Promoting Self-Determination in Health

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This dedicated community [of people with intellectual disabilities] can teach us a great deal.... Perhaps the greatest lesson is that as a society we have not really been listening and paying attention to them.... Just as important, we have not found ways to empower them to improve and protect their own health. No one who cares would suggest this is acceptable.

(U.S. Public Health Service, 2002, p. v.)
The Surgeon General’s Call to Action to Improve the Health and Wellness of Persons with Disabilities

- Good health is necessary for persons with disabilities to secure the freedom to work, learn and engage in their families and communities
  
  - Goal 3: Persons with disabilities can promote their own good health by developing and maintaining healthy lifestyles

  (U.S. Department of Health and Human Services, 2005)
Why is Promoting Self-Determination in Health Important?

- Active Involvement vs. Passive Involvement
- Self-Selected vs. Other-Selected Goals
Sources of Health Disparities

- **Health System Factors**
  - How health care is financed and structured and how health promotion activities are designed and delivered

- **Patient Level Factors**
  - How well people understand and have the necessary supports to follow through on health promotion activities and medical advice

- **Patient/Provider Communication Issues**
  - How effectively the person can communicate their health needs and develop a trusting relationship with their provider
  - How willing providers are to support people to be actively, rather than passively, involved in decisions related to their health
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- Information
- Motivation
- Skills
The adoption of a healthy lifestyle requires skills and knowledge that need to be linked to an understanding of health. This understanding, developed through education, can then be used to formulate attitudes and values, which subsequently form the basis up on which individuals can take responsibility and begin to self-regulate their own health behaviors. As a result individuals can undertake a range of actions that they believe improve their health.

(Jobling, 2001, p. 313)
Promoting Self-Determination in Health

- Self-Regulation of Behavior
  - Goal Setting
  - Self-Monitoring
  - Self-Evaluation
  - Self-Reinforcement
Self-Determined Learning Model of Instruction

Set A Goal

Take Action

Adjust Goal or Plan

Wehmeyer et al. 2000
Phase 1: Set A Goal
What is my goal?

4 Questions:

1. What do I want to learn?
2. What do I know about it now?
3. What must change for me to learn what I don’t know?
4. What can I do to make it happen?
Phase 2: Take Action
What is my plan?

4 Questions:

1. What can I do to learn what I don’t know?
2. What could keep me from taking action?
3. What can I do to remove these barriers?
4. When will I take action?
Phase 3: Adjust Goal or Plan

What have I learned?

4 Questions:

1. What actions have I taken?
2. What barriers have been removed?
3. What has changed about what I don’t know?
4. Do I know what I want to know?
Integrated View of Health and Healthy Lifestyles

- Physical
- Emotional
- Social
What we can do...

- Increase our attention to issues of self-determination in health
  - How can we support consumers to learn more about their health, participate in health promotion activities, and better understand the relationship between their behaviors and their health?

- Advocate for more health promotion and health education materials designed with the needs of people with intellectual and developmental disabilities, and their support providers, in mind

- Foster collaboration between people with disabilities and their families and support providers, professionals in the disability field, and professionals in the medical and public health fields