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Reducing Health Disparities for Adults with Developmental Disabilities: Exploration of Health Promotion Services, Systems and Strategies in Bernalillo County

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Background

Health disparities experienced by adults who have intellectual and developmental disabilities (I/DD) are influenced by personal and environmental factors and include increased incidence of obesity, diabetes, heart disease, oral diseases, polypharmacy, iatrogenesis, social isolation, less active lifestyles and poor nutritional habits. Health practitioners receive little training about the health habits and potential of adults with I/DD. Limited access to transportation, 70% unemployment and a poverty rate that is double that of the general population influence the health condition of adults with I/DD. To address these barriers, disability policy must recognize the desire of adults with I/DD to have the same choices and opportunities as anyone else and encourage wellness (Marks & Heller 2003).

In New Mexico, health and safety information about individuals served on the Developmental Disabilities Waiver Program is documented on the Individual Service Plan (ISP). However, there is no section on the ISP to systematically document common health indicators such as body mass index, diabetes status, or osteoporosis status (NMDOH DDSD, 2009a). Additionally, the state of New Mexico, the Metro Region and Bernalillo County do not have a formal system of cataloging health related information for individuals served on the DD waiver. In 2008, a non-scientific survey of ISPs, that included Bernalillo County revealed that only 22 of 47 surveyed ISPs had documentation of adequate team discussion of the person's health-related issues. (NMDOH DDSD).

Project Aims

Using a Community Based Participatory Research (CBPR) approach, the project partners worked to clarify the health promotion needs of adults with developmental disabilities, identify strengths and weaknesses of the current system, and develop an action plan. Through this action plan, community agencies and therapists would become empowered to address needs, build ongoing community capacity to respond to emergent health/wellness needs, and advocate for appropriate systems of care.

Project partners included UNM Occupational Therapy Graduate Program (faculty and students), ARCA, a community-based organization that has offered an innovative health and wellness curriculum to adults with I/DD since 2005, and RDH Occupational Therapy Professional Corporation (community-based therapists who work extensively with adults with developmental disabilities).

Study Design

Three focus groups conducted in the Spring of 2009 included ARCA staff members (health & wellness instructors, nursing, nutritionists, administrators, and group home staff) community therapists (OT, PT, SLP and BSC) and family members of individuals with I/DD. ARCA and RDH identified the purposeful sample of focus group participants. The principal investigator (Dr. Betsy Vanleit) facilitated the focus group conversations on the following three areas of inquiry:

1. How are health promotion interventions currently being provided to adults with developmental disabilities in Bernalillo County?
2. What are the factors that support the health and wellness of adults with DD?
3. What are the barriers to health and wellness of adults with DD?

The group format provides opportunity for member interaction and contains in-depth data about the process explored (Corring, 2001).

Data Analysis

Verbatim transcriptions of the focus groups were reviewed by project partners to identify recurring themes. Internal validity was ensured the process of member checking, in which all community partners verified the initial codes and keywords accurately reflected the transcribed data (Henderson & Rheault, 2004). A codebook was developed from common themes and keywords recognized by all community partners in the preliminary data analysis, inclusion and exclusion criteria, and sample quotes from the transcripts.

Sample Code-Book Data

Code	Keyword	Sample Text
Caregiver Modeling	Excitement	"You know, if the staff are motivated and hyped about it, a lot of times, the individuals will be too." (2/23/2009)
Financial Concerns	Grocery Budgets	"I think that money and staffing really affect what people eat." (4/15/2009)
Social Support	Social Motivators	"We all can find excuses for not choosing good lifestyle choices, and people with disabilities are no different than the rest of the population." (4/16/09)

Results

Transcript analysis and codebook development revealed a pattern of enabling and disabling factors influencing the health and wellness of adults with I/DD in Bernalillo County. Factors related to the individual (values, choices, abilities and understanding), direct supports (knowledge, modeling, motivation, values and financial concerns) and the larger social context (culture, policy, resources, marketing, service delivery access, and social norms) can be supports or barriers to wellness of adults with I/DD. A model of supports and barriers to wellness for the population of people is proposed. The model demonstrates the importance of the relationship between direct care staff and the individual and how contextual factors (both social and political) impact this fundamental partnership.

Recommendations/Implications for Practice

Direct care supports drive wellness for this population: provide training and help create buy-in.



More resources (time, staff, money) are needed in health promotion efforts for adults with IDD.

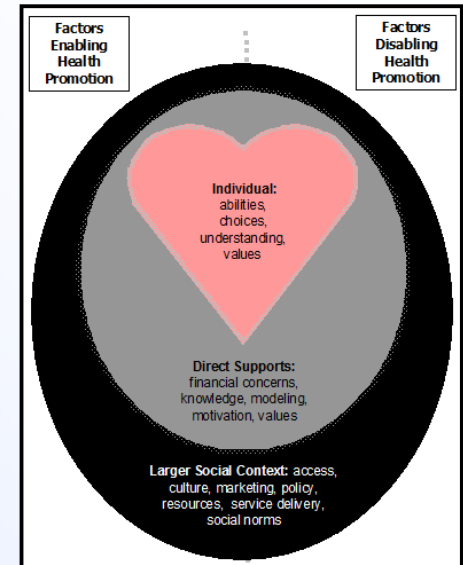
Make health promotion information available; make it fun; make it motivating.

Systematic surveillance instruments are needed in New Mexico to fully comprehend and address health promotion needs of adults with IDD.

There should be flexibility in direct care staff training so that specific skills can be applied to further promote health and wellness for adults with IDD.



Proposed Model



Bernalillo County Model

Factors of the individual, direct support and larger social context that may promote wellness, or may be barriers to wellness for adults with I/DD

Limitations and Future Research

There are several limitations to our study. The convenience sample of focus group participants was largely comprised of higher level professionals (therapists, medical staff, and administrative personnel) with family members and direct care staff members underrepresented overall. Future research should include perspectives from individuals served and more from direct supports. Additionally, future research should include viewpoints from a variety of community agencies and from representatives of the DD Waiver system itself.

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