

## Editorial

**Welcome to the Conference Proceedings of the 37<sup>th</sup> Annual**

**Pacific Rim International Conference on Disability & Diversity 2022**

Kiriko Takahashi<sup>1</sup>, Hye Jin Park<sup>2</sup>, and Tom Conway<sup>2</sup>

<sup>1</sup> Conference Chair 2022

<sup>2</sup> Conference Co-Chair 2022

<sup>5</sup> Center on Disability Studies, University of Hawai'i at Mānoa

## Abstract

This is a welcome message for the Conference Proceedings of the 37th Annual Pacific Rim International Conference on Disability & Diversity 2022 at the Center on Disability Studies at the University of Hawai'i at Mānoa.

*Keywords:* Pacific Rim, disability, conference, COVID-19

**Welcome to the Conference Proceedings of the 37<sup>th</sup> Annual  
Pacific Rim International Conference on Disability & Diversity 2022**

We are pleased to share the Conference Proceedings for the 37<sup>th</sup> Annual Pacific Rim International Conference on Disability and Diversity 2022. This collection documents papers shared live remotely in the conference in Spring 2022 during the global pandemic. While the conference is generally a live, in-person, annual Hawaii tradition, 2022's conference was held completely online, making it one of only two Pacific Rim conferences ever (along with 2021) to do so. 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, advocates, entrepreneurs, policymakers, advocates, and others from across the globe to come together to 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 2022. Drawn together by the Conference's theme, *Mobilize for Action*, participants were invited to consider the ways in which their work might help invite attendees to take collective action to amplify our power for change.

Presentations and events at the conference were organized within five broad, general strands:

- (1) Communities: Autism & Neurodiversity; Deaf Community; Family Engagement; Indigenous & Cultural Diversity;
- (2) Education: Higher Education, Disability, & COVID-19; PreK-12 Education, Disability, COVID-19; Social-Emotional Learning;

(3) Employment and Career: Accessibility & Accommodation Issues; COVID-19 and Employment Issues; Innovations and Challenges in Career Development; Transition from Postsecondary Education to Employment;

(4) Health & Well-being: Disability and Health; Mental Health Issues & COVID-19; Well-being and Flourishing; and

(5) Disability Studies & Diversity Issues: Disasters and Emergency Preparedness; Disability Policy and Advocacy; Creativity, Media & the Arts; Disability Studies & Intersectionality.

Within these strands, the contributions herein reflect a broad, cross-section of work in the field. In “Autistic Adults as Educators: Exploring Parent Perceptions of Autistic Presenters,” Blagrove, Koch, and Widgay highlight the important role Autistic voices may play in both supporting the development of young people with Autism and in providing confidence to their parents. Turning to gaps in support, Pfeiffer, Bower, and Rumrill’s “The Current State of Air Travel for Americans with Disabilities: Considerations for Policy, Enforcement, Implementation, and Advocacy” brings attention to the continued challenges that exist for disabled travelers in having full access to the freedom travel allows. In other domains, Tuhakaraina’s “Karawhiua:

Mobilizing own Language Journey” speaks to the freedom and power our own identities and languages may provide. Additionally, Takeuchi, Takahashi, and Umenaga address some of the challenges of restarting services in post-pandemic landscapes in their “How to Restart an Inclusive Camping While Preventing COVID-19 Outbreak.”

Furthermore, within the collection, Cleveland, Tassin, Love, Deere, Cope, and Gangluff consider how diagnosis may be leveraged for access in their “An Interdisciplinary Approach to Increasing Access to Care for Individuals with Fetal Alcohol Spectrum Disorders.” And Schaffer’s “Disabilities in Disaster Situations: How a Rescuer Handles What They Encounter” considers key strategies to mitigate the additional vulnerability of people with disabilities in disasters. Turning to the power of advocacy, Guthrey’s “Advocacy 101: Discover Your Personal Style” looks at strategies for effective advocacy. And Hamamatsu and Shibata’s “Focusing on Essential Functions for Persons with Disabilities to Improve Working Environments: From a Survey on Coffee Workers in Japan” looks at the critical importance of listening to disabled voices in designing meaningful accommodations.

Other works in the collection include Matsuzaki and Shibata’s “Information Accessibility for Kanji: A Pilot Project for Academic Translation and Learning” and its

consideration of the unique challenges associated with language and transmission of information. Finally, “Deaf Community and DiDRR: Supporting a Twin-Track Approach” by Craig, Cooper, Takayama, and Klein considers the effectiveness of using approaches tailored to Deaf communities to ensure all receive the essential information they need. For all contributions to this volume, plain language versions of abstracts may be accessed at: <https://rdsjournal.org/index.php/journal/plain-language-37th-pac-rim-proceedings> .

We wish to thank all of the attendees and presenters attending the event. The 38th Pacific Rim Conference was just held in person in Honolulu, Hawaii shortly before the time of this writing. We invite readers to join us next year for the 39<sup>th</sup> Annual Pacific Rim International Conference on Disability and Diversity on March 4<sup>th</sup> and 5<sup>th</sup>, 2024.



**Editorial: Welcome to the Conference Proceedings of the 37th Annual Pacific Rim International Conference on Disability & Diversity 2022**

<https://rdsjournal.org/index.php/journal/article/view/1260> is licensed under a [Creative Commons Attribution 4.0 International License](https://creativecommons.org/licenses/by/4.0/). Based on a work at <https://rdsjournal.org>.

**Autistic Adults as Educators:****Exploring Parent Perceptions of Autistic Presenters**

Josephine Blagrave<sup>1</sup>, Aaron Koch<sup>2</sup>, and Amanda Widgay<sup>3</sup>

<sup>1, 2, 3</sup> California State University, Chico

**Abstract**

In the field of disability studies, Autistic voices have been historically excluded from the autistic narrative, and it is time for Autistic voices to be heard. The purpose of this qualitative study was to consider how autistic adults are viewed by parents of autistic children and how these parents make use of the information provided by autistic adults. Results of this study indicate that parents of autistic children hold a positive view towards autistic adults and value information shared by autistic adult presenters. The research showed that mothers of Autistic children have more hope for the potential of their Autistic children if there are other Autistic role models in their children's lives. The research study focused on the importance of mothers in the lives of Autistic children as mothers often play the most important role in raising children. In cases of

children with disabilities, the mother will try to seek out every avenue to provide the most supports to their child, often feeling they must be the biggest advocate for their disabled child.

*Keywords:* autism, autistic adults, lived experience, parent education, autistic child, family



### **Autistic adults as educators—exploring parent perceptions of autistic presenters**

As we move towards a more connected society, information has become easier to access, digest, and disseminate. Through this process of increased connectivity, minority voices have gained access to spaces that were previously unavailable (Ashing et al., 2017). Understanding the ‘lived experience’ of minority groups has provided insight to broader stakeholder groups and helped improve services and outcomes (Bernard & Harris, 2019; Corby, Taggart, & Cousins, 2018; McAuliffe, Upshur, Sellen, & Di Ruggiero, 2019; Mouchet, Morgan, & Thomas, 2019; van Zelst, 2020). Autistic voices, often conspicuously absent from the narrative of their experiences, have been amplified by both autistic and non-autistic populations. For example, the past five years have seen a call to increased autistic inclusion in research (Nicolaidis et al., 2019), a rise in media representation (Wolff, 2018), and an increased presence in social media (Beykikhoshk, Arandjelović, Phung, Venkatesh, & Caelli, 2015).

Through this increased exposure, there has been a heightened increase of autistic culture and autistic identity that mirrors the understanding and embracing of deaf culture (Beykikhoshk et al., 2015). Language use and identity first identification of

those who are autistic (Kenny et al., 2016) have shifted the narrative from “cure” to “acceptance,” with a growing number of adolescent autistic individuals embracing their autistic identity (Cage, Bird, & Pellicano, 2016). As parents seek to understand and support their autistic child(ren), many have turned to social media platforms and parent support groups to gain insight into their child’s behaviors and needs in an effort to provide better accommodations and supports both at home and school (Shepherd, Goedeke, Landon, & Meads, 2020). This shift has led to greater understanding by parents of autistic children and has increased the prevalence of a strengths-based approach to autism (Teti, Cheak-Zamora, Lolli, & Maurer-Batjer, 2016) and consideration for all stakeholders of the autistic community (Gibson & Hanson-Baldauf, 2019).

Research has included parents, professionals and autistic adults in exploration of the meaning and process of an autism diagnosis (Crane et al., 2018) and has shown that autistic individuals are the experts in their lived experience (Gillespie-Lynch, Kapp, Brooks, Pickens, & Schwartzman, 2017). While there has been an upsurge in the acceptance, celebration and experience of the autistic voice, no study to date has explored how parents with autistic children view autistic adults who are presenting information in a formalized setting, nor the implementation of that information by

parents. To that aim, the purpose of this qualitative study was to explore how autistic adult presenters are perceived by parents who have autistic children and how parents of autistic children utilize the information provided by autistic adults.

### **Methods**

All research activities were approved by the California State University, Chico Institutional Review Board. Participants for this study were purposively recruited through an attendee pool from the 3<sup>rd</sup> annual Northern California Autism Symposium via opening remarks for the program, and material in the program booklet to identify participant needs. Interested participants responded to the researchers by email or phone, and a follow-up phone call was held to discuss the general overview of the study, answer any potential questions, and schedule a day, time, and location for the interview. Inclusion criteria for this study were to self-identify as a) a parent of an autistic child and b) to attend an autistic adult's presentation. Table 1 shows participant demographics.

**Table 1***Participant Demographics*

Participant	Age of Autistic Child	Age Diagnosed	Number of People in Household
Rebecca	26	14	2
Tracy	5	3	5
Jasmine	10	3	4
Shelly	5	3.5	4
Karen	5	3.5	3
Kylee	50+	5	1
Grace	6	2.5	3

Parents in the study had children ranging from 5 to 50+ years old. Though not a criterion for this study, only mothers were represented in this sample. Most children in the study were diagnosed under the age of 5 with a diagnosis for at least 1.5 years.

Household size varied between families ranging from 1 to 5 members, and there was only one autistic child in each family units.

### **Interviews**

Semi-structured interviews were conducted with each participant and lasted approximately 30 minutes. Interview questions followed the same order for each participant, with follow-up prompts as needed. Interview questions are shown in Table

2.

**Table 2**

*Interview Schedule*

- 
- Have you heard autistic adults speak about their experiences in the past?
  - If yes, please explain that setting/feelings it gave you, etc.
  - What autistic adults did you hear speak?
  - Before hearing autistic adults speak, what were your perceptions of what that would be like?
  - What were your perceptions about your child with Autism Spectrum Disorder (ASD)'s future before hearing the speakers? Did your perceptions change in any way (positive or negative) after hearing this?
  - Was there a big "take away" message you heard from the autistic presenters? If so, can you please share and describe why that resonated with you?
  - Do you think hearing autistic adults share their experiences are important (why or why not?)
  - Who are your child's role models? (If respondent did not identify anyone on the spectrum: is it important for your son or daughter to have role models who are on the spectrum? Why? Why not?)
  - Was there anything that was discussed by the autistic adults that was unexpected or eye-opening? If yes, what and why?
  - Was there anything that was not discussed by the presenters that you wish would have been?
  - Do you use identity first (autistics) or person first (individual with ASD)? Can you explain why that is the language preference for your family?
  - Is there anything else you would like to share, either positive or negative about the experience of autistic adult speakers?
-

Interviews were audio-taped and transcribed verbatim for analysis. Data were hand-coded by all three authors using a first-cycle coding method, looking for exploratory categories as described by Miles, Huberman, and Saldana (2014). Thematic analysis was used in a linear method using the following steps outlined by Braun & Clarke (2006): 1) familiarization with the data; 2) coding; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; and 6) the writing up. All authors independently identified categories and themes and then reviewed each other's for similarities and differences. Any differences in interpretation were discussed and resolved through that discussion process.

## Results

Through analysis, three themes emerged from the experience of those with autistic children of hearing autistic adults speak: (1) "always trying to see around the corner": gaining insight from autistic adults; (2) "guilty of misconceptions": ideas about autistics from non-autistic parents; and (3) "it's important to show them what's out there": the importance of diversity and role models.

### ***"Always trying to see around the corner": gaining insight from autistic adults***

This theme was defined as any time a parent discussed obtaining insight autistic

adult presenters or the wish to gain more insight about the autistic experience. Parents in this study shared that they were always on the lookout, anticipating what is next for their child, trying to see how they can support their child, and getting information from as many sources as possible. For these parents, autistic adults provided meaningful insights in multiple ways as to how they could better support their child. For Jasmine, how she interacted with her child in public shifted dramatically once she heard autistic adults share their experiences:

It makes me think of the things as a parent that I would do wrong. It has taught me to—hearing adult speakers and their experiences teaches you as a parent, “Oh I need to do more of this or less of this. When I am in public, I don’t jump to tell he has autism to make a ‘problem’ ok or not even a ‘problem’ or make a situation ok.”

This shift happened for all of the parents in the study. Presenters changed how parents advocated for their children in school and in extracurricular activities, what services they sought out or rejected for their child, and what sensory supports they put in place in their child’s daily life. Parents were constantly worried about their child’s future and wanted as much information as possible on what autistic adults thought they

should be doing as parents. These parents really wanted to get it right and felt that hearing autistic adults' perspectives was important. For example, Tracy shared that hearing from an autistic adult who had considered ending her own life because she didn't feel accepted or understood really made Tracy think about how to support her own child and how she felt about parenting:

“I feel like I am always questioning, like am I doing all the things I can or making all the wrong choices, which I think we all do no matter what our kids are or what is going on, but they [autistic adults] have a unique perspective.”

For all the parents in the study, it was important for them to hear from autistic adults so that they could learn as much as they could about neurodiversity as well. It was one thing, parents shared, to learn from professionals, but quite another to hear from those with the lived experience. Rebecca offered, “I find it's not just a preference, it's a need to listen to people who are neurodivergent speak about neurodiversity. I can't say it enough.”



***“Guilty of misconceptions”*: ideas about autistics from non-autistic parents of autistics**

This theme was defined as any time a parent discussed misconceptions they had before they heard autistic adults speak. More than half of the parents in the study initially shared a general idea that an autism diagnosis was a barrier to their child having a successful or fulfilling life, and that they expected the autistic adult presenters to be socially isolated. Jasmine found comfort in learning that the autistic adult presenters “do have friends, and they’re not by themselves, and they’re not on the street.” This sentiment was echoed by Karen: “This will happen. It’ll just take time, and it will happen on [my son’s] own terms.”

Parents also shared that they were nervous for the presenters at first and felt protective of them, like they would for their own children. Shelly reported her expectation that:

It might be hard for [the autistic adults] with so many people in the room. I was not quite expecting so much humor, which was really refreshing for me...My son is very rigid, so I expected it to be that way...I always worried about him being teased, and hearing Alex talk about how he was teased but then found his

place made me hopeful that my son's going to find his place and 'his people' so to speak.

Grace shared a similar view: "It was inspirational to see that we can carve out spaces for our kids to exist in the culture and it doesn't have to be this [segregated] society that we perceive it to be." Her original perception of autism was that it was "scary" because the representation of autistic people has been limited to the dichotomy of savants and autistic people identified as developmentally disabled, but the autistic adult "speakers have shown us what they really can be like. Even with the successful examples, it's still real."

Another shared belief was that autism was a negative identity. This perception was also swayed by hearing from the autistic adults. Grace shared her understanding that autism is "not the death sentence that some of us are really made to feel... This doesn't feel bad. It's just different, it's not bad." Shelly gave a similar response, considering the possibility of autism as a positive trait: "It's a positive thing. It doesn't mean you're less at something, it just means you do things in a different way... [it's] okay to be who you are. It's not like a lot of these behaviors are negative. There's a lot of positive attributes to it."

This shift from “scary” to “this is my child; they are their own person” was something that caused a shift in thinking that was translated and promoted to extended family members, friends and professionals who interacted with their children. For some parents, it helped to shift their tone in parent support groups and to challenge negative stereotypes when encountered in the community.

***“It’s important to show them what’s out there”*: the importance of diversity and role models**

This theme was defined as any time a parent discussed the importance of diversity and role models for their autistic child. Parents were asked if they used identity-first or person-first language and to explain why their family chose the language they did. Many of the parents shared that they had initially used person-first language because that is what they had heard from professionals and other parents. However, after hearing autistic adults speak, all but one family chose to use identity-first language and to promote that type of language use in the autism community in which they participated. This change would not have occurred or may have come more slowly had they not been exposed to autistic speakers who explained why they thought identity first language was important. Grace shared, “I probably didn’t pay as much

attention to language until it was brought forward by autistic adults. I do it [use identity first language] forcefully now because I've heard from autistic adults it's important to them.”

All participants in this study attended multiple presentations led by autistic adults. Many parents spoke about how that range of autistic experience was important and that hearing those with varying experiences was important in helping them understand how to best support their child. Additionally, parents wanted even more breadth of experience, with parents asking for more female representation and to hear from autistic adults who use augmented communication. Tracy summed up parental feelings about autistic speakers best:

If parents are really willing to listen to [autistic adults] and accept what their experiences are, I think it helps us make better decisions for our children while they can't communicate. I think it's really important to listen to autistic adults of how they felt about things that were done to them or the therapies they had to go through and really respect what they have to say.

All parents shared that although their autistic kid(s) did not currently have autistic people that they looked up to as role models, they felt like it was very important

for that to be a possibility for their child. Grace added how “important [it is] to have autistic role models. I think that it’s an opportunity to make it better for our kids. Maybe he would connect more and have human role models if he felt he could see himself in them.”

### Discussion

This study is the first to explore how parents of autistic children perceive information from autistic adult presenters. Each of the seven participants reported a positive experience attending the presentations of autistic adults and wished to hear more information as a result. Additionally, parents attributed changes in their parenting behaviors and attitudes to insight gained from these experiences. For example, many parents began using and promoting identity-first language, implementing various sensory tools, and taking a step back to understand some of their child’s behaviors as communication of anxiety or a need.

By improving understanding between stakeholders in the autistic community, parents may gain insight from autistic adults who have the expertise of their lived experiences. For the parents in this study, a majority of their children did not have expressive verbal language skills, which left many parents unsure of what needs were

being met, or not met, what experiences may be too overstimulating, or what therapies were more harmful than helpful to their child. While professionals in the autistic community are a valuable resource, unless they themselves are autistic, there is a component of the lived experience that may be missing from their interpretation of autistic behavior. As such, listening to autistic adults is a critical step in improving understanding of their autistic child for parents who themselves are not autistic.

While this study provided insight to a newly explored area of the literature, there were limitations. One, this study was exploring the experience of parents who have an autistic child qualitatively. The nature of qualitative studies requires a small sample size, which cannot be generalized to the greater autism parenting community. Additionally, the parents in this study were asked to reflect on presenters they have heard at a smaller autism symposium in a rural area in Northern California. As such, these experiences might not be the same as parents in more rural areas or other parts of the country.

While the idea of autistic people as educators may be simplistic in nature, the concept of having autistic adults share their experiences, expertise and knowledge is not yet mainstream. Organizations and educational institutions should work with autistic

adults and autistic research networks to provide spaces where parents of autistic children and autistic adults can come together to help provide support for families who are raising autistic children. One of the parents in the study summarized this need, stating “it’s important to keep offering these experiences to community members because, if we don’t provide the platform for [autistic adults] to speak, we’re never going to hear them.”

### Conclusion

In this discussion, we have considered a research study about the opinions and impressions of parents with Autistic children. The qualitative research study analyzed many questions mothers of Autistic children worry about daily, including what kind of identifying language (person first language or disability first language) they should use about their Autistic children. The research study focused on mothers as mothers often play the most important role in raising a child with a disability. Mothers believe they know what is best for their child and how to navigate a world not set up for their child’s disability. However, as the research suggests, mothers of Autistic children often struggle with providing the best environment for their children. Towards this end, this article suggests we need more research from the perspective of Autistic people as most

research that is available is not. Additionally, we need to provide more supports for Autistic people to voice their concerns and to direct their lives so they may have the most independence.

Towards this goal, Autistic voices need to be heard and not silenced. This is the only way we will learn more about the lived experience of those with ASD. As the authors continue to create more supports for Autistic children to grow up and to live an independent life, we also hope there will continue to be more opportunities where Autistic children can communicate and learn from Autistic adults. We believe interacting with others with a similar disability will create a supported environment. Furthermore, the issues of the effects of Autism need a greater spotlight. As we continue our work in the field of disabilities, we will create more avenues for those with Autism. We hope to have greater research on the field and the effects of Autism. We will continue the work for those with Autism and all other disabilities and long for a day where people with disabilities are fully included in society at large. Until then, we will redouble our efforts. When one of us is discriminated against, so are we all. Our work will never be done, and we thank all mothers raising children with disabilities. We appreciate your efforts and know that you are trying your best to get the help your child needs. We know this journey may be long and hard, but there is hope.



### References

Ashing, K., Serrano, M., Rosen, S. (2017). Abstract LB-052: Using community team science: An advocacy engaged approach to recruit ethnic minorities in cancer research. *Cancer Research*. 77(13\_Supplement): LB-052.

<https://doi.org/10.1158/1538-7445.AM2017-LB-052>

Bernard, C., Harris, P. (2019). Serious case reviews: The lived experience of Black children. *Child & Family Social Work*, 24(2), 256-263.

Braun, V., Clarke, V. (2006). *Using thematic analysis in psychology*, *Qualitative research in psychology*, 3(2), 77-101.

Beykikhoshk, A., Arandjelović, O., Phung, D., Venkatesh, S., Caelli, T. (2015). Using Twitter to learn about the autism community. *Social Network Analysis and Mining*, 5(1), 22. <https://doi.org/10.1007/s13278-015-0261-5>

Cage, E., Bird, G., Pellicano, L. (2016). 'I am who I am': Reputation concerns in adolescents on the autism spectrum. *Research in Autism Spectrum Disorders*, 25, 12-23. <https://doi.org/10.1016/j.rasd.2016.01.010>

Corby, D., Taggart, L., & Cousins, W. (2020). The lived experience of people with

intellectual disabilities in post-secondary or higher education. *Journal of*

*Intellectual Disabilities*, 24(3), 339–357.

<https://doi.org/10.1177/1744629518805603>

Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L. A., Hill, E., L. (2018).

Autism diagnosis in the United Kingdom: Perspectives of autistic adults, parents and professionals. *Journal of Autism and Developmental Disorders*, 48(11),

3761-3772. <https://doi.org/10.1007/s10803-018-3639-1>

Gibson, A, N., Hanson-Baldauf, D. (2019). Beyond sensory story time: An

intersectional analysis of information seeking among parents of autistic individuals. *Library Trends*, 67(3), 550-575.

<https://doi.org/10.1353/lib.2019.0002>

Gillespie-Lynch, K., Kapp, S. K., Brooks, P. J., Pickens, J., Schwartzman, B. (2017).

Whose expertise is it? Evidence for autistic adults as critical autism experts.

*Frontiers in Psychology*, 8(438). <https://doi.org/f9z2kk>

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., Pellicano, E. (2016).

Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism 2016*, 20(4), 442-462.

<https://doi.org/10.1177/13623613155882>

McAuliffe, C., Upshur, R., Sellen, D. W., Di Ruggiero, E. (2019). The lived experience of global public health practice: A phenomenological account of women graduate students. *Health and human rights*, 21(1), 115.

Miles, M. B., Huberman, A.M., Saldaña, J. (2014). *Qualitative data analysis: A methods sourcebook*. 3rd ed. Sage.

Mouchet, A., Morgan, K., Thomas, G. (2019). Psychophenomenology and the explicitation interview for accessing subjective lived experience in sport coaching. *Sport, Education and Society*, 24(9), 967-980.

<https://doi.org/10.1080/13573322.2018.1495189>

Nicolaidis, C., Raymaker, D., Kapp, S. K., et al. (2019). The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism*, 23(8), 2007-2019.

<https://doi.org/10.1177/1362361319830523>

Shepherd, D., Goedeke, S., Landon, J., Meads, J. (2020). The types and functions of social supports used by parents caring for a child with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 1-16.

<https://doi.org/10.1007/s10803-019-04359-5>

Teti, M., Cheak-Zamora, N., Lolli, B., Maurer-Batjer, A. (2016). Reframing autism:

Young adults with autism share their strengths through photo-stories. *Journal of pediatric nursing*, 31(6), 619-629. <https://doi.org/10.1016/j.pedn.2016.07.002>

van Zelst, C. (2020). Integrating lived experience perspectives into clinical practice. *A*

*Clinical Introduction to Psychosis: Elsevier*, 687-703. <https://doi.org/j2nd>

Wolff, S. “Because He Is Different”: Shifts in Discourse and the Increasing Presence

of Autism in Fictional Television [Master’s Thesis, The University of

Wisconsin-Milwaukee]. (2018).



**Autistic Adults as Educators: Exploring Parent Perceptions of Autistic**

**Presenters** by Josephine Blagrove, Aaron Koch, and Amanda Widgay

<https://rdsjournal.org/index.php/journal/article/view/1160> is licensed under a [Creative](https://creativecommons.org/licenses/by/4.0/)

[Commons Attribution 4.0 International License](https://creativecommons.org/licenses/by/4.0/). Based on a work at

<https://rdsjournal.org>.

**The Current State of Air Travel for Americans with Disabilities:  
Considerations for Policy, Enforcement, Implementation, and Advocacy**

Julie L. Pfeiffer, PT, DPT, MS<sup>1</sup>, Walt Bower, Ph.D.<sup>2</sup>, and Phillip Rumrill, Ph.D.  
<sup>3</sup>, CRC.

<sup>1, 2, 3</sup>Human Development Institute, University of Kentucky

**Author Note**

Correspondence concerning this article should be addressed to Phillip Rumrill,  
Human Development Institute, University of Kentucky, 120 Graham Avenue,  
Lexington, KY 40506, United States. Email: [phillip.rumrill@uky.edu](mailto:phillip.rumrill@uky.edu)

### Abstract

For over thirty years, Federal legislation has existed to improve accessibility during air travel. Yet, disability-related complaints continue to increase. Americans with disabilities report physical, organizational, and service barriers during air travel. Therefore, it is necessary to explore whether this problem is attributable to policy, enforcement, implementation, and/or advocacy issues.

*Keywords:* Accessible transportation, accommodations, flight

## **The Current State of Air Travel for Americans with Disabilities:**

### **Considerations for Policy, Enforcement, Implementation, and Advocacy**

Engracia Figueroa, a prominent advocate for the inclusion and independence of people with disabilities, was flying home to Los Angeles after advocating for the rights of domestic workers at a march in Washington, D.C. in July, 2021 (Reyes, 2022). Upon landing in Los Angeles, Figueroa discovered that United Airlines workers had broken her \$30,000 custom power wheelchair (Miranda, 2021). Figueroa required a custom power wheelchair designed specifically for her body to perform everyday activities following a spinal cord injury and left leg above knee amputation (Reyes, 2022). She was forced to sit in an airport transport chair that stripped Figueroa of her independence for nearly five hours at the Los Angeles International Airport while filing a damage report and waiting for United Airlines to provide the required loaner wheelchair (Miranda, 2021). Sitting for multiple hours in the transport chair with poorly supported posture and without the ability to perform pressure relief led to the reopening of a pressure wound (Reyes, 2022). Figueroa experienced “excruciating” pain and was admitted to the hospital shortly after returning home (Miranda, 2021). As Figueroa fought with United Airlines to replace her severely damaged power wheelchair, she had no alternative but to use an ill-fitting loaner wheelchair for several months. During this

time, the pressure wound became infected. The infection then spread into her hip bone, requiring emergency surgery. On October 31<sup>st</sup>, 2021, just over three months after her wheelchair was broken, Engracia Figueroa died from complications of emergency surgery (Reyes, 2022). She was 51 years old.

### **Background**

Full participation in work, leisure, and family roles is largely dependent on physical proximity, which can be achieved through various modes of transportation (Urry, 2002). Air travel has become a vital form of transportation for participation in these roles. In 2017, half of all airline passengers reported flying for leisure activities, followed by work and non-leisure purposes like college, family events, and medical appointments (Salas, 2021). For persons with disabilities, accessible public transportation has been shown to increase participation in recreation and leisure activities (Páez & Farber, 2012). However, air travel continues to be challenging, and sometimes impossible, for many individuals with disabilities (Dempsey et al., 2021).

The air travel experience is often divided into four phases: pre-travel, pre-flight, in-flight, and post-flight. Barriers to air travel can occur in any of these phases and often vary depending on the individual's type of disability (Davies & Christie, 2017;



Dempsey et al., 2021; Poria et al., 2010). Significant stress during air travel is caused by periods of waiting, crowds, and sensory stimuli for Autistic passengers, typically during the pre-flight and in-flight phases (Dempsey et al., 2021). Individuals with mobility impairments often report boarding and deboarding the aircraft to be the largest barrier to participation in air travel (Davies & Christie, 2017; Poria et al., 2010). Wheelchair users frequently experience physical pain and bodily injury with manual handling during transfers to and from the aisle chair that is required pre-flight and post-flight (Davies & Christie, 2017; Poria et al., 2010). Blind passengers report difficulties with receiving reliable information about changes to flight information because of ambient airport noise (Poria et al., 2010). Due to these concerns and inadequate accommodations provided by airlines, individuals with disabilities are limiting their use of this form of transportation, which in turn limits their participation in important life roles (Van Horn, 2007).

The main concerns of passengers with disabilities during air travel have not changed in the last 25 years. A survey conducted by the Paralysis Society of America in 1996 revealed that more than half the respondents had their mobility aids returned broken or damaged and 49% reported experiencing disability stereotyping by airline personnel (Bristo, 1999). Van Horn (2007) found that passengers with disabilities

continued to encounter barriers at the airport and with airlines during the early 2000s where physical obstacles, service/personnel problems, and long lines were indicated as the primary obstacles (Van Horn, 2007). More recently, a survey found that loss of or damage to wheelchairs, need for additional disability-related training for employees, and increased wait times during the travel process continue to be prevalent concerns of passengers with disabilities (Major & Hubbard, 2019).

These concerns are not unfounded. The total number of disability-related complaints received by domestic and foreign air carriers has more than doubled from 14,006 to 36,930 in the last decade with the total number of complaints increasing each year (United States Department of Transportation, 2019). The majority of complaints are related to an airline's failure to provide assistance, seating accommodation issues, service animal problems, and stowage and handling of assistive devices (United States Department of Transportation, 2019). In 2019, US air carriers reported damaging or losing an average of 29 wheelchairs and scooters each day. The percentage of assistive devices lost or broken is more than 2.5 times the percentage of baggage lost or damaged over the same timeframe (United States Department of Transportation, 2020). The number of disability-related complaints increased 7.5% between 2017 and 2018 while the number of boarded passengers increased only 4.99% over the same calendar year

indicating that the increase in disability-related complaints is not due solely to the increase in individuals utilizing air travel for transportation (United States Department of Transportation, 2019).

Therefore, it is vital to explore whether the increase in disability-related complaints is attributable to regulation, implementation, enforcement, and/or advocacy issues. The purpose of this policy review is to summarize existing Federal statutes related to accessible air travel for Americans with disabilities; analyze enforcement issues under these laws; describe current accessibility and accommodation policies and procedures of major US airlines; and provide recommendations for change at national, state, and local levels.

**Table 1**

*Federal policies governing accessibility in air travel in the United States*

**Federal Policies**

Federal policies governing accessibility in air travel in the United States				
	Section 504	ADA		ACAA
		Title II	Title III	
<b>Airports Operated by Public Entities</b>				
Receive federal financial assistance	X			
Airport Terminals		X		
Surrounding Parking Lots		X		
Ground transportation to/from		X		

Restaurants, shops, conference center			X	
<b>Airports Operated by Private Entities</b>				
Receive federal financial assistance	X			
Airport Terminals			X*	
Restaurants, shops, conference center			X	
<b>All Airlines flying to/from/within the United States</b>				X
*Only for new construction or alterations				

Three major Federal legislative acts govern accessibility in U.S. airports and among airlines: Section 504 of the Rehabilitation Act of 1973 (Section 504), the Air Carriers Access Act of 1986 (ACAA), and the Americans with Disabilities Act of 1990 (ADA). These Federal laws prohibit discrimination based on disability, mandate accessibility through uniform design standards, and set training requirements for airline personnel. However, the governing of accessibility in air travel is complicated as different policies regulate various components of the travel experience as seen in Table 1.

Most airports operated in the United States are subject to regulations defined by Section 504 and the ADA. Section 504 prohibits exclusion, denial of benefits, and discrimination toward qualified individuals with a disability by programs receiving Federal financial assistance ("Section 504 of the Rehabilitation Act of 1973"). In 2021,

airports in 49 states received Federal funding for infrastructure projects through the FAA's Airport Improvement Plan and therefore must comply with Section 504 (Federal Aviation Administration, 2021).

The ADA prohibits discrimination based on disability in various areas of life. Titles II and III of the ADA set forth regulations for programs and services provided by public entities as well as places of public accommodation ("Americans with Disabilities Act of 1990," 1990). Under Title II of the ADA, U.S. airports operated by local, state, or Federal governments cannot deny services to any individual based on disability ("Americans with Disabilities Act of 1990," 1990). All but one commercial airport in the U.S. is owned or operated by local, state, or regional authorities. Components of air travel subject to Title II of the ADA include airport terminals, surrounding parking lots, and ground transportation to and from the airport. Privately operated airports are not subject to Title II of the ADA.

Title III of the ADA prohibits discrimination on the basis of disability in privately-held places of public accommodation ("Americans with Disabilities Act of 1990," 1990). Within airports, both privately and publicly operated, restaurants, shops, lounges, and conference centers are considered places of public accommodation.

Airport terminals are not considered places of public accommodation under this regulation. As set forth by subparts B and C of Title III of the ADA, terminals in privately operated airports are not prohibited from discriminating against individuals on the basis of disability. However, Title III subpart D does require newly constructed or altered places of public accommodation and commercial facilities to comply with ADA accessibility standards ("Americans with Disabilities Act of 1990," 1990). Although privately operated airport terminals are not considered places of public accommodation, they are considered commercial facilities. Therefore, private airport terminals are subject to the new construction and alterations accessibility requirements under subpart D of Title III of the ADA if they are newly constructed or undergo renovation ("Americans with Disabilities Act of 1990," 1990). Although the ADA covers public transportation services, such as city buses and subway stations, and private transportation services, including hotel shuttles and airport buses, air carriers are not covered under the ADA.

All flights operated by U.S. airlines and all flights operated by foreign airlines that begin or end in the U.S. are subject to the ACAA. The ACAA prohibits discriminatory practices by air carriers against individuals with disabilities and outlines minimum service and accessibility requirements to which air carriers must adhere ("Air

Carrier Access Act of 1986," 1986). Rules related to aircraft and airport facility accessibility, seating and service accommodations, stowage and handling of assistive devices, service animals, and personnel training as it relates to passengers with disabilities are outlined in the ACAA.

### **Requirements of the ACAA**

Specifically, regulation 14 CFR part 382 of the ACAA set requirements of air carriers in relation to passengers with disabilities ("Part 382 - Nondiscrimination on the Basis of Disability in Air Travel," 2008). Subpart B addresses nondiscrimination requirements and access to services for individuals with disabilities. Passengers must be allowed to self-identify as an individual with a disability and are not required to provide proof of said disability (14 CFR §382.23) or advanced notice of intention to travel (14 CFR §382.25), except in limited circumstances. The number of individuals with disabilities on a flight cannot be limited (14 CFR §382.17) and air carriers cannot deny transportation to individuals with disabilities unless transporting them would result in a safety concern or violate an FAA safety regulation (14 CFR §382.19). If an individual with a disability is denied service because of a safety concern, the air carrier must provide a written explanation for the refusal within 10 calendar days of the incident (14

CFR §382.19). Airlines may not require a person with a disability to travel with another person except in limited circumstances in which safety is a concern (14 CFR §382.29).

When an individual with a disability, or someone acting on the individual's behalf, requests an accommodation required by Part 382 the airline must provide the disability-related accommodation and cannot charge for such services (14 CFR §382.31).

However, air carriers cannot require individuals with disabilities to accept special accommodations or services.

Subpart C and D of the ACAA outline requirements related to access to information. Passengers with disabilities must be provided prompt access to the same information provided to other passengers (14 CFR §382.53). Such information includes, but is not limited to, gate assignments, flight delays, volunteer solicitation on oversold flights, and emergencies (14 CFR §382.53). Any service the air carrier provides to the public via telephone must also be made available via text telephone (TTY) (14 CFR §382.43). Websites owned or controlled by air carriers selling tickets to the U.S. public must conform to the Web Content Accessibility Guidelines 2.0 Level A and Level AA (14 CFR §382.43). Additionally, the carrier website must inform consumers how to obtain an accessible copy of the ACAA regulations (14 CFR §382.45).



Air carriers must also comply with accessibility standards for newly built aircraft, which vary greatly based on size of the aircraft. Aisle armrests must be movable on at least half of the aisle seats, proportionately equitable in all classes, on new aircrafts with 30 or more seats (14 CFR §382.61). Airlines may not keep anyone out of a specific seat or require anyone to sit in a particular seat on the basis of disability, except to comply with FAA or foreign-government safety requirements (14 CFR §382.87). Service animals must be allowed to accompany a passenger with a disability in the cabin, consistent with FAA safety requirements (14 CFR §382.117). Accessible lavatories are only required for newly built aircrafts with two or more aisles (14 CFR §382.63). Additionally, only aircraft with an accessible lavatory which also have 60 or more seats are required to have an on-board wheelchair (14 CFR §382.65). It is unfortunate to note that, under these requirements, it is acceptable for an aircraft to have an accessible lavatory but no means for an individual with a mobility impairment to access said lavatory. Single-aisle aircrafts are also more frequently being used for longer routes including transatlantic flights to and from the U.S. (Pallini, 2022). There is no requirement that passengers are afforded access to a bathroom on these multi-hour-long flights.

Airlines are required to provide timely assistance boarding, deplaning, and making flight connections including providing proper equipment and trained personnel. Preboarding must be offered to passengers with disabilities who self-identify as requiring additional time to board (14 CFR §382.93). Where level-entry boarding is not available, there must be ramps or mechanical lifts to service most aircrafts at U.S. airports with over 10,000 annual enplanements (14 CFR §382.95). Mobility aids and assistive devices stored in the cabin must conform to the FAA rules on the stowage of carry-on baggage; however, mobility aids and assistive devices may not count against any limit on the number of pieces of carry-on baggage (14 CFR §382.121). Wheelchairs and other assistive devices must be given priority over other items for storage in cabin stowage areas (14 CFR §382.67) and within the cargo compartment (14 CFR §382.125). Airlines must accept battery-powered wheelchairs, including the battery, for stowage in the cargo compartment (14 CFR §382.127). Assistive devices and mobility aids must be promptly returned (14 CFR §382.125) to the passenger with a disability in the same condition in which they were received by the carrier (14 CFR §382.129). The ACAA does not define a timeframe for prompt return.

The ACAA also requires training to be provided to airline and contractor personnel of carriers that operate aircrafts with 19 or more passenger seats and who deal

with the traveling public (14 CFR §382.141). Airline personnel must be trained “to proficiency” on the requirements of the ACAA and other Federal regulations related to passengers with disabilities (14 CFR §382.141). Proper use of accommodation equipment including safe boarding and deboarding assistance procedures, ability to recognize requests for communication accommodations, and how to respond respectfully to passengers with disabilities are required training under the statute. Airlines are responsible for developing their own disability-related training programs but must consult with disability organizations during the creation of training materials (14 CFR §382.141). Well-defined training outcome measures and minimum training hours are not provided.

Another important regulation, outlined by Subpart K, defines complaint and enforcement procedures under the ACAA. Anytime a passenger brings a complaint or concern about discrimination on the basis of disability to the attention of any airline personnel, that personnel must inform the passenger of their right to contact a Complaints Resolution Official (CRO) (14 CFR §382.151). CROs, who are specially trained on ACAA regulations and compliance, must be available in person, by phone, or by TTY service to address disability-related complaints. Airlines are required to have at least one trained CRO available at each airport in which they operate. When a passenger

informs a CRO of an alleged ACAA violation, the CRO must make a determination of agreement or disagreement that a violation occurred (14 CFR §382.153). No matter the determination, the CRO must provide a written response to the passenger within 30 calendar days of the complaint (14 CFR §382.153). The written response must also inform the passenger of the right to pursue Department of Transportation (DOT) enforcement (14 CFR §382.153). Even if airlines are compliant with these procedures, there is no guarantee that the alleged violation will be investigated by the DOT.

### **Implementation of the ACAA by Airlines**

The public-facing websites of the four U.S. air carriers with the highest numbers of disability-related complaints (Delta, American, United, and Southwest) were analyzed to determine strategies for implementation of the ACAA by the airline industry. Three of the four airlines highlighted their dedication to providing a safe and positive experience for all passengers in a statement at the top of the webpage dedicated to accessible travel. Delta stated, “We believe travel is for everyone. It’s our priority to deliver the best services to ensure accessibility for all Delta customers. Before boarding, in the air, at your destination and anywhere in between, our gate agents and attendants will be available to assist.” (Delta Airlines Inc., 2022a). All airlines agreed, in rhetoric,

that they have a responsibility, that is a top priority, to provide individuals with disabilities a safe and accessible flight experience. However, there is little evidence that the policies and procedures of said airlines are designed to achieve this stated belief.

In general, the airlines' accessible travel webpages tend to include minimal information about the responsibilities of airlines in serving individuals with disabilities, especially services provided for individuals who are Deaf or hard of hearing, blind or low vision, or have cognitive and developmental disabilities. For these passengers, the airlines place much of the responsibility on the individual. Southwest and Delta identify the process by which passengers can self-identify a disability and request accommodations at the time of booking. Additionally, Southwest asks that passengers who "require assistance identify themselves and the type of assistance they require upon arrival at the airport, at the gate, onboard the aircraft, and at any connection points" (Southwest Airlines Co., 2022). Several of the airlines imply that self-identification of the passengers' needs at these various points in the journey will allow the airline to better assist the passenger and provide the appropriate accommodations. Yet, the airlines rarely specify what the passenger can expect from the airline in terms of type of assistance or accommodations that will be available, timeframe for receiving assistance, and communication of needs between airline personnel at various stages of travel.

Most of the information provided to the public concerning accessibility and accommodations are related to individuals with mobility impairments, which may be related to the fact that nearly half of all disability-related complaints received by airlines concern passengers who use wheelchairs (United States Department of Transportation, 2019). Some airlines provide detailed recommendations of procedures the passenger should follow to ensure safe and proper stowage of their wheelchairs in the cargo compartment (Delta Airlines Inc., 2022a). Yet, the same specificity is not provided for the procedures taken by the airline to ensure safe handling. Additionally, the accessible travel webpages are riddled with broad and vague statements. American makes the blanket statement, “If you’re traveling with any medical device, a wheelchair or other mobility device we’re here to help – we offer pre-boarding, deplaning and airport assistance” (American Airlines, 2022). Although air carriers likely have detailed internal policies and procedures related to “pre-boarding, deplaning, and airport assistance,” the airline websites do not present these policies to the public. By not elaborating on the type of assistance provided, American can publicize that they value passengers with disabilities while doing the bare minimum to assist passengers. Other broad statements are used to shift the responsibility from the airlines to the passenger in determining the accessibility of a particular flight. Delta reports that “many of our larger

aircraft have an onboard wheelchair-accessible lavatory. This feature depends on the age, size and configuration of the airplane” (Delta Airlines Inc., 2022b). Instead of listing the accessibility features of each aircraft in their fleets, the airlines place the responsibility on the passenger to call the company’s representatives to determine if a wheelchair-accessible lavatory is available on their flight.

The accessible travel pages rarely discuss the rights of the passenger who uses a wheelchair or other assistive device. No airline reports that they are required to provide priority storage to wheelchair and assistive devices, both in cabin and within the cargo compartment. Some airlines discuss the option for personal wheelchairs stowed in the cargo compartment to be returned to the passenger at the gate of their destination (Delta Airlines Inc., 2022b; Southwest Airlines Co., 2022). However, none of the airlines report how quickly they must return wheelchairs to the passenger, although “timely” return of the wheelchair is required by the ACAA. Additionally, the ACAA requires that assistive devices be returned to the passenger in the same condition in which they were received. Both Delta and United identify how to report damage to an assistive device to the airline (United Airlines Inc., 2021). However, neither company identifies procedures the airline will follow for repairing or replacing damaged wheelchairs.

Additionally, no airline reports their responsibility to fully compensate the passenger for

loss or damage, or that the airlines' liability is the original purchase price of the assistive device for domestic flights.

When it comes to the rights of the passenger to file a disability-related complaint, the airlines are troublingly quiet. Three of the four airlines use deceptive language to describe the role and availability of Complaint Resolution Officials (CROs) while American had no mention of CROs on their accessibility website. Delta promotes the role of CROs as being “responsible for ensuring that disabilities policies and procedures are properly implemented” and meeting “the needs and concerns of our passengers with disabilities” (Delta Airlines Inc., 2022a). Delta does not mention that CROs are responsible for ensuring that the airline is in compliance with the ACAA. Additionally, airlines water down the role of CROs by using passive language including “concerns” and “questions” instead of “complaint,” which is the language used by the Office of Aviation Consumer Protection website. No airline clearly indicates the responsibility of airline representatives to inform passengers of the right to contact a CRO when bringing forth a disability-related complaint. In addition, airlines often direct passengers to talk with any airline personnel when an issue arises, which could be interpreted as an attempt to circumvent passengers from talking directly with a CRO. Southwest is the only airline to clearly state that passengers with a disability have the



right to speak with a CRO.

To summarize, airlines appear to do the bare minimum to comply with Federal regulations concerning accessibility and discrimination against passengers with disabilities. In general, airlines are apt to document their rights as an air carrier under the ACAA but rarely identify their responsibilities to or the rights of passengers with disabilities. Air carriers appear to be in compliance with posting the required information, per the ACAA, to their accessible travel webpages. However, information related to the rights of passengers, specifically those frequently violated by airlines, are rarely discussed. Although not required by Federal regulations, Delta and United have created Advisory Boards to improve policies and procedures related to accessible air travel. Yet, it is difficult to determine how the implementation of an Advisory Board has improved the airline's policies and procedures when reviewing the accessible travel website.

### **Enforcement of the ACAA**

Unlike the ADA, the ACAA statute does not permit a private right of action ("Boswell v. Skywest Airlines," 2004; "Segalman v. Southwest Airlines," 2018; "Stokes v. Southwest," 2018). An individual who feels that they have experienced

discrimination by an air carrier on the basis of disability does not have the right to file a lawsuit or take individual legal action to enforce the ACAA regulations. The courts have determined that the U.S. DOT is responsible for investigating potential ACAA violations and has the authority to initiate enforcement actions. Therefore, the only action an individual can take is to file a complaint of alleged ACAA violations with the offending airline and/or the DOT. In 2018, domestic air carriers reported receiving 30,950 disability-related complaints. By contrast, in the same year, the DOT received only 827 disability-related complaints filed directly with the DOT (United States Department of Transportation, 2020). The drastic difference in disability-related complaints reported by air carriers and those received by the DOT is a cause for concern as investigation of these complaints are handled differently.

When a passenger brings a disability-related complaint to the attention of a specific air carrier, airline personnel are trained to immediately resolve the issue. Resolution of the complaint often comes in the form of providing the requested accommodation or offering compensation, via airline vouchers or loyalty points, to assuage the customer. Even if the complaint is resolved to the passenger's liking, the air carrier is required to report all disability-related complaints to the DOT. Individual air carriers are responsible for organizing each disability-related complaint into categories

based on the nature of the complaint and the type of disability. Most complaints in 2018 alleged disability-related discrimination concerning ‘failure to provide assistance,’ ‘seating accommodation,’ and ‘service animal problems.’ Failure to provide assistance for passengers who used a wheelchair accounted for nearly half (47%) of all complaints (United States Department of Transportation, 2019). To ensure accuracy of individual air carrier reporting procedures and policies, the DOT will perform an audit “as it deems necessary” (United States Department of Transportation, 2019).

As required by the ACAA, the data submitted to the DOT by each regulated air carrier with passenger business to, from, and within the U.S. are compiled into the *Annual Reports on Disability-Related Air Travel Complaints*. According to the DOT this report is used in the following manner:

To conduct a comprehensive review of air travel service complaints annually to determine the extent to which regulated entities are complying with the laws that it enforces and to track trends or spot areas of concern that may warrant further action. This review may form the basis for investigations and possible enforcement action and regulatory actions. (Office of Aviation Consumer Protection, 2021)

As this passage indicates, the DOT does not investigate each complaint filed directly with the air carriers it regulates to determine if an ACAA violation has occurred. Instead, the DOT uses the aggregated data to investigate air carriers if annual data reveal a significant increase in total complaints or substantial variation in complaints by category from year to year (United States Department of Transportation, 2019). This process in investigating complaints relies heavily on the accuracy of reporting and categorizing of alleged ACAA violations by individual airlines.

In contrast, the DOT investigates each complaint its office receives directly from a passenger. When a passenger files a disability-related complaint with the DOT, the complaint is first forwarded to the airline. The airline is required to respond to both the passenger and the DOT concerning the alleged violation. An analyst and attorney then review the disability-related complaint and the airline's response to determine if an ACAA violation has occurred. In this process, the individual who files a disability-related complaint with the DOT can only wait, often for a year or more, for the DOT to investigate and potentially hand down an enforcement order, which may or may not include penalties to the airline.

In the last decade, fewer than 30 ACAA enforcement orders have been issued by

the DOT against airlines even though disability-related complaints topped 247,000 during that time. Several of these enforcement orders resulted in a decision of no further action and/or a dismissal of the complaint filed as a result of the airline's intention to implement changes to policies and procedures. Each of the four airlines with the most disability-related complaints in 2018 has committed repeated ACAA violations that resulted in the issuance of an enforcement order.

In February of 2011, Delta Air Lines was assessed a \$2 million penalty for egregious violations in failure to provide assistance to passengers with disabilities during enplaning and deplaning (Knapp, 2011). Additionally, the DOT determined that Delta Air Lines failed to respond appropriately to written allegations of ACAA violations and demonstrated improper coding of disability-related complaints according to type of disability and nature of the complaint (Knapp, 2011).

In November of 2013, Southwest Airlines Co. failed to respond to passengers' disability-related complaints in a manner and timeframe required by the ACAA. Instead of addressing the specific complaints of each passenger, Southwest Airlines Co. merely responded with a blanket statement of the airline's disability-related policy (Podberesky, 2013a).

United Airlines was fined \$2 million in January of 2016 for failure to provide adequate and timely assistance with boarding and deboarding the aircraft and moving within the airport terminal at five major U.S. airports. United Airlines also failed to return assistive devices, including wheelchairs, in a timely manner and in the condition in which United received them on numerous occasions (Workie, 2016).

In November of 2013, US Airways, which has since merged with American Airlines, violated the ACAA by failing to provide assistance moving within the terminal to passengers at their Philadelphia and Charlotte airports. US Airways was assessed a \$1.2 million civil penalty for these repeated ACAA violations (Podberesky, 2013b).

### **Actionable Steps**

Through this review of the air travel experience of persons with disabilities, we have identified issues related to Federal policy, implementation, enforcement, and advocacy efforts. Although there are several larger issues, provided below are easy-to-implement recommendations that these authors believe can quickly reduce service gaps and improve the air travel experience for individuals with disabilities.

### ***Recommendations for Policy***

The current ACAA policy does not adequately address training of airline

personnel. The ACAA designates that certain airline and contracted personnel must receive training on a variety of topics related to individuals with disabilities, depending on their job duties. Training may cover topics such as understanding Federal regulations, proper use of equipment used to accommodate individuals with disabilities, and respect for and awareness of various types of disabilities. However, it is up to the individual airline's discretion regarding the breadth and depth of disability-related training as long as the airline trains to proficiency. This has created a lack of consistency in training among airline personnel who deal with the traveling public and across airlines.

Universal requirements should be issued by the DOT to improve compliance with disability-related training. Requirements should include a set of explicit disability-related competencies that personnel must demonstrate, set a minimum number of training hours personnel must complete, and require hands-on training. Universal competencies should also define performance actions personnel must reach to demonstrate proficiency. Competencies should continue to be individualized based on job duties. However, all airline personnel should receive training to better understand a variety of disabilities and public facing personnel must be required to demonstrate appropriate interactions with individuals with many types of disabilities.

*Recommendations for Enforcement*

In contrast to other Federal legislation that guarantees rights to individuals with disabilities (Section 504 and the ADA), the ACAA does not expressly grant individuals a private right of action. Additionally, several courts have determined that the ACAA does not provide an implied private right of action. Therefore, individual citizens have no power to enforce the ACAA. Section 504 and the ADA, which offer protections at airports that receive Federal funding or are operated by public entities, include a private right of action. Yet, there is no private right of action to enforce Federal legislation protecting individuals with disabilities on airplanes. Without a private right of action, enforcement of the ACAA is not as strong as intended. These authors agree with the various organizations who support amending the ACAA to expressly provide a private right of action. Although amendments to the ACAA have been introduced on several occasions, the bills have not been passed. Representatives tend to respond more to personal stories from the constituents in their districts and states than they do to aggregate empirical data. Therefore, it is recommended that individuals with disabilities show support for an ACAA private right of action amendment by contacting their legislators and sharing their personal stories.



### *Recommendations for Implementation*

Implementation of the ACAA falls to the individual airlines. As has been shown in this review, the policies and procedures of individual airlines lack specificity and demonstrate little consistency across airlines. These aspects are likely contributing to the central concerns of individuals with disabilities during air travel, namely, damage to wheelchairs and lack of disability-related training of airline personnel. Two recommendations for airlines to improve ACAA policies and procedures are implementation of a streamlined wheelchair handling form and bringing more people with disabilities to the table as consultants. A standard wheelchair handling form should be used by all airlines to reduce differences in language and included information. A diagram of the wheelchair should be included on which the passenger indicates correct lifting points and how the wheelchair is to be safely tied down. The standard handling form should also include universal phrases that the passenger can select to describe how to operate, disassemble, and reassemble the wheelchair. Airlines must also increase not only employment of people with disabilities but also placement of people with disabilities in decision making positions. Doing so will give a stronger voice to the disability community when decisions are made concerning accessibility and accommodations.

### *Recommendations for Advocacy*

In 2018, the DOT received 827 disability-related complaints while airlines received 36,930 disability-related complaints (United States Department of Transportation, 2019, 2020). This indicates that for every 1 complaint the DOT received related to disability, airlines receive nearly 45 complaints. This stark difference in complaint rates is likely due to passengers' being unaware of their right to file a complaint with the DOT. In part, this lack of complaints filed directly with the DOT may be related to lack of knowledge about the investigative processes of complaints based on how they are filed. As previously mentioned, each disability-related complaint filed directly with the DOT is investigated. The DOT will only investigate complaints received by the airlines if the aggregate data indicate a significant increase in overall disability-related complaints toward a specific airline or a spike in a specific category of disability-related complaints. Therefore, it is recommended that education of passengers about their rights and the process of investigation be increased.

Currently, the DOT educates passengers about their rights through the Aviation Consumer Protection website. However, this information may not be getting to the

individuals impacted most. There is a current bill that will require airlines to post a passengers' bill of rights to their website and to provide this document to all passengers who request disability-related assistance. It is recommended that the DOT create explicit rules concerning where the bill of rights must be posted, including prominent display on the main accessibility website of airlines. This requirement would improve visibility of passengers' rights while preventing airlines from burying the posting several layers into the website.

Additionally, it is recommended that the DOT create a plain language explanation of the purpose of the Aviation Consumer Protection website that includes how to file a complaint and the process of complaint review. To improve education of passengers about their rights, how to file a complaint, and the process of enforcement, the DOT should require airports to display this information on video boards, provide audio announcements, and include this excerpt on the passenger's bill of rights.

Advocacy should occur on two levels: self-advocacy from persons with disabilities and advocacy from service providers. Self-advocacy must include improved reporting of ACAA violations to the DOT by passengers with disabilities. For the DOT to properly enforce the ACAA, they must be made aware of the true frequency in which

violations occur. This starts with increased consistency in reporting violations to both the airline and directly to the DOT. We recommend that passengers with disabilities take the following steps when encountering an alleged ACAA violation:

1. Document the alleged violation. Take pictures and videos of your wheelchair before and after stowage. Take detailed notes of circumstances and events.
2. Ask to speak directly with a CRO. Ensure that the CRO has been trained in compliance of the ACAA. Always keep a copy of the ACAA with you during travel to point to specific regulations.
3. File a complaint with the airline through their website, creating a paper trail. File as soon as possible, preferably within 24 hours of landing from a domestic flight. Keep a copy of all correspondence with the airline including receipt of filing the complaint, emails, and letters.
4. File a complaint directly with the DOT for every alleged violation. No alleged ACAA violation is too small to report.

Service providers, including but not limited to healthcare professionals, vocational rehabilitation professionals, and assistive technology and seating and

mobility specialists, should also improve advocacy for their clients. Service providers have a responsibility to provide current data and accessible information to their clients with disabilities who have participated in air travel in the past or indicate a desire to travel. The DOT has developed a variety of accessible disability-related training materials intended for the traveling public. We recommend that service providers distribute these materials along with the Passengers' Bill of Rights, when it is approved, to ensure that individuals are receiving complete information. Service providers should ensure that clients not only receive, but also understand, the information.

## References

Air Carrier Access Act of 1986, 100 Stat. 1080 (1986).

American Airlines. (2022). *Mobility and medical devices*. Retrieved 3/29/2022 from

<https://www.aa.com/i18n/travel-info/special-assistance/mobility-and-medical-devices.jsp>

Americans with Disabilities Act of 1990, Pub. L. No. 101-336, § 2-3, 104 Stat. 328

(1990).

Boswell v. Skywest Airlines, Inc., 361 F.3d 1263 (10th Cir. 2004).

Bristo, M. (1999). *Enforcing the civil right of air travelers with disabilities:*

*Recommendations for the department of transportation and congress.*

Davies, A., & Christie, N. (2017). An exploratory study of the experiences of

wheelchair users as aircraft passengers—implications for policy and practice.

*IATSS research*, 41(2), 89-93.

Delta Airlines Inc. (2022a). *Accessible Travel Services*. Retrieved 3/28/2022 from

<https://www.delta.com/us/en/accessible-travel-services/overview>

Delta Airlines Inc. (2022b). *Wheelchair Information*. Retrieved 3/29/2022 from

<https://www.delta.com/us/en/accessible-travel-services/wheelchair-services>

- Dempsey, R., Healy, O., Lundy, E., Banks, J., & Lawler, M. (2021). Air travel experiences of autistic children/young people. *Annals of Tourism Research Empirical Insights*, 2(2), 100026.
- Federal Aviation Administration. (2021). *FAA Airport Improvement Program Grant Detail Report*.  
[https://www.faa.gov/airports/aip/grantapportion\\_data/media/FY21-AIP-Grants-Only-Announced-Cumulative.pdf](https://www.faa.gov/airports/aip/grantapportion_data/media/FY21-AIP-Grants-Only-Announced-Cumulative.pdf)
- Knapp, R. A. (2011). *Delta Air Lines, Inc.; Violations of 14 CFR Part 382 and 49 U.S.C. §§ 41310, 41702, 41705 and 41712* (2011-2-10, Issue.
- Major, W. L., & Hubbard, S. M. (2019). An examination of disability-related complaints in the United States commercial aviation sector. *Journal of Air Transport Management*, 78, 43-53.
- Miranda, G. (2021). Disability rights activist says United Airlines damaged her \$30,000 wheelchair. *USA Today*.
- Office of Aviation Consumer Protection. (2021, February 18, 2021). *Air Travel Complaints*. Retrieved February 2, 2022 from  
<https://www.transportation.gov/airconsumer/complaint-process#:~:text=DOT%20requires%20airlines%20to%20acknowledge%20consu>

[mer%20complaints%20within,respond%20to%20consumer%20who%20file%20complaints%20with%20them.](#)

Páez, A., & Farber, S. (2012). Participation and desire: leisure activities among Canadian adults with disabilities. *Transportation*, 39(6), 1055-1078.

Pallini, T. (2022, January 8, 2022). Small aircraft are flying longer routes, including across the Atlantic. See inside the \$130 million Airbus A321neo pioneering the trend. *Business Insider*. <https://www.businessinsider.com.au/see-inside-airbus-a321neo-pioneering-long-haul-single-aisle-trend-2022-1>

Part 382 - Nondiscrimination on the Basis of Disability in Air Travel, 14 C.F.R. § 382.17 - 382.153 (2008).

Podberesky, S. (2013a). *Southwest Airlines Co.; Violations of 14 CFR 259.7(c), 14 CFR 382.155, and 49 U.S.C. §§ 41702, 41705, and 41712.*

Podberesky, S. (2013b). *US Airways, Inc.; Violations of 14 CFR Part 382 and 49 U.S.C. §§ 41310, 41702, 41705 and 41712.*

Poria, Y., Reichel, A., & Brandt, Y. (2010). The flight experiences of people with disabilities: an exploratory study. *Journal of Travel Research*, 49(2), 216-227.

Reyes, E. A. (2022). An airline broke an activist's wheelchair. Her death months later amplified call for change. *Los Angeles Times*.



Salas, E. B. (2021, July 21, 2021). *U.S. air passengers' main trip purposes in 2017, by type*. Statista. Retrieved from <https://www.statista.com/statistics/539518/us-air-passengers-main-trip-purposes-by-type/>

Section 504 of the Rehabilitation Act of 1973, Pub. L. No. 93-112, 87 Stat. 394.

Segalman v. Southwest Airlines Co., No. 17-15196 (9th Cir. 2018).

Southwest Airlines Co. (2022). *Customers with Disabilities*. Retrieved 3/29/2022 from <https://www.southwest.com/html/customer-service/unique-travel-needs/customers-with-disabilities-pol.html>

Stokes v. Southwest Airlines, No. 17-10760 (5th Cir. 2018).

United Airlines Inc. (2021). *Customer wheelchair equipment*. Retrieved 3/28/2022 from <https://www.united.com/ual/en/us/fly/travel/special-needs/disabilities/customer-wheelchair.html>

United States Department of Transportation. (2019). *Annual report on disability-related air travel complaints received during calendar year 2018*. Retrieved from <https://www.transportation.gov/sites/dot.gov/files/2020-03/Summary%20Report%20of%20CY2018%20Disability%20Complaints.pdf>

United States Department of Transportation. (2020). *Air Travel Consumer Report*.

<https://www.transportation.gov/individuals/aviation-consumer-protection/february-2020-air-travel-consumer-report>

Urry, J. (2002). Mobility and proximity. *Sociology*, 36(2), 255-274.

Van Horn, L. (2007). Disability travel in the United States: recent research and findings.

11th International Conference on Mobility and Transport for Elderly and Disabled Persons (TRANSED)–‘Benchmarking, Evaluation and Vision for the Future’, at the Palais des congrès de Montréal,

Workie, B. A. (2016). *United Airlines, Inc.; Violations of 14 CFR Parts 259 and 382 and 49 U.S.C. §§ 41310, 41702, 41705, and 41712*.



**The Current State of Air Travel for Americans with Disabilities: Considerations for Policy, Enforcement, Implementation, and Advocacy** by Pfeiffer, Bower and Phillip Rumrill

<https://rdsjournal.org/index.php/journal/article/view/1166> is licensed under a [Creative Commons Attribution 4.0 International License](https://creativecommons.org/licenses/by/4.0/). Based on a work at <https://rdsjournal.org>.

## Karawhiua: Mobilizing own Māori Language Journey

Sandra Tuhakaraina,

Te Maioha Early Childhood New Zealand Aotearoa

### Author Note

Sandra Tuhakaraina is a Senior Lecturer at Te Maioha Early Childhood New Zealand Aotearoa. She is a course leader and teaches in the program for the Bachelor of Education. Her early childhood experience was in the movement, Te Kohanga Reo.

### **Abstract**

Mobilizing the Māori language in Aotearoa is critical if the language is to thrive. An Indigenous ethnography approach is used to tell my personal and professional bicultural and bilingual experiences in teaching and learning. These lived Māori world views and experiences also illustrate how technology is transforming language opportunities.

*Keywords:* indigenous language; revitalization; communities

### **Karawhiua: Mobilizing own Māori Language Journey**

Māori is the only Indigenous language to Aotearoa New Zealand. Like most Indigenous languages, the Māori language is a minority language in its own country (Hanemann, 2020). Even more alarming is the claim from Benton (2015) that “Māori is in grave danger of being eclipsed as the country’s second language.” Historically, the Māori language was a flourishing language and was spoken in various dialects throughout Aotearoa New Zealand. The effects of colonisation, assimilation, and urbanisation has actively deterred mobilizing the Māori language as a right for Māori and all Aotearoa New Zealand citizens.

Furthermore, Benton’s 1970s research findings on Māori communities showed the Māori language was in rapid decline and in danger of disappearing as more Māori parents were accepting English as the preferred language of communication (Benton, 1997). Māori language revitalization was critical to prevent the language from dying. In response, Māori leaders and communities asserted rangatiratanga (authority) to strive for change. They petitioned the Government and dreamed and designed strategies of

innovation to nurture Māori language revitalization. Tuhakaraina and Dayman (2020, p. 92) describe some key drivers of innovation in Aotearoa: (1) Nga Tamatoa in 1970s challenged tertiary institutions to honour Te Tiriti o Waitangi; (2) Te Ataarangi model, using cuisenaire rods was developed for language learning method with adults and whanau; and (3) Te Kohanga Reo, Māori language nest, were set up in 1982 to revitalise te reo me ōna tikanga Māori and to empower whānau development and management (2020, p. 92).

These innovations were a response by Māori for Māori to address historical failures of government. To reclaim mobilization of the Indigenous language in domains of influence, education and media, Indigenous Māori asserted their political sovereignty to regain Indigenous rights to language, culture, identity in education.

The Māori language was rightfully recognized as an official language in 1987, a taonga (treasure), which was guaranteed protection under Te Tiriti o Waitangi / Treaty of Waitangi according to Kegan et al. (2011). The role of new technologies in promoting Māori language were critical in mobilizing language learners in the technology spaces. In the twenty-first century, digital technology is helping the revitalisation of te reo Māori. For example, Kupu is an app that translates objects into te

reo Māori (Buchanan, 2019; Johnsen, 2020). Furthermore, increasing numbers of Māori people are using the Internet, listening to relatives, and attending hui instead of the classroom setting (O'Connor, 2021). There is some evidence that the Internet supports the acquisition of language and cultural knowledge. For example, Crystal and Swapna (2020) found that students improve language skills and cultural knowledge as a result of virtual interactions with native speakers. Technology is enhancing how learners are able to access language learning 'a tōna wā', meaning when the time is right for them, as Rocca (2018, p. 2) states, "anytime, anywhere."

### **Indigenous ethnography**

According to Ellis (2004), indigenous ethnographies share a history of colonialism. Indigenous ethnography is the approach I use to permit my voice as an Indigenous person to be the character of my personal and professional experiences in teaching and learning te reo me ōna tikanga Māori (Māori language and Māori customs). These lived Māori world views and experiences also share how technology is transforming new opportunities to my role as pouako in tertiary education and my involvement in a government and community professional development called Te Ahu o te reo Māori (The future pathway of the Māori language).

### **Indigenous knowledge and language in Te Kohanga Reo**

The establishment of Te Kohanga Reo in 1982, was to “arrest the decline of Māori speaking people” (Kā’ai, 2004, p. 205). Māori whānau and communities throughout Aotearoa New Zealand responded quickly to set up Māori language nests in support of revitalization of the Māori language. This movement has been a positive model of self-determination by Māori for Māori to strengthen Māori language, whānau involvement, accountability and wellbeing. More than 60,000 individuals have graduated from kohanga reo and have contributed to the revival of the language (Calman, n.d.). The movement marked 40 years on 12 April 2022.

Te Kohanga Reo is where my journey into a Māori worldview began. I was a young mother in my early twenties, on the mat with my two-year old daughter and the rest of the whānau, listening to the language and knowledge of my ancestors. Krashen’s “affective filter hypothesis” (Lightbown & Spada, 2006, p. 37) is drawn on to explain my early memories of anxiety and moments of immobilization to acquire Māori language skills. However, we were socialised in to the kohanga reo learning environment surrounded by other parents, children, aunties, uncles and grandparents that helped to mitigate my barriers and allowed my language learning to take place.



Mobilizing te reo Māori was transmitted and influenced by kaumātua (elders) as the wisdom shared by native speakers. Kaumātua were critical in teaching and supporting the development of future generations of people, like myself, who had either limited or no knowledge of te reo Māori and cultural ways of doing things. Kaumātua conversed in the native language consistently to each other but would transition between Māori and English to support us, the second language learners. Cultural values, aroha and manaakitanga, were illustrated naturally by kaumātua as they supported “nurturing relationships” (Mead, 2016, p. 33) to create a safe, caring, and positive place for knowledge and language learning to occur.

Whanaungatanga, another cultural value was experienced daily, is where all whānau took responsibility for each other. As a parent and learner, I was not just responsible for my child but all children as is traditional practice of whānau. The notion of whanaungatanga, according to Mead (2016, p. 32), claims that “whanaungatanga embraces whakapapa and focuses on relationships.” To promote whanaungatanga amongst the whānau, mihimihi, an introduction of ko wai au, who I am and my sense of whakapapa and belonging that connects me to people, place and things, was a valued learning custom. This daily ritual occurred every morning and involved oneness as the whole whānau gathered together on the whāriki (mat), inclusive of children, adults and

kaumātua to take turns saying our whakapapa relationships. The listening and observing of each person saying mihimihi empowered me, and giving it a go ‘a tōku wā’ (in my time) was reassuring. Learning about my whakapapa meant learning about my grandparents’ names and where they were from. There were many conversations with my parents that helped me discover names and stories associated to my ancestors. My mother’s whakapapa connects me as tangata whenua, people of the land of Aotearoa. My ancestors arrived on the waka, Tākitimu and Kurahaupō. Tākitimu waka travelled and landed in various places throughout the length of Aotearoa. In the lower South Island, there are mountains named after the ancient waka Tākitimu. The waka Kurahaupō connects me to one of the iwi in Te Taihū, the top of the South Island.

On my father’s side, my ancestors arrived in Aotearoa on ships, not waka. My father explained that “his maternal grandmother was born on the ship called Arawa when sailing to New Zealand from England in the 1800s. Her given name, Arawa Husband Cullen. Arawa was the name of the ship; Husband, the name of the Doctor who delivered her; and Cullen her family name. The name Arawa carries on in my whānau whakapapa.

The learning of mihimihi strengthened my sense of identity. Learning about my

native culture makes me feel connected to my ancestors and ancestral landscape in the Hawkes Bay region, and it also bolsters my feeling of belonging to the area where I currently live. The concept *tūrangawaewae* is described as where my feet are located to place and people (Mead, 2016).

Karanga is a call of welcome, a customary practice of welcome onto the marae. Karanga is the role of *kuia* (elders) and women. It is the first voice to hear when being called onto the marae. I liken karanga as a medium of communication between the *kaikaranga* (callers) as they transmit information both physically and spiritually for the living and non-living.

Our day at *kohanga* would start with a karanga by our *kuia* (elder) to the *whānau*. This ritual would start outside, and by the time the three karanga were finished, we would arrive inside ready for the next ritual, *karakia*. Our *kuia*, aunty Rangiruhia Lucy Elkington, would begin by calling ‘*nau mai, haere mai e te whānau*’ (welcome, welcome family), and in response we called ‘*karanga mai, karanga mai, karanga mai*’ (call us, call us, call us). As learners of the art karanga, we would call in small groups, then move to taking individual turns at calling. We learned that the first karanga was to be about a call of welcome to the visitors or people of the marae. The second karanga

was about the physical and spiritual connection between the living and non-living. The third karanga was about the purpose of the visit and to the wharenuī (meeting house). Our kuia were visionary and empowering as they prepared us wahine (females) for the role of kaikaranga on the marae.

Another significance daily practice was the learning of a wide range of waiata (songs). According to Hemara, waiata are “important educative tools” (2000, p. 23) that tell the history, stories and events of whānau, hapū and iwi. We sang waiata called moteatea that were long verses of history and waiata to support welcoming people into the kohanga or the marae. The adults would relax on the whāriki and around the tamariki as they slept to sing these kinds of waiata. Contemporary waiata for tamariki included cultural tools, such as poi, tī rākau, haka, and actions songs with different rhythms and beats. Learning the Māori language through waiata helped my early pronunciation and confidence in a socialised setting.

Karakia are prayers that happened daily. Kaumātua would lead the karakia, and whānau mimicked the language patterns. Karakia kai (meal time prayers) were observed across meals demonstrating a respect for the food and where the food came from, Papatūānuku (mother earth). A cultural value that embraces the gifting of food is

manaakitanga, hospitality of care to each other is paramount in te ao Māori. Other engagements of karakia happened when planting and gardening in Papatūānuku. Whānau going on trips into the ngahere (bush) or to the moana (sea). Karakia was observed when taking gifts from these domains. My experiences into these practices developed my cultural competence when transitioning into domains outside and inside the kohanga. From a linguistic perspective, karakia gave me language strategies to use in other contexts.

My time in Te Kohanga Reo was a treasured moment as I was indulged in my ancestors' knowledge and language from kaumātua of our community. These rich experiences continue to guide my teaching practice today. I went on to become a kaitiaki and kaiako (Custodian and teacher) delivering the philosophy of the kohanga and the cultural knowledge and practices passed on to us from kaumātua. The enormous role and responsibility to stay committed to the philosophy made us undertake early childhood training and kohanga reo training. Cassette tapes were popular tools in my early days of kohanga to help with my pronunciation of kupu and waiata away from kohanga. Compact discs emerged and then phone devices making learning of words and songs more readily available.

I stayed in the movement for twenty-five years, full of joyful opportunities and memories alongside many whānau, including my own four children and my eldest mokopuna. The philosophy created a safe place for whānau Māori to succeed and thrive in te ao Māori, Māori world view of values and beliefs. My work in Te Kohanga Reo is one of support as I took up a new teaching position in initial teacher education.

### **Indigenous knowledge and language in tertiary education**

I moved from Te Kohanga Reo to my current tertiary position at Te Rito Maioha Early Childhood New Zealand (ECNZ) in 2007. ECNZ has more than 55 years of experience in teacher education, advocacy, and promotion of world-leading early childhood education. The tertiary provider specializes in teacher education, offering a range of diplomas, degrees, and postgraduate programs. All programs are taught primarily online. ECNZ programs reflect a commitment to bicultural practices that demonstrate Mātauranga Māori (Māori knowledge), Māori culture and Māori language.

To promote Māori language learning, ECNZ designed He Pātaka Reo, a te reo Māori course. He Pātaka Reo has been designed with multimedia cultural materials, including videos, audio clips, quizzes, vocabulary lists, and templates. Students are required to engage in the language topics and then take their learning back into their

early childhood settings to engage and encourage the use the Māori language. There are 18 language topics that students engage in, and they complete tasks and submit for feedback from lecturers.

He Pātaka Reo is a requirement by the New Zealand Teaching Council as a means of monitoring the progression of all students' competency and confidence using te reo Māori across all initial teacher education programs. He Pātaka Reo is making language learning more accessible in the 21st century. The course demonstrates a positive reaction in exemplifying the Crown action, whakaako, where ECNZ is playing a "role in providing access to te reo Māori learning for adults which helps to build teacher capability in te reo Māori" (Te Kawanatanga o Aotearoa, 2019, p. 29).

Moreover, in relation to Te Tiriti o Waitangi partnership, educators are encouraged to use and promote te reo Māori me ngā tikanga Māori (Education Council, 2017).

Research shows that mobilizing learning language "anywhere, anytime" (Rocca, 2018, p. 2) enables learners to create their own learning environments. In my personal learning, I have found this slogan (anywhere, anytime) to be true. I learn effectively not only in the classroom but also outside of the classroom setting. Leading weekly Zoom hui to promote te reo Māori language enables learners to connect from their devices

whether they are at home or away from home and in the car, train, or bus. Therefore, technology is “providing opportunities for more exposure and more practice, with learners feeling more in control and enjoying themselves in the process.” (Rocca, 2018, p. 1).

Learning te reo Māori online has become a popular way of accessing learning of te reo Māori with apps such as Kupu o te Rā whereby a word a day is sent to one’s email address. I find learning a new word a day is adding onto my vocabulary. Included in a word a day are sentences that challenge and support a higher level of learning. Additionally, Te aka Māori dictionary (Moorefield, n.d.) is an online dictionary and available as a hard text (McDonald & Moorfield, 2006). The website is one of my main dictionaries when I am unsure if the kupu has a macron or am searching for a kupu. There are audio files to support how to pronounce words correctly.

Additionally, a new app called Panga is a Māori version of Wordle. Panga is described as “a very simple, brainteaser-style word game,” and since the launch of Panga, meaning riddle or puzzle, the game has been popular. Players have six attempts to guess the word. Challenges like Panga keeps my language learning interesting, and sometimes challenging (Donovan, 2022).



There is even a newly developed phone app called Kōrerorero which teaches beginner te reo Māori speakers how to use language in everyday situations such as getting up in the morning or making breakfast. The purpose of the application is to facilitate learning anywhere, anytime (Rocca, 2018). Hemi Kelly states that Kōrerorero helps to “breakdown that barrier of time” (cited in Johnsen, 2020) to travel to a classroom domain for learning. Mobilizing language learning of te reo Māori from devices, such as computers, handheld devices, etc, and learning language a tōna wā, in one’s preferred time, allows the language to develop and for language teaching to occur (Rocca, 2018).

ECNZ programs are primarily taught online. When Covid began to disrupt our daily lives, we were positioned well to carry on teaching and learning from the classroom platform. Our noho marae stay had to be adapted to a virtual noho marae. The virtual program enabled students and staff to come together online to demonstrate te reo Māori, discuss cultural customs, and hear from tangata whenua speakers to share knowledge about their iwi and cultural customs, education strategy and economical practices.

Te Rito Maioha Early Childhood prides commitment towards bicultural

practices in the teaching programs and in the organization ethos. One example of active engagement to promote bicultural and bilingual practices in the organization involves monthly wero. Wero are challenges, and the current wero is for te reo Māori to thrive as a living language across the eleven regional education centers and our national office. Wero are organized by each regional educational center to promote and engage staff in learning te reo me ōna tikanga Māori. Wero activities have been varied from learning karakia, whakataukī (proverbs), mihi and waiata (singing). Some wero have involved researching places of significance to tangata whenuatanga, places in our communities, as a way of getting to know about our tūrangawaewae or where our feet are planted. These learnings about our communities were shared in text and video to connect our Takiwā ako – Regional education centers. Another opportunity is for early childhood teaching teams and ECNZ staff to enroll in He Pātaka Reo course for professional learning and to develop and increase their confidence to use te reo Māori.

### **Te Ahu o Te Reo Māori – The future pathway of te reo Māori**

Teacher mobilization of the Māori language and customs finds my participation in an exciting initiative within Te Tauihu o te Waka – The Top of The South Island called Te Ahu o Te Reo Māori. The program is relevantly new to Te Tauihu region. The

delivery is a blend of face-to-face learning and online learning via video conferencing and a noho marae stay over. Teaching in a program whose curriculum is bound to Te Taihū iwi (Māori people) cultural narratives and language is breath-taking. These are significant changes for Te Taihū iwi to be the leading parties in ensuring local-level language revitalization in this program. The program is offered to all Te Taihū education principals, teachers, teacher aids and administrators.

Te Ahu o Te Reo Māori is a program funded by Te Tāhuhu o Te Mātauranga (Ministry of Education) to develop teacher competency in te reo Māori (specifically pronunciation and use of te reo Māori), tikanga Māori and improved understanding of local stories.

The report Evaluation of Te Ahu o Te Reo Māori findings showed that the program is more than a te reo Māori program. It is also an opportunity for teachers to engage and understand a different worldview, to engage in cultural practices, narratives and histories relevant to Aotearoa and to the system that supports the education of all students. The program has enabled teachers with different skills and knowledge, from different schools, and from different sectors to come together in a safe place to learn. The program has challenged, overwhelmed, invigorated, and inspired. Participants

agreed that Te Ahu o Te Reo Māori has added real value to them and the tamariki they teach, and to see the training come to an end would be a lost opportunity to build on the momentum Te Ahu o Te Reo Māori has created (Smith et al., 2020).

### Conclusion

In conclusion, my humble beginnings to participate in Te Kohanga Reo has led me on a personal and professional journey of success in te ao Māori, proficient levels in speaking, listening, reading and writing of the Māori language and to be competent to provide high-quality Māori language education and professional development to current and future teachers in Tauihu and across Aotearoa. The challenge is to make sure local-level language revitalization in Te Tauihu communities have access to Māori language technology and to ensure that indigenous people are driving the Māori language revitalization movement.

## References

- Benton, A. R. (1997). *The Māori language: dying or reviving? A working paper prepared for the East-West center alumni-in-residence working paper series.*
- NZCER.
- Buchanan, F. (2019). *In light of Māori language week, here's three apps helping revive te reo Māori.* <https://idealog.co.nz/tech/2019/09/apps-helping-revive-te-reo-maori>
- Benton, R. A. (2015). Perfecting the partnership: Revitalising the Māori language in New Zealand education and society 1987–2014. *Language, Culture and Curriculum*, 28(2), 99-112. <https://doi.org/10.1080/07908318.2015.1025001>
- Calman, R. (n.d.). 'Māori education – mātauranga - Kaupapa Māori education', Te Ara - the Encyclopedia of New Zealand. <http://www.TeAra.govt.nz/en/maori-education-matauranga/page-5>
- Crystal., M. & Swapna, K. (July 2020). Authentic language learning through telecollaboration in online courses. *TechTrends*, 64(4), 628-635.
- <https://doi.org/10.1007/s11528-020-00488-2>
- Donovan, E. (2022). *Panga: Te reo Māori Wordle.* <https://www.rnz.co.nz/news/te->

[manu-korihi/459308/panga-te-reo-maori-wordle](https://doi.org/10.1007/s11159-020-09846-x)

Ellis, C. (1950). *The ethnographic I: A methodological novel about autoethnography*.

Oxford.

Hanemann, U. (2020). *A world of Indigenous languages: Politics, pedagogies and*

*prospects for language reclamation*: Eds. McCarty, T. L., Nicholas, S. E.,

Wigglesworth, G. *Multilingual Matters*, Bristol, 2019, 264 pp. Linguistic

Diversity and Language Rights series, vol. 17. *International Review of*

*Education: Journal of Lifelong Learning*, 66(4), 603–607.

<https://doi.org/10.1007/s11159-020-09846-x>

Hemara, W. (2000). *Māori pedagogies: A view of literature*. NZCER.

Internet driving te reo Māori up. [Podcast]. Radio New Zealand.

[https://www.rnz.co.nz/news/te-manu-korihi/451464/te-reo-maori-growth-](https://www.rnz.co.nz/news/te-manu-korihi/451464/te-reo-maori-growth-boosted-by-apps-social-media)

[boosted-by-apps-social-media](https://www.rnz.co.nz/news/te-manu-korihi/451464/te-reo-maori-growth-boosted-by-apps-social-media)

Johnsen, M. (2020). *Te reo Māori digital technology helps language to thrive*. Radio

New Zealand. [https://www.rnz.co.nz/news/te-manu-korihi/451464/te-reo-maori-](https://www.rnz.co.nz/news/te-manu-korihi/451464/te-reo-maori-growth-boosted-by-apps-social-media)

[growth-boosted-by-apps-social-media](https://www.rnz.co.nz/news/te-manu-korihi/451464/te-reo-maori-growth-boosted-by-apps-social-media)

Keegan, P., Keegan, T. T., & Laws, M. (2011). Online Māori resources and Māori

initiatives for teaching and learning: Current activities, successes, and future directions. *MAI Review*, 1, 1-13.

Ka'ai, T. M. (2004). Te mana o te tangata whenua: Indigenous assertions of sovereignty. In T. Ka'ai., J. Moorfield., M. Reilly., & S. Mosley (Eds.), *Ki te whaiao: An introduction to Māori culture and society*. Pearson Education.

Lightbown, P., & Spada, N. (2006). *How languages are learned*. (3rd.). Oxford.

Mead, H. M. (2016). *Tikanga Māori: Living by Māori values* (2nd.). Huia.

McDonald, J., & Moorfield, J. C. (2006). Te Whanake Online: An interactive resource for Māori language learning. He Puna Korero: *Journal of Māori & Pacific Development*, 7(2), 62–67.

Moorefield, J. C. (n.d.). *Te aka Māori dictionary*. Te Muramāra Foundation.

<https://maoridictionary.co.nz/search?idiom=&phrase=&proverb=&loan=&keywords=Te+Aka>

McDougall, W. (2022). Panga: Te reo Māori wordle. Radio New Zealand.

<https://www.rnz.co.nz/news/te-manu-korihi/459308/panga-te-reo-maori-wordle>

O'Connor, M. (2001). Te reo Māori growth boosted by apps, social media. Radio New

Zealand. <https://www.rnz.co.nz/news/te-manu-korihi/451464/te-reo-maori-growth-boosted-by-apps-social-media>

*Our code our standards: Code of professional responsibilities and standards for the teaching profession* (n.d.). <https://teachingcouncil.nz/professional-practice/our-code-our-standards/>

Rocca, S. (2018). Introducing the special issue: Mobilizing language learning in the 21st century. *Languages*. 3(1):2. <https://doi.org/10.3390/languages3010002>

Smith, R., Bennett, C. H., Edwards, S., Paipa, K., & Kelly, M. (2020). Evaluation of Te Ahu ministry o Te Reo Māori. *Education Counts*.

Te Kawanatanga o Aotearoa: Te Puni Kōkiri. (2019). *Maihi karauna: the Crown's strategy for Māori language revitalisation, 2018-2023*.

Tuhakaraina, S., & Dayman, T. (2020). Whiria te tangata, whiria te reo Māori: Weaving people, weaving the Māori language. In A. Card. & J. Carroll-Lind (Eds.). *Tōku anō ao Māori: My very own world*. (pp. 124-130). Occasional paper series: Number 3. Te Rito Maioha Early Childhood New Zealand.



*Te Whāriki – Education in New Zealand* (n.d.). <https://www.education.govt.nz/early-childhood/teaching-and-learning/te-whariki/>



**Karawhiua: Mobilizing own Māori Language Journey** by Tuhakaraina <https://rdsjournal.org/index.php/journal/article/view/1168> is licensed under a [Creative Commons Attribution 4.0 International License](https://creativecommons.org/licenses/by/4.0/). Based on a work at <https://rdsjournal.org>.

## How to Restart an Inclusive Camping While Preventing COVID-19

### Outbreak:

### Interdisciplinary Study on the Utilization of ICT Support System to Create Inclusive Outdoor Education to Enhance QOL for Persons with Disabilities

Yasuko Takeuchi<sup>1</sup>, Kiriko Takahashi<sup>2</sup>, and Yuji Umenaga<sup>3</sup>

<sup>1</sup> St. Andrew's Momoyama Gakuin University

<sup>2</sup> Center on Disability Studies, University of Hawai'i at Mānoa

<sup>3</sup> Waseda University

### Abstract

Since March 2020, most camps for people with and without disabilities were canceled because of Sars-CoV-2 (COVID-19). How to restart recreational activities, such as camping, is an important issue for both health and mental well-being. This essay addresses the efforts of Campwith to restart their camping activities for people with and without disabilities during the pandemic in October 2021.

*Keywords:* inclusive camping, assistive technology, COVID-19, ICT, disabilities

## **How to Restart an Inclusive Camping While**

### **Preventing COVID-19 Outbreak:**

#### **Interdisciplinary Study on the Utilization of ICT Support System to Create Inclusive Outdoor Education to Enhance QOL for Persons with Disabilities**

Since March 2020, most camps for people with and without disabilities were canceled because of Sars-CoV-2 (COVID-19). National Center for Child Health and Development in Japan (2021) shows that many children do not have enough opportunities to exercise and to meet their friends. In this paper, we introduce the efforts of one camp in Osaka, Japan, called “Campwith,” in restarting camping activities for people with and without disabilities during the pandemic in 2021.

Restarting recreational activities, such as camping, is important for both physical and mental health of people with and without disabilities. Coyne and Fullerton (2004) and Samuel, Lieberman & Murata (2012) describe the importance of physical education and physical activities, recreation, leisure, and sports to enhance children’s

well-being and improved self-confidence and self-esteem. Takeuchi and Sakamoto (2018) indicate that benefits of inclusive camping include inviting students to feel safe towards new situations and developmental stages. In addition, this study shows that a camper-centered approach is important: (1) for campers, to create their space, (2) for families, to innovate their child-care style, and (3) for staff, to learn social-skills and social-work practice.

### **About Campwith**

Campwith builds on other developments in inclusive education in Japan. Yoshitoshi and Takahashi (2021) describe a history of Japanese law pertaining to special education and its change towards a more inclusive education with Japan's ratification of United Nations Conventions of the Rights of People with Disabilities. It is believed that the first organized camp for children with disabilities in Japan was held in Yoshima, Kagawa Prefecture in 1953, organized by the Asahi Shimbun (a newspaper), Social Welfare Organization, and Kobe YMCA. Since then, groups such as social welfare, parental and charitable organizations have developed camps for people with disabilities.

Campwith was founded in Osaka, Japan in 1998 as a volunteer organization. It

became a non-profit organization in 2002. Before the Covid-19 pandemic, Campwith held over 40 camps a year. The Mission Statement of Campwith is to “facilitate quality of life for all people with or without disabilities through outdoor and recreational activities, regardless of gender, age, or race.” Many of the participants are people with cognitive and developmental disorders who live in western Japan. The Camp staff are mainly students connected with St. Andrew’s University in Japan. In 2017, Campwith started “With Ashiya,” a Type B Employment Support Center, and “Hirano cafeteria for all.”

### **Reopening Camp During the Pandemic**

From June 2021, Campwith implemented the “*Waku Waku Kids Camp Project*” to restart camping. This project worked in four phases to ensure that nature experience activities would be safe while still allowing students opportunities to cooperate with others. The four phases included: (1) Kids’ Meeting, (2) Staff Training, (3) Inclusive Camping, and (4) Reviewing and Sharing (see Table 1). These phases were partially funded by Ministry of Education, Culture, Sports, Science and Technology.

**Table 1**  
*Four Phases of the Project (Members)*

Date	Phase	Details
August 28, 2021	<b>Phase I</b>	<b>Kids' Zoom Meeting (Kids, Parents, Staff)</b> 1) Goals of meeting 2) Ice breaking activity 3) Project description 4) Sharing of what kids want to do at the camp
September 5, 2021	<b>Phase II</b>	<b>Pre-camp Training (Team A staff)</b> Campfire day camp to learn how to connect to campers' needs while preventing Covid-19 spread.
October 5, 2021		<b>Pre-camp Training (Team B staff)</b> Zoom meeting about cooking day camp to learn how to connect to campers' need while preventing Covid-19 spread.
October 30, 2021	<b>Phase III</b>	<b>Inclusive Fire Day Camp (Team A)</b> to connect camper A's requested programs; Halloween Craft activity, dinner, and campfire with melted marshmallow.
October 31, 2021		<b>Inclusive Cooking Day Camp (Team B)</b> to connect with camper B's requested programs; Emergency Cooking, Melted Marshmallow, and doing a Halloween Craft.
November 2021	<b>Phase IV</b>	<b>Reviewing and Sharing time (Kids, Parents, Staff)</b> through Google Form for campers, families, and staff.
December 20, 2021		<b>ICT &amp; AT Training (Staff)</b> Zoom meeting to learned how to share campers' needs and expression. 1) Virtual self-introduction 2) CDS Projects 3) ICT/AT Resource such as IdeaBoardz, Kahoot!, Nearpod, Telepresence Robot, and Immersive.
January 9, 2022		<b>Zoom meeting (Kids, Parents, Staff)</b> to share their review, comments, and future visions through ice-breaking, camper's presentations, and project reports.

Source: Waku Waku Kids Camp  
Project Report (2021)

After sharing what the children wanted to do at the kids' meeting (August 28, 2021), we examined an order-made camping program (while taking preventative measures against Covid-19) through staff training and meeting (September 5 and October 5, 2021). The final program was restructured with the advice of adapted camp specialists, a doctor and a nurse.

To conduct campers' requested programs, Inclusive fire day camp was included along with Halloween Craft activity, dinner, and campfire with melted marshmallows for Camper A (October 30, 2021). Inclusive cooking day camp was included along with Emergency Cooking, melted marshmallow, and doing a Halloween Craft for Camper B (October 31, 2021) camping.

Afterwards, efforts were made to get feedback on participants' experiences. During November, we had a reviewing time through Google Form for campers, families, and staff. The survey included questions such as: (1) evaluations about programs and preventions for camping; (2) comments for changes; and (3) hopes after camping. All participants responses showed positive evaluation and comments. Camper A's parent wrote "she tended not to go to school, but she changed her mind through

camping.” Also, Camper B’s parent wrote “[We] refreshed with family! He doesn’t cook at home, but he enjoyed cooking at the camp.” Camp staff also provided positive feedback from their experience in implementing the camp.

To then learn how to share campers’ needs and expressions by using ICT, Staff learned about virtual self-introductions, CDS Projects, and ICT Resource (On December 20, 2021). On January 9, 2022, 2 families and 4 staff members had an hour Zoom meeting to share their review, comments, and future visions through an ice-breaking activity, camper’s presentations, and project reports. The camper chose to share his most meaningful pictures. These reviews, comments, and observation reports revealed campers’ positive attitudes, behaviors, and sense of achievement. This included: (1) feeling refreshed; (2) improved camping skills; and (3) improved social skills.

In conclusion, although this reopening of camping in phases was a success, we also discussed several challenges moving forward. To create a safe and enjoyable camping experience with participants, families, and staff, we have to prepare for: (1) COVID-19 Safety Check; (2) ICT/AT Training Series; (3) Decision-Making Setting; (4) Flexible Programming; (5) the need for additional funds and staff training aligned with



the current pandemic situation; (6) Balancing intimacy and social distancing for safety;  
and (7) Studying Other Inclusive Camp Models.

## References

Campwith website (n.d.). <https://campwith.jp/>

Coyne, P. & Fullerton, A. (2004). *Supporting Individuals with Autism Spectrum Disorder in Recreation*. Sagamore Pub. p.108

Hodge, S. R., Lieberman, L. J., & Murata, N. M. (2012). *Essentials of teaching adapted and general physical education: Culture, diversity and inclusion*. Holcomb Hathaway, Publishers.

Lieberman, L., & Murata, N. M., Gonnelli, M., & Larranaga, J. (2018). Assistive technology: What physical educators need to know. *Journal of Physical Education, Recreation & Dance*, 89(3), 38-45.

Ministry of Education, Culture, Sports, Science and Technology (n.d.). Youth independence support project through hands-on activities.  
[https://www.mext.go.jp/a\\_menu/sports/ikusei/taiken.htm](https://www.mext.go.jp/a_menu/sports/ikusei/taiken.htm)

National Center for Child Health and Development in Japan (2021). September 2021 Urgent Survey: National Online Survey of Children's Well-being During the

COVID-19 Pandemic in Japan.

[https://www.ncchd.go.jp/center/activity/covid19\\_kodomo/report/CxC6\\_digestEn.pdf](https://www.ncchd.go.jp/center/activity/covid19_kodomo/report/CxC6_digestEn.pdf)

Special Needs Camp Network website (n.d.). <https://sn-camp-net.wixsite.com/sn-camp-net>

Takeuchi, Y., Sakamoto, A. (2018). A case study on the positive effects of camping on a child with a developmental disorder, the child's family and the camp's staff. *Japan Outdoor Education Journal*, 22(1), 37-49.

Takeuchi, Y., Ishida, Y., Noguchi, K., and Takase, H. (2020). Camping for Everyone: Assessment of Benefits for Children with Developmental Disorders and Challenges facing Camping Organizations. *St. Andrew's University Bulletin of the Research Institute* 46(1) 19-35.

Umenaga, Y. et al. (n.d.). Jiheisho LABO <https://www.jiheisyolabo.com/about/>

Waku Waku Kids Camp Project Report (Ministry of Education, Culture, Sports, Science and Technology "Youth Independence Support Project through Experience Activities" commissioned project for promoting nature experience activities for the healthy development of children's mind and body).

[https://campwith.jp/?page\\_id=107](https://campwith.jp/?page_id=107)

Yoshitoshi, M., & Takahashi, K. (2021). A critical analysis of court decision on mainstream school attendance of a child with medical care needs in Japan: A long way towards inclusive education, *International Journal of Inclusive Education*. <https://doi.org/10.1080/13603116.2021.1888322>



**How to Restart an Inclusive Camping While Preventing COVID-19 Outbreak: Interdisciplinary Study on the Utilization of ICT Support System to Create Inclusive Outdoor Education to Enhance QOL for Persons with Disabilities** by Takeuchi, Takahashi and Umenaga.

<https://rdsjournal.org/index.php/journal/article/view/1159> is licensed under a [Creative Commons Attribution 4.0 International License](https://creativecommons.org/licenses/by/4.0/). Based on a work at <https://rdsjournal.org>.

**An Interdisciplinary Approach to Increasing Access to Care for  
Individuals with Fetal Alcohol Spectrum Disorders**

Elizabeth Cleveland, PhD, CCC-SLP <sup>1</sup>

Tiffany Lepard-Tassin, MS, CGC <sup>2</sup>

Albrey Love, APRN <sup>2</sup>

Andrew Cope, MHA

David Deere, MSW, LCSW

Jessica Gangluff, BS <sup>1</sup>

<sup>1</sup> University of Central Arkansas, Conway, AR

<sup>2</sup> University of Arkansas for Medical Sciences, Little Rock, AR

**Abstract**

Fetal alcohol spectrum disorders (FASD) have a prevalence of roughly 1 in 20, making it one of the most prevalent disorders in the United States (May et al., 2018). However, FASD has a diagnostic rate of less than 1%, resulting in late diagnosis, identification, and intervention (May, Baete, & Russo, 2014; May, Chambers, Kalberg, et al, 2018;

Cleveland, Deere, Kyzer, & Smith, 2020). Only a handful of physicians regularly diagnose FASDs, even further decreasing access to care (Manning & Hoyme, 2007). In response, the Specialty Diagnostic Resource Center (SDRC) in Arkansas developed the following interdisciplinary approach to FASD diagnosis. Seventy-seven individuals ages four months to 37 years were evaluated for Other Specified Neurodevelopmental Disability: Neurodevelopmental Disability Associated with Prenatal Alcohol Exposure (ND-PAE) between April 2020 and February 2022; 54 individuals were diagnosed. Trends were identified for individuals given a ND-PAE diagnosis and analyzed, with Spearman-rho analysis conducted. As FASDs are widely underdiagnosed, an approach similar to SDRC may assist other interdisciplinary teams in efforts to increase access both to diagnosis and intervention.

*Keywords:* fetal alcohol spectrum disorders, FASD, interdisciplinary care, access to care

## **An Interdisciplinary Approach to Increasing Access to Care for Individuals with Fetal Alcohol Spectrum Disorders**

Fetal alcohol spectrum disorders (FASD) is an umbrella term that encompasses a variety of disorders caused by prenatal alcohol exposure (Vaurio, Riley, & Mattson, 2008; Astley, Aylward, Olson, Kerns, Brooks, Coggins, ... & Kraegel, 2009; Riley, Infante, & Warren, 2011; Paolozza, Rasmussen, Hanlon-Dearman, Nikkel, Andrew, McFarlane, ... & Reynolds, 2014; Hoyme, Kalberg, ... & May, 2016; Thorne & Coggins, 2016; Terband, Spruit, & Maassen, 2018). Diagnoses that fall under the FASD umbrella include: (a) Fetal Alcohol Syndrome (FAS); (2) Partial Fetal Alcohol Syndrome (pFAS); (3) Alcohol Related Birth Defects (ARBD); (4) Alcohol Related Neurodevelopmental Disorder (ARND); (5) Prenatal Alcohol Effects (PAE); (6) Fetal Alcohol Effects (FAE); (7) Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure (ND-PAE); (8) and many others (Hoyme et al., 2016; Kable & Mukherjee, 2017). May and colleagues (2018) identified a prevalence of 1 in 20 first graders in the US. Although this category of disorders is almost twice as prevalent as autism spectrum disorder (APA, 2013), less than 1% of children that meet criteria for

FASD are actually given a diagnosis (May et al., 2018). Underdiagnosis to this extent often results in a misinterpretation of the common behaviors and characteristics associated with brain damage caused by prenatal alcohol exposure (Rasmussen, Benz, Pei, Andrew, Schuller, Abele-Webster, Alton et al., 2010; McLaughlin, Thorne, Jirikowic, Waddington, Lee, & Astley Hemingway, 2019; Cleveland et al., 2020).

The level of impairment for the FASD diagnoses vary depending on several factors, including amount of alcohol exposure, timing of exposure, and epigenetics (Riley & McGee, 2005; Moore, Ward, ... & Foroud, 2007; Astley et al., 2009, Mattson, Crocker, & Nguyen, 2011; Feldman, Jones, ... & Chambers, 2012). Each disorder has some combination of impairment in neurological structure, impairment in adaptive or educational functioning, cognition, and/or behavioral characteristics that have been impacted by prenatal alcohol exposure (Vaurio et al., 2008; Astley et al., 2009; Riley et al., 2011; Paolozza et al., 2014; Thorne & Coggins, 2016; Terband, et al., 2018).

Although there is a spectrum of severity of symptoms associated with each FASD diagnosis, there are also some common behavioral and structural characteristics that have been identified in all FASD diagnoses (Astley et al., 2009; Cook, Green, Lilley, Anderson, Baldwin, Chudley, ... & Mallon, 2016). Functional magnetic resonance imaging (fMRIs) indicates that, although damage from prenatal alcohol exposure can



happen anywhere in the brain, it is commonly seen in the corpus callosum and in the frontal lobe (Astley et al., 2009; Paolozza et al., 2014). Damage to these areas can cause decreased cognitive and executive functioning skills, like problem solving, organizing, understanding cause and effect, and ability to attend (Paolozza et al., 2014; Petrenko & Alto, 2014; Thorne, 2017). The absence or dysfunction of these skills may impact many areas of a person's life, including their ability to adapt to and function in the environment, which can then lead to behavioral characteristics such as inappropriate outbursts, impulsivity, and irregular social interactions (Fahy, 2014; Popova, Lange, Burd, & Rehm, 2014).

Many individuals with FASD are misdiagnosed as having attention deficit/hyperactivity disorder (ADHD), autism spectrum disorder (ASD), oppositional defiant disorder (ODD), disruptive mood dysregulation disorder (DMDD) and many others (Malbin, 2002; Popova, Lange, Bekmuradov, Mihic, & Rehm, 2011; Lange, Shield, Rehm, & Popova, 2013; Popova, Lange, Shield, Mihic, Chudley, Mukherjee, Bekmuradov, & Rehm, 2016; Craig, Margari, Legrottaglie, Giambattista, & Margari, 2016). Lack of FASD diagnosis has resulted in societal misunderstanding of these disorders and ultimately the lack of appropriate supports and interventions for people with FASD (Carmichael-Olson, Ohlemiller, O'Connor, Brown, Morris, & Damus,

2009). Without an official diagnosis of an FASD, it may be difficult to understand these children and their deficits, which in turn may create more complication for practitioners in attempting to provide the best level of care (Carmichael-Olson, et al., 2009).

### **Access to FASD Diagnosis**

Although the importance of getting an FASD diagnosis has been well documented (Vaurio et al., 2009; Riley, Infante, & Warren, 2011; Paolozza et al., 2014; Hoyme et al., 2016; Thorne & Coggins, 2016; Terband, Spruit, & Maassen, 2018; Cleveland, et al., 2020), resources for diagnosis and intervention services continue to be minimal across the United States (Lange et al., 2013; Papov, et al., 2016; Petrenko & Alto, 2017; May et al., 2018; Cleveland et al., 2020). Very few physicians specialize in developmental and behavioral pediatrics, much less specifically specializing in fetal alcohol spectrum disorder (Manning & Hoyme, 2007). Arkansas, like many other states, has very limited access to FASD diagnosis and care (Cleveland et al., 2020). The Specialty Diagnostic Resource Center (SDRC), Arkansas's only FASD-specific diagnostic clinic, has utilized an interdisciplinary approach to care for individuals suspected of FASD. By identifying trends in diagnosis and symptomology like those identified through SDRC, other interdisciplinary teams across the country may be able

to increase access to care in their own states.

### Method

Analysis of the data collected through SDRC was conducted under IRB #20-153 at the University of Central Arkansas. An interdisciplinary team consisting of a speech-language pathologist, social worker, genetic counselor, and nurse practitioner was utilized for each SDRC evaluation. This team members are also current or former faculty members of the Arkansas Leadership Education in Neurodevelopmental Disabilities (AR LEND) grant-funded training program. Because the nature of the clinic is a training clinic, students from a variety of disciplines also participate in each evaluation.

#### **Diagnostic Criteria for Other Specified Neurodevelopmental Disorders:**

##### **ND-PAE**

SDRC evaluated 77 individuals between April 2020 and February 2022 using the criteria for Other Specified Neurodevelopmental Disability: Neurodevelopmental Disability Associated with Prenatal Alcohol Exposure (ND-PAE) from the DSM-5 (APA, 2013; Kable & Mukherjee, 2017). Criteria for ND-PAE can be found in Table 1.

<b>Table 1</b>
----------------

*DSM-5 Diagnostic Criteria for ND-PAE*Other Specified Neurodevelopmental Disorder: Neurodevelopmental Disorder  
Associated with Prenatal Alcohol Exposure - 315.8 (F88)

- A. History of more than minimal levels of prenatal alcohol exposure
- B. Neurocognitive Impairment (one or more of the following)
  - 1. Global intellectual impairment
  - 2. Impairment in executive functioning
  - 3. Impairment in learning
  - 4. Impairment in memory
  - 5. Impairment in visual spatial reasoning
- C. Impairment in self-regulation (one or more of the following)
  - 1. Impairment in mood or behavioral regulation
  - 2. Attention deficit
  - 3. Impairment in impulse control
- D. Deficits in adaptive functioning skills (two or more of the following, including at least one that is criteria [1.] or [2.]).
  - 1. Communication deficit
  - 2. Social impairment
  - 3. Impairment in daily living
  - 4. Motor impairment
- E. Onset of disturbance is before 18 years of age.
- F. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.
- G. The disturbance is not better explained by the direct physiological affects associated with postnatal use of a substance, other known teratogens, a genetic condition, or environmental neglect and/or abuse.

(Alternate text description for Table 1: This table shows the DSM-5 criteria for

Other Specified Neurodevelopmental Disorder: Neurodevelopmental Disorder

Associated with Prenatal Alcohol Exposure. The billing codes for the disorder are 315.8

(F88).)

Participants were evaluated using an interdisciplinary approach to the diagnosis,

meaning that all professionals evaluated the participants simultaneously. Due to

restrictions put in place as a consequence of the COVID-19 pandemic, only a certain number of team members were physically present with the participants and their families. The other team members connected to the evaluation by means of a virtual platform and utilized telemedicine to complete their assessments.

The evaluation began with a detailed interview, including questions about pre- and post-natal care, other medical, and social history. Participants were screened for hearing difficulties using a 20dB pure-tone audiometric evaluation at 1,000 Hz, 2,000 Hz, and 4,000 Hz. After the hearing evaluation, participants partook in a battery of assessments to investigate current level of functioning in areas related to diagnostic criteria for ND-PAE.

Students from the speech-language pathology graduate program conducted the static and dynamic assessment measures under the supervision of a licensed speech-language pathologist. Each participant was given an individualized testing battery which included a combination of assessments. Most of the assessments utilized by the team were norm-referenced, although criterion-referenced assessments were used occasionally. Assessments commonly used in SDRC include the *Behavior Rating Inventory of Executive Function (BRIEF-2)*, which is often used to assess the

participant's executive function. The *BRIEF-2* is a caregiver questionnaire in which the caregiver ranks the participant's executive function and related behaviors within the last six months. To assess for communication, a language assessment like the *Clinical Evaluation of Language Fundamentals, 5<sup>th</sup> Edition (CELF-5)* or the *Oral and Written Language Scales, 3<sup>rd</sup> Edition (OWLS-III)* is often used. Both the *CELF-5* and the *OWLS-III* are norm-referenced assessments used to evaluate the participant's understanding and use of a variety of types of language, including receptive language, expressive language, language content, and overall language. The *Social Skills Improvement System (SSiS)* is often used to assess social skills in children and teens ages 3-18 and the *Vineland Adaptive Scales, 3<sup>rd</sup> Edition (Vineland-3)* is often used to assess adaptive function. Both the *SSiS* and the *Vineland-3* are also rating systems ranked by the caregiver on frequency of certain behaviors. Depending on the concerns expressed by caregivers and participants, additional assessments may be used during an evaluation session. The SDRC diagnostic team also utilizes existing information, like comorbid disorders and existing diagnoses to help make the decision for diagnostic criteria.

To confirm or rule out the presence of ND-PAE, the SDRC team utilizes the combination of a detailed case-history interview, client observations during the

evaluation session, norm- and criterion-referenced assessments, and the client's existing medical diagnoses. For the purposes of this study, 77 participants were evaluated using the described SDRC diagnostic procedure. Information utilized for analysis included gender, age, confirmation of alcohol and/or drug exposure, whether an ND-PAE diagnosis was given, and whether the participant was referred to a geneticist to rule out fetal alcohol syndrome or test for other syndromes. This information regarding these factors can be found in Table 2.

<b>Table 2:</b>	
<i>Participant Information</i>	
Total participant population	n=77
Gender	Male: n=42 Female: n=33 Nonbinary: n=0
Age:	Mean: 8.83 Median: 7.67 Standard Deviation: 6.357
Confirmed alcohol exposure:	Yes: n=73 No: n=4
Confirmed additional drug exposure:	Yes: n=72 No: n=5
Diagnosis given at evaluation:	Yes: n=53 No: n=24 (including suspected FASD but not confirmed: n=13)
Referral to genetics for further evaluation:	Yes: n=16 No: n=61

(Alternative text description Table 2: This table shows Participant Information, which includes the total participant population [n=77], gender [Yes: n=73, No: n=4], age [Mean: 8.83, Median: 7.67, Standard Deviation: 6.357], confirmed alcohol exposure

[Yes: n=73, No: n=4], confirmed additional drug exposure [Yes: n=72, No: n=5], diagnosis given at evaluation [Yes: n=53, No: n=24 (including suspected FASD but not confirmed: n=13)], and a referral to genetics for further evaluation [Yes: n=16, No: n=61]).

### Results

The diagnostic method used by SDRC has been utilized for 77 individuals and families over the past two years. A Spearman rho correlation coefficient was conducted to identify trends and any relationships between the study variables, including diagnosis given at an evaluation, age, gender, confirmed alcohol exposure, confirmed drug exposure. Although many of the relationships between these variables were not significantly correlated, there were relationships identified. Using an alpha of 0.05, the following relationships were identified: A negative correlation was identified between “gender” and “referrals to genetics,”  $r(75) = -.254$ ,  $p(2\text{-tailed}) = .026$ . Another negative correlation was identified between “chronological age” and “confirmed alcohol exposure,”  $r(75) = -.249$ ,  $p(2\text{-tailed}) = 0.029$ . Likewise, a negative correlation between the “diagnosis given at the time of evaluation” and “chronological age,”  $r(75) = -0.445$ ,  $p(2\text{-tailed}) < 0.001$ . Finally, a positive correlation was identified between



“confirmation of alcohol exposure” and “confirmation of drug exposure,”  $r(75) = 0.651, p(2\text{-tailed}) < 0.001$ . These results indicate that younger participants are more likely to have confirmed alcohol exposure than older participants, males are more likely to be referred to genetics, younger children are more likely to be given a diagnosis at the time of the evaluation. Finally, participants that had alcohol exposure were more likely to also have drug exposure. These results can be seen in Table 3.

**Table 3**  
*Pearson Product Correlation Between Variables*

			Diagnoses given at evaluation (yes=1; no=2)	Gender (male=1; female=2)	Confirmed alcohol exposure (yes=1; no=2)	Confirmed drug exposure (yes=1; no=2)	Referral to genetics (yes=1; no=2)	Chronological age
Spearman's rho	Diagnosis given at evaluation (yes=1; no=2)	Correlation Coefficient	1.000	.079	.222	.164	-.208	-.445**
		Sig (2-tailed)		.494	.053	.154	.069	.000
		N	77	77	77	77	77	77
Gender (male=1; female=2)	Correlation Coefficient	Correlation Coefficient	.079	1.000	.028	-.128	-.254*	-.084
		Sig (2-tailed)	.494		.812	.267	.026	.467
		N	77	77	77	77	77	77
Confirmed alcohol exposure (yes=1; no=2)	Correlation Coefficient	Correlation Coefficient	.222	.028	1.000	.651**	-.169	-.249*
		Sig (2-tailed)	.053	.812		<.001	.143	.029
		N	77	77	77	77	77	77
Confirmed drug exposure (yes=1; no=2)	Correlation Coefficient	Correlation Coefficient	.164	-.128	.651**	1.000	.005	.005
		Sig (2-tailed)	.154	.267	<.001		.965	.967
		N	77	77	77	77	77	77

Referral to genetics (yes=1; no=2)	Correlation Coefficient	-.208	-.254*	-.169	.005	1.000	.172
	Sig (2-tailed)	.069	.026	.143	.965		.134
	N	77	77	77	77	77	77
Chronological age	Correlation Coefficient	-.445**	-.084	-.249*	.005	.172	1.000
	Sig (2-tailed)	.000	.467	.029	.967	.134	
	N	77	77	77	77	77	77

\*\* Correlation is significant at the 0.01 level (2-tailed)  
\*Correlation is significant at the 0.05 level (2-tailed)

(Alternate text description for Table 3: This table shows the Pearson product correlation between variables. There are 6 rows and 6 corresponding columns with the following areas intersecting: Diagnosis given at evaluation (yes=1; no=2), Gender (male=1; female=2), Confirmed alcohol exposure (yes=1; no=2), Confirmed drug exposure (yes=1; no=2), Referral to genetics (yes=1; no=2), and Chronological age)

### Discussion

There is ample evidence that individuals with FASD, including ND-PAE, have difficulty in areas like cognition, executive function, social skills, and more (Paolozza et al., 2014; Popova et al., 2014; Thorne, 2017). The trends identified from the SDRC data may be helpful when adding parameters to an existing diagnostic clinic, especially if referral numbers and wait lists are high. For example, the confirmation of alcohol exposure was significantly correlated with a participant receiving a diagnosis of ND-

PAE. By adding questions confirming alcohol exposure to an intake form or during a case-history interview, this may increase the likelihood of an individual exposed to alcohol receiving a diagnosis of ND-PAE, and subsequently receiving services for areas of impairment.

FASD is a condition that affects an enormous population of the world, including 1 in 20 first graders in America (Lange et al., 2013; May et al., 2018; Lange et al., 2019). Unfortunately, the amount of resources available for individuals and families with FASD is lacking and the resources that are available are incredibly hard to access (Rasmussen, et al., 2010; McLaughlin et al., 2019; Cleveland et al., 2020). The diagnostic method that SDRC uses may assist other clinics in addressing the access to care for individuals and families with FASD.

There are potential limitations that clinics may encounter when attempting to implement the SDRC method. An interdisciplinary team of professionals is most appropriate when assessing for ND-PAE, considering the variety of symptomology and criteria associated with the condition. For example, in SDRC a speech-language pathologist is able to assess for communication and social impairment, a social worker is able to assess for mood disorders, a nurse practitioner is able to assess the physicality

of the patient, and a genetic counselor is able to rule out the possibility of undiagnosed genetic conditions that may explain a combination of symptoms better than an ND-PAE diagnosis. However, the professions involved in SDRC do not define the ideal professional mix for a clinic. These are the professions that are currently available for that team. In previous semesters, a psychologist and an occupational therapist have been team members and were quite useful.

Other clinics may not have access to this type of team. However, that should not discourage a clinic from attempting to identify areas of impairment. The DSM-5 diagnostic criteria for ND-PAE can be utilized as a pathway to resources (APA, 2013). If a clinic has access to only a speech-language pathologist, for example, they can confirm or rule out the presence of a) executive dysfunction, b) communication impairment, and/or c) social impairment. Subsequently, the SLP can refer for further testing by a professional qualified to identify a mood or impulsivity impairment.

FASD remains an underdiagnosed and underserved population of individuals (Paolozza et al., 2014; Popova et al., 2016; Petrenko & Alto, 2017; Thorne, 2017). By utilizing existing resources, individuals with FASD may be identified earlier and may have access to resources sooner, making the opportunity for success more achievable.

### References

American Psychiatric Association (APA). (2013). *Diagnostic and statistical manual of mental disorders, fifth edition (DSM-5®)*. American Psychiatric Pub.

Astley, S. J., Aylward, E. H., Olson, H. C., Kerns, K., Brooks, A., Coggins, T. E., Davies, J., Dorn, S., Gendler, B., Jirikowic, T., & Kraegel, P. (2009). Magnetic resonance imaging outcomes from a comprehensive magnetic resonance study of children with fetal alcohol spectrum disorders. *Alcoholism: Clinical and Experimental Research*, 33(10), 1671-1689.

Carmichael-Olson, H. Ohlemiller, M., O'Connor, M., Brown, C., Morris, C., & Damus, K. (2009). *A Call to Action; Advancing Essential Services and Research on Fetal Alcohol Spectrum Disorders*. A Report of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect.

Cleveland, E., Deere, D., Kyzer, A., & Smith, S. (2020). Fetal alcohol spectrum disorders advocacy in Arkansas. *Journal of Arkansas Medical Society*. May 2020 Issue.

Cook, J. L., Green, C. R., Lilley, C. M., Anderson, S. M., Baldwin, M. E., Chudley, A. E., Conry, J.L., LeBlanc, N., Looock, C.A., Lutke, J., & Mallon, B. F. (2016).

Fetal alcohol spectrum disorder: A guideline for diagnosis across the lifespan.

*Canadian Medical Association Journal*, 188(3), 191-197.

Craig, F., Margari, F., Legrottaglie, A. R., Palumbi, R., De Giambattista, C., & Margari,

L. (2016). A review of executive function deficits in autism spectrum disorder and attention-deficit/hyperactivity disorder. *Neuropsychiatric disease and treatment*, 12, 1191.

Feldman, H.S., Jones, K.L., Lindsay, S., Slymen, K., Klonoff-Cohen, H., Kao, K., Rao,

S., Chambers, C. (2012). Prenatal alcohol exposure patterns and alcohol-related birth defects and growth deficiencies: A prospective study. *Alcoholism, Clinical and Experimental Research*, 36(4), 670-676.

Hoyme, H.E., Kalberg, W.O., Elliott, A.J., Blankenship, J., Buckley, D., Marais, A.S.,

Manning, M.A., Robinson, L.K., Adam, M.P., Abdule-Rahman, O., Jewett, T., Coles, C.D., Chambers, C., Jones, K.L., Adnams, C.M., Shah, P.E., Riley, E.P., Charness, M.E., Warren, K.R., May, P.A. (2016) Updated clinical guidelines for diagnosing fetal alcohol spectrum disorders. *Pediatrics*, 138(2).

Kable, J. A., & Mukherjee, R. A. (2017). Neurodevelopmental disorder associated with

prenatal exposure to alcohol (ND-PAE): A proposed diagnostic method of capturing the neurocognitive phenotype of FASD. *European Journal of Medical*

*Genetics*, 60(1), 49-54.

Lange, S., Shield, K., Rehm, J., & Popova, S. (2013). Prevalence of fetal alcohol spectrum disorders in child care settings: a meta-analysis. *Pediatrics*, 132(4), e980-e995.

Malbin, D. (2002). Fetal Alcohol Syndrome and Alcohol-related Neurodevelopmental Disorders: Trying Differently Rather Than Harder. Tectrice, Incorporated.

Manning, M. A., & Hoyme, H. E. (2007). Fetal alcohol spectrum disorders: a practical clinical approach to diagnosis. *Neuroscience & Biobehavioral Reviews*, 31(2), 230-238.

Mattson, S.N., Crocker, N., Nguyen, T.T. (2011) Fetal alcohol spectrum disorders: Neuropsychological and behavioral features. *Neuropsychology Review*, 21, 81-101.

May, P., Chambers, C., Kalberg, W., Zellner, J., Feldman, H., Buckley, D., Kopald, D., Hasken, J.M., Xu, R., Honerkamp-Smith, G., & Taras, H. (2018). Prevalence of fetal alcohol spectrum disorders in 4 US communities. *Journal of the American Medical Association*, 319(5), 474-482.

McLaughlin, S. A., Thorne, J. C., Jirikowic, T., Waddington, T., Lee, A. K., & Astley Hemingway, S. J. (2019). Listening difficulties in children with fetal alcohol

spectrum disorders: More than a problem of audibility. *Journal of Speech, Language, and Hearing Research*, 62(5), 1532-1548.

Moore, E.S. Ward, R.W., Wetherill, L.F., Rogers, J.L., Autti-Rämö, I., Fagerlund, A., Jacobson, S.W., Robinson, L.K., Hoyme, H.E., Mattson, S.N., & Foroud, T. (2007). Unique facial features distinguish fetal alcohol syndrome patients and controls in diverse ethnic populations. *Alcoholism, Clinical and Experimental Research*, 31(10), 1707-1713.

Paolozza, A., Rasmussen, C., Pei, J., Hanlon-Dearman, A., Nikkel, S., Andrew, G., McFarlane, A., Samdup, D., & A., Samdup, D., & Reynolds, J. (2014). Working memory and visuospatial deficits correlate with oculomotor control in children with fetal alcohol spectrum disorder. *Behavioural Brain Research*, 263, 70-79.

Petrenko, C. L., & Alto, M. E. (2017). Interventions in fetal alcohol spectrum disorders: An international perspective. *European journal of medical genetics*, 60(1), 79-91.

Popova, S., Lange, S., Bekmuradov, D., Mihic, A., & Rehm, J. (2011). Fetal alcohol spectrum disorder prevalence estimates in correctional systems: a systematic literature review. *Canadian Journal of Public Health*, 102(5), 336-340.

Popova, S., Lange, S., Burd, L., & Rehm, J. (2014). Canadian children and youth in



care: The cost of fetal alcohol spectrum disorder. *In Child & Youth Care Forum* 43(1), 83-96.

Popova, S., Lange, S., Shield, K., Mihic, A., Chudley, A. E., Mukherjee, R. A., Bekmuradov, D., & Rehm, J. (2016). Comorbidity of fetal alcohol spectrum disorder: A systematic review and meta-analysis. *The Lancet*, 387(10022), 978-987.

Rasmussen, C., Benz, J., Pei, J., Andrew, G., Schuller, G., Abele-Webster, L., Alton, C., & Lord, L. (2010). The impact of an ADHD co-morbidity on the diagnosis of FASD. *Journal of Population Therapeutics and Clinical Pharmacology*, 17(1), e165-e176.

Riley, E. P., Infante, M. A., & Warren, K. R. (2011). Fetal alcohol spectrum disorders: An overview. *Neuropsychology Review*, 21(2), 73-84.

Riley, E.P., McGee, C.L. (2005). Fetal alcohol spectrum disorders: An overview with emphasis on changes in brain and behavior. *Experimental Biology and Medicine*, 230, 357-365.

Terband, H., Spruit, M., & Maassen, B. (2018). Speech impairment in boys with fetal alcohol spectrum disorders. *American Journal of Speech-Language Pathology*, 27(4), 1405-1425.

Thorne, J. C. (2017). Accentuate the negative: Grammatical errors during narrative production as a clinical marker of central nervous system abnormality in school-aged children with fetal alcohol spectrum disorders. *Journal of Speech, Language, and Hearing Research, 60*(12), 3523-3537.

Thorne, J. C., & Coggins, T. E. (2016). Cohesive referencing errors during narrative production as clinical evidence of central nervous system abnormality in school-aged children with fetal alcohol spectrum disorders. *American Journal of Speech-Language Pathology, 25*(4), 532-546.

Vaurio, L., Riley, E. P., & Mattson, S. N. (2008). Differences in executive functioning in children with heavy prenatal alcohol exposure or attention-deficit/hyperactivity disorder. *Journal of the International Neuropsychological Society, 14*(1), 119-129.

Wilhoit, L.F., Scott, D.A., Simecka, B.A. (2017) Fetal alcohol spectrum disorders: Characteristics, complications, and treatment. *Community Mental Health Journal, 53*, 711-718.

 **An Interdisciplinary Approach to Increasing Access to Care for Individuals with Fetal Alcohol Spectrum Disorders**  
<https://rdsjournal.org/index.php/journal/article/view/1172> is licensed under a [Creative Commons Attribution 4.0 International License](https://creativecommons.org/licenses/by/4.0/). Based on a work at <https://rdsjournal.org>.

**Disabilities in Disaster Situations:  
How a Rescuer Handles What They Encounter**

Daryl Schaffer,

University of Alaska Fairbanks

**Author Note**

Daryl Schaffer, retired USCG Captain; Certificate in Instructional Design, Masters in Human Resource Management, Marymount University; Masters in Homeland Security and Disaster Management University of Alaska Fairbanks (Aug 2022); and Military Wounded Warrior.

Correspondence regarding this paper should be addressed to

[dschaffer2@alaska.edu](mailto:dschaffer2@alaska.edu).

### Abstract

Individuals with disabilities are often disproportionately affected by disaster. With little research focused on rescue operations impacting individuals with disabilities during large disasters, three themes are reviewed: re-leveling expectations; misunderstanding of triage and crisis medical protocols; and light switch fallacy by responders and individuals with disabilities before, during, and after rescue operations.

*Keywords:* Disaster, responders, disability

## Disabilities in Disaster Situations:

### How a Rescuer Handles What They Encounter

In this discussion, we will examine the effects of natural disasters and how this effects people with disabilities. People with disabilities are often left behind during a natural disaster. This could lead to pain or death to the person with a disability. Most disaster shelters are not designed to support people with physical disabilities. The disaster shelters are also often staffed with volunteers who do not know how to provide support. This discussion will examine a literature review of research done on effects of natural disasters on people with disabilities. The major argument of this essay is that there is not currently enough supports for people with disabilities during a natural disaster. There needs to be more supports for people with disabilities in the aftermath of a natural disaster. This is a topic on which the disability community needs to come together to help the public. The disability community needs to be included in the planning process of how a city will react to natural disasters. In Hawaii, we are faced with the threat of the effects of a natural disaster on a yearly basis. If a large natural disaster were to hit Hawaii, many with disabilities would not be supported. This is a

topic that should be important to those with a disability and is clearly a topic that we in the disability community need to do more work on.

In the effects of a natural disaster, some people are impacted by disasters more than others. The research states that people with disabilities are often more severely affected by the aftermath of natural disasters (Fjord & Manderson, 2009; IOM, 2009; Stough & Mayhorn, 2013; Alexander, 2015; Twigg et al., 2018; Ton, et al., 2019; Pyke & Wilton, 2020). Many factors play into this matter including individual disability, physical location, regional evacuation and recovery planning, community social structure, emergency notification, responder capabilities, medical protocols, recovery center accessibility, the immediate personal desire to be rescued, and even assumption of expectations of preferential treatment during the actual rescue. Individuals with disabilities were not involved in developing preparatory information during planning (Priestley & Hemingway, 2007; Twigg et al., 2018), lacked proper immediate emergency notification during response (White, B, 2006); White, G, et al., 2007; Stough & Mayhorn, 2013), and experienced inability to access facilities in recovery (Jones, 2010; Leong, et al., 2020; Pyke & Wilton, 2020). In their literature review, Stough & Mayhorn summarized “[t]he bulk of the limited research literature on disability and disaster has focused on evacuation” (Stough & Mayhorn, 2013, p. 390). While the

Americans with Disabilities Act (ADA, 1990) does not specifically address disasters, the Congressional Research Services found the nondiscrimination provisions can be applied to the mitigation efforts of emergency preparedness and disaster response efforts (Jones, 2010). The National Council on Disability has additionally provided guidance on emergency preparedness and disaster relief efforts (Jones, 2010). While progressive research, guidance, and improvements have been made in both the planning and recovery phases, a lack of research was noted on impact in the actual functions of rescue operations of individuals with disabilities during large mass-casualty events, in particular after passage of the ADA 2007 (Stough & Mayhorn, 2013; Stough & Kelman, 2017; Pyke & Wilton, 2020).

The Congressional Research Service referenced the Conference Report on the DHS Appropriations Act of 2006 which said progress and substantial improvements to state and large urban contingency plans had been made (Jones, 2010). Research has reviewed the continued progression of disability awareness and involvement by advocacy groups for the planning and recovery phases of a disaster (Jones, 2010; Stough & Mayhorn, 2013; Ton, et al., 2019; Leong, et al., 2020; Pyke & Wilton, 2020) with a noted lack of research on the actual rescue operations of individuals with disabilities during large mass-casualty events (Alexander, 2015; Stough & Kelman,

2017; Pyke & Wilton, 2020). This paper will focus on three themes addressing the impact in rescue operations during disasters on individuals with disabilities not previously noted in research literature. Theme 1, the re-leveling of expectations for incident-driven relationships on assumptions of preferential treatment before a predictive disaster and actions during a no-notice disasters. Theme 2, the misunderstanding in application of triage and crisis medical protocols during disaster situations for any victim with or without disabilities. Theme 3, how to recognize and mitigate the light switch fallacy, an immediate gratification attitude, by responders and individuals with disabilities before, during and after disaster rescue operations.

### **Literature Review**

It is estimated between 10 percent (Stough & Mayhorn, 2013, p. 387) and 15 percent (Leong, et al., 2020, p. 1) of the world population have some form of disability. Alexander (2015) describes a wide range of afflictions and conditions as forms of disability while Stough & Mayhorn expressed disability “is not consistently defined” (Stough & Mayhorn, 2013, p. 385) noting differences within psychological and mobility impairments. Ton, et al., defined disability as “a deviation from biomedical norms or limitations in functioning” (Ton, et al., 2019, p. 12) attributed to impairments. While old



age is not specifically a disability, it can be accompanied by frailty and lack of mobility substantially limiting a major life activity, thus creating a vulnerability during an emergency event (Alexander, 2015). The definition of a disability accepted within the disaster and emergency management professional field is directly taken from 42 U.S.C. §12102(1)(A) as “a physical or mental impairment that substantially limits one or more of the major life activities of such individuals.” (ADA, 1990; Jones, 2010, p. 40).

One approach to view how different people are negatively affected by disasters is the notion of social vulnerability (Morrow, 1999; Hewitt, 1983, 1997; Lewis, 1999; Wisner, et al., 2004, as cited in Kelman & Stough, 2015). In viewing the social vulnerability of a community, Lewis (1999), Edwards (2000), Van Willigen, et al., (2002), and Pyke & Wilton (2020) each noted disasters do not discriminate against any group of people but expose pre-existing inequalities of chronic community conditions. Societal practices and attitudes placed socially vulnerable populations at greater risk through advertent or inadvertent interaction of the impairment, institutions, and the physical environment (Kelman & Stough, 2015; Twigg et al., 2018). Hurricane Katrina in 2005 exposed this vulnerability profoundly “as seventy-one percent of the 1,330 known fatalities” were over age sixty with disabilities a correlating factor (Alexander, 2015, p. 389).

This social vulnerability aspect in both the planning and recovery was highly influential in the creation of the Post-Katrina Emergency Reform Act of 2006 and spurred amendments to the Americans with Disabilities Act which required state and local emergency management systems to ensure both disability inclusion in disaster planning and disability compliance in recovery efforts were addressed (Post-Katrina, 2006; ADA, 2008). In *The Federal Response to Hurricane Katrina Lessons Learned*, only a few passing mentions were noted of various “disparate citizen preparedness programs” recommending combining them and establish specialized preparedness programs “for those less able to provide for themselves during disasters such as children, the ill, the disabled, and the elderly” (Townsend, 2006, p. 80). Regional disability organizations and advocates coordinated with local jurisdictions to include greater engagement by individuals with disabilities during disaster incident planning phase (Twigg et al., 2018) which resulted in some changes to afford equal access of post-disaster event shelters for individuals with disabilities (ADA 1990, 2008).

While the major event of Hurricane Katrina in 2005 profoundly changed the entire emergency management process from planning to recovery, improvements have not been realized equally across all communities. The Congressional Research Service noted local emergency preparedness and response programs are required to be made

accessible to individuals with disabilities in accordance with the ADA but cited “few plans recognized the legal obligations imposed by the ADA.” (Jones, 2010, p. 5). In the post-Katrina era, advocates for disabilities made significant inroads by gaining inclusion of initiatives specific to vulnerable populations in the Sendai Framework for international disaster management (UNISDR, 2015) and several scholars (Jones, 2010; Twigg et al., 2018; Pyke & Wilton, 2020) cited advancements domestically in the preparatory stages with the inclusion of individuals with disabilities in the planning process and improvements in emergency notification systems. Leong, et al., (2020) noted an ongoing need for information sharing throughout the three main phases of an emergency (planning, response, and recovery) from individuals, disability service providers, academia, and practitioners. Other research reflects some improvements on accessibility changes to recovery facilities and challenges of long-term assistance (Stough & Mayhorn, 2013; Pyke & Wilton, 2020) however many efforts remain deficient (Twigg et al., 2018; Pyke & Wilton, 2020). Fifteen years post-Katrina, Pike and Wilton recognized “[d]espite the high visibility of Katrina, subsequent U.S. studies suggest that planners have been slow to learn from the failures in New Orleans.” (Pike and Wilton, 2020, p. 2).

## Theme 1

Identify steps individuals with disabilities can take on re-leveling of expectations for incident-driven relationships on assumptions of preferential treatment before a predictive disaster and actions during a no-notice disaster. How one prepares for a disaster is just as important as how rescuers prepare to respond to a disaster.

### *Evidence Theme 1*

The definition of a disaster could be as simple as an event that has unfortunate consequences; or this may be expanded to a sudden calamitous event bringing great damage, loss, or destruction; or complex to include functional, temporal, theoretical, and societal aspects in professing a disaster as “an accidental or uncontrollable event” (Neal, 1997, p. 242). A clearer contextual disaster definition is “when a community intersects the path of an event which creates a disruption to their society and requires resources beyond their capability” (Kelman, 2019, p. 1; Schaffer, 2021, p. 246).

Categorization of a disaster can be expressed from either their formation as natural, such as a tornado or tsunami, versus human-made, such as a cyberattack or failure of a structure (Schwab, 2010). A more impacting and beneficial classification can be made according to their progression as a predictive disaster which is forecasted and can

provide several days advance planning, such as a hurricane or snowstorm, versus a no-notice disaster which may occur instantly with zero or only a few minutes warning, such as an earthquake or explosion (IOM, 2009; Grajdura, et al., 2011; Golshani, et al., 2019; Kelman, 2019; Schaffer, 2022). If no preparatory action is taken in advance of a predictive disaster to alleviate the impacts, the situation will become a no-notice disaster (Schaffer, 2022).

Under either progression, each disaster can impact a community in a similar manner by disrupting regular activities and personal safety. Ensuring personal safety is the key for resiliency from a disaster which is realized in the recovery mode (McEntire, et al., 2002). Recovery to bring the community back can range from self-contained efforts to utilization of community resources to assistance from beyond the local capability. With self-safety efforts at the core, Alexander noted among the recommendations made by FEMA was that individuals with disabilities “should estimate their own capacity to respond with self-protective actions in the event of a crisis.” (Alexander, 2015, p. 393). Self-sufficiency would be foremost by having an emergency kit and evacuating before a predictive disaster or by knowing self-survival skills within the capacity of an individual with disabilities in order to survive a no-notice disaster (Fugate, 2009; Schaffer, 2022).

A goal of emergency management professionals is to reduce vulnerability (Fjord & Manderson, 2009; Schwab, 2010; Smith, 2011) yet this inclusive manner of all people in a community has remained a “neglected concept for both scholars and practitioner” (McEntire, et al., 2002, p. 273). The World Health Organization recognized “while all populations remain vulnerable to catastrophic events particular populations remain more vulnerable than others. These populations ... should be given particular attention to make sure their unique needs are considered in disaster planning and response efforts.” (IOM, 2009, p. 90). Twigg, et al., specifically noted exclusion from emergency planning of individuals with disabilities “particularly at local levels.” (Twigg et al., 2018, p. 4). Examining the premise on what emergency planners should do when all residents in a disastrous event are affected by the same barriers and impairments, Fjord and Manderson (2009) asked, “Why not place disability-centered approaches at the core of disaster planning and ensure that the probable needs of most residents are accommodated?” (Fjord & Manderson, 2009, p. 65).

The basis for re-leveling expectations begins with the overarching authorization from the ADA in terms of what a direct threat risk means which establishes its clear points of purpose:

A public entity must make an individualized assessment, based on reasonable judgment that relies on current medical knowledge or on the best available objective evidence, to ascertain: the nature, duration, and severity of the risk; the probability that the potential injury will actually occur; and whether reasonable modifications of policies, practices, or procedures or the provision of auxiliary aids or services will mitigate the risk. (USDOJ, 2010, 28 CFR 35.139(b))

Risk mitigation is a significant recipient from this section of the ADA with the poignant identifiers expressed as individualized assessment, reasonable judgment, current knowledge, best available evidence, probability, and reasonable modifications. Response plans have been implementing this ADA language in updated disaster planning and recovery efforts (Jones, 2010; Fugate, 2011; Stough & Mayhorn, 2013; UNISDR, 2015; Ton, et al., 2019; Leong, et al., 2020; Pyke & Wilton, 2020) but language in the ADA is specifically lacking on its application during rescue operations (Alexander, 2015; Stough & Kelman, 2017; Pyke & Wilton, 2020) which is actually a benefit for individuals with disabilities. This lack of language in the ADA does not imply preferential treatment nor condone discriminatory decisions during large mass-casualty events, rather it affords responders to conduct triage using reasonable judgment under crisis standards of care when on-scene during a disaster event (IOM, 2009; Jones,

2010).

### *Discussion Theme 1*

When reviewing preparations before the Hurricane Katrina landfall in August 2005, Priestley & Hemingway (2007) recognized very little involvement from individuals with disabilities in the planning process, White, B, (2006) and White, G, et al., (2007) found inaccessible emergency notification systems, including radio or television, for individuals with disabilities, and Fjord & Manderson identified the inclusion of “vulnerable populations” during emergency planning exercises was “putting an able-bodied participant in a wheelchair or placing a blindfold over their eyes” (Fjord & Manderson, 2009, p. 67).

Rescue and recovery actions can be dramatically different depending on the type of incident, length of incident, location and breadth of the impacted area, and range of victims involved. Responder skills are honed by training and experience but not all rescuers know, nor have been trained, on how to specifically handle every single variable of disabilities (Fay, 2022; Schaffer, 2022). The lack of involvement from individuals with disabilities was not limited to the planning or recovery efforts, but training as well (Fjord & Manderson, 2009). It is a completely different situation to



have a simulated victim who actually has no sight to make the responder not assume visual directions or to have somebody without feeling in their legs so responders have to strap non-responsive limbs onto a stretcher (Fay, 2022; Schaffer, 2022). Realistic training helps both responders and individuals. The same disaster situation when approached by different responders can result in immensely different actions which can also dramatically affect the outcome of that rescue. When progressing after the rescue operations, “The disaster recovery process is typically more complex and lengthy for individual with disabilities and required negotiation of a service system that is sometimes unprepared for disability-related needs.” (Stough & Mayhorn, 2015, p. 391).

Alexander summarized three recommendations from the FEMA emergency preparedness guide for individuals with disabilities: Assess the types of hazards they encounter in work or home; create a support network of cohorts at each site; and estimate their own capability to take action during a disaster (Alexander, 2015). Understanding one’s own functional capabilities and being able to relay that best available objective evidence greatly increases the knowledge for the responder to conduct triage and make a reasonable accommodation during a rescue event.

### *Summary Theme 1*

Individuals with disabilities can re-level expectations for incident-driven relationships based on knowing their own capabilities, adequately preparing for a predictive disaster, and knowing how to relay information to responders during a no-notice disaster (Alexander, 2015). Personal preparation for a disaster is just as important as how responders prepare for a disaster to include getting involved with local emergency training (Fay, 2022; Schaffer, 2022). The ADA does not grant preferential treatment nor specifically mandate reasonable accommodations during rescue operations, but it does afford for decisions by on-scene responders based on a risk assessment from available information using triage under crisis standards of care (IOM, 2009; Jones, 2010; USDOJ, 2010).

### **Theme 2**

The misunderstanding in application of triage and crisis medical protocols during disaster situations for any victim with or without disabilities can cause more harm. Responders want to save as many lives as quickly as possible so they assess a situation and problem-solve to get people safely out of a dangerous situation (Fay, 2022; Schaffer, 2022). They have to make a reasonable judgment based on the best

available evidence to figure out the potential for injury (IOM, 2009; USDOJ, 2010; Stough & Mayhorn, 2013). This is normally done based on their experience in training to standards of care (IOM, 2009).

### *Evidence Theme 2*

Responders and hospitals are guided by medical standards of care which “describe the type and level of medical care required by professional norms, professional requirements, and institutional objectives” (AHRQ, 2005b; Hick, Barbera, and Kelen, 2009; Pegalis, 2009, as cited in IOM, 2009, p. 45). This is balanced with the legal standards of care which guides what a responder would do in a current situation “based on what a reasonable and prudent practitioner would do in similar circumstances” (Mastroianni, 2006; Dobbs, 2000; Hood v Phillips, 1977, as cited in IOM, 2009, p. 45). Together, these guidelines lead to crisis standards of care which the Institute of Medicine defined as “the level of care possible during a crisis or disaster due to limitations in supplies, staff, environment, or other factors.” (IOM, 2009, p. 112).

Individuals with disabilities may have conditions which need particular attention not covered in a broad disaster risk recovery plan and may even need special preparations by both the individual and responder. “In an emergency situation it is

comparatively easy to fail to recognise the type of handicap experienced by a particular individual, and thus to offer the wrong kind of assistance.” (Alexander, 2015, p. 390). Special consideration of treatment options may be needed during a disaster which could also be different between a predictive and no-notice disaster. In establishing medical and ethical conventions for crisis standards of care regarding individuals with disabilities, the National Academy of Sciences specifically states, “[t]he needs, challenges, and barriers to caring for [individuals with disabilities] must also be considered for integration into the overall disaster response effort prior to the implementation of crisis standards of care” (IOM, 2009, p. 42).

Crisis standard of care involves triage of a situation (IOM, 2009; Clarkson & Williams, 2021). Triage is “the process of sorting patients and allocating aid on the basis of need for or likely benefit from medical treatment” (IOM, 2009, p. 117). Triage makes an assessment of the patient’s condition and available resources and can occur multiple times in the field, in the emergency room, and in other treatment areas (IOM, 2009). Triage and crisis medical protocols are used to provide fair and equitable resource allocation within the elements of incident management (Hick, et al., 2009, as cited in IOM, 2009). This triage is done when weighing the option of the chances of survival where “one critically ill patient may consume the resources that could save

several other patients” (Christian et al., 2006, as cited in IOM, 2009, p. 84).

During a disaster, a color-code system has become a standard of use to triage people as they are moved away from the incident and towards a care center. Green are people who are okay or have very minor injuries; Yellow are serious injuries but not immediately life-threatening; Red signify immediate with severe injuries yet high potential for survival with treatment; Black are deceased, near death, or have injuries so severe the likelihood of survival is minimal (Clarkson & Williams, 2021).

Responders use the same check for injuries, called the primary and secondary assessments, for everyone during a disaster as they would in a normal response - this is triage (IOM, 2009). They will be sensitive to individual needs but a mass-casualty disaster, whether predictive or no-notice, may preclude reasonable accommodation. Thus, an individual with disabilities will likely not be the only victim in a major disaster and, depending on the triage, may not be the most critical in need of immediate care from the responder (Schaffer, 2022).

Crisis standards of care is “a substantial change in usual healthcare operations and the level of care it is possible to deliver, which is made necessary by a pervasive (e.g., pandemic influenza) or catastrophic (e.g., earthquake, hurricane) disaster” (IOM, 2009, p. 3). In looking at a continuum of care from conventional to contingency to crisis

(Hicks, et al., 2009 as cited in IOM, 2009), during a disaster response the medical system is normally forced into crisis standards of care due to resources insufficient to meet the needs (IOM, 2009) - the same language in the definition of a disaster.

### *Discussion Theme 2*

Individual actions can dramatically change a rescue operation whether it is the same disaster with a different responder or a different disaster with the same responder. Disasters affecting a large area will bring responders from across the country and those teams may have developed different methods for an extrication than local teams for individuals with disabilities (Schaffer, 2022) or as Alexander states, “no single emergency response strategy is valid for all types of disability” (Alexander, 2015, p. 392). This was recognized overall in the formal Hurricane Katrina Lessons Learned report when it expressed inequities in existing incident management plans at every level noting they “fell short of what was needed” (Townsend, 2006, p. 19) which included the breakdown between what was planned and what trained resources were able, or not able, to execute.

Responders train regularly to maintain their skills. Training is a way to hone individual techniques and does not need to be encompassed or combined in a larger-

scale formal exercise. Firefighters train on putting out fires so that when they respond to an actual fire they know ways to address it and also work with standardized equipment; in turn, most of their firefighters can then be interchanged with another crew (Fay, 2022). Medical responders walk through simulated patient scenarios to assess what treatment might be necessary; this is also how triage and the crisis medical protocol are applied (IOM, 2009).

Personal readiness should not wait for higher levels of governments to implement crisis standards of care. The federal government and every state or territory provide varied authorizations between a declaration of emergency versus a declaration of disaster which can impact crisis standards of care (IOM, 2009). This can create challenges in rescue operations when a disaster impacts adjoining states and authorizations are not similar thus restricting responder access and capabilities to execute rescues (post-Katrina, 2006; Townsend, 2006). Individuals with disabilities and the general public are not expected to be legal or medical experts to interpret these declarations just as they are not expected to be highly trained in specialized extrication techniques. In many cases, family and neighbors are the first ones to respond in a disaster, especially for individuals with disabilities, before the organized responders arrive (Fugate, 2009; Alexander, 2015). And regardless of the type of declaration, in

learning to cope with a disaster Alexander noted from Lathrop that individuals with disabilities who live more independent lives may have greater resiliency and ability to face disaster than able-bodied people in the same affected community. Officials should not assume this resourcefulness will allow individuals with disabilities to make their way from a disaster (Lathrop, 1994 as cited in Alexander, 2015, p. 390). However, officials should support the position of personal readiness as vital since “every family that fails to take even the most basic preparedness actions ... is a family that will pull responders and critical resources away from those who truly need such assistance, such as persons with disabilities” (Fugate, 2009, p. 10). However, this effort to change the community mindset is not an immediately implementable solution and will not produce instant results.

### *Summary Theme 2*

Responders want to save as many lives as quickly as possible during a disaster based on crisis standards of care (IOM, 2009; Fay, 2022; Schaffer, 2022). They must make a reasonable judgment based on the best available evidence to figure out the potential for injury (USDOJ, 2010; IOM, 2009; Stough & Mayhorn, 2013). Responders and the medical support system are forced to use triage and crisis medical protocol due



to resources insufficient to meet the needs (IOM, 2009) - the core definition of a disaster. Individuals with disabilities may have conditions which may need special attention, but they may not be the most critical in need of immediate care from the responder based on triage and crisis medical protocol. The presumption of need for immediate care is a light switch fallacy.

### **Theme 3**

There is a way to recognize and mitigate the light switch fallacy, an immediate gratification attitude, by responders and individuals with disabilities before, during, and after disaster rescue operations. In a mass-casualty or wide-spread disaster event, responders cannot reach every incident victim at the same time or even right away. Rescue, transport, or recovery do not happen instantaneously, and this false expectation of immediate results can be termed the light switch fallacy. “The light switch cannot just be turned on, everything is solved, and life goes back to normal” (Schaffer, 2021, p. 250; 2022). A recognition and readjustment of the light switch fallacy to get instantaneous results is needed to ensure the safety and success to all parties involved in a disaster situation.

*Evidence Theme 3*

In one of his first statements to Congress, former FEMA Administrator Craig Fugate stated, “Business as usual will not work in a catastrophic disaster” (Fugate, 2009, p. 7). An expansion of this expression is a disaster will impact all ways of life from food availability, infrastructure, cell phones and electrical power, and everyone, including the local first responders, will all be hit by the same catastrophic event (Townsend, 2006; White, B, 2006; Priestley & Hemingway, 2007; Fugate, 2009, May 2011; Schaffer, 2021). The old disaster recovery adage was to be self-sufficient for about three days then either the conditions would return to normal or higher levels of government would be able to assist (Townsend, 2006; Fugate, 2009). “If every family maintained the resources to live in their homes without electricity and running water for three days, we could allocate more Federal, State, and local response resources to saving lives” (Townsend, 2006, p. 80). But in the technology-driven age, people want the answers and recovery immediately (Tauberfeld, 2017; Ackerman, 2018; Schaffer, 2021). Disaster situations spotlight and magnify the light switch fallacy at all levels including victims, responders, emergency managers, local to federal executives, politicians, news media, and the public.

The modern world has become impatient and consumed with immediate gratification, the tendency to obtain more immediate benefit (Ackerman, 2018), which has continued to grow as more people want the gratification of immediate internet and social media information (Tauberfeld, 2017). “The expectation of rescuing 30,000 people from their rooftops in one day...was not possible due to the lack of helicopters and boats - and even then, once on dry land, there were no buses to take people to a recovery center” (Schaffer, 2021, p. 249). In 2020 during vaccine development for the COVID-19 response, not enough volunteers from diverse backgrounds were enrolled to provide proper population balance delaying one clinical study to which their executive replied, “You can’t fix that overnight” (Steenhuysen, 2021).

Everyone wants an immediate solution, but not everything can be fixed right away, and most people do not understand the multiple integrated, parallel, and serial steps required. People at all levels no longer comprehend the actual time needed to have a situation fixed; they need to understand most disasters take time to resolve and how a situation resolves is affected by many factors outside of their control (Schaffer, 2021). For a predictive disaster, the light switch fallacy was nearly continuous at all levels during the response to Hurricane Katrina - which from the planning, rescue, and recover aspects was widely considered by many scholars to have been highly deficient (Post-

Katrina, 2006; Townsend, 2006; White, B, 2006; Priestley & Hemingway, 2007; White, G, et al., 2007; Jones, 2010; Stough & Mayhorn, 2013; Alexander, 2015; Stough & Mayhorn, 2015; Twigg et al., 2018; Leong, et al., 2020; Pyke & Wilton, 2020). Higher levels of government do not always secure a fix, quick or otherwise, as Keating noted regarding a June 2001 unrehearsed pandemic exercise, “Dark Winter quickly punctured the myth that every level of government would work together because each knew its role and that state and local officials would salute smartly when the feds walked in the room” (Keating, 2020).

Resolution of issues and reduction of the light switch fallacy involves each individual understanding their role and responsibilities. Reducing the light switch fallacy begins with re-leveling of expectations (Theme 1) of a direct threat through risk assessment. A public entity or individual can make a risk assessment based on reasonable judgment and best available evidence of the probability of injury and if reasonable modifications will mitigate the risk. (USDOJ, 2010; Stough & Mayhorn, 2013).

### ***Discussion Theme 3***

Regardless of the type of disaster incident, the goals of and resultant interactions

between responders and victims can be defined in relatively simple terms: From the responder view, *save as many lives as quickly as possible*; from the victim view, *save me now!* (Schaffer, 2021, 2022; Fay, 2022). Everyone is not always on the same wavelength of thinking which can be the source of many problems, mainly a “Why has this particular person not been rescued yet?” inquiry. Media and now social media play an ever-increasing part to informing people, thus instead of hyperbolizing a disaster, “efforts should be made to sensitize the mass media to their potential role as purveyors of emergency information to people with disabilities.” (Alexander, 2015, p. 392).

The public entity emergency manager can explain the end goal, what products or achievements are needed along the way, potential setbacks, provide a reasonable timeline to reach the end goal, and provide the wide range of possibilities from the best to worst case scenarios from an emergency response and recovery perspective (post-Katrina, 2006; Townsend, 2006; Schwab, 2010; Smith, 2011). Planners for the emergency manager look at the nature, duration, and severity of possible disasters to determine the practices and procedures needed to safely mitigate or respond to the event. This includes the recovery element to ensure reasonable modifications of provisions will accommodate all victims, develop the strategies for progression from the current moment to the end state, and how to address concerns along the way (post-

Katrina, 2006; Townsend, 2006; Schwab, 2010; Smith, 2011; Schaffer, 2021). The developed plans guide how the first-on-the-scene emergency responders triage or react with an incident victims and how prioritization or crisis of standards care are implemented so they can save as many lives as possible (Post-Katrina, 2006; Townsend, 2006; IOM, 2009; Schaffer, 2022).

Personal preparedness is vital to survival, so an individual has a great deal of responsibility. Disaster response plans should address what public information is available on self-awareness, self-readiness, self-survival, and advocacy groups for unique needs or challenges (USDOJ, 2010; Fugate, 2009, Oct 2011; Stough & Mayhorn, 2013; UNISDR, 2015; Leong, et al., 2020; Schaffer, 2022). Have an emergency kit and evacuate before the disaster is foremost as “personal disaster preparedness is and must be a national priority, and every elected and appointed official at every level of government must make it a priority” (Fugate, 2009, p.11).

Planning is conducted by emergency management services in anticipation of predictive and no-notice disasters (Schwab, 2010; Smith, 2011) and a no-notice disaster exposes a typical light switch fallacy reaction. On March 22, 2014, near the town of Oso in Snohomish County, Washington, a landslide of 18 million tons of earth struck at

over 40 miles per hour, covering an area about one square mile. In less than one minute, over 40 homes were demolished, one mile of a state highway was blocked, and the Stillaquamish River was dammed. Light switch fallacy: Just go in and pick the people up. Reality: Initial response crews were only 15-30 minutes away, but full rescue and recovery operations including helicopters took extra time due to the location, access, and the instability of the area from floodwater, mud, and debris. The immediacy of operations focused on the likelihood of finding anyone alive which took into account the conditions, crisis standards of care, triage and crisis medical protocols, and the safety of all responders. The last of 15 persons rescued was 5 hours after the incident, the last of 43 victims was recovered after 115 days, and the road opened six months after the incident (Lombardo, 2014; Benda, 2020; Schaffer, 2021, 2022; Fay, 2022).

While the actual process is considerably more complex (Schwab, 2010; Smith, 2011), emergency planning comes down to a basic if-then concept: If (fill-in an incident) occurs, then (figure out) response options are possible. Once a plan is developed, an exercise is conducted to see how the plan works, improvements are made, and the process begins again (Townsend, 2006; Schwab, 2010; Smith, 2011). For many plans, responders rely heavily on technology from hardwired electricity at a command center to battery powered cellular, satellite phones, and even drones when doing remote

field work. In a disaster, good technology works...until it does not. Social media notifications, hearing aids, mobile voice-to-text, voice translator, wheelchairs, and remote controls all work well until the batteries run out or the cell towers are down (White, B, 2006; Grajdura, et al., 2011; Fay, 2022). Even writing on an e-notebook is not the same as having an interpreter speaking sign language (Schaffer, 2022). As a contrast to the days to months without phone service after Hurricane Katrina (Schaffer, 2021), the cellular infrastructure after the 2010 Haiti earthquake returned quickly allowing information to be passed to the responders (Fugate, May 2011).

Overall, technology has its benefits and when appropriately integrated “is frequently considered a serious way to involve people with disabilities” (Hans and Mohanty 2006; Fu et al., 2010, as cited in Alexander, 2015, p. 392). In directing a shift of governmental policy, former FEMA Administrator Fugate noted social media can be used to immediately disseminate vital information to the public while also receiving specific, real-time, first-hand updates (Fugate, May 2011). Responders can now make decisions from on-scene drone video to pinpoint victims which can quickly facilitate more efficient rescue operations. The challenge for the emergency operations center is that many drones, social media videos, and 911 calls coming in identifying victims in various locations can potentially add more delays when prioritizing the deployment of



one asset to rescue multiple diversely located victims (Schaffer, 2021, 2022).

The light switch fallacy is a contrast to reality. Even the idea of recovery operations integrating into long-range mitigation efforts takes time to enact (Townsend, 2006; UNISDR, 2015). While the economy, living conditions, and infrastructure in Haiti were poor due to multiple natural disasters before the 2010 earthquake struck, subsequent disasters plagued even short-term recovery efforts in the ensuing years. Functional earthquake-resilient infrastructure and facilities could have been constructed in Haiti, but who will fund it, what facilities are a priority, how quickly can it be done? (Kahn & Pierre, 2020; Schaffer, 2021).

### *Summary Theme 3*

To wallow in the light switch fallacy and ignore the necessary parallel and serial steps will significantly erode all rescue and recovery efforts. Reducing the light switch fallacy begins with re-leveling of expectations (Theme 1) of a direct threat through risk assessment. A risk assessment can be made based on reasonable judgment from best available evidence of the probability of injury and if reasonable modifications will mitigate the risk. (USDOJ, 2010; Stough & Mayhorn, 2013). Victims, responders, emergency managers, local to federal executives, politicians, news media, and the

public can be educated on how mitigations, rescues, and recoveries happen to learn how their role plays a part in reducing the light switch fallacy (Schaffer, 2021). Technology has its place and time in a disaster but is only good if it works (White, B, 2006; Grajdura, et al., 2011; Fay, 2022).

### Summary and Conclusion

Individuals with disabilities are often disproportionately or more severely affected by a disaster than others in the same area, and while some improvements in the planning and recovery have included individuals with disabilities, progress still remains (Fjord & Manderson, 2009; IOM, 2009; Jones, 2010; Stough & Mayhorn, 2013; Alexander, 2015; Twigg et al., 2018; Ton, et al., 2019; Leong, et al., 2020; Pyke & Wilton, 2020).

With a noted lack of research on the actual rescue operations for individuals with disabilities during large mass-casualty events (Stough & Mayhorn, 2013; Alexander, 2015; Stough & Kelman, 2017; Pyke & Wilton, 2020), this paper focused on three themes addressing the impact in rescue operations during disasters on individuals with disabilities not previously noted in research literature: Theme 1, the re-leveling of expectations before a predictive disaster and actions during a no-notice disaster; Theme

2, the misunderstanding of triage and crisis medical protocols during disaster situations; and Theme 3, how to recognize and mitigate the light switch fallacy before, during and after disaster rescue operations.

How rescuers prepare to respond to a disaster is just as important as how individuals with disabilities personally prepare for a disaster, including getting involved with local emergency training (Fay, 2022; Schaffer, 2022). The statement by Fjord and Manderson, “Why not place disability-centered approaches at the core of disaster planning and ensure that the probable needs of most residents are accommodated?” (Fjord and Manderson, 2009, p. 65) is the foundation of what planning should be considering. Responders want to save as many lives as quickly as possible during a disaster based on triage under crisis standards of care (IOM, 2009; Fay, 2022; Schaffer, 2022) and they must make a reasonable judgment based on the best available evidence to figure out the potential for injury (USDOJ, 2010; IOM, 2009; Stough & Mayhorn, 2013). The ADA does not grant preferential treatment nor specifically mandate reasonable accommodations during rescue operations (IOM, 2009; Jones, 2010; USDOJ, 2010), but it does allow for triage decisions by on-scene responders based on a risk assessment from available information using crisis standards of care (IOM, 2009). Language should therefore not be added to the ADA restricting the decision-making

abilities of on-scene responders.

Individuals with disabilities can mitigate threats by conducting a personal risk assessment, participating in local emergency management training exercises, evacuating before a predictive disaster, and preparing for a no-notice disaster. Re-leveling of expectations (Theme 1) of a direct threat through risk assessment and understanding priorities in triage crisis medical protocols (Theme 2) can reduce the light switch fallacy (Theme 3). People with or without disabilities can make a risk assessment based on reasonable judgment and best available evidence of the probability of injury and if reasonable modifications will mitigate the risk (USDOJ, 2010; Stough & Mayhorn, 2013). “Personal preparedness among the individuals, families and communities we serve is one of the most important keys to our [FEMA] success” (Fugate, May 2011, p. IV).

### Postscript

Continued research is needed to ensure the functional application of the concepts and understand the benefits of greater inclusion of individuals with disabilities in the preparatory planning phase as well as the recovery operations phase of disaster planning. Due to the near zero research found in the specific realm of the rescue phase of disaster response, this area would be recommended for greater effort of inclusion.

## References

- Ackerman, C.E. (June 19, 2018). *What is instant gratification? A definition+16 examples and quotes*. Positive psychology website. Retrieved November 28, 2020 from <https://positivepsychology.com/instant-gratification/>
- Alexander, D. (2015). Disability and disaster: An overview. *Disability and disaster*, 15-29.
- Americans With Disabilities Act of 1990 (ADA), 42 U.S.C. ch. 126 *et seq.* PL 101-336 104 Stat. 327 (1990).
- Americans With Disabilities Amendments Act of 2008. Public Law 110-325, 122 Stat. 3553 (2008).
- Benda, E. (December 4, 2020). *2014 Oso landslide, Washington*. Environmental Systems Research Institute. Retrieved February 2, 2022 at <https://storymaps.arcgis.com/stories/ebdfd4e93aa747dabede00d50b5019f8>
- Clarkson L, Williams M. (August 13, 2021). *EMS Mass Casualty Triage*. In: *StatPearls* [Internet]. Treasure Island, FL: StatPearls Publishing; 2022 Jan-. Retrieved from <https://www.ncbi.nlm.nih.gov/books/NBK459369/>

Edwards, B. (2000). *Disasters, diversity and equity: Disproportionate impact and uneven access to recovery resources among residents of eastern North Carolina following Hurricanes Bonnie, Dennis, and Floyd*. 25th Annual Workshop on Hazards Research and Applications, Boulder, CO.

Fay, R. (personal communication, January 26, 2022).

Fjord, L., & Manderson, L. (2009). Anthropological perspectives on disasters and disabilities: An introduction. *Human Organization*, 68(1), 64-72.

Fugate, C. (July 27, 2009). Written statement. *In Subcommittee Hearing: Post-Katrina: What it Takes to Cut the Bureaucracy and Assure a More Rapid Response After a Catastrophic Disaster*. House Subcommittee of Economic Development, Public Buildings and Emergency Management. Washington, DC: Committee on Transportation and Infrastructure, US Congress. House of Representatives.

Fugate, C. (May 4, 2011). Written statement. *In Subcommittee Hearing: Understanding the Power of Social Media as a Communication Tool in the Aftermath of Disasters*. Subcommittee on Disaster Recovery and Intergovernmental Affairs. Washington, DC: Committee on Homeland Security and Governmental Affairs, US Congress. Senate.

Fugate, C. (October 25, 2011). "Written statement." *Five Years Later: An Assessment of the Post Katrina Emergency Management Reform Act*. House Subcommittee on Emergency Preparedness, Response, and Communications. Washington, DC: Committee on Homeland Security, US Congress. House of Representatives.

Golshani, N., Shabanpour, R., Mohammadian, A., Auld, J., & Ley, H. (2019).

Evacuation decision behavior for no-notice emergency events. *Transportation research part D: transport and environment*, 77, 364-377.

<https://doi.org/10.1016/j.trd.2019.01.025>

Grajdura, S., Qian, X., & Niemeier, D. (2021). Awareness, departure, and preparation time in no-notice wildfire evacuations. *Safety science*, 139, 105258.

Institute of Medicine (IOM) Gostin, L. O., Hanfling, D., Hanson, S. L., Stroud, C., & Altevogt, B. M. (Eds.). (2009). *Guidance for establishing crisis standards of care for use in disaster situations: a letter report*. National Academies. The National Academies Press.

Jones, N.L. (December 29, 2010). *The Americans with Disabilities Act and Emergency Preparedness and Response*. Congressional Research Service (CRS Report No. RS22254).



Kahn, C., and Pierre, J. (January 12, 2020). *A 'Lost decade': Haiti still struggles to recover 10 years after massive earthquake*. National Public Radio. January 12, 2020. Retrieved November 27, 2020 from

<https://www.npr.org/2020/01/12/794298546/a-lost-decade-haiti-still-struggles-to-recover-10-years-after-massive-earthquake>

Keating, F. (April 20, 2020). Compilation of coronavirus and the military war-gaming the next pandemic. *Wall Street Journal*. Retrieved November 27, 2020 from

<https://www.wsj.com/articles/war-gaming-the-next-pandemic-11587310321>

Kelman, I., & Stough, L. (2015). *Disability and disaster: Explorations and exchanges*.

Palgrave MacMillan. [https://doi.org/10.1057/9781137486004\\_1](https://doi.org/10.1057/9781137486004_1)

Leong, G., Stodden, R., & Balikuddembe, K. J. (2020). Disability and Disaster: What to

Know - What to Do. *Pacific Rim International Conference on Disability and*

*Diversity Conference Proceedings*. Honolulu, Hawai'i: Center on Disability

Studies, University of Hawai'i at Mānoa.

Lewis, J. (1999). *Development in Disaster-Prone Places: Studies of Vulnerability*.

Intermediate Technology Publications.

Lombardo, K., Boggs, J., Boudreau, J., Chiles, P., Erickson, J., Gerstel, W.,  
Montgomery, D., Shipman, L., Radcliff-Sinclair, R., Strachan, S., Sugimura, D.,  
Trimm, B. (December 15, 2014). *The SR 350 landslide commission final report*.  
State of Washington.

McEntire, D.A.; Fuller, C; Johnston, C.W.; & Weber, R. (May-June 2002). A  
Comparison of Disaster Paradigms: The Search for a Holistic Policy Guide,  
*Public Administration Review*, May-June, 2002, 62(3), 267-281,  
<https://www.jstor.org/stable/3110212>

Neal, D.M. (August, 1997). Reconsidering the phases of disaster. *International Journal  
of Mass Emergencies and Disasters*. 15(2), 239-264.

Post-Katrina Emergency Management Reform Act of 2006. Public Law 109-295, 120  
Stat. 1394 (2006).

Priestley, M. & Hemingway, L. (February 15, 2007) Disability and disaster recovery: a  
tale of two cities? *Journal of Social Work in Disability & Rehabilitation*. 5(3-4),  
23-42.

[https://doi.org/10.1300/J198v05n03\\_02](https://doi.org/10.1300/J198v05n03_02)

Pyke, C. & Wilton, R. (December 2020) Planning for inclusion? An assessment of

Ontario's emergency preparedness guide for people with disabilities.

*International Journal of Disaster Risk Reduction*. 51.

<https://doi.org/10.1016/j.ijdr.2020.101888>

Schaffer, D. (2021). The light switch fallacy: Emergency management and recovery in

an on-demand world. *Journal of Emergency Management*, Vol 19, No 3. (2021,

May/June).

<https://doi.org/10.5055/jem.0545>

Schaffer, D. (March 1, 2022). *Disabilities and disasters: How a rescuer handles what*

*they encounter*. [Conference session, on-demand]. 37th Annual Pacific Rim

International Conference on Disabilities and Diversity, University of Hawai'i at

Mānoa.

Schwab, J. (2010). *Hazard Mitigation: Integrating best practices into planning*.

American Planning Association, Planning Advisory Services Report No. 560.

Federal Emergency Management Agency.

Smith, G. (2011). *Planning for Post-Disaster Recovery: A review of the United States*

*disaster assistance framework*. The Public Entity Risk Institute.

Steenhuysen, J. (October 6, 2020). *Moderna vaccine trial contractors fail to enroll enough minorities, prompting slowdown*. Reuters News. Retrieved November 27, 2020 from <https://www.reuters.com/article/us-health-coronavirus-vaccine-moderna-ex/exclusive-moderna-vaccine-trial-contractors-fail-to-enroll-enough-minorities-prompting-slowdown-idUSKBN26R1SP>

Stough L.M., & Kelman I. (2018). *People with Disabilities and Disasters*. In: Rodríguez H., Donner W., Trainor J. (eds) *Handbook of Disaster Research* (pp. 225-242). Handbooks of Sociology and Social Research. Springer, Cham. [https://doi.org/10.1007/978-3-319-63254-4\\_12](https://doi.org/10.1007/978-3-319-63254-4_12)

Stough, L.M., & Mayhorn. (2013). Population segments with disabilities. *International Journal of Mass Emergencies and Disasters*. 31(3), 384-402.

Taubenfeld, E. (March 23, 2017). The culture of impatience and instant gratification. *Study Breaks*. Retrieved November 28, 2020 from <https://studybreaks.com/culture/instant-gratification/>

Ton, K.T.; Gaillard, J.C.; Adamson, C.E.; Akgungor, C.; Ho, H.T. (March 2019). Expanding the capabilities of people with disabilities in disaster risk reduction.

*International Journal of Disaster Risk Reduction*, 34:11-17.

<https://doi.org/10.1016/j.ijdr.2018.11.002>

Townsend, F.F. (February 2006). *The Federal Response to Hurricane Katrina Lessons*

*Learned*. George W. Bush White House archives. Retrieved December 6, 2021

at <https://biotech.law.lsu.edu/katrina/govdocs/katrina-lessons-learned.pdf>

Twigg, J., Kett, M., & Lovell, E. (2018). Disability inclusion and disaster risk reduction.

*Briefing Note*. London: Overseas Development Institute.

United Nations International Strategy for Disaster Reduction (UNISDR). 2015. *Sendai*

*framework for disaster risk reduction 2015–2030*. Geneva: UNISDR

United States Department of Justice (USDOJ), Code of Federal Regulations, General

Requirements, 28 CFR 35 *et seq.* (2010).

Van Willigen, M., Edwards, T., Edwards, B., Hesse, S. (August 2002). Riding out the

storm: Experiences of the physically disabled during Hurricanes Bonnie, Dennis,  
and Floyd. *Nat. Hazards Rev.*, 2002, 3(3): 98-106.

[https://doi.org/10.1061/\(ASCE\)1527-6988\(2002\)3:3\(98\)](https://doi.org/10.1061/(ASCE)1527-6988(2002)3:3(98))

White, B. (2006). Disaster Relief for Deaf Persons: Lessons from Hurricanes Katrina

and Rita. *Review of Disability Studies: An International Journal*, 2(3).

White, G. W., Fox, M. H., Rooney, C., & Cahill, A. (2007). Assessing the impact of Hurricane Katrina on persons with disabilities. *The Kansas nurse*, 82(6), 9.



**Disabilities in Disaster Situations: How a Rescuer Handles What They**

**Encounter** by Daryl Schaffer

<https://rdsjournal.org/index.php/journal/article/view/1173> is licensed under a [Creative Commons Attribution 4.0 International License](#). Based on a work at <https://rdsjournal.org>.

**Advocacy 101: Discover Your Personal Style**

Areta Guthrey,

The Disability Information Network

**Author Note**

Areta K. Guthrey, J.D., *The Disability Information Network*, California, United States.

Areta Guthrey has been an attorney for 37 years. She has been an advocate for disability rights and inclusion for more than 25 years and founded the Disability Information Network in 2019.

Correspondence concerning this article may be submitted to the author at [akguthrey@disabinfo.net](mailto:akguthrey@disabinfo.net).

### **Abstract**

Advocacy makes a difference for all people with disabilities. “Advocacy 101” discusses a variety of advocacy techniques, types of advocacy, and personal styles. Personality types and their various strengths are examined. Unique and educational advocacy that departs from standard phone calls and letter writing is explored.

*Keywords:* disability, advocacy, activism



### **Advocacy 101: Discover Your Personal Style**

During the 2022 Pacific Rim Conference on Disability and Diversity, advocates from around the world came together to educate, and be educated, about Disability Advocacy. “Advocacy 101: Let’s Learn How” focused on the often-overlooked fundamentals of activism, i.e., that we can all participate in changing the world through our own individual strengths. The presentation was designed to teach Disability Advocates, whether beginners or experts, to examine their goals and talents to make their greatest impact. Advocacy is equal parts teaching and learning. We all have the ability to teach, and there is always something to be learned from others. We must learn about ourselves, find our own unique voices and communicate our needs and desires to teach others.

#### **Who Can Be an Advocate?**

Disability Advocacy is acting, speaking, or writing to promote, protect, and defend the human rights of people with disabilities. *Anyone* can be an advocate, whether they are living with a disability or not. Advocacy can be done *anytime* and *anywhere*. We can educate others just by our presence in the community, promoting inclusion,

justice, access, and equality. We can make ourselves heard at community advisory committee meetings that focus on disability related issues such as special education, state councils on developmental disabilities, and at public meetings, which are not necessarily disability focused.

### **Common Forms of Advocacy**

“Advocacy 101” began with a review of some of the most common types of advocacy: Self-Advocacy, Group Advocacy, and Systems Advocacy. *Self-advocacy* is person centered; the goal is to get what you need or want as an individual. This type of action requires us to understand our own needs and rights before we can speak up for ourselves. We use this form of activism to communicate our interests and desires, to teach others that we are experts on ourselves, and, to contribute opinions to the discussion of issues which affect us personally. *Supported self-advocacy* gives us one-on-one support from an advocate of our choice to work with us on our advocacy efforts. Help and encouragement can come from family members, friends, caregivers, or paid advocates. People with similar experiences or issues can often provide the assistance we need if we are new to advocacy or unable to advocate for ourselves.

There are two general types of supported self-advocacy: *directed* and *non-*

*directed*. For directed advocacy, we can choose someone we know and trust to work with us to identify the issues we face and decide on the type of change we want or need. We are in control; the advocate's role is to assist. We give instructions and make our own decisions. It is up to us whether we want to speak for ourselves, or let the advocate do the talking. With non-directed advocacy, close friends or family members speak for those of us who do not have the ability or capacity to represent ourselves. Actions are person-centered and based on the belief that all people have common fundamental rights. A non-directed advocate will act in the best interests of the person with a disability to secure any necessary supports or services. Anyone interested in finding advocates to assist them, can make use of the various nonprofit and government legal assistance programs such as family resource centers and family education centers that can be found at [parentcenterhub.org](http://parentcenterhub.org).

*Group Advocacy* occurs when people with shared goals and values meet to talk and listen to each other. They speak out collectively for the common good, and act as a group to impact and change public opinion. People who work to change a system, or a social norm, are *Systems Advocates*. They work to change laws and policies which impact people with disabilities as individuals or as part of a group. Moreover, there are no strict rules about the types of advocacy we can be involved in. In fact, the varieties

often overlap. An individual may be a self-advocate within a group of systems advocates who are working to change a law or policy that affects all of them.

### **The 5 Ws of Advocacy**

Planning an advocacy campaign requires us to consider some important questions to give our efforts focus and keep us on track toward our goals:

**Who** is the audience? Political decision makers? School officials? Other Influencers?

**What** are the values, ethics, and solutions you are advancing?

**When** does change need to happen? Is this a long-range goal, or is it time sensitive?

**Where** do you want to end up, i.e., what is the change you want?

**Why** is the current policy harmful?

### **The How of Advocacy**

For many of us, learning how to advocate is an important first step. We must

learn how to approach others and incorporate their interests into our presentations. We should be complimentary and empathetic whenever possible. Remember that most decision-makers are good people; they may simply be unaware of the ramifications of their actions. It's also important for us to understand that other people have their own, or the same, issues which may make it difficult for them to harness the energy needed to make change. Part of our job is to present information in an easily accessible and understandable way.

As more people with disabilities hold positions of power, remember that they are on our side. They may have invisible disabilities, or family members and friends with disabilities, which can make it easier to empathize, but harder to do the work needed.

### **Addressing Barriers to Effective Advocacy**

There may be barriers to communication and understanding on the part of the advocate or the audience which will have to be addressed. For example, lack of eye contact from people with autism spectrum disorder, or other neurological conditions such as PTSD, social anxiety, or generalized anxiety can be perceived as problematic. Many people believe that people who do not look others in the eye when speaking to them lack credibility. We can address those issues openly with our listeners or we can

choose to engage in another form of communication which makes us more comfortable.

Other issues which may impact our ability to advocate can include mobility issues and communication issues. If a meeting is taking place in a building which is not accessible, a person with a mobility issue will need to plan accordingly and tailor their advocacy to address the lack of accessibility while still conveying their messages. Others may have communication issues, such as a lack of interpreters, inability to speak, or a lack of familiarity with the method of communication being used, such as Zoom.

As an example, I explained my own barrier to advocacy. I am bipolar, and confrontation triggers a fight or flight loop in my brain which is referred to as “amygdala hijacking.” Essentially, the neurons in my brain don’t communicate sufficiently between my amygdala and my frontal lobe, which is designed to process the fight or flight response and turn it off when there is no danger. Confrontation can be very stressful and may do long term damage to the brain.

For many years, I believed that I could not be an effective advocate because of my aversion to confrontation with other people. I have since learned that there are many forms of advocacy and that each one of us can be a powerful advocate by relying on our

own personal strengths. I am comfortable writing and teaching others in a non-confrontational way about the various issues that affect people with disabilities. We are happier, and better advocates, when we discover how to make change with our own unique talents.

### **Personal Style**

To increase our effectiveness as advocates, we can each develop a personal style that relies on our gifts and assets. We can ask ourselves what makes us feel and work best at our best. Some of the things to consider are: are you an introvert or an extrovert; are you an artist; do you have a personal preference for working in audio presentations or video presentations? Do you work better in a classroom environment as a teacher or in a more crowded or noisy rally?

Generally speaking, there are 16 personality types. These are not emotions; these are characteristics of your personality that are more or less consistent overtime. For example, many people believe that being an introvert means that a person is shy. However, shyness is not an emotion; it is how you feel at a particular moment around other people. A personality type, such as introversion, has specific characteristics around the ways in which we function.

Exploring your personality type can be informational and entertaining. The Myers-Briggs Type Indicator is a self-test that is available at [www.verywellmind.com](http://www.verywellmind.com). By answering a series of questions, the online program will produce a profile on your personality: extraversion versus introversion; sensing versus intuition; thinking versus feeling; and judging versus perceiving.

Once you learn the general characteristics of your personality, you can research them on the site to discover more about your style of working and communicating. This will give you a good start toward identifying the types of advocacy that will suit you best.

### **Introvert or Extrovert?**

An introvert is described as someone who is inward turning, reserved and private. Introverts are particularly good at slowing down and thinking deeply. They tend to look inward for inspiration and creativity, and they dislike working in large groups or being around other people while they are working. Introverts tend to enjoy being alone or working in small groups, one on one. They are most comfortable meditating on the issues and making plans. If you are an introvert, thoughtful, personal activism may be your greatest strength.



As such, “quiet” forms of activism are often carried out by introverts. Reading reports, researching what works, and compiling statistics for presentations are introvert superpowers. Working behind the scenes, gathering donations or organizing supplies, introverts excel at the “hidden” parts of activism which are necessary for success.

Some of these strengths of introverts are addressed by Sarah Corbett, an activist in England, in her Ted talk, “Activism Needs Introverts.” Corbett describes how she felt a sense of failure because she became overwhelmed by the stress of requesting signatures on petitions and other activities, but she longed to participate. In a flash of genius, she formed groups of artists and made gifts for people in power. She describes how some of the politicians who received their gifts were strongly impacted by the gesture and often felt more inclined to engaged with the advocates.

In one case, the artist activists made small scrolls with messages on them about the impact of fast fashion on the environment. They tied up the scrolls and hit the streets of London, depositing the scrolls in the pockets of garments hanging in the clothing shops. When customers tried on the clothing, or purchased it, they would find the scrolls in the pockets with the message to think about the impact they were having on the earth with their choices.

On the other hand, extroverts have their own strengths in advocacy. They tend to be outward turning, sociable, and assertive. They enjoy attention and excitement, and they thrive in the world of public speeches, protests, and rallies. The web site [www.simplypsychology.org](http://www.simplypsychology.org) has more information about the contrast between introverts and extroverts.

With all of this in mind, it's important for all of us to realize that while extroverts can march in large groups waving signs, the signs were probably made by the introverts. Also, extroverts may excel at attending and speaking at government meetings and lobbying, but much of the research has been conducted and synthesized by the introverts. We can all work together to strengthen our advocacy projects.

### **What's Your Superpower?**

There are many different ways to engage in advocacy. If you enjoy writing, composing letters to government representatives and editors of newspapers and magazines can have a great impact. Writers can also create online newsletters or email chains that educate a wider audience. Digital, video, and spoken word poetry presentations need writers to be successful. (For reference, sample advocacy letters may be found in the resources section of the [www.familyrn.org](http://www.familyrn.org) website.)

In addition to considering the unique contributions introverts and extroverts may make, during advocacy 101, we also talked about the contributions that artists can make. Provocative art which tells a story or highlights an issue can be quite persuasive. Beautiful posters or signs that catch the public's attention can contain information that gets people to think. Crafting or painting together can help advocates to engage with others and design advocacy projects. The resulting crafts can be worn or distributed to other advocates or to decision-makers, e.g., T-shirts, wristbands, posters, or cards.

### **Get started**

Now is the time to start your journey to becoming a disability advocate. Discover and value the skills and the traits that you already have. Make a list of the activities you enjoy the most, whether it is talking on the phone, reading, writing, or making art. Focus on your strengths. Are you detail oriented? Do you like large crowds?

It's also important to realize that many of us are not able to engage in the everyday activities of organized advocacy; however, anyone can provide valuable support to advocacy organizations. Many organizations need financial support, administrative assistance, and gathering materials for their events. There is something

for everyone.

Most importantly, remember that our greatest advocacy tool is our right to

VOTE.



**Advocacy 101: Discover Your Personal Style** by Areta Guthrey

<https://rdsjournal.org/index.php/journal/article/view/1174> is licensed under a [Creative Commons Attribution 4.0 International License](#). Based on a work at <https://rdsjournal.org>.

**Focusing on Essential Functions for Persons with Disabilities  
to Improve Working Environments:  
From a Survey on Coffee Workers in Japan**

Wakaba Hamamatsu<sup>1</sup> and Kuniomi Shibata<sup>2</sup>

<sup>1,2</sup> Department of International & Cultural Studies and Inclusive Education Support  
Division, Tsuda University

**Abstract**

This article analyses the effects of reasonable accommodations given to persons with disabilities in the workplace in Japan. The author demonstrates that when persons with disabilities are provided reasonable accommodations, their production increases significantly. The article also gives a comparison between types of reasonable accommodations provided in Japan and the United States of America, using the coffee industry in Japan as an example. The author is starting their own coffee company to see if providing reasonable accommodations to workers with disabilities is a direct correlator to the increased productivity. The article provides examples of how workers in Japan are listened to by their employers. In one example where the worker's disability is not taken very seriously, the accommodation provided is to read a comic

book. When the reasonable accommodation fits the worker's abilities, production of coffee greatly increases. The author wants readers to understand that when people are given reasonable and proper accommodations, they can compete in the workplace. This is true both in Japan and in the United States of America.

*Keywords:* employment, disability, Japan, accommodations, COVID-19

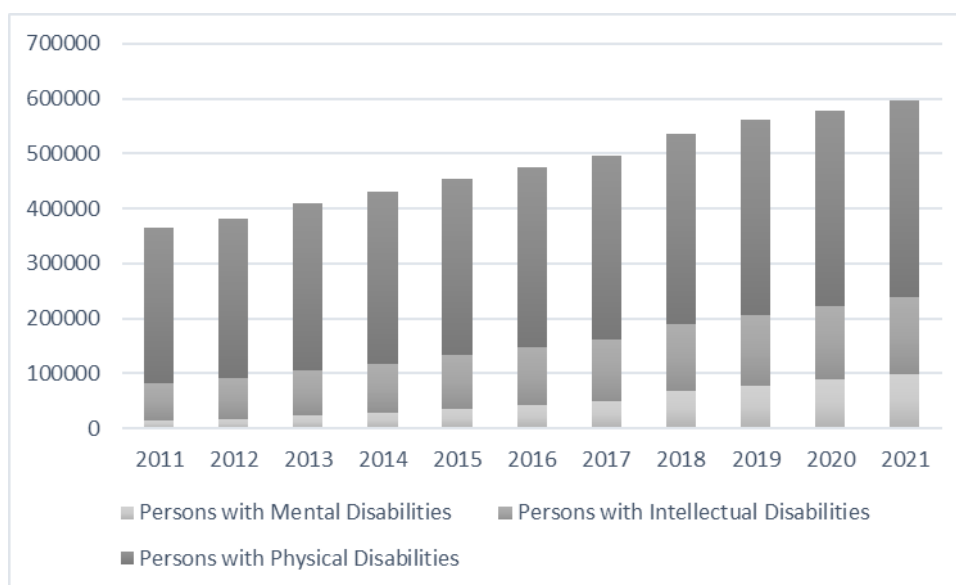
**Focusing on Essential Functions for Persons with Disabilities  
to Improve Working Environments:  
From a Survey on Coffee Workers in Japan**

**Persons with Disabilities Working in Japan**

According to the Ministry of Health, Labor, and Welfare, the number of persons with disabilities employed in Japan was 366,199 in 2011 (Ministry of Health, Labor, and Welfare, 2021a). In 2021, this number increased to 597,787. Figure 1 shows an annual increase in the employment rate of persons with disabilities in Japan (Ministry of Health, Labor, and Welfare, 2021a). If we focus only on the number of persons with disabilities working in Japan, which has increased steadily each year, it might seem that there is no serious problem.

**Figure 1**

*Employed Persons with Disabilities in Private Companies in Japan*



NOTE: This graphic is based on data from the Ministry of Health, Labor, and Welfare (2021).

At the same time, according to some persons with disabilities, they are unable to fully utilize their abilities in their place of employment. For example, a person with a mental disability indicated to the author that he obtained a mental disability certificate and joined a company with a disability employment quota. "I joined the company because I wanted to work, but my boss told me to browse the comics at a convenience



store. My boss doesn't understand me at all." This highlights the problem that, in Japan, the purpose of employing persons with disabilities at times appears simply to hire them; companies may only see persons with disabilities without understanding and utilizing their gifts and talents. Consequently, many Japanese companies cannot envision how persons with disabilities work.

To clarify the structure of the problem, I would like to focus on the discussion of essential functions. Essential functions are an unfamiliar concept in Japan's system of hiring persons with disabilities. This is due to the belief that clarifying the essential functions of work in Japan leads to a merit system that creates persons with disabilities who cannot work. For example, Hanada (1991) and Yashiro (1991) pointed out that focusing on essential functions in Japan makes it impossible for persons with disabilities to obtain jobs. Therefore, when hiring persons with disabilities, most Japanese employers provide reasonable accommodations without considering the concept of essential functions.

Instead of focusing on essential functions, regarding the employment of persons with disabilities in Japan, greater attention is often given to communication skills. Analyzing previous papers on the abilities required of persons with disabilities in

Japanese workplaces Kodama et al. (2020) found that, for persons with disabilities to demonstrate their abilities in the workplace, their work attitude and cooperation with superiors and colleagues are important. In 2005, the Ministry of Economy, Trade, and Industry published "Essential Competence." Kodama et al. pointed out that, out of the 12 elements of these guidelines, six relate to the ability to work in a team (2020). Furthermore, Inoue et al. (2012) bring attention to the fact that interpersonal communication skills are important for persons with disabilities to obtain employment. These discussions clearly suggest that many Japanese people view communication skills as a condition of employment.

Similarly, the Ministry of Health, Labor, and Welfare promote social skills training for the employment of persons with disabilities (2021b). It can be said that Japan's employment policy for persons with disabilities emphasizes social skills training. Communication problems are often considered the reason persons with disabilities cannot find employment. Social skills training may have some positive aspects for improving the employment status of persons with disabilities. However, if a person with a disability cannot attain a job or adjust to a workplace after undergoing social skills training, he or she may be considered the cause of the problem. In other words, the problem is personalized. Therefore, Japan's vocational perspective, which

emphasizes communication skills, may hinder the employment of persons with disabilities.

### **Definitions of Essential Functions in the U.S.**

Now, let us examine a discussion of essential functions of the workplace in the United States. According to The U.S. Equal Employment Opportunity Commission (EEOC), essential functions of the workplace are defined as the basic job duties that an employee must be able to perform with or without reasonable accommodation.

According to Brannick (1992), the ADA requires employers to focus on the essential functions of a job to determine whether a person with a disability is qualified to perform the major functions of the job at hand. This clearly suggests that, in the United States, employers are required to pay attention to the "essential functions" and "reasonable accommodations" at work for a person with a disability to be recognized as a "qualified individual in the workplace."

### **Differences between the U.S. and Japan**

To summarize the discussion thus far: in the United States, most people focus on the essential functions of a job and clarify the skills required for persons with disabilities to work. Consequently, people with disabilities can work to their full

potential with the reasonable accommodations necessary to perform their jobs. In contrast to this, in Japan, most people do not focus on the essential functions of a job, and the skills required for persons with disabilities to work are ambiguous. Consequently, many people with disabilities cannot use their abilities to work because most receive only communication support.

### **Focusing on Coffee Workers with Disabilities in Japan**

In Japan, which has a background of avoiding discussions of essential functions, there is insufficient research focusing on essential functions as a key to improving the work environment for persons with disabilities. However, some examples that Japanese society has evaluated as successful have many similar stories to those discussed in the United States in the context of essential functions. A typical example is a coffee worker with a disability.

For example, the *Nikkei* (2022) reports the following: an increasing number of employment support establishments and special subsidiaries are adopting "coffee" for work involving persons with disabilities. The work includes the production of one cup of drip bag and the operation of a cafe. These initiatives suggest positive outcomes with respect to division of labor, cooperation, and exchange. "Canvas," a business

establishment that supports the employment of persons with disabilities in a commercial facility in Shizuoka City, is surrounded by a rich aroma after 10 am. "The feature of this work is that the work can be sorted according to the characteristics of our members," says Michiaki Mochizuki, the administrator. Kento Izumi, who dyes his hair pink and is registered with a modelling agency, says, "I am good at picking (selecting defective beans)" (*The Nikkei*, 2022).

These examples suggest that the coffee industry has been attracting attention as persons with disabilities have the opportunity to demonstrate their abilities and work.

Good examples can be found all over Japan. One is Worker's Home in Okinawa Prefecture, where employees with disabilities grow coffee on the land, roast it in-house, and serve the coffee at a cafe. Correspondingly, persons with disabilities can play an active role in coffee-related work even if they lack the communication skills required by Japanese society.

By focusing on the coffee industry, it may be possible to establish a relationship between essential functions and qualified individuals in the employment of persons with disabilities in Japan. A question based on our research is whether focusing on essential functions when companies hire persons with disabilities may allow the

clarification of conditions under which persons with disabilities become qualified individuals and realizing the value of their employment.

### Methods

Targeting all prefectures in Japan, we surveyed 401 companies and organizations in which persons with disabilities are engaged in coffee-related work. The survey period was July 31 to September 25, 2021. We received valid responses from 81 organizations, representing a response rate of 20%. We extracted groups by searching for the keywords "coffee," "café," and "roasting" in the activity introduction text of the registered group information of the Japan National Council of Social Welfare. From the organizations that employ persons with disabilities, we extracted the workplaces, organizations, and companies that appeared to be engaged in coffee-related business by conducting a thorough Internet search. We then excluded those that were clearly out of business or were considered inappropriate, listed the groups/companies by prefecture, and used them as a sample.

The questionnaire items revolved around the characteristics of facilities (sales, facility size, number of persons with disabilities, etc.), methods of managing employees

with disabilities, types of work performed by persons with disabilities, reasonable accommodations for workers with disabilities, and the effects of COVID-19 on work.

### Results and Discussion

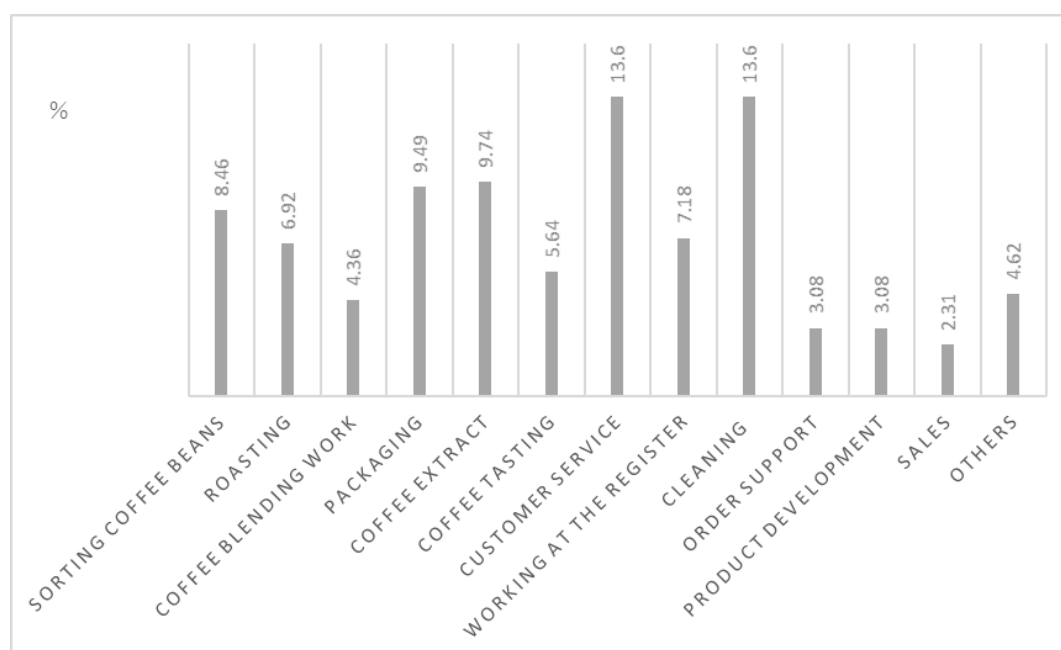
First, the companies, organizations and individuals included in this research were as follows. Companies accounted for 15%, nonprofit organizations for 28%, social welfare corporations for 40%, and others for 17%. Social welfare corporations were the most common, at 40%. Regarding the types of disabilities of the employed persons, people with mental disabilities accounted for the largest proportion at 30%, followed by those with intellectual disabilities at 25%, and those with visual disabilities at 21%. The number of persons with hearing disabilities was 5%, the number of others was 4%, and the least was persons with visual disabilities at 3%. The average monthly wages for persons with disabilities were as follows. The rate of 16,300 yen or less is the highest, at 48%. More than 78,900 yen accounted for 32%, and more than 169,000 yen accounted for 15%. Regarding the last 5%: 4% earned between 5,000 and 16,300 yen, and 1% earned 220,000 yen or more.

Figure 2 addresses the question, "What kind of work is a person with disabilities in charge of?" Customer service and cleaning account for 13.6%, the highest

percentage.

**Figure 2**

*Work Performed by Persons with Disabilities*



NOTE: This figure demonstrates the percentage of each job that a person with a disability oversees. The rate of sorting coffee beans is 8.46%. The rate of roasting is 6.92%. The rate of coffee blending work is 4.36%. The rate of packaging is 9.49%. The rate of coffee extraction is 9.74%. The rate of coffee tasting is 5.64%. The rate of customer service is 13.6%. The rate of working at the register is 7.18%. The rate of cleaners is 13.6%. The rate of order support is 3.08%. The rate of

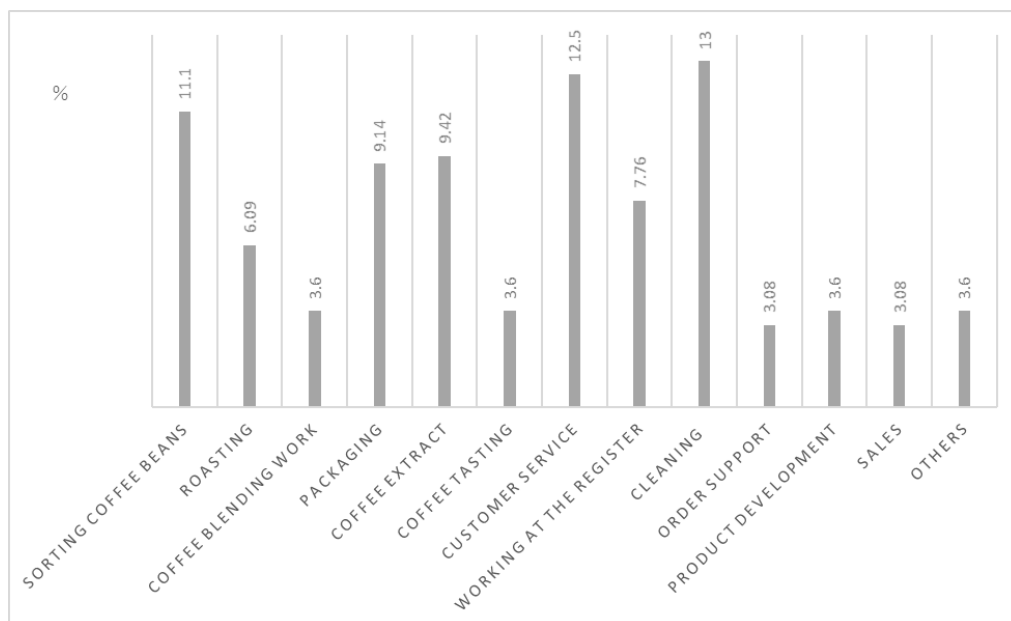


product development is also 3.08%. The rate of sales is 2.31%. The rate of others is 4.62%.

Figure 3 addresses the question, "What kind of work do you think is suitable for persons with disabilities?" The percentage of respondents who answered, "Sorting coffee beans" showed an increase from 8.46% to 11.1%.

**Figure 3**

*Types of Work Suitable for People with Disabilities*



NOTE: This graph illustrates each percentage of work

considered suitable for persons with disabilities. The rate of sorting

coffee beans is 11.1%. The rate of roasting is 6.09%. The rate of coffee

blending work is 3.6%. The rate of packaging is 9.14%. The rate of coffee extract is 9.42%. The rate of coffee tasting is 3.6%. The rate of customer service employees is 12.5%. The rate of working at the register is 7.76%. The rate of cleaners is 13%. The rate of order support is 3.08%. The rate of product development is 3.6%. The rate of sales is 3.08%. The rate of others is 3.6%.

This result inspired us to analyze the response data for the questionnaire in more detail. We suspected that the group conducting in-house roasting increases the proportion of sorting coffee beans. The group performing in-house roasting was defined as group A1, and the group not roasting coffee beans in-house was defined as group A2. Next, the response results were compared.

We conducted a Chi-square test, and the results revealed significant differences among the conditions ( $\chi^2(2) = 4.260$ ,  $p = 0.0221704$ ,  $\phi = 0.213$ ). Residual analysis revealed that group A1 preferred sorting coffee beans significantly more than group A2, and group A2 preferred customer service significantly more than group A1. In other words, it can be said that the group conducting in-house roasting could pay more attention to the essential functions required of coffee workers. It can also be said that

organizations that do not perform in-house roasting place more emphasis on customer service skills that can be acquired through social skills training.

Then, which group of persons with disabilities is more valued by society? We re-analyzed the average monthly wage data and compared groups A1 and A2. The average monthly wage was 22,932 yen for group A1 and 18,797 yen for group A2. Thus, there was a difference of 4,135 yen between groups A1 and A2. Organizations with employees with disabilities who sort coffee beans can pay higher wages. This result demonstrates that, that by focusing on the essential functions of coffee-related work, persons with disabilities can demonstrate their abilities and be evaluated by society through their work.

Among the groups of persons with disabilities who engage in coffee-related work, those who place importance on sorting coffee beans can perceive of jobs unique to the coffee industry as essential functions. However, organizations that emphasize customer service may not be able to focus on the essential functions that people with disabilities need to become qualified coffee workers.

## Conclusion

The survey showed interesting results when considering the relationship between essential functions and qualified individuals. Organizations that consider bean sorting an essential function tend to pay higher wages to persons with disabilities compared to organizations that consider customer service an essential function. Whether the person in charge of the organization can conceptualize the skills necessary for coffee-related work as essential functions may be a condition for whether persons with disabilities can utilize their abilities to work. Promoting people with disabilities who work as qualified individuals may enhance their social evaluation through work. I am working on a project, the Manakiki Blend, to verify whether employees with disabilities can increase coffee sales by advertising that they are qualified individuals.

Unfortunately, our study did not include sufficient online participant observations and interview data. A more detailed analysis is needed to develop a complete solution to improve working environments for persons with disabilities. In the future, through this project, we will analyze whether companies and organizations can focus on essential functions so that people with disabilities can be regarded by society as qualified individuals and society can work with their abilities.

## References

Brannick, J. P., & Levine, E. L. (1992). Job analysis, personnel selection, and the ADA.

*Human Resource Management Review*, 2(3), 171–182. [https://doi.org/10.1016/](https://doi.org/10.1016/1053-4822(92)90010-N)

1053-4822(92)90010-N

Hanada Syuncho. (1991). *ADA hou yabunirami* [Casting our eyes to the ADA]. In Yash

iro Eita & Tomiyasu Yoshikazu (Eds.). *ADA no shogeki* (pp. 122–130).

Inoue Masashi, Inoko Hidetaro, Kudo Takeshi, Ozawa Michimasa, Kikuchi Kazufumi,

Wakui Megumi, & Osaki Hirofumi. (2021). *Tokubetsushiengakko (chitekishog*

*a) kotobu niokeru keidochitekishogainoaru seitoni taisuru kyoikukateini kansu*

*ru kenkyu: Hitsuyosei no takai shidonaiyo no kento* [Study on a curriculum for

students with mild intellectual disability in a special needs school (intellectual

disability) high school: Examination of highly necessary instruction content] N

ational Institute of Special Education.

Kodama, M., & Takamura, T. (2020). *Hattatsushogaisha no shuroshien no genjo to kad*

*ai: Shokuba no ningenkankei ni chakumoku shite* [Current status and challenge

s in employment support for persons with developmental disabilities: Focusing

on interpersonal relationships in the workplace]. *Bulletin of Center of Clinical*

*Psychology & Counseling at Ochanomizu University*, 22, 63–74.

Ministry of Health, Labor, and Welfare. (2021a). *Reiwa sannendo shogaisha koyojokyo no shukeikekka* [Reiwa 3<sup>rd</sup>-year total results of employment statuses of persons with disabilities]. Retrieved March 29, 2022, from <https://www.mhlw.go.jp/content/11704000/000871748.pdf>.

Ministry of Health, Labor, and Welfare. (2021b). *Hattatsushogaisha shienseisaku no gaiyo* [Outline of support measures for persons with developmental disabilities]. Retrieved March 29, 2022, from [https://www.mhlw.go.jp/stf/seisakunitsuite/bunya/hukushi\\_kaigo/shougaishahukushi/hattatsu/gaiyo.html](https://www.mhlw.go.jp/stf/seisakunitsuite/bunya/hukushi_kaigo/shougaishahukushi/hattatsu/gaiyo.html).

The Nikkei. (2022, January 6). Coffee work encourages people with disabilities, coordinates with the Division of Labor, and refines barista skills. *The Nikkei*. <https://www.nikkei.com/article/DGKKZO78981550W2A100C2KNTP00/>

Yashiro, E. (1991). *Nichibei kankei Kokusai kankei soshite Nihon* [US–Japan relations, international relations, and Japan]. In Yashiro Eita & Tomiyasu Yoshikazu (Eds.). *ADA no shogeki* (pp. 369–416).



**Focusing on Essential Functions for Persons with Disabilities to Improve Working Environments: From a Survey on Coffee Workers in Japan** by Wakaba Hamamatsu and Kuniomi Shibata

<https://rdsjournal.org/index.php/journal/article/view/1175> is licensed under a [Creative Commons Attribution 4.0 International License](#). Based on a work at <https://rdsjournal.org>.

**Information Accessibility for Kanji:  
A Pilot Project for Academic Translation and Learning**

Yoshimi Matsuzaki<sup>1</sup> and Kuniomi Shibata<sup>2</sup>

<sup>1</sup> Toyo University

<sup>2</sup> Tsuda College

**Author Note**

Yoshimi Matsuzaki, Department of Sociology, Toyo University and Counter Learning Crisis Project; Kuniomi Shibata, Department of International & Cultural Studies and Inclusive Education Support Division, Tsuda University.

This research was supported in part by grants from JSPS KAKENHI Grant Number 20K12550.

Correspondence concerning this proceeding should be addressed to Yoshimi Matsuzaki, Department of Sociology, Toyo University, 5-28-20 Hakusan, Bunkyo-ku, Tokyo 112-8606 Japan. E-mail: [matsuzaki046@toyo.jp](mailto:matsuzaki046@toyo.jp), and Kuniomi Shibata 2-2-Kodaira, Tokyo, 187-8577, Japan, E-mail: [kshibata@tsuda.ac.jp](mailto:kshibata@tsuda.ac.jp).



**Information Accessibility for Kanji:  
A Pilot Project for Academic Translation and Learning**

**Abstract**

This essay considers difference among transmission means and showed that braille users might have trouble accessing Japanese texts containing abstract terms, usually containing many Kanji, a unique writing system in Japan. Therefore, we considered characteristics of Kanji for learning and making information more accessible.

*Keywords:* Japanese Kanji, Information Accessibility, Reading Literacy

### 1-1. Characteristics of Japanese writing

Information accessibility has long been discussed in Japan. However, there are few studies that consider the difficulties related to Kanji, a writing system in Japan. The Japanese language has three separate writing systems: Hiragana, Katakana, and Kanji. The Hiragana and Katakana versions are phonograms that correspond to each syllable in Japanese. Kanji is an ideogram where each character has its own meaning. With Kanji, writers can choose most suitable Kanji character. Kanji that is used in texts has a vital role in determining the direction of the entire text.

This is reflected in the ways in which the word “disability” may be written. For example, "disability" is "shogai" in Japanese, and it has various written forms: 障害, しょう害, 障碍, and しょうがい, all meaning "disability." There are various patterns for writing the word "shogai" because each writer interprets the word in a different way.

The way in which “disability” is written can also dialogue with the framework through which it is understood. The medical model of disability views disability as a defect or pathology and places the responsibility of overcoming disability on individuals through medical intervention or sheer willpower. On the other hand, the socio-political model of disability views disability as a part of diversity and believes that society has a responsibility to help disabled people by reducing physical and structural barriers. Written in Kanji, "shogai" means obstruction or hindrance. As such, some people believe that writing it in Kanji is careless, especially when considering these models. Therefore, some believe writing the word in Hiragana is better because using expressions such as "obstruct," or "hindrance" can be directly avoided.

On the other hand, some people choose to use Kanji for the word because they think it accurately reflects that there are barriers, not solely for people with disabilities, but for

society in general. Such people believe that they should highlight the existence of such barriers in society by using Kanji. Formal discussions regarding the more suitable way of writing "shogai" were held in the Japanese cabinet (Council to Promote Reform of the System for Persons with Disabilities, 2010). Ultimately, the choice of writing depends on the writer. The different ways of writing "shogai" are not merely a superficial preference; instead it may reflect the writer's perspective on disability.

### **1-2. Pitfalls of information accessibility in Japan**

With this in mind, these distinctions in Japanese writing become especially important to understand in academic contexts. In higher educational institutions, students must read academic texts carefully for deeper understanding and for critical analysis. Universities deal with Japanese language texts containing many Kanji characters that express abstract concepts. Students with disabilities handle texts in a suitable format, e.g., in braille or speech format for students with visual disabilities, and those with hearing disabilities may use notetaking or interpret text from sign language services (Jasso, 2019). However, based on the discussion mentioned above, unique Japanese characteristics regarding Kanji use can create difficulties for students with disabilities.

For example, Japanese braille does not distinguish between the three Japanese writing systems of Kanji, Hiragana, and Katakana. Therefore, braille users sometimes refer to translators' annotations. The speech format also does not display how sentences are written, and the listener cannot distinguish between the three Japanese writing systems. Generally, braille users and listeners of the speech format interpret homonyms based precisely on the context. However, when the text contains homonyms with the same sound and meaning but a slightly different nuance, they face difficulties in understanding, and this sometimes can even lead to mistakes and misinterpretation. Moreover, although there are annotations, some points

affecting the writing style in academic texts are overlooked in annotations because they require knowledge of academic details.

With this in mind, Japanese sign language (JSL) is becoming the choice for students with hearing disabilities for information accessibility (Sasaki, 2019). However, it is a unique language, and is very different from the Japanese language. The main features of sign language are liquidity and flexibility; sign language users express themselves appropriately through the community group, generations, and localities (Sakata et al., 2008). These characteristics are inherent in oral communication, but could probably become ambiguous for expressing a concept; therefore, as sign language is unique for people with hearing disabilities, precise information accessibility is an important concern. Sign language tends to express something concretely by performing the process to convey the meaning. However, academic concepts are often abstract, and students learn the meaning of each interpretation; that is, academic concepts must have space for discussion because there are various ways of interpreting and understanding them.

## 2. Empirical study for assessing qualitative differences in transmission

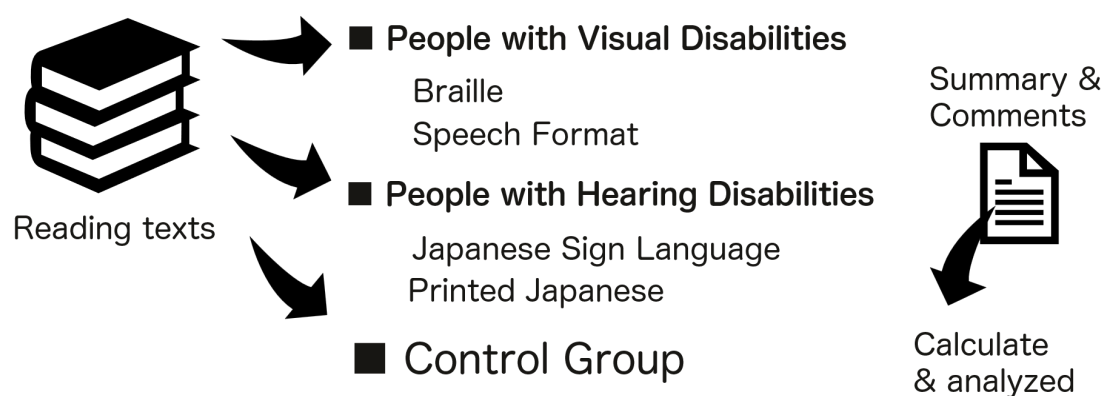
### 2-1. The RARA Project

We focused on the qualitative differences in transmission through various formats—braille, speech, and sign language in providing information accessibility that require modifying text into suitable formats for students with disabilities in universities (Matsuzaki, Hamamatsu & Shibata, 2020). The RARA was designed as a longitudinal postal study, and the target participants comprised of persons with visual and hearing disabilities, and a control group. The RARA project prepared six reading texts containing three texts each of basic

interpersonal communicative skills (BICS) and cognitive academic language proficiency (CALP). The six reading texts fall into these two categories, which are associated with the challenges of acquiring second language skills. Cummins (1984) explained the difference between CALP and BICS using two terms: cognitive and context. He argued that learners need a certain type of knowledge to read and understand complex texts. He asserted that BICS is “context-embedded” and “cognitively undemanding” (Cummins, 1984). Students’ literacy evolves from BICS to CALP as they move through school, and students in universities often deal with texts requiring CALP skills.

**Figure 1**

*The Flowchart of the Process of RARA Project*



The RARA project selected the following texts containing CALP: first, a few paragraphs from “Plastic Words: The tyranny of a Modular Language,” by Uwe Pörksen, a German linguist, and translated in 2007; second, text from “Big data-- Citizenship-Rated Society: Independent of the People with Disabilities and for our ‘True Stories,’” by Kuniomi Shibata, a Japanese researcher specializes in assistive technology, especially focusing on information technology for persons with disabilities; and the final text is “On the Government

of the Living: Lectures at the College De France 1979–1980” by Michel Foucault.

Similarly, the following are three texts for BICS: first, “Heritage” by Michio Hoshino in 2002, a wildlife and nature photographer and essayist; his central active field was in Alaska, USA. Second, “A trip to Joshu Yujuku Onsen,” by Tsuge Yoshiharu, an essayist and cartoonist. And thirdly, a prologue section of the book titled “Memorizing Body” written by Asa Ito, a researcher specializing in aesthetics with a particular focus on the aesthetic experiences of people with disabilities. These are texts for university discussion seminars in universities.

Each text was distributed: the braille format was sent by post, the speech format was made available on YouTube or in MP3 format, and the sign language format was made available on YouTube. The braille format was translated by an experienced translator from a braille translating circle. After receiving the texts, the respondents summarized and commented on each text before returning them to the researchers. Based on the grades score for each response, we calculated and analyzed their final scores. First, we compared the primary analysis of RARA with the results of text from BICS and CALP for the transmission of each format of information. Generally, the score for BICS is presumed to be higher than that of CALP, regardless of the transmission format. Next, we performed content analysis based on respondents’ summaries and comments.

## **2-2. Results of the RARA Project**

### *(1) The case of participants with visual disabilities: braille and speech formats*

The RARA project showed that braille users tend to have trouble reading when accessing text containing elements of CALP (Matsuzaki & Shibata, 2022). In fact, braille

users read and interpreted the content of BICS better than the control group, although their tendency to understand CALP was lower than the control group. Such outcomes mean that braille users may have difficulty describing the CALP content, and we assumed that Kanji influenced reading accessibility for some people with disabilities. This study analyzes and discusses comments from respondents with visual disabilities who read braille or texts in speech format.

The comments from respondents with visual disabilities showed the difficulty level in reading, especially when they encountered synonyms and unfamiliar words. For example, Foucault's use of the word "truth" is awkward because when the text is translated into Japanese, it is expressed as "真," pronounced as "shin," which can make readers imagine some other words that have different meanings but the same pronunciation. Words containing "shin" have various Kanji forms; "神" meaning "god," and 心 meaning "heart," and 芯 meaning "core." Each "shin" word is a common word used in daily life. However, even if the general word is written without Kanji, it becomes difficult to understand the text. People with visual disabilities interpret words through their context; however, this case written by Foucault is complex because every word containing "shin" is inferred as natural from the context, and subsequently it is difficult to judge which is the most suitable.

Similarly, unfamiliar words may also pose difficulty. Such unfamiliar words may include "Zhima Credit" or "Sesame Credit," a private credit scoring and loyalty program system developed in China. Another case of a strange word is "alethourges," an abstract concept, which means "manifestation of the truth," as explained by Michael Foucault. Most participants, including people with visual disabilities, were unfamiliar with such words. However, participants with visual disabilities found such words difficult to read. At the same time, these words are not essential for creating summaries because they are not at the core of

each text; therefore, participants in the control group seemed to be able to read the text without understanding these particular words, as these words would not interfere with their reading.

The difference in responses to unfamiliar words between the braille and speech format group and the control group seems to be derived from transmission. For readers, visibility is a critical feature of written text. Walter Ong (1982–1991) explains how the transition from orality to literacy restructures culture and human consciousness, and written text enables readers to review previous sentences quickly.

The braille format is tactile printing, but the complexity of expressing Japanese braille requires more space for articulating sentences. In addition, braille does not distinguish between writing systems in Japanese and does not have any abbreviations. Therefore, to express Japanese text in braille much more paper is required. Moreover, braille users' tactile and perceptual abilities and skills are critical to understanding the braille sentences. Such characteristics of braille make readers with visual disabilities take a long time in picking up and reviewing some specific words in previous sentences. The speech format is also difficult to review because it is not visible. As a result, participants reading the speech format must listen repeatedly to the text. Furthermore, when the text contains CAPS, it is more abstract, and the logic is difficult to grasp. However, participants with visual disabilities must have time for reviewing, which interrupts their smooth reading and grasp of logic.

For solving these difficulties, participants with visual disabilities pointed out that texts need many more annotations in Kanji. The braille format used in this project was prepared using the experience of a braille translator, who mentioned the importance of annotations by translators as the method to read difficult text. However, the translator also mentioned the risk factors involved in frequent annotations, specifically to comprehend



complex reading. This study suggests that more information about Kanji is required when the text tends to contain a greater number of CALP factors.

*(2) The case of participants with hearing disabilities: sign language format*

Since August 2021, the RARA project has successfully recruited participants with hearing disabilities; so far, there have been four applications, but the responses are yet to be returned. Although most people with hearing disabilities are assumed to have the ability to read Japanese written text, a few scholars mentioned the importance of information accessibility in translating Japanese into JSL for people with hearing disabilities (Hatano, 2019). Indeed, some practice has been reported about integrating descriptions of exhibits and other museum services into sign language to facilitate information accessibility for people with hearing disabilities (Egusa et al., 2015).

We considered the outcomes observed in preparing the sign language format, which shows some characteristics derived from it. The RARA project prepared each video translated into JSL, which is a language system that can express situations explicitly. For example, the verb “to eat” is expressed more concretely in JSL than in Japanese. This is because JSL describes how to eat something (e.g., with chopsticks, fingers, a spoon). In addition, JSL should include more detailed descriptions of the action because it needs details to express information concretely, and this is the unique aspect of JSL (Sakata, Yano & Yoneyama, 2008).

However, this characteristic was the factor underlying certain difficulties in some word translations. "Dialectical tension" in the text of “Plastic Words: The tyranny of a Modular Language” by Uwe Pörksen is a typical example of difficulties, and it is too abstract

to explain concretely. A deaf JSL translator was puzzled about how to express it.

Furthermore, texts translated into JSL must guarantee space to discuss essential topics for readers' understanding. This implies that the translator must keep the word abstract to avoid inferring from the translator's interpretation. Finally, the translator decided to use Kanji for translating into JSL. This translation by referring to Kanji has been observed in the works of other translators in this project. Translating by referring to Kanji is the best way to express the meaning of each Kanji. As the Kanji writing system is an ideogram, an abstract word is informed by expressing which Kanji character is used in the word, instead of explaining it based on translator interpretation.

### **2-3. A summary of the RARA Project**

The RARA project, focusing on possible differences in the comprehensibility of information transmission among braille, speech format, and sign language, showed that braille users face difficulty in reading when accessing texts containing elements of CALP. Braille users read and interpreted the content of BICS better than the control group, although their understanding of CALP was lower than the control group. This outcome showed that it may be difficult to describe CALP content in braille, and we assume that Kanji influenced the reading accessibility of some people with disabilities.

Kanji cannot be used to express braille text and the speech format; therefore, people with visual disabilities have to spend more time interpreting the meaning of words, homophones, or unknown words. Although annotation is a powerful tool for understanding text, it requires readers to know Kanji.

In the sign language format, translators must focus on making nonbiased translation,

especially texts used in an academic context. This is because students can build their understanding by considering the meaning of words and concepts. For many translators, referring to Kanji is the way of translating abstract words and concepts. This implies that users of sign language also need to know Kanji.

### **3. Discussion and conclusion**

#### **3-1. The importance of learning Kanji**

Kanji is essential for information accessibility in Japan, especially in higher educational institutions, as students must understand the specific variations in Kanji use. Furthermore, when people with disabilities express their opinion, they must have knowledge of Kanji. With the development of information and communication technology, people with or without disabilities can use various tools for expressing their opinions. For example, people with visual disabilities can construct Japanese sentences containing some writing systems through voice recognition software and a computer keyboard that suits their physical condition. Even if people with visual disabilities do not see Kanji, they must recognize Kanji characters that are suitable for them to communicate. Likewise, people with hearing disabilities must also understand Kanji.

As a rich heritage, Japanese literature contains Kanji characters, including some difficult ones, and readers must read the texts patiently to benefit from them. Learning Kanji can help ensure access to learning by reading. Authors and writers choose their preferred writing style for a better expression, and readers imagine and consider authors' and writers' intentions in writing. We should not deprive readers of such a process.

### 3-2. Kanji learning for students with disabilities

Ancient Japan did not have its own writing system. Kanji is a unique writing system that was imported from China more than 3300 years ago, and after reaching Japan about 1600 years ago, it has given rise to various pronunciations. A fascinating feature of Kanji is that some letters are created by combining basic Kanji ideograms. Primary school children learn simple and basic Kanji in their early grades, most of which is driven by nature. Generally, many Kanji letters contain other simple basic Kanji, and each element influences both meaning and pronunciation.

However, Kanji learning has not considered the background or origin of Kanji. As part of the curriculum, Japanese elementary and junior high school students learn more than 2000 Kanji characters. They usually focus on efficiently memorizing forms and orders rather than understanding the background of Kanji (Michimura, 2010.) Students with visual disabilities learn simple primary Kanji forms in school by touching tactile objects. The tactile objects have limited variations, and students learn the patterns of Kanji idioms by repeatedly reading sentences. This style is not a match for people with disabilities as some dislike Kanji because it is complex and burdensome. For students with disabilities, Kanji learning may pose some limitations. For example, students with hearing disabilities may struggle to grasp the pronunciation of Kanji, and often cannot use a dictionary for referring to the various meanings.

Moreover, the COVID-19 pandemic has exaggerated the pattern of memorizing Kanji because learning only involved practice and submitting it as homework assignments. As a result, most children missed the opportunity to learn and understand stories about the origin of Kanji and ended up memorizing Kanji to score well on quizzes. Furthermore, this

has led to some children, with or without disabilities, to dislike Kanji learning.

### **3-3. Future work through Kanji learning**

The current practice of Kanji learning focuses on the origin of Kanji formation. The creation of Kanji may be compared to cooking. As in cooking, where flavor and texture are both essential for relishing the food, in Kanji learning, flavor refers to the meaning of Kanji, and texture refers to its pronunciation; therefore, both are required in the learning process. Moreover, as it is crucial in cooking to learn the essentials of the presentation of food, it is important to place individual elements in a particular space and order in Kanji, as it denotes a form of Kanji.

Memorizing or learning by rote is based on the concept that children must learn to read and write Kanji; however, memorization does not refer to why or how Kanji is formed or pronounced in specific ways. Understanding the background and origin of Kanji provides a significant advantage in grasping more detailed information. “Kanji cooking” can be an alternative way to learning Kanji, possibly by motivating learners.

Our Kanji learning project is attempting to create another tangible learning alternative through a 3D Kanji block puzzle for more enjoyable “Kanji cooking.” In addition, we are also planning a few Kanji learning programs for children with disabilities and expect to launch them shortly. In the Kanji learning programs, we plan to conduct observations and interviews with children, thereby contributing to better information accessibility for both elementary and junior school children and university students.

## References


- Council to Promote Reform of the System for Persons with Disabilities (2010). “*Shōgai*” no *hyōki ni kansuru kentō kekka ni tsuite* – [Result about consideration of notation of “disability”]. Cabinet office.
- Egusa, R., Hoshina, H., Namatame, M., Ogawa Y., Kobayashi, M., Terano, T., & Inagaki, S. (2015). National survey on the information accessibility of the exhibitions in science museums. *Japan Society for Science Education Research Report*, 29(6), 43–46.  
[https://doi.org/10.14935/jsser.29.6\\_43](https://doi.org/10.14935/jsser.29.6_43)
- Foucault, M., Hirose, K., trans. (2015). *Seija tachi no Tochi College De France Kogi 1979-1980 Nendo* – [On the Government of the Living: Lectures at the College De France 1979-1980] Tokyo: Chikuma-Shobo, 11-12. (Graham Burchell, trans., 2016.) Picador.
- Hatano, M. (Chair). (2019 Feb 2). *Gakujutsu shuppan no accessibility wo kangaeru -shoseki no shuwa honyaku no jissenn kara-* [Considering the Accessibility of Academic Publishing: From the Practice of Sign Language Translation of Books] Symposium conducted at the meeting of Faculty of Library Information and Media Science, University of Tsukuba.
- Hoshino, M. (2002). *Nagai Tabi no Tojō* - [On the way of a long journey]. Bungei shun-ju.
- Japanese Student Services Organization. (2019). *The Handbook of Reasonable Accommodation*. The Earth Kyoikusha.
- Matsuzaki, Y., Hamamatsu, W. & Shibata, K. (2020). *Reasonable accommodation and information accessibility by various formats: The difference between braille, sign language, and speech format*. 2020 Pacific Rim International Conference on

Disability & Diversity Proceedings.

- Matsuzaki, Y. & Shibata, K. (2022). Reasonable accommodation and information accessibility for students with disabilities in Japanese higher education. In *Diversity and Inclusion in Japan* (pp. 119-135). Routledge.
- Michimura, S. (2010). *Kuchi de iereba Kanji wa Kakeru! Mōgakkō kara hassin shita Kanji gakushū-hō* - [You can write Kanji if you know how to write it! Kanji learning method from a blind school]. Shogaku-kan.
- Ito, A. (2019). *Prologue: Kyukyoku no local rule* – [Prologue: Extreme local rule], *Kioku suru Karada* – [A Body to Memorize]. Shunju-sya.
- Porksen, U. (2007). *Plastic words: The language of an international dictatorship* (Kasuya, K. Trans: Tokyo: Fuziwara Shoten.). Stuttgart: Klett-Cotta (original work published 1988).
- Sakata, K., Yano, K., Yoneyama, A. (2008). *Odoroki no shuwa “Pa” “Po” honyaku*— [Fantastic sign language “Pa” “Po” translation]. Seiko-sya.
- Shibata, K. (2019). *Big Data Citizenship-Rated Society: Shogai-sha no jiritsu to watashitachi no “Shinjitsu no monogatari”* - [Big data-- Citizenship-Rated Society: independent of the people with disabilities and for our "true stories", Gendai shiso – [La revue de la pensée d'aujourd'hui] 47(6), 76-77.
- Sasaki, G. (Chair). (2019 July 28). *Kōtō kyōiku kikan ni okeru shuwa tsūyaku shien-shuwa tsūyaku ga motome rareru riyū to jitsugen ni muketa kadai* – [Support for Sign Language Interpretation in Higher Education Institution: Reasons for Sign Language Interpretation and Issues for Realization] Symposium conducted at the meeting of Platform Higher Education and Disability, Research Center for Advanced Science and

Technology the University of Tokyo.

Tsuge, Y. (1995). *Joshu Yujuku Onsen no Tabi* – [A Trip to Joshu Yujuku Onsen]. Shincho bunko.

 **Information Accessibility for Kanji: A Pilot Project for Academic Translation and Learning** by Yoshimi Matsuzaki and Kuniomi Shibata <https://rdsjournal.org/index.php/journal/article/view/1176> is licensed under a [Creative Commons Attribution 4.0 International License](https://creativecommons.org/licenses/by/4.0/). Based on a work at <https://rdsjournal.org>.



**Deaf Community and DiDRR: Supporting a Twin-Track Approach**

Leyla Craig<sup>1</sup>, Audrey Cooper<sup>2</sup>, Kota Takayama<sup>2</sup>, and Herbert Klein<sup>3</sup>

<sup>1</sup> University of Sydney

<sup>2</sup> Gallaudet University

<sup>3</sup> World Federation of the Deaf, Disaster Risk Reduction Expert Group

**Abstract**

To address Deaf Communities that are continually excluded from Disability inclusive Disaster Risk Reduction (DiDRR), community-based research and practices have found that adopting a twin track approach tailored to each deaf group and its specific communication practices are more effective than combining disaster training for all disability groups.

*Keywords:* Deaf communities, disasters, communication

### **Background: DiDRR**

*A definition of language is always, implicitly or explicitly, a definition of human beings in the world. - British Cultural Studies Scholar, Raymond Williams, 1977:21*

The concept of Disability inclusive Disaster Risk Reduction (DiDRR) was established to support and ensure that people with disabilities are included in all emergency and disaster management planning. This idea has garnered support from many countries where this initiative brings people with disabilities, government, and non-government organizations together to heighten their DRR (Disaster Risk Reduction) and DiDRR knowledge, skills, and practices. With cases of DiDRR projects and training workshops designed to increase people with disabilities' resilience to natural hazards and disasters, some countries erroneously perceive people with disabilities as 'one homogenous group' by combining disaster training for all disability groups. This is problematic given that what sets Deaf Communities apart from disability groups is the language and culture.

### **Deaf Community: Disability and Linguistic Groups**

According to the World Federation of the Deaf (WFD), an international non-governmental organization that advocates for the human rights of more than 70 million deaf people in the world, Deaf Communities are in a unique position with respect to disability given their shared experiences of societal barriers and oppression and aims for equality rights and access (Burch & Kafer, 2010). The common goal of making society accessible and inclusive to people of different abilities is what brings the Deaf Community together with the international disability movement (WFD, 2019). However, from a cultural perspective, language is also seen as an important aspect to linguistic minority communities that identifies the Deaf Community as group and cultural identity. As disabled people often identify and use the dominant language(s) of their country of origin, Deaf Communities' primary languages

are sign languages, known to be non-dominant and a fundamental element of Deaf Culture (Lane, 1992). The cultural language differences and lack of equity with communication divides the experiences and stances between Deaf Communities and other disability groups (Padden & Humphries, 1988, 2005; WFD, 2019); this is why Deaf Communities justify recognizing themselves as a cultural and linguistic group under the United Nations Convention for the Rights of Persons with Disabilities (UNCRPD). Furthermore, the intersectionality of deaf, disability, and linguistic groups together has multiple dimensions and considerable demographic intersectional features, including race, gender, sexuality, heritage cultures, ethnicities, and so forth; this includes in connection to multimodal uses of the body and languages (De Meulder et al., 2019; Harrelson, 2019). With the diverse deaf population involving deaf, culturally Deaf, hard of hearing, and deaf-plus; there are also further aspects pertaining to racism, sexism, audism, ableism, ageism, religion discrimination, as well as cultural and language practices related to their affiliation with local Deaf Communities too.

### ***Deaf Communities and Language Access***

As one of the few research studies that offers disaggregated data demonstrating the percentage of people affected from different disability groups, Takayama (2017) reveals that deaf people experienced higher rates of mortality and morbidity during and after the 2011 Japanese earthquake and tsunami, citing 0.76% of the deaf population compared to 0.17% of the hearing population (Takayama, 2017). The issue here is deaf people being more impacted not because they are deaf, but because they have almost no access to disaster preparedness and protection resources. There are multiple reasons for this, starting with language.

Language is a critical part of the human experience. According to the WFD, only 20% of deaf people around the world have access to formal education. Furthermore, only

21.2% of countries around the world recognize their national sign language. This has led many Deaf Community members facing communication barriers due to inaccessible information (Calgaro et al., 2021; Cooper et al., 2021; Cripps et al., 2016; Engelman et al., 2013; Takayama, 2017). This has posed challenges for disaster management as to whether their disaster messaging, especially on the language use, is readily understood by deaf people. Lack of proper access to emergency information and services further heightens Deaf Communities' risks to disasters. This is an ongoing problem where some barriers are firmly embedded in DRR policies and practices.

### **Deaf and DiDRR**

To achieve DiDRR requires a fundamental shift in DRR strategy and practice that is central to people with disabilities. Those best placed to demonstrate DiDRR successes involve challenging the stigmatizing perceptions of people with disabilities and convince DRR actors and governments to fundamentally change the way they approach DRR that enables people with disabilities opportunities to fully participate and learn by doing alongside their DRR counterparts. This will enable people with disabilities trained to work in the DiDRR space, which will in turn help expand networks to support future professionals and practitioners with disabilities in this field. The concept itself is very progressive yet the implementation and practices remain questionable, particularly for Deaf Communities who continue to remain underserved in DiDRR.

Given that language and cultural practices is what brings Deaf Communities together, this is also what sets them apart from other disability groups in DiDRR. In the disaster context, communication is seen as the biggest language barrier for Deaf Communities stemming from the lack of qualified sign language interpreters, provision of sign language interpreters, and inaccessible disaster information in plain language, visual pictures, and/or in

sign language. Research suggests deaf people are particularly vulnerable to increasing risks due to inaccessible emergency information, and efforts to support them in these capacities continue to fall short of their needs (Cooper et al., 2021; Engelman et al., 2013; Takayama, 2017).

As mentioned earlier, some DiDRR approaches erroneously perceive people with disabilities as one homogenous group where one training is provided for all. This has proven to be ineffective as the outcomes have made little impact on Deaf Communities' ability to learn and increase their resilience to natural hazards and disasters. There are DiDRR training offered for deaf people to join, but the training itself is often provided and designed by and to fit people who are hearing. Most of the training workshops are heavily auditory based, which has placed challenges for deaf people to follow discussions and activities. This hinders deaf people from advancing on the same playing field with other disability groups, highlighting several underlying issues starting with "access" versus "inclusion." Just because there are interpreters provided in the training does not guarantee the inclusiveness of deaf people. There are also two potential layers of challenges in addition for deaf people using sign language interpreters in DiDRR training workshops: (1) having interpreters selected by hearing non-signers who may not know the difference in competencies of interpreters; or (2) having an interpreter with limited knowledge or understanding of the DRR context. The competencies and DRR knowledge that the interpreter has determines whether the information delivered will be accessible for deaf people to understand and whether the training process will be inclusive.

Furthermore, exclusionary communication and language practices were also found in the access planning process as well (Calgaro et al., 2021; Calgaro & Dominey-Howes, 2013; Cooper et al., 2021; Craig et al., 2019; Craig, 2017; Engelman et al., 2013; Takayama, 2017).

The needs of deaf people are also often given little to no attention in DRR policies and regulations (Ivey et al., 2014). Moreover, emergency preparedness training designed for deaf people are unheard or unaccounted for, along with the lack of standardization, evaluation, or mainstreaming in disaster management infrastructure and practice (Engelman et al., 2013).

### **Twin Track Approach**

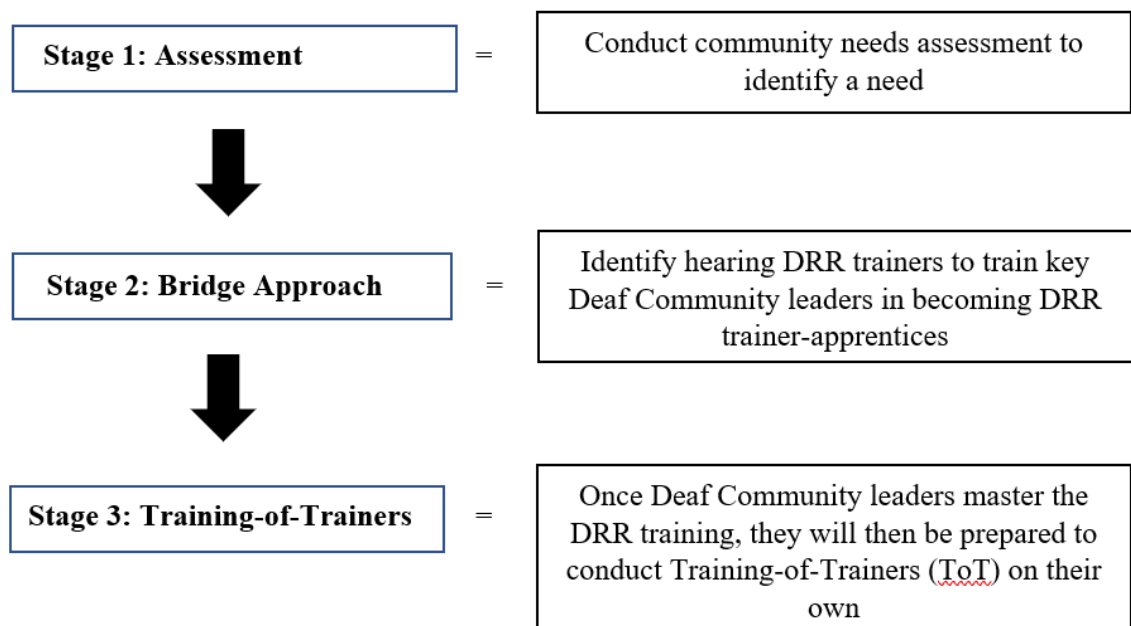
To achieve and sustain mainstreaming DiDRR approaches and practices, the training needs to be central to the targeted audience and its cultural, language, and/or access practices. One training for all disability groups does not work as there is no such thing as a “one size that fits for all.” On the contrary, the “twin track” approach proposes tailoring training to a group and its specific practices. For this case, a Deaf DiDRR training is needed to accommodate each deaf group (deaf, deafblind, hard of hearing, deaf-plus) and each group’s communication and language practices. When a DiDRR training is tailored to a deaf group, this enables deaf people to maximize their abilities to acquire the knowledge and skills delivered in their native language. Once they master the training, they can then become sustainable agents of change by serving as a bridge to future DRR training and participate in broader DiDRR activities.

Drawing case studies from four different countries, three stages were identified in recognizing a DiDRR training for their local Deaf Communities. The first stage is identifying a needs assessment through conducting community research. This will assist in recognizing the gaps and what type of training is needed to support Deaf Communities in the DRR space. The second stage is where the action happens. Deaf Community leaders with their sign language interpreters identify emergency service agencies who can train deaf people in becoming DRR trainer-apprentices. This part is key to creating sustainable key agents of change as the training will give deaf people the knowledge and skills for preparing,

responding, and recovering from DRR. Once Deaf Community leaders have mastered the DRR training sessions, they will be well placed to conduct a fully deaf-led Training-of-Trainers (ToT) on their own with their local communities (see Figure 1 below).

**Figure 1**

*Stages for DiDRR Twin Track Approach*



The four case studies –Indonesia, Vietnam, Australia, and Japan, all have conducted a project that focuses on or related to DRR through one of the three stages. Indonesia and Vietnam are currently at Stage 1 where a needs assessment has been conducted and the recognition for DRR training is needed. Australia has already conducted a needs assessment on Deaf Communities in the state of New South Wales (NSW) and has moved forward towards Stage 2 where deaf people were trained by the state’s emergency service agencies. Japan, which has had its fair share of disasters in the last decade, has surpassed Stage 1 and Stage 2 where community needs and training by its emergency services has been conducted. Japan is now in the advanced stage where it may offer deaf-led ToT on DRR to Deaf

Communities throughout Japan. Further details on each case studies are highlighted below based on their current stages.

### **Case Studies Stage 1: Assessment**

#### **Indonesia: Assessment by Deaf Organizations and Collaborating Partners**

Indonesia is one of the disaster-prone countries in the world. With 17,000 islands, the country has the fourth largest population in the world with 280 million people from five different religion groups where 85% are practicing Muslims. Within that population, there are roughly 40 million who are deaf non-signers, hard of hearing, and late deafened, where 4 million of them use Bahasa Isyarat Indonesia (BISINDO) Sign Language (Palfreyman, 2019) to communicate (Statistics Indonesia, 2015).

Deaf Communities who use BISINDO experience multiple barriers in Indonesia, one of them involving mental health services. This is critical because the country is home to numerous disasters per year, which can be traumatizing for many deaf people if they have no access to information and services. There is a Deaf organization called Gerkatina (Indonesian Deaf Association) with 30 branches and 50 BISINDO interpreters throughout the country, yet they are under-resourced and have limited capacity in responding and supporting those affected. The challenges are greater for those in remote or isolated areas.

In 2015, Indonesia passed a new law, the Mental Health Act, based on the significant impacts the 2004 tsunami and earthquake in Aceh had on local people and their communities. Before the law, mental health services were delivered in institutions that were overcrowded and in terrible and unsanitary conditions. There were people in “pasung” shackled cages or chained to the wall and wooden stocks tied up for many years. The new law was implemented to change the system, employing approximately 1000 psychiatrists to serve the



entire country. Out of 34 provinces, 27 of them implemented the new law while the remaining could not be due to cultural barriers on tribal islands.

As a retired Deaf Mental Health Advisor, Herbert Klein collaborated with Laura Lesmana Wijaya, Head of the Sign Language Center in Indonesia, on conducting community-based research in 10 different places in Indonesia on mental health awareness for Deaf Communities. Undertaking this research involved three different sign languages translated to communicate with local Deaf Communities: (1) Klein, as a foreigner, used International Sign Language; (2) Wijaya used International Sign Language and BISINDO; and (3) the last was a local person from each place who understood BISINDO and the local sign language used on that respective island. The research consisted of a set of questionnaires where each question was processed through a PowerPoint presentation and delivered in the following communication methods: role playing, gesturing, facial expressions, visual pictures, simple language, and video clips. It was important to document every participant's response through any of the methods to meet the varying communication needs of each deaf participant before moving on to the next question.

200 deaf people participated in the questionnaires where results showed that 90% of them exhibited signs of depression and anxiety with three notable case studies that emerged from this research that revealed insufficient mental health support, information and advice provided by local services for deaf people:

*Case A:* A deaf woman with schizophrenia was unable to communicate and stayed home most of the time. As a result, she was often ignored by her family because they believed she could not communicate but after Wijaya and Klein interacted with her, she responded very well after being asked to perform certain tasks (i.e., picking up a cup, pouring water, etc.). She was also able to maintain eye contact through sign language. The mother

showed the medication her daughter was on and lacked understanding of what condition her daughter had and the treatment (Haloperidol, Risperidone) she was taking.

Case B: A deaf man with schizophrenia often wandered the streets, exhibited violence and begged for food. He talked to himself via sign language and shouted at people often. It was difficult to communicate or maintain eye contact with him. His parents showed the medication he was on (Clozapine) but they were unaware of what it was for other than what his local doctor labelled as: '*Deaf and mute*'.

Case C: A deaf woman came stating that she had suffered abuse from her husband. Her arm was bruised, and she felt she could not ask for help because the local social services assumed that Deaf Community members do not experience any abuse and that there is a lack of shelters for domestic violence catered to the needs of deaf women. When this was addressed again with social service, they advised to ask the Deaf Centre. The problem with the Deaf Centre is that they lack the qualifications needed to support deaf women in domestic violence situations, and the head of the Deaf Centre was, in fact, the abuser in this case.

Given this was the first time a research study had been conducted in Indonesia, it was successful because of language access through the use of local BISINDO and Deaf Relay interpreters to translate sign languages tailored to suit local deaf people. It was critical that language access and communication needs be factored in for any activities involving Deaf Communities and notably, for future disasters as well.

The data thus collected was used to consult with the government's Department of Health team, universities, and Ibundi (Indonesian Psychology Association) to heighten the awareness on Deaf Communities and their mental health needs, including applying this for future disaster events. It is hoped that this will help push for a change to the mental health

system for Deaf communities. Future planning in the works includes:

- Establishing Deaf Mental Health Training for clinical professionals on understanding different communication needs and cultural differences within the Deaf Community as that could potentially impact diagnosis and treatment plans;
- Conducting further research projects to improve Deaf Communities and their access to social, mental and physical health, with particular attention around disasters,
- Increasing communication support in the form of both hearing and deaf sign language interpreters to accommodate the varying communication needs of deaf people,
- Providing more Deaf Mental Health Training for the Deaf Indonesian Community on understanding and recognizing mental health issues in oneself and others as well as empowering them to establish better mental health mechanisms in their communities.

### **Vietnam: Deaf-Led Organizations Assessment and DRR Action**

Global indexes rank Vietnam among the top ten countries impacted by extreme weather events and natural disasters, with a 3260 km coastline, 15 major islands and thousands of islets (2020 Global Climate Change Risk Index; cf. 40/191, 2019 World Risk Report). The 2021 Vietnam Disaster Management Reference Handbook further underlines that the country is one of the most “hazard-prone countries in the Asia-Pacific region” due to a high risk of flooding, landslides, and coastal erosion related to extreme storms, tropical cyclones, typhoons, and monsoon. Vietnam also has a disproportionately high disability prevalence, particularly in areas impacted by the toxic defoliant Agent Orange used by the

United States military during the American-Vietnam war (Le, Pham, & Polachek 2021). The 2016 Vietnamese National Survey on People with Disabilities reports that 7.06% of the population, or 1 out of every five households, has a family member with a disability; of these, about 1.3 million people are deaf or hard of hearing (GSO 2016).

Research conducted in 2019 on deaf-led organizations and disasters in Vietnam identified that deaf people are overwhelmingly impacted by disaster and extreme weather events, and overwhelmingly excluded from Disaster Risk Reduction (DRR) activities in the country, including public information and communication of extreme weather forecasting, emergency alerts, and disaster events (Cooper et al., 2021). Conducted by one US-based researcher (co-author of this conference paper) and six researchers associated with deaf organizations in North, Central, and South Vietnam: Hà Nội (northern, metropolis), Huế (central, flood plains), Đà Nẵng (central, coastal), Hồ Chí Minh City (southern, metropolis), Tiền Giang (southern, Mekong Delta), and Cần Thơ (southern, Mekong Delta). Study methods included interviews with 28 deaf organizations leaders, group surveys with 83 deaf organization members, auto-illustrations and photography of disaster events, and participant observation in all six sites. According to the six deaf organization leaders who collaborated on the 2019 research, deaf people's involvement in DRR activities began in 2011–2012 when an INGO-supported Disability-Led Organization in Vietnam invited deaf organization leaders to join DRR training. Deaf organizations also began posting disaster-related content in social media posts at this time.

Deaf community leaders reported that they initially saw their participation in DRR training activities as promising, with efforts made by several disability-led organizations to provide interpretation for deaf and hearing participants in DRR training. However, only a very small number of deaf community members were invited to participate (under 10), six of whom participated in the 2019 research project and who reflected that the training had many

barriers to accessing vital DRR content, due to the following constraints: “training designed for hearing people and delivered in spoken Vietnamese; interactions mediated by Vietnamese Sign Language(s)-Vietnamese interpreters, with hearing participants talking quickly or at the same time preventing interpreters from capturing the content; presenters privileging interactions with other hearing people; and, lack of training content specifically addressing DRR with deaf communities” (Cooper, et al 2021: 10). In addition to these constraints, research participants reported that their access to public sources of disaster information and communication was nearly nonexistent: 100% (28/28) of interviewees and 91.5% (76/83) of survey participants reported that they received no information from broadcast media or government sources (Cooper et al., 2021: 8).

As there are no formal interpreter training programs in the country (though several are in development), a national association would also provide a platform for mobilizing and advocating for advanced sign language training and interpreter training. Sign language interpretation in trainings and televised broadcasts (two 30-minute daily news broadcasts, one from Hà Nội and one from Hồ Chí Minh City) might be perceived as a solution to deaf community participation and leadership in DRR activities; however, televised content is disaster-specific. Moreover, there is an extreme human capital shortage where interpreters are concerned, as Vietnam does not have formal signed-spoken language interpreter training programs, nor systems for assessment and credentialing, so all services are delivered through largely self- and community-taught intermediaries who are also self-governed. Given these circumstances, data on deaf community use of televised news broadcasts is understandable:

100% of deaf leaders interviewed and group survey participants reported that they were aware of interpreted news broadcasts; however, no (0) interviewees and only 8.43% (7/83) of survey participants reported watching the interpreted news. The reasons that participants gave for not viewing the broadcast news centered on the kind and quality of the

sign language interpretation and on the lack of closed captioning (Cooper, et al., 2021: 8). It is in the context of these multi-layered circumstances, that deaf community leaders began mobilizing to develop their own disaster information. Unsurprisingly, the majority of research participants reported that they rely on deaf community sources and networks for disaster/emergency information, especially communication in sign language by deaf community members via Facebook as a main source of information, as well as videos received from deaf community members through Zalo (video messaging platform) (Cooper, et al., 2021: 8).

The above research data make clear that, particularly with present constraints on the production and circulation of disaster information in signed languages in Vietnam, deaf people face routine marginalization, even in settings where interpreters are provided for DRR training. The immediate solution posed to this situation by deaf community leaders is that DRR training should be provided by deaf people in sign language “to ensure access to information and applicability of the content to deaf communities in Vietnam,” but until such time as “deaf people have developed DRR training capacity, hearing trainers-of-the-trainers might be needed to bridge training expertise” (Cooper, et al 2021: 10). Deaf community leaders further recommended that such bridge training involve a minimum of hearing lead-trainers or other hearing participants, in order to maximize the deaf-cultural and linguistic shaping of DRR training approaches, and deaf self-determination in the training setting.

### **Case Study Stage 2: Bridge Approach**

#### **Australia: Piloting Training-the-Trainers Bridge Approach**

The state of NSW, Australia is prone to multiple hazards, yet emergency warnings and messaging continues to be inaccessible for deaf people to gain information on how to

best prepare, respond, and recover from emergency and disaster events. To address this oversight, the University of NSW (UNSW) partnered with the Deaf Society of NSW, Fire and Rescue NSW (FRNSW), NSW Rural Fire Services (RFS), and the State Emergency Services (SES) on a two-year project entitled *Increasing the resilience of the Deaf Community in NSW to natural hazards and disasters* (Calgaro & Dominey-Howes, 2013) as part of the Stage 1: Assessment. It aimed: (1) to increase the resilience of Deaf Community to future natural hazards and disasters through improved access to and provision of emergency management information; and (2) maximize resources, knowledge, and skills between emergency service agencies and Deaf Communities on disaster and hazards and Deaf Awareness.

The project concluded with a series of recommendations designed to: (i) increase deaf people's accessibility to and provisions of emergency management information and programs; (ii) strengthen social capital within communities and build stronger institutional linkages; (iii) increase the capacity of NSW emergency service organizations to better support the Deaf Community in hazard situations and meet their identified needs; and (iv) facilitate greater Deaf Community engagement in and shared action on disaster and emergency preparedness (Calgaro and Dominey-Howes, 2013). These recommendations resulted in two 'big wins'. First, Australian Sign Language (Auslan) interpreters were provided on TV emergency live news for the first time in NSW during the Blue Mountains 2013 Bushfire. Having Auslan interpreters included in live emergency broadcasts was a major communication breakthrough, enabling the NSW Deaf Community to gain crucial access to emergency information and news in their own language.

The second win of this project was a critical aspect of Stage 2 where a follow-up project in 2016 entitled *Get Ready Deaf Community NSW* achieved implementing one of the key recommendations of work - the training pilot of Deaf Liaison Officers (DLOs) (Roberts, 2018)

through a twin-track approach. DLOs are deaf volunteers who bridge information and skill sharing between Deaf Communities and emergency services. Through this project, up to 14 DLOs fluent in both Auslan and English from six regions across NSW, received training from the Office of Emergency Management, NSW RFS, NSW SES, Fire and Rescue NSW, Australian Red Cross, and The Deaf Society in the following capacities: basic emergency management; emergency preparedness; leadership; community development; workshop delivery and mentoring. As gatekeepers to the Deaf Community, DLOs also provided emergency preparedness information and workshops for deaf people through Deaf Communities' networks; Deaf Awareness Training for emergency services staff (benefitting 351 staff); advised emergency services on accessibility and cultural appropriateness of resources, and promoted campaigns and services delivered by emergency services organizations.

Since its implementation, post-project interviews were conducted in 2020 and onwards with 8 DLOs and 5 representatives from emergency services on the successes and shortcomings of this project. Among what was achieved includes heightened the awareness within emergency services on the diversity of Deaf Community members and the different communication approaches involved; generated deaf peoples' interest in becoming involved with their local emergency services and changed their views on being expected to be assisted by emergency services to taking responsibility of their own emergency preparations and response. However, this was not without limitations as well. There were three main shortcomings to this project that involved the need to develop a training curriculum tailored for deaf people as the one provided through the project was catered for and by hearing people. Secondly, the majority of the project focused more on the provision of the training and community workshops and little attention towards strengthening team capacity building. As a result, the quantity was valued more than the quality of how the training and workshops were delivered. Lastly, there was



internal support from the emergency services' ends; however, red tapes of getting funding hindered the continuation of this project.

### **Case Study Stage 3: Bridge and Twin-Track Approaches**

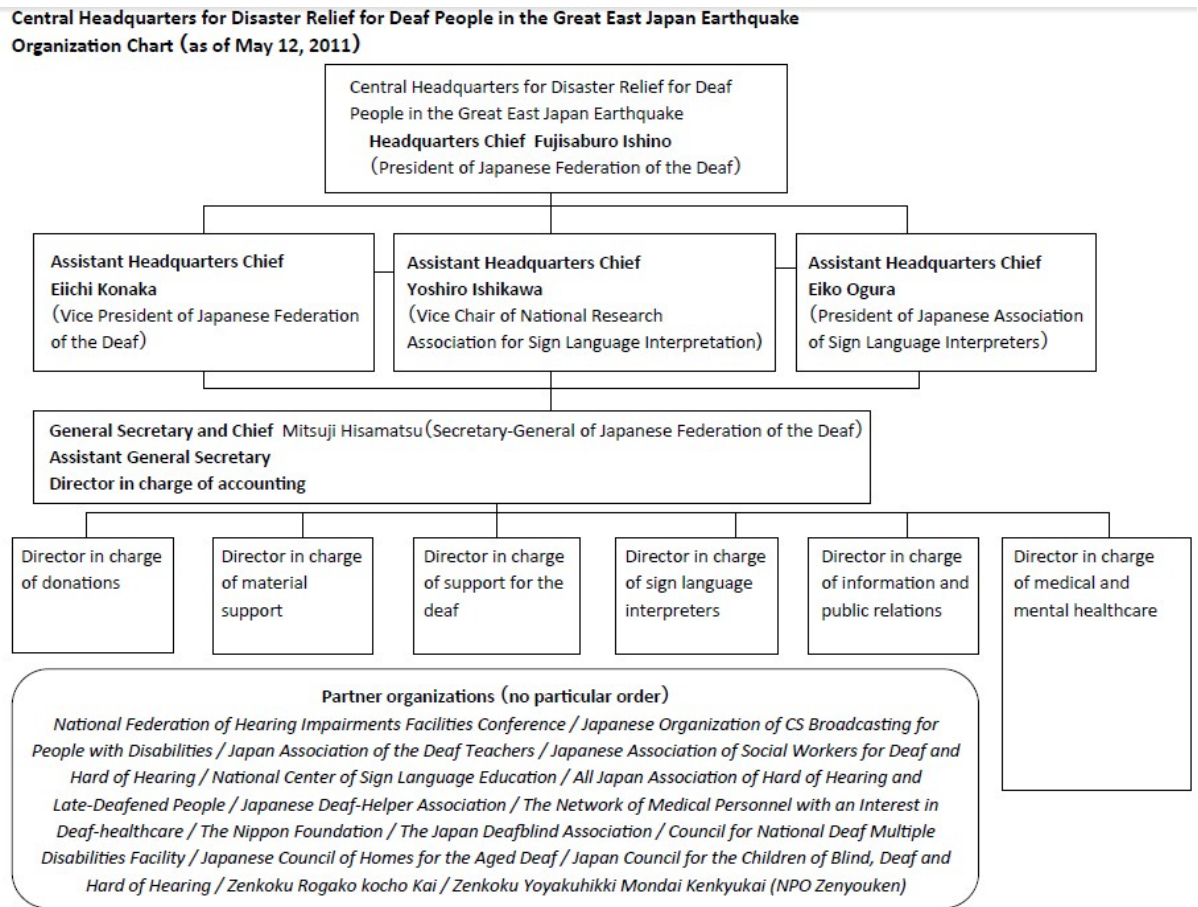
#### **Japan: Sustaining Deaf-Led Training-the-Trainers**

Historically, Japan has a large population that has been affected by earthquakes and other disasters with the ratio of disaster mortality increasing (Nakabayashi, 2012). In March 2011, Japan experienced a giant earthquake and tsunami that claimed the lives of approximately 15,000 people. According to a survey related to the Tohoku earthquake (Fujii, 2015), the mortality rate of people with disabilities was more than twice as high compared to people without disabilities. In the Tohoku earthquake alone, 75 deaf people died from the combination of powerful earthquakes and tsunami waves (Takayama, 2017).

The Japanese local governments took responsibility in responding to the large-scale environmental disaster. However, the local government's disaster relief support to the deaf community was systematically lacking and was ineffective due to insufficient training on providing accessible support for the deaf and hard of hearing communities affected (Takayama, 2017). In addition, they were not able to identify the cultural and linguistic needs of deaf people in the pre and post disaster phases. In response, the Japanese Federation of the Deaf (JFD), along with other deaf-led professional organizations, established central headquarters to provide disaster relief support during the post-Tohoku earthquake (see Figure 2). With JFD's coordination, the Japanese Association of Social Workers for Deaf and Hard of Hearing (JASWDHH) conducted an unofficial needs assessment under a deaf licensed social worker's supervision 7 days after the Tohoku earthquake.

Figure 2

Central Headquarters led by Japanese Federation of the Deaf (2012)

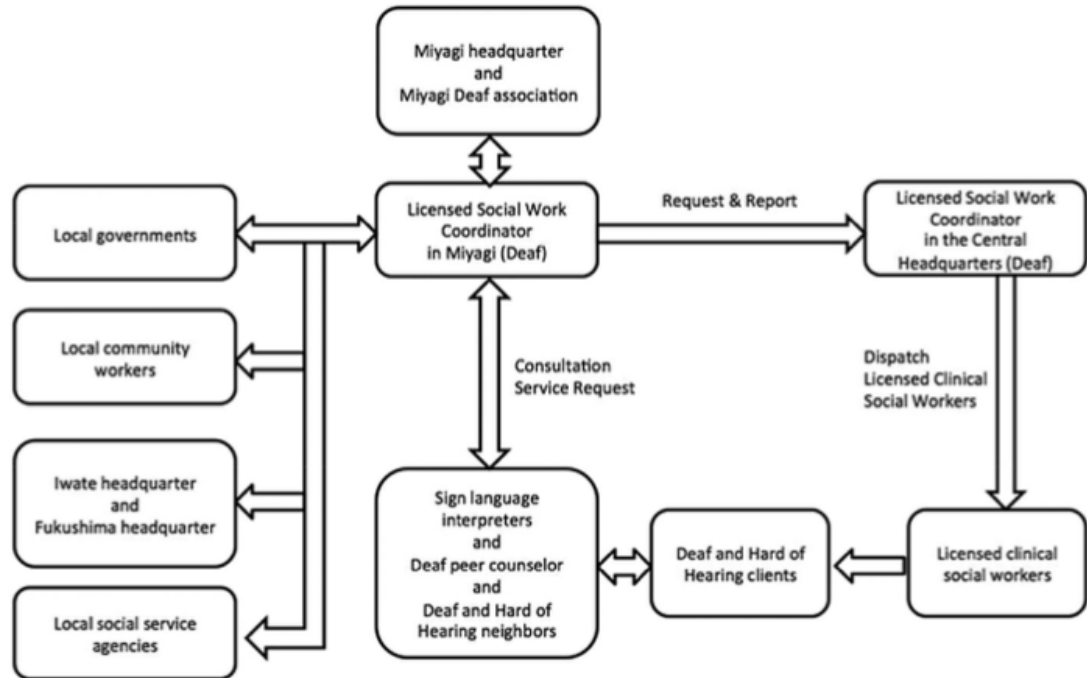


The JASWDHH started the disaster relief project called Deaf Support Nakama funded by the Nippon Foundation and American Jewish Association in July 2011 (JASWDHH, 2012). The Deaf Support Nakama project delivered psychotherapy and case management services provided by licensed clinical social workers with knowledge of the deaf population and fluency in Japanese Sign Language (see Figure 3) through 2011 to 2015. The JASWDHH also sent a deaf licensed social work coordinator to Miyagi Prefecture, and that coordinator remained through the 2011–2012 year. The office of the coordinator in Miyagi was located in the Prefecture’s JASWDHH headquarters, where the deaf licensed social work coordinator consulted and supervised Miyagi deaf peer counselors and sign language interpreters, and

provided outreach supports in Fukushima and Iwate prefectures to develop their DRR and emergency plannings with local governments. The social work coordinator also provided consultation for local governments and local community agencies unfamiliar with how to work with deaf and hard of hearing populations. After the social work coordinator engaged with the intake of deaf clients, requests were sent to the central headquarters to dispatch a licensed clinical social worker to provide case management and counseling. The Deaf Support Nakama and JFD's central headquarters also provided professional DRR training to local deaf and hard of hearing leaders to be a DRR and Emergency Planner for their local deaf communities. In addition to the training, the Deaf Support Nakama developed a program on Psychological First Aid (PFA), which was translated into Japanese Sign Language by a deaf social worker and deaf psychologist and made available on YouTube to increase its dissemination to the deaf community. Years after the post-Tohoku earthquake, many local deaf associations successfully conducted DRR training projects and emergency plannings with their local governments (Kurano, 2021; Tokyo Newspaper, 2022).

Figure 3

*JASWDHH's Deaf Support Nakama*



### Conclusion

Twin-track approaches have been used in various domains of development practice for some time and have been shown to have demonstrably better outcomes for training with historically marginalized and multiple intersectional communities (CBM International 2021; UNDESA 2016). Accordingly, proposing a twin-track approach to DRR training would seem to be uncontroversial; however, in practice, particularly in the context of the global disability inclusion projects, all four authors have witnessed growing resistance to proposals that involve twin-track training for deaf communities, including ideological reference to separatist intentions. These claims obscure the fact that most deaf people around the world have limited access to education—and thereby also limited access to information and communication in majority languages, and also limited access to multilingual sign language and communication

resources and services. Presenting DRR training in a majority language (i.e., PowerPoint with signed-spoken language interpretation) does not resolve the impacts of educational or social resource exclusion. Bridge approaches to training and twin-track training thereby utilize the collective knowledge, skills, and organizing power of deaf communities to redistribute decision-making power and resources, enabling deaf people to guide their own DRR training processes and capacity development.

## References

- Burch, S., & Kafer, A. (2010). *Deaf and Disability Studies : Interdisciplinary Perspectives*. Gallaudet University Press.  
<http://ebookcentral.proquest.com/lib/usyd/detail.action?docID=4860676>
- Calgaro, E., Craig, N., Craig, L., Dominey-Howes, D., & Allen, J. (2021). *Silent no more: Identifying and breaking through the barriers that d/Deaf people face in responding to hazards and disasters*. <https://hdl.handle.net/2123/24662>
- Calgaro, E., & Dominey-Howes, D. (2013). *Increasing the resilience of the Deaf Community in NSW to natural hazards*.
- CBM International. (2021). *Disability-Inclusive Development Toolkit*. Germany: CBM International.
- CFE-DMHA. (2021). *Vietnam Disaster Management Reference Handbook*. Hickam, Hawai'i: Center for Excellence in Disaster Management and Humanitarian Assistance.
- Cooper, A. C., Bui, H. T. T., Nguyễn, L. T., Nguyễn, P. K., Nguyễn, T. H. T., & Phan, D. P. N. (2021). Deaf-led organizations and disaster communication in Việt Nam: Interdisciplinary insights for disability inclusive disaster risk reduction planning. *International Journal of Disaster Risk Reduction*, 65, 102559.  
<https://doi.org/https://doi.org/10.1016/j.ijdr.2021.102559>
- Cooper, A.C. and Nguyễn, N.T.T. (2015). Signed Language community-Researcher Collaboration: Challenging Language Ideologies, Creating Social Change. *Journal of Linguistic Anthropology*, 25(2): 105–128.
- Cooper, A.C. (2017). *Deaf to the Marrow: Deaf Social Organizing and Active Citizenship in*

- Việt Nam*. Washington, DC: Gallaudet University Press.
- Craig, L., Craig, N., Calgaro, E., Dominey-Howes, D., & Johnson, K. (2019). People with disabilities: Becoming agents of change in disaster risk reduction. In F. I. Rivera (Ed.), *Emerging Voices in Natural Hazards Research* (327-356). Butterworth-Heinemann <https://doi.org/10.1016/B978-0-12-815821-0.00020-5>
- Craig, L., Johnson, K., Calgaro, Emma. (2017). *Disability and Disasters: Empowering people and building resilience to risk*.
- Cripps, J. H., Cooper, S. B., & Austin, E. N. (2016). Emergency Preparedness with People Who Sign: Toward the whole community approach. *Journal of emergency management (Weston, Mass.)*, 14(2), 101-111. <https://doi.org/10.5055/jem.2016.0277>
- De Meulder, M., Kusters, A., Moriarty, E., & Murray, J. J. (2019). Describe, don't prescribe. The practice and politics of translanguaging in the context of deaf signers. *Journal of Multilingual and Multicultural Development*, 40(10), 892-906. <https://doi.org/10.1080/01434632.2019.1592181>
- Engelman, A., Ivey, S. L., Tseng, W., Dahrouge, D., Brune, J., & Neuhauser, L. (2013). Responding to the deaf in disasters: establishing the need for systematic training for state-level emergency management agencies and community organizations. *BMC health services research*, 13(1), 84-84. <https://doi.org/10.1186/1472-6963-13-84>
- Harrelson, E. M. (2019). Deaf people with “no language”: Mobility and flexible accumulation in languaging practices of deaf people in Cambodia. *Applied Linguistics Review*, 10(1), 55-72. <https://doi.org/doi:10.1515/applirev-2017-0081>
- Ivey, S. L., Tseng, W., Dahrouge, D., Engelman, A., Neuhauser, L., Huang, D., & Gurung, S. (2014). Assessment of state- and territorial-level preparedness capacity for serving deaf and hard-of-hearing populations in disasters. *Public health reports (Washington, D.C. : 1974)*, 129(2), 148-155. <https://doi.org/10.1177/003335491412900208>

- Lane, H. (1992). *The mask of benevolence : Disabling the deaf community* (1st ed.). Knopf.
- Padden, C., & Humphries, T. (1988). *Deaf in America : Voices from a culture*. Harvard University Press.
- Padden, C., & Humphries, T. (2005). *Inside deaf culture*. Harvard University Press.
- Palfreyman, N. (2019). De Gruyter Mouton. <https://doi.org/doi:10.1515/9781501504822>
- Roberts, G. (2018). Get Ready: A model for deaf community leadership and preparedness. *Australian Journal of Emergency Management*, 7-8.  
<https://knowledge.aidr.org.au/resources/ajem-jul-2018-get-ready-a-model-for-deaf-community-leadership-and-preparedness/>
- Statistics Indonesia. (2015). *Profile of Indonesia Population*  
<https://www.bps.go.id/publication/2016/11/30/63daa471092bb2cb7c1fada6/profil-penduduk-indonesia-hasil-supas-2015.html>
- Takayama, K. (2017). Disaster Relief and Crisis Intervention with Deaf Communities: Lessons Learned from the Japanese Deaf Community. *Journal of Social Work in Disability & Rehabilitation*, 16(3-4), 247-260.  
<https://doi.org/10.1080/1536710X.2017.1372241>
- WFD. (2019). Complementary or diametrically opposed: Situating Deaf Communities within 'disability' vs 'cultural and linguistic minority' constructs: Position Paper.
- World Risk Report. (2019). World Risk Report - Focus: Water Supply. Bonn & Berlin, Germany: Bündnis Entwicklung Hilft.



**Deaf Community and DiDRR: Supporting a Twin-Track Approach** By Leyla Craig, Audrey Cooper, Kota Takayama, and Herbert Klein  
<https://rdsjournal.org/index.php/journal/article/view/1178> is licensed under a [Creative Commons Attribution 4.0 International License](https://creativecommons.org/licenses/by/4.0/). Based on a work at <https://rdsjournal.org>.



**Notes from the Field:****Mobilize for Action: Interactive Poster Presentations**

Genesis Leong<sup>1</sup>, Nicole Schlaack<sup>2</sup>, Erico Abordo<sup>3</sup> and Jared Galeai<sup>2</sup>

<sup>1</sup>Dept. of Urban and Regional Planning, University of Hawai‘i at Mānoa

<sup>2</sup>Center on Disability Studies, University of Hawai‘i at Mānoa

<sup>3</sup>Architects for Accessibility

**Abstract**

This is an overview of the posters presented at the 37th Annual Pacific Rim International Conference on Disability and Diversity.

*Keywords:* communities, disability studies, diversity issues, education, employment, career, health, well-being

## Notes from the Field:

### Mobilize for Action: Interactive Poster Presentations

We sought to create a reflective digital space that highlights disability and diversity issues from across fields, a lifespan and the world. Derived from the 37th Pacific Rim International Conference on Disability and Diversity on February 28th - March 1st, the goal of this article is to '*Mobilize for Action*' beyond the experiences of the virtual conference. Representing researchers, practitioners, students and advocates, the authors have assembled a collection of four summarizing perspectives presenting the conference's five strands—*Communities; Disability Studies & Diversity Issues; Education; Employment and Career; and Health & Well-being*. By building a common connection between the conference posters and live poster presentations, this article will continue to highlight actions done and actions needed.

#### **Dr. Nicole Schlaack: Building Capacity within Communities**

The Communities strand offered opportunities for presenters to share knowledge on: Autism & Neurodiversity; Deaf Community; Family Engagement; and Indigenous and Cultural Diversity. Communities offer a sense of belonging and are central to our human experiences. The presentations demonstrated that an engaging community allows us to share and relate with one another and to learn and develop new ideas. Communities become origins for knowledge and inspiration, a place to make connections and have access to resources, and a source for genuine support. Presentations included:

#### ***Communities for Learning***

Galeai (2022) shared the rewards and challenges of social work internships.

Placements at national and international schools connected the social work student with the community of a school. Students valued the opportunity to be engaged, to build relationships, and to learn from the partners in the community for strong family-school partnerships. School social workers internationally continue their efforts to concurrently support the academic and social emotional needs of students.

### *Art as a Community Connector*

Bell (2022) is part of the Navajo tribe. Learning the traditional skills of the Navajo weaver became her artform for expression and finding meaning in society. The strong connections of the Navajo weavers offer the community a sense of belonging.

### *Communities Provide Resources*

The collaborative presentation by Robinson, Okihiro, Matayoshi, and Leslie (2022) presented the successes of interdisciplinary teams to support children with disabilities and their families across the Pacific. The CAP Academy teams share their perspectives across disciplines. Applying the method of Design Thinking, the team explored ideas and resources in response to the needs of students and families' priorities.

### *Relationship Building for Student Success*

Chu and Jhou (2022) investigated parent professional partnership for promoting transition skills for young children with disabilities to be ready for the first-grade entry. Building this partnership was valued by families and the schools' professionals, making this an example of community building as an important pillar for connecting home and school environments.

### *Interactive Play*

Koizumi and Kojima (2022) cautioned that the lack of interpersonal interaction due to a restrictive lifestyle during the pandemic can have negative effects on the language development in children with developmental disabilities. Evaluating play and toys that were

used at home to foster language development demonstrated that simple rules were most effective.

### *Responsibilities for Communities*

Lindsay (2022) illuminates the relationships between race, ethnicity and school and work outcomes for youth with disabilities. Findings see a clear disparity for ethnic minority youth and call for more support and access to resources.

### *Understanding your Community*

Tomas (2022) shares how autistic youth and young adults navigate workplace disclosure. While men attributed workplace accommodation as a reason for disclosure, women spoke to increasing autism understanding.

### **Erico Abordo: Building Capacity with Disability Studies & Diversity Issues**

What is disability? How do the ways we as cultures answer this question impact access and equity? This strand invites contributions to the rich, diverse conversations that make up the interdisciplinary dialog of Disability Studies and Diversity Issues. The strand provides an exciting forum to explore some of the central questions animating Disability studies and inquiries into diversity issues. Identified topics this year include: Disasters and Emergency Preparedness; Disability Policy; Creativity, Media & the Arts; and Disability Studies & Intersectionality. This series of poster presentations offers a venue to understand issues in disability and diversity. No two topics are the same, as all issues are inherently different in terms of culture, experience, and approach to the identified issues or concerns. Presentations included:

### *Tenets of Resistance*

Fuller (2022) realizes that ignorance is never bliss. And all individuals must stand against ableism and racism, as a way of becoming activists to bring about future change.

### ***Defiance through Photography***

Tourigny and Daniel (2022) hand out cameras to Persons with Disabilities and transform their self-awareness into a diaspora of expression outside the box. Photography transcends boundaries; talent abounds from everyone.

### ***Evacuating Persons who Need Extra Care***

Goto and Kawashima (2022) go in depth with the teachings of their culture on how to handle people during evacuations and how to treat them with respect and dignity. This is followed by a further discussion into its applicable components into other countries and contrasting cultural traits.

### ***Skills for People with Intellectual Disabilities***

Kojima (2022) shows that employment opportunities must be for all, especially for Persons with Disabilities. This presentation opens the fact that skills needed for employment for the sector are not being developed. But this study opens doors through its voice for exemplifying the voracious capacity of Persons with Disabilities to be independent and willing to learn new relevant skills.

### ***Islamophobia and Mental Health***

Abdullah & Hendricks (2022) sees religion in all aspects as a love letter to all: boundaries are broken with just a little more understanding about the beliefs of thy neighbor. Ultimately, we are all here to lighten the burden of everyday living. But only when we broaden our horizons can we alleviate everyone's mental health.

Inspiration may come from tragedy, or hardship, or even defiance. But all inspiration stems from hope, from the thought of making the future a better place for everyone. The presenters for this year's Disability Studies and Diversity Issues had struggles aligning what they see in front of them, and then bent them to become something acceptable and inclusive. Their ideas awakened within them a raw power of will and determination. Their ideas and

research now pave the way for something new and provide a pathway to a broader dream.  
And a little more hope.

### **Jared Galeai: Building Capacity within Employment and Career**

The Employment and Career Strand represents the progress of workers with disabilities in finding inclusion and success. We must mobilize to combat the challenges and seize the opportunities of a turbulent global economy. Strand topics include Accessibility and Employment issues, COVID-19 and Employment, Innovations and Challenges in Workforce Development, and the Postsecondary Transition to Employment. Presentations included:

#### ***Comparative Study on the Employment of People with Mental Illness: Who Gave Up Working vs. Who Continues Searching for Jobs***

Yuzawa (2022) shared her study on how to support people with mental illness who have barriers to work. Her study was conducted in Japan. The purpose of the study was to determine what influences and motivations of persons with mental illness who will continue to locate employment vs. those who choose to stop looking. The process of self-determination is coached towards making a final decision. Final findings supported that it is essential for supporters to keep positive and suggest that clients continue looking for employment.

#### ***The Maverick Entrepreneurs***

Ruffner (2022) discussed neurodiversity in business today and the future that transcend cultural barriers. Businesses are looking for ways to better their hiring practices and introducing different ways their employees can create an advantage over competition. This doctoral dissertation study reviews a cross disciplinary view of neurodiversity's connection to entrepreneurship, specifically those with dyslexia and Attention Deficit Hyperactivity

Disorder.

***Training Adults through Research, Group Education, and Treatment (TARGET): A Transition-Focused Program for Young Adults with Fetal Alcohol Spectrum Disorders***

Cleveland (2022) discusses the TARGET (Training Adults through Research, Group Education and Treatment) Program which is a virtual summer program for young adults with fetal alcohol spectrum disorders in regards to employment and transition. The program was developed by the Arkansas Leadership Education in Neurodevelopmental Disabilities which encourages group involvement during the COVID-19 pandemic.

***Employer Support in the Employment of Persons with Autism in Japan***

Umenaga (2022) presents the lack of employment supports for people with developmental disabilities by companies in Japan. The development of a guide for employers to promote employment for persons with autism. The guide can be used to educate employers about the characteristics of autism which may lead to a progression of employment for persons with autism.

***A Qualitative Study on the Function of ICT Utilization in Teaching Students with Intellectual Disabilities***

Maebara, Yamaguchi, Suzuki & Imai (2022) conducted interviews with teachers who are working with students that use Information and Communication Technology (ICT) in their classroom. ICT learning is one of the most effective considerations for promoting learning for students with intellectual disabilities. The study will give teaching/coaching techniques some ways to rethink the use of ICT.

***Disability as a “Superpower”: Understanding Marginalization and Equity in the Health Professions***

Owen & McMillan (2022) present findings of recent research which explored the everyday work experiences of health professionals marginalized by race, ethnicity,

indigeneity, social class, disability and/or sexual/gender identity. The poster focuses on some innovative ways health care professionals with disabilities have reshaped their experiences.

### ***Scavenger Hunt to Raise Awareness of Assistive Technology and Inclusion***

Zheng & Pedersen (2022) look at Assistive Technology (AT) use and training on a college campus. Events were conducted on campus that were open to all students, faculty and staff to explore AT items in the Department of Special Education lab. Visitors to the events at the lab were invited to explore, given questions to come up with quick solutions and given prizes for responding to the poll. The scavenger hunt activity survey data was used for strategies about raising AT awareness.

### ***School and Employment-related Barriers for Youth with and without Disabilities during the COVID-19 Pandemic***

Lindsay (2022) explored barriers to school and employment for youth with and without a disability during the COVID-19 pandemic. Interviews were conducted with youth and young adults in regards to these barriers. Some of those barriers included difficult transition to online school and work, uncertainty about employment opportunities, and missed opportunities for career development because of the pandemic.

### ***Trends of Home Based Vocational Training and Telework-based Employment Support for Individuals with Disabilities during COVID-19 in Japan***

Yamaguchi, Yaeda, Maebara & Nozaki (2022) conducted a study to look at the status of home-based training for people with disabilities and the trend of telework based employment support during COVID-19 in Japan. The study also looks at what is available regarding the implementation of telework based vocational rehabilitation. The study also reviews how Information Communication Technology (ICT) is used and what struggles with work performance are due to issues with communication, training on ICT and daily workflow.



### **Genesis Leong: Building Capacity within Education**

The Education topic strand focuses on the experiences and outcomes of people with disabilities in education. Projects address barriers to access and participation as well as innovation and success in reimagining education across early childhood education, elementary education, secondary education, higher education, and informal and alternative education and examine disability as a core component of diversity. Key takeaways and ways to Mobilize for Action include:

#### ***STEM Education***

The emergence of STEM education is highlighted in an introduction presentation provided by Jenda (2021) on NSF INCLUDES Alliance TAPINTO-STEM that includes the history, successful interventions and improvements for STEM students with disabilities nationwide.

#### ***Accommodations and Assistive Technology***

The growing need to create safe environments during the pandemic included Kirshira & Sasaki's (2022) students with disabilities in distance learning environments, Watanabe, Fujii, Hosho & Asaishi (2022) assistive technology for students with disabilities, and Kataoka (2022) learning disabilities obtaining reasonable accommodations.

#### ***Inclusive Campus Environments***

To address the needs of students and educators with multiple identities and disabilities, the emergence of education projects, support services and curriculum were present at the conference. This included: Kim & Govin (2022), SPEDucators Project aimed at building community; Pham (2022), social support and school belonging for English learners with disabilities; and Sedgwick (2022), activist learning activities for disabled learners.

## **Genesis Leong: Building Capacity within Health & Well-being**

Mental health was the key connecting factor of the Health & Well-being strand. Research findings reinforce the importance of building capacity within our spaces. Key takeaways and ways to Mobilize for Action include:

### ***Self-worth and Self-esteem***

Ogawa and Kojima (2022) found that “athletic competence, academic competence, interpersonal relationships, and enthusiastic activity affect self-esteem.” In line with *Mobilizing for Action!*, they suggested a “high level of enthusiastic activity promotes positive evaluation of the self by making it easier to have hopes for the future and to accept the past and [these are] factors that increase self-esteem” (Erico et al., 2021).

### ***Dementia-friendly Gardening***

Halzel (2022) proposes that gardening can “impact health and quality of life for Alzheimer’s disease and related dementias.” By removing barriers (attitudinal, communication, physical, programmatic, transportation) and using ADA guidelines, gardening can be used as an activity to provide sensory, memory, inclusive participation, and social interactions.

### ***Equitable Use & Performing Arts***

Potter (2022) shares a best practice guidebook, *Universal Design in the Performing Arts* by enforcing how equitable spaces help to improve “experiences for everyone.” This is done by integrating Universal Design Learning (UDL) practices into common performing arts practices such as ticketing, use of plain language, and sensory theme-colored lighting.

### ***COVID-19 & Mental Health Maintenances***

Lindsay (2022) aimed “understand the facilitators for helping youth and young adults with and without disabilities to copy during the COVID-19 pandemic.” By taking the key themes (social support; financial support; keeping busy; and work-life balance), we are better

able to provide coping strategies and personal growth within COVID-19's current and long-term effects.

### ***Islamophobia Misconceptions & Mental Health***

Abdullah & Hendricks (2022) provided awareness to the common misunderstandings shaping Islamophobia (terrorism; Middle Eastern; Arab; Shariah law; arranged marriage; polygamy; dressing). By better understanding cultures and religion, as individuals we can avoid the decline of mental health, hate crimes and trauma due to Islamophobia (Abordo et al., 2022).

The Health & Well-being live interaction sessions were integrated into the other strands. The ease of placement signifies that mental health, well-being and flourishing is in many cases the foundational factor that has driven much of research and best practices across the 2022 Pacific Rim Conference presentations.

## References

- Abordo, E. (Moderator), Tourigny, L.A., Daniel, J., Fuller, G., & Potter, H. (2022, February 2-March 1). *Poster Interactive Session: Disability Studies & Diversity Issues (Morning)* [Conference Session]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Abordo, E. (Moderator), Goto, Y., Kawashima, S., Kojima, M., Abdullah, J., & Hendricks, F. (2022, February 2-March 1). *Poster Interactive Session: Disability Studies & Diversity Issues (Morning)* [Conference Session]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Abdullah, J., & Hendricks, F. (2022, February 2-March 1). *Islam and Islamophobia: Implications for the Practice of Occupational Therapy and Mental Health* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Bell, A. J. (2022, February 2-March 1). *The Navajo Spider-women Teaching of Creating a Navajo Loom* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Chu, S.Z., & Jhou, R.A. (2022, February 2-March 1). Family Matters: Parent-Professional Partnership for Promoting Transition to First Grade [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Cleveland, E. (2022, February 2-March 1). *Training Adults through Research, Group Education, and Treatment (TARGET): A Transition-Focused Program for Young Adults with Fetal Alcohol Spectrum Disorders* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Fujii Yamaguchi, A., Yaeda, J., Maebara, K., & Nozaiki, T. (2022, February 2-March 1). *Trends of Home Based Vocational Training and Telework-based Employment Support*

- for Individuals with Disabilities during COVID-19 in Japan* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Fuller, G. (2022, February 2-March 1). *The Seven Tenets of DisCrit* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Fuller, G., & Leong, G.M.K. (2022, February 2-March 1). *Building a Campus Culture of Preparedness* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Galeai, J. (Moderator), (2022, February 2-March 1). *Poster Interactive Session: Employment and Career (Morning)* [Conference Session]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Galeai, J. (Moderator), (2022, February 2-March 1). *Poster Interactive Session: Employment and Career (Afternoon)* [Conference Session]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Galeai, K. (2022, February 2-March 1). *A Case Study Evaluation of Contextual Influences for Effective Interpersonal Supervision for School Social Work Interns in International School Settings* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Goto, Y., & Kawashima, S. (2022, February 2-March 1). *Evacuation of Persons who Need Care in the 2018 West Japan Heavy Rain* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Halzel, M. (2022, February 2-March 1). *Guidelines & Strategies to Implement an Inclusive Garden for People with Dementia* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.

- Ito, T. (2022, February 2-March 1). *Characteristics of Children in the Developmental Support Center of our University Hospital* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Jenda, O. (2022, February 2-March 1). *NSF INCLUDES Alliance: The Alliance of Students with Disabilities for Inclusion, Networking, and Transition Opportunities in STEM (TAPDINTO-STEM)* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Kataoka, M. (2022, February 2-March 1). *A Process and Issues of Support Acquisition at School in Japan: How does a Junior High School Student with LD Obtain Reasonable Accommodation?* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Kim, J., & Govin, D. (2022, February 2-March 1). *SPEDucator Project: Power of Changing the Narrative and Building Community* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Kishira, H., & Sasaki, G. (2022, February 2-March 1). *Research on the Use of Information and Communication Technology by Students with Disabilities in Distance Learning* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Koizumi, M., & Kojima, M. (2022, February 2-March 1). *Development of Parent-child Play to Foster Language Development in Children with Developmental Disabilities* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Kojima, M. (2022, February 2-March 1). *Supporting Self-Advocacy Skills Acquisition of People with Intellectual Disabilities in Japan* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.

- Lindsay, S. (2022, February 2-March 1). *Exploring the Relationships Between Race and Ethnicity on School and Work Outcomes Among Youth and Young Adults with Disabilities* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Lindsay, S. (2022, February 2-March 1). *Facilitators for Coping with the COVID-19 Pandemic among Youth with Disabilities* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Lindsay, S. (2022, February 2-March 1). *School and Employment-related Barriers for Youth with and without Disabilities during the COVID-19 Pandemic* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Maebara, K., Yamaguchi, A., Suzuki, T., & Imai, A. (2022, February 2-March 1). *A Qualitative Study on the Function of ICT Utilization in Teaching Students with Intellectual Disabilities* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Miller, A. (Moderator), Jenda, O., Kishira, H., Sasaki, G., Pham, Y., Watanabe., T., Fujii, H., Hosho, T., & Asaishi, Y. (2022, February 2-March 1). *Poster Interactive Session: Education (Morning)* [Conference Session]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Miller, A. (Moderator), Ogawa, S., Kojima, M, Kim, J., & Govin, D. (2022, February 2-March 1). *Poster Interactive Session: Education (Afternoon)* [Conference Session]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Ogawa, S., & Kojima, M. (2022, February 2-March 1). *Contingencies of Self-Worth, Contentment of Sources of Self-Worth, and Self-Esteem of Japanese High School*


- Students* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Owen, M., & McMillan, S. (2022, February 2-March 1). *Disability as a “Superpower”*: *Understanding Marginalization and Equity in the Health Professions* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Pham, Y. (2022, February 2-March 1). *Social Supports and School Belonging for English Learners With Disabilities: Analysis From NLTS2* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Potter, H. (2022, February 2-March 1). *Increasing Access to the Performing Arts: Using Universal Design to Make the Arts Better for Everyone* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Robinson, N.B., Okihiro, M.M., Matayoshi, R., & Leslie, S. (2022, February 2-March 1). *Collaboration Across the Pacific (CAP) Academy: Sharing Technology and Skills for Serving Children with Disabilities and their Families* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Ruffner, J. (2022, February 2-March 1). *The Maverick Entrepreneurs* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Sedgwick, M. (2022, February 2-March 1). *Imagining Disabled Learner Identities: Analyzing Activists' Talk While Designing a Learning Activity* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Schlaack, N. (Moderator), Galeai, K., & Bell, A. (2022, February 2-March 1). *Poster*



- Interactive Session: Communities (Morning)* [Conference Session]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Schlaack, N. (Moderator), Chu, S.Z., Jhou, R.A., Koizumi, M., Kojima, M., Robinson, N.B., Okihiro, M.M., Matayoshi, R., & Leslie, S. (2022, February 2-March 1). *Poster Interactive Session: Communities (Afternoon)* [Conference Session]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Tomas, V. (2022, February 2-March 1). *Using the COM-B Model and Theoretical Domains Framework to Understand the Workplace Disclosure Experiences, Influencers, and Needs of Autistic Youth and Young Adults in Canada* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Tourigny, L.A., & Daniel, J. (2022, February 2-March 1). *A Thousand Words Photography Project* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Watanabe, T., Fujii, H., Hosho, T., & Asaishi, Y. (2022, February 2-March 1). *Interview Survey on Provision of Assistive Technology Services for Students with Disabilities under COVID-19 Pandemic* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Whiteley, A., & Atkins, C.G.K. (2022, February 2-March 1). *Technological Exclusion: How Research Tools Exclude Disability Perspectives in Disability and Employment Research* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.
- Yuzawa, Y., & Yaeda, J. (2022, February 2-March 1). *Comparative Study on the Employment of People with Mental Illness: Who Gave Up Working v.s. Who Continues Searching for Jobs* [Poster Presentation]. Pacific Rim International Conference on Disability and

Diversity, Honolulu, HI, United States.

Zheng, W., & Pedersen, H.F. (2022, February 2-March 1). *Scavenger Hunt to Raise Awareness of Assistive Technology and Inclusion* [Poster Presentation]. Pacific Rim International Conference on Disability and Diversity, Honolulu, HI, United States.

 **Notes from the Field: Mobilize for Action: Interactive Poster Presentations** by Leong, Schlaack, Erico Abordo, and Galeai <https://rdsjournal.org/index.php/journal/article/view/1263> is licensed under a [Creative Commons Attribution 4.0 International License](https://creativecommons.org/licenses/by/4.0/). Based on a work at <https://rdsjournal.org>.