

Living Well With A Disability

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Primary Goal

Explore how culturally competent service providers and a health promotion program that integrates the service sectors (medical, behavioral, prevention, rehabilitation, etc.) can be effective in reducing secondary disabilities and enhancing quality of life for people with disabilities, including minorities and underserved populations.

Learning Objectives

After this session participants are expected to:

1. Identify major health disparities experienced by people with disabilities;
2. Understand some myths and culture-based misconceptions that impact our interactions with people with disabilities, including foreign-born and minority consumers;
3. Help break barriers by learning what consumers have to say is “very important” in achieving access and culturally competent care or community services;

Learning Objectives continued

Participants are also expected to:

4. Discover an evidence-based health promotion program – ***Living Well / Vivir Bien***, that views health as a ‘means to an end’ and is effective in improving quality of life by reducing secondary disabilities; and,
5. Take away additional resources to help improve outreach to individuals and families who experience disability, including foreign-born and minority consumers.

Key Concept

A person with a disability IS ABLE to be healthy

Health ... is a complete state of physical, social and mental wellbeing and not merely the absence of disease.

Disability ... is a reduction in function, or need for assistance.

Key Concept

Disability is neither inability nor sickness...

- Most persons with disabilities are as healthy as people who don't have disabilities; however, persons with disabilities are at greater risk for illness and behavioral health problems, including substance abuse.
- Different kinds of disabilities affect people in different ways. The same kind of disability can affect each person differently.

Health Disparities

People who self-report disability also report:

- Poorer health
- Less use of clinical preventive services
- More difficulty in accessing needed health services

Foreign-born consumers and other minorities with disabilities experience cultural and language barriers as well.

Health Disparities

The major causes for disability in the U.S. are changing ***from medical to social and behaviorally-related conditions***. Increasingly these involve complications such as substance abuse, violence and poor mental health.

Note: Disability paradigms are also changing from the “medical” model to the “social” model, and more recently to the “environmental” model.

Health Disparities

People with disabilities have a risk of substance abuse (alcohol, tobacco and other drugs) that is 2-4 times that of the general population.

Risk factors include:

- Health problems and use of medications;
- Secondary disabilities i.e. chronic pain, fatigue, sleep disturbances, pressure sores, depression, etc.
- Societal enabling that undermines independence;
- Social isolation;
- Lack of regular physical activity;
- Lack of identification of potential problems;
- Lack of accessible and appropriate services.

Myth or Misconception

Some experiences from every day life:

- My doctor and other service providers seem to start with the assumption that because I have a disability I must not be healthy and, somehow I need to get “cured” or “fixed”.
- If I use a wheelchair I must need your help with a push. **WRONG!**
- If I use a wheelchair I must also be hard of hearing or have a learning disability.

Myth or Misconception

More experiences from every day life:

- If I carry a white cane or use a service animal I must also be deaf and not able to make my own consumer choices, like what to order in a restaurant.
- People with disabilities are not able to be productive and therefore have limited value in our society.

Double Jeopardy

Eliminating health disparities in one of two overarching goals in Healthy People 2010. This goal also applies to minorities with disabilities.

Having both attributes, *minority* and *disability*, creates a double jeopardy because of persistent racial and ethnic health disparities, cultural distinctions, prejudice, discrimination and economic barriers that are coupled with environmental and access issues. [CDC Minorities with Disabilities]

Myth or Misconception

Medical vs. Spiritual Paradigm

Medical Assumptions:

- Disability is a physical condition;
- Disability is an individual condition;
- Disability is a chronic illness;
- Disability requires a “cure” or “fixing”

Spiritual Assumptions:

- Disability is a spiritual condition;
- Disability is a group condition;
- Disability is a time-limited condition;
- Disability must be accepted.

Myth or Misconception

The Spiritual View and Culture-Based Beliefs:

- Disability is a punishment for past sins
- Disability is a condition to test your endurance
- A child with a disability is an act of God and is beyond human comprehension and ability to cure
- A child with a disability is an ancestor who came back to the family
- Taking care of a family member with a disability will clean your soul and your spirit

Myth or Misconception

Attitudes toward life events differ among various cultures; therefore, there are culturally – based attitudes of resignation and acceptance.

Passive attitudes of Hispanics and Asians should not be misunderstood and confused with lack of interest or feelings of guilt and resignation.

Myth or Misconception

Among the Asian cultures these challenges may be perceived as part of the family's "karma" before entering another level of existence.

For the Hispanic culture it may be perceived as "destiny" and an opportunity to become a better person.

The voice of physicians on barriers to providing better care

#1 Time

#2 Insurance issues

#3 Understanding /
comfort

#4 Lack of patient
interest

#5 Care coordination

#6 Communication
problems

#7 Lack of educational
materials

#8 Mental / intellectual
challenges

#9 Multiple
medications

The voice of consumers

Rated as “very important” in a national, cross-disability survey:

- Health insurance 95%
- Provider attitudes 89%
- Provider knowledge 81%
- Attitudes of clinic staff 76%
- Location of clinic 38%
- Aids and services 31%

The voice of consumers

Recommendations for culturally competent care

1. Please understand my health in the context of disability and my culture.
2. Help me find a provider that accepts my insurance and won't punish me or discriminate for "pre-existing conditions".
3. Help me minimize out of pocket expenses and co-pays. I want food on the table this week.
4. Help me find and use transportation to allow me to get to my appointments and access my community.

The voice of consumers

Recommendations for culturally competent care, continued

5. Schedule the time needed to listen and observe.
6. Demonstrate an attitude that shows me you really care.
7. Help reduce my “fear”.
8. Ask me! Do not assume or base actions on limited knowledge about what services I need.

The voice of consumers

Recommendations for culturally competent care, continued

9. Understand that I, or my family, may have limited communication skills to advocate for what I need.
10. Help identify and clarify the role of family support and our respective responsibilities, especially in a new and different culture.
11. Design accessible urgent care and physician offices with appropriate assistive technologies.

The voice of consumers

Recommendations for culturally competent care, continued

12. Increase your personal, professional and agency capacity to recognize people with hidden disabilities.
13. Encourage, and respect consumer choice.

The voice of consumer advocates

Recommendations for culturally competent care, continued

1. Utilize interdisciplinary, comprehensive care and include people with disabilities
2. Integrate strategies in service delivery to prevent secondary disabilities and/or provide early interventions
3. Develop capacities through service integration and culturally sensitive management.
4. Investigate models and adopt a framework for health promotion.

Framework for Health Promotion

GOALS

- Reduce disparities
- Increase prevention
- Enhance coping & resiliency
- Expand happiness

MECHANISMS

- Provide life skills training
- Foster self-care and empowerment
- Cultivate peer support / mutual aid
- Create healthy, accessible environments

STRATEGIES

- Advocacy
- Promote public participation
- Integrate healthy public policies
- Strengthen community services
- Encourage Cultural Competency

Living Well with a Disability

Vivir Bien Con Una Discapacidad

A research-validated health promotion curriculum designed to prevent secondary disabilities and minimize unnecessary use of costly health care services



A Different View of Health

Living Well helps participants
come to view one's health as
'a means to an end'
rather than
health for its own sake.



SMILE's primary targets for Outreach

- Adults with physical disability or chronic health problems
- Un/underserved populations including mono-lingual Spanish
- Un/underserved rural communities i.e. La Paz County
- Un/underserved youth – under 18 years of age

Living Well Basics

Living Well With A Disability:

- Developed by University of Montana Rural Institute on Disabilities, with funding from CDC
- Based on 16-hour structured curriculum
- Participants follow Living Well workbook
- Materials also available in alternate formats – large print, Braille, audio tape, CD/text
- Workbooks available in English and Spanish

Living Well Basics *continued*

- Sessions are peer facilitated
- Facilitator training available
- Low cost complement to traditional Independent Living core services
- Research validated and results demonstrated (evidence-based)

Major findings from original research:

- 12 – month follow up showed reductions in limitation from secondary conditions, reduced ‘symptom days’, and reduced health care utilization over the intervention period.
- Effects on secondary condition maintained for 12 months

Significant Depression at Baseline

Key Findings:

- Before Living Well / Vivir Bien more than one in three participants had symptoms of depression.
- Twenty participants completed both pre-test and post-test Beck Depression Indicator (BDI) surveys revealing nine significant findings.

Post test shows lower mean depression scores

59% Improvement – Mean depression score across 15 symptoms is significantly lower

- 71% Improvement – The number of participants who had to drop many of their activities and interests in previous month;
- 70% Improvement – Number who often felt bored;
- 100% Improvement – Number who were in good spirits;
- 67% Improvement – Number who felt happy most of the time;
- 71% Improvement – Number who felt helpless;
- 58% Improvement – Number who often felt full of energy;
- 80% Improvement – Number who felt their situation is hopeless;
- 60% Improvement - Number who thought most people were better off than they were.

Significant Ailments at Baseline

More than 25% of participants reported these ailments in pre-test:

- 27% - Arthritis
- 27% - Fatigue
- 26% - Circulation Problems
- 30% - Joint and Muscle Pain
- 27% - Isolation
- 40% - Sleep Problems and Disturbances

Post test using Montana Survey shows significant improvements

Key Findings - **Fewer General Ailments**

- 16% Improvement – Fewer injuries and reports of loss of sensation;
- 31% improvement – Fewer problems with contractures
- 30% Improvement – Fewer problems with sexual dysfunction
- 22% Improvement – Fewer problems with muscle pain
- 32% Improvement – Reduced feelings of isolation
- 22% Improvement – Fewer problems with anemia
- 36% Improvement – Fewer sleep problems and disturbances

Support for Living Well / Vivir Bien

- Cenpatico Behavioral Health Services of Arizona (from federal Substance Abuse Prevention & Treatment grant)
- Arizona Department of Health Services, Behavioral Health programs (SAP grant)
- United Way of Yuma County
- SSBG Locally Planned (WACOG) with DES - Orientation & Adjustment to Disability

Contact

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Conclusion

All professionals engaged in planning, delivery and evaluation of health and human services must have as core value enhancing quality of life for the consumer and his/her family. Ongoing study and efforts to become and remain culturally competent play an essential role in our profession across all sectors.

Therefore, it is vital that we gain a better understanding of the implications of chronic illnesses, disabilities and secondary conditions, listen to the voice of consumers and apply a framework for health promotion to our daily practices.

Living Well / Vivir Bien

Thank you
Questions?

