The Meaning of DEI for Persons with IDD

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Abstract

Diversity, equity, and inclusion (DEI) collectively provide a foundation for the fair treatment and active participation in society for persons with intellectual and developmental disabilities (IDD). Diversity recognizes the unique qualities and characteristics of individuals with IDD and acknowledges their strengths and talents as well as their weaknesses, differences, and unique needs. Equity focuses on the provision of equal access to opportunities and life experiences for individuals with IDD. Inclusion emphasizes the active engagement of students and adults with IDD in school and community, respectively.

Keywords: Developmental disabilities; autism spectrum disorder; Down syndrome

Abbreviations: DEI: Diversity equity and inclusion; IDD: Intellectual and developmental disabilities; ASD: Autism spectrum disorder; DS: Down syndrome

The Meaning of DEI for Persons with IDD

Diversity, equity, and inclusion (DEI) has become a popular organizational framework for promoting "the fair treatment and full participation of all people, including populations who have historically been underrepresented or subject to discrimination because of their background, identity, disability, etc." [1]. Given the nature of DEI, it is not surprising that its popularity has been accompanied by controversy [2]. Each of the three concepts—D, E, and I—is important but may mean different things depending on the nature of the diversity and the way(s) in which equity and inclusion can be achieved for someone. In this essay, we consider the meanings of the D, the E, and the I that are most important for individuals with intellectual and developmental disabilities (IDD). It is apparent to us that DEI has different meanings or implications, depending on just what diversity is involved.

Although our focus is on IDD, some of these individuals may also have a diagnosis of autism or autism spectrum disorder (ASD). Some individuals have only ASD. Some have only IDD, and some have both. Regarding the prevalence of these disorders, it is reasonable to conclude that approximately 2% to 3% of the population may be identified with one of these disabilities, in some cases both (that is, IDD without ASD or ASD with IDD) [3-6]

(USDOE). It might therefore be estimated that as many as 1 in 40 Americans may have a disability falling under the IDD umbrella.

The Nature of Diversity and IDD

Diversity is a term easily misunderstood. The misunderstanding is typically a result of greatly underestimating the diversity in what is included in the term. Currently, in the social sciences, the term usually is used to indicate differences in "race" or heritage involving skin color or gender (including gender-identity). Less often, it involves political affiliation (or orientation), other belief systems (e.g., religion), class distinction (e.g., socio-economic status), or education (degree, type, or place of). And it is used to indicate policy in considering the hiring or appointment of individuals to certain positions of responsibility or authority. Sometimes, diversity is used to indicate differences in particular abilities or classifications of disability. Here, the nature of diversity is critical and the requirements of the job or position for which one is being considered must be thought through lest DEI become a farce. For example, putting someone with only rudimentary intellectual skills (an individual with an intellectual disability) in a position in which an extremely high level of intelligence is required would make a mockery of DEI.

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Such might be done maliciously by someone trying to discredit DEI involving disabilities or naively by an advocate for those with disabilities who overestimates an individual's abilities or underestimates the intellectual demands of the position—or both Here, caution is required in understanding the nature of diversity and its relevance to the requirements of the task. Caution is required for two reasons.

First, the abilities of many people with disabilities, including IDD, can be seriously underestimated. For example, the range of competence in various activities (e.g., acting, playing musical instruments, cooking, reading) of individuals with Down syndrome (DS) is enormous. Some individuals with DS function with little impairment, a few are successful in ways that many of us are not ; https://youtube.com/@drawingsbytrentofficial?feature=share9; https://www.bbc.com/news/business-65388131, and some have very seriously impaired intellect and require significant and sustained support to accomplish everyday tasks. Some individuals with disabilities, including IDD, can do things that are surprising to most people, so it is important to assess the talents of the individual and how those talents match (or do not match) the demands of the job. Second, there are often multiple ways to accomplish a given task. The task in question or achieving a particular goal might be accomplished in a different way.

Equity for People with IDD

Equity, as it applies to individuals with intellectual and developmental disabilities, centers on their equitable access to life experiences. Given the historical limitations placed on individuals with disabilities in terms of opportunities, equity thus is conceptualized herein as the question of personal choice and decision-making for these individuals that mirror such opportunities for the population in general. One important aspect of equity for persons with IDD is *self-determination*, just as is the case for us all self-determination refers to deciding one's own work and one's own course of action [7,8]. It is associated with autonomy, self-regulation, self-realization, and empowerment. The skills required for self-determination include making decisions, making personal choices consistent with one's preferences and interests, advocating for yourself, setting goals, and solving personal problems. It provides the opportunity for people with IDD to express their own dreams, desires, and goals and to indicate ways that they may prefer doing things [9,10]. It relates to core personal freedoms (e.g., living where you want, choosing who to live with, earning money at a job that you enjoy, eating where/when you want, choosing how to spend your free time, and deciding how to spend your money) [11].

Self-determination is associated with positive outcomes in terms of academic success, school transition, employment, independent living, and quality of life [12-15]. It is a central part of planning for people with IDD, and some persons with IDD will be able to do more of it than others. The issue is how to maximize self-determination consistent with the abilities of persons with IDD. Self-determination and the opportunity to make personal choices about one's own life are essential to ensuring the dignity of individuals. And a key aspect of dignity, and thus of equity, is dignity of risk. Some choices involve risks that should be avoided for everyone, including those with IDD. However, it can be argued that too much time and effort is spent protecting people with disabilities from tolerable risk, and consequently that such overprotectiveness may prevent them from having important life experiences [16].

Risks can take many forms and may include traveling in the community, having romantic relationships, seeking new employment, engaging in new sports and games, and so on. Although support remains important, they need to be creatively applied to maximize independence. Personal choice-making is something that many of us take for granted, but individuals with IDD have historically not been provided the opportunity to choose for themselves when they should. Personal choice and decision-making are the foundation of the dignity of risk. Perhaps surprisingly, some data suggest that an increase in choice, in terms of participation and opportunities, has been associated with a corresponding decrease in sustaining injuries [17].

Inclusion of People with IDD

Inclusion has many definitions [18]. Particularly important here is the difference between inclusion as the bodily presence in general education and inclusion in appropriate educational activities. That is, inclusion in education of individuals with IDD is an important issue for those of school age. For adults, the primary issue of inclusion is how and where they live, work, travel, and participate in community events. For the school-age population (ages 6–21 years), virtually all students with IDD attend regular schools. Only 6.7% of students with IDD are educated in other environments different from the regular school setting, such as special schools or residential programs [6]. Data from the USDOE [6] indicated that 17.9% of students with intellectual disability spent 80% or more of their educational day in the general education setting, while 27.9% spent between 40%-79% in general education classes. Slightly less than one-half (47.6%) spent less than 40% of their school day in a general education setting [6]. However, in the United States, there is significant variance across the states in placement practices. For students with IDD spending 80% or more of their time in the general education setting, the range across states was from 73.7% to 3.8% [19]. For students with significant (severe) disabilities, there has been limited change in inclusion over the past two decades with only 7% in general education classes over 40% of the time e.g.,, [20].

Given these statistics from the USDOE, we can assume that about half of all students with IDD are now included within general education programs for a significant portion of the school day.

However, while there are many advocates who have argued for full inclusion (i.e., no alternatives to placement in general education, e.g. [21], the movement toward full inclusion in general education classes for students with disabilities has not been realized, and some have argued for alternative (i.e., specialized) educational placements for some individuals with IDD e.g., [22]. Regardless of where they are educated, children with IDD are integral members of their local school communities [6]. Increasingly, adults with IDD and other disabilities are continuing their education at the postsecondary level in colleges and universities [23]. There are now 312 colleges nationwide offering programs for these students [24,25]. Over 6000 students with ID are enrolled in post-secondary education programs [25].

Living in a home community, not in an institution, is now clearly the norm for adults with IDD. The number of persons living in public residential facilities (in 2019) dropped dramatically to 16,200 (i.e., less than 0.04% of adults with IDD) [26], which was down from the high mark of 194,650 in 1967 [27-29]. Over one-third of all states have abolished all such institutions [27-30]. Instead, adults with IDD are living within the community, in their own family homes, in independent housing options, and in supported community settings. About 12% of adults with IDD live in homes they own or lease [11].

Conclusion

Considerations of diversity, equity, and inclusion are paramount for individuals with IDD. The concept of diversity emphasizes the unique qualities and characteristics of individuals. It recognizes that people with IDD have diverse goals, preferences, and interests, as does the general population. Equity focuses on the provision of equal access to life experiences for individuals with IDD. Within this context, it means considering personal choice and individual decision-making. Equity involves promoting self-determination, in which autonomy, self-regulation, and empowerment are fostered and those with IDD are actively involved in planning their goals and aspirations. Equity also involves affirming the personal dignity of individuals with IDD and includes the "dignity of risk." Dignity of risk refers to the equitable consideration of allowing individuals with IDD to make personal choices about activities in which they may engage, even as these activities may involve risk.

In terms of the third consideration of inclusion, students with IDD receive their education in regular schools over 93% of the time [6]. However, "full inclusion," defined as students spending most or all their instructional day in the general education classroom, is not yet a widespread reality. Some researchers have suggested that special education settings are able to be more effective because the instruction can be more individualized, explicit, systematic, and intensive [31] and the curriculum more functional [22]. Inclusion is also increasingly found in post-secondary educational programs. These programs in colleges and universities range from fully integrated programs to differentiated curricula, significant supports, and learning accommodations [31]. Relative to adults with IDD and inclusion, the great preponderance of persons lives in their home community. Only a very small number of adults with IDD remain in segregated, residential facilities. Commitment remains important to promote diversity, to ensure equity in access, and to foster inclusion in school and community for individuals with IDD [32].

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