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

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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