

The Need for a Dialogue
Commentary on Stowe et al., Journal on Developmental
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In reading the article by Stowe, Turnbull, Schrandt, & Rack on "Looking to the Future: Intellectual and Developmental Disabilities in the Genetics Era" (this issue), I was left with two questions and one prediction. The two questions were: What is good science? and What is good practice? The prediction was that as the genetic era continues to emerge, issues related to quality of life and clinical judgment will become paramount. The purpose of this invited response is to continue the dialogue begun in the article when the authors discussed such topics as the bright and dark history of medical progress; the ethical, legal, and social implications of [genetic] scientific inquiry; the ELSI projects and the public dialogue on the implications of genetic research for persons with disability; and the effects of the genetic revolution on the family and society.

I would like to contribute to this dialogue based on two endeavors that I have been involved in over the last few years: first, our attempts to conceptualize, measure, and apply the concept of quality of life to persons with intellectual and closely related developmental disabilities (Brown, Keith, & Schalock, 2004; Schalock, 2005; Schalock & Verdugo, 2002); and second, our recent efforts to formulate and use clinical judgment in the diagnosis, classification, and planning of individualized supports to persons with intellectual and closely related developmental disabilities (Schalock & Luckasson, 2005). What I propose is that we begin developing a set of guidelines that encompass ethics, professional standards, and clinical judgment strategies that pertain to: a) genetic testing and screening, which represent measurement; and b) genetic counselling and therapy, which represent application. To facilitate communication, I have merely summarized the respective guidelines.

Measurement Guidelines

1. Adheres to non-maleficence (i.e., do no harm by maximizing benefits and identifying and respecting differences (Beauchamp & Childress, 1983)).
2. Is carried out for a clear, practical purpose that supports people moving towards better lives and is described within a framework that is potentially

positive, neutral, or negative, suggesting that it is possible to move toward the very positive.

3. Recognizes that the meaning of positively valued life experiences varies across time and among cultures and that the measurement framework provides a clear way to demonstrate the positive value of life.
4. Includes indicators of experiences both common to all humans and those unique to others.
5. Adheres to technical standards, accurate and detailed reporting, and systematic inquiry. This requires exploring with the persons involved the strengths and shortcomings of the questions asked and the various approaches that might be used to answer the question(s).

Practice Guidelines

1. Adheres to the principle of beneficence (i.e., the quality of doing good, taking positive steps to help others and promote actions that benefit others).
2. Uses a broad range of life domains including those related to emotional well-being, physical well-being, interpersonal relations, material well-being, personal development, self-determination, social inclusion, and rights.
3. Conducts a thorough social history that addresses issues related to the individual and his or her family's past, present, and future so as to formulate hypotheses about present and future behaviors and life situations.
4. Aligns data and their collection to the critical question(s) at hand to avoid confusion, misunderstanding, or a common pitfall of being "data rich and information poor".
5. Suggests best practices for intervention. Intervention strategies for persons with disabilities have changed significantly over the last four decades due in part to three phenomena: (a) research-based knowledge; (b) a new vision of persons with disabilities that encompasses human potential, equity, and personal well-being; and (c) the emergence of the ecological-behavioral perspective that stresses the functionality of behavior and the significant ameliorating and enhancing roles that environments can play in a person's life (Schalock & Verdugo, 2002).

Such guidelines as these 10 are increasingly important since, as the authors correctly point out, research on human genetics has the “potential for broadly and directly affecting the rights and services of individuals with disabilities and their families” (this issue, p. 1). I agree with the authors that the leadership of the disability field is compelled to take into account services, policy, history and its lessons, and ethics. A good place to begin that process is to continue a dialogue about measurement and practice guidelines such as those suggested above. In pursuing this dialogue, I am reminded of Socrates' invitation found in *The Apology of Socrates*:

As for you who voted for my acquittal, I should very much like to say a few words to reconcile you to the result, while the officials are busy and I am not yet on my way to the place where I must die. I ask you, gentlemen, to spare me these few moments: There is no reason why we should not exchange fancies while the law permits. I look upon you as my friends, and I want you to understand the right way of regarding my present position.
(Tredennick, 1969, p. 74)

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