

Chronic Disease Self Management Education: Toolkit for Being Inclusive of Participants with Disabilities



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EXECUTIVE SUMMARY

The purpose of this document is to share best practices for planning, promoting, recruiting, and facilitating Living Healthy Chronic Disease Self Management Education Programs (CDSME) at Centers for Independent Living and/or with participants with disabilities.

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INTRODUCTION

Definition of a Disability

According to the Americans with Disabilities Act (ADA), a person is considered to have a disability if:

- i. Have a physical or mental impairment that substantially limits one or more major life activities
- ii. Have a record of such impairment
- iii. Are regarded as having such an impairment

Under this definition, most (if not all) of the participants attending a Chronic Disease Self-Management Education workshop may be considered a person with a disability.

Perspectives on Disability

The **social model** of disability (in contrast to the medical model) does not focus solely on the health condition of a person.

The social model defines a disability as a result of the limitation experienced in the context of the community and society in which the individual lives.

In simple terms, the environment needs to support a person's particular level of functioning; otherwise it is the environment that is disabling.

Some examples:

- It is not the inability to walk that makes a person who uses a wheelchair "disabled", but the fact that the person cannot enter a building with stairs and no ramp.

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- It is not the inability to read a health education handout that makes a person who is blind “disabled”, but the lack of accessible and appropriate alternative information sources for the individual (i.e. Braille, audio tape, large print, etc.)
- It is not the loss of hearing that makes the individual who is deaf “disabled”, but the lack of a qualified sign language interpreter who can enable effective communication.

Accessibility According to the the Americans with Disabilities Act (ADA)

The ADA was passed in 1990 and is a civil rights law that requires state and local government programs as well as places of public accommodation (any place or program open to the public) to be accessible to people with disabilities.

People with disabilities have the right to request reasonable accommodations according to the ADA. Reasonable accommodations can assist in removing barriers to participation for individuals with disabilities.

According to the ADA, barriers to serving individuals with disabilities must be addressed when:

- It is readily achievable to do so
- Barrier removal does not fundamentally alter the services offered
- Barrier removal does not pose a danger to others

Participants in CDSME workshops cannot be charged for barrier removal or reasonable accommodations, including sign language interpreters.

COMMUNICATION BASICS

People-First Language

A disability descriptor is simply a medical diagnosis; People First Language respectfully puts the person before the disability.

| Instead of Saying... | Say... |
|--|--|
| Disabled person, different-abled, challenged, handicapped | People/person with a disability |
| Handicapped (physical space) | Accessible (i.e. accessible parking space) |
| Mentally retarded/challenged | Person with an intellectual disability |
| Physically challenged | Person with a physical disability; person with _____ (i.e. Cerebral palsy, spina bifida, etc.) |
| Wheelchair-bound | Person uses a wheelchair |
| Autistic, learning-disabled | Person with autism, person with a learning disability |

DISABILITY AND CHRONIC DISEASE

According to the Centers for Disease Control and Prevention (CDC), 22% of adults in the United States have some type of disability, with rates of disability increasing with age. This may include a disability in mobility, cognition, independent living, vision, hearing, and/or self-care. While

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people with disabilities represent a diverse group, they are more likely to be obese, smoke, have high blood pressure, be inactive, and have not completed high school. This results in adults with disabilities being 3 times more likely to have heart disease, stroke, diabetes, or cancer.

Chronic Disease Self Management Education

The Chronic Disease Self-Management Education Program (CDSMP) was developed by Stanford University and is a two-and-a-half-hour workshop offered once a week for six weeks in community settings. People with different chronic health problems attend together, with the sessions facilitated by a pair of leaders. CDSMP workshops are designed to help people gain self-confidence in the ability to control their symptoms and learn how their health problems affect their lives. Subjects covered include: 1) techniques to deal with problems such as frustration, fatigue, and pain, 2) appropriate exercise for improving strength, flexibility, and endurance, 3) ways to manage medications, 4) communicating effectively with family, friends, and health professionals, 5) nutrition and healthy eating, and 6) techniques to problem solve and make decisions. In North Carolina, CDSMP is branded “Living Healthy.”

Research shows that CDSMP helps people with medical conditions such as diabetes, arthritis, and hypertension develop skills and coping strategies to manage their symptoms; and employs action planning, interactive learning, behavior modeling, problem-solving, decision-making, and social support for change. The health benefits of completing a CDSMP workshop include:

- Improved self-reported health
- Improved health status: fatigue, shortness of breath, depression, pain, stress, and sleep
- Improved health-related quality of life
- Improved communication with doctors, medication compliance, and health literacy

Accessible Recruitment Materials

Accessible recruitment tools and techniques are vital to promoting and recruiting the CDSME workshops.

Tips on how to make materials more accessible:

- Give the most important information first
- Choose words carefully – limit jargon, keep language clear and consistent, and use concrete examples
- Do not use fancy or script fonts, limit use of italics and underlines
- Use dark letters on a light background or vice versa (high contrast)
- Include pictures/images of people with disabilities on promotional materials

Consider sharing participation guidelines for interested participants, for example:

- Ability to tolerate being in a room with 8 or more people
- Ability to tolerate a 2 ½ hour workshop, with a break

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- Ability to stay focused on topics or activities
- Possess reading skills and/or be willing to be paired with another participant

Accessible Websites

Websites with CDSME recruitment materials should also be accessible (e.g., easy to read/understand, adaptable to screen-readers and other technology).

World Wide Web Consortium (W3C) Web Accessibility Initiative (WAI) has developed accessibility standards for websites and IT, and it has a comprehensive list of evaluation tools:

<http://www.w3.org/WAI/ER/tools/Overview.html>

Section 508 of the Rehabilitation Act sets accessibility standards for Federal government websites:

<http://www.section508.gov/summary-section508-standards>

COMMUNICATING WITH PEOPLE WITH DISABILITIES: GENERAL TIPS

Some overall tips include:

- Relax! Be yourself
- Be mindful of the language you use (see Person First Language)
- Keep it positive (don't say someone is a "victim" of a particular disability/condition or is "suffering")
- Treat adults as adults – don't speak in "baby talk" or talk down to the person
- Avoid over-asking participants with disabilities if they are okay or need anything
- Review the expectations and guidelines for the workshop so that participants know what is expected of them
- Study techniques for redirection and cueing the participants to stay on-task. This can include referring to the guidelines and information on the flipcharts, transitioning to new topics, and mentioning the need to stay on-task
- Consider ways to reduce distractions for the participants
- Be open to participants writing notes, coloring, playing with stress balls, and doodling
- Some participants may need extra attention during breaks and before/after workshop to review information or discuss action plans
- A caregiver can be invited to attend the workshop sessions if the participant desires it
- Be aware of the need to repeat items, talk slowly and distinctly, and use easy-to-follow language. Be sure to repeat brainstorming questions

Many of the following tips and strategies are the same across participants and disabilities, some people may have multiple disabilities as well. These are not hard and fast rules -- it is always best to ask the person how they prefer to communicate, how they identify, and what needs they may have.

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Interacting with a Participant with an Intellectual Disability

- Keep communication simple, using short sentences and completing one topic before moving on to the next
- Use repetition as needed
- Complete topics before moving on to the next subject
- Refer to charts when discussing topics
- If possible, provide information ahead of meetings in simple language – consider holding a “Session 0” prior to CDSME workshops to help introduce topics to participants who need preparation before attending
- Ask questions that require brief answers

Interacting with a Person who is Blind/has Vision Loss

- In advance of the workshop, ask if large print or an electronic or Braille version of documents is needed
- Always identify yourself and others in the group; take turns speaking
- When talking, say the name of the person to whom you are speaking
- Speak in a normal tone of voice
- Indicate when you are moving from place to place – don’t leave the room without saying you are leaving
- Be aware of lighting, glare, contrast, and magnification needs
- When offering directions, use descriptive language such as “left in 100 feet” or clock orientation such as “poster is located at 3 o’clock”
- When taking a break, describe what is available for snacks and offer to provide or describe where they are at, also describe where rest rooms are located
- Provide sighted guide services if needed
- If a person has a service animal with them, never pet or distract a working service animal

Interacting with a Person who is Deaf/has Hearing Loss

- Speak in a normal tone of voice
- In advance of the workshop, ask if an interpreter or devices such as a pocket talker is needed
- If they are using an interpreter, talk directly to the person who is deaf or hard of hearing, not the interpreter
- Let the person know if you cannot understand them; confirm that they can understand you as well
- Face the person to whom you are speaking, if you are writing a message, do not talk at the same time
- Be patient with lag times or delays
- Make sure you have the attention of the person before you begin communicating with them

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- Confirm with the interpreter and the participant the day before each workshop to be sure they are attending/providing services

Interacting with a Person with a Speech Disability

- Talk to people with speech disabilities as you would talk to anyone else
- Give the person your undivided attention
- Tell the person if you do not understand them
- Don't attempt to finish a person's sentences; be patient and let them finish their statements
- To obtain information quickly, ask short questions that require brief answers or a head nod
- You may ask the person to write down their answers or questions

Interacting with a Person with a Physical Disability

- If the individual uses any equipment (wheelchair, cane, walker, etc.), consider this an extension of the person. Do not touch, grab, or lean against a person's mobility equipment
- If the individual uses a wheelchair, do not push their chair without first asking if they would like to be moved
- Always ask if the individual needs assistance before you give it to them.
- Don't be afraid to use phrases like "run to the store" or "let's go for a walk"
- Be sure the space is arranged appropriately
- Allow for food and drinks to be within reach of seated position

RECRUITMENT AND ACCOMMODATIONS BEFORE THE WORKSHOP BEGINS

In reaching out to the Center for Independent Living, consider multiple approaches—participate in the agency's community events, request to present at a staff meeting, meet with interested staff members, and if invited, be willing to be a part of their events such as potluck dinners. Consider and share specific ways that the CDSME programs will meet the needs of those with disabilities. Past participants can be inspiring champions to encourage others to attend the workshops.

Often it can be helpful to have a "Session 0" to introduce the program to interested staff and participants. A Session 0 refers to a 30-45 minute presentation that reviews the objectives of CDSMP and facilitates some of the interactive activities.

When reaching out to interested participants, multiple calls may be helpful (an initial call to describe the workshop and a call the week of first class to remind of the workshop). It will also be important to be encouraging, as it can be very difficult for participants to be in new social situations.

Consider and share participation guidelines for interested individuals in advance, including:

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- Ability to tolerate being in a room with 8 or more people
- Ability to tolerate a 2 ½ hour workshop, with a break
- Ability to stay focused on topics or activities
- Possess reading skills and/or be willing to be paired with another participant

Access

Access starts before the workshop begins. As a part of the registration process, make it standard procedure to ask potential participants if they need accommodations. Not all individuals who fit under the ADA definition of a disability may identify as a person with a disability – however, you can still ask if there is any assistance or accommodations needed during workshop. You may not ask what a person’s disability is, although they may volunteer this information.

Be sure to visit the workshop site before it begins in order to identify accessibility of the front entrance and bathrooms, and the layout of the building. Accommodations can range from providing interpreters to simply moving furniture around a room.

Print Materials for People with Low Vision

- Text should have high color contrast with the background
- Large Print: Type should be a minimum of 16-18 point font
- Avoid fancy or narrow fonts like *this* or *This*
- Avoid using all caps. Use bold for emphasis
- Do not use glossy or shiny paper
- Do not use decorative fonts like *this* or *this*
- Shading and overlays can make reading difficult

Resources for print materials include:

“Simply Put, A Guide for Creating Easy-to-Understand Materials”
www.cdc.gov/healthliteracy/pdf/simple_put.pdf

Transportation

For many participants with disabilities, access to transportation is a significant issue. When possible, host the workshop at a facility that is on a public transportation route, including a Center for Independent Living. Be sure there are sidewalks or other smooth pathways to get to the building’s entrance.

Check to see what transportation options are available in the community and let participants know ahead of time.

Workshop Location/Space

When choosing a location for the workshop, some building features to look for include:

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- Accessible parking (parking spaces with designated signage and space beside the parking space for someone with a wheelchair or mobility equipment to enter and exit their vehicle)
- Curb ramps and flat surface/sidewalk to entrance
- Classroom on the first level or elevator access to higher levels
- Clear pathway/hallway to the classroom (at least 3 feet wide)
- A wheelchair accessible restroom (one stall or restroom that is at least 5ft by 5ft wide)
- Enough space in the meeting room/classroom for participants in wheelchairs or scooters
- Chairs and tables that can be moved/shifted around
- Reconsider using rooms that are really large or loud

Finding Interpreters

The NC Division of Services for the Deaf and Hard of Hearing has Regional Resource Centers:
<http://www.ncdhhs.gov/assistance/hearing-loss/regional-centers-for-the-deaf-hard-of-hearing>

They also have a directory of Sign Language Interpreters:

<http://www.ncdhhs.gov/assistance/hearing-loss/sign-language-interpreter>

Workshop participants cannot be charged for interpreters – this must be provided by the organization offering the CDSME workshops.

Service Animals

In North Carolina, a service animal is defined as a dog or a miniature horse. Service animals must be allowed unless doing so poses a danger to others or the animal is out of control (e.g. growling or barking, or if the animal is not housebroken).

Service animals are not pets, and they are also not comfort or therapy animals. Service animals are specifically trained to provide a service to a person with a disability.

Before a workshop begins (or if a participant shows up to a workshop with an animal), you may ask the individual:

1. Is this a service animal?
2. What tasks is it trained to perform?

If the answer is no/none, then you are not required by law to let the animal stay.

You may not ask the individual what their disability is or require documentation for the animal.

A service animal may or may not be wearing a vest designating it is a service animal.

Allergies or a fear of animals is generally not a reason to prohibit a service animal. Work with the participant to create a plan of action before workshop begins to address this barrier if it is present.

IMPLEMENTATION AND ACCOMMODATIONS DURING THE WORKSHOP

Remember to review the Guidelines for Workshop Participation and Agenda, as well as the need to keep the workshop moving. Describe that participants can get up and stand or move if they need to, as well as to use the restroom as needed.

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Placement of American Sign Language (ASL) Interpreters

- There should be a clear line of sign between the interpreter(s) and the participant who needs interpretation
- Let the ASL interpreter(s) and participant(s) sit where it is most comfortable/convenient for them
- Do not distract the interpreter(s) or ask them to perform tasks outside of their interpreter role

Accommodating Individuals with Intellectual Disabilities

- Review rules of the workshop at the start of every session
- Encourage caregivers or other social supports to help review materials between workshops
- Emphasize that action plans need to focus on self-management or health
- If someone is agitated, speak in a calm tone of voice. Repeat information if necessary
- Identify and meet with staff/caregivers if a participant is acting out or not understanding the activity goals

Physical Accommodations

- There should be a clear 36" wide path of travel to all areas of the room
- Paths of travel should be on smooth, flat, level surfaces. Be mindful of things like area rugs or carpet that can buckle and cause a trip hazard
- Chairs/tables may need to be moved around to make the room more accessible
- Food/drinks are placed within reach of a seated position. If an individual is blind or has low vision, you may need to describe what is available to them and assist them if they need it
- Provide assistive listening devices if needed
- Scent-free environments: Keep environments free from strong chemicals or fragrances that may cause a physical reaction in some participants

Facilitation Guidelines:

- Be sure to review the expectations and guidelines for the workshop, so that participants know what is expected of them
- Study techniques for redirection and cueing the participants to stay on-task. This can include referring to the guidelines and information on the flipcharts, transitioning to new topics, mentioning the need to stay on-task, etc
- Consider ways to reduce distractions for the participants. For example, in how the room is set up—windows have blinds down, not too much other noise outside of the meeting space. Also, be open to participants writing notes, coloring, playing with stress balls, etc
- Some participants may need extra attention during breaks and before/after workshop to review information or discuss action plans
- A caregiver can be invited to attend the workshop sessions

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- Be aware of the need to repeat items, talk slowly and distinctly, and use easy-to-follow language. Be sure to repeat brainstorming questions
- As much as possible, refer to visuals like the flipchart and book to complement the auditory learning and group sharing
- When describing the pieces of an action plan, focus on the specific questions of the action plan and refer to the flipchart paper
- Participants consistently express that they enjoy the group interaction and the tips and techniques

RESOURCES

Centers for Independent Living in North Carolina

<http://www.ncsilc.org/centers/>

An example of a Center for Independent Living, DisAbility Partners is a private, non-profit, community-based organization with the mission of partnering with individuals and the community to enhance, advocate for and support personal choices, independent living and community inclusion. They have resources for people with all types of disabilities, regardless of income. Services include: information and referral, independent living skills training, peer counseling, advocacy, social activities, community assistance, ADA (Americans with Disabilities Act) consulting, and an ADA resource library.

NC Center for Health and Wellness at UNC-Asheville – Healthy Aging NC Resource Center

<http://healthyagingnc.com/>

The North Carolina Center for Health and Wellness (NCCHW) anchored at UNC Asheville received funding through the Administration for Community Living to increase the number of older adults and adults with disabilities in underserved populations participating in the Living Healthy with Chronic Disease Self Management Education Programs and create the systems to embed these programs into an integrated, comprehensive, sustainable statewide network.

North Carolina Office on Disability & Health, Division of Public Health, North Carolina

Department of Health and Human Services

<http://www.ncdhhs.gov/assistance/disability-services>

The North Carolina Office on Disability and Health (NCODH) was a partnership effort between the Women's and Children's Health Section of the Division of Public Health and the Frank Porter Graham Child Development Institute. The mission of NCODH was to promote the health and wellness of children, youth, and adults with disabilities in North Carolina and to address health disparities experienced by persons with disabilities across the life span.

Centers for Disease Control and Prevention (CDC), Disability and Health

<http://www.cdc.gov/ncbddd/disabilityandhealth/people.html>

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The Centers for Disease Control and Prevention (CDC) has been involved in disability and health activities since 1988. The mission of the CDC Disability and Health Branch is to promote the health and full participation in society by people with disabilities across the lifespan.

National Council on Aging (NCOA)

<https://www.ncoa.org/healthy-aging/chronic-disease/>

The National Council on Aging (NCOA) is a respected national leader and trusted partner to help people aged 60+ meet the challenges of aging. NCOA partners with nonprofit organizations, government, and business to provide innovative community programs and services, online help, and advocacy. NCOA provides technical support and assistance to the CDSME grant program at UNC Asheville.



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