

National Leadership Consortium **Bulletin**

A Global Lens to
Disability Leadership

**NATIONAL
LEADERSHIP
CONSORTIUM**



ON DEVELOPMENTAL DISABILITIES

October 2024 • Issue 12

National Leadership Consortium **Bulletin**

About the Bulletin

The National Leadership Consortium Bulletin is a free, web-based publication dedicated to providing relevant, trustworthy, and thought-provoking information to leaders, practitioners, and people with disabilities and their families involved in the field of developmental disabilities support services. The Bulletin will serve as a bridge between scientific journals and day-to-day leadership, exploring timely research and policy issues in the leadership and disabilities fields with the aim of promoting organizational change and assisting leaders to support people with disabilities to experience inclusive, valuable, and meaningful lives.

About the National Leadership Consortium

Leadership, Values and Vision: Transforming Lives and Organizations

The National Leadership Consortium was founded in 2006 to develop current and future generations of disability sector leaders to have the knowledge, skills, and values needed to transform services and systems to be responsive to the needs, wants, and rights of people with disabilities. Our mission is to provide quality training, technical assistance, and support aimed at the development of values-based leadership in disability sector leaders. The National Leadership Consortium is focused on promoting the rights of people with disabilities to direct their services and lives and to fully belong in their chosen communities. One way the National Leadership Consortium works to meet this mission is through a nationally recognized, intensive leadership development program, the Leadership Institute. These in-person or virtual trainings focus on knowledge, skills, and supports leaders need to transform systems and organizations in the disability service sector.



Contact Us

<https://natleadership.org/bulletin> • bulletin@natleadership.org

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Table of Contents

Introduction: A Global Lens to Disability Leadership	3
Supporting the Involvement of People with Intellectual Disability in the Decision-Making and Governance of Community Organizations	4
A Call for New Priorities: Advancing Research on Refugees with Disabilities	7
The Kenya Association of the Intellectually Handicapped (KAIH): Promoting Inclusive Development and Empowerment for People with Intellectual Disabilities	11
How Accessible Is Your Written Content?	13
Research from Ireland Highlights Opportunities for More Community Participation	16
Expert Q&A: A National Leadership Consortium Bulletin Conversation with Diane Richler, Sue Swenson, and Steven Eidelman: Reflections on International Disability Advocacy	19
Expert Q&A: Don't Put Us Away: Memories of a Man with Learning Disabilities	26
Organizations with Resources to Help You Learn More About Disability Rights, Advocacy, and Services Around the World	28
What We're Reading, Viewing, and Listening To	31
Upcoming Events	33

Contributors:

Caitlin Bailey, PhD, *Co-Director, National Leadership Consortium*

Bernadette Curryer, PhD, *Research Officer, Side by Side Advocacy*

Rooshey Hasnain, PhD, *Clinical Associate Professor and Community-Engaged Researcher, University of Illinois at Chicago*

Tedros Markos, *Self-Advocate*

Fatma Wangare, *Secretary General, Kenya Association of the Intellectually Handicapped*

Cathy Basterfield, *Founder and Owner, Access Easy English*

Cory Gilden, PhD, *Research and Evaluation Manager, National Leadership Consortium*

Diane Richler, *Joseph Kennedy, Jr. Foundation International Fellow*

Steven Eidelman, *Co-Founder, National Leadership Consortium on Developmental Disabilities*

Sue Swenson, *President, Inclusion International*

Amanda Rich, PhD, *Director, Institute of Social Healing at York College of Pennsylvania*

Richard Keagan-Bull, *Self-Advocate and Research Assistant, Kingston University*

Managing Editor: Cory Gilden, PhD

Consulting Editor: Amanda Rich, PhD

If you would like to contribute a reflection, strategy, position piece, or research to the Bulletin please contact us at bulletin@natleadership.org.

Even if you have not written for publication before, the team at the Bulletin would love to help you develop your ideas.

Introduction: A Global Lens to Disability Leadership

The Bulletin team decided to dedicate our 12th issue to highlighting international innovations, research, and issues to increase readers' awareness of similarities and differences in disability fields around the world. Right now, we're in a time of significant global progress and conflict — both of which deeply impact the lives of people with disabilities and their loved ones. Global progress provides field leaders insight into opportunities to continually improve services, focus on inclusive advocacy and decision-making, and replicate evidence-based strategies. Global conflict exacerbates challenges for people with disabilities who become refugees and asylum seekers and struggle to access healthcare and support when both are scarce. Conflict also essentially guarantees that the number of people with disabilities worldwide will increase, putting more pressure on already strained systems of support.

This is a rich issue of the Bulletin that is filled with insights, evidence-based practices, and recommendations to improve the lives of people with disabilities around the world. As you read, you will likely notice that many of the articles mention or heavily use the UN Convention on the Rights of Persons with Disabilities (CRPD) as a foundational tool and guide for research methods, advocacy strategies, and service practices. If you are from the U.S., you may know that our country has not ratified the CRPD, so it's not something we refer to enough. You can find the full or accessible version on the [United Nations website](#) to better familiarize yourself.

In this issue, you'll read about research needs and efforts in multiple countries, including a synopsis of an Ireland longitudinal study on aging by Cory Gilden, the results of the Inclusive Governance Project by Bernadette Curryer, a study aimed at understanding the experiences of people with disabilities who serve on governing boards of Australian organizations, and a call to advance research that includes and is led by refugees to document the growing needs of refugees with disabilities around the world by Rooshey Hasnain and Tedros Markos. The issue also highlights organizations that are enhancing advocacy and accessibility in various countries, including a description of the Kenya Association of the Intellectually Handicapped, an advocacy and rights protection organization in Kenya, by Fatma Wangare, and an overview of an Australian Easy English model that helps people with disabilities be fully informed by Cathy Basterfield. Two interviews, one with Richard Keagan-Bull sharing about his life and powerful compilation of personal stories in his book, *Don't Put Us Away: Memories of a Man with Learning Disabilities* (edited by Cory Gilden) and the other with Steve Eidelman, Diane Richler, and Sue Swenson focused on global advocacy and human rights (edited by Amanda Rich) are both filled with moving examples and ideas to promote the rights of people with disabilities around the world. Finally, Amanda Rich wraps up this issue with a useful list of organizations that provide resources and information to help field leaders learn more about disability rights, advocacy, and services.

On reading each of the articles, I was reminded how interconnected we all are; the work we do in one part of a country to improve the lives of people with disabilities can impact people around the world. I hope you take some ideas and practical resources from this issue. As ever, we welcome feedback and questions to bulletin@natleadership.org.

Caitlin Bailey

Caitlin Bailey is the Co-Director of the National Leadership Consortium. She holds a Ph.D. in Human Development and Family Science. Caitlin is passionate about enhancing leaders' skills and evidence-based practices in our field. Contact Caitlin at cbailey@natleadership.org.



Supporting the Involvement of People with Intellectual Disability in the Decision-Making and Governance of Community Organizations

By Bernadette Curryer

- Inclusive governance means that all people, including people with intellectual disabilities, have a chance to be involved in the decisions that community and disability organizations make.
- To prepare people with intellectual disabilities to be involved in decisions, they need to learn about governance. They also need people to share information in a way they understand and give them support that meets their needs.
- Organizations need to value the ideas of people with intellectual disabilities. Organizations need to be willing to provide the resources needed.

What was the intent of the study and the work you do?

[The Inclusive Governance Project](#) wanted to explore the inclusion of people with intellectual disabilities in the decision-making and governance of disability and community organizations in Australia. We did this by conducting qualitative research to understand the experiences of board members with and without intellectual disabilities, senior staff, and board support people. We wanted to recognize board structures, policies, and procedures that promote the inclusion of people with intellectual disabilities and support their recruitment, decision-making, and leadership.

Why is this an important topic to study?

The [United Nations Convention on the Rights of Persons with Disabilities in preamble 'O'](#) (UN, 2006) identifies the right of people with disability to be given the opportunity to be actively involved in policy and program development and other organizational decision-making that impacts their lives. While there appear to be more people with disabilities in governance roles, the inclusion of people with intellectual disabilities is still not generally practiced, even by organizations where people with intellectual disabilities are the key stakeholders.

What were the key findings of the study and your work?

Five themes emerged from the interviews in our study (Curryer et al., 2024a):

Theme 1: Impact of inclusion in governance

When people with intellectual disabilities are included in governance:

- they feel respected, have a valued role, and have their voice heard
- organizations receive an additional perspective and skill to their decision-making
- stereotypes are challenged

Theme 2: Pathways to board membership

Board membership is more likely when:

- skill development and the opportunity for a variety of experiences are available to people with intellectual disabilities (for example, organizational membership, advisory groups, co-design, and sub-committees)
- inclusion is embedded throughout an organization

- accessible training is available

Theme 3: Experiences impact inclusion within boards

The sense of inclusion is impacted by:

- board culture
- board structure
- communication practices
- meeting processes
- decision-making processes
- any experience of exclusion

Theme 4: Support provision

Skilled, individualized support is required including:

- meeting preparation
- support during meetings
- contact between meetings

The support role is complex, and supporter training is needed.

Theme 5: Concerns become barriers to inclusion

Participants reported the following concerns:

- complexity of the board role
- legal responsibility
- meeting support needs
- perceived conflict of interest
- current board culture
- fear of tokenism

How can organizations use this information to better include people with disabilities in boards, committees, organizations, etc.?

The findings informed the development of [5 Principles of Inclusive Governance](#)

- ① Inclusion of people with intellectual disabilities in the decision-making and governance of community organizations is valued.
- ② There are clear pathways to board membership for people with intellectual disabilities.
- ③ Board meetings and activities are accessible, meeting the inclusion needs of people with intellectual disabilities.
- ④ Individualized, skilled support is provided.
- ⑤ There is a commitment to making Inclusive Governance work.

These principles can be used as a framework to guide an organization towards an inclusive model of governance.





Source: Curryer et al., 2024b

Suggested actions for organizations looking to be more inclusive:

- Involve all stakeholders
- Discuss each principle, together with relevant findings from the study
- Recognize current practices that promote inclusion
- Identify gaps or barriers to inclusion
- Discuss options to increase inclusion, recognizing required resources
- Agree to actions, timeframes and person or people responsible
- Review plans on a regular basis.

Resources from the study, including a report providing more details about the study and its findings and an Action Plan template, are freely available on Side By Side Advocacy's Inclusive Governance Project webpage: <https://sidebysideadvocacy.org.au/inclusive-governance/>

Curryer, B., Donnelly, M., Roots, K., Spencer, M., Harding, W. & Sneath, K. (2024a). Inclusion of people with intellectual disability in the decision-making and governance of disability and community organisations. Manuscript submitted for publication.

Curryer, B., Donnelly, M., Roots, K., Spencer, M., Harding, W., & Sneath, K. (2024b, August). Inclusive Governance: a guide to including people with intellectual disability in the decision-making of community organisations. Poster session presented at the IASSIDD Congress, Chicago.

Bernadette Curryer is the Research Officer for Side by Side Advocacy, an affiliate of the Centre for Research Policy and Practice at the University of Sydney, and the Vice President of the Australasian Society for Intellectual Disability (ASID). Contact Bernadette at igp@sidebysideadvocacy.org.au.



A Call for New Priorities: Advancing Research on Refugees with Disabilities

By Rooshey Hasnain and Tedros Markos

- Refugees and asylees are people who have left their own countries because they are at risk.
- The United States has welcomed many refugees of all ages living with disabilities.
- Refugees with disabilities in the U.S. have little access to services.
- More research done together with people with disabilities is needed to better understand the experiences and needs of refugees with disabilities.
- We need Community-Based Participatory Research (CBPR) to better understand the experiences of refugees with disabilities. This means that people working in disability services and refugee support, along with researchers, should [work together to gather important information](#) about the unique challenges faced by refugees with disabilities. Research must be conducted by the disability and refugee service sectors as well as academic institutions to better understand the experience of people with disabilities who are refugees.
- Cooperation and collaboration between self-advocates, community groups and leaders, educators, researchers, service providers, and practitioners are important to design, launch, and complete CBPR projects. By combining knowledge from disability studies and refugee studies, programs and activities can be created that truly make a difference.
- A better understanding of the lives and experiences of refugees with disabilities — including their needs, challenges, and strengths — will help make the resettlement process smoother and more effective for them.

Background of Refugee and Disability Status

[Refugees and asylees](#) are people who have fled their home countries but are unable or unwilling to return, most often because of persecution or well-founded fears of persecution based on race, religion, nationality, ethnicity, or political affiliation. As of December 2023, [approximately 117.3 million people globally were forcibly displaced](#); of these, 43.4 million were officially classified as refugees.

According to the United Nations Convention for the Rights of Persons with Disabilities (CRPD), [disability](#) “refers to having a chronic physical, mental, intellectual/developmental, psychological, or sensory impairment that, when combined with other obstacles, may prevent an individual from fully or equally participating in society.”

The [aim of the CRPD](#), so far the most comprehensive human rights treaty of the twenty-first century, is to find ways to reduce inequities worldwide for people with disabilities and to promote their human rights and opportunities. Although precise figures about the number of refugees who have disabilities are not available, estimates range from 13% to 20%. The World Health Organization (WHO) estimates that about [1.3 billion people](#), approximately one in six people (16% of the world’s population), experience some kind of disability, and many of them are refugees.

Resettlement Challenges for Refugees with Disabilities

With a refugee resettlement quota of 125,000 for fiscal year 2024, the [U.S. is a leading destination](#) for refugees in the Western world. A [recent report](#) by the U.S. Committee for Refugees and Immigrants is bringing attention to an important issue: many refugees come to the U.S. from regions of the world where disability rates are high (for example, Asia, Africa, Latin America, and the Caribbean), which means that the numbers of refugees with disabilities entering the U.S. are likely high as well.

In addition, this segment of the disability community often faces [significant challenges](#) wherever they live, including 1) risk of violence, poverty, and exploitation; 2) barriers and oppressive structures, both societal and institutional, that hinder their access to necessary services and resources; and 3) exclusion from critical life opportunities in education, employment, housing, assistive technology, and transportation. Social isolation, which limits integration and empowerment in community life, compounds these challenges. Besides the multiple layers of exclusion that refugees with disabilities endure both before and during migration, their rehabilitation needs often remain unmet once resettled; therefore, the [challenges they may have arrived with are made worse](#), and in their new country, they find themselves marginalized and unable to advocate on their own behalf.

A large body of scholarly literature indicates that, in addition to pre-migration histories that are likely to include trauma and loss, refugees with disabilities face [significant barriers](#) in accessing the services and resources necessary for their integration into American life. Many have already spent years in camps or makeshift dwellings. Resettling means they must navigate the dual challenges of forcible displacement from their home countries while adjusting to their new surroundings. In most cases, refugees and asylees in the U.S. are culturally and linguistically distinct from other marginalized groups. In addition, those with disabilities are [likely to experience social and economic discrimination, stigma, and exclusion](#) within their own communities, as well as in mainstream American society, both during and after resettlement. Unfortunately, service providers and refugee-serving entities frequently perceive these people as poor candidates for assistance. They are rarely recognized as skilled people who contribute meaningfully to their communities, as well as American society, when provided with the right supports. To address these issues, [information sharing and collaboration](#) are vital among refugee-serving agencies, governmental and nongovernmental groups, academic institutions, training and research centers, human and civil rights organizations, and disability advocacy groups.



Closing the Research Gap

Although disability research tends to include individuals of all ethnic, racial, cultural, and linguistic backgrounds, proactive outreach to refugee communities remains limited even though numerous well-established minority groups began as refugees (the [history of Irish Americans](#) provides a good example). Having data that takes [both refugee status and disability](#) into account is important in two ways. First, such information will improve the quality of services to refugees with disabilities. As it is, mainstream disability and rehabilitation service providers often lack an understanding of the refugee experience and the unique challenges faced by this group. Second, such information will help refugee-serving agencies develop the awareness and capacity they need to connect their clients with disabilities to appropriate resources and opportunities. In any case, the growth in the number of refugees with disabilities in the U.S. calls for enhanced funding and training for agencies that serve them.

Although awareness of disability within refugee populations is increasing, the progress in our disability sectors remains insufficient. The lack of necessary background information — the facts and figures not presently available — calls for targeted research and documentation of practice-based interventions at all levels: individual, community, and systemic. There is an immediate, critical need to connections and establish collaborative research agendas that include incoming resettled refugees with disabilities and the disability service delivery sector. A small but growing body of academic and service development scholarship is applying [Community-Based Participatory Research \(CBPR\)](#) with refugee communities, with the goal of better understanding and addressing refugee-related quality of life outcomes. There is some current U.S.-based research on minority ethnic communities, but it often overlooks refugee communities. As a result, insights into the lived experiences of refugees with disabilities are limited. [Some research studies](#) have been conducted in the Global South (Africa, Asia, Latin America, Africa, and the Middle East) and the Global North (Belgium, the United Kingdom, Sweden, Finland, Australia, and Canada), but researchers in the U.S. have yet to make meaningful, helpful contributions of their own.



Along with researchers, [disability and refugee providers play essential roles](#) in fostering the successful societal integration of refugees with disabilities. Therefore, we need more dedicated practice-based studies that explore how disabled refugees in the U.S. engage with CBPR and how public policy influences not only their self-advocacy but also advocacy on their behalf. For such studies to be useful, refugees with disabilities must lead and engage in discussions about disability rights, migration experiences, humanitarian efforts, and human rights advocacy and activism. This inclusivity will strengthen their empowerment and agency and bring attention to them as a group that has been overlooked and underserved for too long.

Recommendations

We propose five primary solutions that will promote U. S.-based advocacy-driven research on the intersection of disability and refugee status.

- **Encourage refugee-led advocacy** It is critical to engage resettled refugees with disabilities in the development of appropriate research and advocacy activities; disability justice cannot proceed without their input.
- **Widen data collection.** Researchers must begin to gather comprehensive and specific data on refugees with disabilities of all ages and across the full range of relevant domains, including but not limited to employment, education, housing, assistive technologies, and therapeutic services.
- **Diversify narrative sharing.** Input from refugees with disabilities to guide and inform best practices can be gathered in many ways, such as in-depth interviews with them about their pre- and post-migration experiences.
- **Require policy evaluations.** Practitioners and researchers should routinely audit existing policies and practices that affect refugees with disabilities to determine where they are effective and where they need improvement.
- **Diversify funding** Funders must reshape their philosophies to include support for initiatives that are targeted to this underserved, understudied demographic.

By prioritizing the above recommendations, we can build a more inclusive and supportive environment for refugees with disabilities in the U.S.

Rooshey Hasnain, Ph.D., is a Clinical Associate Professor and Community-Engaged Researcher with the Department of Disability and Human Development (DHD) and the Undergraduate Rehabilitation Sciences Program at the University of Illinois at Chicago (UIC). In addition to her work at UIC, she has been actively affiliated with the Association of University Centers for Excellence in Developmental and Related Disabilities (UCEDD) in Oregon, Massachusetts, and Chicago. She has a long history of engaging in community-university partnerships that address multicultural and multilingual disability and quality-of-life concerns, particularly in immigrant and refugee communities. Contact Rooshey at roosheyh@uic.edu.



Tedros Markos is an Eritrean refugee and self-advocate who, after five years of taxing life in exile, arrived in Chicago in December 2017. Virtually 20 years into journalism, he has written, edited, and translated numerous articles, as well as hundreds of documents from international agencies. Mr. Markos has interviewed dozens of refugees who have survived traumatizing experiences. Mr. Markos has a Master's in rehabilitation counseling from Northeastern Illinois University. Contact Tedros at Tedros.markos@gmail.com.



The Kenya Association of the Intellectually Handicapped (KAIH): Promoting Inclusive Development and Empowerment for People with Intellectual Disabilities

By Fatma Wangare

- The Kenya Association of the Intellectually Handicapped (KAIH) is an organization that promotes the rights and inclusion of people with intellectual disabilities and their families in Kenya.
- KAIH has over 3,000 members who are mostly self-advocates and family members.
- The organization works to build a society that recognizes and protects the rights of all persons with intellectual and developmental disabilities. KAIH is currently focusing on several priorities, like raising awareness, social inclusion, and offering support services.

[The Kenya Association of the Intellectually Handicapped](#) (KAIH) is a non-governmental organization dedicated to promoting the rights and full inclusion of people with intellectual disabilities and their families in all aspects of life. Established in 1996, KAIH aims to create a society that recognizes and protects the rights of people with intellectual disabilities and their families, ensuring they are included in all aspects of life within their communities.

Objectives and Priorities

KAIH's overall objective is to advocate for a society that recognizes and protects the rights of people with intellectual disabilities and their families through advocacy, empowerment, and information exchange. **The organization's priorities include:**

- **Inclusive development:** Advocating for environments where people with disabilities have equal access to opportunities, resources, and services and are able to fully participate and contribute to society.
- **Education and training programs:** Providing education and training programs for people with intellectual disabilities, their families, and caregivers in different topics.
- **Support services:** Offering support services, such as respite care for families, provision of support persons, and social and recreational inclusion.
- **Raising awareness:** Raising awareness about intellectual disabilities and challenging persistent stigma and discrimination.
- **Social inclusion:** Formation and empowerment of self-advocacy and family support groups and their empowerment in the community.

Partnerships

KAIH partners with various organizations, including:

- International and regional organizations, such as Inclusion International and Inclusion Africa.
- National umbrella federation of persons with disabilities in Kenya, the United Disabled Persons of Kenya, and other organizations of people with disabilities.
- Government ministries, such as the Ministry of Labour and Social Protection, Ministry of Education, and Ministry of Health in Kenya.
- Community-based organizations and self-advocacy groups.

Personal Experience

I am a mother to a daughter with an intellectual disability and a disability rights advocate. I became involved in this work after experiencing frustrations in finding inclusive services for my daughter with an intellectual disability. Through interactions with people with intellectual disabilities and their families, I recognized the need for a more comprehensive approach to supporting people with intellectual disabilities and their families in the communities in a dignified way. I have been doing this work for 17 years now, I must say, there has been some transformation and recognition of KAIH's work not only by KAIH members but also by government and communities.

Challenges and Opportunities

Some unique challenges faced by people with intellectual disabilities in Kenya include:

- Limited access to quality and inclusive education and employment opportunities.
- Stigma and discrimination from the community.
- Lack of access to healthcare and social services.
- Limited awareness and understanding of intellectual disabilities.
- Negative cultural practices, such as infanticide of children with disabilities and forced sterilization of women with intellectual disabilities.

On the other hand, some opportunities include:

- Growing awareness and recognition of the rights of people with intellectual disabilities.
- Strengthening partnerships between organizations and government agencies to promote inclusion and empowerment.
- Recognition of families and their roles in supporting people with intellectual disabilities.

International Support

International readers can support KAIH's work in several ways, including:

- Informing themselves and encouraging contacts in Kenya to support the respite care program to help alleviate the burden of care in families.
- Developing and sharing easy-to-read information about topics that KAIH focuses on.
- Sharing training for support persons and justice intermediaries (people who act as intermediaries between people with disabilities and justice systems in some countries).
- Partnering with KAIH to develop joint projects and initiatives that promote the rights of people with intellectual disabilities and their families.

KAIH plays a critical role in promoting the rights and inclusion of people with intellectual disabilities and their families in Kenya. By understanding the unique challenges and opportunities faced by people with intellectual disabilities in Kenya, international readers can support KAIH's work and contribute to creating a more inclusive and equitable society for all.

Fatma Wangare is the Secretary General of the Kenya Association of the Intellectually Handicapped and the Regional Coordinator of Inclusion Africa. She is a lead facilitator and trainer on disability rights and inclusive development. She is currently pursuing a master's degree in forensic psychology. Fatma is passionate about self-advocacy and supporting the strengthening of inclusive communities that respect diversity. Contact Fatma at fatma@kaihid.org or fatma@inclusionafrica.africa.



How Accessible Is Your Written Content?

By Cathy Basterfield

- The UN Convention on the Rights of Persons with Disabilities Article 21, says all people must have access to the information they need in a way they can use.
- Many people across the world face challenges with reading or understanding written information in the way it is written.
- Easy English or Easy {your language} is an approach to sharing information to make it accessible for more people.

The [United Nations Convention on the Rights of Persons with Disabilities \(UNCRPD\)](#) was adopted in 2006. Article 21 of the Convention recognizes that people with a disability need to have access to the information they need in a form they can understand and meaningfully use — and in the same timeframe as the rest of the community.

The Scale of the Problem

When organizations only provide written information in complex (or even [plain](#)) language, they are not meeting their obligation under Article 21. The percentage of the population that have literacy challenges is larger than many realize. It is an enormous hidden disability across all communities.

The Programme for the International Assessment of Adult Competencies (PIAAC, 2012), an international assessment of adult literacy skills, managed by The Organization for Economic Cooperation and Development (OECD), assessed adult literacy competency across 39 countries. This was the third variation of this data collection across more than 15 years.

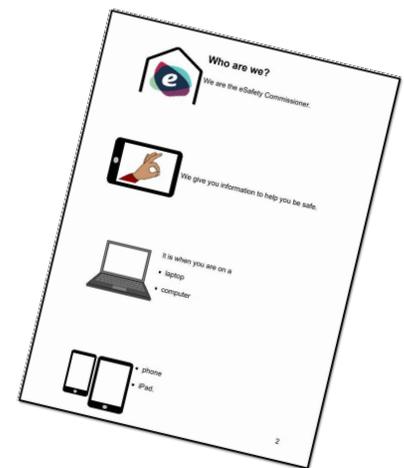
In Australia, for example, the study found 44% of the adult population (16-65 years) did not have the literacy skills to manage a range of day-to-day reading tasks — a figure that did not include Aboriginal and Torres Strait Islander people, nor people in institutions. In the U.S., it was [52% of the adult population](#) (over 100 million adults), once again not including people who lived in institutions. New data is being released in late 2024 that is expected to find at least as many or possibly more people do not have literacy skills to manage day-to-day reading tasks.

Plain Language

The definition of plain language is

‘A communication is in plain language if its wording, structure, and design are so clear that the intended readers can easily find what they need, understand what they find, and use that information.’¹

Last year (2023), the International Standards Organisation (ISO) released ISO 24495-1:2023(en) - Plain language — Part 1: Governing principles and guidelines² to further guide development.



1 <https://www.iplfederation.org/plain-language/>

2 <https://www.iso.org/standard/78907.html>

Some specific criteria a plain language writer considers in their development is the logic of content, removal of technical words or jargon and the construction and length of sentences.

Critically, plain language considers the intended reader, as being the person with competent literacy, usually an adult with at least low to mid-secondary school level reading skills. With these reading skills, a person uses their reading skills to 'read to learn.'

Ask yourself, how many hours, you, as a competent reader spend reading in your day – both at home and work and all other daily activities. As a competent reader, you should be able read, understand and use plain language, even if you are not highly knowledgeable on that topic. As noted above, in Australia this is only useful to 56% of the adult Australian adult population, and 48% of the American adult population.

Easy English or Easy [your language]

To meet the needs of people with low literacy, information needs to be available in an easy-to-read version. It must never be a 'nice to do' option at the end of a project.

Easy English uses the same definition for Plain Language and follows ISO 24495-1:2023(en) - Plain Language.

The intended reader for Easy English though, is a person who does not see themselves as being a reader, or does not usually engage in reading tasks by preference. It is a hidden disability, as shown by the data above, that is rarely, if ever considered in the development of information for the general population or in workplaces or in the community.

Hence, you will see differences with Easy English in areas such as:

- the amount of white space on a page
- the removal of further more complex, technical or jargon-based words that a more competent reader may know or be able to read, understand and use
- sentences range in length from 5 to 8 words.

For the last 20 years in Australia, our team have been developing and writing evidence based best practice Easy English. We run regular training and webinars on a range of topics as they relate to Easy English, including "Digital literacy for people with low literacy." (Hint: the person with low literacy is highly unlikely to be able to use websites — websites are based in literacy).

In more recent years, we have been working with communities in other countries and other languages, including Canada, Singapore, and Malaysia.

The Easy English audience is **any person** with low literacy. Easy English uses universal design principles to reduce barriers for any person who has low literacy, irrespective of their background or the reason for their need of Easy English, i.e., people with different disabilities, people with changing or deteriorating abilities, First Nations peoples, older people, culturally and linguistically diverse communities, and all other people of different ages with low levels of literacy.

In addition, anyone may, at some point in their life, have low literacy, including during emergencies, during health events, or in legal contexts. Using a trauma-informed lens, recognizing that trauma can adversely affect an individual's well-being, including physical and mental health you, as the creator, do not know who may need Easy English. Making Easy English readily available increases access for all.

Quality best practice Easy English ranges in language reading equivalence from grade 0 to grade 3, with an **average of grade 1 6** reading skill equivalence, depending on the specific topic. This must never be the sole measure of Easy English. Other indicators the language is in Easy English include:

- one idea per sentence
- 5–8-word sentences
- all in active tense

Images are simple, clear, iconic, and are highly guessable. There are specific guidelines for the layout. All these elements combined make it an effective tool to be developing and making available to any person with low literacy.

Who may need Easy English?

The person with low literacy, but not the only audience, are people who:

- do not see themselves as readers
- rarely sit to attempt to read, often describing themselves as perhaps reading only 15 minutes a day, if they have to.
- rarely choose to read anything
- do not expect to be able to read and understand any written content.

Many report having low self-esteem and low confidence in reading.

Readers describe Easy English as having:

- few words
- short sentences
- use more words they know
- more space on a page.

They report often being surprised about how many words they can read and then understand when it is in Easy English.

Following our research, quality Easy English has measurable and repeatable guidelines which all trained writers can implement. Easy English incorporates the [International Organization for Standardisation \(ISO\) Technical Standards for Plain Language writing \(T37\)](#), and [Plain Language ISO 24495-1 \(2023\) Governing Principles and Guidelines](#). We were involved in early phases of the technical standards development.

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 - Knox City Council - What to do when it is hot. <https://accesseasyenglish.com.au/knox-council-heat-related-illness-and-food/>
 - Central and Eastern Sydney Primary Health Care network – A check up with your doctor. Do it each year. (for people with intellectual disability) <https://accesseasyenglish.com.au/central-and-eastern-sydney-primary-health-network-see-your-doctor-each-year/>
 - City of Adelaide Disability Action and Inclusion plan. <https://accesseasyenglish.com.au/city-of-adelaide/>
 - Dept of Regional NSW – 13 fact sheets based on legal content about the 2022 post flood housing options. <https://accesseasyenglish.com.au/nsw-floods-project/>

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Cathy Basterfield is the founder and owner of Access Easy English, based in Australia. She and her team are passionate about ensuring people with low literacy are included in all communities. Cathy holds a Bachelor of Applied Science (Speech Pathology) from Lincoln Institute of Health Sciences. She is recognised as the national and international leader in the development of Easy English for people with low literacy. Contact Cathy at cathy@easyenglish.com.au.



Research from Ireland Highlights Opportunities for More Community Participation

By Cory Gilden

- Researchers in Ireland have been studying trends in the disability field in aging adults with IDD since 2010.
- Trends in Ireland related to community participation, including employment, where people live, and their technology use, are similar to trends in the U.S. There is progress in some areas, like fewer people with IDD who are aging and living in congregate settings, but more progress needs to be made, like getting more employment and learning more technology skills.
- Looking at research results from other places in the world can help field leaders learn more about people with IDD and better understand and plan for future needs.

What Does the Research Say?

More people with IDD are living longer than they have at any other time in history, making research about older people with IDD increasingly important. Researchers at the [Trinity Centre for Ageing and Intellectual Disability](#) at Trinity College Dublin, Ireland, have been studying aging among older people with intellectual disability (more than 40 years old) in Ireland using the [Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing \(IDS-TILDA\)](#) since 2010. This massive longitudinal study has collected five waves of data at different time points throughout the last 14 years, with the most recent fifth wave of data collection in 2023. The IDS-TILDA collects information about seven categories of information: ① Social determinants of health: choice, interpersonal relationships, and community participation; ② Multimorbidity and physical health trajectories in people with intellectual disability; ③ Behavioral lifestyles; ④ Psychological well-being and cognitive health; ⑤ Healthcare utilization; ⑥ Oral health; and ⑦ Family carers.

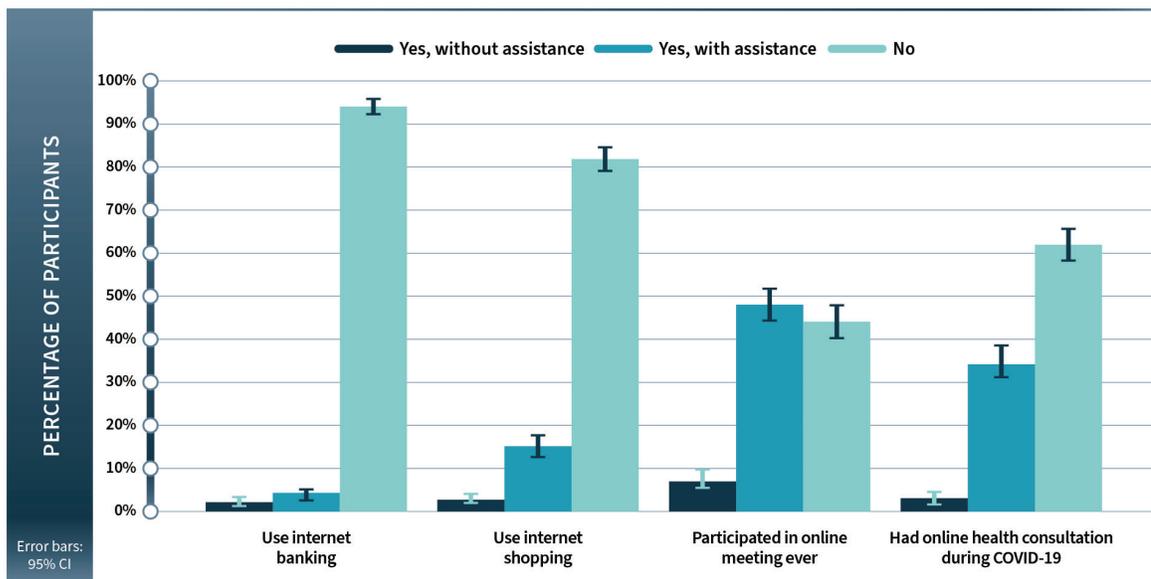
The most recent report on the data, [2023 Longitudinal Dynamics in the Ageing of People with an Intellectual Disability](#), highlights important findings in these areas, not only with the most recent data, but also in changes compared to the previous waves of data collected. The report shares key findings that show progress in the field in some areas, and plenty of room for improvement in others. For example, the report shows that between Wave 2 and Wave 5, self-choice increased in every age category, with the most notable increase being in those less than 50 years old. But, results also show that very few people with IDD marry or have their own children. While the IDS-TILDA shares a lot of data about many areas of life, this article will focus on results related to an area of policy change and interest in North America: community participation.

What Does It Mean for Our Field?

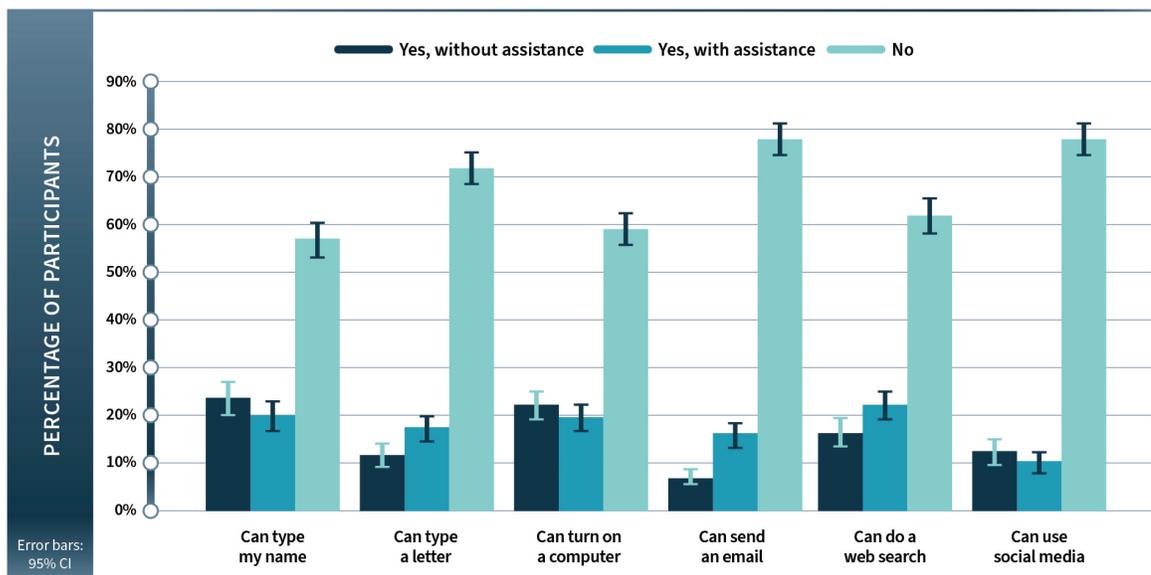
While lifestyles, politics, and access to resources and services may vary widely from country to country, looking to international data sources for common themes and relatable information can help advance service delivery in North America by emphasizing areas of need. The IDS-TILDA study found that only about 11% of people with disabilities were in paid employment, lower than the [19% in the U.S. with employment](#), both of which still have a lot of room for improvement. Another commonality between the disability field in Ireland and North America is the lack of staff — one in five participants of Wave 5 of the study reported staying home due to lack of staff and resources, and 19.4% said they spent the majority of the week at home, with 5% not leaving their house in the past week. Following similar trends

as the U.S., fewer participants in Wave 5 who were under 50 years old reported living in residential care (7.7%) than in Wave 1 (44.8%), with more moving to community group homes (49% v. 34% in Wave 1) and living independently or with family (46.4% v. 21.2% in Wave 1). Unfortunately, more than half of participants (53.1%) reported having difficulty getting around their community, especially those who were over 65 years old (60.6%) and those with higher support needs (70.9%).

The IDS-TILDA also investigates technology use among older people with IDD as an important means of community participation. Key findings from 2023 showed that mobile phone ownership doubled from Wave 1 (23%) to Wave 5 (44.7%) but was still lower in comparison to the general population (96%). Similarly, access to and use of the internet at home also increased over time, from 7.3% in Wave 1 to nearly 90% in Wave 5 having access to the internet. Although the report showed that tablets, smartphones, and computers have been more commonly used in recent years, it also found that most older adults with IDD remain dependent on others to use technology for common things like internet shopping, participating in online meetings, sending emails, and online health consultations.



Source: *2023 Longitudinal Dynamics in the Ageing of People with an Intellectual Disability*, p. 38



Source: *2023 Longitudinal Dynamics in the Ageing of People with an Intellectual Disability*, p. 37

What Does It Mean for Me?

Findings from the 2023 IDS-TILDA offer many suggestions for areas of support for field leaders to focus on.

- The majority of study participants (81.4%) attended a day program or received services daily in their homes, but a portion of those people with IDD (12.3%) reported that they did not do anything specific during the day. These statistics signal the need for more active engagement in activities of interest for people with IDD who receive services.
- There was an increase in social activities that people engaged in between Wave 3 and Wave 5 of data collection for the study, with the average number of regular community activities per person being 5.6. However, this number was significantly lower for people with more needs (average of 4 activities) and for those over age 65 (average of 4.7 activities). More creative ways of creating community participation opportunities for these groups are needed.
- The report showed that around half of participants living in residential care (49.3%) and one-third in community group homes (36.7%) did not use any smart devices. With the prevalence of smart devices in use and the near necessity of technology for things like directions, banking, and communication, providers can do more to ensure access to and use of technology by providing devices and training to the people they support. Similarly, it should not be assumed that people supporting those with IDD are knowledgeable about technology, so devices and training should be provided to frontline professionals who can then also serve as resources and support people to use technology.
- Results from the report revealed that people with smartphones used them mostly to connect with family (88.6%) and friends (60.8%) and also leisure, entertainments, and gaming (35.4%) and social purposes (29.7%). Professionals working with people with IDD could help train users to generalize the use of smartphones to all areas of life, including shopping, banking, navigating the community, and more.

Examining data from other places, such as the IDS-TILDA from Ireland, can contribute to knowledge about people with IDD and help providers better understand and plan for future needs. This rich data set points to many areas that have improved over time and many that are primed for growth in the near future. Learn more about the recent findings of this study by visiting <https://idstilda.tcd.ie/>.

Cory Gilden is the Research and Evaluation Manager of the National Leadership Consortium. Cory holds a Ph.D. in Urban Affairs and Public Policy and works with local and national organizations, conducting research and advocating for people with disabilities and their families. Contact Cory at cgilden@natleadership.org.



A National Leadership Consortium Bulletin

Conversation with Diane Richler, Sue Swenson, and Steven Eidelman: Reflections on International Disability Advocacy

By Amanda Rich

*This article is taken from an interview with **Diane Richler**, **Steven Eidelman**, and **Sue Swenson**, who have all worked in disability advocacy in their countries (the United States and Canada). They have also been involved with international advocacy efforts, including shaping and implementing the UN Convention on the Rights of Persons with Disabilities. The three shared their thoughts and reflections on international disability advocacy.*

- The needs of people with intellectual disabilities to access their rights and community are not always the same as the needs of people with other types of disabilities like sensory impairments or physical disabilities.
- Disability advocacy is human rights advocacy, and human rights are connected to the idea of democracy.
- People who work in disability advocacy and services internationally and at home must make sure their work is grounded in an understanding of human rights.



Among other roles, [Diane Richler](#) is a Joseph Kennedy, Jr. Foundation International Fellow, the former Chair of the International Disability Alliance, past President of Inclusion International, and was one of the Civil Society Leaders in the negotiations on the UN Convention on the Rights of Persons with Disabilities. Additionally, Diane served as a Consultant to governments and organizations such as the World Bank, UNICEF, UNESCO, and the Organization for Economic Cooperation and Development.



[Steven Eidelman](#) is a Co-Founder of the National Leadership Consortium on Developmental Disabilities, a past President of the American Association on Intellectual and Developmental Disabilities, former Executive Director of The Arc of the United States, former Member of the board of directors of the Mental Health Initiative of the Open Society Institute, and the University of Delaware's H. Rodney Sharp Professor of Human Services Policy and Leadership. Additionally, Steve served as a Senior Advisor to the Chairmen of Special Olympics International. Part of his work has centered around the implementation of Article 19 of the UN Convention on the Rights of Persons with Disabilities, focusing on deinstitutionalization.



[Sue Swenson](#) has been appointed to disability leadership positions by three U.S. presidents and serves as the President of Inclusion International. She also held the position of the Executive Director of the Joseph P. Kennedy Jr. Foundation and an Associate Executive Director of The Arc. Sue has presented to the UN Committee on the Rights of Persons with Disabilities. Additionally, Sue serves on the board of the International Disability Alliance. Sue learned about rights and was inspired to advocate by her middle son Charlie, who lived for 30 years with profound disabilities.

The Interests of People with Intellectual Disabilities in Global Advocacy

The group discussed how, early in their work, it was hard to see where or by whom the interests of people with intellectual disabilities and their families were being represented in global disability advocacy. For some, parts of that process changed the way they approached domestic and international advocacy.

Sue Swenson: “I first got interested in international disability advocacy when [Gunner Dybwad](#) made a presentation to my Partners in Policymaking class in 1989. Ed Roberts was part of that group as well. He was then very active at and had co-founded the [World Institute on Disability](#). It was a rocky introduction. He wanted to introduce me to other people there who were working on different things. He walked me around to talk to his staff, and nobody would even look at me. I said, Ed, ‘Why did you do this to me?’ And he said, ‘I just wanted you to see how welcome parents are in disability advocacy world at an international level.’ That was kind of shocking, but he expressed that he had a lot of faith in me and so it was okay.

Before I went to the CRPD [Convention on the Rights of Persons with Disability], I was invited to the [Montreal Delectation on Intellectual Disabilities](#). It was interesting to me, seeing how people came together to try to discuss important issues, some of which they had no direct knowledge about. The people who spoke the most tended to have some oddball ideas about things.

I learned that there are many different communities within groups of people advocating for disability rights. People with psychiatric disabilities had an entirely different way of looking at things from people with intellectual disabilities, and people with physical or sensory disabilities were, in some ways, camped out on their own turf. The meeting was productive, though, and that was interesting to me. Even though I thought it was a very difficult situation, it was productive.

Later, through my work with The Arc, I was sent to New York to work with the people who were drafting the [Convention on the Rights of Persons with Disabilities \(CRPD\)](#). I held up my hand when they were discussing things, and the two people who were chairing the meeting wouldn’t call me. When I asked them, ‘Who’s going to speak for people with intellectual disabilities? There’s nobody here. It’s a room full of geniuses in wheelchairs,’ they said, ‘Well, if you want your son to have his voice heard, you need to bring him and let him speak for himself.’ I think I might have said, ‘That would be a damn miracle.’

Steve agreed to let me go up to New York a second time for the next piece, and [Robert Martin](#) put together a panel of people with intellectual disabilities to talk about legal capacity and inclusive education. I brought my son, Charlie. That was something that changed my whole approach to advocacy.

They told me to bring him, and he would speak for himself, and I thought they were crazy. They were discussing legal capacity, and that no one should ever have guardianship or representation. I just asked Charlie what he thought about that, and I stood back and let him not speak for a couple of minutes. I reported to them, then, that I had had an epiphany. They told me if I brought him, he would speak for himself, and I didn’t think he would. But I thought he did. Now the question was, did they have enough empathy to understand what he was conveying to them that he couldn’t represent himself in legal proceedings and really needed a team to work on that? I wasn’t speaking in favor of guardianship by any means. They changed their draft and added some supported decision-making language to it. So that was very empowering. The way it changed my advocacy is I never went out again to advocate for Charlie without Charlie.





I started taking him into the halls of Congress and meetings, where people with disabilities like Charlie's just didn't go. If I could gain access to the room, he was there, and sometimes with a lot of Congressional Capital security looking around to try to figure out who was yelling."

Steve Eidelman: "You know, the language of advocacy is strident. It goes from firm to really, sometimes violent words. The language of diplomacy is about compromise and process. I'll never forget that one time, I think this was the first Conference of State Parties, I met with a couple of UN staffers and realized they didn't know much about disability, but they understood the process of diplomacy. The UN staffing structure is based very much like a government structure in terms of advancing by position and not topic. If you want to advance your position, you shift over to this position, but that may mean focusing on completely different issue areas or topics than your past position. As such, you had people, some of whom were very smart, working on issues like intellectual disability, that they knew very little about."

Diane Richler: "This would have been a completely different conversation if you had invited three people from other disability movements. During the development of the CRPD, before the International Disability Alliance had really coalesced, most of the other members, such as The World Federation of the Deaf, the World Blind Union, and the Federation of Deaf Blind, all had their list of entitlements, that they wanted the CRPD to contain. That's what they fought for during the negotiations. Inclusion International was asked by the other organizations to come up with our list of what people with intellectual disabilities need from the Convention. We answered that we didn't have a list of specific provisions like a ramp or braille or sign language. It's not something specific or tangible in that sense.

We need communities to change, to allow people with intellectual disabilities to participate. We were looking for much more substantial changes that would support people's human rights and ability to participate. That's why inclusive education works so much for our members because when parents understand what the benefits of inclusion can be, they want their kid with disabilities and their kid who doesn't have disabilities to go to the same school. They want to belong to only one PTA, not two. They want both their kids to learn how to be part of a community where everybody fits in."

Universal Human Rights as the Underpinning to Domestic and International Intellectual Disability Rights Advocacy

The CRPD is fundamentally about human rights. Grounding intellectual disability advocacy in human rights helps connect domestic and international efforts. Additionally, human rights (of course, including disability rights) are integrally linked to ideals and acts of democracy or building a society for all. The group discussed the role of the CRPD.

Sue Swenson: "I don't think we quite have a sense in the United States about why human rights are important. It's not so that we get what we need. It's so that we build a community that works for everybody, because that's how we support democracy.

[The Universal Declaration of Human Rights](#) is the foundation of the CRPD. The CRPD doesn't create new rights. It's just a new lens on old rights. We, the U.S.A., signed the Universal Declaration immediately. When we did that, we promised to teach it everywhere and always, and that was a direct promise, but we didn't. We don't teach it a lot in the United States.

I think one of the problems we have is not recognizing the intimate connection between human rights writ large and democracy. I think that Americans have a sense that what other people want from us or what other countries want from us is our money. I don't think they want our money. I think they want to know how we kept a democracy going for such a very long time. It is imperfect. Our Constitution is old,

and it is imperfect, and nevertheless, it's almost 250 years old. That's something."

Diane Richler: "In many ways, we saw international intellectual disability advocacy as a way to promote domestic agendas. We thought by having Canada take a position on the world stage that we could then use that to build our credibility with our Federal Government, and for policies at home.

The president of Inclusion International was trying to foster regional groupings of the members in different places. They wanted the Canadian Member to establish ties with people in Central America the founding meeting of the Inter-American members of Inclusion International in Santiago, Chile. Someone convinced someone in the Canadian Government to pay my way to the founding meeting in Santiago, Chile. Since they did that, I couldn't say no. I went to this meeting in 1991. There were people there, mostly parents; I would say all parents except for me as a godmother. People were from Nicaragua, Argentina, Guatemala, El Salvador, and other countries.

What was fascinating to me during the conversations was that many of these countries had just emerged from dictatorships. Their conversation was not about services. It wasn't about budgets. It was about where do our sons and daughters fit into these new democracies. They were really framing disability as a citizenship issue.

Canada had just adopted a [Charter of Rights and Freedoms](#), which places disability in a citizenship framework. I never really understood what that meant before until I heard people who were used to living in dictatorships try to figure out how their sons and daughters would fit in.

Because of that experience, when the Prime Minister created a pot of money to promote the [Convention on the Rights of the Child](#), we proposed a proposal to work with our colleagues in the Americas to promote the Convention by promoting disability as a human rights issue. That was, I believe, the first time that disability was really promoted as a human rights issue on a huge scale.

In all those cases, in seminars that we had around the region we were trying to look through a human rights lens. What was instructive was that at our first hemispheric meeting in 1993, we came up with what became the [Declaration of Managua](#), which talks about society for all. It was our framework for what we would do for the next long time. Then, we took that, and we used that domestically so that when Canada hosted the G7 or the G20 summits or participated in other meetings, we would use things that Canada had supported as a way of getting disability on those agendas and in those declarations. That helped us to meet a lot of politicians and a lot of people who worked in ministries, and that, in turn, helped us to shape some federal policy.

Our initial motivation was very much what we could learn from others how we could exploit what Canada was doing internationally to promote things on that domestic scene."

Sue Swenson: "I think that a focus on CRPD would be very useful for states for domestic issues. When you talk about the systems advocacy and systems outcomes for all the stuff that we fund, they're siloed. It's healthcare, education, community living, transportation, etc. Everything is in a little silo. There's no measure of how we are doing from a human rights perspective, which is really what this all should be about.

Given the fact at least a few years ago, anyway, the largest and most uncontrollable part of any governor's budget was special education and Medicaid. I would think that those in power would be particularly interested in understanding how these various budget categories interact with each other and how to be efficient and effective at trying to achieve something."

Disability, Conflict, and Peacemaking

The group discussed how war and global conflict always leads to more people with disabilities. Disability is a natural part of the human experience that cuts across national borders, politics, faith, and cultural traditions. Disability advocacy, from a human rights lens, has the potential to promote peace.

Diane Richler: “The previous Special Rapporteur on the rights of persons with disabilities, [Gerard Quinn](#), who happens to be from Ireland, devoted a large part of his mandate to looking at the link between disability and peacebuilding. He prepared some [excellent papers](#) which became part of his official report to the UN. I think it’s interesting that it was someone from Ireland whose family had experienced the trauma of the Troubles and whose grandmother was shot because of her religion.”

Sue Swenson: “I think that’s probably my strongest lesson from any international work that I’ve done. There’s a lot to learn from people when the reality is a human reality, not just a budget, service, or how to get some money to do something reality.”

[Ambassador Jean Kennedy Smith](#) invited me to Dublin to chair and facilitate a one-day meeting between mothers of people with disabilities from the North and mothers of people with disabilities from the South, from the Republic during [The Troubles](#). The meeting was basically to discover that everyone was in the same boat. Jean told me multiple times she always thought that the disability agenda was a major part of peacemaking in Ireland, and I don’t see why it couldn’t be part of peacemaking in the Middle East and in other places in Africa, places where there’s war. Where there’s war, there is always more disability.”

Pitfalls and Challenges to International Advocacy

Sue, Steve, and Diane discussed several challenges to ethical and effective international disability advocacy. They included the risk of little oversight, a lack of grounding in human rights, American exceptionalism, and isolationism.

Steve Eidelman: “I got dragged, kicking and screaming, into international work thanks to this Diane Richler person sitting over there. When I was with The Arc, The Arc had dropped out or just didn’t pay dues for years to Inclusion International. There was a lot of pressure from Inclusion International to get something done. At the time there was a donor who was interested in it so long as they remained anonymous, so The Arc started tiptoeing into the field internationally.

Personally, I didn’t want to do that in part because there are so many things to do domestically. How do you take off for somewhere else?

I watched some of the U.S. organizations involved in international work and realized that several were not doing great work in the United States yet were portraying themselves as experts internationally. There were certainly exceptions to that. There are some who are doing great work, for instance, in Moldova. Others, however, our organization would not work with domestically due to their poor quality, yet they presented themselves as experts on an international stage.

One of the differences in the U.S. from, for instance, Canada is that there’s no central authorizing environment in terms of doing international work. There’s stuff out of the State Department, stuff out of the Commerce Department, a little bit out of education, but there’s no one specifically focused on disability policy. Policy discussions are mostly at the state level, not exclusively obviously. But our whole structure is not to look outwards; it’s to look inward.

I think if you look at how, in the U.S., we train professionals or clinical professionals — we don’t train them in human rights. It’s not part of most graduate programs. There’s a certain haughtiness about people who are involved in international work, and they’re involved without an authorizing environment. People can do work internationally without anyone in the U.S. having control of the strings. There isn’t a governing body that controls ‘you can say this, you can do this. This is where we are going.’ People just do it based on their work, and some do it well. But anyone could go in from anywhere. There is no U.S. policy that says this is what international advocacy should look like; this is what the rights of people with disabilities are. This is how we are going to help people attain those rights. It’s all sort of a theoretical exercise.

I remember in Kenya I went to a couple of job training sites. One was a place where they were teaching people how to work on engines. There were about seven or eight people with disabilities, with hammers and screwdrivers for about a half hour, pounding on this block of an engine where it had no relationship to anything in terms of fixing the engine. They were just kept busy, and too often, the ideas for those practices were brought in from elsewhere.”

Sue Swenson: “Americans, in general, are not particularly well versed in human rights. So that’s one problem that I have. It’s not just the service providers. Steve, you put your finger on something that bugs the hell out of me — when I see people who are failed service providers here in other countries present like, ‘Oh, we’re American. We know what we’re doing’ [gagging noise]. Individual consultants also can go out and do work, and even big organizations can go out and do work without internationally having the grounding in CRPD and that can be harmful.”

American Isolationism and Exceptionalism as Barriers to Effective International Work and the Implications of the U.S. Not Ratifying the CRPD

The group discussed how American partisanship, isolationism, and exceptionalism have influenced approaches to international advocacy and serve as some of the reasons the United States has not ratified the CRPD. The decision of the United States not to sign on to the CRPD has implications internationally and domestically.

Steve Eidelman: “As someone working on the state level as a state director and deputy secretary, I had a very narrow focus on domestic policy, but when the CRPD came about, I sort of sat back and watched and thought, ‘Why isn’t the U.S. participating?’ The Administration at the time said, ‘Well, we do all that stuff anyhow, with IDEA and with the Americans with Disabilities Act. We don’t need to have this other document.’

Some were even saying extreme things like, ‘Well, the United Nations is going to write IEPs for your kids.’ Another said there would be UN helicopters coming to pick up your disabled children even if they just wear eyeglasses.

There is a loss there. We’ve [the U.S.] lost as a country a little bit of credibility because whatever excuses there are about not ratifying the CRPD, that’s just what they are: excuses.”

Diane Richler: “I don’t know what the proportion is now, but I know years ago less than half the members of Congress had passports. Generally, I think, in the U.S. there’s much less of an openness to seeing other parts of the world and understanding other parts of the world. It’s much more of what we can do for the world. I think that affects the approach to international activities.”

Steve Eidelman: “And we’ve got this whole strain, especially in conservative politics of American exceptionalism. You know — we are the best at everything since sliced bread. If you work with people with disabilities and countries in their government, it’s not a good approach to come at it from the standpoint of, ‘We know everything. We know what to do. We know how to do it. Sit back and relax.’ That does not work well, and it’s often untrue.

Somehow, the issue of international disability advocacy became a partisan issue as opposed to an issue that was not partisan.”

Sue Swenson: “Right, during the CRPD ratification process, two of the biggest sponsors of it were John McCain and Bob Dole. Bob Dole wasn’t in the Senate anymore, but he came the day that they voted. He had promises from most of the Republicans, and they voted ‘no’ right over his head as he sat on the floor as their guest. It was disgusting.”

Steve Eidelman: “Because we have not ratified the CRPD, we’re not members of the club. We’re poorer for not being involved, because there’s a richness in different cultures and richness in nations in different stages of development than there is here. We tend to gloss over that just.”

Diane Richler: “There’s also a formal requirement that any country that’s ratified the Convention must submit reports on a regular basis to the committee that’s responsible for reviewing the implementation of the Convention. Part of the process is that, in addition to the government’s report, which they prepare, civil society organizations prepare their own report. That is generally quite different from the government’s report. First, there’s a meeting where the government presents and civil society presents, and then the committee sends back questions to the government asking for follow-up on some things where there might be some discrepancies between the two reports. Then, the government replies, and a final report is written by the Committee. That means that there’s an external review of what’s happening in countries that have ratified the CRPD.

I don’t think there’s any such process in the U.S. where there’s a coming together of all disability organizations and anyone else who wants to do it to evaluate where things are. I think that’s a very concrete and practical advantage to having ratified the Convention. Governments pay attention to it when there’s a headline in the national newspaper, saying, ‘The UN committee chastises X Country for maintaining institutions or for keeping segregated schools, or for not providing healthcare.’ Then people pay attention.”

Cautions and Advice for International Work

The group offered some advice and cautions for engaging in international disability advocacy.

Sue Swenson: “I think having your eyes open to how things work in other parts of the world is extremely important to bolster advocacy here in the United States. I think I have entirely different visions of what we are doing, and how good it is based on the recognition that these are acts of Congress. They’re not acts of God. I mean, there’s nothing perfect about IDEA. There’s nothing perfect about Medicaid. Politically, the difficulty is addressing them.

I think recognizing that there are other countries that do economic and social rights far better than we do, for example, is a really important piece to recognize. What I’m seeing now in a lot of places, around economic and social rights is coming in through dignity and the question of, ‘What does it mean to have a dignified life?’”

Steve Eidelman: “‘Clean your own house first.’ Though there is much to learn and gain from international efforts, make sure you are modeling it a home. If you work for a domestic provider organization, make sure to do the things you say are important when working in other countries and ensure they are grounded in supporting human rights.”

Amanda J Rich is the owner and CEO of [Open Road Inclusive Community Consulting](#) and the managing editor of the [National Leadership Consortium Bulletin](#). Amanda holds a Ph.D. in Human Development and Family Sciences and is interested in the health and well-being of the human service workforce, trauma-informed and healing-centered practices, and disability justice. Contact Amanda at openroadicc@gmail.com.



Don't Put Us Away: Memories of a Man with Learning Disabilities

British author **Richard Keagan-Bull**, self-advocate and Research Assistant at Kingston University, recently presented his book, *Don't Put Us Away: Memories of a Man with Learning Disabilities**, at the International Association for Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) conference in Chicago. We spoke with Richard and his colleague Irene Tuffrey-Wijne, Professor of Intellectual Disability and Palliative Care at Kingston University, after the conference to learn more about Richard's book and podcast.

**Richard refers to "intellectual disabilities" as "learning disabilities"*

What inspired you to write this book?

Someone died in the community, and I went to their funeral. At the funeral, they were talking about this person's story. I live on my own independently and do a lot of things on my own, so people don't always get to see what I do. I said to a lady I knew at the funeral, 'Who's going to tell my story?' Because I live on my own and people don't see me every day. And she said, 'Well, I can write some things down for you just to keep as a memory.' But then it just grew bigger and bigger and bigger. More stories kept getting written down. Originally, it was just going to be a birthday present for my mother, but ten years later, Irene, the professor I work with (we wanted her to give it a once over to see what she thought of it), thought that it should be properly published for lots of people to be able to read it.

Irene was asked to write an introduction to the book and helped with its editing. After being rejected by the first publisher after a year, the book was accepted right away by the second publisher after a week. Since October 2022, when the book was officially launched, Richard has been touring with it, selling at events and conferences, and even getting his book presented to government representatives by his local member of parliament.

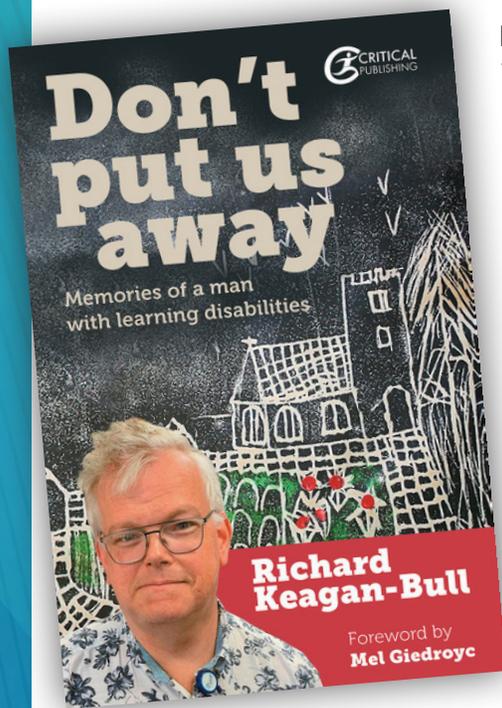
It's definitely done a lot bigger than what I thought it would do, and I think it's done a lot bigger than what my family thought it would do. I just hope this book helps inspire other people so that they can go write a book.

Why do you think it's important for people with disabilities to have projects like this, that they're passionate about?

I think it's important that people with learning disabilities get their stories out there and be seen and heard and let it known that we do have a story to tell about all the battles from where it started from to where I am now. The headmaster at my first school said I couldn't be taught and threw my schoolwork out the window. The doctors at the hospital in England said to my mom and dad to just forget about us and that my brother and I wouldn't do anything.

Both Richard and his brother were diagnosed with intellectual disabilities at a young age. Richard shares what happened when he first introduced the book to his father, who was struggling with dementia.

My dad couldn't come to all the stuff for my book because he had to go to hospital because he had a fall. I showed him the book in the hospital, and he burst into tears [when he saw the title]. He couldn't remember why he ended up in hospital, but he could remember what was said to him and my mom 50 years ago when I was born to just forget about us. It was a difficult time when we were born because



people with learning disabilities back then were seen a lot differently than they are now. The people who got me where I am today were my mom and my dad, especially my mom because she's the one who fought hard for me and my brother to stand up in the world. So, I dedicated the book to my mom and my dad. Now I work at the university, and I'm a professional, and I go to international conferences.

What can other people do to help people with disabilities fulfill their dreams and the things they're excited about?

Just listen to them and help them. If they're passionate about doing a sky dive and they need support to do it, try and help them do it. If they want to go into politics, help them have their dream. You might have to find a different way to do it. For me at university, there's a team that helps me to understand complex or difficult words. If someone wants to try and do something, don't try and stop them, and if they can't do it, find another way to help them.

Why did you start your podcast?

Just a few months ago, there was a program on television where a famous actor was being interviewed by a group with learning disabilities and autism, and it was just so natural listening to them and talking to them and taking time to have them ask their questions. It got us thinking we could do our own program. Since then, we've had nine people come on the podcast. We talk about subjects that we talk about here at work, about end-of-life care and getting older, and about things I'm interested in. So, to get some international listeners, that'd be good.

To learn more about Richard's book, *Don't Put Us Away*, or to buy it from the publisher, visit <https://www.criticalpublishing.com/dont-put-us-away>

The book can be purchased on Amazon at https://www.amazon.com/s?k=don%27t+put+us+away&crd=2CCHW8B0FX5PH&srefix=don%27t+put+us+away%2Caps%2C133&ref=nb_sb_noss_1

Listen to Richard's podcast, *Cuppa Tea with Richard*, at <https://soundcloud.com/cuppa-tea-with-richard>

Richard Keagan-Bull is a self-advocate and Research Assistant at Kingston University and author of the book, *“Don't Put Us Away: Memories of a Man with Learning Disabilities.”* Contact Richard at r.keagan-bull@kingston.ac.uk.



Organizations with Resources to Help You Learn More About Disability Rights, Advocacy, and Services Around the World

- People with disabilities are the world’s largest minority group.
- Though we often focus on disability leadership, services, and advocacy at a local level, we live in a global community where people, ideas, and things move across nations.
- Having an international understanding of the experience of people with disabilities, services, and advocacy efforts can help bring new ideas and help us better understand the international forces that can influence the lives of people with disabilities.
- The following organizations and resources can help you learn more.

Resource	Published By	Types of Information				Description
		General Information, Reports or Position Statements	Tool Kits	Accessible Language	Videos & Training	
Inclusion International Resource Page	Inclusion International	x	x	x	x	Inclusion International is an international network of people with intellectual disabilities and their families. They have resources on many topic areas including family advocacy, inclusive education, ending institutionalization, employment, and violence prevention. They have resources in three different languages and plain language.
World Down Syndrome Day Resource Hub	Down Syndrome International		x	x		This site has resources that include organizational tool kits to support the inclusion of people with IDD, guides for talking to children about difference, self-advocacy tool kits, and fundraising guides.
International Disability Development Consortium Library	International Disability Development Consortium	x	x			IDDC is a group of civil society organizations that have come together to promote inclusive international development and humanitarian action with a focus on human rights of people with disabilities. The resources and tool kits focus on policy accessibility, frameworks for international collaboration, and status reports.

Resource	Published By	Types of Information				Description
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<u>Treaty Bodies: Committee on the Rights of Persons with Disabilities</u>	<u>United Nations Human Rights Office of the High Commissioner</u>	x				This site provides general information about the CRPD, past committee session reports, and reports from nations that have ratified the CRPD.
<u>International Disability Alliance Resource Page</u>	<u>International Disability Alliance</u>	x	x		x	The IDA is an alliance of 14 global and regional organizations of people with disabilities that advocate at the United Nations for a more inclusive world. Their resource page has advocacy tool kits, information on the CRPD, position statements, webinars, and technical papers that help to understand current priorities, the nature, and the processes of the CRPD.
<u>African Disability Forum Resource Page</u>	<u>African Disability Forum</u>	x				ADF seeks to advance the rights of people with disabilities, strengthen and unify the voices of Africans with disabilities, their families, and organizations. Their website and resource page highlights news, events, programs, campaigns, and status information for several countries in Africa.
<u>European Disability Forum Resource Page</u>	<u>European Disability Forum</u>	x	x		x	EDF is an umbrella organization of people with disabilities that defends the interest of people with disabilities across Europe. Their resource page contains advocacy tool kits, reports, webinars, and funding opportunities that can be useful for those wanting to better understand the context of life for people with disabilities across Europe and who work in or are interested in doing service or disability advocacy work in Europe.

Resource	Published By	Types of Information				Description
		General Information, Reports or Position Statements	Tool Kits	Accessible Language	Videos & Training	
World Institute on Disability Resources and Library	World Institute on Disability	x	x	x	x	WID is a disability lead organization with the mission of creating a pan-disability solidarity movement that works to design, build, and support whole community solutions by removing barriers to include people with disabilities. They have informative reports and tool kits on inclusive disaster preparation and response, community inclusion, accessibility, and universal design.
Partnership for Inclusive Disaster Strategies Useful Info	Partnership for Inclusive Disaster Strategies	x	x	x		The Partnership for Inclusive Disaster Strategies is a U.S. lead organization that works domestically and internationally to support equity for people with disabilities before, during, and after disasters and emergencies. They have resources on the experience of refugees and asylum seekers with disabilities, planning resources, support hotlines, facts, and tip sheets.

Amanda J Rich is the owner and CEO of [Open Road Inclusive Community Consulting](#) and the managing editor of the *National Leadership Consortium Bulletin*. Amanda holds a Ph.D. in Human Development and Family Sciences and is interested in the health and well-being of the human service workforce, trauma-informed and healing-centered practices, and disability justice. Contact Amanda at openroadicc@gmail.com.



What We're Reading, Viewing, and Listening To

Title: International Day of Persons with Disabilities: Voices from the Ground: The Stories From People with Disabilities Who Have Endured Humanitarian Crises

Author/Editor: Philippa H. Stewart/Human Rights Watch (2017)

Description: This publication shares the stories of five people with disabilities from around the world who have endured humanitarian crises. It discusses the unique obstacles refugees with disabilities face in accessing services.

Title: Care Work: Dreaming Disability Justice

Author: Leah Lakshmi Piepzna-Samarasinha (2018)

Description: This collection of essays explores the spaces of care created by and for disabled, queer, and multiply marginalized communities. It is both a celebration of radical love and a tool kit for those seeking to build resilient, inclusive communities for all.

Title: International Disability Law: A Practical Approach to the United Nations Convention on the Rights of Persons with Disabilities

Author: Coomara Pyaneandee (2018)

Description: This book provides a guide to international disability law. It analyzes international human rights treaties such as CRPD and provides an important global perspective on disability rights.

Title: An Inclusive Community for All: A Guide Towards Denationalization of Persons With Disabilities

Author: IDACRPD Forum (2022)

Description: This brief, instructional video outlines new guidelines adopted by the United Nations Committee on the Rights of Persons with Disabilities for supporting inclusion, including in emergencies.

Title: How Disabled People Achieve Good Lives in Three African Countries

Author: Tom Shakespeare/The British Academy (2020)

Description: In this video, Professor Tom Shakespeare discusses how people with a range of disabilities in Kenya, Uganda, and Zambia have achieved educational, employment, and family success. This video highlights key findings from an academic research project.

Title: Why International Charities Need to Make Themselves Redundant

Author: Weh Yeoh/Tedx Haymarket (2018)

Description: In this talk, non-profit founder Weh Yeoh discusses why it is important for nonprofits to have a clear end date and should have the goal of creating spaces for local people to create solutions to their own problems.

Title: 5 Strategies for Successful Collaboration in Global Organizations

Author: Lars Sudmann (2017)

Description: In this practical blog post, Sudmann describes five strategies for effective cross-national team building and collaboration.

Upcoming Events

Winter 2025

The Virtual Leadership Institute will be held via Zoom in **Winter 2025**, beginning **January 22 and ending February 13, 2025**. Applications are open now. [Click here for more information or to apply](#). This Institute is open to all Disability Sector Leaders. If you are a leader with a disability, or a Direct Support Professional, you can apply for scholarship support to cover your tuition!

Upcoming Workshops

December 2024 – June 2025

The Keys to Leadership: A Five Part, Virtual Workshop Series

We know that there are leaders at every level of organizations and systems and at each level there are unique challenges and opportunities that exist for leaders in the positions. Throughout this Series, we will explore some of the key areas of leadership success including:

- The Human Side of Leadership
- The Challenging Side of Leadership
- The Relational Side of Leadership
- The Business Side of Leadership
- The Data Side of Leadership

For this Five Part Workshop Series, attend one or all (or any combination) of the workshops. Sessions will begin in Fall 2024 and run through Summer 2025.

Please add your information to [the list here](#) so we can share more information about dates, number of sessions, and cost with you! Registration will open soon.



Contact Us: <https://natleadership.org/bulletin> • bulletin@natleadership.org

If you have any trouble accessing the referenced material, please email Amanda J. Rich at openroadicc@gmail.com.