies; Practices;
 Policies and Services; Inclusive Pre-K-12; Higher Education;
 Indigenous Culturally Responsive Pedagogy; Transition Planning,
 Instruction, Programs, and Support Services;
- (4) Employment First, Employment for All: Employment First Policy as Systemic Approach in Creating a Reality of Meaningful Work for All People with Disabilities; Equity through Diversity and Inclusion in the Workforce; Work Incentives and Strategies on Managing Benefits While Returning to Work; Transitioning from High School to Further Education and the Workforce; Assistive Technology as Tools for Bridging the Gaps in Employment; Professional Development, Trainings and Services;

- (5) <u>Family, School, and Community Engagement</u>: Students' Sense of Belonging in Schools; Attendance in School; Mental Health; Learning; Special Education;
- (6) <u>Healthy Bodies and Minds Access for All:</u> Physical Activity Across the Lifespan; Mental Health; Well-Being.

Within these strands, the contributions herein reflect a broad, cross-section of work in the field. In "Creation of a New Professional Position of 'Assessor' in Japanese Institutions of Higher Education -- Introduction to the University of Tsukuba's Initiatives," Nakano, Takahashi, Okazaki, Shinoda, Waki, Takeda, and Sasaki discuss the rise in recent years of the number of students with disabilities in Japan's higher education and describe initiatives to professionally assess relevant conditions. Jensen, Lee, Hughes, Vollmer, and Maroushek's "Effective Inclusion Practices for Neurodiverse Children and Adolescents in Informal STEM Learning: A Systematic Review" examines preliminary findings from a review of programmatic elements in STEM learning for neurodiverse youth in informal learning settings. "Raising Children's Voices: Lessons Learned from EC Place" by Follari, Lawless, and Wallace describes the design and practices contributing to gains in skills and outcomes in a program supporting language, communication, and social development of children with significant disabilities within a public preschool setting. Schaffer's "The Resolute Resistors: How Vulnerable Populations Are Not As Vulnerable As Presumed" considers how disabilities or being from vulnerable populations do not restrict one's societal contributions. Leong examines "Community-Based Participatory Research (CBPR) Outcomes: 2023 Pacific Rim Conference Accessible and Affordable Housing Discussion" to understand the challenges and advocacy approaches for those with intellectual and developmental disabilities seeking housing.

For all contributions to this volume, plain language versions of abstracts may be accessed at: https://rdsjournal.org/index.php/journal/plain-language-38th-pac-rimproceedings

We wish to thank all the attendees and presenters attending the event. The Center on Disability Studies at the University of Hawai'i at Mānoa is honored to host this important yearly event for our global community. At the time of writing, we are eagerly anticipating the 39th Pacific Rim Conference taking place at the Hawai'i Convention Center to be held in person in Honolulu, Hawai'i, February 27 to February 28, 2024. We invite readers to watch for announcements of forthcoming conference proceedings. The conference theme is *Beyond Access: Building a Culture of Belonging*, and it invites us to think about how we may collectively foster inclusivity and belonging. We are hopeful we will see many of you there and thank you for all your continued efforts toward these shared goals.

Editorial: Welcome to the Conference Proceedings of the 38th Annual Pacific Rim International Conference on Disability & Diversity 2023 by Manaseri, Takahashi, and Park. <u>https://rdsjournal.org/index.php/journal/article/view/1339</u> is licensed under a <u>Creative</u> <u>Commons Attribution 4.0 International License</u> and based on works at <u>https://rdsjournal.org</u>.

Research Articles and Essays

Creation of a New Professional Position of "Assessor" in Japanese Institutions of Higher Education - Introduction to the University of Tsukuba's Assessor

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Abstract

The number of students with disabilities enrolled in Japanese institutions of higher education has been on the rise in recent years, and the percentage of those with developmental disabilities is increasing. However, due to differences in the understanding of a given disability on the part of those providing the considerations, differences in the way records are tracked, the fact that a variety of conditions may be indicated by the same diagnosis, and the relationship between the specific functional impairment caused by a given disability, this matter has not been sufficiently investigated. In light of this, the University of Tsukuba, with the assistance of the Ministry of Education, Culture, Sports, Science and Technology (MEXT), has created a new professional position of "assessor," with reference to the initiatives of universities and other organizations in Japan and abroad. In this paper, we will describe these initiatives and provide an overview of the position and the requisite skills.

Keywords: Japan, disability, higher education, developmental disabilities

Creation of a New Professional Position of "Assessor" in Japanese Institutions of Higher Education - Introduction to the University of Tsukuba's Assessor

Current Status of Higher Education Institutions in Japan

According to 2021 statistics from the Japan Student Services Organization (JASSO), the number of students with disabilities enrolled in Japanese institutions of higher education has been increasing in recent years, with a particularly high percentage of students with developmental, mental, and internal disabilities. In Japan, developmental disabilities are typically considered to include Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), and Specific Learning Disorder (SLD). 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 (JASSO, 2022; Kondo, Takahashi, & Shirasawa, 2015).

In 2016, the Law for the Elimination of Discrimination against Persons with Disabilities came into effect in Japan; and in 2021, as a result of a partial amendment to the law, the provision of reasonable accommodation for students with disabilities became mandatory for all higher education institutions, including private universities. These initiatives contribute to a growing momentum to support students with developmental disabilities.

As the number of students with disabilities in Japan is increasing, and the need for development of a study support system for these students is more urgent than ever, the Ministry of Education, Culture, Sports, Science and Technology issued the Report of the Study Group on Study Support for Students with Disabilities (Second Summary) (MEXT, 2017), which outlines important and as yet insufficiently addressed issues regarding the study of students with disabilities in higher education. Although "training and assigning personnel to provide support to students with disabilities" was cited as a major issue that each university should address, the overall assessment, selection and provisional system in Japanese universities is not necessarily adequate compared to other countries, especially due to a lack of personnel with assessment-related skills.

In the MEXT report, the following documents are listed as evidence that may call for reasonable accommodation of students with disabilities: certificates that include the type, grade, and classification of disability; medical certificates based on appropriate medical diagnostic criteria; the results of standardized psychological tests, etc.; the findings of experts on and off campus; and data on the status of support before entrance to university or other schools such as upper secondary schools and special support schools. In order to determine the appropriate content of consideration, explanatory materials (etc.), wherein the individual objectively comprehends and analyzes his/her own disability status, are also considered effective; and it is necessary to properly comprehend the disability status of each individual student by taking into account a composite of available evidence materials. However, it is important to note that, depending on the nature of the disability, it may be difficult to submit these materials. Thus, it is important to provide assistance to students with disabilities in obtaining evidence, and to consider providing reasonable accommodation regardless of the presence or absence of materials, if the need to remove social barriers is evident to the individual through constructive dialogue, etc. (MEXT, 2017).

Reasonable accommodation is defined, in the U.N. Convention on the Rights of Persons with Disabilities, as "necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms." Similarly, Japan's domestic law, the Law for the Elimination of Discrimination against Persons with Disabilities, stipulates that social barriers shall be removed "when a person with disabilities expresses the actual need for the removal of social barriers and the burden associated with the implementation is not excessive" (JASSO, 2018).

In terms of the current situation regarding reasonable accommodation at Japanese higher education institutions, though there is recognition of the need for such accommodation, there are differences in the understanding of disabilities and the ways the accommodations are tracked by those providing accommodation (instructors in charge of classes, universities and other higher education institutions, etc.), differences in the content of accommodation that can realistically be provided, among other factors. This situation is also influenced by the fact that there are individual differences in the conception of a given condition even with the same diagnosis. Moreover, the relationship between the functional impairment caused by a given disability and the content of considerations has not been sufficiently investigated (Matsuse, Sakamoto, and Matsuse, 2018). As a result, there is a need for "assessors," specialized personnel capable of properly assessing students' functional disabilities and study environment.

The Position and Importance of an Assessor in Japan

In Japan, the term "assessor" is currently used mostly in the fields of business and nursing care, and is still uncommon in the field of education, especially in higher education. The term "developmental disabilities" is gaining recognition in Japan, but there are still cases of misuse and misunderstanding. We believe that the training of specialized personnel (assessors) with the requisite professional qualifications for individual psychological and educational assessment in higher education institutions is an important issue.

The role and position of assessor in foreign countries seems very clear. For example, Specific Learning Difficulties (SpLDs), which account for roughly half of all students with disabilities in the United Kingdom, are determined by psychologists or specialized faculty with SpLD assessment qualifications (Ryder & Norwich, 2018). In the case of higher education institutions in the U.S., qualified psychologists, such as school or clinical psychologists, conduct psycho-educational assessments regarding developmental disabilities (Eurich, Krause, Cigularov, and Thornton, 2009).

In Japan, Osaka University is implementing advanced initiatives. Since 2016, the University has established a system to assess functional impairment using standardized objective assessment tools, and students who are found to have such impairment are addressed according to a systematic flow, including assessment of student needs and determination of their appropriateness (Suwa, Mochizuki, Yoshida, Nakano, & Kusunoki, 2017).

As mentioned, the number of students diagnosed with developmental disabilities enrolled in higher education in Japan is on the rise, and it is anticipated that an assessor, who will judge the needs of students and the appropriateness of their learning support needs, will be positioned as essential professionals at universities and other institutions in the future.

On the other hand, considering the professional system in Japan and the resources available to each university, it can be assumed that the duties to be performed by such assessors will be very diverse. The primary role of the assessor will be to properly utilize objective assessment tools, as well as to properly interpret the results of assessments conducted at medical institutions outside the university, and to communicate and collaborate with the educational organization to which the student concerned belongs. In considering reasonable accommodations at institutions of higher education, in addition to determining the presence or absence of a disability and the student's functional impairment, it may also be necessary to assess various aspects, such as the organization of the educational program, the competencies positioned in each class, the resources available at each institution, support that does not conflict with the nature of the class, and an assessment of its appropriateness.

In particular, the basis for all assessments is consideration of problems in the learning environment, with a focus on assessing functional impairment, to determine effective methods of consideration and ensure educational equity. However, as noted above, regarding developmental disabilities, there are significant individual differences in the conception of a given condition, and cases where consideration is determined according to the general characteristics of the disability and the individual's claims, without a full functional evaluation. While overestimation of the importance of objective assessment tools should be avoided, making consideration decisions without adequate assessment of which, and to what extent, student functions are affected by the given disability may also deprive the student of learning opportunities and equity. While it is important to conduct such assessments, given the reality that universities in Japan face various constraints in conducting inspections (such as human and material costs), they may have to rely on findings from external organizations. As a result, the specifics of how to proceed with this series of processes vary depending on the policies and resources of each university.

Initiatives to Create a New Professional Position of "Assessor" - Example of the University of Tsukuba

With the assistance of the Ministry of Education, Culture, Sports, Science and Technology (MEXT), the University of Tsukuba has launched an initiative entitled Implementation of Psycho-educational Assessment Functions to Maximize Performance of Diverse Students: Building an Advanced Study Support System for All Students, Including Potential Students with Developmental Disabilities. As a part of this initiative, a new professional position of "assessor" was created in Fiscal Year 2021 to support students' learning and assess students' diverse capabilities, with reference to the aforementioned initiatives of domestic and overseas universities and other institutions. The University of Tsukuba promotes understanding of students' individual developmental characteristics and career aptitude, regardless of whether they have been diagnosed with a developmental disability, and provides student assistance for guidance in the educational organization. One of these educational supports is "individual psychological and educational assessment."

"Individual psychological and educational assessment" is available on the website pertaining to support for students with disabilities at the University of Tsukuba, and students may request an assessment at any time. A system has also been established to conduct individual psychological and educational assessments to objectively evaluate students with high-support needs, as identified through a voluntary university-wide screening survey called the Strength and Difficulties Questionnaire; this assesses their developmental disability tendencies, intellectual abilities, and level of adaptation to social life. A full-time assessor with the necessary professional qualifications to conduct such assessments is assigned to conduct individual assessments of around 100 high support needs students each year. If the results of the assessment suggest that a student may have a developmental disability, we recommend the WEB-based Learning Support Book (LSB), a storehouse of student-designed techniques aimed at enhancing self-help skills. (Incidentally, the LSB, a WEB service that distributes support information, won a bronze award in the Communication Design category of the IAUD International Design Award 2020.)

Similarly, we may introduce or lend students support tools and applications or refer them on to staff responsible for academic support. The staff member in charge of academic support will liaise with medical and welfare institutions both inside and outside the university as necessary and may also provide consultation to educational organizations when educational considerations and support are needed. They also provide coaching (which we term "study-skill coaching") when specialized academic support is deemed necessary.

In this way, an assessor plays an important role in supporting students, by interviewing them about their study environment in classes and learning assignments, conducting standardized psychological tests and other assessments, and providing feedback, which is positioned as a prerequisite for study support and reasonable accommodation. In addition to objectively assessing student functioning and interpreting how it relates to the student's difficulties and competencies, the assessor is also expected to develop support or considerations that can be implemented in the university environment, and explain these to the faculty and the student himself/herself.

Summary and Future Prospects

In Japanese universities, the percentage of students with developmental disabilities is increasing, and assessment is important to confirm the evidence regarding applications for support from such students, and to better understand their individual characteristics. However, consideration of the content of such support, and the provision of reasonable accommodations, are currently left to the individual efforts of faculty and staff at each university, etc., and it is believed that some faculty and staff find it difficult address the needs of such students.

It is important to share the results of standardized psychological tests and other assessments, as well as the difficult situations faced by such students, with the staff in charge of support for study and the teachers in charge of classes, etc., to determine adjustments that can be made to the considerations that the assessor discussed during the interview, in order to make adjustments to the environment during class time, etc., and link these to study considerations.

However, many questions remain: how to establish a study support system and conduct assessments appropriately with limited resources and human and material costs, where and from whom to request assessments when it is difficult to conduct assessments on campus, how to utilize the assessment results obtained, and how an assessor is expected to be involved and fulfill their responsibilities in the assessment process—these questions are still in the process of being answered in Japan.

References

- Eurich, T. L., Krause, D. E., Cigularov, K., & Thornton, G. C. (2009). Assessment centers:
 Current practices in the United States. *Journal of Business and Psychology*, *24*(4), 387-407.
- Kondo, T., Takahashi, T., & Shirasawa, M. (2015). Recent Progress and Future Challenges in Disability Student Services in Japan. *Journal of Postsecondary Education and Disability*, 28(4), 421-431.
- Matsuse, R., Sakamoto, G., & Matsuse, Y. (2018). Reasonable accommodation for ASD students and the challenges faced by teachers: Mainly in small private universities. *The Japanese Journal of Autistic Spectrum*, *16*(1), 57-66. (in Japanese)
- Ministry of Education, Culture, Sports, Science and Technology (2017). Report of the Study Group on support for students with disabilities' study (Second summary). (in Japanese)
- National Center For Education Statistics (2011). Students with Disabilities at Degree-Granting Postsecondary Institutions. U.S. Department of Education.
- Japan Student Services Organization (2018). Reasonable Accommodation Handbook for Faculty and Staff Supporting Students with Disabilities. The Earth Kyoiku Shinsha Co., Ltd (in Japanese)
- Japan Student Services Organization (2022). Report on the Results of the 2021 Survey on Support for Students with Disabilities at Universities, Junior Colleges, and Colleges of Technology (in Japanese)

Ryder, D., & Norwich, B. (2018). What's in a name? Perspectives of dyslexia assessors working with students in the UK higher education sector. *Dyslexia*, 24(2), 109-127.

Suwa, E., Mochizuki, N., Yoshida, Y., Nakano, S., & Kusunoki, K. (2017). Towards

Equality in Supporting Disabled Students: Practice at the University of

Westminster. Osaka University Higher Education Studies, 5, 1-8. (in Japanese)

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Research Articles and Essays

Effective Inclusion Practices for Neurodiverse Children and Adolescents in Informal STEM Learning: A Systematic Review

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Abstract

Informal learning settings are valuable environments for students to learn beyond the classroom. This article describes the preliminary findings from a systematic review that explored programmatic elements associated with science, technology, engineering, and mathematics (STEM) learning, knowledge, identity, and self-efficacy for neurodiverse youth in informal STEM learning environments.

Keywords: informal learning, STEM, neurodiverse

Effective Inclusion Practices for Neurodiverse Children and Adolescents in Informal STEM Learning: A Systematic Review

Informal science, technology, engineering, and mathematics (STEM) learning occurs outside the traditional classroom and includes a variety of settings, such as clubs, museums, and public libraries (Roberts et al., 2018; Stanford et al., 2018). Unlike traditional classroom settings, informal learning settings are often accessible to more diverse students from varying backgrounds (Bell et al., 2009). Informal learning environments also provide many different benefits to learning, including exploration of STEM environments with minimal risk (e.g., exploring the STEM environment freely without the pressures associated with testing, making mistakes, or taking additional time or repetitions needed to fully explore and learn) (Bales et al., 2015; Dabney et al., 2012; Denson et al., 2015; Lavigne et al., 2007; Lin & Schunn, 2016; Reich et al., 2010; Roberts et al., 2018; Schnittka et al., 2012).

The term "neurodiverse" comprises individuals with various conditions, including autism spectrum disorder (ASD), developmental learning disorders, or attention deficit hyperactivity disorder (ADHD). Neurodiverse students sometimes face additional challenges in traditional classrooms, such as modified daily routines, understanding social interactions, and barriers associated with their conditions (Chandrasekhar, 2020; Mellifont, 2021; Schindler et al., 2015). Studies reporting on informal STEM learning opportunities in museum settings and makerspace programs with neurodiverse students demonstrated an increase in STEM engagement as well as positive social interaction with peers (Bargagna et al., 2019; Howard & Park, 2014; Langa et al., 2013; Lussenhop et al., 2016; Riccio, 2022).

The purpose of this paper is to briefly present the preliminary results of our systematic review as we aim to answer the following research question: What characteristics of informal learning experiences correlate with increased STEM identity, self-efficacy, interest, and learning in neurodiverse K-12 students? These preliminary results reveal ways that learning about STEM in informal settings can help neurodiverse youth increase their interest in STEM fields, shape their STEM identity, and increase their self-efficacy for furthering their learning in STEM.

Method

As a systematic review, the project team worked with a social sciences librarian to conduct a thorough literature search. Academic literature was retrieved from seven databases in October 2021: PsycINFO, ERIC, Education Full Text, Academic Search Complete, Cochrane Library, Science Direct, and Web of Science. The project team also completed a comprehensive grey literature search. Grey literature includes work that contains information that is produced by the government, business, and industry sources rather than traditional publication channels (Bonato, 2018). The grey literature search included published conference proceedings, informal science online resources managed by the Center for Advancement of Informal Science Education (CAISE), and final reports from related National Science Foundation grants.

All academic and grey literature was evaluated based on the following criteria:

- 1. Makes reference to neurodiverse students,
- 2. Focuses on students between the ages of 5 to 19,
- Focuses on science, technology, math, or engineering (STEM) informal learning,
- 4. Focuses on informal learning settings (e.g., after school programs), and
- 5. Occurs in the United States.

Two independent research team members reviewed all abstracts and articles. If there

were disagreements in the reviews, a third reviewer assisted with reviewing the content.

Results

After data screening, there were a total of 19 products, including 11 studies and eight artifacts. Artifacts refer to content gathered from the grey literature search, which included evaluations, conference proceedings, a case study, and a podcast. The majority of studies included qualitative research designs (n = 6, 32%; Chen et al., 2021; Dunn et al., 2015; Ehsan & Cardella, 2019; Fisher et al., 2019; Powers et al., 2015; Syharat et al., 2020) and fewer were quantitative and mixed-method research designs (n = 5, 26%; Chen et al., 2020; Gregg et al., 2017; Martin et al., 2020; Sowers et al., 2017; Wright & Moskal, 2014).

Sample Sizes

The sample sizes of the products in this systematic review varied greatly, ranging from a case study of two participants to approximately 400 participants. Students with ASD were the most represented neurodiverse condition across products (n = 16, 84%). Students with ASD were the sole focus of 12 of the 19 products (63%). Significantly less research was conducted on other specific neurodiverse conditions, including dyslexia (n = 1, 5%; Wright & Moskal, 2014) and ADHD (n = 1, 5%; Syharat et al., 2020). In some cases, researchers grouped together a variety of neurodiverse conditions (n = 5, 26%). As this study focused on K-12 learners, we found that the majority of products reported on programs designed for middle or high school students (n = 14, 73%; Chen et al., 2020, 2021; Cominsky et al., 2022; Dahleh & Jonathan, 2018; Elsayed et al., 2022; Fisher et al., 2019; Gregg et al., 2017; Lesser, 2018; Martin et al., 2019, 2020; Nguyen et al., 2021; Powers et al., 2015; Sowers et al., 2017; Valcarcel et al., 2021).

Description of Informal STEM Learning

Informal STEM learning opportunities occurred mostly in after-school settings such as after-school clubs (n = 7, 36%; Chen et al., 2020, 2021; Fisher et al., 2019; Lesser, 2018; Martin et al., 2019, 2020; McCarthy et al., 2021) or at summer camps/programs (n = 7, 36%; Cominsky et al., 2022; Dahleh & Jonathan, 2018; Elsayed et al., 2022; Nguyen et al., 2021; Syharat et al., 2020; Valcarcel et al., 2021; Wright & Moskal, 2014). Many products included an aspect of mentorship (n = 7, 36%; Cominsky et al., 2022; Elsayed et al., 2022; Gregg et al., 2017; Powers et al., 2015; Sowers et al., 2017; Syharat et al., 2020; Valcarcel et al., 2021) with most interventions lasting a few weeks (n = 3, 15%; Dunn et al., 2015; Syharat et al., 2020; Wright & Moskal, 2014) to a few months (n = 5, 26%; Cominsky et al., 2022; Elsayed et al., 2022; Powers et al., 2015; Sowers et al., 2017; Valcarcel et al., 2021). However, many programs/interventions were of indeterminate length (n = 9, 47%; Chen et al., 2020, 2021; Dahleh & Jonathan, 2018; Fisher et al., 2019; Lesser, 2018; Martin et al., 2019; McCarthy et al., 2021; Nguyen et al., 2021).

Description of Preliminary Findings

When describing informal STEM learning, three categories of program elements emerged: (a) environment/learning structure, (b) learning supports, and (c) learning types. Environment/learning structure refers to the settings and programmatic structures that the informal STEM program put into place to engage neurodiverse students in the STEM content. Examples include how programs incorporated student interest into activities or how flexibility was incorporated into program curriculum. Learning supports are the extra steps that informal STEM programs took to connect the neurodiverse students to STEM learning. Use of mentors and accommodations are examples of learning support. Learning types include the instructional strategies used by the informal STEM program. The use of technology, hands-on learning activities, and collaborative learning (peer-to-peer) are examples of learning types.

Environment/Learning Structure

In our review, one program demonstrated how the environment and learning structures can have an impact on STEM interest and self-efficacy for STEM learning. The Inventing, Designing, and Engineering for All Students (IDEAS) Maker program, which is described in multiple products (n = 5; Chen et al., 2020, 2021; Lesser, 2018; Martin et al., 2019, 2020), was co-created with experts in education, engineering and technology education, and inclusion. A key element to the structure of the IDEAS program was its strength-based approach to neurodiverse students' interests rather than framing highly focused interests as deficits. Facilitators of the program included one special education teacher and one subject teacher (science, art, or math). The program was held in an afterschool setting and began with 12 hands-on activities, including learning about motors, light emitting diodes (LEDs), and circuits, which built off one another and led to a culminating final project (Chen et al., 2021). The curriculum also incorporated elements to assist with learning, including explicit strategy instructions to support problem-solving using the engineering design processes (EDP). The EDP provided a structured visual guide for students to utilize and assisted with goal setting and monitoring project progress. The IDEAS program was organized in a manner where students were able to explore their STEM interests in social environments with their peers. Students were given the freedom to build upon their own interests, which were integrated into their final projects, illustrating the provision of agency and autonomy to students. Having a structured yet flexible program was associated with positive STEM outcomes. Positive STEM outcomes were expressed qualitatively through

semi-structured focus groups with students that participated in the IDEAS program and teachers who facilitated the IDEAS program (Chen et al., 2021) and quantitatively with a STEM self-efficacy career interest survey (Chen & Usher, 2013).

Indication of how engaging the IDEAS program was for neurodiverse students was captured in a quote from one teacher: "[Teachers] observed that some students who normally would complete the bare minimum to get through their classes would create careful and detailed projects when they were allowed to pursue what they cared about (for example, memes, food, video game characters, anime)" (Martin et al., 2020, p. 15). Some students commented on how the IDEAS program influenced them to consider STEM careers or determine that they might want to have a future job with elements they were exposed to in the IDEAS program. One student with autism commented, "[An engineer] might be something I want to be when I grow up." Another student stated, "What I've enjoyed doing is coming up with a bunch of ideas of what could potentially become successful ... engineering products" (Chen et al., 2021).

Overall, the IDEAS program had an effect on student self-efficacy for STEM learning. Researchers involved in the IDEAS program assessed students at the beginning and end of their engagement in the program activities, using a researcher-developed instrument shown previously to yield strong reliability coefficients. The results showed that the IDEAS maker group had higher scores than the comparison group (no participation in the IDEAS maker group) on engineering and technology self-efficacy with a Hedge's g effect size of .82 (Martin et al., 2020).

Learning Supports

Learning support primarily included mentoring, accommodations, and modifications to programmatic elements (n = 9; Cominsky et al., 2022; Dunn et al., 2015; Elsayed et al.,

2022; Gregg et al., 2017; McCarthy et al., 2021; Nguyen et al., 2021; Powers et al., 2015; Sowers et al., 2017; Syharat et al., 2020; Valcarcel et al., 2021), where mentoring was the most commonly used learning support across all products (n = 5; Dunn et al., 2015; Gregg et al., 2017; Powers et al., 2015; Sowers et al., 2017; Syharat et al., 2020). Two products evaluated a STEM mentoring program for youth with disabilities on career planning outcomes. Researchers randomly assigned 78 youth with disabilities to either mentors with disabilities, mentors without disabilities, or a control group (Powers et al., 2015; Sowers et al., 2017). Mentors with disabilities were either employed in a STEM career or in a postsecondary STEM education program and were provided with coaching that emphasized the importance of mentors engaging in fun interactions as well as STEM career exploration. Examples of these activities included the student shadowing the mentor at work, reviewing high school transcripts together, and coming up with a course plan for college. One study used focus groups with students who had mentors with disabilities and mentors without disabilities to evaluate the impact of the mentoring program (Powers et al., 2015). The other study administered quantitative questionnaires at three different time points to determine if there were differences between the students with mentors with disabilities and students with mentors that did not have disabilities on career planning outcomes (Sowers et al., 2017).

Many neurodiverse youths in the mentoring program described how their mentor exposed them to STEM career opportunities in addition to contributing to STEM career aspirations. One student discussed how mentors exposed them to different types of STEM jobs: "This taught me, like, all the different types of jobs out there, like engineering jobs and just all the possibilities" (Powers et al., 2015, p. 30). Another student commented on how their mentor made obtaining a STEM job seem more achievable:

My mentor just kind of like opened my eyes to the possibilities of getting into a

STEM career. And like helped me realize that it's not impossible to do stuff like that. She made me like science and math even more. (Powers et al., 2015, p. 31)

Researchers that conducted the mentoring programs examined changes in selfefficacy for participating students (Sowers et al., 2017). They measured STEM self-efficacy and confidence by adapting the Disability Related Self-Efficacy Scale (Powers et al., 1995). The authors used the adapted scales to evaluate the degree to which students believed they could get into college, do well in STEM classes, and obtain a STEM job. Students in the intervention group made greater improvements in STEM career planning confidence than the control group; however, this effect was less apparent over time.

Learning Types

Learning types included collaborative learning (peer-to-peer), hands-on learning, and real-world STEM applications. Collaborative learning was the most frequently cited learning type, in which some element of peer-to-peer STEM learning occurred in most products. Collaborative learning was observed in multiple formats, most frequently occurring informally as students worked together based on how the program was set up rather than being paired up or grouped by program facilitators. In the IDEAS program, program facilitators noted when relationships would form where there was a common interest or as students started to assist others in the program (e.g., peer teaching). Over time, participants were seen as valuable to their peers.

One observation drew a connection between the social aspects of the program and STEM learning. The program facilitator describes this informal collaborative learning:

Students were comfortable and willing to share their projects with peers and with adults and were enthusiastic to offer help and suggestions to each other. Teachers also reported observing spontaneous social interactions in students on the spectrum during the program. (Chen et al., 2020, p. 8)

A student with autism implicitly draws the connection between the social aspects and STEM learning by noting how the program allowed for students to not be fearful of failing. As he explains, "We're always testing our prototypes. If it fails, it's not a big deal because we have plenty of time to try it" (Chen et al., 2021). As another example, a program facilitator described how learning about the EDP was beneficial for students as they all were experiencing the same challenges, and that the EDP outlines the next steps if an experiment does not go as planned:

For us, we go over the engineering design process, we go over the steps, and we name them . . . It's more comforting for them to say, "Oh, OK, so we go through this when a prototype fails. We go through iteration. We change it and then we improve it." (Martin et al., 2020, p. 11)

Discussion

These preliminary findings provide evidence of some programmatic factors being key to positive outcomes for neurodiverse students. The programmatic factors included hands-on learning, goal-setting activities, collaborative/social-driven learning, mentoring, and program flexibility to allow students to follow their interests. Common across these programmatic factors is that each is a way of fostering student engagement in STEM. Each of these programmatic factors has a long history of being applied to formal learning settings and to instruction of non-disabled students. But collectively, they illustrate the theoretical relationship between informal STEM learning experiences that provide options for student engagement and positive effects on STEM learning, STEM self-efficacy, and STEM identity. With roots in Social Cognitive Career Theory (Maiorca et al., 2021), this theoretical relationship between forms of social engagement in STEM learning and positive outcomes is not new. However, for neurodiverse students, it is interesting how these programmatic factors are fine-tuned to increase the likelihood of their engagement. For example, receiving mentoring from someone who shares similar interests, whether that be in STEM or other topics, was effective for neurodiverse students. As another example, offering social learning opportunities provided enriching STEM learning experiences for neurodiverse students, who can often feel excluded from social learning formats in school.

Some programs used a control group of students without neurodiverse conditions, where in many cases it was evident that both groups of students benefited from these programs designed for neurodiverse learners, indicating that many aspects of these STEM interventions could be beneficial to a wide variety of students. Students with ASD were represented significantly more than other types of neurodiverse conditions; future informal STEM programs should consider recruiting students with other types of neurodiverse conditions to expand our knowledge on the impact of informal STEM learning programs did not take place in public settings such as a public library or local museums. Most informal STEM programs were offered in collaboration with schools. To be more accessible to a wide variety of neurodiverse students, including those with varying backgrounds, future informal STEM programs should consider how to integrate their programming into public programs that could reach a wider audience.

As we continue with our analysis, we will probe further into the nuances of the programmatic features that distinguish the programs and outcomes for neurodiverse students and the features that are commonly indicative of informal STEM learning. Being able to distinguish important nuances will provide further recommendations for future informal STEM programs on improving their programs for neurodiverse students. Additionally, it is expected that many of the recommendations will also be enhancements that would improve programs overall for all students.

References

Bales, S., Volmert, A., & Kendall-Taylor, N. (2015). The power of explanation: Reframing STEM and informal learning. Frameworks Institute. <u>https://www.frameworksinstitute.org/publication/the-power-of-explanationreframing-stem-and-informal-learning/</u>

Bargagna, S., Castro, E., Cecchi, F., Cioni, G., Dario, P., Dell'Omo, M., Di Lieto, M., Inguaggiato, E., Martinelli, A., Pecini, C., & Sgandurra, G. (2019). Educational robotics in down syndrome: A feasibility study. *Technology, Knowledge and Learning*, 24(2), 315–323. <u>https://doi.org/10.1007/s10758-018-9366-z</u>

 Bell, P., Lewenstein, B., Shouse, A., & Feder, M. (2009). Diversity and equity. In National Research Council (Ed.), *Learning Science in Informal Environments: People, Places, and Pursuits*. The National Academies Press. <u>https://doi.org/10.17226/12190</u>

Bonato, S. (2018). Searching the grey literature: A handbook for searching reports, working papers, and other unpublished research. Rowman & Littlefield.
 https://books.google.com/books/about/Searching_the_Grey_Literature.html?id=3Hle
 DwAAQBAJ

Chandrasekhar, T. (2020). Supporting the needs of college students with autism spectrum disorder. *Journal of American College Health*, 68(8), 936–939. https://doi.org/10.1080/07448481.2019.1686003

Chen, J., & Usher, E. (2013). Profiles of the sources of science self-efficacy. Learning and

Individual Differences, 24, 11-21. https://doi.org/10.1016/j.lindif.2012.11.002

- Chen, Y., Murthi, K., Martin, W., Vidiksis, R., Riccio, A., & Patten, K. (2021). Experiences of students, teachers, and parents participating in an inclusive, school-based informal engineering education program. *Journal of Autism and Developmental Disorders*, 52(8), 3574–3585. <u>https://doi.org/10.1007/s10803-021-05230-2</u>
- Chen, Y., Patten, K., Martin, W., Vidiksis, R., & Hupert, N. (2020). Making for inclusion: Collaborative creation of an engineering design program in autism-inclusion middle schools. *Proceedings of the 2020 AERA Annual Meeting*. 2020 AERA Annual Meeting. <u>https://doi.org/10.3102/1578616</u>
- Cominsky, L., Riccio, A., Martin, W., Peticolas, L., Mendez, B., Perez, S., Williams, G.,
 Grillo-Hill, A., & Valcarcel, J. (2022). NASA's neurodiversity network (N3). *Revista Mexicana de Astronomía y Astrofísica Serie de Conferencias*, 54, 61–65.
 https://doi.org/10.22201/ia.14052059p.2022.54.13
- Dabney, K., Tai, R., Almarode, J., Miller-Friedmann, J., Sonnert, G., Sadler, P., & Hazari, Z. (2012). Out-of-school time science activities and their association with career interest in STEM. *International Journal of Science Education, Part B Communication and Public Engagement*, 2(1), 63–79. <u>https://doi.org/10.1080/21548455.2011.629455</u>
- Dahleh, M., & Jonathan, B. (2018). Using informal learning environments to encourage more diverse engineers. 2018 World Engineering Education Forum Global Engineering Deans Council (WEEF-GEDC), 1–4. <u>https://doi.org/10.1109/WEEF-GEDC.2018.8629626</u>

Denson, C., Austin, C., Hailey, C., & Householder, C. (2015). Benefits of informal learning

environments: A focused examination of STEM-based program environments. Journal of STEM Education, 16(1), 11–15. <u>https://www.learntechlib.org/p/151634/</u>

- Dunn, L., Diener, M., Wright, C., Wright, S., & Narumanchi, A. (2015). Vocational exploration in an extracurricular technology program for youth with autism. *Work*, 52(2), 457–468. https://doi.org/10.3233/WOR-152160
- Ehsan, H., & Cardella, M. (2019). Investigating children with autism's engagement in engineering practices: Problem scoping (Fundamental). 2019 ASEE Annual Conference & Exposition Proceedings, 33022. <u>https://doi.org/10.18260/1-2--33022</u>
- Elsayed, R., Melchior, K., Nguyen, K., & Valcarcel, J. (2022). *Evaluation memo on N3* professional learning sessions on neurodiverse youth in April and May 2022. WestEd.
- Fisher, K., Gallegos, B., & Bousfield, T. (2019). Students with autism spectrum disorders who participate in FIRST robotics. *Proceedings of the Interdisciplinary STEM Teaching and Learning Conference*, 3(1). <u>https://doi.org/10.20429/stem.2019.030105</u>
- Gregg, N., Galyardt, A., Wolfe, G., Moon, N., & Todd, R. (2017). Virtual mentoring and persistence in STEM for students with disabilities. *Career Development and Transition for Exceptional Individuals*, 40(4), 205–214.
 https://doi.org/10.1177/2165143416651717
- Howard, A., & Park, H. (2014). Using tablet devices to engage children with disabilities in robotic educational activities. *Journal on Technology and Persons with Disabilities*, 2(16). <u>http://hdl.handle.net/10211.3/133378</u>
- Langa, L., Monaco, P., Subramaniam, M., Jaeger, P., Shanahan, K., & Ziebarth, B. (2013). Improving the museum experiences of children with autism spectrum disorders and

their families: An exploratory examination of their motivations and needs and using web-based resources to meet them. *Curator*, *56*(3), 323–335. https://doi.org/10.1111/cura.12031

- Lavigne, G., Vallerand, R., & Miquelon, P. (2007). A motivational model of persistence in science education: A self-determination theory approach. *European Journal of Psychology of Education*, 22(3), 351–369. <u>https://doi.org/10.1007/BF03173432</u>
- Lesser, M. (2018, July 3). *MakerEd & autism* (No. 34). [Audio podcast episode]. In *No such thing: Education in the digital age*. <u>https://podcasts.apple.com/us/podcast/makered-autism/id1279984850?i=1000415173101</u>
- Lin, P., & Schunn, C. (2016). The dimensions and impact of informal science learning experiences on middle schoolers' attitudes and abilities in science. *International Journal of Science Education*, 38(17), 2551–2572.
 https://doi.org/10.1080/09500693.2016.1251631
- Lussenhop, A., Mesiti, L., Cohn, E., Orsmond, G., Goss, J., Reich, C., Osipow, A., Pirri, K., & Lindgren-Streicher, A. (2016). Social participation of families with children with autism spectrum disorder in a science museum. *Museums & Social Issues*, *11*(2), 122–137. <u>https://doi.org/10.1080/15596893.2016.1214806</u>
- Maiorca, C., Roberts, T., Jackson, C., Bush, S., Delaney, A., Mohr-Schroeder, M., & Soledad, S. (2021). Informal Learning Environments and Impact on Interest in STEM Careers. *International Journal of Science and Mathematics Education*, 19(1), 45–64. https://doi.org/10.1007/s10763-019-10038-9

Martin, W., Vidiksis, R., Patten, K., & Chen, Y. (2019). Making on and off the spectrum

[National Science Teaching Association]. *Connected Science Learning*. <u>https://www.nsta.org/connected-science-learning/connected-science-learning-april-june-2019/making-and-spectrum</u>

- Martin, W., Yu, J., Wei, X., Vidiksis, R., Patten, K., & Riccio, A. (2020). Promoting science, technology, and engineering self-efficacy and knowledge for all with an autism inclusion maker program. *Frontiers in Education*, *5*, 75. <u>https://doi.org/10.3389/feduc.2020.00075</u>
- McCarthy, B., Brenner, D., & Morgan, C. (2021). Science learning with Hero Elementary: Blended learning resources to reach students with disabilities. WestEd.
- Mellifont, D. (2021). Ableist ivory towers: A narrative review informing about the lived experiences of neurodivergent staff in contemporary higher education. *Disability & Society*. <u>https://doi.org/10.1080/09687599.2021.1965547</u>
- Nguyen, K., Grillo-Hill, A., Valcarcel, J., & Elsayed, R. (2021). *Redeveloping resources Y1: Results from observations and interviews with instructors and their students about the resource redevelopment process*. WestEd.
- Powers, L., Schmidt, J., Sowers, J., & McCracken, K. (2015). Qualitative investigation of the influence of STEM mentors on youth with disabilities. *Career Development and Transition for Exceptional Individuals*, 38(1), 25–38. https://doi.org/10.1177/2165143413518234
- Powers, L., Sowers, J., & Stevens, T. (1995). An exploratory, randomized study of the impact of mentoring on the self-efficacy and community-based knowledge of adolescents with severe physical challenges. *Journal of Rehabilitation*.

https://www.semanticscholar.org/paper/An-Exploratory%2C-Randomized-Study-ofthe-Impact-of-Powers-Sowers/6c98e9a292e34a56427275faa58827663c6c4d35

Reich, C., Price, J., Rubin, E., & Steiner, M. (2010). Inclusion, disabilities, and informal science learning. Center for Advancement of Informal Science Education (CAISE) Access Inquiry Group.

https://www.informalscience.org/sites/default/files/InclusionDisabilitiesandInformalS cienceEducation.pdf

- Riccio, A. (2022). Building engineering interest and resilience through maker programming in autism-inclusion schools. *ASEE 2022 Annual Conference: Excellence through Diversity*, 8. <u>https://peer.asee.org/building-engineering-interest-and-resilience-</u> <u>through-maker-programming-in-autism-inclusion-schools</u>
- Roberts, T., Jackson, C., Mohr-Schroeder, M., Bush, S., Maiorca, C., Cavalcanti, M.,
 Schroeder, D., Delaney, A., Putnam, L., & Cremeans, C. (2018). Students'
 perceptions of STEM learning after participating in a summer informal learning
 experience. *International Journal of STEM Education*, 5.
 https://doi.org/10.1186/s40594-018-0133-4
- Schindler, V., Cajiga, A., Aaronson, R., & Salas, L. (2015). The experience of transition to college for students diagnosed with Asperger's Disorder. *Open Journal of Occupational Therapy*, 3(1). <u>https://doi.org/10.15453/2168-6408.1129</u>
- Schnittka, C., Brandt, C., Jones, B., & Evans, M. (2012). Informal engineering education after school: Employing the studio model for motivation and identification in STEM domains. *Advances in Engineering Education*, 3(2).
 https://files.eric.ed.gov/fulltext/EJ1076077.pdf
- Sowers, J., Powers, L., Schmidt, J., Keller, T., Turner, A., Salazar, A., & Swank, P. (2017). A randomized trial of a science, technology, engineering, and mathematics mentoring program. *Career Development and Transition for Exceptional Individuals*, 40(4), 196–204. <u>https://doi.org/10.1177/2165143416633426</u>
- Stanford, A., Wilson, C., & Barker, E. (2018). Renovating our science learning centers: Informal learning centers transcend disciplinary boundaries as students address realworld applications. *Science and Children*, 55(9), 62–67.
- Syharat, C., Hain, A., & Zaghi, A. (2020). Promoting neurodiversity in engineering through specialized outreach activities for pre-college students. *Journal of Higher Education Theory and Practice*, 20(14), 111–123.
- Valcarcel, J., Grillo-Hill, A., Nguyen, K., & Elsayed, R. (2021). Mentor feedback on N3 training sessions: Results from interviews with N3 SME mentors about their experiences with program training sessions in May 2021. WestED.
- Wright, L., & Moskal, B. (2014). Including children with disabilities in STEM: An outreach program for dyslexic students (Research to practice). 2014 ASEE Annual Conference & Exposition Proceedings, 24.726.1-24.726.12. <u>https://doi.org/10.18260/1-2--20618</u>

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Research Articles and Essays

Raising Children's Voices: Lessons Learned from EC PLACE

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Abstract

The Early Childhood Program for Language Acquisition and Community Engagement (EC PLACE) is a program designed to support language, communication, and social development of children with significant disabilities within a public preschool setting. This article describes program design and eight effective program practices which contributed to remarkable gains in children's skills and outcomes.

Keywords: preschool intervention, autism, early childhood special education

Raising Children's Voices: Lessons Learned from EC PLACE

Most preschool classrooms are cheerful, colorful, busy places with lots of joyful noise and extensive peer socialization. For most typically developing children, these settings are conducive to play, social engagement, and positive learning outcomes. For some children, particularly children with autism, language, communication, or behavior delays or disabilities, these settings can be challenging. The bright and crowded environment, busy or noisy social activities, and pace of activities can cause some children to become stressed, anxious, overwhelmed, and overstimulated. These feelings can lead children to withdraw or engage in challenging behaviors that create a barrier to positive learning and developmental outcomes in preschool (Dye, 2018).

This paper describes a specialized program designed intentionally around strengths and areas for growth of children with significant language, communication, and behavior support needs, with structured inclusion of typically developing peers. The case study public preschool in a rural community was designed in response to the early childhood special education (ECSE) preschool teacher/director noticing significant enrollment increases of children with autism in the preschool, and the challenges the typical preschool program was posing for those children. The director noticed that children were stressed, overwhelmed, and engaging in self-injurious behaviors in the typical classroom, but when they were in a quieter setting with fewer children and more teachers, they were able to relax and engage more productively with language and social learning activities and make deeper relationships with teachers. With teacher designed supports, the children were then able to engage with peers in play and learning activities, with teacher facilitation and support. From these observations, the Early Childhood Program for Language Acquisition and Community Engagement was designed and launched.

Foundational Framework for Discussing dis/Ability: Disability as Social Construct

Our work as educators and researchers is rooted in the belief that the concepts and definitions of ability and disability are socio-political constructs, grounded in an ableist lens, which have been designed and used to marginalize and segregate people based on socially constructed definitions of fitness and ability, in essence used as tools of exclusion (Hamilton, 2019; Liachowitz, 2010). We approach our work with and for children from a place of respect for human dignity, a curiosity about how we can support each child's optimal growth, development, and learning, and a recognition that we are operating within systems and structures that can be limiting at times. We view our role as educators and advocates for all children as that of guides and facilitators within these limiting structures, striving to help children and families navigate complex and often exclusionary structures in services to support each child's growth, development, and learning.

In this paper, we discuss public school-based interventions for preschool children with documented disabilities, as defined by current legal frameworks. Within this context, we use labels for disabilities as defined by laws which impact school-based interventions, such as the labels and definitions in the Individuals with Disabilities Education Act (IDEA). However, the legally defined labels are used here only in the context of public-school structures, which require the use of disability labels to access resources to support individualized interventions tailored to nurture optimal learning and developmental outcomes for each child. Our discourse around disabilities, labels, and interventions warrants a clear grounding in our unwavering advocacy for full and meaningful inclusion of all people across settings, and deeply held belief that diversity of all kinds is the natural state of being human. In this stance,

all humans with all manner of diversities are viewed as inherently valuable, natural, and important to co-creating organically representative settings and authentic experiences among all people. In this philosophical stance grounded in inclusion, we do not generally impose deficit-oriented labels or view human diversity as a "disability." We use such labels in this paper, with this important caveat, because we are operating within the legal frameworks of school-based intervention and special education programming provided in the case study program.

The Origins of the EC PLACE Program

The Early Childhood Program for Language Acquisition and Community Engagement (EC PLACE) began in a small rural public preschool, located in the public elementary school, in response to increasing enrollment of young children diagnosed with autism, children with limited communication or non-verbal communication, and children with significant behavioral support needs. The preschool Early Childhood Special Education teacher (ECSE), also the preschool director, began noticing increased needs for individualized supports in preschool and observed the challenges the preschool children were facing in their elementary school years. In addition to persisting needs for intervention services in the subsequent years, the ECSE noticed significant barriers to the preschool children being able to engage and participate meaningfully in preschool environments. She began to document observations of children's skills, strengths, areas of need for intervention, and individualized supports she and her team were providing to increasing numbers of children.

Over the next year, the ECSE/Director continued observing and documenting the interventions the preschool team were developing and implementing to meet children's needs

and began having more dialogues with administrators and teachers across the elementary grades. The preschool team began making significant changes to the environment and curricular approach to tailor support to the growing number of non-verbal children enrolling in the program. The team adjusted the ways in which materials were displayed and presented to reduce stimulation and distractions, encouraging children to seek and engage with high-interest items and tasks. Visual supports were used by teachers and children throughout the day, including color-coding and using pictures cards (along with verbal cues) to communicate behavior goals, schedule activity sequences (first this, then that), and describe material uses. The team implemented a constant data collection, assessment, and feedback routine which gathered, tracked, and shared information on children's individual interventions and progress, which was used by the preschool team but also shared continually with families and kindergarten teachers.

It became apparent that the preschool children who entered the program with significant communication and behavior needs benefitted from the highly specialized individual supports and the changes the team was making to the program approach. The ECSE/director recognized the need for an intentionally designed specialized preschool intervention program tailored around the needs and goals of children with significant delays in communication, language, and social skills with an emphasis on intensive individual interventions and peer engagement. From this early groundwork, the Early Childhood Program for Language Acquisition and Community Engagement (EC PLACE) was born.

The ECSE director described the experiences that led to the EC PLACE program development, saying:

In my traditional preschool class, the class was designed for typical peers. Most of the

time this was fine but one year I ended up with six students who were nonverbal, had no communication skills, very low language, poor social skills and social communication. All of these students had a lot of sensory defensiveness and the lack of structure in the room compounded by the noise and busy-ness of the other 12 children caused anxiety in my students. Challenging behaviors increased and they were not in the state of mind to focus on learning. They were not making progress in communication, language, or social skills. That was when I realized that I must change the environment to meet the needs of all students. I had to ensure that every child was safe, happy, and successful!

Foundations of EC PLACE Program Design

Research on Effective Early Intervention

Typical preschool programs are designed for neurotypically developing children, with bright and colorful spaces full of lots of materials always available, energetic whole and small group social interactions, and active routines. But for children with autism spectrum disorder, this kind of environment can prompt an overload of sensory stimulation, leading to highly stressed emotional states, behavior challenges, and sensory defensiveness. In this stressed state, preschool children are not able to meaningfully process and engage in skill practice and guided instruction and miss out on essential early learning experiences (Dye, 2018). Missing these important preschool learning and development foundations can then set children with significant delays in communication, language, and social skills on a trajectory for continued and increasing involvement with special education services throughout their school years (Jónsdóttir et al., 2018).

The purpose of Early Intervention (EI) is to engage young children at risk for or with

delays or disabilities in individualized, evidence-based experiences which are intentionally designed to address areas of identified need and support their growth, development, and learning (Division for Early Childhood, 2014). The goal is to identify areas of need and provide interventions and supports as early as possible, to increase children's functioning and outcomes over the short and long term. Engaging young children with delays or disabilities in early interventions demonstrates the potential to radically improve their developmental outcomes across their school years, reducing needs for on-going special education services and improving learning outcomes (Eldevik et al., 2009).

EC PLACE Program Features and Impact

Grounded in the core foundations of special education practice, to monitor, identify, and implement effective collaboration, assessment, and individualized instruction using evidence-based practice (McLeskey et al, 2017; Cook et al., 2008), the preschool team created two dedicated classrooms designed specifically for children with language and communication delays and behavior support needs. Each classroom supported 4–6 children ages 3–5 years, with 2–4 teaching staff per room, guided by the ECSE-licensed director. The classroom environments were designed to be clutter-free, soothing spaces where children could orient themselves in a feeling of safety and predictability and begin to engage in simple to more complex activities and tasks as their skills developed. The teachers used language and visual communication tools to build up and encourage children's own language production and communication as they worked on meaningful tasks. Preferences and interest items and activities were used to reinforce desired outcomes, along with close, warm relationships and encouragement from teachers. The curriculum for the program centered



Figure 1 *EC PLACE integrates peer partners, technology, visual supports, and child choice preferences.*

around building communication and language competencies through use of intentional verbal cues, picture cards, color coding as visual cue, individualized goals, daily progress monitoring, interest- and preference-based task choices, peerassisted play sessions, technology supports, and daily engagement with typically developing peer partners (selected and paired by program teachers). (See Figure 1). The program activities and experiences were also closely tied to children's Individual Education Plans (IEP).

Instructional interventions were always embedded in routines and natural contexts to

encourage strong transferability, facilitating the children's application of skills in meaningful ways. The low child-to-teacher ratio allowed for extensive interactions and deep relationships to develop between children, families, and teachers, enduring all throughout the children's elementary school years. The quality of these relationships became a hallmark of the program, along with eight effective practices which resulted in incredible gains in children's language, behavior, and learning outcomes. Almost all of the EC PLACE children moved into general education classrooms full time in kindergarten, requiring very little special education services throughout their elementary grades.

The ECSE team described how their program's philosophy of inclusion was demonstrated in their program design:

We designed a classroom using evidence-based practices for children with autism including visual structure, functional communication instruction, authentic environments for skill development on meaningful tasks, child driven choices, and positive reinforcement. Although designed to meet the needs of students who require an abundance of visual structure and intensive language instruction, the program also meets the needs of neurotypical students. The classroom structure, schedule, visual supports, and intentional instruction on communication and language skills decreased the students' anxiety. They were in a mindset to learn, and they made significant progress in communication, language, social, play and classroom behaviors. After one year, two of them graduated into a general education classroom rather than the centerbased classroom. Especially with our youngest learners, it's not best practice to make them adapt to the general education environment which doesn't make sense to them. Rather, we need to adapt the general education environment to meet their needs. True inclusion is about designing an environment and a curriculum that meets the needs of all learners, not making our struggling students just adapt. And this is not only true in the school setting, but in the community and the workplace.

Effective Practices for Student Success: Intentionality Across Curriculum and Environments

Effective early intervention encompasses many aspects of programming, including staff professional preparation and credentialing, environment design, purposeful grouping, intentional data-driven planning and decisions, ongoing assessment and collaborations, and individualizing across the program. Effective programming to support success for each and every child, especially those with disabilities, demands dedicated attention and effort on behalf of all adults supporting children's growth, development, and learning. The EC PLACE

program exemplified this core early childhood special education approach, and additionally teachers attribute the children's highly successful outcomes to eight intentional practices: color coding, visual cues, transition items, adapting materials, communication systems, penny boards, and data binders.

Color Coding (Everywhere, Everything)

Beginning with a clutter-free space, the environment was specifically left a little sparse as far as materials displays, items on walls, and furnishings. There were individual small group spaces created with small cubbies, soft cushions, and small tables/chairs. All materials were in bins to keep items together and in defined spaces, and bins were color coded to connect to different learning areas (yellow for manipulatives, green for cars, etc.). Each child was assigned a color at the enrollment point, which became an important visual cue to denote that child's schedule, preferred materials, learning center tasks, and personal cubby for belongings. Family photos were put into each child's unique colored frames. These color cues allowed children to easily locate their own special places, items, and routines in the environment. This strategy increased children's ownership of the space and increased their independence by being able to locate their own schedule, tasks, and materials.

Additionally, the color-coding enabled all the teachers to quickly identify each child's routines and learning and development goals. At each learning area, color-coded cards were posted with the child's specific task or focus skill, along with specific verbal cues and phrases that were being used with the child. These "goal cards" connected to each child's IEP goals, allowing for more time working on children's intervention services and goals. Using the color-coding system for children and adults alike made sure that all teachers could quickly and easily find and integrate important practices and cues for each child, thereby ensuring

they were maximizing each child's targeted interventions. The team also created extensive data binders, which were color coded for each child so all related service providers, families, and teachers could easily locate children's data on interventions, progress monitoring, assessments, outcomes and goal achievement.

Visual Supports and Cues

Integrating visual cues into classroom practice has long been recognized in research as an effective practice to support communication, autonomy, comprehension, and social engagement for children with disabilities, particularly autism spectrum disorder, as well as being an effective practice to support all learners (Ganz & Flores, 2010). Visual cues can include integrating picture symbols either alongside written words or alone, directional signs, activity sequence charts, sets of picture cards on a ring used to communicate ideas and needs/wants, color coding, direction or instruction cards, and varied signs.

Visual supports in EC PLACE extended to the use of movable schedules and sequence charts, which involved having picture cards stuck on hook and loop tape to be able to move from one side to the other on a task card or schedule. Children, families, and teachers worked together to create communication boards, which included picture cards unique to children's needs and goals or devices with apps to add verbal response to children's picture selections. The teachers used colored masking tape on the floor to create borders and pathways for children to learn to navigate different spaces in the room. The use of a visual timer app was particularly popular with the children. Together with the teacher, the children would set the app for a designated time, and as the time ticked down around a clock face, a favorite image would appear. The use of interest and preference items supported children's ability to transition when the timed activity was over. Children would cheer as the final moment ticked down and name the pictured item.

Transition Item

While the widespread use of visual supports was an important practice in the EC PLACE classroom, children also needed explicit instruction and practice in using the picture cards and visual tools. For example, the picture card schedule on hook and loop tape helped children track routines and progress, but directions like "put items away and line up for playground time" were still too vague for some children to effectively follow. The use of transition items supported children's follow through on routines and tasks by giving children an item to carry from one place to another as they transitioned. For example, a child would move the picture card for cleanup, pull off the card for line up for playground time, and take the playground card over to the classroom door. Having the item in their hand as they transitioned from one activity to another, or especially from one space to another, provided children with a concrete, tactile cue in addition to the visual cue, providing more structure to stay on task and follow through. Transition items could be a picture or word cue on a flat wooden stick, a preferred item like a small stuffed toy, car, or plastic food, based on the particular transition in routine or setting the child is making.

The director described a simple transition item strategy:

Once we begin any transition, we provide a transition item. For example, when we transition from carpet to line up for recess, I'll hand each student a "check schedule" stick. They hold the stick while walking over to their individual schedules. They then place the stick in the pouch and pull the next picture from their schedule. Understanding the structure and expectations of the classroom (through visual representation) decreased the anxiety of our students and therefore the challenging

behavior that typically happens during transitions.

Adapting Materials

An overarching goal of the EC PLACE program is to ensure all children have access to and are able to meaningfully participate in all aspects of the preschool curriculum with all supports needed. Access, participation, and support are widely considered the three essential



Figure 2 Adapted children's book about kittens including spiral bound book copy, picture cards, and various stuffed animals corresponding to book theme.

pillars of high-quality inclusion for children with disabilities (Buysse, 2011). While all the EC PLACE practices are centered around these essential elements, adapting materials is most clearly connected with curricular access and engagement. Adapting materials involves the teaching team assessing the preschool learning goals through the lens of each child's strengths and needs and creating supports and individualized pathways for each child to accomplish either the stated learning goal, or an individually modified version of the stated learning goal. For the EC PLACE team, this meant creating numerous versions of materials, books, lessons, and experience plans to ensure each child's meaningful engagement and learning.

EC PLACE teachers created tactile and hands-on manipulatives to align with children's books that would allow children the opportunity to hold and manipulate items related to learning topics and themes. (See Figure 2). They created movement experiences and sensory experiences for children who were ready for those opportunities, and utilized lots of visual cues, simplified language, picture cards, some hand-over-hand modeling, video reviews, and repetition. The more they made such adaptations to typical books and materials, the more deeply the children engaged with the content and the faster they tracked learning goal attainment. As children found more meaning in the brief periods of focused academic learning activities, they were able to extend their time in the activities, promoting even stronger learning gains.

Communication Systems

As an early childhood educator wholly centered around inclusion, the EC PLACE director designed and built the program to fully focus children's time and efforts around building and expanding communication. An essential context for all communication and language development and use is the recognition that communication (verbal and non-verbal) is rooted in social connectedness and important to children's abilities to develop important relationships (Kaiser et al., 2001). Informed by extensive research touting the importance of communication skill development for young children's capacity to have needs met, comprehend, and communicate thoughts and ideas, and deepen their meaningful relationships with the people around them (Gooden & Kearns, 2013), the EC PLACE teachers created continuous opportunities for children to develop and use communication. Teachers collaborated closely with the speech-language pathologist who provided services based on children's individualized education plans and continued those interventions throughout each day. This approach allowed for more continuity for children's interventions and resulted in much stronger gains in language skills.

Throughout the environment, the team looked for every opportunity to create

opportunities for the children to use communication (verbal, visual, and gestures) as a means for increasing children's internal motivation and practice in authentic situations. For example, children would find limited materials accessible on shelves, and additional desired materials were stored in bins that children had to use language to request. When children would gesture or use their picture cards, teachers would acknowledge, model verbal language, encourage children's efforts to repeat verbal requests, and provide the materials the child was seeking. The teachers ensured that children saw the need, purpose, function, and benefit to using communication tools and strategies throughout their daily routines and play activities. Throughout the constant opportunities for language development, the team engaged children with peers and adults in prompting and using verbal communication, which boosted children's friendships as well as their communication and social skills development.

As one teacher described, the language and communication skills supports were integrated into natural routines:

We all knew that Zac's favorite thing was trains. We set up a train table with two pieces of track and one train car. We had more tracks and cars and engines in a bin on the shelf. Of course, as soon as he came in, he lit up when he saw it. "Tays! Tays! [trains]" he cried, and immediately went to play. "Yes, Zac! We have trrrainnns out today just for you!" We extended the /r/ and /n/ sounds in our response to encourage him to hear the complete word. Soon he was looking around for more tracks and cars. Just as he was starting to get upset, which we were carefully watching for, we asked him, "More trrrainnns, Zac? More?" He looked at us, picked up, and showed the picture card with a train engine. We nodded said the exact same words again, with him watching our faces. "Mo taynnn," he said slowly and deliberately. We just about threw him a party; we were so excited to hear him adding the new sound to his word!

We immediately got him more tracks and trains and joined in his play. We sang train songs and followed his lead in lining up the cars on the track and driving the train around. He was absolutely beaming with enjoyment! By creating a need and internal motivation to work at expanding his verbal skills, he very carefully made the effort. Not because we forced or asked him to, but because his verbalizations were important to getting his needs and desires met; he could see the functional purpose and reward for his verbal communication. This kind of scene was repeated all day, every day for all our kiddos. They took such ownership over their language, and we saw amazing gains in their development!

Peer Supports

In alignment with the EC Place program's heavy emphasis on language modeling by adults, the team also designed intentional opportunities to generalize and practice language with peers during the typical routines and practices of the day. Research has shown that through these interactions, each partner can increase their use of language and build social skills such as turn-taking, self-confidence, and initiative (Harris et al., 2009). Peers from kindergarten classrooms (neurotypically developing) were selected to regularly join the EC PLACE classrooms. In addition to being informal peer play partners, the teachers also created meaningful opportunities for peers to model skills and behaviors and engage with preschoolers in tasks related to the children's specific IEP goals.

Peer support and modeling has long been an effective practice for enhancing learning and development outcomes for children with disabilities, just as much as it has shown important benefits for children without disabilities (Carter et al., 2015). An essential element of maximizing peer engagement is for teachers to facilitate meaningful interactional activities and provide support for peers (Brock et al., 2016). The EC PLACE teachers prepared peer mentors ahead of time by discussing the target child's strengths and areas for growth, their interests and preferences, and specific language cues the teachers and peer would use in the play and learning tasks on which the children would collaborate. With this preparation, the peers took on a mentor or learning support role but they also engaged as authentic and natural play partners. Within this environment and with the teachers facilitating relationships, all children demonstrated genuine enjoyment and warm friendships which persisted through the elementary grades.

Penny Board

The EC PLACE classroom was designed to provide the necessary visual support for students with autism to understand the world around them and therefore decrease anxiety and the problem behaviors associated with that anxiety. Children with autism often prefer a predictable routine and struggle with flexible thinking and changes in routine (Iseminger, 2009). That is often why children with autism prefer the social company of adults to peers because adults are more predictable and more accommodating. The natural unpredictability of preschoolers can cause high levels of anxiety in our students with autism (Dye, 2018). They are more likely to be successful in an environment that is structured and with a few number of peers. Although EC PLACE students need to be taught to be flexible, tolerate changes in routine, and tolerate loud and busy environments, these skills are taught gradually.

All of the teaching in the EC PLACE classroom is very intentional and direct. EC PLACE staff are intentionally teaching requesting, labeling, commenting, and listener responding—all of which cannot be taught without reinforcement. Reinforcement is the most important tool in a teacher's toolbox for increasing skills and decreasing undesired behavior.

Reinforcement is always working, works on all people, is always determined by the student,

and always increases future occurrence of behavior. Reinforcement is not a bribe, it is not optional, and it is not determined by the teacher. Characteristics of reinforcement used in the EC PLACE classroom include the following: (a) reinforcement given immediately after the behavior or skill, (b) preferred reinforcers increase future occurrence of the targeted behavior or skill, (c) can be naturally occurring in the environment, can be "contrived," and (d) can be used to turn a naturally occurring neutral consequence into a reinforcing consequence (praise, for example). The types of reinforcement in EC PLACE are found in two categories: (1) natural (praise, attention, and breaks), and (2) contrived (token, sticker, edibles, and tangibles). The two main uses for reinforcement in EC PLACE are using reinforcement to teach new skills and using reinforcement to change unsafe behaviors.



Figure 3 Image of child's penny board, with movable pennies on hook and loop tape to track child's progress on tasks and towards earning preferred rewards.

The contrived reinforcer, a token, was used in EC PLACE in what they called a penny board. (See Figure 3). The penny board increased students' delayed gratification/stamina and improved consistency in teacher expectations and is faded slowly over time, providing a visual cue for progress on desired behaviors and tasks.

The teacher described an essential aspect of using reinforcers, saying: The child always chooses their reinforcer. See here on the back of the board-he has 4 things that we know are highly reinforcing to him based of the reinforcer survey. He works for dinosaurs, fruit snacks, stuffed dinosaurs, and popcorn. You've got to be sure the reinforcers on the back of the board are things the child really likes and wants. If the penny board is not working, the reinforcer isn't high enough. When you first start to teach the penny board, you'll go through the 10 pennies quickly: "Great sitting!" Then move a penny down. "Good job using safe hands!" moving down another penny. Over time, you'll increase the length of time in which you move pennies down. Once you move all 10 pennies down, the child gets their reinforcer: the picture/item in the middle of the front of the penny board.

Data Binders/ Student Portfolios

High quality early childhood special education requires two essential elements: intentional assessment and effective collaboration. Implementing evidence-based practice is built on a foundation of systematic assessment, progress monitoring, analysis of child data, and sharing progress reports. To effectively support and nurture optimal outcomes in children's growth, development, and learning, early intervention teachers, service providers, and families need to collaborate seamlessly and integrally on children's behalf. The EC PLACE program cleverly integrates these two pillars of effective practice with the use of extensive data binders.

The EC PLACE data binders were created for each child and housed every possible item of documentation on the child. Families provided important background surveys, children's interests and preferences, favorite items and activities, areas of strengths and areas for growth, ways to motivate children, and important family goals. Teachers build on these foundational elements and added all intake and on-going assessments, highlights and success stories, notes, photos, and work samples, goals and progress reports. The data binders were always available for all teachers and families and were updated daily. Each week, the teaching team would review and analyze notes and children's progress and make instructional and intervention changes as needed based on weekly data. The data binders became like individual child encyclopedias, giving the team all the information they needed to effectively support and nurture each child's optimal growth, development, and learning.

As the EC PLACE director literally hugged a child's binder to her chest, she said: These binders represent all the love and support we pour into our kiddos. They are like a treasure trove of our journey together, sometimes for three years of our lives together! In here we have a beautiful picture of who the child is, what incredible progress they have made, the bright future they are heading into. On a practical side, these binders are the most effective way we could share so much data and information—such a rich picture of the child—with so many people. The occupational and speech therapists, they grab the binder every time they come in and can easily see and track the work and progress on IEP goals. And I've had so many parents sit at the table with the binder, just smiling through tears with pride in what their children are accomplishing! I always make and keep a copy when my kiddos move up to kindergarten, and I pass up their binder to their teachers. I want them to see this child's amazing journey and know them as deeply as we have. These binders are a beautiful time capsule of their incredible PLACE experience.

Conclusion

The EC PLACE program was the result of a deeply dedicated ECSE team's efforts responding to increasing enrollment of young children with autism demonstrating language, communication, and behavior support needs, and recognizing that the current preschool program was not designed to maximize children's success. With the ultimate goal of full inclusion in general education for all children, the ECSE director created the Early Childhood Program for Language Acquisition and Community Engagement within the public elementary school to serve and support preschool children with significant disabilities.

By designing the program for children with disabilities first, and integrating typically developing children through structured peer partnerships, the EC PLACE program became an environment where preschoolers with disabilities were valued for who they are while having the resources and support to grow essential skills across all domains. The teachers welcomed each and every child exactly as they were, and intentionally created personalized spaces, meaningful activities, intensive interventions, strong peer partnerships, warm adult relationships, individualized interest-based materials, and richly descriptive assessment reports to nurture growth, development, and learning in each child and effective collaborations across families and teams. The powerful results of this incredible effort were a unique and effective program that changed the school culture to one that highly values inclusion and changed the school and life outcomes trajectory for every child involved in the program.

As children completed one to three years in the EC PLACE program as preschoolers, their social, communication, verbal language, and behavior skills grew quickly and in the first five years of the program, every single EC PLACE participant demonstrated on target age and grade level competencies in communication. Of all EC PLACE participants, 80% of the children went on to be fully included in kindergarten, spending 80% or more of their school day in the general education classroom with minimal need for support. Just over 50% of the children who completed two preschool years in the EC PLACE program moved on to kindergarten without needing any additional special education services and achieved out of needing any additional IEP.

As the director said with a big, tearful smile:

My primary objective in creating and implementing the EC PLACE program was to put the elementary special education department out of business! I knew that intensive interventions implemented early in our children's lives could change the whole trajectory of their educational future. And that's just what we were able to accomplish here for every one of our children.

References

- Brock, M. E., Biggs, E. E., Carter, E. W., Cattey, G. N., & Raley, K. S. (2016).
 Implementation and generalization of peer support arrangements for students with severe disabilities in inclusive classrooms. *The Journal of Special Education*, 49(4), 221-232.
- Buysse, V. (2011). Access, participation, and supports: The defining features of high-quality inclusion. *Zero to Three (J)*, *31*(4), 24-31.
- Carter, E. W., Moss, C. K., Asmus, J., Fesperman, E., Cooney, M., Brock, M. E., Lyons, G.,
 Huber, H. B. & Vincent, L. B. (2015). Promoting inclusion, social connections, and
 learning through peer support arrangements. *Teaching Exceptional Children*, 48(1), 9-18.
- Cook, B. G., Tankersley, M., Cook, L., & Landrum, T. J. (2008). Evidence-based practices in special education: Some practical considerations. *Intervention in School and Clinic*, 44(2), 69–75. <u>https://doi.org/10.1177/1053451208321452</u>
- Division for Early Childhood. (2014). *DEC recommended practices in early intervention/early childhood special education 2014*. <u>http://www.dec-sped.org/recommendedpractices</u>
- Dye, H. (2018). The impact and long-term effects of childhood trauma. *Journal of Human Behavior in the Social Environment, 28*, 381–392. https://doi.org/10.1080/10911359.2018.1435328

Eldevik, S., Hastings, R. P., Hughes, J. C., Jahr, E., Eikeseth, S., & Cross, S. (2009). Metaanalysis of early intensive behavioral intervention for children with autism. *Journal of Clinical Child & Adolescent Psychology*, 38, 439–450.

https://doi.org/10.1080/15374410902851739

- Ganz, J. B., & Flores, M. M. (2010). Implementing visual cues for young children with autism spectrum disorders and their classmates. *Young Children*, 65(3), 78.
- Gooden, C., & Kearns, J. (2013). The importance of communication skills in young children. Research Brief. Summer 2013. *Human Development Institute*.
- Hamilton, L. (2019). Disability as social construct: Investigating how autism is represented in the mainstream media. *Prism: Casting New Light on Learning, Theory and Practice,* 2(2), 20-38.
- Harris, K. I., Pretti-Frontczak, K., & Brown, T. (2009). Peer-mediated intervention: An effective, inclusive strategy for all young children. *Young Children*, *64*(2), 43-49.
- Iseminger, S. H. (2009). Keys to success with autistic children: Structure, predictability, and consistency are essential for students on the autism spectrum. *Teaching Music*, 16(6), 28.
- Jónsdóttir, S. L., Brynjarsdóttir, B., Saemundsen, E., & Sigurdsson, J. F. (2018). Long-term outcome of children with autism who received different forms of early intervention during their preschool years: A pilot study of 15 young adults. *Scandinavian Journal* of Child and Adolescent Psychiatry and Psychology, 6(1), 28–39. https://doi.org/10.21307/sjcapp-2018-006
- Kaiser, A. P., Hester, P. P., & McDuffie, A. S. (2001). Supporting communication in young children with developmental disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 7(2), 143-150.

Liachowitz, C. (2010). *Disability as Social Construct: Legislative Roots*. University of Pennsylvania Press.

McLeskey, J., Barringer, M.-D., Billingsley, B., Brownell, M., Jackson, D., Kennedy, M., Lewis, T., Maheady, L., Rodriguez, J., Scheeler, M. C., Winn, J., & Ziegler, D. (2017). *High-leverage practices in special education*. Council for Exceptional Children & CEEDAR Center. <u>https://ceedar.education.ufl.edu/wp-content/uploads/2017/07/CEC-HLP-Web.pdf</u>

Sainsbury, C. (2009). Martian in the Playground. Lucky Duck Books.

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Research Articles and Essays

The Resolute Resistors:

How Vulnerable Populations Are Not As Vulnerable As Assumed

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Abstract

Disabilities or being of vulnerable populations does not serve to restrict societal contribution. Three themes will be addressed regarding an individual with disabilities or of a vulnerable population: human resource knowledge, skills, and abilities for job hiring or retention; input of specific knowledge for the emergency management community; and accentuating personal experience.

Keywords: vulnerable, disability, KSA

The Resolute Resistors: How Vulnerable Populations are Not as Vulnerable as Assumed

A school guidance counselor, professional human resource (HR) manager, or career transition personnel will ask two relatively standard questions of an individual. What do you want to be when you grow up or graduate, and ultimately will you have the means in which to retire? Do you have something to contribute that will benefit a process or society? These professionals want to identify, develop, match, and use each person's knowledge, skills, and abilities (KSAs) to direct that individual toward a functional career path.

But when these questions are asked of an individual with disabilities or an individual of a vulnerable population, are or should the responses be the same? Obviously, every answer will most likely be different based upon the individual, their disability, or vulnerable situation. The answer will be dependent on each person's understanding of their ability to gain knowledge to learn a skill to accomplish a task. Some people have diminished skills and limited ability but have immense underlying knowledge. Some have the skills and knowledge but lack the ability to accomplish a task. Some have the ability but lack the specific knowledge or skills. How well an individual sees and understands their disability or vulnerable situation will help identify their KSAs. How an employer defines a disability or vulnerable population can differ from the individual view and can impact how KSAs are used for jobs.

The definition from the U.S. Americans with Disabilities Act (ADA), 42 U.S.C. §12102 (1)(A), is widely accepted and even used as a template for other countries. It reads, in part, that a disability is "a physical or mental impairment that substantially limits one or more major life activities of such individual" (ADA, 2008, p. 3555). The term "vulnerable population" has become more widely accepted as an in-vogue and less dismissive phrase and which is more inclusive as a descriptor beyond referencing just physical, mental, or medical disabilities. Yet actions or policies developed from these terms sometimes assume certain limitations. To state a person in a wheelchair can likely not climb stairs is a reasonable assumption which affords a reasonable accommodation. But to say a person in a wheelchair cannot be part of a disaster planning group because they are in a wheelchair is an unreasonable and perhaps irrational reaction.

From a HR management perspective, having a disability or being of a vulnerable population should not restrict one's contribution to society, especially when they have pertinent KSAs to contribute. A soldier with 25 years of service trained in defusing anti-tank mines lost a leg in an explosion. This soldier now has a prosthetic and expresses the desire to be treated as a normal [sic] person living a normal life, but also wants to get back to their unit because "I need to pass my experience to the other guys" (Lawrence, 2023, p. 1). Accomplished classical composer and musician Ludwig van Beethoven experienced diminished hearing by around age 30 and eventually had complete hearing loss. Even though he retained the knowledge and ability of a pianist and composer, some might express doubt about his ability to produce music due to hearing loss. Some interpreted from a writing known as his Heiligenstadt Testament that Beethoven had contemplated suicide (Knittel, 2002), saying "only art it was that withheld me, ah, it seemed impossible to leave the world until I had produced all that I felt called upon to produce" (Mitchell, 1980, p. 7). Beethoven continued composing for another 20-plus years, even writing most of the well-known Fifth Symphony after losing his hearing (Budden & Knapp, 2023).

These two examples address the core HR inquiry of contributing your experience to benefit a process or society. An individual with a disability has likely developed numerous

adaptations. Daily routines make take a bit more time, and they plan a route to the office so their wheelchair can avoid curbed intersections or stairs. By necessity, a disabled individual may need to be more ready for unexpected events. For example, someone may plan the timing of medications needed throughout the day and keep extra batteries to power medical equipment needed during a power outage. Lathrop suggested in a study after the 1989 Loma Linda, CA, earthquake, based on the daily dealings of local situations and physical obstacles regularly encountered in daily life, that persons with disabilities "have a psychological advantage" (Lathrop, 1994, as cited in Alexander et al., 2012, p. 390). He suggested this resulted in a reduced likelihood of distress during and in the aftermath of the earthquake.

With this in mind, the following research question evolved: How vulnerable is the vulnerable population? This paper will review three themes on contributions of individuals with born, developed, or incurred disabilities: Theme 1, recognize what knowledge, skills, and abilities (KSAs) should be focused on for job hiring or retention; Theme 2, understand why specific knowledge is needed as input into the emergency management fields of preparation, response, and recovery; and Theme 3, how to accentuate personal experience for others to learn. For this paper, the author used extensive military-related research studies and included examples of military members, also known as wounded warriors, based on their publicly available information. The core human resource elements remained applicable to military or civilian employment for individuals with disabilities or of vulnerable populations.

Literature Review

The Society for Human Resources Management (SHRM, 2023) defines KSAs as employment competencies and qualities needed to perform work. KSAs are not a stagnant function as they need to be continually developed and new ones learned. The U.S. Office of Personnel Management (OPM, 2023) encourages employees to enhance their KSAs, listed as talent management competencies, to be productive members for their government agency. Cegielski and Jones-Farmer (2016) found business school graduates met basic KSAs for entry-level business analytics positions, however, would not be suitable for strategic or organizational level decision-making. From a disaster management aspect, Said and Chiang (2020) identified a critical need for nurses, beyond the normal competencies, to enhance their knowledge and skills in psychological preparedness before major destructive disasters to care for both the victims and themselves. KSAs are critical to define job requirements at all levels as well as to determine a job applicant's eligibility or competency (Cegielski & Jones-Farmer, 2016; Said & Chiang, 2020; Saunders, 2020). People with disabilities cannot change the KSA requirements for a particular job but of course may be able to improve the KSAs they possess to be more marketable and eligible for the job.

The formal designation of KSAs for many jobs is a relatively modern concept. Peter Drucker's 1959 book, *The Landmarks of Tomorrow*, describes the transition during the mid-20th century from industrial workers who had skills and abilities to do manual tasks to a new class of workers who "require a habit of continuous learning" or knowledge, labeling them "knowledge workers" (Drucker, 1994, p. 8). Some knowledge work can be derived from the skills used in manual labor while a lack of other knowledge skills could preclude a person from certain fields of work. Merely having the ability and skills but not the knowledge would not allow someone to hold certain jobs (Drucker, 1994). Drucker noted this change in social structure during the lead-up to World War I and resulting from World War II, most significantly in the discipline of management "to make knowledges productive" (Drucker, 1994, p. 18). This is how employers met the needs of the Department of War, which met the needs of the nation. As the Department of War transitioned to the Department of Defense (DoD), expansion of opportunities for this knowledge worker became foremost.

Specific to the modern DoD, Werber (2021) reviewed 31 RAND Corporation studies that highlighted the need for "knowledge worker talent management" (p. xii) in the hiring and retention of military civilian workers. This review also found challenges within DoD regarding which competencies/KSAs were needed in certain fields, due to "imprecise definitions of STEM (science, technology, engineering, and mathematics) to estimate workforce requirements" (p. 9). One study specifically looked at civilian employment barriers in DoD for individuals with disabilities. This study recommended targeted outreach or awareness campaigns to encourage individuals with disabilities to become DoD civilian employees (Matthews et al., 2018e, 2021). The candidate pool includes active and reserve military members transitioning out of uniform, either with or without visible and invisible disabilities (Ainspan, 2011).

For active and reserve military members, the U.S. military maintains stringent and long-standing medical and physical requirements (Ainspan, 2011; Krull et al., 2019; Duquette, 2022). While some options are available for members of the military to remain on active duty, those jobs or opportunities are limited (Dalzell et al., 2019; Duquette, 2022), and many are based on the medical fit-for-duty evaluation (Ainspan, 2011; Duquette, 2022; Krull et al., 2019; Rennane et al., 2022). One post-World War II study recommended retention and "utilization of physically handicapped officers in Navy billets," specifically citing their loss as a "waste of experienced and trained…personnel" (Mather, 1949, p. 1). Duquette repeated this sentiment 73 years later stating, "retaining injured and disabled talent is especially pertinent as the military faces recruitment and retention barriers" (Duquette, 2022, p. 7). Moreover, wounded warriors discharged or retired with visible or invisible medical issues have encountered significant problems in post-employment (Ainspan, 2011; Dalzell et al., 2019; Duquette, 2022; Matthews et al., 2018; and Werber, 2021).

Employment barriers due to identified disability or being from a vulnerable population are seen in all facets of the business world and the government, not just the military. Earlier policies and procedures for disaster mitigation, planning, response, and recovery operations reflected these same assumptive limitations (GAO, 2008; Fjord & Manderson, 2009; Flanagan, 2011; Post-Katrina, 2006). Continuing efforts have changed some of these policies and procedures with input from people with disabilities and of vulnerable populations, but more work is needed (Duquette, 2022; FEMA-NRI, n.d.; FEMA, 2016, 2017, 2019; Post-Katrina, 2006).

Theme 1

Recognize which knowledge, skills, and abilities (KSAs) should be the focus for job hiring or retention. Understand KSAs are important from both the employer and employee viewpoints but are key for individuals with disabilities or of a vulnerable population in gaining or retaining employment.

Evidence Theme 1

In the HR arena, KSAs are the foundation for any job description; likewise, knowing one's personal KSAs is key for current or prospective employees (Cegielski & Jones-Farmer, 2016; HRM, 2023; OPM, 2023; Said & Chiang, 2020; Saunders, 2020; SHRM, 2023; Stevens & Campion, 1994; Werber, 2021). Awareness of one's personal KSAs can help one identify strengths, weaknesses, what may be needed to continue to move up a career ladder, and even eligibility for a job (Cegielski & Jones-Farmer, 2016; Drucker, 1994; HRM, 2023; Stevens & Campion, 1994; Said & Chiang, 2020; Saunders, 2020; Werber, 2021).

Chapter 7 of the Oxford Handbook of Personnel Assessment and Selection provided the context for the following definitions of KSA: *Knowledge* can be defined as the information or education needed to do a task; *skill* is the measurable proficiency of psychomotor functions at conducting a task; and *ability* is the potential or capacity to perform a task (Brannick et al., 2012). Thus, an individual with a disability may possess the knowledge but have limited ability, which precludes a skill or may require an adaptation to allow an individual to perform a task. Citing a well-known example, after being diagnosed with amyotrophic lateral sclerosis, with appropriate accommodations, Stephen Hawking continued to serve as a professor, teaching and writing papers for many years. (Hawking, 2013).

Beyond the KSAs, individuals with disabilities or of a vulnerable population face additional challenges with employment and retention in the workforce (Ainspan, 2011; Dalzell et al., 2019; Duquette, 2022; Matthews et al., 2018; Rennane et al., 2022). While Ainspan (2011) noted a 10% unemployment rate for Americans, 14.5% was noted for those with a disability, and some reports reflected 40%–90% unemployment for those with hidden disabilities. Determining how many individuals with disabilities work for an organization depends on is asked and how disability is defined, both by the organization and the individual. The Americans with Disabilities Act Amendment Act of 2008 broadly expanded the definition of disability (ADA, 2008), expanding the number of those who may be considered disabled. This had unintended consequences. Since this redefinition increased the number of disabled already employed, an organization would not necessarily need to hire new individuals with disabilities to meet an existing standard or goal.

Some companies and government entities have targeted goals for hiring and retaining individuals with disabilities. In 2017, the U.S. Equal Employment Opportunity Commission
issued a rule, 29 CFR part 1614, setting a representation goal for the federal workforce of 2% covering people with targeted disabilities (EEOC, 2017). Authors of a 2018 RAND Corporation study said they could not determine if the 2% set by EEOC was accurate, over representative, or under representative (Matthews et al, 2018) because they could not establish the prevalence of the targeted disabilities in the population. In 2022, the U.S. Centers for Disease Control and Prevention estimated 26% of U.S. adults have some type of disability (CDC, 2022).

Looking specifically at DoD data from 2017, the RAND study found DoD did not meet the EEOC 2% goal. The department had achieved less than 1% representation. But nearly 46% of the civilian workforce were veterans, and 10% had a disability rating over 30% (Matthews et al., 2018, Table 5.1). More than 57,000 veterans were hired by the federal government in 2017, yet only half (28,500) disclosed a disability, and only 19,000 had a disability rating over 30% (OPM, 2018, Table 3). The study authors noted veterans were reluctant to disclose disabilities when applying for federal jobs, a significant finding from this data. Ainspan (2011) noted employers may have conscious or unconscious fears and misconceptions of people with invisible disabilities and thus may choose to discriminate and avoid them. Alleviating these fears through education of an employer can send a clear directive of support for hiring individuals with disabilities who possess applicable KSAs (Matthews et al. 2018).

KSAs and Contributions to Society

When asked, "What is your ultimate goal?" Kristin Duquette responded: "Am I helping others? Am I contributing to the greater good?" (Garrity, 2016, p. 1). A competitive swimmer with muscular dystrophy, Duquette experienced discrimination from a head coach

when she was asked to leave the team and was mistaken by event officials "as an audience member rather than a competitive athlete" (Duquette, 2016, p. 1). She became a Team USA paralympic swimmer and served as director of diversity and inclusion for the Federal Emergency Management Agency (FEMA)'s Women's Leadership Forum. She is now a preparedness officer for FEMA Transportation Security Grant Program and published her master's thesis on how the military can feasibly use wounded warrior individuals with disabilities in non-kinetic warfare at the Naval Postgraduate School (FEMA, 2020; Duquette, 2023). Through gaining more knowledge and improving skills, she became a highly regarded specialist, leveraging her experience with disability to contribute to disaster emergency management.

Summary Theme 1

Being cognizant of the relation between one's KSAs and the KSAs necessary for job retention or for a desired employment position is critical to taking advantage of potential employment opportunities, as is recognizing potential employer perceptions.

Theme 2

Needles from vulnerable populations may have specific knowledge that is needed as input into the emergency management fields of preparation, response, and recovery. But often missing is their input on the threats, assets, vulnerability, and risks to inform preparation, response, and recovery efforts in disaster emergency planning.

Evidence Theme 2

While often used interchangeably, vulnerability is not the same as vulnerable population. As a noun, vulnerability means a susceptibility to danger (Oxford, 2023) while,

as an adjective, vulnerable expands an associated noun, in this context, a population most likely to be affected by a danger (Oxford, 2023). From an emergency management viewpoint, vulnerability "is the extent to which persons or things are likely to be affected" (Flanagan et al., 2011), which includes people, buildings, internet, cities, infrastructure, crops, social networks, culture, and other assets (FEMA-NRI, n.d.; Alexander, 2015; FEMA, 2016, 2017, 2019, 2022-2026). Thus, the vulnerability of a population creates a vulnerable population.

Many words or euphemisms, sometimes offensive, are often used for inclusion (Waisel, 2013; Rukmana, 2014; EEOC, 2017). A current functional definition of vulnerable population was established as requirements in human subject research. In 1964, with amendments through the present day, the World Medical Association (WMA) adopted its Declaration of Helsinki regarding medical research. This defined vulnerable individuals or groups as ones that "may have an increased likelihood of being wronged or of incurring additional harm" (WMA, 2022, p. 1). This clean and succinct statement can indicate three situations:

- 1. Many individuals with disabilities are considered vulnerable.
- 2. Being vulnerable does not automatically include all disabilities.
- 3. Vulnerable populations may not be as vulnerable as some may assume.

For disaster planning and response, FEMA uses a National Risk Index and Social Vulnerability rating score to indicate "susceptibility of social groups to the adverse impacts of natural hazards, including disproportionate death, injury, loss, or disruption of livelihood." (FEMA-NRI, n.d.). Researcher Bruce Gordon put vulnerability more simply as "the risk of some sort of harm beyond that of other persons in the same" circumstance (Gordon, 2020, p. 35). He said vulnerability is also not a constant nor a definitive "all or none" but rather a sliding scale based on the situation (Gordon, 2020); for example, a person identifying as ablebodied using crutches for a broken leg would be assigned a temporary higher vulnerability.

Risk, threat, and vulnerability are basically synonyms with the same meaning: An asset is in danger. Yet each word describes a unique piece in disaster planning. Risk is the resultant loss from what can happen, threat is how something can happen, vulnerability is the susceptibility of an asset, and asset refers to what is affected (FEMA-NRI, n.d.; FEMA, 2016, 2017, 2019). Flanagan (2011) described the formula "Risk = Hazard * (Vulnerability - Resources)" (p. 1), with hazard used in place of threat and resources referring to assets that are used to reduce the impact of the threat. The Threat Analysis Group uses the equation A+T+V=R to depict the relationship (Threat, 2010). The relationship between these terms could be expressed in the sentence: How (threat) is this (asset) susceptible (vulnerability) to loss (risk)? For an individual with disabilities or of a vulnerable population, what impact does all this asset, threat, vulnerability, and risk mean and what can they do about it?

Good emergency planning—even when applying asset, threat, vulnerability, and risk factors—does not always go as expected during real events. Hurricane Katrina in 2005 was a turning point in many ways. It was a stark display of how vulnerable populations were viewed from previous disaster management procedures or policies (Fjord & Manderson, 2009; Flanagan, 2011). Emergency managers want to rescue everyone, but the preventive mitigation measures and evacuations for disabled or vulnerable populations were developed from ableist or non-vulnerable viewpoint. Congress directed the emergency management system to change that view (Post-Katrina, 2006; GAO, 2008). A disaster study by Fjord and Manderson (2009) asked: "Why not place disability-centered approaches at the core of disaster planning and ensure the probable needs of most residents are accommodated?" (p. 65). The HR professional wants to link an individual with appropriate KSAs to an applicable career that infers the questions: Why do we have non-disabled people creating solutions for disabled issues? Did anyone ask disabilities or of vulnerable populations what they think? This is where an individual with disabilities or of a vulnerable population can make an impact.

Preparedness includes the development of preventive mitigation measures and is such an area where the knowledge from individuals with disabilities and of vulnerable populations is needed. Disasters affect vulnerable populations more than others (Alexander et al., 2012; Alexander, 2015; Fjord & Manderson, 2009); they know what resultant damage will look like for themselves. They can define the problem and help develop the functional mitigation to aid themselves. Another part of preparedness is understanding the limitations of individuals with disabilities and of vulnerable populations for evacuation. How do people move and are there challenges in maneuvering in the area? What is needed to see and hear announcements. Are additional measures needed to express directions and post appropriate signage? What other adaptive equipment and resources will be needed. A typical city transit bus can seat 30 people but only 2 wheelchairs (City-Transit, 2022), which is no good when only one bus is sent to evacuate 30 wheelchair-bound people from one facility. An understanding of the result is needed to enable appropriate planning; thus, more individuals with disabilities should be involved in exercise and training events to help make such events more realistic and effective.

Summary Theme 2

Adaptations of the response, rescue, and post-event recovery procedures are needed based on the skills within the vulnerable population. Simulations with a non-disabled person placed in a wheelchair or putting on a blindfold for a disaster exercise obviously does not truly reflect the realities a disabled person may experience. Instead of waiting for an exercise to obtain this input, individuals with disabilities or from vulnerable populations should be hired for planning jobs at the emergency management office. A disability coordinator was created at the FEMA administration level (Post-Katrina, 2006) with subsequent specialists at each of the 10 U.S. FEMA regions, but their influence is mostly to consult and provide guidance to ensure a process or plan has addressed disabilities. Referencing Theme 1, this could be construed as filling the token disability employment checkbox but without the employee truly involved in the full disaster management process. To accurately capture the specific experiences and views from individuals with disabilities or of vulnerable populations, regular staff members, including contingency plan developers, exercise planners, response trainers, and executives at federal, state, regional, and local levels, need to be individuals with disabilities or of vulnerable populations.

Theme 3

This theme is concerned with how to accentuate personal experience for others to learn. Theme 3 focuses on examples of how U.S. military members with incurred disabilities can be retained by the service based on their existing, redeveloped, or newly learned KSAs to further benefit the military or be released from duty then transferred, redeveloped, or taught new KSAs to benefit their society.

Evidence Theme 3

All six U.S. military services currently use medical criteria and kinetic tests—the physical push-ups, sit-ups, and run—as simple measures of combat readiness to perform military service and for general long-term medical health (DoD, 2018, 2022). However, some individuals with disabilities are much more capable of non-kinetic work than current non-

disabled service members (Ainspan, 2011; Reynolds, 2019; Duquette 2022). Some U.S. service members with incurred visible or invisible injuries can meet these kinetic physical requirement measures, yet basic policy states they are no longer eligible to serve in uniform (Ainspan, 2011; DoD, 2020; Duquette, 2022). Duquette (2022) noted no U.S. Code or Code of Federal Regulation specifically prohibits individuals with disabilities from being a part of the military services, but respective service secretaries are afforded discretion to determine what is acceptable based on role-specific KSAs. Ainspan (2011) noted changes in military culture, newly developed technology in disability accommodations, and better overall awareness of the capabilities of individuals with disabilities now allow members to remain in the service versus automatic medical retirement or separation. While the core military medical retention policy remains, flexibility is more available for each service to determine if, for example, a wounded warrior is eligible to remain on active duty (Ainspan, 2011; Reynolds, 2019; Rennane, et al., 2022).

Some studies question if military services should even use 'fitness' standards (Reynolds, 2019; Matthews, et al., 2022; Duquette, 2022). Non-kinetic warfare—which does not rely on physical force—is regaining new life in cyber warfare with more psychological functions desired and even reduction in the war planning ideas of physical hand-to-hand combat (Mather, 1949; Reynolds, 2019; Werber, 2021; Duquette, 2022). Performing strenuous physical exercises are not required to be a cyber-specialist who can debug a program from a secure room or remotely control a drone from thousands of miles away. Individuals with autism spectrum disorder level 1 have been defined as being quite successful at reviewing algorithms or creating computer scripts, tasks many people may deem tedious (Reynolds, 2019). Approximately 200,000 members leave military service annually (DoD, 2023). As of September 30, 2020, over 2 million members were receiving retired pay (DoD, 2021, p. 16). Yet only 128,911 were listed as disabled (p. 22) and of the 45,149 new retirees in 2020 (p. 39) only 5,316 were disabled (p. 46). As these numbers reflect only members receiving retired pay and not medically separated members, it would appear there is a pool of disabled military candidates who could be retained in service, if their KSAs allowed.

As a demonstration of this theme, publicly available information was reviewed on six wounded warriors with incurred disabilities to see how they were retained on active duty based on their existing KSAs or if they achieved other positions in society through transferred, redeveloped, or newly learned KSAs.

Staff Sergeant Kevin Nguyen enlisted in 2011 and developed the ability and skills of a rifle specialist before loss of a foot in combat. He then was retained on active duty as an instructor with the Army Marksmanship Unit. A World Para rifle shooting champion, Para Pan American Games champion, and 2020 Paralympian, Nguyen currently has 12 years active duty (Team USA, 2022). Sergeant First Class Elizabeth Marks enlisted in 2008, developed the KSA to be a health care specialist before sustaining bilateral hip injuries in combat. Using swimming as rehabilitation to return to 'fit-for-duty' status, she became a 2016 and 2020 Paralympian, received the 2016 Pat Tillman Award for Service, was named a member of the 2023 Paralympics Swimming National Team, and currently has 15 years active duty (Team USA, 2022). Staff Sergeant John Wayne Joss, III, enlisted in 2004 then developed the skills and ability to become an indirect fire infantryman before loss of a lower leg in combat. He asked to remain on active duty as a mortar gunnery instructor with the Army Marksmanship Unit, became a U.S National rifle shooting champion and record holder, World Shooting Para Sports medalist, 2016 and 2020 Paralympian, and currently has 19 years active duty (Team USA, 2022). All three service members were injured during combat operations, remained on active duty based on the KSAs learned in their respective

military occupational specialty and, with appropriate accommodations, because of their skills and performance, were retained in the Army World Class Athlete Program.

After loss of a right arm in combat, U.S. Army captain and recipient of the Congressional Medal of Honor Daniel Inouye used his KSAs to study law. He was elected to the Hawai'i Territorial House of Representatives, become the first U.S. representative for Hawai'i, then served as U.S. senator for 31 years. His service culminated in his selection as president pro tempore of the U.S. Senate (Inouye, 2023). After incurring a double leg amputation from combat injury, Tammy Duckworth used KSAs to remain in the military and retire as an Army lieutenant colonel, was appointed as an assistant secretary of Veterans Affairs, elected as a U.S. representative, and serves as an elected U.S. senator for Illinois (Duckworth, 2023). After their military service, both members used their KSAs and experience to advocate for individuals with disabilities in high-level policies.

Having already served over 20 years as a pilot in the U.S. Navy, Kyle Cozad was a two-star rear admiral leading the Naval Education and Training Command when an at-home accident resulted in paralysis from the waist down. Therapy and support for necessary accommodations helped him return to his duties where he continued to command as a wheelchair user. He retired two years later, became CEO of the Naval Aviation Museum, and wrote a book based on his experience (Faram, 2019; Cozad, 2022). This is an example of ways in which appropriate accommodations allow one to continue to contribute.

Summary Theme 3

The debate over military medical and fitness standards has been a continuing point of interest and will be subject to further studies as the services project their future needs. In the ensuing time, service members will continue to incur or develop combat and non-combat

related visible or invisible injuries. They should receive an appropriate evaluation to determine whether they are to remain on active-duty service for the military based on established objective standards as well as subjective KSAs they possess. The six examples presented, of course, are not exhaustive nor are they representative of all; same time, they clearly suggest that individuals with appropriate KSAs, when given appropriate accommodations, can continue to serve.

Conclusion

With appropriate accommodations, many with visible and/or invisible injuries continue to serve, depending on each case, filling a specific job, remaining in their primary role, transfering to an alternate profession, or transitioning to non-work status. The focus should be on what knowledge, skills, and abilities are needed for hiring or retention. In particular, the specific KSAs and unique experiences of individuals with disabilities or of vulnerable populations are greatly needed in the emergency management field for the preparation, response, and recovery phases of a disaster.

Continued research should review the military accession and release processes to determine how members with functional and needed KSAs should be eligible to apply or remain in uniform. A more in-depth review of emergency management staffing should be conducted to consider the benefits of having individuals with disabilities or of vulnerable population included as staff members. Nearly everyone wishes to make a contribution, whether in uniform or as a civilian, and individuals may not be as vulnerable as others assume.

References

Ainspan, N. D. (2011). From deployment to employment for veterans with psychological disabilities, finding a job can be as effective at treating symptoms as prescribing medication. *Proceedings, U.S. Naval Institute, 137*(2).

https://www.usni.org/magazines/proceedings/2011/february/deployment-employment

 Alexander, D., Gaillard, J. C., & Wisner, B. (2012). Disability and disaster. The Routledge handbook of hazards and disaster risk reduction, 1, 384-394.
 https://www.researchgate.net/profile/Ben-
 https://www.researchgate.net/profile/Ben-
 https://www.researchgate.net/profile/Ben-

Alexander, D., (2015). Disability and disaster: An overview. In *Disability and Disaster: Explorations and exchanges*, 15-29, Palgrave Macmillan UK.

Americans with Disabilities Act (ADA) Amendment Act, Publ. L. No. 110-325, 42 U.S.C. § 12101 (2008). <u>https://www.eeoc.gov/statutes/ada-amendments-act-2008</u>

- Brannick, M. T., Cadle, A., & Levine, E. L. (2012). Job analysis for knowledge, skills,
 abilities, and other characteristics, predictor measures, and performance outcomes. In
 N. Schmitt (Ed.), *The Oxford handbook of personnel assessment and selection*, 119146. Oxford University Press.
- Budden, J. M. & Knapp, R. L. (2023, March 22). *Ludwig van Beethoven. Encyclopedia Britannica*. <u>https://www.britannica.com/biography/Ludwig-van-Beethoven</u>

Cegielski, C. G., & Jones-Farmer, L. A. (2016). Knowledge, skills, and abilities for entry-

level business analytics positions: A multi-method study. *Decision Sciences Journal* of Innovative Education, 14(1), 91-118. <u>https://doi.org/10.1111/dsji.12086</u>

- Centers for Disease Control and Prevention (CDC). (2022, May 19). *Disability and Health Data System (DHDS)*. Retrieved January 10, 2023, from <u>https://dhds.cdc.gov</u>
- *City-Transit Buses*. (2022). Dimensions. Retrieved March 24, 2023, from https://www.dimensions.com/element/city-transit-buses
- Cozad, K. (2022). *Relentlessly positive. A common veteran battling uncommon odds*. Ballast Books.
- Dalzell, S., Dunigan, M., Carter, P., Costello, K., Donohue, A. G., Phillips, B., Pollard, M., Resetar, S. A., & Shurkin, M. (2019). *Manpower alternatives to enhance total force capabilities: Could new forms of reserve service help alleviate military shortfalls*.
 RAND Corporation. <u>https://apps.dtic.mil/sti/pdfs/AD1086690.pdf</u>
- Department of Defense (DoD). (2018). *Medical standards for military service: Appointment, enlistment, or induction.* DOD Instruction 6130.01, Volume 1. Department of Defense.

https://www.esd.whs.mil/Portals/54/Documents/DD/issuances/dodi/613003_vol1.PD F?ver=7fhqacc0jGX_R9_liexudA%3d%3d

Department of Defense (DoD). (2020). *Medical standards for military service: Retention*. DOD Instruction 6130.03, Volume 2. Department of Defense. <u>https://www.esd.whs.mil/Portals/54/Documents/DD/issuances/dodi/613003_vol02.PD</u> <u>F?ver=vx1spUpNVLcc-0-rov00Sg%3d%3d</u> Department of Defense (DoD). (2022). DoD physical fitness/body composition program,

DoD Instruction 1308.03. Department of Defense.

https://www.esd.whs.mil/portals/54/documents/dd/issuances/dodi/130803p.pdf

- Department of Defense (DoD) Office of the Actuary. (2021). *Statistical report on the military retirement system, Fiscal year ended September 30, 2020.* Department of Defense. <u>https://actuary.defense.gov/Portals/15/MRS_StatRpt_2020%20%5BSept_%202021%</u> <u>5D_1.pdf</u>
- Department of Defense (DoD) SkillBridge. (2023). *Military discharge data*. Department of Defense.
- Drucker, P. F. (1959). The landmarks of tomorrow: A report on the new "post-modern" world. Harper & Row.
- Drucker, P. F. (1994). The age of social transformation. *Atlantic Monthly*, 274(5). https://www.theatlantic.com/past/docs/politics/ecbig/soctrans.htm
- Duckworth, T. (2023). *Tammy Duckworth biography*. U.S. Senate. https://www.duckworth.senate.gov/about-tammy/biography
- Duquette, K. (2016, July 21). *Disability activist Kristin Duquette addresses the U.N.* One Young World. <u>https://www.oneyoungworld.com/blog/disability-activist-kristin-</u> <u>duquette-addresses-un</u>
- Duquette, K. (2022). The disabled soldier: A case for disabled Americans in the US Armed Services. [Master's thesis, Naval Postgraduate School]. https://apps.dtic.mil/sti/pdfs/AD1173289.pdf

- Equal Employment Opportunity Commission (EEOC). (2017, January 3). Questions & answers: The EEOC's final rule on affirmative action for people with disabilities in federal employment. <u>https://www.eeoc.gov/laws/guidance/questions-answers-eeocs-final-rule-affirmative-action-people-disabilities-federal</u>
- Faram, M. (2019, April 12). *Meet the admiral who leads from a wheelchair*. Navy Times. <u>https://www.navytimes.com/news/your-navy/2019/04/12/meet-the-admiral-who-leads-from-a-wheelchair/</u>

Federal Emergency Management Agency National Risk Index (FEMA-NRI). (n.d.). Social vulnerability. https://hazards.fema.gov/nri/social-vulnerability

Federal Emergency Management Agency (FEMA). (2016, June). *National disaster recovery* framework, 2nd ed. <u>https://www.fema.gov/emergency-managers/national-</u> <u>preparedness/frameworks/recovery</u>

Federal Emergency Management Agency (FEMA). (2017, October). National incident management system, 3rd ed. https://www.fema.gov/emergency-managers/nims

Federal Emergency Management Agency (FEMA). (2019, October 28). *National response* framework. <u>https://www.fema.gov/emergency-managers/national-</u> preparedness/frameworks/response

Federal Emergency Management Agency (FEMA). (2020, September 9). *We are FEMA: Meet Kristin Duquette*. <u>https://www.fema.gov/blog/we-are-fema-kristin-duquette</u>

Federal Emergency Management Agency (FEMA). (2022). 2022-2026 FEMA strategic plan. Building the FEMA our nation needs and deserves. https://www.fema.gov/about/strategic-plan

- Fjord, L. & Manderson, L. (2009). Anthropological perspectives on disasters and disability: An introduction. *Human Organization*, 68(1), 64-72. https://doi.org/10.17730/humo.68.1.j6811546lm75n218
- Flanagan, B. E.; Gregory, E. W.; Hallisey, E. J.; Heitgerd, J. L.; & Lewis, B. (2011). A social vulnerability index for disaster management. *Journal of Homeland Security and Emergency Management*, 8(1). <u>https://doi.org/10.2202/1547-7355.1792</u>
- Garrity, A. (2016). Athlete turned activist Kristin Duquette on being a champion: "Trust yourself and trust your journey." 1000 Dreams Fund. <u>https://1000dreamsfund.org/kristin-duquette/</u>
- Gordon, B. G. (2020). Vulnerability in research: Basic ethical concepts and general approach to review. *The Oschner Journal*, 20(1), 34-38. <u>https://doi.org/10.31486/toj.19.0079</u>

Hawking, S. (2013). My brief history. Bantam.

- Human Resources Management (HRM) Handbook. (n.d.). Recruitment and staffing. https://hrmhandbook.com/hrp/recruitment/
- Inouye, D. (2023). Daniel Inouye: A featured biography. U.S. Senate. https://www.senate.gov/senators/FeaturedBios/Featured Bio Inouye.htm
- Knittel, K. M. (2002). Testament und Totenmaske: Der literarische Mythos des Ludwig van Beethoven. <u>https://www.jstor.org/stable/pdf/3526388.pdf</u>
- Krull, H., Armour, P., Edwards, K., Abel, K. V., Cottrell, L., & Azhar, G. S. (2019). The

relationship between disability evaluation and accession medical standards. RAND Corporation. <u>https://www.rand.org/pubs/research_reports/RR2429.html</u>

- Lathrop, D. (1994, November). *DISASTER! If you have a disability, the forces of nature can be meaner to you than anyone else. But you can fight back. Be prepared.* Mainstream magazine. <u>http://www.accessiblesociety.org/topics/independentliving/disaster.htm</u>
- Lawrence, Q. (2023, February 7). Ukrainian soldiers benefit from U.S. prosthetics expertise but their war is different. National Public Radio. <u>https://www.npr.org/2023/02/07/1153472827/ukrainian-soldiers-benefit-from-u-s-prosthetics-expertise-but-their-war-is-diffe</u>
- Mather, F. I. (1949). Utilization of physically handicapped officers in navy billets. [Doctoral dissertation, Ohio State University]. Dudley Knox Library, Naval Postgraduate School. <u>https://calhoun.nps.edu/handle/10945/6607</u>
- Matthews, M., Schulker, D., Curry Hall, K., Haddad, A, & Lim N. (2018). Representation of persons with targeted disabilities: An analysis of barriers to employment in the Department of Defense civilian workforce. RAND Corporation. <u>https://www.rand.org/pubs/research_reports/RR2297.html</u>
- Matthews, M., Sims, C. S., Robson, S., Walsh, M., Rennane, S., & Snoke, J. (2022). *Physical fitness standards to support readiness and deployability: An examination of Department of the Air Force policies and culture*. RAND Corporation.
 https://www.rand.org/pubs/research_reports/RRA552-2.html
- Mitchell, T. (1980). The relationship between Beethoven's Heiligenstadt Testament and his Nine Symphonies (1639). [Honors thesis, Western Michigan University].

https://scholarworks.wmich.edu/honors_theses/1639

Office of Personnel Management (OPM). (2023). Talent management.

https://www.opm.gov/policy-data-oversight/human-capital-framework/talentmanagement/#url=Overview

Office of Personnel Management (OPM). (2018). *Federal civilian employment*. <u>https://www.fedshirevets.gov/veterans-council/veteran-employment-</u> <u>data/employment-of-veterans-in-the-federal-executive-branch-fy2018.pdf</u>

Oxford University Press. (2023). Vulnerability. In OED.com dictionary. Retrieved February

```
1, 2023, from
```

https://www.oed.com/view/Entry/224871?redirectedFrom=vulnerability#eid

Oxford University Press. (2023). Vulnerable. In *OED.com dictionary*. Retrieved February 1, 2023, from https://www.oed.com/view/Entry/224872?redirectedFrom=vulnerable#eid;

Post-Katrina Emergency Management Reform Act of 2006, Pub. L. No. 109-295, 120 Stat.

1394.

https://www.doi.gov/sites/doi.gov/files/uploads/Post_Katrina_Emergency_Manageme nt_Reform_Act_pdf.pdf

Rennane, S., Asch, B. J., Mattock, M. G., Krull, H., Ligor, D. C., Dworsky, M., & Kempf, J. (2022). *Fit for duty: Alternative approaches for determining Department of Defense disability compensation*. RAND Corporation.
https://www.rand.org/pubs/research_reports/RRA1154-1.html

- Reynolds, R. (2019, April 30). *The airmen we need: Americans with disabilities in the Air Force*. War on the Rocks. <u>https://warontherocks.com/2019/04/the-airmen-we-need-americans-with-disabilities-in-the-air-force/</u>
- Rukmana, D. (2014). Vulnerable populations. In A.C. Michalos (Ed.), *Encyclopedia of quality of life and well-being research*. Springer. <u>https://doi.org/10.1007/978-94-007-0753-5_3184</u>
- Said, N. B., & Chiang, V. C. (2020). The knowledge, skill competencies, and psychological preparedness of nurses for disasters: a systematic review. *International emergency nursing*, 48, 100806. <u>https://doi.org/10.1016/j.ienj.2019.100806</u>
- Saunders, L. (2020). Core knowledge and specialized skills in academic libraries. *College & Research Libraries*, *81*(2), 288. <u>https://doi.org/10.5860/crl.81.2.288</u>
- Society for Human Resource Management (SHRM). (2023). *HR glossary: Knowledge, skills, and abilities (KSAs)*. <u>https://www.shrm.org/topics-tools/tools/hr-glossary#K</u>
- Stevens, M. J., & Campion, M. A. (1994). The knowledge, skill, and ability requirements for teamwork: Implications for human resource management. *Journal of Management*, 20(2), 503–530. <u>https://doi.org/10.1177/014920639402000210</u>
- Team USA. (2022). Elizabeth Marks. United States Olympic and Paralympic Committee. <u>https://www.teamusa.org/Team-USA-Athlete-Services/Paralympic-Sport-</u> <u>Development/Programs-and-</u> Events/Military/~/link.aspx? id=6CA00328259D4843A182FD736B25AC68& z=z
- Team USA. (2022). John Joss. United States Olympic and Paralympic Committee.

https://www.teamusa.org/Team-USA-Athlete-Services/Paralympic-Sport-

Development/Programs-and-

Events/Military/~/link.aspx?_id=66A42198C0654E698161A271DC40ACE5&_z=z

Team USA. (2022). Kevin Nguyen. United States Olympic and Paralympic Committee.

https://www.teamusa.org/Team-USA-Athlete-Services/Paralympic-Sport-Development/Programs-and-

Events/Military/~/link.aspx?_id=6F01BE23168A4450ADEC0DA577F7FF92&_z=z

- Threat Analysis Group. (May 3, 2010). *Threat, vulnerability, risk Commonly mixed-up terms*. <u>https://www.threatanalysis.com/2010/05/03/threat-vulnerability-risk-</u> commonly-mixed-up-terms/
- U.S. Government Accountability Office (GAO). (2008, November 21). Actions taken to implement the Post-Katrina Emergency Management Reform Act of 2006. <u>https://www.gao.gov/products/gao-09-59r</u>
- Waisel, David B. Vulnerable populations in healthcare. *Current Opinion in Anaesthesiology*, 26(2),186-192, April 2013. <u>http://doi.org/10.1097/ACO.0b013e32835e8c17</u>
- Werber, L. (2021). Talent management for U.S. Department of Defense knowledge workers: What does RAND Corporation research tell us? Rand Corporation. https://www.rand.org/pubs/research_reports/RRA950-1.html
- White House. (2023). Franklin D. Roosevelt: The 32nd President of the United States. The White House. <u>https://www.whitehouse.gov/about-the-white-</u> <u>house/presidents/franklin-d-roosevelt/</u>

World Medical Association (WMA). (2022, September 6). Declaration of Helsinki - Ethical

principles for medical research involving human subjects.

https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-

for-medical-research-involving-human-subjects/

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Research Articles and Essays

Community-Based Participatory Research (CBPR) Outcomes: 2023 Pacific Rim Conference Accessible and Affordable Housing Discussion

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Abstract

How do we understand the challenges, and policy driven advocacy approaches for people with intellectual and developmental disabilities seeking housing? Using community-based participatory research (CBPR), researchers and advocates from the Center on Disability Studies, University of Hawai'i at Mānoa partnered with community organizations to discuss housing challenges during the 2022 and 2023 Pacific Rim International Conference on Disability and Diversity. The goal was to use CBPR approaches and discussions to develop data-driven strategies for policy makers. Discussion points included: government initiatives to address housing issues; post-pandemic economic development, State of Hawai'i housing policies, along with socioeconomic challenges among the intellectual disability and developmental disability (IDD) community. Outcomes from the discussion include the need for disability data, awareness of housing options, and community-based working groups.

Keywords: accessible housing, affordable housing, intellectual disability,

developmental disability, policy

Community-Based Participatory Research (CBPR) Outcomes: 2023 Pacific Rim Conference Accessible and Affordable Housing Discussion

With the passage of the Americans with Disabilities Act of 1990 and Individuals with Disabilities Education Act (IDEA) of 1973, individuals with disabilities have been able to experience greater access and inclusion in society; however, they are still underserved and underrepresented in many areas (Resnik & Galloway, 2020). Affordable housing is one such area that needs more attention (Resnik & Galloway, 2020). As parents of individuals with disabilities age, affordable housing for their adult children becomes a key concern. Parents are left to decide what housing options may be most appropriate for their adult children to live in that best meets their needs. While legislation may vary by state pertaining to housing for individuals with disabilities, the issues are similar. Nationwide, common issues include: types of housing available (single dwelling, group home, community setting, developmental disabilities domiciliary homes; independent living; assisted living), housing adaptations and accommodations to name a few (Dunn, 1990; Mackie, 2012). In the State of Hawai'i, cost is also a significant consideration as the cost of living in Hawai'i is the highest in the nation (MERIC, 2023). As a result, securing housing for individuals with disabilities in Hawai'i is more challenging than in the Mainland US. Regardless, finding the most suitable option for an adult child with disabilities is critical for them to live to their fullest potential (Mackie, 2012).

One way to determine housing issues in a given geographical area throughout states

and regions is to use a community-based participatory research (CBPR) model.

Community-based participatory research (CBPR) is a research model that utilizes a collaborative approach involving researchers and community stakeholders addressing critical issues such as housing for adults with disabilities and engaging in the decision making process (US Department of Health and Human Services; US HHS). The key to the CBPR model is community engagement to ensure that interventions developed align to identified community needs (Blumenthal, 2011; US HSS). To accomplish this, community stakeholders and researchers collaborate on all aspects of the research including needs assessment, planning, intervention design, implementation, and evaluation (US HSS). The CBPR model is typically used to address health behaviors, health outcomes, and health disparities (US HHS), and has been used among other researchers to address housing challenges (MacKinnon, 2018). Affordable housing for individuals is directly related to health outcomes. The ability to live in an environment suitable for individual needs affects overall health and wellbeing.

Creating collaborative discussions in familiar and safe spaces in Hawai'i such as the Pacific Rim International Conference on Disability and Diversity (Pac Rim) allows engagement from advocates, researchers, practitioners and community members. In addition, the mission of Pac Rim conference is to provide a forum for participants from around the world to share the latest disability and diversity research and best practices and to connect with each other with the aim of taking what was learned and sharing or implementing these ideas in their own settings. Capacity-building workshops and lunchtime discussions are typically used to provide an opportunity for community members and stakeholders to meet and discuss important issues with the goal of developing and strengthening processes and resources that communities need. This article will address outcomes from a facilitated housing discussion that presented findings from the 2022 Pac Rim Conference and provided further findings from the 2023 Pac Rim Conference facilitated by Dr. Kelle L. Murphy, Dr. Patricia Morrissey, and Daintry Bartoldus, with contributing team members Genesis M.K. Leong and Saint-Marie Gough. To provide a background to the 2023 lunchtime discussion, we will first briefly mention the outcome of the 2022 workshop. Both the workshop and lunchtime discussion utilized a CBPR model.

2022 Pacific Rim Conference

During the 37th Pacific Rim International Conference on Disability and Diversity, advocates, community stakeholders, individuals with IDD, and local politicians collaborated on a workshop entitled "Expanding Hawai'i's capacity to House and Support Individuals with Intellectual and Developmental Disabilities (IDD)." This workshop served as Phase I of a CBPR approach to the topic. The purpose was to have an open discussion to identify housing needs and challenges specific to the disability community in Hawai'i. The end result was the development of a committee charged with writing and sending a letter with recommendations to address housing issues in Hawai'i to the former Governor. The committee consisted of five members: 4 parent advocates and directors of various non-profit organizations for individuals with disabilities and 1 representative in higher education. Committee members later met with the new Governor to discuss the recommendations made in the letter and to discuss his plans to address affordable housing for the disability community in Hawai'i. His plan at that time was to assign a Housing Czar to address housing issues, something he has since done.

2023 Pacific Rim Conference

The 38th Pacific Rim International Conference on Disability and Disability lunchtime discussion hosted on Tuesday, March 7, 2023 served as Phase II of a CBPR approach to the topic and was entitled "Accessible and Affordable Housing: Challenges for Creating Housing Options for Adults with Intellectual and Developmental Disabilities." Parents, advocates, individuals with disabilities, and community stakeholders were in attendance. The goals were: 1) understand challenges and issues; 2) understand what actions have been taken since Pac Rim 2022 workshop; and 3) offer suggestions for moving forward. The discussion focused on the following guiding questions:

 How do we assist families and people with IDD to navigate housing options in Hawai'i?

2. What are the barriers to promoting and acquiring more accessible affordable housing?

3. How can we create representation that includes parents, advocates, and individuals with disabilities in housing working groups?

4. How do we motivate and promote these housing issues in a systematic way?

Results of Audience Discussion

The following suggestions were given by audience attendees to continue to adequately address the topic in Hawai'i:

Working group for Governor's task force - It was determined after the 2022 Pac
 Rim workshop that a working group designated by the Governor was needed and was one of

the recommendations. The suggestion is that the group should include community members directly impacted such as individuals with disabilities, parent advocates, community stakeholders, as well as politicians. The disability perspective is critical to include in policymaking conversations. The recommendation was made to the current Governor, and he has appointed a Housing Czar to address the issues. The creation of the working group would be the next step.

2. **Data collection** - Appropriate data for policy and decision making is needed and the state of Hawai'i lacks data pertaining to housing issues for the IDD community. In addition, data collection needs to be continuous to be able to make comparisons and determine trends over time. Suggestions for types of data collection included: transitional housing approaches; housing that meets cost of living for IDD; impact of housing on disabled families; inaccessible housing; and unsustainable capital and asset loss. Audience attendees felt that addressing different ways people identify or do not identify with IDD to avoid skewed data is important. They felt that there is a need to address disability within a diversity, equity, and inclusion (DEI) framework.

3. Educational seminars - Navigating the system can be both overwhelming and confusing. Educational seminars that teach steps to navigate, alternative solutions, terminology, along with various types of housing options and how to determine which would be most appropriate and affordable was a recommendation by the audience attendees. The thought was that more education on the process would lead to more confidence for advocates to be able to successfully navigate the complex system.

Conclusion

While both the workshop and discussion resulted in productive outcomes, there clearly is more work that needs to be done to adequately serve the disability community in

Hawai'i. Involving those directly impacted by the policies and allowing their opinions and voices to be heard is a critical piece that has been missing from the process. Adequate housing affects a person's overall health and wellness. When housing is comfortable and appropriate for individual needs, their overall wellness increases. This needs to be a priority for all citizens.

References

- Dunn, P. A. (1990). The impact of the housing environment upon the ability of disabled people to live independently. *Disability, Handicap & Society, 5*(1), 37–51.
- Garboden, P. M., Leventhal, T., & Newman, S. (2017). Estimating the effects of residential mobility: A methodological note. *Journal of Social Service Research*, 43(2), 246–261. <u>https://doi.org/10.1080/01488376.2017.1282392</u>
- Garboden, P. M. E., & Newman, S. (2012). Is preserving small, low-end rental housing feasible? *Housing Policy Debate*, 22(4), 507–526. <u>https://doi.org/10.1080/10511482.2012.697909</u>
- Jull, J., Giles, A., & Graham, I. D. (2017). Community-based participatory research and integrated knowledge translation: Advancing the co-creation of knowledge.
 Implementation Science, 12(1), 150. <u>https://doi.org/10.1186/s13012-017-0696-3</u>
- Leake, D. W. (2018, October 1). Why Maui should mandate visitability in housing [I.E.M. Committee Maui Council Council].
- Leake, D. W., DeWoody, H., Chow, S., Tom, T., & Kong, E. (2016). State of Hawai'i analysis of impediments to fair housing choice with a focus on people with disabilities. Report prepared for Hawai'i Housing Finance and Development

Blumenthal, D. S. (2011). Is community-based participatory research possible? American Journal of Preventive Medicine, 40(3), 386–389. https://doi.org/10.1016/j.amepre.2020.11.011

Corporation, State of Hawai'i Department of Hawaiian Home Lands, State of Hawai'i Department of Human Services, Hawai'i Public Housing Authority, City and County of Honolulu Department of Community Services, Hawai'i County Office of Housing and Community Development, Kaua'i County Housing Agency, and Maui County Department of Housing and Human Concerns at the Center on Disability Studies, University of Hawai'i at Mānoa, United States.

- Mackie, P. K. (2012, September). Housing pathways of disabled young people: Evidence for policy and practice. *Housing Studies*, *27*(6), 805–821.
- MacKinnon, S. (Ed.). (2018). Practising community-based participatory research: Stories of engagement, empowerment, and mobilization. Purich Books. https://doi.org/10.59962/9780774880121

Missouri Department of Higher Education and Workforce Development's Office of Performance & Strategy (MERIC). (2023). Cost of Living Data Series. <u>https://meric.mo.gov/data/cost-living-data-series</u>

- Resnik, D. D., & Galloway, D. K. (2020). A place in the world: Fueling housing and community options for adults with autism and other neurodiversities.
- U.S. Department of Health and Human Services. (n.d.). National Institutes of Health. https://www.nih.gov/

USA.gov. (n.d.). Community-based participatory research. https://usa.gov

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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

 Atra, M. (2024). Teachers' Self-Efficacy When Instructing Students with Emotional and Behavioral Disorders in Inclusive Classrooms (Order No. 30992232). [Dissertation: Walden University]. ProQuest Dissertations & Theses Global. (2925381190).

Capolongo, E. C. (2024). The Story of Sexual Health Curriculum Development for Individuals with Intellectual Disabilities: A Multisite Case Study (Order No. 30816126). [Dissertation: The George Washington University]. ProQuest Dissertations & Theses Global. (2899503025).

- Hill, M. (2024). Queer Crip Generativity (Order No. 30690406). [Dissertation: Trent University]. ProQuest Dissertations & Theses Global. (2904369818).
- Schlicting, M. D. (2024). A Transportation Study with Implications for Those With Disabilities (Order No. 30988621). [Dissertation: University of Wisconsin-Madison]
 ProQuest Dissertations & Theses Global. (2911758312).
- Kryger, K. (2023). Challenging Neuronormativity: A Disability Studies Framework for Communal Justice in Writing Assessment (Order No. 30485955). [Dissertation: The University of Arizona]. ProQuest Dissertations & Theses Global. (2829333459).
- Roders, D. M. (2023). Beyond Deadly Sins and Virgin Impairments: Medieval Bodies in Disability Studies (Order No. 30501530). [Dissertation: Purdue University]. ProQuest Dissertations & Theses Global. (2827704634).
- Stewart, R. (2023). Nothing About Us Without Us: A Qualitative Inquiry of Disabled Student Activists Creating Disability Cultural Centers on College Campuses (Order No. 30489361). [Dissertation: California State University, Sacramento]. ProQuest

Dissertations & Theses Global. (2829668095).

- Tyman, S. K. (2023). Accessing the Alternative Food Movement: Considerations Towards Disability Justice (Order No. 30317901). [Dissertation: University of Washington.]
 ProQuest Dissertations & Theses Global. (2863680066).
- West, K. W. (2023). *Disability in the World of Cicero* (Order No. 30575163). [Dissertation: University of Pennsylvania]. ProQuest Dissertations & Theses Global. (2868554044).

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