

HealthyME HealthyU, a training program for individuals with disabilities

Presented by

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The logo for HealthyME HealthyU is displayed on a black rectangular background. The word "Healthy" is written in white, "ME" is in green, and "Healthy" is written in white again, with a yellow smiley face "U" at the end.

**HealthyME
HealthyU**

Background to the Project

- Among Alabamians of all ages, an estimated 741,500 (16%) had some type of disability in 2008

Three primary disabilities

- ambulatory (10%)
- independent living (7.6%)
- cognitive (6.7%)

- This project addressed the Developmental Disabilities Assistance and Bill of Rights Act and ACDD federal outcome to *support training and policy development in healthcare issues for consumers and health care professionals*



Project Purpose and Methods

To educate...

1. Individuals, families and caregivers about personal health management
2. Professionals, individuals and caregivers about effectively utilizing digital health information
3. Medical community about best practices regarding access to health care for persons with disabilities

Project Framework

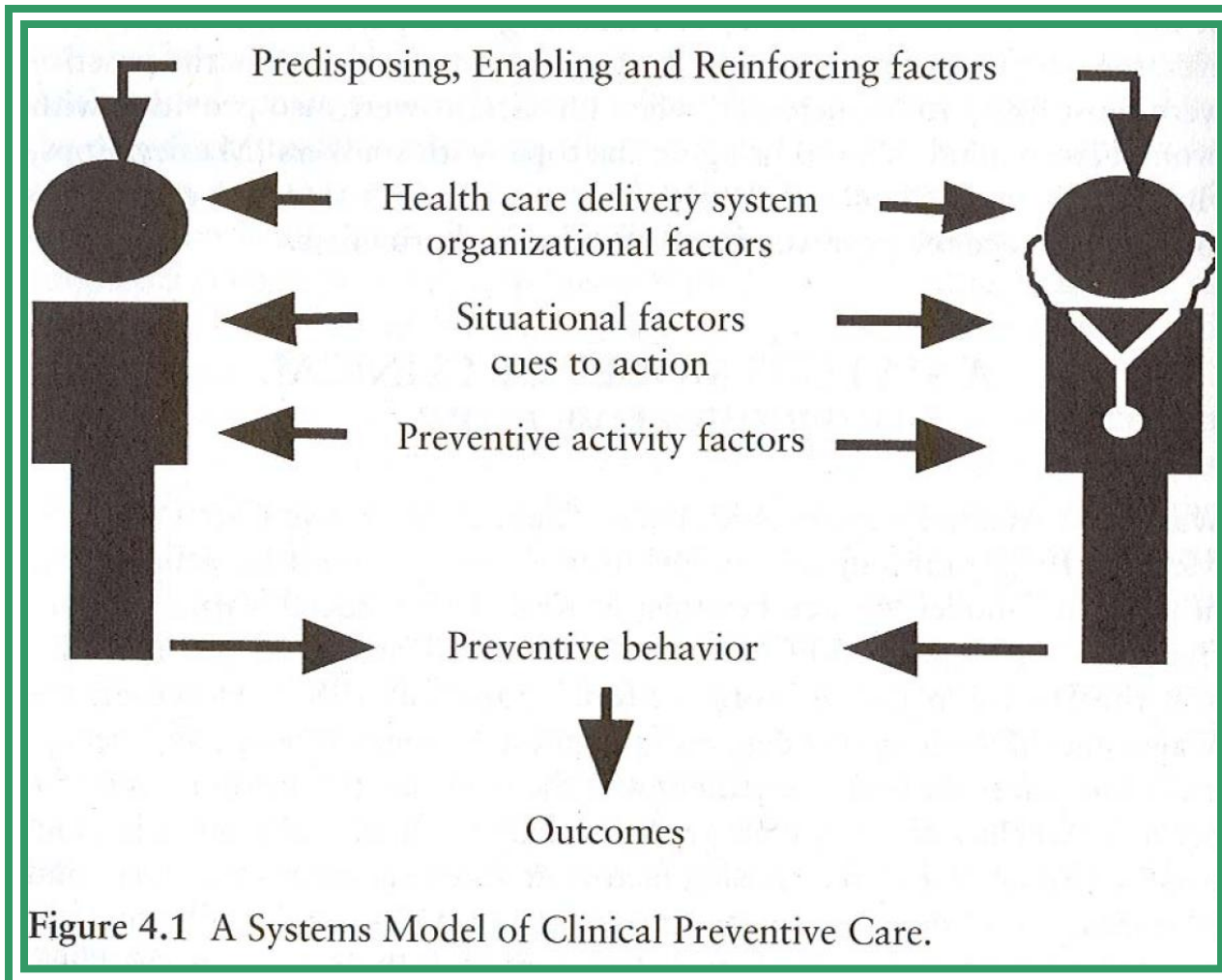
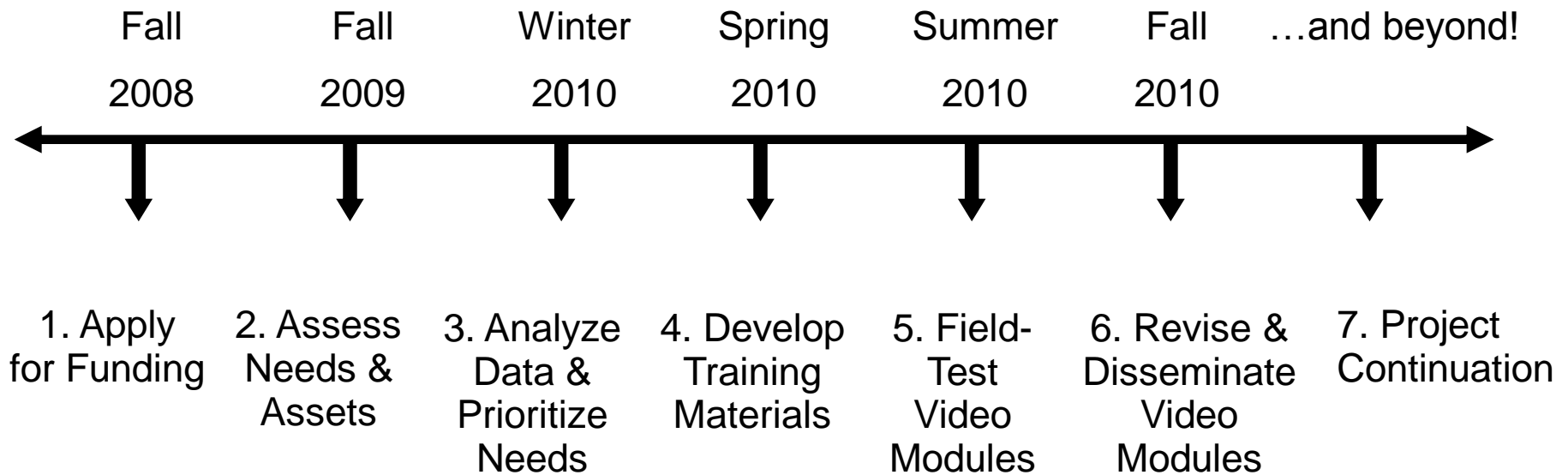


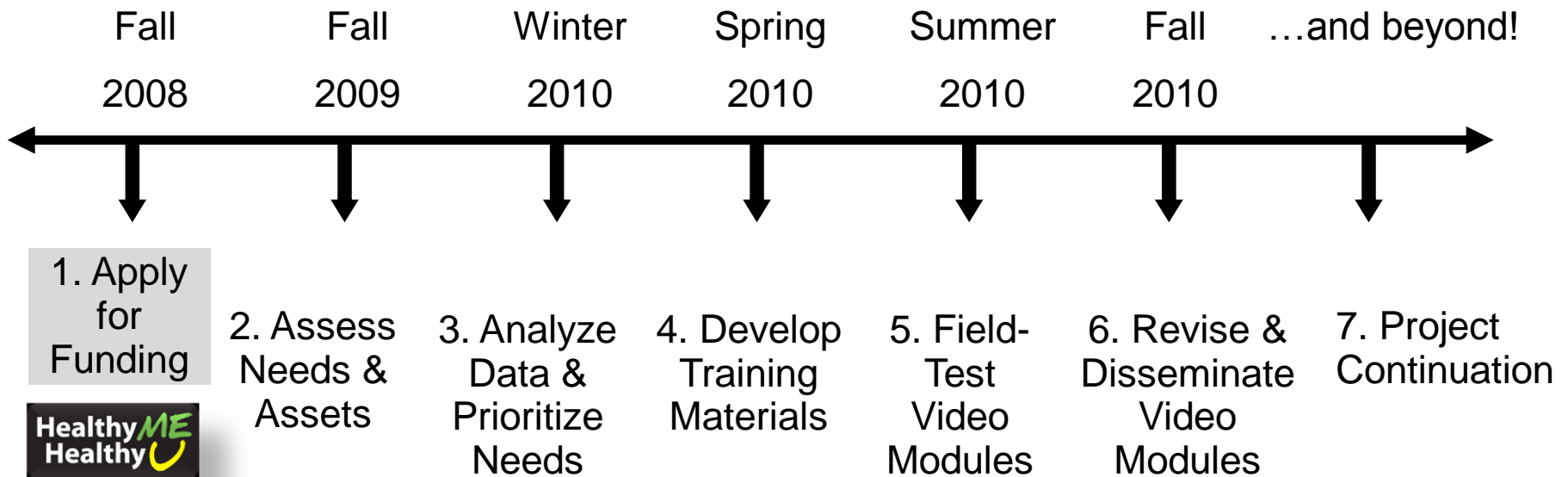
Figure 4.1 A Systems Model of Clinical Preventive Care.

Walsh JM and McPhee SJ. A Systems Model of Clinical Preventive Care: an analysis of factors influencing patient and physician. *Health Educ Q* 1992;19:157-75.

Project Timeline & Methodology



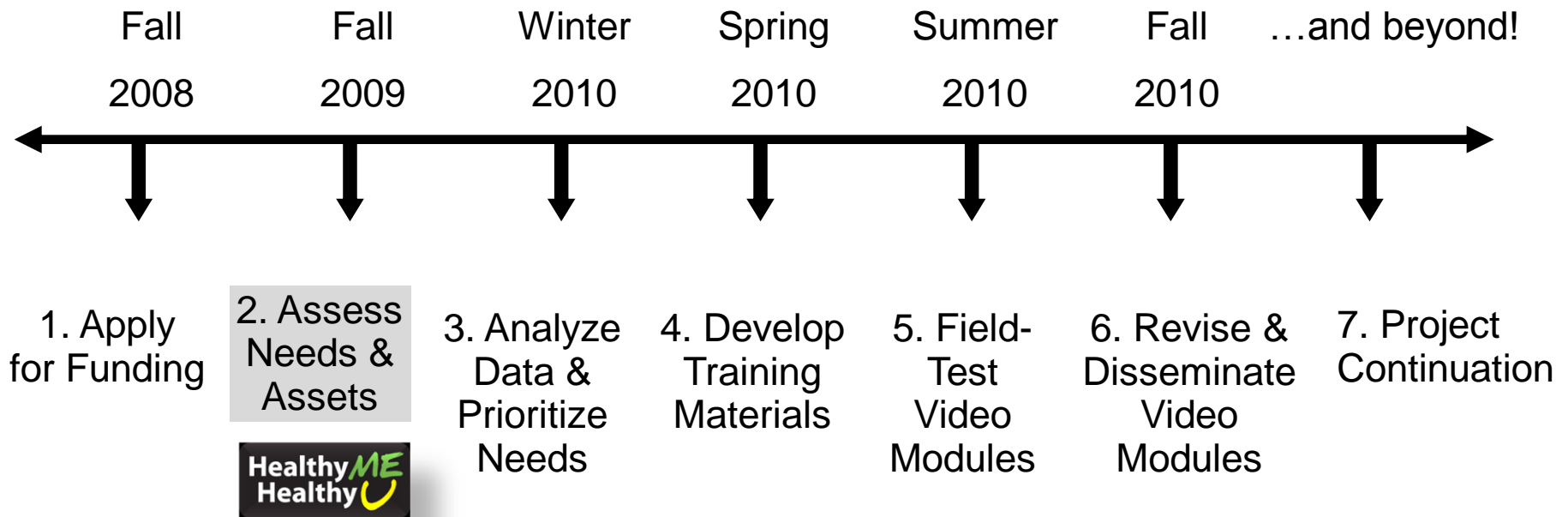
Project Timeline & Methodology



Step 1 – Apply for Funding

- ACDD rfp *to develop best practices for medical education about modifications for improved access to healthcare by individuals with disabilities and to develop and provide training modules to educate the medical community regarding accessibility and healthcare issues*
- \$50K award to UCP of Greater Birmingham with UAB and others as collaborators, 2008-09

Project Timeline & Methodology



Step 2 – Assess Needs & Assets

- Convened two groups of project advisors
 1. Professionals - researchers, clinical service providers
 2. Consumers & Family Members
- Identified health information and service needs
- Guided development of assessment instruments for four audiences
- Considered existing instruments

Step 2 – Assess Needs & Assets

Selected four key constructs from NCI's **Health Information National Trends Survey (HINTS) 2007**
Annotated Version

1. *Seeking Information About Health* (Access to Information)
2. *Ways You Might Get Health Information* (Internet Use)
3. *Your Use of Health Care Services* (Health Care Access and Use)
4. *About You and Your Household* (Demographics)

Step 2 – Assess Needs & Assets

Developed parallel items for **4 audiences**

- a) Clinical service providers
 - b) Consumers
 - c) Families and other caregivers
 - d) Health professions students
- Reviewed and revised content and format
 - Translated by native Spanish speakers who are health professionals
 - Reviewed and revised content and format

Step 2 – Assess Needs & Assets

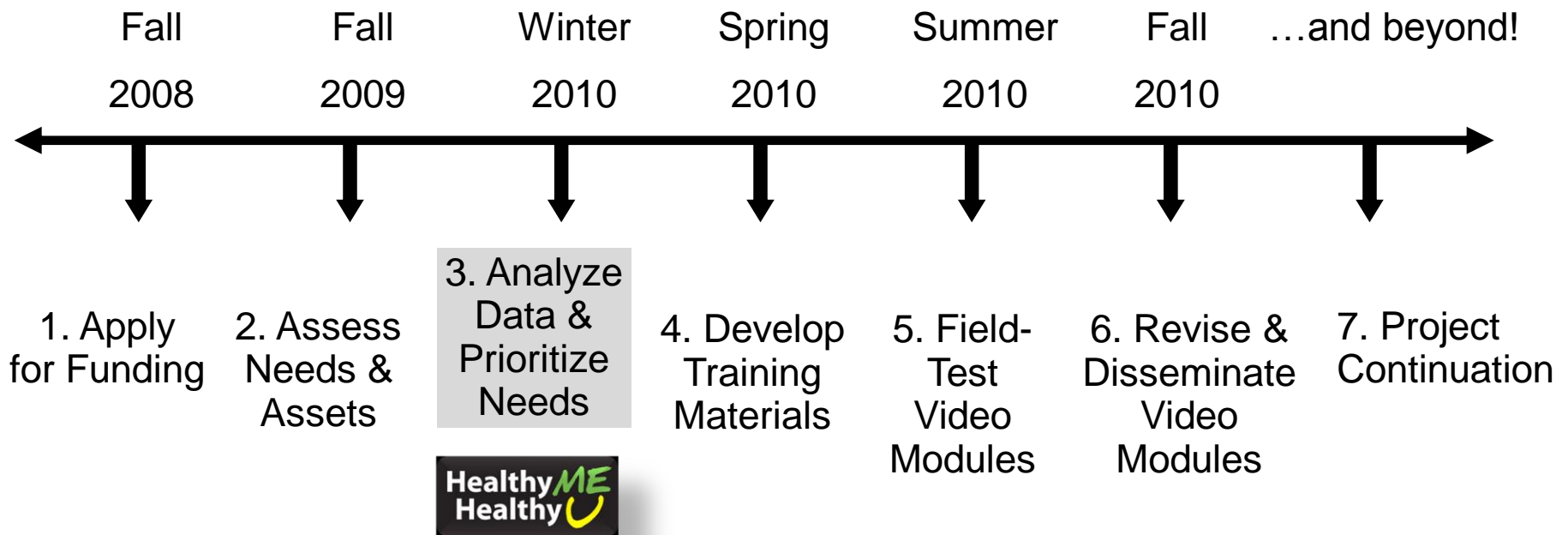
Number of Survey Items by Category and Audience

Item Category	Consumers / Caregivers	Service Providers / Students
Demographics	6 and 11	6 and 5
Disability Characteristics	13	11
Internet Use	31	24
Health Care Access & Use	16	1
Quality of Care	24	10
Access to Information	18	19

Step 2 – Assess Needs & Assets

- Administered surveys through universities, state and nonprofit agencies serving clients with disabilities
 - Posted survey links on agency websites
- Telephone administration
- Electronic and print PSAs
- Administered surveys in person during
 - preservice university classes
 - local and state meetings of professionals and families
 - consumer health screening events (*Special Olympics of Alabama*)

Project Timeline & Methodology



Step 3 – Analyze Data & Prioritize Needs

- **Disability Caregivers (n=251)**
- **Individuals with Disabilities (n=87)**
- **Clinical Service Providers (n=110)**
- **Health Professions Students (n=570)**



Step 3 – Analyze Data & Prioritize Needs

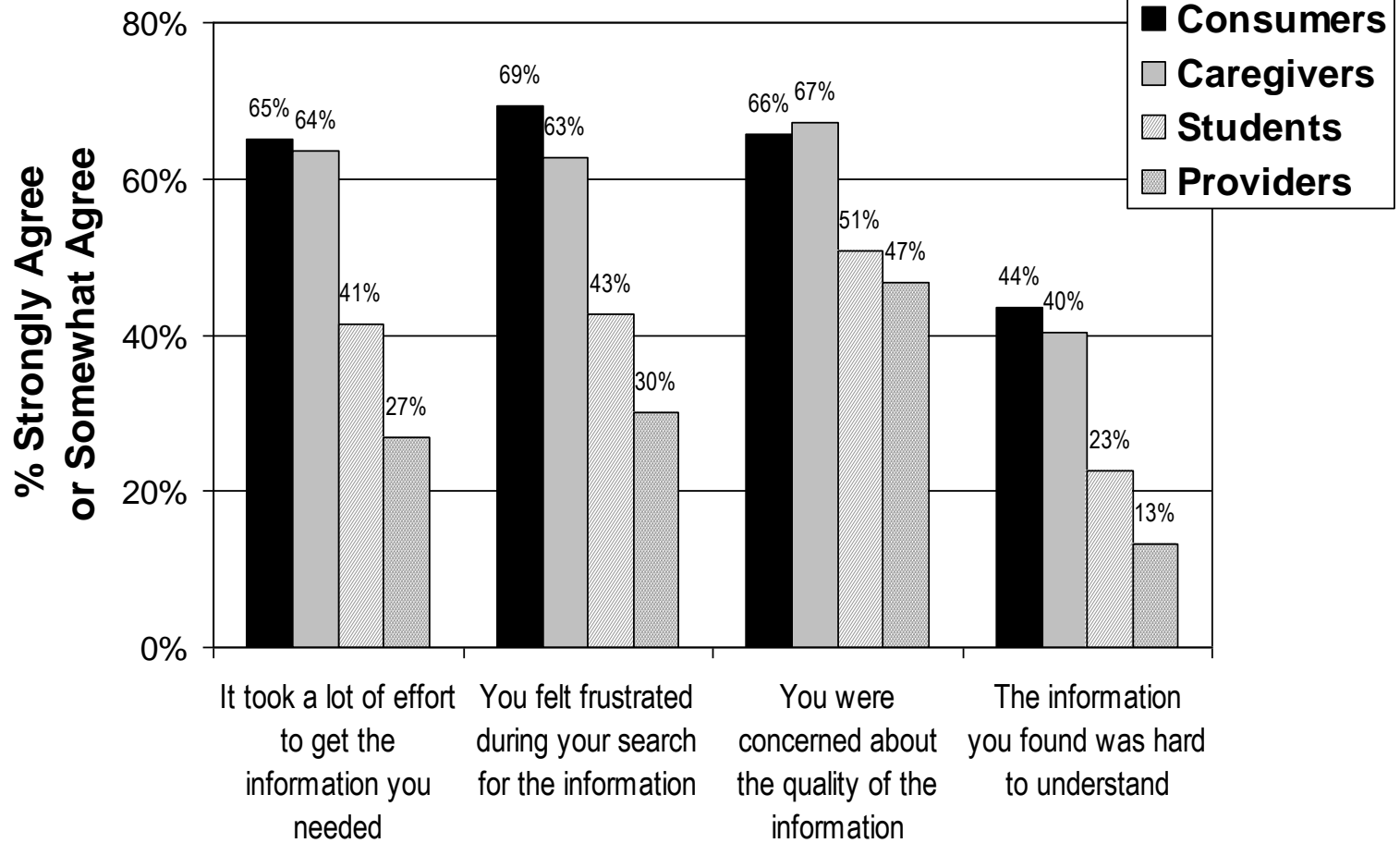
- Convened 4 interest groups to review results
 - **Health service providers**
 - **Families, caregivers and individuals with disabilities**
 - **Students in health service professions**
 - **Digital health information accessibility**
- Identified most common practices and perceptions across respondent groups

Step 3 – Analyze Data & Prioritize Needs

Facilitated discussion about data

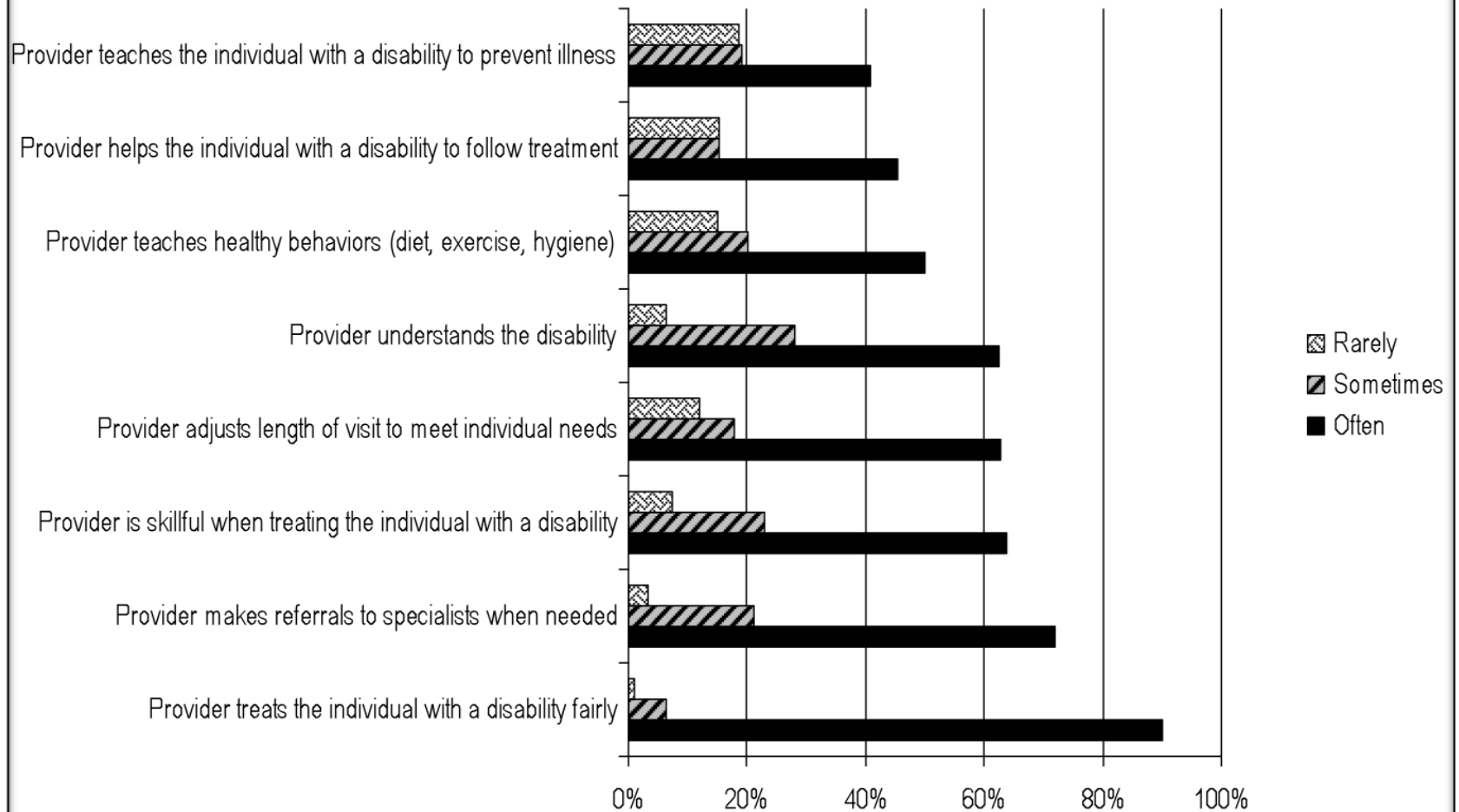
1. **Reviewed results** applied to interest group
2. How to use data to **plan training** for each audience
3. **Identified potential talent** (clinicians, consumers, medical librarian, radio announcer)
4. **Identified field testers** of training modules

Searching for Health Information



Items and Groups

Perceptions of Family Caregivers (n=227)



Step 3 – Analyze Data & Prioritize Needs

List 3 high priority training needs for treating individuals with developmental disabilities

Health professions students' responses:

- 1) Understanding disabilities (n=110)
- 2) Communication issues (n=100), including general patient (n=84) and provider-to-caregiver (n=16)
- 3) Teaching patients self-care (n=73)

Selected Responses - Student Training Needs

- “I need clear guidelines about the differences in treating a patient with a certain disability vs. a *normal* patient” (emphasis added)
- Learn to be “comfortable with accommodating disabled patients”
- “Need information about accessibility, common disorders, etc.”
- “Comprehension and understanding between the individual (patient) and you”
- “Learning how to communicate effectively with patients who have some baseline MR”
- “How to involve the caregiver in the conversation without having so much say that the patient's concerns are overruled”
- “Developing age appropriate materials for developmentally disabled people”

Selected Responses - Student Training Needs

- “Helping us (to) understand the best way to care for these patients”
- “How can we set up a team approach in our practice once we are done with residency?”
- “Learning specific challenges unique to each disabled patient”
- “Maybe a pocket guide with a summary of disorders would be good to have to pull out to refresh your memory real quick when you have a special needs patient”
- “Provide health care providers with concrete examples of commonly encountered problems when treating an individual with a developmental disability”
- “Treating disabled individuals fairly and equally”

Step 3 – Analyze Data & Prioritize Needs

List 3 high priority training needs for treating individuals with developmental disabilities

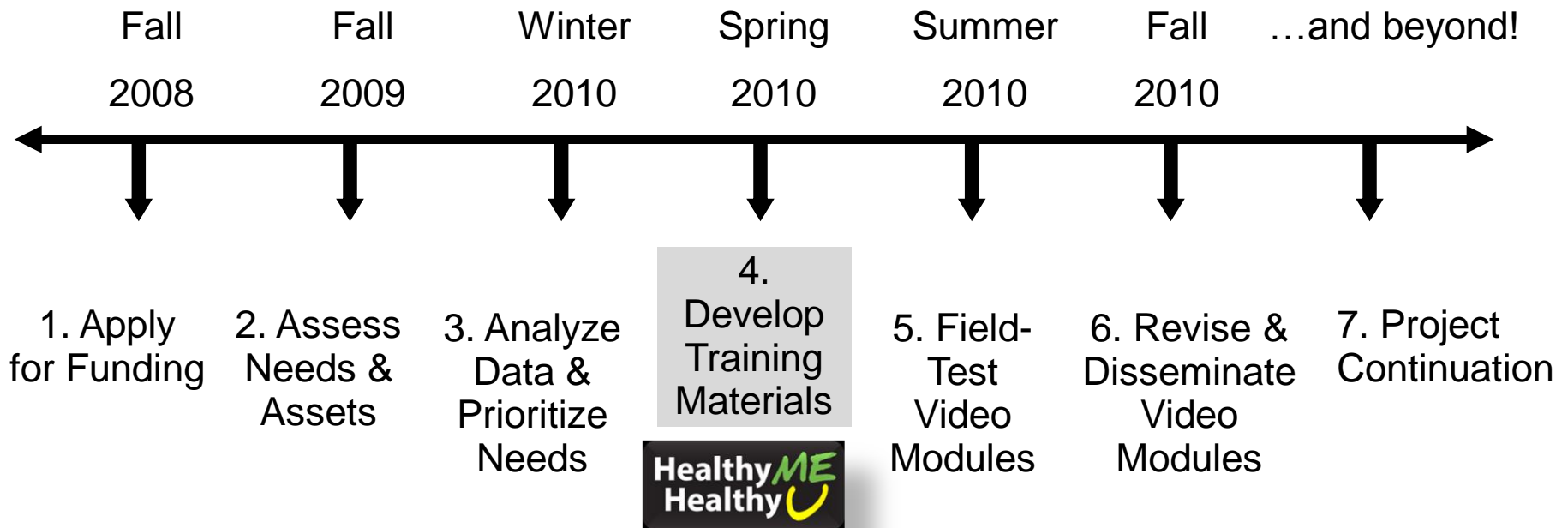
Service providers' responses:

- 1) Accessing resources and coordinating health services (n=45)
- 2) General training on disabilities, identifying and evaluating patient needs, and practice accommodations (n=42)
- 3) Communication issues (n=29)

Selected Responses - Provider Training Needs

- Understanding “family interaction/dynamics”
- “Learning to talk directly to them instead of *at* them or *about* them”
- “Proper use of ER and physicians”
- “Best practice of communication with other providers”
- “Understanding medical terminology/conditions/treatments”
- “View individual as a whole, not just their disability”
- “Education for all professionals who interact with individuals with developmental disabilities about the benefits of recommending and practicing only empirically-validated, evidence-based interventions”
- “Hands on experience while in professional training”

Project Timeline & Methodology



Step 4 – Develop Training Materials

- Drafted scripts for training modules
- Structured review by interest groups
 - 8 service providers and health professions students
 - 8 consumers with disabilities
 - 8 family caregivers
- Rated items about Informational Content and Presentation Format using Likert-type scale (Strongly Agree to Strongly Disagree)
- Explained ratings in writing and orally

Completed Modules & Transcripts

- Digital health information module
- Health services modules (2 titles)
- Consumer, family and other caregiver modules (3 titles)
- Each is 4-6 minutes, closed-captioned, with English language transcripts in regular and large font
- Consumer, caregiver videos have Spanish language transcripts
- Posted on UCP YouTube channel

Step 4 – Develop Training Materials

HealthyME
HealthyU

For consumers and caregivers...

Staying Healthy Between Doctor Visits

Offers tips to stay healthy between trips to the doctor or dentist

Staying Healthy Between Doctor Visits



Step 4 – Develop Training Materials



For consumers and caregivers...

Preparing to Visit Your Healthcare Provider

Discusses barriers that hinder people with disabilities from receiving timely, appropriate and complete medical care

Preparing to Visit Your Healthcare Provider



Dr. Rodney Marshall
General Dentist
Tuscaloosa, AL

Dr. Hanes Swingle
Developmental Pediatrician
University of South Alabama

Step 4 – Develop Training Materials



For consumers and caregivers...

Using the Internet to Learn about Your Health

Recommends sources of valid health information,
presented by a medical librarian



Step 4 – Develop Training Materials



For service providers and
health professions students...

Disability Etiquette

Effective first-person communication with those who
have disabilities and their caregivers



Step 4 – Develop Training Materials

HealthyME
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For service providers and
health professions students...

Practice Accommodations for Patients with Disabilities

Accommodations to meet consumers' needs



Step 4 – Develop Training Materials

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For service providers and
health professions students...

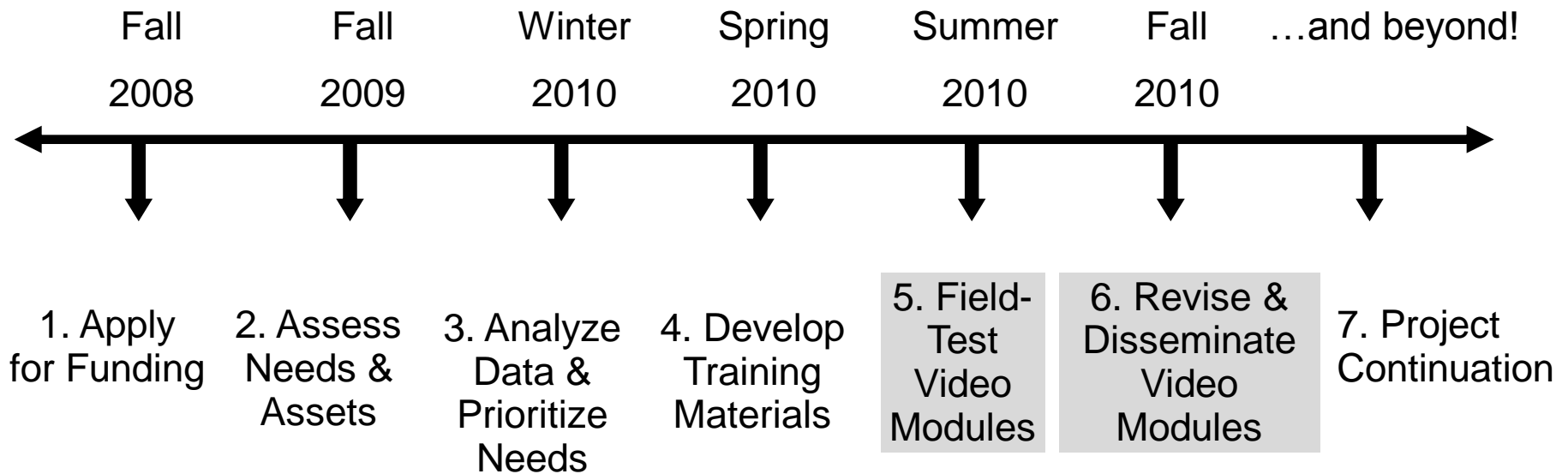
Preparing Patients with Disabilities for a Successful Office Visit

Advance planning for effective medical care

Preparing Patients with Disabilities for
a Successful Office Visit



Project Timeline & Methodology



Steps 5 & 6 – Field-test and Disseminate Video Modules

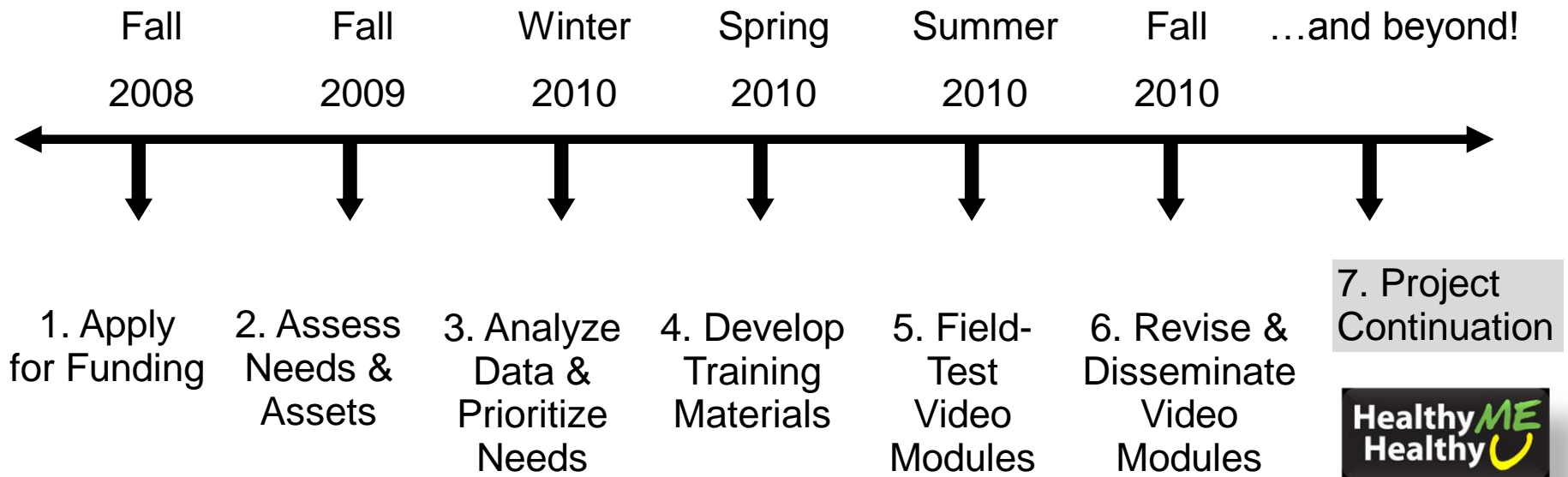
Field tested 6 modules with 162 consumers, coaches and family caregivers

Revised modules as needed

Disseminated modules, transcripts, links and methodology

1. Premiere public event
2. Faculty who educate health professionals
3. Professional organizations for service providers
4. National, State and local health agencies
5. Consumers, families and other caregiver groups
6. Scholarly papers

Project Timeline & Methodology



Step 7 - Project Continuation

- *Special Athletes: Building Strength and Endurance*
- *Special Athletes: Everyday Aerobics*
- *Special Athletes: Staying Fit and Healthy*
- *Special Athletes: Healthy Eating*



Step 4 – Develop Training Materials



For consumers and caregivers...

About Respite Care

(new title under development)

Purpose and uses of short-term planned and urgent respite for family caregivers



For More Information

Please visit: www.youtube.com/user/UCPBirmingham

Geiger, B.F., O'Neal, M.R., Firsing III, S.L., Hogan Smith, K., Chandan, P., Schmidt, A., & Jackson, J.B. 2010.

HealthyME HealthyU©, A collaborative project to enhance access to health information and services for individuals with disabilities. *J Health Comm: Internat Perspec*, 15 Suppl 3:46-59.

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