

What do we really mean by “Inclusion?” The importance of terminology when discussing approaches to
community engagement

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Throughout history, autistic individuals (and those with other disabilities) have been excluded from opportunities to participate fully in their communities, make their own decisions, and influence the power structures designed to support them –often to their detriment and the detriment of society at large. In response to this problem, inclusion of autistic individuals into society is increasingly a focus of advocacy, research, and policy; it is also a topic often considered in our journal (Bolte, 2019; Pellicano et al., 2018). Most of the conversations about community engagement and accessibility, including the American with Disabilities Act (1990) focus primarily on physical disabilities; however, with autism, social communication features are part of the diagnostic criteria and thus must also be considered. Historically, inclusion for children on the autism spectrum (or those with other related disabilities) has focused on integrating children into various school settings. More recently, however, discussions regarding inclusion have moved beyond the classroom toward increasing opportunities for engagement and full participation in all facets of life, including employment, community events, and social affairs. While these opportunities require access to various physical spaces such as airports, stores, hotels, and places of worship, access to these spaces alone is not enough to ensure that autistic individuals will benefit from meaningful social, educational, or otherwise enriching experiences.

Examples of popular current approaches to support community engagement of autistic individuals include sensory-friendly events and modified hiring practices. Sensory-friendly events are an attempt to create separate, accessible spaces for autistic individuals and other neurodivergent people with sensory differences. These events may include modifications such as being held outside of regular business hours, being offered exclusively for people with disabilities, diminishing sounds and lights, or offering headphones and fidget toys. Organizations are also beginning to change their hiring practices to be more inclusive; however, they often do not follow through with the appropriate cultural or environmental workplace adaptations necessary for *all* employees to succeed. The question becomes

ethical--do these and similar approaches hiding under the *inclusion* moniker provide genuinely inclusive and meaningful opportunities for autistic individuals?

One can argue the examples above—often advertised as promoting inclusion—are missing essential components to community engagement necessary for them to be truly inclusive. In other words, these practices may allow individuals physical access to a space or opportunity without supporting significant social participation. As autistic individuals encounter an increasing number of accessible spaces, we feel it is beneficial to incorporate a common terminology that accurately reflects the level of community engagement in an activity or program experience. Furthermore, we posit that it is necessary to identify the components required to achieve a full-inclusion experience. As a result, we propose the *community engagement continuum* (CEC)—a framework to describe and define levels of community engagement. Utilizing a common framework allows us more clearly to identify, communicate, and research best practices for organizations striving for full inclusion.

The lowest and most basic attempt to promote community engagement is the approach of *tolerance*. *Tolerance* occurs when an individual uses tools like headphones, fidgets, or sensory rooms to be physically present and *tolerate* an unmodified environment. At the *tolerance* level, autistic individuals incur separate experiences while in the same physical space as non-autistics. Note that the tools utilized do not support meaningful social participation and, as a result, deny the individual a sense of belonging and an opportunity to contribute. However, this approach might be appropriate for experiences or environments involving health and safety, such as medical procedures and transportation.

The second level of community engagement is the approach of *accessibility*. *Accessibility* occurs when the host provides accommodations or supports for physical access to an environment but does not make changes necessary to support social engagement opportunities. At the *accessibility* level,

successful social engagements depend upon an individual's adaptive and social skills. However, to expect any individual to conform to the needs of the majority as the only opportunity for participation can be discriminatory in nature. An example of successful *accessibility* would be allowing a child who has the appropriate social, emotional, and academic skills the opportunity to participate in the same math classroom using the same lesson as their neurotypical peers. *Accessibility* builds on the CEC level of *tolerance* by physically allowing the opportunity for participation based on one's skills but does not include any accommodations or modifications to the social fabric of the classroom that might increase the likelihood of successful participation.

The next level of approach – and often the best place to begin efforts to promote community engagement – is *integration*. Pellicano and colleagues (2018, p. 386) define *integration* as “an individual adapting to a given mainstream.” Put another way, *integration* promotes an individual's participation in a physical space created to meet the needs of the majority of users. As opposed to accessibility, which focuses on physical engagement, integration encourages both physical and social engagement. Note that participation does not look the same for everyone, and thus the focus should be placed on the term *meaningful*. Tools used to create predictability or clarify expectations can help individuals successfully and meaningfully participate socially in a variety of settings¹.

One example of *integration* is providing tools to support social opportunities for participation in a worship service. Prior to attendance, a host may share social expectations such as when to sit or stand, procedures for entering and exiting the space, appropriate attire, appropriate responses to activities, etc. Providing information using evidence-based methods of communication may benefit an individual's ability to participate in the service in a way that is meaningful to them.

¹ The National Clearinghouse of Autism Evidence and Practice has identified a number of evidence-based tools to support accessibility for autistic individuals. See <https://ncaep.fpg.unc.edu/>

The highest level of engagement on the CEC is that of *inclusion*. In this approach, a host creates tools and incorporates modifications that allow *all* individuals to belong and make meaningful contributions to a space and/or program. For individuals to feel a sense of belonging, the culture of the organization or group must allow each individual to feel valued and comfortable bringing their strengths, sharing their challenges, and asking for help. Inclusion is not only being invited to the dance and being asked to dance, but also creating an environment where everyone is comfortable dancing. And like a dance, *inclusion* is a dynamic principle. It is an ongoing process of evaluation and adaptation designed to continually meet the needs of individuals. The process is never ending because there is always room for improvement and growth. Not only can an organization assess its ability to become more inclusive to those outside the organization, but it can also strive to maximize the potential of its employees regardless of ability.

One example of *inclusion* according to the CEC involves modifying hiring practices and providing employee support programs that encourage a neurodiverse workforce. During a hiring process for example, assessors could decrease the primacy of social abilities and instead emphasize one's ability to complete relevant tasks. Ongoing support, accommodations and modifications could then be implemented to create a working environment that will allow for the person to work comfortably and effectively. An inclusive workplace culture equally values *all* employees and positively responds to opportunities for all employees to advocate for themselves.

It is important to note that none of the approaches described above are necessarily harmful unless we apply them incorrectly or are satisfied with the results and not continuously striving for successful inclusion. Creating a sensory room at an airport will not help individuals be more successful flying. Providing headphones alone will not allow an individual to be able to participate and interact with others. The act of certifying a program as *inclusive* does not encourage the critical element of dynamism

that is the essence of *inclusion*. Moreover, it does nothing to perpetuate the dialogue necessary to improve inclusion beyond the *sensory friendly* experience. Until community engagement offerings move from *tolerance* to *inclusion*, autistic individuals may never know the richness of true community engagement or know the sense of empowerment that comes with using one's abilities to contribute to the common good.

As for our professional community working with autistic individuals, we must disseminate accurate information about *tolerance*, *accessibility*, *integration*, and *inclusion*. There is evidence to suggest that people are motivated to solve the current challenges with access and inclusion in communities. Still, we are not communicating well on how to help people be successfully included. Finally, and perhaps most importantly, it is essential that we ensure that autistic individual's voices are not merely considered but also amplified in discussions around community engagement and inclusion. Being clear in our terminology and putting autistic individuals in the driver's seat will help to ensure that community engagement efforts are moving toward true, meaningful inclusion for those on the autism spectrum.

References

Americans With Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 328.

Bölte S. (2019). Hey autism researcher, what's on your mind today about inclusion? *Autism*, 23(7), 1611-1613. doi:10.1177/1362361319870994

Pellicano, L., Bölte, S., & Stahmer, A. (2018). The current illusion of educational inclusion. *Autism*, 22(4), 386–387. <https://doi.org/10.1177/1362361318766166>