Intellectual and Developmental Disabilities

Toward Freedom and Dignity: Comments on the Publication of the AAIDD 12th Edition Manual

--Manuscript Draft--

Manuscript Number:	IDD-D-21-00029
Article Type:	Perspectives
Keywords:	Dignity, autonomy, choice, self-determination, participation
Corresponding Author:	Michael L. Wehmeyer University of Kansas Lawrence, Kansas UNITED STATES
First Author:	Michael L. Wehmeyer
Order of Authors:	Michael L. Wehmeyer
Manuscript Region of Origin:	UNITED STATES
Abstract:	This perspective provides a reflection on how the 12 th Edition AAIDD Definition, Diagnosis, Classification, and Systems of Supports Manual might move the field of intellectual disability forward.

Toward Freedom and Dignity: Comments on the Occasion of the Publication of the 12th Edition

of the AAIDD Definition and Classification Manual

Toward Freedom and Dignity: Comments on the Occasion of the Publication of the 12th Edition

of the AAIDD Definition and Classification Manual

I was asked to provide a short (always a challenge), thoughtful (even more of a challenge!) commentary on the occasion of the publication of the 12th Edition of the AAIDD *Definition, Diagnosis, Classification, and Systems of Supports Manual* (Schalock et al., 2021). To paraphrase the invitation email, my purpose was not to provide a *review* of the 12th Edition *Manual*, but to reflect on how the 12th Edition *Manual* might move the field of intellectual disability forward.

Having had the privilege of serving on the AAIDD Terminology and Classification Committee for the 11th Edition *Manual* (Schalock et al., 2010), I fully recognize the tension that exists when engaged in such an exercise between creating a product that can move the field forward versus providing a tool that can be used by the field immediately. A manual such as this must walk a tightrope between innovation and reality, theory and practice, and utility and practicality. Certainly, the 12th Edition *Manual's* authors are uniquely adept at walking that tightrope and have provided a product and a tool that can achieve both ends.

The 12th Edition *Manual* rightly situates context as having an important role in the integrated model of human functioning that provides the theoretical and practical basis of the systems described in the *Manual*, and the research cited in that section illustrates the significant progress in conceptualizing this critical element since the publication of the 11th Edition. But the development of a manual like the AAIDD *Definition, Diagnosis, Classification, and Systems of Supports Manual* itself exists within a context. That is, diagnosis and classification are important elements in manuals such as this *because* of how we, as global societies, have chosen to structure the systems that support people in these societies who benefit from different types and levels of

support to live, learn, work, and play in their community. Independent of whether or not they would have been inclined to do so otherwise, the authors of the 12th Edition *Manual* were obligated to include major sections on these processes because the medical, educational, vocational, and other systems in place to support people for whom typically-available supports are not adequate or appropriate require such processes.

But I think it is important to note that it does not have to be that way. For the most part, just as we, as a global society, have chosen to create systems built on diagnosis and classification, we, as a global society, could chose to build systems that approach supports outside of a diagnostic and classification approach. My observation here is not without support in recent iterations of the AAIDD *Manual*. The 10th Edition *Manual* observed that:

> …intellectual disability "is not something you have, like blue eyes or a bad heart. Nor is it something you are, like being short or thin. It is not a medical disorder … nor is it a mental disorder … it refers to a particular state of functioning that begins in childhood, is multidimensional, and is affected positively by individualized supports" (Luckasson et al., 2002, p. ii).

The 12th Edition *Manual* stated this same phenomenon as such:

> ID is more than a biomedical or psychoeducational deficit; ID is also a social construct that is based on the interaction of people and their contexts, the human and legal rights operating within those contexts, and the roles played in society by persons with ID and their families (Schalock et al., 2021, p. 77).

That, in turn, sounds a lot like pioneering psychologist Seymour Sarason's observation in 1985 that what we now call intellectual disability "is never a thing or a characteristic of an individual,

but rather a social invention stemming from time-bound societal values and ideology that makes diagnosis and management seem both necessary and socially desirable" (p. 233).

If intellectual disability is not something one has, but instead is bound to societal values and the contexts created by societies, then there is a great deal we, as citizens of those societies and communities, can do to change how we frame and construct systems and supports. I have always thought the assumptions regarding the application of the definition of intellectual disability are, in many ways, more important than the actual definition. They state that:

1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.

2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.

3. Within an individual, limitations often coexist with strengths.

4. An important purpose of describing limitations is to develop a profile of needed supports.

5. With appropriate personalized supports over a sustained period, the life functioning of the person with ID generally will improve (Schalock et al., 2021, p. 1).

Within social-ecological models of disability such as the AAIDD model and the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (WHO, 2001), disability exists only in the gap between what a person can do and what a person wants to do. The impetus shifts from fixing a person to identifying what supports a person needs to do what they want to do. This, in turn, shifts the responsibility for imagining and designing such supports to our respective societies.

Further, I do not think that the notion that we should and can create systems that move away from diagnosis and classification are all that unrealistic and impractical. That is one of the strengths of the 12th Edition *Manual*, building on AAIDD manuals since 1992. That is, there is a framework and a pathway to something beyond what exists today; toward, I would argue, freedom and dignity. Led ably by IDD editor Jim Thompson, the work conceptualizing and understanding supports and of building systems of supports has made remarkable progress in two decades, a fact that is represented in the 12th Edition *Manual*. From early on, as we were developing the first version of the AAIDD *Supports Intensity Scale*, it seemed obvious to me (and others) that the most important aspect of that process was a fundamental proclamation reflected in the assessment process: that with appropriate types and intensities of supports, all people can be successful in all contexts.

The roadmap to this alternative reality exists within the 12th Edition *Manual*. Look at the first two bullets on page 46 justifying the approach to classification in the 12th Edition *Manual*:

- the increased application of the supports paradigm;
- the increased emphasis on the individual's capacity and personal outcomes.

And check out Table 5.3 (Coordinated and Interrelated Systems of Support Elements) on page 71, which identifies choice and personal autonomy, inclusive environments, generic supports, and specialized supports as those key support elements. Now, turn a couple of pages to Table 5.4 (Generic Support Components) on page 75; two of these generic support components are *Dignity and respect* and *Personal strengths/assets*.

As noted previously, the 10th Edition of the AAIDD *Definition, Classification, and Systems of Supports Manual* (Luckasson et al., 2002) aligned the AAIDD framework with that of the World Health Organization's (WHO) International Classification of Functioning, Disability

and Health (ICF, WHO, 2001) and its important shift toward a social ecological model of disability. This alignment was strengthened in the 11th Edition and continues in the 12th Edition. The 11th and 12th Edition *Manuals* also brought into the discussion the United Nations Convention on the Rights of Persons with Disabilities (CRPD)(United Nations, 2006). I believe that aligning the AAIDD definition system with the CRPD is as important now as aligning it with the ICF was in earlier editions.

The standard set by the CRPD in Article 3—General Principles for how we, as societies, treat and support people with disability is one of "respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and the independence of persons" (United Nations, 2006, p. 5). I am sure that most AAIDD members who read that statement nod their head in agreement. It aligns with the beliefs and values expressed by the association. But take a moment to consider what it really is saying. It is a proclamation first and foremost of the *inherent dignity* of all people, including people with disability. Inherent means a permanent and inseparable element, quality, or attribute. Dignity means a state of worthiness and honor; elevated rank or grandeur. When we claim the inherent dignity of people with intellectual disability, we are staking out a claim for their innate, immutable worthiness and value. That just societies are founded upon principles of compassion, equal justice, and respect for human dignity seems self-evident and axiomatic. Yet from antiquity forward, people with disabilities have been viewed through the lenses of medical and biological formulations of disease and pathology, economic models emphasizing social blight and destruction, and so forth. Those were the foundations of our systems and in too many ways remain the foundations of our systems.

One can argue that diagnosis and classification serve to identify people who need such extraordinary supports. Fair enough, but to what end? Several years ago I was asked to provide a

reflection in an AAIDD plenary of the state of the field with regard to systems of supports. As I thought about that task, I realized that in virtually every domain—educational, vocational, residential, etc.—we were stuck in the 1980s. Congregate group homes remain the prevalent mode of 'community residential supports;' sheltered workshops remain the dominant form of 'employment support;' and segregated, separate classrooms remain the primary 'educational environment.' All of these were new and exciting innovations in the 1980s. But we are 40 years past that era. Should not more have changed?

There are consequences to our lack of advancement and change. This has been an extraordinarily difficult year for so many people. Members of our own community have suffered heartbreaking losses, but perhaps none more so than people with intellectual disability, who were disproportionately impacted by Covid-19. A recent *New England Journal of Medicine* review concluded that "having an intellectual disability was the strongest independent risk factor for presenting with a Covid-19 diagnosis and the strongest independent risk factor other than age for Covid-19 mortality" (Gleason et al., 2021, p. 2).

On April 30, 2020, in the *New York Times* printed an obituary for Mr. Willie Levi. Written by Dan Barry, the author of *Boys in the Bunkhouse: Servitude and Salvation in the Heartland*, Mr. Levi's obituary began:

> If Willie Levi had enjoyed choice in life, he would have gone back to Texas — back to the small city of Orange, where he had played the spoons, sung the blues and lived in a shotgun house crowded with cousins.
>
> But Mr. Levi never had much choice. He was sent first to an institution and then to Iowa, where he and other men with intellectual disabilities worked in virtual servitude at a

turkey-processing plant for decades. He never made it back to Orange

(https://www.nytimes.com/2020/04/30/us/willie-levi-73-dies-he-escaped-a-life-of-servitude.html, para. 1 & 2).

If you haven't read *Boys in the Bunkhouse*, you need to do so. A system that utterly and completely failed Willie Levi throughout his life failed him again in the end. When he was released from servitude, the system could not find any family members for him to return to. The *New York Times* located some of these family members, however. In the obituary, a distant cousin said: "They took him away so long ago … nobody even knew that he existed."

Inherent dignity? Worth? Value?

It is a lot to ask of any manual to create meaningful change, but the seeds exist for such change in the 12th Edition *Manual*. The CRPD suggests a roadmap to ensuring the inherent dignity of all people:

…individual autonomy including the freedom to make one's own choices, and the independence of persons (United Nations, 2006, p. 5).

That roadmap is referenced in the 12th Edition *Manual*.

Choice.

Dignity.

Respect.

Autonomy.

Participation.

Full citizenship.

It is up to us to take and sow those seeds. I believe that we know how to create systems that support people to live full, meaningful, self-determined lives. It is a matter of the will to do so.

References

Gleason, J., Ross, W, Fossi, A., Blonsky, H., Tobias, J. & Stephens, M. (2021). The devastating

impact of Covid-19 on individuals with intellectual disabilities in the United States.

NEJM Catalyst: DOI: 10.1056/CAT.21.0051

Luckasson, R., Borthwick-Duffy, S., Buntinx, W., Coulter, D., Craig, E., Reeve, A., Shogren, K.,

Snell, M., Schalock, R.L., Snell, M.E., Spitalnik, D.M., Spreat, S., & Tasse, M. (2002).

Mental retardation: Definition, classification, and systems of support (10th Ed.).

Washington, DC: American Association on Mental Retardation.

Sarason, S. (1985). *Psychology and mental retardation: Perspectives in change*. Austin, TX:

Pro-Ed.

Schalock, R., Borthwick-Duffy, S., Bradley, V., Buntinx, W., Coulter, D., Craig, E., Gomez, S.,

Lachapelle, Y., Luckasson, R., Reeve, A., Shogren, K., Snell, M., Spreat, S., Tasse, M.,

Thompson, J., Verdugo-Alonzo, M., Wehmeyer, M., & Yeager, M. (2010). *Intellectual*

disability: Definition, classification, and systems of support (11th Ed.). Washington, DC:

American Association on Intellectual and Developmental Disabilities

Schalock, R. L., Luckasson, R., & Tasse, M.J. (2021). *Intellectual disability: Definition,*

diagnosis, classification, and systems of supports (12th Ed.). Silver Spring, MD:

American Association on Intellectual and Developmental Disabilities.

United Nations (2006). *Convention on the rights of persons with disabilities and optional*

protocol. Accessed online at

http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf.

World Health Organization (2001). *The International Classification of Functioning, Disability and Health (ICF).* Geneva, WHO (http://www.who.int/classifications/icf/en/).