Classification in Disability

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Consider the primary functions: What is at stake?

- What is at stake for people with disabilities in:
  1. naming,
  2. defining,
  3. diagnosing,
  4. classifying, and
  5. planning supports?

What are the essential questions in each of the five functions?

<table>
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1. Naming

Requirements:
- Specific
- Be used consistently
- Adequately represent current knowledge
- Robust enough to be used across multiple purposes
- Communicate important values

- How will the status be known?
- What words will attach to the individual and people close?
The name of Intellectual Disability (ID)

- The name/label of ID appears to be stable
  - Rosa’s law (PL 111–256, 2010) replaced “mental retardation” in federal health, education and labor policy with people first language “individual with an intellectual disability” and “intellectual disability.”
  - Expansion by regulation to Social Security (20 CFR 404, 416, 2013)
  - Self-Advocacy community (e.g. Inclusion International, http://inclusion-international.org/about-self-advocacy/)
  - Professional organizations (e.g. AAIDD, The Arc)
  - Convention on the Rights of People with Disabilities (refers to intellectual impairments)
  - Titles of major documents
  - And perhaps, ICD 11?? “Intellectual Disorder”

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2. Defining

- What group will be “in” for protections and benefits, and what group will be “out”?

- What are the elements that must be met in order to come within the definition? Specify each element.
3. Diagnosing

- What assessment steps are required for identifying individuals?

- Evaluation must be aligned to each element of the definition

- Consider Assumptions
  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. Classifying

- How is the total group that was defined as “in” now subdivided based on criteria that are relevant to a specified purpose of subdividing?

- The range of classification systems has expanded, e.g., etiology, pathophysiology, health, fundamental problem (such as executive functioning), IQ score bands, types of support needs, intensity of supports, etc.
Classifying

- The ideal is that classification should be based on the multidimensionality of human functioning (e.g., for ID: IQ, AB, health, participation, context, supports)

- Whichever classification system is selected, it must directly reflect an explicit purpose
What approach does one take to enhancing human functioning?

Consider Assumptions:
- 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 intellectual disability generally will improve.
Planning Supports

- Supports planning should be based on:
  - Personal goals
  - Assessed support needs
  - Desired personal outcomes
  - Supporting decision-making, not automatic guardianship
Circumstances that Arise in the Field that Affect the 5 Functions

- Increased use of genome tests, with resulting increased diagnostic precision, labeling and intervention; therefore children receive a named disorder based on biology rather than a more general ID diagnosis.

- Increased precision in diagnosis of specific syndromes by more detailed descriptions of their actual functioning, and the development and use of more precise psychological tests, e.g. more ADHD.

- Increased use of “less stigmatizing” labels by people afraid of being sued, e.g. schools and diagnosticians. Thus increase in "learning disability" and decrease in "mental retardation".

- Increased involvement by parents in the diagnosis, through the internet and advocacy, and they won’t accept a vague conclusory pronouncement about their child’s global disability.

- Actual improved functioning in some children, beyond what was previously thought possible, through sustained early intervention, special education and intense interventions such as ABA. ID may look somewhat different/more modern now that everyone is not being institutionalized.

- Increased use of prenatal testing and abortion to reduce the numbers, e.g. Down syndrome.

- The expanding of certain diagnoses, as from autism to the broader ASD, probably affects these issues.

- Practice of using of primary diagnosis only, thus other diagnoses may not show up in data.
Example:
Decrease in ID Diagnosis / Increase in Other Mental Impairment Diagnoses

- The proportion of children with intellectual disability (ID) found eligible for SSI appears to be going down while the proportion of children with other mental impairments such as ADHD is increasing. Yet, the overall proportion of children with mental impairments (including ID) found eligible appears consistent over time.

- Professionals in the field are seeing the same children, but their diagnoses (and somewhat their functioning) have changed.
Conclusion

- Consider the differences among the five functions
- Consider what is at stake in each function
- Consider what each function contributes in decision-making
- Regarding the **classification** function, the goals should be:
  - Improved understanding of the person, directed toward improved functioning of the person
  - Rationally linking subgroup characteristics to important actions, e.g., research, funding, supports planning, outcomes evaluation, and societal priorities
  - Fairness and predictability
  - Equitable distribution of resources

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References


Thank you

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