

A collaboration between the Michigan Arthritis Program and the Disability Health Unit at the Michigan Department of Health and Human Services.

Bringing PATH to People with Disabilities

A Practical Guide

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Part I: Frequently Asked Questions

The Stanford Chronic Disease Self-Management Program, or CDSMP (called Personal Action Toward Health, or PATH, in Michigan) was originally created for adults with chronic conditions. Research indicates that people who participate in the program report significant improvement in areas like fatigue, exercise, overall health, managing their symptoms, and communicating with their healthcare providers.

More and more, chronic diseases are impacting people at younger ages; and people with disabilities are disproportionately impacted by chronic health problems. In Michigan, people with disabilities are about three times more likely to have chronic diseases like arthritis, diabetes, heart disease, and depression. For this reason, it's important to make sure this population is not left behind when implementing PATH.

The Michigan Arthritis Program, the Michigan Disability Health Unit (both at the Michigan Department of Health and Human Services), and the National Kidney Foundation of Michigan have worked together to bring PATH to people with disabilities since 2008. This guide is an effort to consolidate and share the knowledge gained from these efforts. Part I is laid out in an easy to understand, question and answer format that reflects the questions most often asked by PATH leaders and program coordinators who are working with this population for the first time, and from disability advocates looking for an appropriate health promotion program. Part II offers specifics on how to make PATH workshops accessible and welcoming for people of all abilities. Part III provides guidance on implementing PATH workshops for people with intellectual or developmental disabilities.

What is a disability, anyway?

Very often, when we think of disability, we think of something visible: a person who uses a wheelchair, or someone with Down Syndrome. We've found it helpful to take a more functional view of disability. On our data forms, we ask two questions:

- Are you limited in any activities because of physical, mental or emotional problems?
- Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone?

For our purposes, a 'yes' answer to either or both of these questions defines the respondent as having a disability. If instead we asked, "Do you have a disability?" we would miss all those who have limitations because of their health, but don't identify themselves as disabled.

Is this a lot of extra work?

This is a question that would not likely be asked about the delivery of programs to people in other underserved populations, and yet people still ask it when it comes to people with

disabilities. The very first thing to understand is that *if you are offering PATH workshops, you are already serving people with disabilities*. PATH is for people who want to improve their health and manage an ongoing health problem. That means your participants are more likely to have a disability or some kind of limitation due to aging or their chronic conditions. For this reason, it's important to do all you can to make your program accessible and inclusive. (We'll talk about how in Part II of this guide.)

Reaching out to include people who would like to use to PATH to help manage a disability, or a disability in addition to a chronic disease, helps you fill your workshops. Equal access just makes sense, given the population PATH serves; but it's also the law. Everyone (*yes, everyone*) offering services to the public must make them equally accessible to people with disabilities. As a bonus, it's the right thing to do: you know you're serving the people who can benefit most from what you and PATH have to offer. And take heart – it won't be as much 'extra work' as you might fear.

What makes PATH appropriate for people with disabilities?

One of the things that makes PATH so useful is that it is not specific to any one condition. It offers participants skills and tools to manage the symptoms and difficulties that are common to nearly any ongoing health problem: for example, managing pain and fatigue, making decisions, or communicating with healthcare providers.

And while people with disabilities often have chronic conditions as well, the tools learned in PATH can easily be applied to managing the disability itself.

Isn't there a special program for people with disabilities?

We chose to implement PATH, a 'mainstream' health promotion program, in an accessible, inclusive way, rather than finding or creating a special program just for people with disabilities. This was a deliberate strategy on our part, and there are several reasons for it. First, there are many things about PATH that are already inclusive (more about that below), and the content, as explained above, was an excellent fit. There was already a strong implementation network for the program in place in the state – which meant we would be able to reach more people with disabilities than if we tried to start from scratch with a special program. At the same time, broadening the reach of PATH helps existing programs become more robust and sustainable. And people with disabilities have every right to participate in the same quality programs, like PATH, that are available to the general public. When they do, both people with disabilities, and people without, benefit.

Is PATH inclusive and accessible?

Many aspects of PATH are inherently inclusive. All of the content is delivered verbally in class; reading assignments are optional and the book is available on CD, so it's possible for non-readers and people with low vision to participate. Caregivers are welcome, and workshops can be made even more accessible if the leaders or coordinators follow a few simple guidelines. Part II of this guide will show you how.

Part II: How to create accessible, inclusive workshops

We're going to talk about both *access* and *accommodation*.

Access refers to the things you do for all of your workshops, to make sure there are no barriers to people with disabilities or other limitations.

Accommodation refers to things you do upon individual request, to make it possible for that individual to participate.

There are several components to making your workshops inclusive and accessible to people with disabilities. Below you'll find recommendations in each area, and there's a checklist in Appendix B to help you pull it all together.

Physical Access

Physical access is perhaps the most important, because if you can't get into or move around in a location, you can't take part. As a result, the location of your workshop is a priority. Here are things to look for.

Parking and approach. The parking, approach to the building, and entry must be accessible. This means there are accessible (handicap) parking spots available, and someone who uses a wheelchair, scooter or other kind of mobility equipment can safely get into the building and to the workshop location. The restrooms, break rooms, water fountains and phones must be accessible, as well as any other public features participants could reasonably be expected to use.

Workshop space. The room your workshop is in will have good lighting, be well ventilated, and have adequate space for a person who uses a mobility aid to get around the room. Consider leaving a few empty spaces at tables, to make room for people who use wheelchairs or scooters. The building's emergency evacuation plan should take everyone into account, and you should be able to post directional signs at regular intervals.

Logistics and recruiting

Make sure your location can be reached by local public transit. When you schedule workshops, be aware of the constraints participants have around public transportation. People who use public transit – most often seniors and people with disabilities – have less (and sometimes no) control over their arrival and departure times.

Avoid early morning events. People who use public transportation, or who rely on personal care attendants or caregivers to help get ready for the day, often can't attend in the early morning. If it seems appropriate, offer help filling out forms, but be sure not to start the workshop late because of it. Take scheduled breaks.

Consider promoting your workshops at disability advocacy and service locations. Or, just hold some workshops where the people are: like Centers for Independent Living (CILs), mental health drop-in centers, or senior centers.

Accommodation

Accommodation sometimes makes leaders nervous – they'd like to have a checklist and be able to be done with it all at once. But accommodation is different from access; it happens one person at a time. The good news is it's usually not complicated, and you don't have to be the one to figure it out.

Make asking about accommodations a part of your sign-up or confirmation process for new participants. If you have recruiting or sign-up materials, you can include a statement like:

If you need an accommodation to fully participate in this workshop, please contact Dana Smith at (555) 555-5555 or Dana.Smith@gmail.com no later than June 15.

Or, simply ask when you confirm a new participant's registration. You're doing this part for you; so you know what your participants' accommodation needs are, and have time to meet them, rather than scrambling once the workshop is already underway.

When someone does request an accommodation, just ask what they need. People are their own best experts in what works for them. Most are simple and low or no-cost.

Here are some examples of accommodations.

- Someone with a severe peanut allergy may ask you to be sure any snacks are nut free, and to ask the other participants not to open nut-based foods in the room.
- Someone with vision loss may ask to be seated in the front of the room.
- A person who uses an assistive listening device may give you a microphone to wear that amplifies your speech for him.
- A participant who needs a sign-language interpreter will often be able to tell you where you can find one.

Your participants are the ones experienced in living with their condition, and they will be able to tell you what they need from you.

Before you offer any workshops, know where to go to find sign language interpreters or CART providers. (CART is Communication Access Realtime Translation – it transcribes spoken words onto a video screen in real time).

If there is a cost involved in the accommodation, do I have to pay for it? The short answer is yes. All public and private agencies that provide services to the public are required to provide equal access. So don't wait for it to surprise you. Plan for this as part of your expenses. Include it in your program budget, or seek donations. You may find it helpful to set aside a certain

amount yearly as an interpreter or accessibility fund; then it's there if you need it. It's the cost of doing business, just like your charts and markers.

Communication Access

The things you do in a workshop to make it easy to see and hear aren't just for people with obvious vision or hearing disabilities. Your aging participants will appreciate them too. Many of us start to have vision and hearing deficits as we grow older, and sometimes we either don't realize it ourselves, or are hesitant to admit it to others. Most of these suggestions will be helpful for making sure everyone can concentrate on the content of your workshop, rather than on struggling to see and hear.

When you write during the workshop, on a flip chart or whiteboard or chalkboard – during a brainstorming session, for instance – speak everything you write. If you have agendas or charts on the walls, don't just point or refer to them. Make sure you read out everything on them. This might feel forced at first, but hang in there and it will soon come naturally.

Make sure that any written materials are simple, clean and easy to read. Write your charts and brainstorms in dark colors – black, dark blue, dark green. Stay away from yellows, reds and oranges, as these are the most difficult colors to see. Do the same with your recruiting materials, and take it easy on bold and underlining. Use one font, preferably a clean and simple one like Calibri (which is the font you're reading now), Arial, or another sans serif font. Sans serif means the letters don't have 'feet.'

Fonts with serifs, like Times New Roman, are not as easy to read.

Complex, small or unusual fonts like this one quickly cause visual fatigue.

When you're speaking in front of a group, use good general principles for public speaking. Don't speak with your back to the group. Don't put your hands (or anything else) in front of your face, or chew gum, and speak at a normal speed and volume. If one participant is brave enough to ask you to speak up, chances are others in the workshop are having trouble hearing you, too.

If there are interpreters or CART screens in your workshop, don't stand in front of them. If someone is using an assisted living device and has given you a microphone, speak into it every time you speak, and repeat participant comments or questions into the microphone too.

Environment

If you're providing food of any kind, know what the ingredients are. Participants with food allergies will need to know whether their trigger foods are present. Avoid wearing perfume, cologne or heavily scented products, and encourage participants to do the same. Consider using low-scent markers.

Service animals. Make sure that office staff and anyone else who comes in contact with your participants knows that service animals are welcome at your program site. Don't make

assumptions about service animals and the people they serve. Not all service dogs are the same size or breed, and they work for people with many conditions other than blindness. Many of these conditions are not visible, including diabetes, seizure disorders and mental illness.

Do not distract, feed or interact with a service animal. It is there to do a job. If another participant says they are allergic to animals, offer them a seat in the workshop farthest from the person with the service animal. You might also check for trash cans outside the facility entrance, near possible relief areas.

Disability Etiquette

You can't go wrong if you treat people with disabilities with the same respect you offer other participants. Here are a few guidelines.

- Don't single a person out publicly because of their condition, or make assumptions about a person's needs.
- Don't ask personal questions unless invited to do so.
- If you think someone needs help, offer – but then be prepared to respect the answer. The answer might sometimes be no.
- Treat mobility equipment as an extension of the person using it, and refrain from touching or moving it unless you're asked to, or unless you ask permission from the user.

People-first language. People-first or person-first language is a way of talking about people and conditions that puts the *person first*. In many ways you do this already: you refer to someone who *has* cancer, you don't say they *are* cancerous. In much the same way, you'll learn to refer to *people with disabilities* rather than *the disabled*. Why? Because people are so much more than their health conditions.

Like the language around racial and ethnic minorities, disability-related language has gone through some transitions in recent years. Using appropriate language isn't about "political correctness" – it's about simple respect. It's also about not telegraphing with your choice of words that you are years out of date.

Instead of...

Fred's asthmatic
Wheelchair bound
Mary is retarded
Dana is Down's
Gene is bipolar
She's brain-damaged

Say...

Fred has asthma
Wheelchair user
Mary has a cognitive disability
Dana has Down Syndrome
Gene has bipolar disorder
She has a brain injury

Avoid words like crippled or gimp. Also avoid the word retarded, in any context. (No, don't even say *has mental retardation*.) The R-word is very offensive to many in the disability community.

People-first language might feel contrived when you first start using it, but will become more natural as you become more familiar. A good rule of thumb is not to say anything about people with disabilities that you wouldn't say about a racial minority group.

Parameters for Inclusion

A Leader or Master Trainer is responsible for holding the needs of the individual in balance with the needs of the group. A guideline we've found useful is that anyone who can attend the workshop without disturbing the other participants may take part. Some examples of how this guideline might work in real life:

- A participant needs her ventilator device loudly suctioned by a caregiver during the workshop. A leader approaches during the break and asks them to do that outside of the workshop room.
- A participant begins wandering from the workshop due to dementia, and one of the leaders must leave the room in order to ensure the person's safety. The leaders speak to the caregiver who brings the participant to the workshop every week. They invite the caregiver to attend as well. If that is not possible, they will counsel that participant out of the workshop. The leaders are not able to ensure the individual's safety, and it is not fair to the other participants to have one leader consistently absent.
- Someone with a brain injury has angry outbursts. The leaders counsel the person out of the workshop, explaining that the outbursts have a chilling effect on the discussion for the other participants, and he is welcome to try another workshop once these are under control.

Sometimes there will be participants who, while they are not disturbing the workshop, seem to be participating on a limited basis. Leaders will occasionally ask, how do I know that participant is getting anything out of this? The answer is – just like with any of your other participants – you don't.

People, both with disabilities and without, participate in PATH at their own level and in their own way. Sometimes there is a visible 'a-ha' moment for a participant, or a noticeable change, during the workshop. But many times there isn't, and the skills and insights we promote may not take root until after the six week workshop has passed. Sometimes a great deal of change has taken place, but the participant is a reserved person and not comfortable sharing it. It can be a kind of arrogance to assume that change must take place on our timeline, rather than the participant's, and must happen where the Leader can see it. Our job as Leaders is to deliver this program to the very best of our ability...and then to let go of the outcome.

Fidelity

Often when people think about bringing PATH to a population of people with disabilities, they begin to ask about 'adapting' the program to fit the population. While this is understandable, it is important to understand that PATH is an evidence-based program. This means that when we deliver the workshop in exactly the way it is written (known as 'program fidelity'), participants

will receive the benefits of the program that are outlined in the research: better self-reported health, and many others.

Without adhering to program fidelity – not delivering the program as written, or adding or removing content - there is no guarantee participants will experience these benefits. True equal access doesn't just mean that there are people with disabilities sitting in your workshops; it means they get the same benefit from your workshops as everyone else. Fidelity and access are two sides of the same coin. *There is no equal access without fidelity.* We don't change the program – we accommodate the people.

Part III: Special Populations - People with Intellectual or Developmental Disabilities

People with intellectual or developmental disabilities (I/DD) can and do benefit from PATH workshops. The National Kidney Foundation of Michigan (NKFM) leads the way in offering PATH workshops for people with I/DD in our state, and based on this experience, offers the following guidelines when implementing the workshop in this population.

What is I/DD? According to [The Arc](#), people with intellectual disabilities have below average cognitive ability, and varying levels of limitation in carrying out everyday life activities. The most common conditions associated with intellectual disabilities are autism, Down syndrome, Fragile X syndrome, and fetal alcohol syndrome. Sometimes intellectual disability is referred to by the broader term, developmental disability.

Workshop logistics

Recruitment/location. As is true in many other populations, the most successful PATH workshops are often located in places the participants were going to be anyway, or already go to participate in other activities. Examples include apartment complexes or group homes, mental health drop-in centers, skill building workshops or outpatient clinics.

Workshop participants. While it is not possible to know who will most benefit from participating in a PATH workshop, the parameters for inclusion are similar to those discussed on page 8. Participants should be able to:

- Attend the 2 ½ hour workshop without disrupting the group (and tolerate being in a room with 12 or more people for that time).
- Stay reasonably focused on the topics and activities at hand.
- Read, or be able to be paired up with a participant or helper who can.

Workshop curriculum

The PATH curriculum is written at roughly an eighth or ninth grade reading level – with some sections at higher levels. This means workshop participants, with disabilities or without, may not be able to read the charts, or may not understand the material if it is presented from the manual word for word. Fortunately, PATH gives us the opportunity to paraphrase the manual in our own words.

When you paraphrase the material, use basic and descriptive terms, and use examples if you need to. You'll have a much easier time doing this if you are very familiar with the curriculum, and plan ahead of time what you will do if the participants don't understand something. Please see Appendix A for a list of the most commonly misunderstood words, phrases or concepts, as well as alternatives.

Specific Activities

Partnering. Throughout the workshop, you'll find activities that require participants to partner with each other in order to complete the activity. You may find some of these activities to be quite challenging for people with I/DD. You're likely to have more success if you encourage partnering between participants who have complementary strengths.

Making Decisions. This activity in session 3 is likely to pose fewer challenges for people with I/DD if you use an example from their daily life. ("Should I start this new medication" on chart 11 may be quite abstract for this population, and not extremely applicable for people whose medications may be dispensed by caregivers.) Consider using a white board with a different example (ask the group or staff for ideas, if necessary) that might be more relevant, such as "Should I move into independent living?" or "Should I get a job?"

Healthy Eating. Both the 'Healthy Eating' activity (session 4) and the 'Making Healthy Food Choices' activities (session 5) have parts that can be challenging for people with limited reading skills, and/or visual impairments. Be prepared to provide one on one assistance to participants when locating portion and food label information from the *Living a Healthy Life* book. In addition, when using 'real' food labels, people with visual impairments are likely to have trouble reading the tiny font on some food labels. One accommodation for people with visual impairments might be to take one of the food labels you use in case participants forget theirs, and enlarge the label portion.

Leader Training for People with I/DD

As is the case in many populations, participants are more comfortable and completion rates are higher if workshop leaders and participants are members of the same community. However, leader training can present challenges for people with I/DD. Currently, our most successful inclusion of people with I/DD as leaders has happened when delivering the program at a service agency for people with I/DD, and training both agency staff and consumers as leaders. The two leader format of PATH is ideal for this kind of inclusion, as workshops can then be delivered with one staff leader, and one leader who has I/DD. The following ideas can help ensure the success of the new leaders and the sustainability of the workshop:

- Make clear to the agency that staff being trained must attend all four days of the training, and partner the same staff member with the same person with I/DD throughout leader training. This ensures a training team who can review and practice together.
- In order to accommodate leaders with I/DD, it may be necessary to vary the format of the training. One accommodation provided was to make the training one day a week, for four weeks, to allow extra time for review and practice of assignments. It also reduced stress for the agency, in arranging for extra staffing and transportation for the participants.

Recruitment

Site recruitment. As mentioned above, the most successful workshops in this population have been located at advocacy and service agencies for people with I/DD. Workshops were piloted at the agency initially, and then staff and consumers were trained as leaders, leaving the agency with a sustainable workshop they could host according to their needs.

Leader training participants. Ideally, leader candidates will possess the following skills and characteristics:

- Past participation in a workshop
- Some level of ability to read and write
- Fairly comfortable pairing with others and/or working as a team
- Some level of comfort or interest in speaking in front of a group
- Willingness/ability to follow through attending the entire four day training
- Willingness to work on assigned practice lessons during the week between each training session

For the staff members, it's also helpful if leader candidates are flexible, enjoy working with people who have disabilities, and are willing to assist their partners with reviewing material and practicing teaching assignments.

If You Need Extra Help

If you have questions that have not been addressed here, please feel free to contact Alice Frame at the Disability Health Unit at FrameA@Michigan.gov.

If you need sign language interpreters, the [Michigan Online Interpreter System](#) can help you find one near you.

Acknowledgements

Many thanks to the National Kidney Foundation of Michigan, a longtime leader in bringing PATH to people with disabilities, and to the Oregon Office on Disability and Health, whose expertise was essential in the creation of the checklist.

Appendix A: Language and Paraphrasing

One of the most inherently flexible and accessible elements of PATH is the instruction in the leader manuals to ‘say in your own words.’ This allows leaders to make themselves clear to people of varying cultures and abilities. The first column in the table below includes words, phrases and concepts that, in our experience, people with I/DD have consistently not understood as written. The second column contains alternate words or phrasings that we have found to be more understandable.

As written in the manual	Suggested alternatives
We will be the <i>facilitators</i> for this workshop	Teachers, trainers, leaders
Chronic condition	Long-term health problem; health problem you have had for a long time
Acute condition	Health problem you have for a short time, like a cold or a broken arm
Health provider	Doctor, nurse
Self-management	Things you can do to take care of yourself and your health
Monitoring and reporting	Keeping track of how you have been feeling, to tell your doctor when you see him/her
Manage	Take care of, control
Fatigue	Feeling very tired
Listen attentively	Listen carefully
Self-defeating thoughts	Thoughts that keep you from doing what you want to do
Irrational thoughts	Thoughts that are not based on facts, thoughts that are not true
Clarify	Make sure you understand what was said
Confidence level (You may have participants who don’t understand the number concept attached to confidence level. When that happens, instead we ask...)	How sure are you that you will do your action plan? Are you very sure, or not so sure that you will do your action plan?
Brainstorm: What are some ways to deal with difficult emotions?	What are things you can do to help yourself feel better, when you have difficult emotions?
Brainstorm: What are some things that help us deal with fatigue?	What are things you can do to help yourself when you feel very tired?
Brainstorm: Can you think of any other tools that might help manage pain?	Can you think of anything else that might help you feel better if you have pain?

Appendix B: Checklist for Accessible PATH Workshops

Priorities for facility access

- Parking, approach and entry are accessible.
 - ✓ Non-drivers can get to the site using public transportation.
 - ✓ Accessible parking spots are available.
 - ✓ Someone using a wheelchair (or scooter or other mobility aid) can safely enter the building, and reach the workshop location, restrooms and any other public spaces.
- Workshop space is accessible.
 - ✓ Good lighting
 - ✓ Well ventilated
 - ✓ Ample space for a person using a mobility aid to navigate
 - ✓ A few empty spaces at tables to make room for people using wheelchairs or scooters
- Restrooms are accessible.
- Water fountains, pay phones and other public features are easy to access.
- Building emergency evacuation plans take everyone into account.
- You may post directional signs in useful locations, and at regular intervals.

Logistics and recruiting

- Be aware of constraints around public transportation; participants who use it may not have much control over their arrival and departure times.
- Offer assistance with filling out forms, but do not start the workshop late as a result.
- Avoid early morning events.
- Take scheduled breaks.
- Give clear verbal directions to restrooms and water fountains (avoid pointing or saying “over there.”)
- Consider promoting workshops at disability-related organizations.
- Include an accessibility statement during your sign-up or confirmation process. For example:

Do you require any kind of accommodation to fully participate in this workshop? If so, please contact (person responsible for making arrangements) at (phone number, email address, and TTY if used) by (date).

Communication

- If you have posters or agendas up during your workshop, or are writing on a board or a flip chart, verbalize everything you write.
- Know where to get sign language interpreters or CART (Communication Access Realtime Translation) providers.
- If there are interpreters or CART screens in your workshop, don't stand in front of them.
- Be prepared to address the issue of payment for interpreters or CART. Make sure to include this in your program budget, or seek donations.
- If someone is using an assistive listening device that involves you wearing a microphone, speak into the microphone *every time you speak*, and repeat participant comments into the microphone.
- Speak clearly at normal speed and volume, don't chew gum, and try not to block your face.
- Make sure the materials you prepare are simple and easy to read: avoid small or fancy fonts, excessive bold and underlining, and text in colors like orange, yellow and red.
- Be prepared to provide your materials in alternate formats, like large print or electronic. (Not many people require Braille anymore, but it doesn't hurt to know where you can go to have materials Brailled.)

Environment

- If you are providing refreshments, know what the ingredients are.
- Avoid wearing perfume, cologne, or heavily scented products and encourage participants to do the same.
- Use low-scent markers.
- If you will be taking pictures and must use a flash, warn people first.

Service Animals

- Make sure receptionists and front line staff know that service animals are welcome at the workshop site. Keep in mind that not all service dogs are the same size or breed, and not all disabilities are visible.
- Do not distract, pet, feed or interact with a service animal.
- If a participant says they are allergic to animals, offer them the seat furthest from the person with the service animal.
- Check for trash cans near possible relief areas outside the facility entrance.

Etiquette

- Do not single people out publicly because of their condition.
- Don't make assumptions about a person's needs – ask, and be prepared to respect the answer.
- Do not ask personal questions unless invited to do so.
- Understand and use people first language.