
FIRSTHAND PERSPECTIVE ON THE IMPACT OF DIVERSITY, EQUITY, AND INCLUSION

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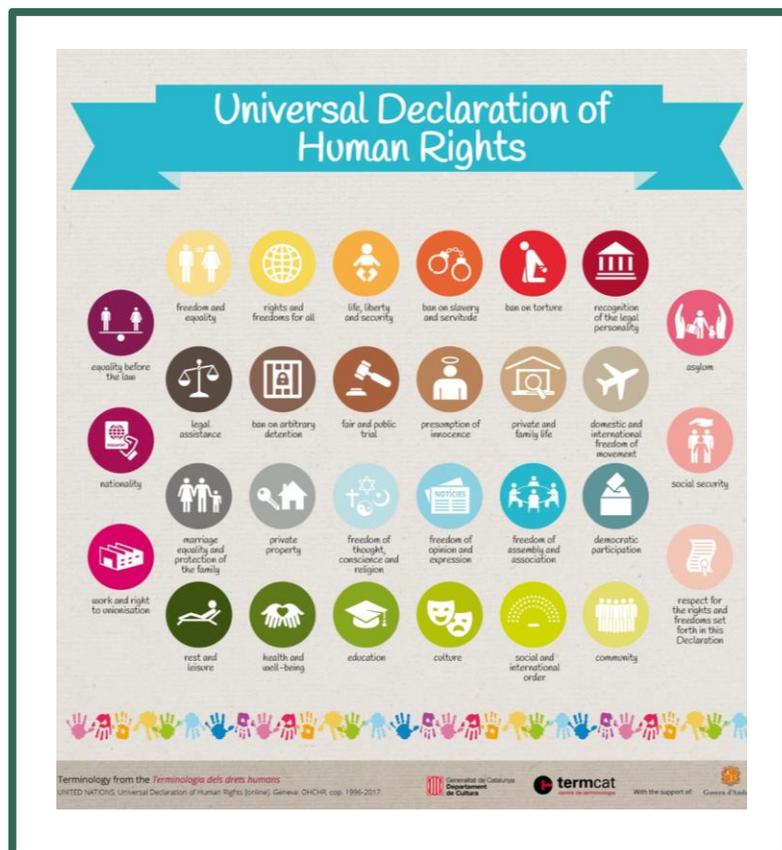


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COMMUNICATION RIGHT

- Article 19 from the UN Declaration of Rights states that **everyone has the right to freedom of opinion and expression**; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers (United Nations, 1948).

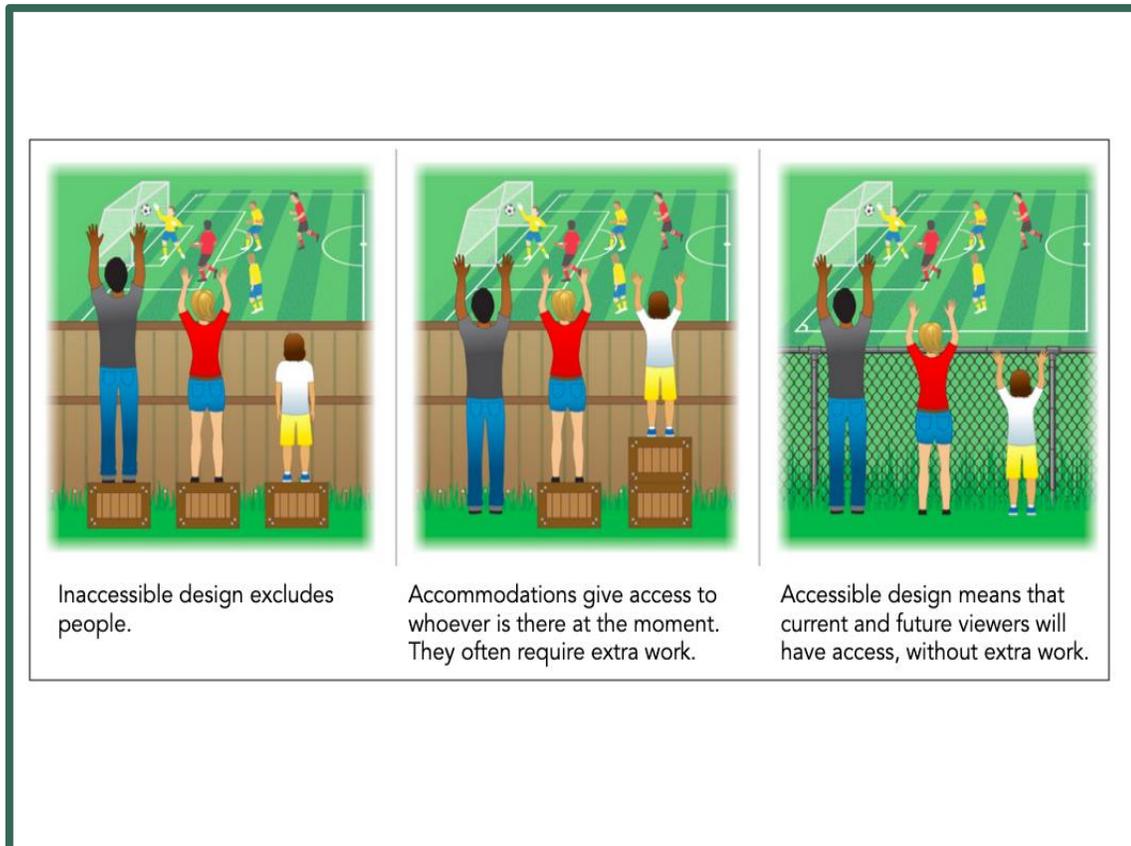


ADA AND COMMUNICATIVE RELATED DISABILITIES



- Under Title II and III of the ADA – state and local governments, businesses and nonprofit organizations that serve the public must communicate effectively with people who have communication disabilities. **Effective communication** means that whatever is written or spoken must be as clear and understandable to people with disabilities as it is for people who do not have disabilities. Covered entities must also **provide aids and services** when needed to communicate effectively with people who have communication disabilities (ADA, 2011).
- In some cases, however disability discrimination still occurs.

REALITY OF RECEIVING ACCOMMODATIONS



- A common myth is that only people with disabilities or severe disabilities are protected by the ADA . **The main concern depends on whether they experienced disability discrimination—** regardless of the existence or severity of disability—resulting in a violation of "their right to equitable social opportunity through accommodations that do not impose undue hardship on other people" (Francis & Silvers, 2016, p. 1030).
- This excerpt begins by framing the experience of the individual with a disAbility first but then ends by focusing on the fact that the accommodation should not impose hardship *on other people*. This highlights a major concern which is the **reality of these community members receiving their due accommodations.**

ETHICS AND PEOPLE WITH CCN & AAC



ETHICS

- People with complex communication needs are frequently excluded from truly participating in "generic research, disability research and augmentative and alternative communication research due to uninformed perspectives from researchers, Human Research Ethics Committees and disability organizations" (Taylor & Balandin, 2020, p. 108).
- Such attitudes disadvantage people with CCN, perpetuate social exclusion and are a breach of human rights under the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006). However, there are indications of improvements in ethical approaches to inclusive research that enable people with CCN to execute their right to be fully involved in research and have their voices heard.

DIVERSITY & DISABILITY IN RESEARCH

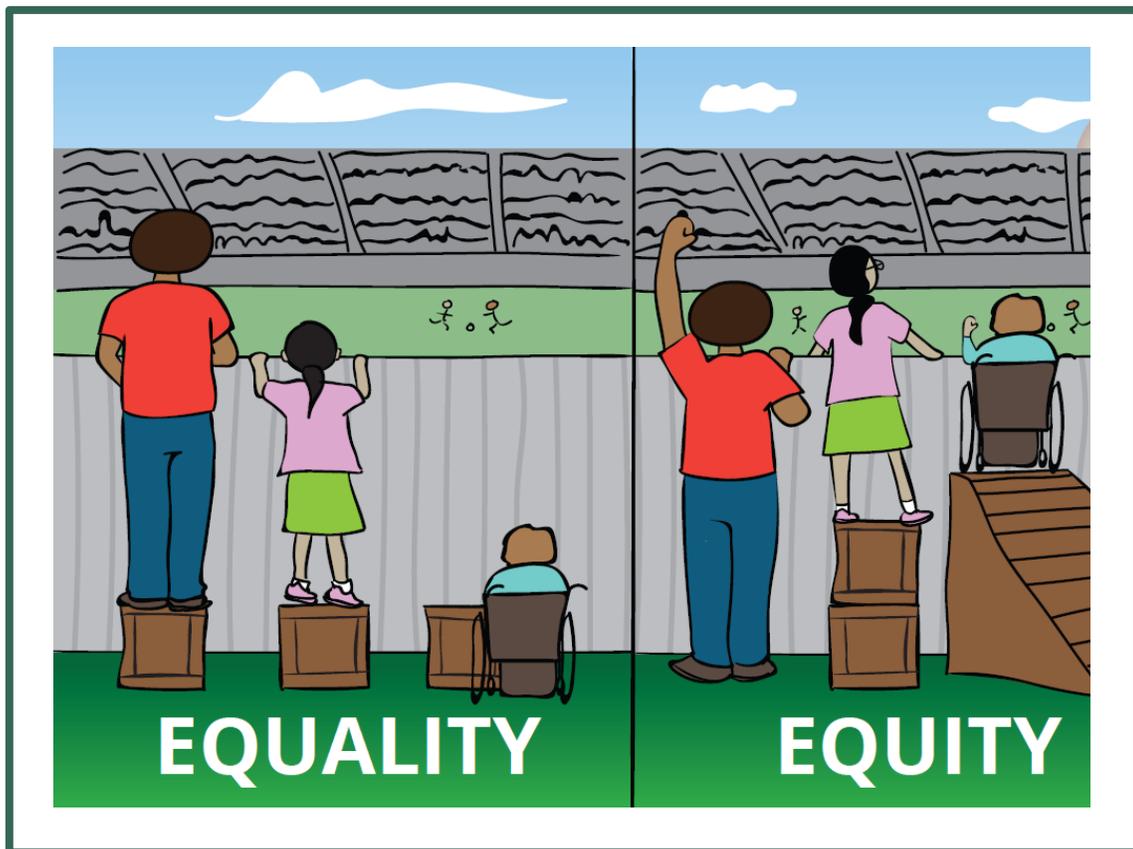


- When gathering the research for this presentation, there was a common theme about diversity and disability:
 - The research was **limited and outdated**.
 - There was a **significant underrepresentation** or lack of representation with diversity and disabilities.
 - The **demographics** of participants followed a similar pattern regarding age, ethnicity, gender, and disability.
- It is important to consider the potential repercussions from a lack of diversity...
 - Lack of representation of these aspects --> disconnect --> delays

DIVERSITY AND DISABILITY STATISTICS

- **Age** - "Nearly 1 in 12 (7.7 percent) U.S. children **ages 3-17** has had a disorder related to voice, speech, language, or swallowing in the past 12 months" (NIH, 2016).
- **Race/Ethnicity** - "Nearly one in 10, or 9.6 percent, of **black children** (ages 3-17) has a voice, speech, language, or swallowing disorder, compared to 7.8 percent of **white children** and 6.9 percent of **Hispanic children**" (NIH, 2016).
- **Gender** - "**Boys** ages 3-17 **are more likely** than girls to have a voice, speech, language, or swallowing disorder (9.6 percent compared to 5.7 percent)" (NIH, 2016).
- **disAbility** - There are few dedicated resources in the literature which provide an overview of qualitative methods to effectively gather the perspectives of people who cannot easily communicate verbally; specifically, people who use AAC. "As a result, **AAC users might be excluded from studies using methods such as interviews or focus groups**, even if they fit the researcher's target population" (Beneteau, 2020, p. 754).

ETHICS & EQUITY OF ACCESS



- What should now be addressed in each case is not whether someone's disability is enough to exercise a right, but whether the interventions and reasonable accommodations together can **achieve equitable access** for that person (Francis & Silvers, 2016).
 - Differing socioeconomic situations, sociocultural values, and languages --> delivery of accessible services from the school, community, and workplace
 - Language/Literacy barriers – ESL, professional jargon, technology
 - Quality and level of training received on how to use certain strategies, tools, devices, equipment, and programs
 - Level of transparency and communicative commitment among the team (individual, family, teacher, SLP, and related professionals)

EQUITY OF ACCESS TO SERVICES STATISTICS

- "**White children** (ages 3-17) with a voice, speech, language, or swallowing disorder are **more likely to have received intervention services in the past 12 months, compared to Hispanic and black children**, at 60.1 percent, 47.3 percent, and 45.8 percent respectively" (NIH, 2016).
- "A total of **N= 11 studies** were selected spanning **almost two decades** of research related to AAC use in **culturally and linguistically diverse populations internationally**" (Kulkarni & Parmar, 2017, p. 170).

EQUITY OF ACCESS TO SERVICES STATISTICS (CONTINUED...)

- A 2011 to 2016 survey of interdisciplinary transition teams from **more than 90 school districts** in the U.S. that attended state capacity-building transition services training institutes.
 - Results revealed that school districts were **not implementing any of the Research Based Practices** to any significant degree and that staff needed cultural competence professional development training.
 - "**Culturally Linguistic and Diverse (CLD) families of transition-aged youth with disabilities lacked access to quality resources and supports, and CLD youth with disabilities lacked opportunities to strengthen their self-determination skills**" (Gothberg, Greene, & Kohler, 2018, p.77).

IMPORTANT QUESTIONS FOR FUTURE RESEARCH



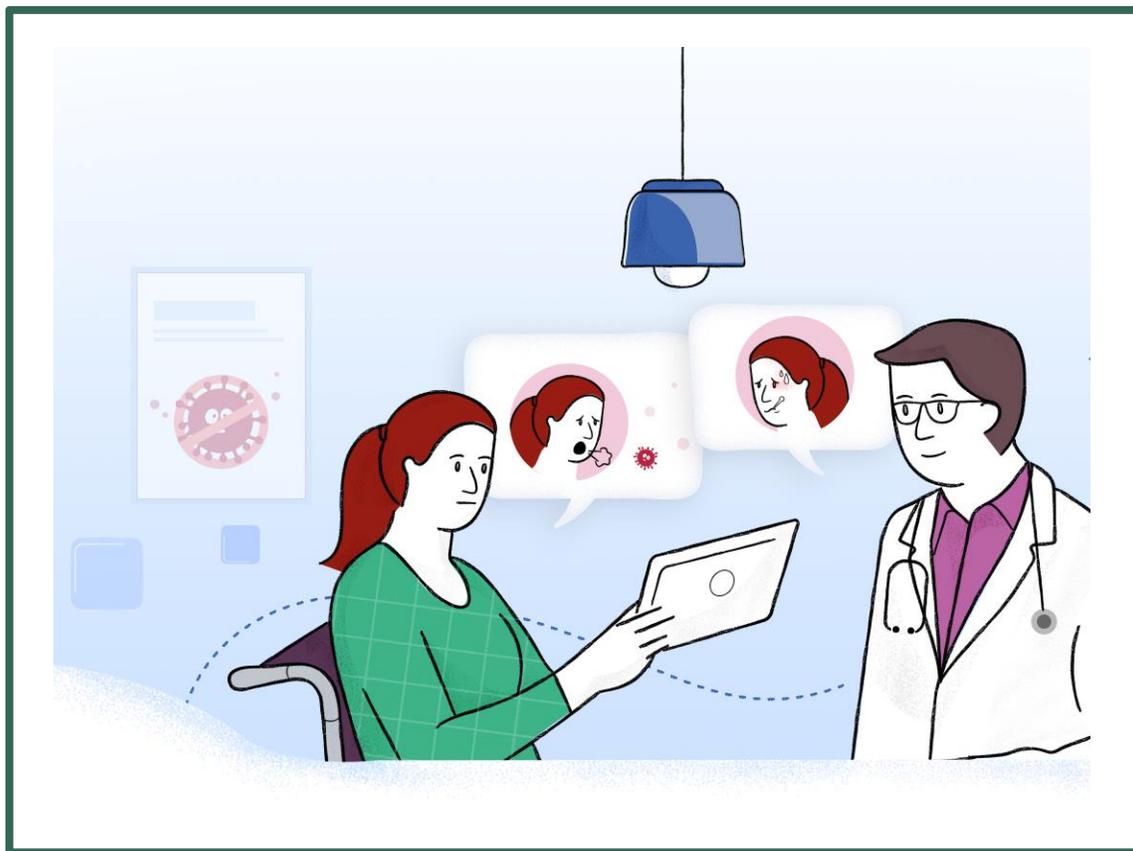
- Who and what constitutes a diverse leadership team?
- Is someone with a disAbility on the team?
- Are all voices being heard and seen?

BUILDING & IMPLEMENTING INCLUSION



- **Education:** Up to 90% of students with CCN enter adulthood without acquiring functional literacy skills (Foley & Wolter, 2010), undermining their educational achievement, their employment options, their social networks, and their access to independent living
 - **MOVING FORWARD:** Incorporate evidence-based teaching practices to improve learner outcomes for students with CCN.
- **Unemployment:** Less than 5% of individuals with CCN are employed even part-time due, at least in part, to a lack of effective and efficient communication and lack of functional literacy skills (e.g., McNaughton & Bryen, 2002; 2007; McNaughton, Light, & Arnold, 2003; McNaughton, Light, & Groszyk, 2001)
 - **MOVING FORWARD:** More staff training, disAbility awareness training, and accountability in the hiring process

BUILDING & IMPLEMENTING INCLUSION (CONTINUED...)



- **Community:** The overwhelming majority of individuals with CCN who are patients in hospitals have no access to appropriate AAC and struggle to communicate medical needs or provide medical information (Blackstone, Beukelman, & Yorkston, 2015); a recent meta-synthesis concludes that they are at substantial risk for poor health outcomes as a result (Hemsley & Balandin, 2014).
- **MOVING FORWARD:** Community areas such as doctor's offices, hospitals, restaurants offer alternative methods of communication such as tablets, white boards, AAC boards, PECs, and more to their consumers as well as provide AAC Awareness Training to staff.

ACTION ITEMS MOVING FORWARD



- Improve **educational and employment outcomes** for AAC Users (e.g. Increased employment and postsecondary opportunities)
- Improve the **workplace culture and environment** to reflect effective communication and inclusion (e.g., Providing chat feature during meetings)
- Increase **access to AAC** within the community and workplace by providing AAC training to staff, AAC equipment in commonly visited areas (e.g., AAC boards in playgrounds)

CONCLUDING REMARKS



- As society begins to **accept diversity** and provide appropriate accommodations, **inclusion and equity shall come automatically** to benefit each and every member of our community!

THANK YOU VERY MUCH



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THE VOICE OF AAC

