

Health Care for People with Disabilities

Health Promotion and Prevention
in the 21st Century

Agenda

- What is disability?
- Status of people with disabilities in Colorado.
- Health Care Needs and Issues for people with disabilities.
- Resources for People with Disabilities.
- Concrete things you can do to help people with disabilities live the best possible life.

Disability definitions

- The ADA defines disability as a substantial impairment in a major life activity. Covered under the ADA are people who are perceived to have a substantial impairment AND people with a history of substantial impairment. Section 504 (covers federal and federally funded agencies) has the same definition but it applies to “qualified individuals with disabilities”. A veteran is a qualified individual to receive services in a VA setting.
- There is no percentage of disability in the ADA
- Other definitions are generally related to specific benefits. For example the Social Security Administration defines disability based on the inability to engage in regular competitive work (SGA). In general as cash or health care becomes available the definition becomes more narrow.
- Congress clarified that mitigating measures may not be used to find someone not disabled for purposes of protection from discrimination. On the other hand, Social Security will at times consider the availability of mitigation when making a decision about disability and ability to work.

Number of Disabled People

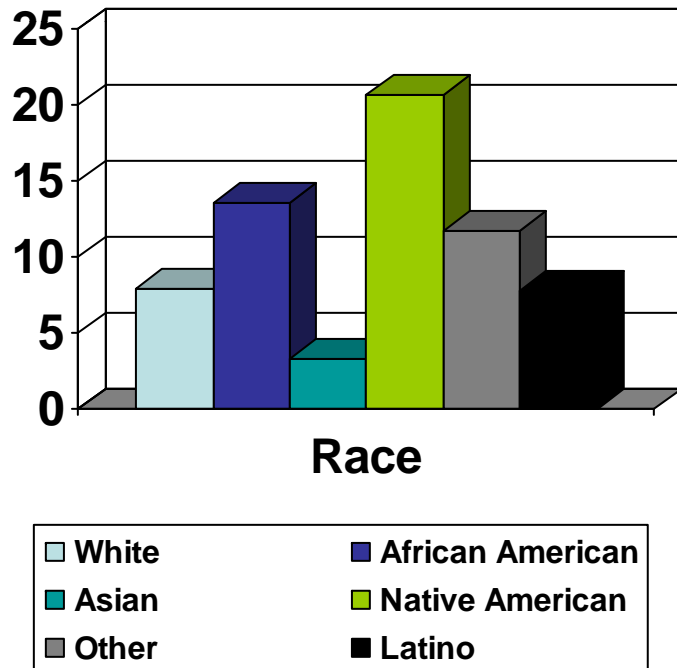
Depending on the definition the number might change.

Colorado has about

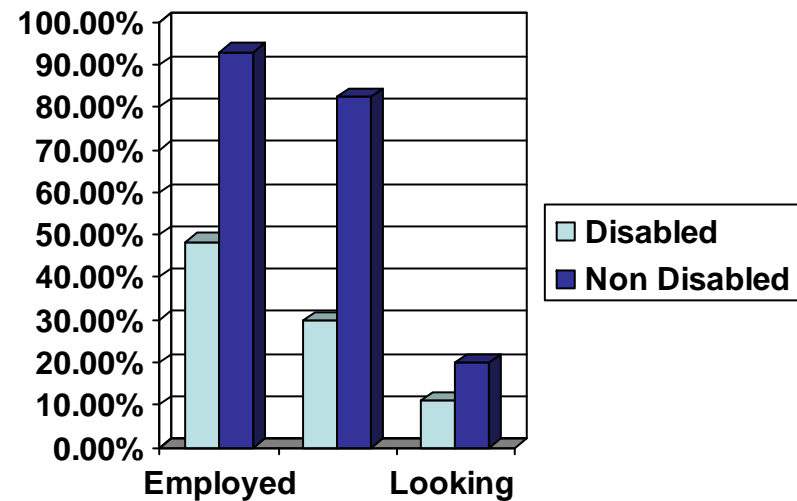
- ✓ % 9.9 of people with disabilities using the census or ADA definition. This is 458,800 people
- ✓ We have over one million handicapped parking tags registered—(remember not all disabled are drivers)
- ✓ 51,335 people under 60 receive Medicaid based on disability (meaning that they are unable to work or meet a “nursing home” level of care.
- ✓ 15,561 people of all ages are in Colorado nursing facilities

Disability Prevalence in Colorado

Disability Prevalance by Race



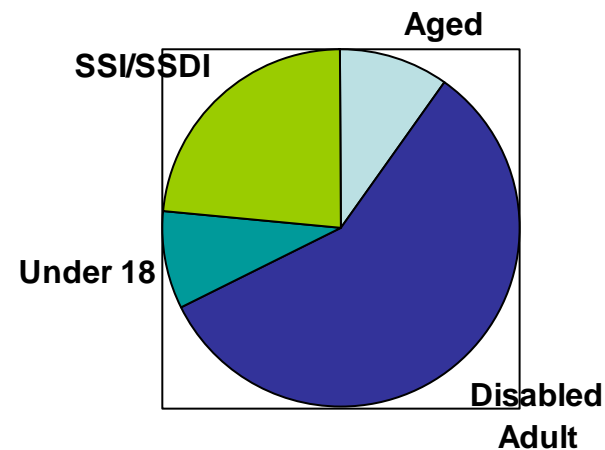
Employment Disparities



Social Security Statistics-SSI

- 13.8% of disabled population in CO is on SSI—in the following categories
- Aged 9,078
- SSI Disabled 52,970
- SSI Under 18 8,103
- SSI 18-64 38,919
- SSI 65+15,026
- SSI and SSDI 21,813

SSI Breakout by age



Social Security -SSDI

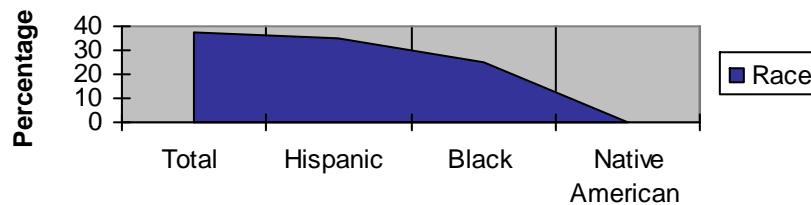
- 84,311 on SSDI in 2008
- Average SSDI amount \$1,063.80
- Median monthly payment \$982.40
- DAC (disabled adult children) 7,269 recipients who average \$690.20
- Disabled widow 1,878 recipients average \$694.20
- SSI FBR is \$674

Current work options

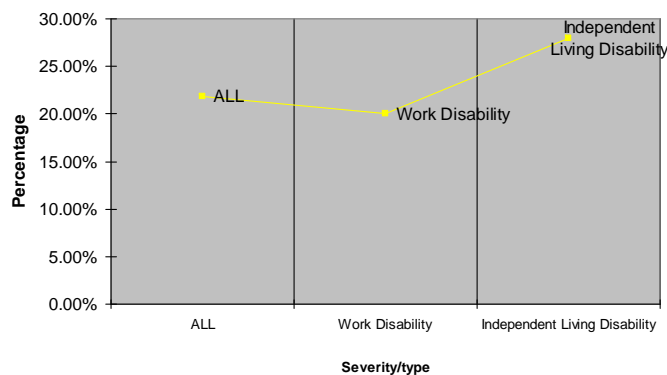
- SSI
 - \$20 a month disregarded
 - \$65 of earned income a month disregarded
 - After that \$85 benefit reduces at a rate of 50% or you lose \$1 of income for every \$2 earned
 - Other disregards if approved
 - 1619 is way to keep Medicaid after you are working
 - **SSI IS AN ENTITLEMENT THAT COMES WITH MEDICAID** –as long as someone gets \$1 in SSI or is on 1619 they are eligible for Medicaid
- SSDI
 - 9 month trial work period
 - PASS (complex program that allows one to save SSDI or earned income and live on SSI to achieve a work related goal)
 - Extended period of eligibility
 - IRWE
 - Ability to earn under current SGA
 - SSDI is insurance, not an entitlement that comes with Medicare. With a few narrow exceptions Medicare has a 29 month wait (24 months from date of eligibility + 5 month wait from date of onset of disability before SSDI kicks in).

Employment Status

Employment by Race



Below Poverty Level



- 37.4% PWD employed
- 27.8 employed full time full year
- Annual earnings are \$35,000
- 35% Hispanic WD employed
- 24.8% black WD employed
- 0% Native American WD employed
- 11% not working but actively looking for work
- 21.8% below poverty level
- Rises to 28% for the 70,000 people with a so called independent living disability (difficulty doing things alone like errands or shopping)
- 40,000 out of 185,000 (or about one in 5) civilian non-institutionalized, men and women with a work limitation, aged 18-64 in Colorado lived in families with incomes below the poverty line**

Education

- ❑ 15.7% of PWD have less than high school education.
- ❑ 17-18 % of those with self care and independent living disabilities have less than high school education
- ❑ 17.4% have a BA or higher (they say 13% of people with cognitive disability have BA or higher) Cognitive disability defined as serious difficulty concentrating, remembering, or making decisions

Health Care Needs and Issues

Needs

- Primary and Preventative care
- Durable Medical Equipment
- Attendant Care
- Mental Health
- Pain Management
- Functional Treatment
- Disease Management that works
- Customer Service
- Consumer Education

Issues

- Lack of access to appropriate primary and preventative care
- Many limits inappropriate
- Quality concerns
- Poor customer education
- Lack of coordination with physical health and inability to provide program access
- Serious problems with labeling people drug addicts, need to be able to treat pain even for addicts
- Treatment should focus on best functional ability not a cure
- Disease management has to incorporate number of conditions and account for economic and educational status of patient
- Many disabled get so frustrated just trying to get in the door that they give up

Legal Requirements of Health Care Providers and Facilities

Application

- Federally funded and federally run facilities liable under section 504 of 1973 Rehabilitation act.
- ADA title 1 affects employment
- ADA title 2 affects state and local government including contractors thereof
- ADA title 3 affects public accommodations (hospitals and doctor offices)

Requirements

- Program access for 504
- Full access for ADA for facilities modified or created after 1992
- Readily achievable access for everything else
- Maintain accessible features
- Make reasonable accommodations and policy modifications when you can do so without fundamental alteration of program, benefit or service (title 2) and undue financial hardship (title 3)
- Provide effective communication

What is Programmatic Access?

- In addition to physical accessibility (ramps, wide doors, moveable exam tables)
- Reasonable modification of policies, practices and procedures
- Effective Communication



Reasonable Modification of Policy, Practice and Procedure

- Generally one must make reasonable modification of policy, practice and procedure when necessary to avoid discrimination and/or to assure services are provided in the most integrated setting unless to do so would create a fundamental alteration of the program, service or benefit.
- The appropriate way to go about making these determinations is to engage in an interactive process with the disabled individual.
- Physicians are VERY IMPORTANT to this process not only in the health care setting but elsewhere. Physicians should be promoting the idea of reasonable modifications to their patients. Many disabled people simply avoid situations that they cannot manage because they do not know that they can ask for things to be done differently. For example a patient with a brain injury will avoid preventative care and annual exam because they fear forgetting the appointment and cannot manage a phone number.

Examples in a Health Care Setting:

- 1) Allow service animals in hospitals (except for OR and areas with invasive procedures being performed)
- 2) Appointment reminders for people who have memory deficits (also modification of no show policy)
- 3) Flexibility with late arrivals for appointments for people with disability related transportation problems
- 4) Allowing extra time for a visit for someone with brain injury who needs more time to process information
- 5) Assuring that forms that patients need for daily life are filled out promptly and properly.
- 6) Allow patients that cannot use phone menus or who have auditory processing deficits to email with their providers
- 7) Giving someone specific appointment times based on disability related needs

THESE ARE JUST EXAMPLES AND NOT MEANT TO BE AN ALL INCLUSIVE LIST

Effective Communication

Means whatever is written or spoken must be as clear and understandable to people with disabilities as it is for people who do not have disabilities. Auxiliary aids and services help people with a wide variety of physical or mental limitations to access jobs and services. Different auxiliary aids and services that may be used to provide effective communication for people with disabilities. **But, remember, not all ways work for all people with disabilities or even for people with one type of disability. You must consult with the individual to determine what is effective for him or her.**

qualified interpreters or note takers

communication boards

communication by email or text messaging or instant messaging

qualified readers or assistance filling out forms

Braille materials or large print materials

Material in electronic format (compact disc with materials in plain text or word processor format)

Types of Communication Needs and Accommodations

Expressive

- Let people provide information in writing including giving email addresses—addresses people with speech impairments and word finding problems
- Patience—people with speech impairments know they are hard to understand, it is ok to ask to repeat themselves—if you cannot understand after a few repetitions then ask them to spell the word, letters are easier than words. DO NOT tell them to calm down—speech is not hard to understand due to the person being upset or nervous
- Allow people to send follow up email or fax after an appointment if they forgot or did not clearly express something
- Encourage use of technology—email is great for people who have expressive problems—some might also have some writing issues but those can be more easily overcome For someone with expressive communication barriers a laptop is medically necessary, they might be able to write notes and communicate even when with someone by writing rather than talking—

- Receptive
- After communication send a short email to make sure they understood the conversation or directions
- Suggest that they bring someone if they tend to scramble or confuse information
- If not possible write down basic instructions
- Suggest neuropsychiatric evaluation if someone consistently misinterprets information or misuses medication if there is a neurological condition
- Support using paid personal assistants for communication support (both receptive and expressive)
- Bullet point complex information
- Help people understand deficit and compensation techniques—often frustration and problems with provider relationships is due to person not knowing why they are never on the same page with others

Primary and Preventative Care

Barriers

- Ignoring routine care due to overwhelming needs related to disability
 - Assumption that all health problems are disability related
 - Lack of understanding of disability specific prevention (bigger dollars on both ends)
- How to help
 - Disability Care Coordination has a model that works (www.coahi.org) We are beginning to implement the pilot in Colorado.
 - Talk to PWD about routine preventative care
 - Realize that work that might have less value (LMN for DME) is often the most significant prevention that can be done.
 - Encourage patient to know their disability and be assertive about needs. Encourage learning about signs of trouble (e.g. infections, skin issues)
 - Assume expertise on the part of the PWD—including people with psychiatric or other mental disabilities.

Durable Medical Equipment

Barriers

- DME limits in private insurance (often \$2,000)
- Medicare restriction on equipment for use in the home
- Lack of patient education about the equipment (including not knowing what is available, not knowing maintenance, not knowing warranty rights, etc)
- Letters of medical necessity have to include all elements –often insurance reviewers do not understand the equipment
- Need to have assessment that includes use in home and community—putting homebound restriction on equipment will not mean that someone only uses it at home—giving someone cheap or inappropriate equipment causes equipment breakdowns and health problems
- Assessment should look at medical needs and functionality

How to Help

- Make sure that people are getting good evaluations –there is no such thing as the ability to assess someone over the phone or guarantee approval overnight.
- Do not support equipment that does not have Colorado location and repair staff
- For wheelchairs for full time adult users always prescribe GROUP FOUR and specify that it must be a group four.
- Support the need for preventative DME (e.g. allow someone to get a tilt before they get a pressure sore)
- Encourage your patients to read up on equipment and to talk to others with similar disabilities before making purchase
- Let your patients know that we have wheelchair and assistive technology lemon laws.
- Be willing to support requests even for non traditional equipment
- Work with advocacy organizations to expand access to DME
- DURABLE MEDICAL EQUIPMENT IS ALWAYS PREVENTATIVE CARE –DME EXPENSES SHOULD INCREASE IN ANY OPERATION THAT SERVES A HIGH NUMBER OF PEOPLE WITH DISABILITIES

Examples of DME for Health Promotion and Prevention



- Bed that raises feet and head with excellent mattress for person who has edema and who is not getting good sleep-consider how many people need increased pain medication, and have decreased function simply due to lack of sleep. Any neurological and mental disorder is immediately worsened by fatigue.
- Using a blackberry or other electronic organizer for memory, organization, and even keeping social cues in notes. (How many patients receive ineffective treatment because they cannot remember appointments and/or they alienate the medical staff because they get so frustrated getting through the system?)

Attendant Care/Personal Care

Barriers

- Lack of knowledge about the better programs (Consumer Directed Attendant Support Services)
- Unable to get attendant care without meeting strict criteria in specific public systems & lack of coordination between systems (no funding through private insurance)
- As a medical benefit it has focus on medical need but that is not appropriate as it is a functional need.
- System still does not adequately recognize need for services that are more supportive/supervision related in nature that cannot be divided into a task that takes a specific number of minutes to accomplish

How to Help

- Make sure you tell your patients to apply when they might qualify
- Know the basic requirements for publicly funded attendant care
- Encourage patients to use self assessment and to really think about their needs ahead of time. All patients that use attendant care should have some sort of attendant management plan (this is required in the CDASS program)
- Let patients know what is a “never event” in this field such as having a worker not show up and not call leaving the disabled person stranded.
- Understand that non discrimination laws require that Medicaid clients get support when the need is cognitive or psychiatric, for example if you need someone to help you shower it does not matter if the reason is that you physically need help getting in the shower and washing or if you need to be reminded to shower and helped with the steps (e.g. getting clothes out first) or whether you have psychiatrically based hygiene needs.

Personal Care Service Delivery Options

	CDAS	IHSS	HOME HEALTH AGENCY
Who	You find, select and hire your own aides.	If you answered yes to this for CDAS but want an agency involved this option might work better for you. You choose aides who are hired by an IHSS agency.	You generally must accept the aides that the agency hires. All aides must be certified by the State. A few agencies allow clients to bring in otherwise qualified aides as employees of the agency.
When	You do your own scheduling. You choose what times your aides will work for you.	You would be allowed to do your own scheduling. However, if you need backup or rely on the aides the agency provides, the agency must assure 24-hour backup care. There would not always be a guarantee of having the aides at the time you want them.	You must accept the schedule that is set up by the agency. The agency is required to provide the visits ordered by the doctor but may not provide the visits at the specific time you request.
Backup care	You handle all aspects of your own attendant care, including arranging for backup if the regular aide is sick or unavailable.	The agency must assure 24-hour backup care, and you can still enjoy the flexibility of self-directed care. This agency has the right to accept or reject you as a client.	A home health agency does all of the scheduling and oversight. If the regular aide is absent, back up may be provided and the agency usually notifies the client up front of their specific policy about absence, no shows, and cancellations.
How Much	You set your own rate for workers within a budget set by the state.	Rates for your care are set by the State.	The agency sets the rates for the workers. The State sets the rates paid to agencies to include overhead for such things as benefits for the caregiver and their cost of supervisory visits.
Agency Involvement	None.	You might be asked to have a contract with the agency regarding backup care. The agency is responsible for providing 24-hour backup.	The home health agency has obligations to arrange and provide their services. However, services may be discontinued with a proper 15 day notice and documentation that the agency made some attempt to resolve the problem.
Managing your care	Your doctor must sign a form saying that you can handle your own health issues.	You must handle your own health issues or, if you cannot handle your own health issues, you can find a family member or friend to do that for you. Do you have someone to help you with this?	Your doctor does not have to say you can handle your own health issues. The agency must conduct, and you must agree to, a supervisory visit by a nurse every 62 days.
Other Requirements	You must have received Medicaid-funded attendant care for the 12-months prior to applying for the program.	You must be in either the HCBS-EBD or the Children's HCBS waiver.	Available to anyone who qualifies for long term home health or HCBS personal care. This is contingent on finding an agency that is willing to provide services and has staff to provide your care.

Mental Health

- Barriers
- Lack of coordination among mental and physical health
- Lack of support for people with health problems related to psychiatric medications or conditions
- Lack of psychiatrists particularly those skilled in treatment of people with multiple disabilities
- How to Help
- Make sure that you offer easy way for patients and mental health professionals to communicate with you.
- If patient is on medication that requires blood work or other monitoring do not assume that someone else is doing this, even if you are not the prescriber
- Advocate for your patient with psychiatric illness if they are having problems getting through the mental health system (s)
- Be careful about what is written in records, especially with the advent of EMRs. One word can make it impossible for someone to receive care elsewhere.

Pain Management

- Barriers
- Pain management is huge problem-lack of appropriate pain treatment leads to self medication OR leads to people over-taking medications
- Addiction concerns are real but are overblown and the distinction between physical and psychological addiction is not addressed.
- People with active addiction issues still need pain management
- How to help
- Listen to your patients
- Let people have a trial for a week or two of a medication
- Use more than one method (e.g. medication and meditation) (mind and body)
- If someone has addiction issues and has real pain issues find a way to do medication safely
- Set reasonable expectations-explain your rationale for narcotics contracts

Functional Treatment

- Functional treatment is providing medical care for people with chronic disabilities that helps the person FUNCTION at the highest level.
- Similar to concept of palliative
- When someone lives with a chronic disability they must have medical support to function. Many of the services we need are medications and equipment for mitigation of symptoms
- This does not mean that people preferring function will never want curative care for specific problems.

Disease Management

- Disease management programs tend to focus on one disease, e.g. asthma and diabetes. For people with disabilities a disease management program must be holistic to be effective. Disease management needs to account for other things like income and issues not related to only the physical components. For example there might be many reasons why people with mental illness do not exercise--

Customer Service

- People without power are afraid of systems
- Many people have learned to get what they need by living in crisis –it takes time to undo that and other maladaptive patterns
- People are often so afraid of not getting what they need that it becomes a self fulfilling prophecy
- Don't believe everything you read—often a chart will label someone as a problem—when we think someone is a problem we react to them differently.
- People calling may be waiting on your signature for something that they need to function
- Time flies for busy people

Resource List

- Medicaid Consumer Directed Attendant Support
<http://www.colorado.gov/cs/Satellite/HCPF/HCPF/1210324172195>
- Colorado Alliance for Health and Independence
www.coahi.org
- Long Term Care Options (Medicaid Entry Point for Long Term Care for Adams, Arapahoe, Denver and Douglas
<http://www.totallongtermcare.org/partners/ltco.aspx>
- National Alliance of Mentally Ill
www.namicolorado.org
- Disability Center for Independent Living
<http://www.dcilwebsite.org/>
- Atlantis Community
<http://www.atlantiscommunity.net/>
- Denver Office of Disability Rights
<http://www.denvergov.org/Default.aspx?alias=www.denvergov.org/disabilities>
- Rocky Mountain Disability and Business Technical Assistance Center
<http://www.adainformation.org/>

Prepared by the Colorado Cross Disability Coalition

Our mission is to promote social justice and create systems change that
benefits people with all types of disabilities.

Cross-Disability means that people with different kinds of disabilities have more
in common than not and that we do better working together.

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SELF-ASSESSMENT FOR PERSONAL ASSISTANCE SUPPORTS AND SERVICES

(Self-Directed Care)

1. After completing this Self Assessment, you should be able to:

- Recognize the care you need, how much you need and in what areas including which specific activities of daily living and instrumental activities of daily living are difficult or impossible for you?
- Determine how you want your care delivered: home health agency care, where you make very few decisions, or one of the self-directed care options.

2. You can use this self-assessment tool to:

- Decide if you want to apply for or request personal assistance services through Colorado Medicaid if your income is under \$2022 in 2010 per month and your assets are under \$2,000. (Different rules apply for married people and the income rate increases slightly each year)
- Talk to a case manager at your local Single Entry Point Agency (SEP) about receiving attendant care through a home health or personal care agency.
- Decide if you want to apply for CDAS or use with your case manager to develop a plan of care for IHSS. (IHSS is available on a limited basis at this time)

3. If you are a client of Colorado Medicaid and want to try self-directed care:

- Take this self-assessment with you to your local Single Entry Point.
- A case manager can answer questions about CDAS or authorize IHSS services through an In-Home Support Services agency. If you have applied for Medicaid in Colorado and your status is pending, this assessment will still be useful to you. Keep it and discuss it with the case manager if you become eligible.
- If you decide to apply for the Consumer Directed Attendant Support program, you can get an application from the case manager and complete it yourself or get an application form from the Health Care Policy and Financing website. The address and contact information is listed at the end of this self-assessment form.

This assessment is designed to help you take a realistic look at your situation and decide whether or not you are interested in one of Colorado's Personal Assistance Supports and Services (PASS) programs.

Your Personal Support System

You are not required to have a personal support system in order to receive self-directed care. The reason this may be an important issue for you is that sometimes people who want to do self-directed care have a friend or family member whom they would like to have provide their care and be reimbursed for the care by Medicaid. You can do that (with the exception of hiring a spouse under in-home support services) if you have a person whom you trust, who would provide the care the way you want it. That is extremely important. If the person is unwilling or unable to provide the care according to your wishes, would you be comfortable firing a family member or friend? It may also be crucial to your success with self-directed care that you have someone who will support your wishes and be there for you when you need and want them.

For example, you may want to live independently, making choices about your life, but not want to live alone. A friend or family member who supports your decisions might be happy to have you live with them but be willing to stay in the background so far as your needs for care are concerned. Or you live with family or friends and want to continue to do so, but they are doing a lot of your care which has become burdensome for them or they have been unable to work and earn enough money for living expenses because they do so much of your care. Self-directed care could relieve some of that pressure and enable you to have a more satisfactory, pleasing life.

Remember, these programs are designed to enable people to live independently.

Do you have a friend or family member you would want to act as your authorized representative, if you needed one?

Note: this question only applies to in-home support services. People in CDAS must be able to manage all aspects of their homemaker and personal care services. However we expect CDAS clients to be allowed to use an authorized representative soon.

HOW DO YOU WANT YOUR CARE DELIVERED?

The purpose of **Consumer Directed Attendant Support (CDAS)**, IHSS and Home Health agency care is to provide services to individuals who have health conditions or functional disabilities that limit their ability to perform activities of daily living. In CDAS, you must have an ongoing need for attendant support. The Home Health care agencies provide both skilled and personal care, and they assign their nurses and home health aides on a schedule provided by the agency. They are supposed to provide oversight to assure your needs are met. The following chart will help you decide which of the personal care options suits you best.

	CDAS	IHSS	HOME HEALTH AGENCY
Who	You find, select and hire your own aides.	If you answered yes to this for CDAS but want an agency involved this option might work better for you. You choose aides who are hired by an IHSS agency.	You generally must accept the aides that the agency hires. All aides must be certified by the State. A few agencies allow clients to bring in otherwise qualified aides as employees of the agency.
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HOW MUCH CARE DO YOU NEED AND IN WHAT AREAS?

This portion of the Self-Assessment will help you figure out how much care you think you need and the areas in which you need it. Be sure to answer the following questions about the level of your ability carefully. You should not attempt to make yourself appear to be more capable than you really are. Medicaid will not cover services that are unnecessary, but if you do not get the services you need, independent living may not work for you.

ACTIVITIES OF DAILY LIVING

EATING/FEEDING—*The ability to eat and drink using routine and adaptive devices.*

1. Are you able to feed yourself? This includes cutting, chewing, swallowing.

Limited assistance	Moderate	Extensive Assistance	Total Assistance
Sometimes someone needs to assist me.	I am unable to feed myself without help.	It may not be safe for me to eat alone.	I must be fed by someone else.

HEALTH AND SAFETY ISSUES

- Have you missed meals because you had no one to help you eat?
- Are you at risk for choking?
- Do you have difficulty swallowing?
- Is this an ongoing problem?

MOBILITY/TRANSFERRING—*Moving from one place to another.*

2. Do you need to do transfers from a chair, bed, walker or wheelchair?

Limited assistance	Moderate	Extensive Assistance	Total Assistance
Hands-on support is sometimes required.	I am unable to keep my balance without help.	I cannot bear weight and need another person to assist me with transfers.	I am unable to do transfers by myself. A lift may be used but must be operated by others.

HEALTH AND SAFETY ISSUES

- Do you sometimes fall and get hurt and need medical attention?
- Have you either stayed in bed longer than you wanted, or slept in a chair, because you did not have help to transfer and were unable or afraid to do it by yourself?
- If you are in bed and forgot something (e.g. to lock the door) how often do you just leave whatever it is you forgot due to fear of doing another transfer without assistance?

OVERNIGHT

3. Once you are in bed, what kind of assistance do you need?

Limited assistance	Moderate	Extensive Assistance	Total Assistance
Hands-on support is sometimes required.	I sometimes need assistance from another human being during the night although he/she doesn't have to be there all the time.	Once in bed I am unable to move at all, and may need assistance before morning.	I am dependent on others for nighttime assistance.

HEALTH AND SAFETY ISSUES

- I use a ventilator or other life-sustaining equipment and cannot operate the equipment or call for help.
- Do you have accidents in bed that you are unable to clean up?
- Do you have sores from lying in your urine overnight?
- Do you ever stay up all night or in bed all day to avoid transferring in and out of bed?
- Do you keep large amounts of food in your bed because you are used to getting stuck?
- How often have you called 911 from bed or due to falls getting into or out of bed in the past year?

GETTING AROUND THE HOUSE—*Getting around the house means walking or moving through your house as needed.*

4. How do you manage getting around the house?

Limited assistance	Moderate	Extensive Assistance	Total Assistance
Help is sometimes needed.	I often need help, depending on my condition at the time.	Support for weight bearing is needed most of the time. I am at risk for falling.	I am dependent on others to help me move around the house.

HEALTH AND SAFETY ISSUES

- Do you regularly miss meals, or fail to put away food because of mobility problems?
- Have you broken furniture or other household items because you were using them to move around, or because you fell on them?

DRESSING AND GROOMING—*The ability to dress or undress as necessary, which includes putting on prostheses or braces and other assistive devices. Grooming means brushing teeth, combing hair, washing and drying face and hands and shaving.*

5. Can you get dressed by yourself?

Limited assistance	Moderate	Extensive Assistance	Total Assistance
Help is sometimes needed.	I can't manage without help or without someone to remind me what to do.	I need physical help to dress within a reasonable amount of time (45 minutes).	I am unable to dress/undress myself..

6. Are you able to do your own grooming?

Limited assistance	Moderate	Extensive Assistance	Total Assistance
Help is sometimes needed.	I can't manage without help or without someone to remind me what to do.	I'm able to do some of the grooming but someone else must help me.	I rely on someone else to make sure my grooming is done.

The following questions deal with **appearance and personal comfort**, but are important. Being able to participate in the community and engage in social activities are quality of life issues for many people.

- Are you sometimes unable to get dressed or undressed because you do not have assistance?
- Have you declined a social invitation that you wanted to attend because you could not dress appropriately?
- Are you sometimes physically uncomfortable because you are unable to take clothes off as the day warms up?
- Do you sometimes use mouthwash instead of brushing your teeth?
- Have you tied up your hair or put on a hat or bandana because you couldn't brush or wash your hair?

BATHING

7. How do you manage bathing or showering for adequate hygiene? Are you able to shower, bathe or take a sponge bath? Getting in and out of the tub or shower can be difficult, and safety may be a concern.

Limited assistance	Moderate	Extensive Assistance	Total Assistance
Can do independently on good days, but need help on bad days.	I can't manage without help.	Can perform at least part of the activity but hands-on assistance needed most of the time.	Others must provide a complete bath.

If your answer to any of the following questions is “yes”, self-directed care can make a significant difference in your quality of life.

- Do you sometimes “wash up” when you would prefer a shower because you have no one to help you shower?
- Are you sometimes unable to get a bath or shower as often as needed because you do not have help and are afraid to do so independently?
- Do you worry that you have body odor?
- Do you have accidents and then can’t get the smell off of your body?

TOILETING—*The ability to use toilet, bedpan, commode or urinal.*

8. Can you take care of your own bladder and bowel needs? Can you adjust your clothing, transfer on and off the toilet, cleanse yourself, and manage an ostomy, bowel program or catheter?

Limited assistance	Moderate	Extensive Assistance	Total Assistance
I can usually go to the bathroom by myself but may need some assistance by another person.	I need help much of the time.	I need help to get on or off the toilet or need assistance with a catheter or ostomy.	I have frequent accidents and need assistance with cleaning myself afterwards.

HEALTH AND SAFETY ISSUES

If you answer “yes” to any of the following questions, enrolling in a PASS option – if you are eligible – will provide you the assistance you need and probably eliminate health and quality of life issues in these areas.

- Do you sometimes stop drinking any liquids to keep from having to urinate?
- Have you not eaten or drank for more than 24 hours to prevent the need to use the toilet, which is very difficult?
- Have you used more than twice the recommended amount of laxatives trying to have a bowel movement, because you can’t do a bowel program?
- If you use a catheter, have you had serious bladder infections? Do you have trouble getting your catheter changed often enough? Does your catheter often get clogged to the point where no urine will drain? An attendant can be trained to do catheter care using proper techniques.

INSTRUMENTAL ACTIVITIES OF DAILY LIVING

These activities are important to living independently and attendant support for these activities is included in care planning. However, these activities are not included as part of the self-assessment process because the Medicaid program does not consider them to determine eligibility for long-term care. If you depend on others and your inability to do things for yourself or participate in household activities is causing problems, consider using self-directed personal assistance services and support (CDAS, IHSS) instead. These programs may help you preserve important relationships and prevent your feeling as though you are a burden.

1. Do you need help with housework, including vacuuming, straightening up, general cleaning?
2. Do you need help to do your own laundry including sorting clothing and other items, using the washer and/or dryer, putting clean laundry away? The importance is to maintain cleanliness of your clothing and household items.
3. Do you need assistance with your shopping? The ability to run one's own errands and shop, to physically acquire items needed to live in one's home and put items away.
4. Are you able to access transportation? What do you have to do in order to leave your home and access transportation services? Reliable Transportation or delivery services are vital to living safely and independently.
5. Can you prepare your own meals? This includes opening containers, using kitchen appliances and equipment.
6. Are you able to clean up after you prepare your meals? Cleaning up after meals is important to avoid insect and rodent invasion due to dirty dishes or spoiled food. This is a health and safety concern.
7. Are you able to take your medicine by yourself? Remembering to take medications as directed by the doctor, opening childproof caps, etc.

HEALTH AND SAFETY ISSUES

- Do you frequently miss your medication because you forgot to take it?
 - Do you sometimes take the wrong medication or take your medication twice?
 - Have you missed medication because you were unable to get to the pharmacy or forgot to call for a refill?
 - Have you missed medication because you were unable to open the bottle or prepare it?
8. Are you able to manage your money? Can you pay your bills, budget, write checks or money orders and manage the necessities – food, clothing, and shelter?
 9. Are you able to access resources? Can you identify your needs – make appointments, call someone about plumbing or electrical problems, etc.?

ADDITIONAL FUNCTIONAL QUESTIONS

The following questions may help determine that CDAS would not be the right choice. However, you may use an authorized representative to direct your care through IHSS.

- Have your friends or family told you that you are becoming very forgetful?
- Have you forgotten to turn the stove off after using it?
- Are you understood when expressing information? If you use a communication device, answer the question within that context. The important issue is whether or not you can make your needs known to others.
- Have you bounced checks? You might need assistance or could use computer software for this activity.
- Have you missed important appointments, frequently, because you forgot about them?

Sometimes when you have a disability things just start feeling very out of control. Often this means that you need some sort of assistance. A person with disabilities or a health condition that interferes with functioning may think that admitting that he or she needs help will make them lose control of their life, and that they should hide it. However, the opposite is true.

The way to keep control of your life is to access the assistance you need and keep control of that assistance.

If you wait too long to ask for assistance, others may come in and take over. If you end up with unexplained bruises, sores, medication problems, if your home gets filthy, etc., social services often is called by some well-meaning person. Often others think that anyone who cannot “take care of themselves” must go to a nursing home. That is not at all true, whether you are on Medicaid or can pay for help yourself.

The best way to avoid the nursing home, and to avoid control by others, is to get the assistance you need when you need it and in the way you want it so that you can remain in control.