

AOTA's Comments on NICHD's Vision Workshop White Paper on Diagnostics and Therapeutics

The purpose of this NICHD Diagnostics and Therapeutics White Paper is to identify goals and objectives related to identifying opportunities for improved diagnosis and treatment of children and individuals with developmental and neurological disorders. The section on neurorehabilitation is predominantly focused on change in underlying structures and increased understanding of basic science. Another research area of importance is the impact of neurological disorders on the individual, their families, or communities. While focusing on the "problem" from the perspective of the physiologic and biologic structures is useful for some research, it would be helpful to consider the impact of the environment on functional performance. As well, the white paper would be strengthened if it included a discussion of how societal factors influence the daily life and recovery of persons with disabilities.

The discussion on measurement, focused primarily at the level of measurement of biological processes or impairments, is extremely important and timely. Although the report acknowledges the use of patient-reported outcomes, further elucidation about how these are related to the biological processes targeted by diagnostic strategies or therapeutic interventions would be beneficial. The report mentions the use of item response theory (IRT) in connection with the use of patient-reported outcomes (PROs), presumably in relationship to the work of the PROMIS Network. Yet whether PROs can, or should, be expected to be sensitive to physiologic or structural changes or aid in diagnosis is not clear. More likely the kinds of outcomes produced by therapeutic changes in neurological structures would be assessed with observations of performance. IRT could be important in addressing issues of rater severity/leniency, which influence outcome measures based on clinical observations. Rater severity is seldom discussed in rehabilitation literature but can have significant effects on patient measures.

Also, we urgently need to develop appropriate and accurate risk adjustment models. While patient-reported and functional outcomes are acknowledged in the paper, this could be expanded to include a discussion on how such results will account for differences in patient severity when interventions are transitioned into real-world contexts. Current case-mix and risk-adjustment methods have been designed to account for differences in mortality rather than morbidity.

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