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Subject: Closing the Quality Gap Series: Revisiting the State of the Science – QI Measurement of Outcomes for People with Disabilities Comments

The **American Occupational Therapy Association (AOTA)**, representing the interests of over 140,000 occupational therapy practitioners nationwide, appreciates this opportunity to comment on the Agency for Healthcare Research and Quality's Draft of Closing the Quality Gap Series: Revisiting the State of the Science – QI Measurement of Outcomes for People with Disabilities.

We are pleased to see this report which clearly identifies research gaps, such as the paucity of studies examining disability as comorbidity.

Historically, occupational therapy has addressed the functional limitations and barriers to activity and participation as defined by the International Classification of Function (ICF) terminology. As stated in the *Occupational Therapy Practice Framework: Domain and Process (2nd Edition)*, occupational therapy supports "health and participation in life through engagement in occupation (AOTA, 2008)." In summary, we define "occupation" as the performance of everyday activity.

Executive Summary

In Table ES-1 (p. ES-2), the third row identifying 'Specific interventions directed at the disability" refers to Common Questions such as "Changes in function, Quality of Life". Although this is probably not meant to be an exhaustive list, AOTA respectfully suggests further explication under "Common Questions". In lieu of "Changes in function, and Quality of Life", we suggest adding "Changes in **Body Structure and Function**, Changes in **Activities** (routine), Changes in **Participation**". We think that including levels of ICF framework in this table would help facilitate analysis of the levels at which

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interventions are directed. We may find that a majority of intervention research are directed at the body structure and function level, but people with disabilities may be concerned with their ability and satisfaction of performing daily activities and participating in their community events. As this report notes in a discussion about the individual's perspective, focus groups revealed that people with disabilities are concerned about: "the ability to function and the opportunity to do what you want, independence and self-determination, an interrelated physical and emotional state of well-being, and being unencumbered by pain" (p.9).

Within the last row of Table ES-1 (p. ES-2), "Comprehensive programs designed to integrate medical and social services", does research aimed at preventing secondary conditions or negative events like falls/accidents fall within this category? AOTA advocates for **preventing secondary conditions** and negative events because research has shown that they can adversely affect one's health and quality of life.

Introduction

Under Disability Paradigms (p.4), we take issue with the implication that only the Social perspective supports and empowers "people who have disabilities to be full participants in their families, communities, and schools, whether or not their disability or related medical conditions can be cured or fixed". Rehabilitation professionals also emphasize **participation** and **healthy adaptation** of clients across the lifespan and across the continuum of care. Examples of rehabilitation interventions that address participation and adaptation include: (a) ensuring safe access to all areas of one's home and work/school, (b) providing adaptive equipment and/or mobility devices for shopping, dressing, and cooking, (c) evaluating driving ability and need for car modifications, and (d) helping people with disabilities to resume or start participating in leisure activities (e.g., adaptive skiing, sports with wheelchair users, low-vision adaptations for crafting/sewing).

While the discussion about type of disability (e.g., acquired, developmental) and treatment continuum e.g., (remediation) is useful in some cases, the reality of most people with disabilities seeking treatment is not so clear cut. In most cases, people with disabilities, or who are at high-risk for a disability, seek remediation as well as compensation/adaptation. Occupational therapists working with a person who has had a stroke may be implementing a constraint-induced movement therapy protocol (i.e., **remediation**) as well as teaching **compensatory** strategies for dressing, cooking, and bathing.

We would also like to comment on the example of a disability activist on p. 8. Although this is a good example of how individuals' priorities may differ at various times, we respectfully suggest deleting the phrases "confined to a wheelchair" and replacing the phrases so that the sentence would read, "A disability activist, who has paraplegia and uses a wheelchair, is visiting his father, who just recently became a wheelchair user because of a stroke."

In the section describing Outcome Measures in Research for People with Disabilities (p.11), we agree with the bulleted list of characteristics of measurement tools that should be considered by researchers. We urgently need more research that examines the outcomes of people with disabilities at the Activity and Participation levels of the ICF. While research is still needed at the body structure and function levels of the ICF, this research should be explicitly linked to Activity and Participation because outcomes need to be meaningful to people with disabilities. As an adult with cerebral palsy stated in a discussion about the need for more research about activities of daily living, "It [ADL] is so important."

We agree with the point that ADL performance can fluctuate widely over time (p.12), due to the variability of the disease (e.g., MS), side effects of certain medications, and even environment. Occupational therapists know that the ADL performance of inpatients may differ greatly once they are home because of differences between hospital (e.g., grab bars in bathroom) and home environments (e.g., lower toilet height).

In Figure 4 (p.14), AOTA views Rehabilitation's role more broadly than the figure depicts. Please see Fig. 1 for our conceptualization of the relationships between ICF and medical and rehabilitation's roles. Occupational therapists view environments and personal factors as important variables that can affect one's abilities and performance, through motivational factors and enabling characteristics of the environment. Similarly, adaptation interventions can influence one's abilities and performance. For example, with a dressing stick and sock aid, a person with paraplegia may be able to don pants and socks independently. In client-centered practice, the treatment or prevention would promote/enable the client to live life (i.e., perform meaningful tasks) to his/her fullest extent.

Methodology

AOTA questions why the search strategy did not include CINAHL database. Much of the allied health literature related to rehabilitation can be found in CINAHL. Therefore, we are concerned about the possibility that some informative studies were excluded from this report.

Reference

American Occupational Therapy Association [AOTA]. (2008). Occupational Therapy Practice Framework: Domain and process (2nd Ed.). *American Journal of Occupational Therapy, 62*, 625-683.

Figure 1 (revised) Adapted ICF Framework