

Constructing Knowledge of Nutrition: A Comparative Study on State Nutrition Policies for Children with Disabilities and Chronic Illness

Dana Lee Baker, PhD
Assistant Professor

Angela Marie Meers
Graduate Student

**Harry S Truman School of Public Affairs
University of Missouri-Columbia
Western Social Science Association**

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Presentation Outline

- I. Knowledge Construction and Agency of Agencies**
- II. The Case of Disability Specific Nutrition Therapies**
- III. Project Methods**
- IV. Preliminary Findings—management, portrayal, communication, hierarchy**
- V. Conclusions and Next Steps**

Knowledge Construction

- ✓ **Knowledge and disability are inherently relativistic**
- ✓ **Construction of knowledge is a locus of government power**
- ✓ **Balance between explicit and tacit knowledge is shifting**

Agency of Agencies

- ✓ **Government entities have personality**
- ✓ **Agencies expected to act in own self-interest**
- ✓ **Agencies make and communicate public decisions about (controversial) information**
- ✓ **Decisions surrounding information create official knowledge**

Disability Specific Nutrition Therapy

- ✓ **Nutrition therapy is vital to management of chronic illness and (some) disability**
- ✓ **Plethora of easily accessible information about nutrition and nutrition therapies**
- ✓ **Scientific evidence and knowledge is evolving**

Nutrition Therapies for Children with Disabilities or Chronic Disease Survey

- ✓ **Ongoing survey launched January 2004**
- ✓ **18 questions, both open and close ended**
- ✓ **Includes behavior, opinion, and knowledge questions**
- ✓ **Invitations to participate sent to agencies in all 50 states**

Preliminary Findings

Management:

- ✓ **42% of respondents indicated their agency recommends disability specific nutrition therapies**
- ✓ **32% of agencies that recommend nutrition therapies had policies regarding the communication of such information**
- ✓ **18% of respondents that reported their agency did not recommend nutrition therapy had policies regarding such information**

Preliminary Findings

Portrayal:

- ✓ **Concern that constructing controversial nutrition information into official knowledge would mislead parents or guardians**
- ✓ **23% reported that their agency would be likely or very likely to discuss controversial or nontraditional nutritional options with parents or guardians of children with disabilities or chronic illness**

Preliminary Findings

Communication:

- ✓ **70% reported using personal communication to convey information about disability specific nutrition therapy to the parents or guardians of children with disabilities or chronic illnesses**
- ✓ **Lack of knowledge was cited frequently as a reason preventing discussion of information regarding disability specific nutrition therapies**

Preliminary Findings

Hierarchy and History:

- ✓ **60% considered it very important or important to discuss disability specific nutrition therapies for physical, neurological and chronic diseases**
- ✓ **Respondents from agencies that did not recommend nutrition therapy consistently rated the importance of discussing nutrition information lower**
- ✓ **Eastern state agencies were less likely to recommend disability specific nutrition therapies**

Conclusions and Next Steps

- ✓ **Observed reliance on medical professionals and established (not necessarily most proven) scientific evidence**
- ✓ **Consistent sense that it was important (or at least not unimportant) to communicate information about disability specific nutrition therapies**
- ✓ **Data collection will conclude in July 2004**
- ✓ **Environmental scan of selected agency websites**