

## **PURPOSE AND RATIONALE FOR THE "CULTURAL INTEGRATION" TRAINING PROPOSAL**

Concerns have been raised by various disability constituencies regarding the effectiveness and appropriateness of interactions with, and training curriculums for, new employees, other staff and related personnel at HCPF, including:

- A need for better understanding by new employees and personnel of HCPF of the world view, needs, hopes, concerns and issues of individuals with disabilities and their families.
- The need for the "disability community," to develop a curriculum for the training and education of employees in the above.
- That some previous curricula actually promoted and perpetuated stereotypes of individuals with disabilities.

### **CULTURAL INTEGRATION SURVEY METHODOLOGY**

To learn what users of the various Colorado disability systems, and particularly the Colorado Medicaid system, thought was important for new Medicaid employees, a survey process was developed to gain their thoughts and ideas.

A group of 6 persons, representing individuals with disabilities and their families, designed an easy, brief internet survey using Survey Monkey. The form was refined and clarified with a review by a larger audience of 20 families and individuals with disabilities, and suggested changes and refinements were incorporated.

The survey was made available to a large group of individuals with disabilities and families through wide dissemination through various listservs, including the Colorado Cross Disabilities Coalition, PAD-CO (Parents of Adults with Disabilities in Colorado), Parent to Parent of Colorado, and the various Arcs. There were 102 responses.

Responses to the survey are shown below.

### **CULTURAL INTEGRATION SURVEY RESULTS**

The survey questions and results are:

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1. How important do you believe it is to have an orientation program for new employees regarding knowing about, and methods of interaction, by Medicaid/HCPF employees with individuals with disabilities, their parents, guardians and/or representatives?

		Response Percent	Response Count
<b>Not important</b>		2.0%	2
<b>Somewhat important</b>		1.0%	1
<b>Important</b>		8.0%	8
<b>Very important</b>		14.0%	14
<b>Extremely important</b>		<b>75.0%</b>	<b>75</b>
		<b>answered question</b>	<b>100</b>
		<b>skipped question</b>	<b>2</b>

2. I have interactions with Medicaid (HCPF) employees

		Response Percent	Response Count
<b>Almost never</b>		17.6%	18
<b>Seldom</b>		13.7%	14
<b>Sometimes</b>		24.5%	25
<b>Often</b>		<b>28.4%</b>	<b>29</b>
<b>A lot</b>		15.7%	16
		<b>answered question</b>	<b>102</b>
		<b>skipped question</b>	<b>0</b>

3. Please tell us the single most important thing you would like a new Medicaid employee to know about understanding the history of the disability movement and what it is like to be an individual with a disability or a parent/guardian or representative of an individual with a disability.

	Response
	Count
<a href="#">Show replies</a>	102
<b>answered question</b>	<b>102</b>
<b>skipped question</b>	<b>0</b>

The raw written responses to question 3 are listed in Appendix 1.

4. Please tell us the single most important item that you would like a new Medicaid employee to know about interacting with individuals with disabilities, their parents, guardians or representative.

	Response
	Count
<a href="#">Show replies</a>	102
<b>answered question</b>	<b>102</b>
<b>skipped question</b>	<b>0</b>

The raw written responses to question 4 are listed in Appendix 2

5. I am a			
		Response Percent	Response Count
<b>Individual with a Disability</b>		33.7%	34
<b>Parent or guardian of an Individual with a Disability</b>		46.5%	47
<b>Representative of an Individual with a Disability</b>		19.8%	20
		<b>answered question</b>	<b>101</b>
		<b>skipped question</b>	<b>1</b>

The raw written responses to question 3 are listed in Appendix 1.

The raw written responses to question 4 are listed in Appendix 2

There were 102 written responses to question #3 (see appendix #1) and 102 written responses to question #4 (see appendix #2) As the written responses were judged to be similar in nature to both questions #3 and #4, the responses were combined. Based upon a review of all the responses, sort categories were determined.

The responses were then sorted into appropriate categories by the team. Each team member verified the appropriate sorting of the other team members. See appendix #3

The various sort categories and the number of responses per category was

- RESPECT (68 responses),
- UNDERSTANDING AND EMPATHY -(45 responses),
- KNOWLEDGE (18 responses)
- SYSTEM - (15 responses)
- PERSON CENTERED - (14 responses)
- HISTORY - (10 responses)
- LAWS AND RIGHTS - (8 responses)
- SERVICES - (6 responses)
- MEDICAL MODEL CONCERNS - (6 responses)
- ADVOCACY - (4 responses)
- LEAST RESTRICTIVE ENVIRONMENT - (2 responses) and
- OTHER - (10 responses)

The team gleaned critical concepts and ideas from the sorted comments. A further syntheses of the critical concepts and ideas was done by the team, ultimately resulting in the development of two learning modules, with some suggested learning activities for each module.

## **Learning Module One: Respect, Understand, Empathize, Person-Centeredness**

As a result of this training, new employees to HCPF will learn to, and will treat, individuals with disabilities and their families with understanding, empathy, and respect using a person-centered approach..

### **They will do this by:**

- Gaining insight into the daily lives of individuals with disabilities and their families, and incorporating this insight into their interactions with individuals with disabilities and their families.
- Acknowledging and presuming that the individual with the disability and/or their families will know more about the impact of the disability than the professional, and incorporating this knowledge into their interactions with individuals with disabilities and their families.
- Actively listening to and clearly communicating in a timely manner with individuals with disabilities and their families.
- Acknowledging that each individual with a disability and their families are unique; thereby, needing support systems that are flexible to meet individualized needs, and incorporating this knowledge into their interactions with individuals with disabilities and their families. .
- Understanding that professional human services positions are dependent upon meeting the needs of individuals with disabilities and their families, and incorporating this understanding into their interactions with individuals with disabilities and their families..
- Remembering that individuals with disabilities and their families have aspirations, hopes, dreams, feelings, and that they can be productive citizens with the right supports, and incorporating this knowledge into their interactions with individuals with disabilities and their families.
- Acknowledging that individuals with disabilities and their families have many facets to their lives apart from “disability,” including raising (other) children, employment, entertainment, travel, etc., and incorporating this knowledge into their interactions with individuals with disabilities and their families.
- Understanding that individuals with disabilities and their families are dealing with multiple agencies; and there may be multiple people with disabilities within a family, including a family member, who may be acting as primary caregiver and incorporating this understanding into their interactions with individuals with disabilities and their families.
- Understanding that disability is a 24/7 lifestyle. There are no weekends or holidays off. Disability does not have an office that closes at 5 pm, and incorporating this understanding into their interactions with individuals with disabilities and their families.

- Acknowledging that individuals with disabilities and their families are doing the best that they can to use support services appropriately to create the best life that they can for themselves and their families. They are not “gaming” systems.
- Understanding the frustration that individuals with disabilities and families endure while accessing necessary supports. Such frustration includes completion of multiple forms, lost paperwork, errors by professionals, phone calls that are not returned, questions that are not answered, being put on hold multiple times, disability-related accommodations, disrespect by professionals, poor communication by professionals, and lack of knowledge-base of professionals, and incorporating this understanding into their interactions with individuals with disabilities and their families..
- Learning that long term care needs are VERY different than Acute care needs and LTC should not LOOK Medical even though some of it is, and incorporating this learning into their interactions with individuals with disabilities and their families.
- Remembering that the professional may be only an accident, a fall, a diagnosis or a birth of a child away from being on the other end of the phone, and incorporating this understanding into their interactions with individuals with disabilities and their families.

Some suggested strategies. It is anticipated that other strategies would be added given appropriate funding and resources, and not all of those suggested below would be used:

1. Employees will take a “pre-test” for them to learn about and self-evaluate their own knowledge of and perceptions about individuals and families with disabilities, including understanding, empathy, and respect and using a person-centered approach.
2. Employees will review and discuss media that accurately depicts the challenges of living with a disability – When Billy Broke His Head; The Sessions; What’s Eating Gilbert Grape; Coming Home; Temple Grandin; My Left Foot; Door-to-Door; Children of a Lesser God; Dance Like Nobody’s Watching; Freaks (1932); One Flew Over the Cuckoo’s Nest; The Other Sister; I Am Sam; Radio; Music Within; Just Like Anyone; Born on the 4<sup>th</sup> of July; Murderball; A Beautiful Mind;
3. Employees will participate in consciousness-raising work groups to gain an understanding of their own preconceptions about life with a disability.
4. Employees might shadow a person with a disability and a family experiencing disability.. A follow-up work group of employees, people with disabilities and family members will serve to address understanding of what they experienced.

5. Additional strategies and methods of deliveries will be developed as allowed by funding and resources.
6. Employees will take a “post-test” for them to learn about and self-evaluate their growth in knowledge of and perceptions about individuals and families with disabilities, including understanding, empathy, and respect and using a person-centered approach.

## **Learning Module Two: History of Disability, Laws/Rights, Advocacy Organizations**

- Employees of HCPF will acquire knowledge of the history of the disability movement, the laws and rights of individuals and their families, and advocacy organizations and their purpose, in order to greater understand the evolution of community-based services and the civil rights model of disability.

### **They will do this by:**

1. Understanding the early perspectives of disability from ancient times to the 20<sup>th</sup> Century and incorporating this knowledge into their interactions with individuals with disabilities and their families.
2. Understanding the impact of institutionalization on people with disabilities, starting in the 19<sup>th</sup> Century, and incorporating this insight into their interactions with individuals with disabilities and their families..
3. Understanding the impact of World War I and subsequent 20<sup>th</sup> and 21<sup>st</sup> Century wars on disability policy and public perspective, and incorporating this understanding into their interactions with individuals with disabilities and their families.
4. Understanding the development and importance of the family, self-advocacy and independent living movement on disability policy, and incorporating this understanding into their interactions with individuals with disabilities and their families..
5. Understanding the movement from a medical perspective to a civil rights perspective of disability, and incorporating this understanding into their interactions with individuals with disabilities and their families..
6. Understanding the history and basic tenants of the Americans with Disabilities Act, and incorporating this understanding into their interactions with individuals with disabilities and their families..
7. Gaining knowledge of national, state and local advocacy organizations, and incorporating this understanding into their interactions with individuals with disabilities and their families.

8. Understanding the history and the concepts of person-centered planning and consumer directed services. Understanding the impact of those concepts nationally and on Colorado. Incorporating this understanding into their interactions with individuals with disabilities and their families.

Some suggested strategies. It is anticipated that other strategies would be added given appropriate funding and resources, and not all of those suggested below would be used:

1. Using disability-written materials, employees of HCPF will explore the history of the disability movement through literature. Examples will include "No Pity"; the writings of Laura Hershey. See sample curriculum:  
<http://faculty.uml.edu/bmarshall/disability%20literature%20course%20proposal.htm>
2. Employees of HCPF will complete a web-based history program. Parallels In Time, (<http://www.mnddc.org/parallels/index.html> ) created by the Minnesota Disabilities Planning Council, will serve as a basis for this course with follow-up discussion with members of the disabilities community.
3. Employees of HCPF will receive and review a compilation of key Colorado and national disability-related organizations.
4. Employees of HCPF will spend a day at 2 disability-related organizations, and/or families and individuals with disabilities.

**Implementation strategy:** Implementation strategies will be premised on training support by HCPF. Possible options include:

9. Requiring a specific number of training hours - i.e., eight - to be spent in workshops, 2 hour brown bag lunches, and other venues.
10. The development of an appropriate Colorado online course or courses;
11. Developing an appropriate Colorado workbook;
12. A review of national exemplary "shadowing" programs for possible implementation;
13. Developing appropriate simulation learning activities such as games;
14. And many other learning opportunities are possible.

## **EVALUATION**

In addition to an evaluation component to the specific learning activities and trainings (as suggested above and to be developed and added as appropriate), the team believes it is critical to have an on-going evaluation to determine if the learning activities and strategies actually make a difference in the behaviors and interactions of new (and possibly continuing) HCPF employees.

The team considered and herein suggests several possibilities:

A process wherein anonymous positive and negative and constructive feedback could be given by individuals with disabilities, such as a web site or a telephone number where specific questions of the success of the interaction could be answered, and further comments could be given by the individuals with disabilities and their families. This would be similar to the feedback asked for and obtained by almost all major customer-based businesses, such as McDonalds.

Monitoring and recording phone calls, with a periodic review by management.

Surveys such as the one developed for this project, asking questions about levels of service, improvement.

HCPF management meeting with advisory committees composed of individuals who utilize Medicaid services.

Having customer/consumer contacts and success included in periodic management evaluation of employees

As the results of evaluation show trends, it could result in further employee training or changes in the training protocols.

Also, this could highlight specific employees who are accomplishing outstanding work, or who may need some remedial training.

## **CONCLUSION**

This presentation is a starting place from which other ideas for training programs and their implementation can be developed. We urge that HCPF consider the ideas presented herein and pledge to work with HCPF to improve interactions between the disability community and employees of HCPF.

## **Appendix 1.**

Raw unordered responses to the open-ended question number 3.:

“Please tell us the single most important thing you would like a new Medicaid employee to know about understanding the history of the disability movement and what it is like to be an individual with a disability or a parent/guardian or representative of an individual with a disability.”

New employees need to understand the history of the disability advocacy movement, not only the past, ut the present. Why there are groups out there still advocating and pushing for change.

That these are not entitlements, they save lives, they rebuild lives and give hope, that they keep people independent and vibrant in community. That common sense and choice trump regs and bureaucrats-so pay attention. Also, the things we need and the form we access them in, are often better for us and the budget--i.e. snf vs community living with hcbs

Correct info. disseminated in a respectful manner.

I have no idea

They need to understand that the system is very confusing and difficult to understand for individuals with disabilities especially those with brain injury.

That we can be productive citizens with the right supports

I would like them to know that just trying to go through a day, doing the things that everyone else does seamlessly, we encounter numerous barriers that have to be navigated.

We are just trying to make life as good as possible for the people with disabilities we support.

Too many people disregard the importance of giving the person with disabilities the courtesy of looking at them and asking them questions and speaking in a normal manner.

Utilizing a wheelchair to get around brings a better understanding of being a person with a disability, and employees should know the history of the ADA.

make sure that you know as much as you can about medicaid before you start to go back to work. Talk with your caseworker about what medicaid has to offer when you do go back to work. It is hard the world is having a hard time adapting to the needs of the disabled community. For the disabled its harder to find jobs, find housing, getting transportation, and just plain old living in general is harder then an abled body person. How to "talk" to clients in simple and clear ways and give timelines.

Not every treatment or method is black and white. One treatment may work with one client where another may reject it or they just plain cannot deal with whatever the med/equipment/therapy, ect. Getting the resources needed to function is absolutely essential to daily life, i.e., preferred size of gauze for g-tube fed individuals or replacement parts of wheelchairs for more active clients, ect. If they need it....allow it.

Disability has been lumped together and it is important to understand that each person is an individual and their needs as well as their strengths need to be considered.

Disabilities are not cattle. They are real live human beings with feelings, needs, desires, and most of all need love and understanding. Some are difficult because what they have had to experience. WE WOULD BE TOO. On the other hand we don't need to make them so spoiled and demanding that no one can stand them. We need to treat them like we would a family member.

They should have shadowed a disabled client for at least a week. they should try and live on the monthly medicaid stipend.

Deinstitutionalization was hoped to be best for all persons with DD in the 1980's, not the case, and as such, placement options are limited and success does not look the same as a person who utilizes home health to a near complete recovery. DD population all have medical issues and more tech dependent folks cost more. DD status is Habilitation, not Re-habilitation so solutions to quality life look very different case by case & most PASAs do not have a knowledgeable nurse in their employ to help weed through rules.

That individuals with disabilities and/or parent/guardian/representatives are people and should be treated as such.

Just what a quagmire it is...finding therapies, decent doctors, know what services are available, etc. There is so much out there and you usually have to find out what you need from other parents. That this is NOT something we choose. A lifetime with a disabled child is a lifetime for the rest of the family...especially the caregiver to give up their life.

that everybody should be treated like everybody else with respect and dignity

One of the common problems with most disabling diseases is extreme fatigue that

interferes with all functions of life:personal, relationships, and most of all with the loss of ability to work.

I would like them to know that just trying to go through a day, doing the things that everyone else does seamlessly, we encounter numerous barriers that have to be navigated.

Please listen to the person with the disability, if they are able to express themselves. They know their limitations.

Understand who they serve

I have been a caregiver for 16 years to a grandchild with a severe disability - hopefully a new Medicaid employee would be a compassionate person and be willing to learn all about the history of the disability movement and why it was started

not sure

Please listen to the people and documentation, don't assume you understand and know what's best, you don't.

It is about basic civil rights. An individual with a disability has the same rights and values as the next person.

Most of us have been advocating for years for our children. It starts when they are diagnosed and we are told what they can't do, then we fight with insurance or in our case, we go to the community to do fundraising wheelchairs, therapy and communication devices. Then, we advocate in the schools, then fight for the few resources in the adult community. We get tired. We don't know the system as well as you might, or in some cases, we know it better. Simply put, we both need to suspend judgement and work together for the good of the client. Most important part...we are not out to cheat the system, just make it work for us.

It is important for people employed by Medicaid to understand the heaps of paperwork involved when someone has a disability and how important it is to find an appropriate way to communicate - some prefer phone, or email, postal service, etc. There is so much communication on a regular basis it is important to get on 'the same page' as the person you are dealing with.

I think its important for new Medicaid employees to understand that the ADA is about preventing discrimination against people with disabilities and assuring that people with disabilities have equal access to government services, employment, public places, etc. The ADA does for people with disabilities what other laws have done to protect against discrimination on the basis of race and gender.

Please tell us the single most important item that you would like a new Medicaid employee to know about interacting with individuals with disabilities, their parents, guardians or representative.

Open-Ended Response

Parents and individuals with disabilities have years and years of interacting with all kinds of professionals, each time having to educate that person about their circumstances, and receiving different responses and understanding.

We are people not forms, listen to us, know us, take your lead from us--we usually drive our life better than you assumptions about them.

use etiquette as you would with anyone without a disability.

I have no idea

We often show up when we are desperate or worse and we do not know how to obtain benefits. It is all new to us and it is not obvious what we need to do.

Tell them that we are people not so different than anyone else and to talk to us when possible...not just our guardians.

Please don't take it personally if we sound irritated on the phone. Let us know that you are interested in helping us get from point A to point B, not in figuring out more ways to

make things difficult for us.

That people with disabilities are people first--to be treated with dignity and respect.

Treat them like any other person. You never know how much they understand.

Treat them as you would any other individual, respectfully. Don't presume, ask about the client needs. Listen to the parents, guardian, or representative as they can provide valuable information.

Just be yourself and treat everyone like an individual.

How to "talk" to clients in simple and clear ways and give timelines.

This is 24hour-7 days a week life that others may take for granted. We do not.

Everyday is made special to give our people self worth. So listening to our needs will be helpful.

Treat them with respect.

See above.

Do not talk down to them...talk to them like they are real people

Most parents, guardians, and host providers are natural solution seekers but may experience "battle fatigue" over the course of years of dealing with high rotating staff turn overs in CCBs- so be patient when explaining your agency policies and be prepared to direct them to a person who can really be part of the solution, not a transfer for convenience sake.

HCPF employees (new & old) are here to serve this population and should have customer service on their minds.

Already said in number 3.

look at the person and talk to them also like an adult and not a 2 year old, and that we are not all the same

Be nice. The process of applying for Medicaid and all human services is difficult and the intake workers make it very hard to find resources for help, long wait times, and grouchy intake worker who make people wait for hours and often send them home for more information, making them come back numerous times for a decision. Please treat all people with respect, and understand that before they get to you, they have had to wait months and even years for help. Health care is expensive. Exchange preventative care with ER visits.

Please don't take it personally if we sound irritated on the phone. Let us know that you are interested in helping us get from point A to point B, not in figuring out more ways to make things difficult for us.

Speak to, not at or around the individual with the disability.

Keep the big picture of all individuals involved not just a select few.

How to speak effectively about their program and what is available to the Medicaid family

Show respect and interest to them. Know that they want a full life.

We have lived with this their whole lives we know their risks and issues as well as what they need better than you ever will.

Treat with respect, presume competence, talk directly with the individual with disability, not the support person.

Go into the interaction with the premise of total quality service. Treat us with respect and dignity and it will most likely be reciprocated.

Please remember that if you are employed with Medicaid that you don't have 'customers' or 'clients' - you have PATIENTS. Medicaid and those programs alike are crucial for people with disabilities and please remember that Medicaid isn't the only program that they have to stay on top of or communicate regularly. As you get frustrated with the patients, they can be equally as frustrated with hoops they themselves have to jump through on a regular basis.

Show respect, not sympathy.

## Appendix 2.

Raw unordered responses to the open-ended question number 4.

“Please tell us the single most important item that you would like a new Medicaid employee to know about interacting with individuals with disabilities, their parents, guardians or representative.

people first.

Do on to others as you would have them do on to you.

speak directly and use words that makes sense to the lay man

Parents and individuals with disabilities have years and years of interacting with all kinds of professionals, each time having to educate that person about their circumstances, and receiving different responses and understanding.

We are people not forms, listen to us, know us, take your lead from us--we usually drive our life better than you assumptions about them.

use etiquette as you would with anyone without a disability.

I have no idea

We often show up when we are desperate or worse and we do not know how to obtain benefits. It is all new to us and it is not obvious what we need to do.

Tell them that we are people not so different than anyone else and to talk to us when possible...not just our guardians.

Please don't take it personally if we sound irritated on the phone. Let us know that you are interested in helping us get from point A to point B, not in figuring out more ways to make things difficult for us.

That people with disabilities are people first--to be treated with dignity and respect.

Treat them like any other person. You never know how much they understand.

Treat them as you would any other individual, respectfully. Don't presume, ask about the client needs. Listen to the parents, guardian, or representative as they can provide valuable information.

Just be yourself and treat everyone like an individual.

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grouchy intake worker who make people wait for hours and often send them home for more information, making them come back numerous times for a decision. Please treat all people with respect, and understand that before they get to you, they have had to wait months and even years for help. Health care is expensive. Exchange preventative care with ER visits.

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Please remember that if you are employed with Medicaid that you don't have 'customers' or 'clients' - you have PATIENTS. Medicaid and those programs alike are crucial for people with disabilities and please remember that Medicaid isn't the only program that they have to stay on top of or communicate regularly. As you get frustrated with the patients, they can be equally as frustrated with hoops they themselves have to jump through on a regular basis.

Show respect, not sympathy.

Caring and concern for all of their needs. Again try to put yourself in each person's shoes and to think about what you would do if you were in their place.

The degree of pain and/or discomfort the individual has to deal with on a daily basis, and how long they have been afflicted with their condition.

We live the experience EVERYDAY. We can help you help persons with disabilities because we are disabled or around it. It's our life.

These programs are in place to equalize the playing field for people with disabilities, not "enhance." Treat individuals from the facilitator perspective.

respect

As a parent, I would like them to know that they are one of many professionals that I interact with weekly. When you say you don't know, find out and get back to me, Don't make me call you again. Be accurate in what you tell me. Be respectful. Don't treat me like an idiot.

Be yourself and treat them as valuable and valued people.

To always be treated with dignity and respect. Also, a warm smile and a sense of caring.

In my attempt to do the best for my daughter, it helps when I interact with people who look at me when they are talking to me or I'm talking to them. I feel like I'm being heard and that can ease my burden as much as having a need approved.

They are people like everyone else.

To understand that the "medical model" of services should be discarded for an enlightend view of that consistently results in the provision of Medicaid services to support us in our goals to engage in a life that is characterized by the same aspirations that more "typical" community members have: to live, love, work and participate in society as each individual sees fit.

Everyone is an individual & treat us with respect

The person will want to learn and understand, and work towards benefiting the disabled

Medicaid employee needs to understand we don't all speak Medicaid lingo, the employee should make sure their information is easy to understand, concise and most important accurate

That there is a necessity for the programs that our loved ones are in need of and that it is their job to make sure the needs are met....not to safeguard the system!!!

Respect, a listening ear, and enough interest to find the correct answer to the problem..

How to keep up with all the rules and regulations is important not only to you but to the client as well.

Learn about, from the individual and/or their parents and/or guardians, about the specific disability and how it affects the particular individual. Do not lump all disabilities and all people with disabilities into one category and assume you understand the needs and strengths of the individual. Educate yourself before making assumptions - otherwise you become a hindrance and not a help to increasing the individual's ability to live as independently as possible and be a contributing member to their community. Remember the Olmstead Act and respect the civil rights of individuals with disabilities to live in their own chosen community.

Every single person has value and is worth being treated with respect.

Understanding language and vocabulary choices to ensure person-centered approach and implementation of services

Communicate with us -- join with us in making things work for the people with disabilities, not just for the system!

Your more experienced colleagues give out misinformation a great deal of the time.

Please take everything you think you know with a grain of salt, and if a parent says they've been told otherwise, ALWAYS respond with a reference to an exact law, policy or regulation number along with the website it is located on. Your own supervisor/trainer may have accidentally misinformed you.

Parents have an almost undoable job - they tend to put things in a better context than they really are and need to be reminded that it's okay to describe their child as s/he is on their worst day because that is the reality. They need to be believed, not patronized. They need to be respected and their dignity validated. No one knows their child as well as they do.

to avoid the medical clinical therapy labeling categorizing trumping approach to communication

Respect and honor

Patience, listening and hearing, guide questions to get to the help the client is asking for their assistance on.

To ask about our circumstances. Not assume they understand it all because they see the "history" on paper.

To ask about our circumstances. Not assume they understand it all because they see the "history" on paper.

That people with disabilities have an opinion about their care.

LISTEN we know the diagnoses and needs. we need help locating resources and navigating paperwork. we DON'T need Medicaid workers telling us their opinions.

They work for us. They are here to assist us in accessing services and supports through their agencies. Without us they are unnecessary.

Understand that we are probably working with multiple agencies, doctors, therapists, organizations and sometimes it's hard to keep everything straight. Working with one

person at an organization who is able to answer all the questions without being routed to a different person all the time is very helpful.

Listen to the parent. Hear what the exact medical problem is, be willing to work on solving the problem. If there is any way to streamline the paperwork each year, so that the kids on Medicaid have their own paperwork, unique to their situation, and different from the general population applying for aid, it would help all of us as parents of special needs children.

Respect.

(see above) Plus training in practicing REFLECTIVE communication, repeating what the customer says until the customer confirms that they have been understood correctly.

Be respectful and put yourself in their shoes- think about accommodations when meeting; always include people (wd)in meetings that develop policy and implement programs to avoid unforeseen consequences

Person-Centered!!!

People with disabilities are the people who know what they need and how they can best be served. Listen to us.

The main thing is you have to learn to listen to individuals. Some individuals have problems with motor and/or speech skills due to the disability.

I would require them to understand that we are not "grown up kids doing tantrums," we are, smart, honourable, hard working and useful members of society. We deserve the same respect, the same treatment and the same obligations than any non-disable citizen.

I would require them to understand that we are not "grown up kids doing tantrums," we are, smart, honourable, hard working and useful members of society. We deserve the same respect, the same treatment and the same obligations than any non-disable citizen.

When the person with the disability is assessed, they are nervous and often omit all of the care needs that affect their daily lives. The ULTC 100.2 and care plan questions aren't the only things you may need to ask questions about. Explain to them verbally and in writing how their care needs are funded in addition to what things they are responsible for knowing and complying with in order to remain qualified for continued funding. .

Respect their time constraints.

That we are not all trying to scam the asystem but are actually seeking their expert assistance.

We respect you and the work you have to do, just be real and explain things when I don't understand. Sometimes appoinments are hard to arrange with childcare, etc when our kids sometimes can not come with. Please be patient.

We need your help; you have the power to make a positive difference in our lives.

As parents, even though we are exhausted, most tend to under-report the struggles. It becomes the "new normal" for us and we lose track of what a typical life looks like, making the exhaustion worse because we beat ourselves up for not being able to do it all, day in and day out. Please prompt us a bit to get at some of the underlying struggles, because they are layer upon layer that needs to be teased out.

Parents may not know everything, but we know what's best for our family :)

patience and try to understand from our perspective

There is a way to work with people with disabilities, their parents, guardians or representatives without talking down at them and acting that you are the expert and they don't know anything--because in reality they know more about themselves and their individual situation than you will ever know!

Pay attention

Don't assume we are all out to embezzle gov't \$. We are just as concerned about cost effectiveness as anyone.

Do not assume that they have all the answers always ask if they would like additional information about programs, figures etc.

Do NOT assume that PWDs or their guardians don't show up for meetings because they are not interested. Their lives are sometimes chaotic and they often have little or no spare time; people who do have not experienced disabilities and/or chronic illness don't understand this.

Some parents are extremely tired and attempting to cope with years of sleep deprivation and/or ongoing very high stress levels. With appropriate sleep and respite, we could be more concise and clear with our communications. That isn't available for most of us, so learning to deal with people who are hyperactive and disorganized is critical.

Presume competence. Long term care needs are VERY different than Acute care needs and LTC should not LOOK Medical even though some of it is

They should be treated as an equal and valued customer, with dignity and respect, should be listened to and their input acted upon in the most favorable manner

How to clearly communicate in writing.

Spend actual time with consumers receive personal assistance services and meeting with the key community organizations serving persons with disabilities, including: CCDC, Family Voices, P2P, the ILC's and ARC's.

Effective communication with an individual with a disability is highly individualized, requires an interactive process, and that employees may need to provide reasonable accommodations to effectively interact with individuals with disabilities.

While interacting with individuals with disabilities, employees must be aware that no one plans to be disabled, however, a willingness to adapt includes all circumstances.

There is a vast (almost yawning) difference between the Medicaid services that are needed to ensure a healthy and inclusive life and those services needed in acute care settings.

These are people we're talking about, be respectful of them and their unique needs.

Never lose sight of the PEOPLE.

See above

We are people with needs, same as you. You could be us at any time --all it takes is a diagnosis, accident, or birth of a child ..... therefore, treat us as you yourself would want to be treated in a similar situation.

dignity and respect. Don't make assumptions. Ask their preferences. What makes sense to an employee might not make sense to a person with disabilities.

Don't talk down to us. Learn people first language. Treat us with respect just like you would your own family.

We are not uneducated morons simply living off the system. We have brains, aspirations and lives. We are not trash and if it were not for us/our loved ones these folks wouldn't have their cushy jobs with all of the fantastic benefits.

### Appendix 3.

Raw answers sorted into categories selected, upon analysis of the responses, by the curriculum development working group.

<b>RESPECT -68</b>
To always be treated with dignity and respect. Also, a warm smile and a sense of caring.
There are many that are respectful and pleasant and some that are indifferent. It is always preferred that the employees treat disabled with care, dignity and respect!! :)
how would you like your grandmother to be treated? think about that at all times.
Please treat us like you would any other client. Please help get in the paperwork on time and response promptly to our calls some of us cannot get into your office easily. We need your help, we really do.
That people with disabilities are human beings.
Parents/Guardians of children with disabilities usually know more than you about the specific diagnoses and needs of their child. LISTEN and use what they can tell you to support them in continuing to find what they need. DO NOT reduce their child to a single goal or numerical quantity.
medicaid employees, and indeed all agency employees, need to recognize that people with disability are whole and complete, have aspirations, feelings, dreams, good days and bad days, just like every one - because we are all part of the whole which makes up the group called 'everyone'. We are busy people because we deal with all of the typical needs of modern life, plus the added demands of dealing with multiple agencies, often as we deal with communicative, mobility, intellectual, and other disabilities. The medicaid staff works for us. Without us they would have no jobs.
ill enjoy arts, entertainment, travel, etc. - the same things as everyone else including privacy. Pity is not an option - neither is inaccessibility.
It could happen to you, so have some respect. I am not disposable because I have a disability, but that is how I am treated by society.
That even when we use more help and/or services, we are equals.
We did not plan this injury so we could live off the government
Parents struggle daily, everyday often with no rest. This is a job that you can leave at 5:00. Be respectful of parents that NEVER get to leave the disability.

**RESPECT -68**

The things we (able bodied) take for granted, like getting to appointments on time, reading materials written for college educated people, filling out forms, being treated as though you're stupid or ignorant.

Respect

Be yourself and treat them as valuable and valued people.

Everyone is an individual & treat us with respect

Every single person has value and is worth being treated with respect.

Respect and honor

They work for us. They are here to assist us in accessing services and supports through their agencies. Without us they are unnecessary.

Respect.

I would require them to understand that we are not "grown up kids doing tantrums," we are, smart, honourable, hard working and useful members of society. We deserve the same respect, the same treatment and the same obligations than any non-disable citizen.

Respect their time constraints.

Don't assume we are all out to embezzle gov't \$. We are just as concerned about cost effectiveness as anyone.

They should be treated as an equal and valued customer, with dignity and respect, should be listened to and thier input acted upon in the most favorable manner

These are people we're talking about, be respectful of them and their unique needs. Never lose sight of the PEOPLE.

We are people with needs, same as you. You could be us at any time --all it takes is a diagnosis, accident, or birth of a child ..... therefore, treat us as you yourself would want to be treated in a similar situation.

dignity and respect. Don't make assumptions. Ask their preferences. What makes sense to an employee might not make sense to a person with disabilities.

Don't talk down to us. Learn people first language. Treat us with respect just like you would your own family.

Correct info. disseminated in a respectful manner.

That we can be productive citizens with the right supports

that everybody should be treated like everybody else with respect and dignity

use etiquette as you would with anyone without a disability.

**RESPECT -68**

Tell them that we are people not so different than anyone else and to talk to us when possible...not just our guardians.

That people with disabilities are people first--to be treated with dignity and respect.

Treat them like any other person. You never know how much they understand.

Treat them as you would any other individual, respectfully. Don't presume, ask about the client needs. Listen to the parents, guardian, or representative as they can provide valuable information.

Just be yourself and treat everyone like an individual.

Treat them with respect.

Do not talk down to them...talk to them like they are real people

HCPF employees (new & old) are here to serve this population and should have customer service on their minds.

look at the person and talk to them also like an adult and not a 2 year old, and that we are not all the same

Speak to, not at or around the individual with the disability.

Show respect and interest to them. Know that they want a full life.

Treat with respect, presume competence, talk directly with the individual with disability, not the support person.

Go into the interaction with the premise of total quality service. Treat us with respect and dignity and it will most likely be reciprocated.

Show respect, not sympathy.

equal rights as any other individual

Do on to others as you would have them do on to you.

PWD do not seek to be pitied, nor are we ashamed of our bodies and minds.

Parents may not know everything, but we know what's best for our family :)

There is a way to work with people with disabilities, their parents, guardians or representatives without talking down at them and acting that you are the expert and they don't know anything---because in reality they know more about themselves and their individual situation than you will ever know!

Disability has been lumped together and it is important to understand that each person is an individual and their needs as well as their strengths need to be considered.

Please listen to the people and documentation, don't assume you understand and know what's best, you don't.

**RESPECT -68**

Please listen to the people and documentation, don't assume you understand and know what's best, you don't.

It is important for people employed by Medicaid to understand the heaps of paperwork involved when someone has a disability and how important it is to find an appropriate way to communicate - some prefer phone, or email, postal service, etc. There is so much communication on a regular basis it is important to get on 'the same page' as the person you are dealing with.

Presume competence. Long term care needs are VERY different than Acute care needs and LTC should not LOOK Medical even though some of it is

We do not all fit into a "one box" description.

Respect, a listening ear, and enough interest to find the correct answer to the problem..

Learn about, from the individual and/or their parents and/or guardians, about the specific disability and how it affects the particular individual. Do not lump all disabilities and all people with disabilities into one category and assume you understand the needs and strengths of the individual

Respect, a listening ear, and enough interest to find the correct answer to the problem..

People with disabilities are the people who know what they need and how they can best be served. Listen to us.

As a parent, I would like them to know that they are one of many professionals that I interact with weekly. When you say you don't know, find out and get back to me, Don't make me call you again. Be accurate in what you tell me. Be respectful. Don't treat me like an idiot.

Be respectful and put yourself in their shoes- think about accommodations when meeting; always include people (wd)in meetings that develop policy and implement programs to avoid unforeseen consequences

We respect you and the work you have to do, just be real and explain things when I don't understand. Sometimes appointments are hard to arrange with childcare, etc when our kids sometimes can not come with. Please be patient.

We are not uneducated morons simply living off the system. We have brains, aspirations and lives. We are not trash and if it were not for us/our loved ones these folks wouldn't have their cushy jobs with all of the fantastic benefits.

Too many people disregard the importance of giving the person with disabilities the courtesy of looking at them and asking them questions and speaking in a normal maner.

**UNDERSTANDING AND EMPATHY -45**

To listen to the disabled person and to take what the disabled person says seriously. Try to put yourself in the disabled person's shoes and think about what would be important to you if you had that disabled person's disability. I think that the orientation process should include a section about the disability movement.

Understanding the needs, moods and OCD tendencies of folks with disabilities is essential for an employee to be able to deliver the appropriate services.

The aspects of day-to-day living and the 24 hour nature of care.

Frustration, Fear that you won't be able to work with someone who has compassion and understanding.

Very frustrating so listen and hear what we say when asking for accommodation

It is sometimes hard to get everything we need in order to receive benefits. Our kids work with many doctors and specialists. If we do our part, we expect you to do yours.

Its tough

If you were unable to wipe your own ass would you prefer a stranger with a medical license wipe it sometime that is convenient for them, or have a choice of who wipes, when they wipe it, and where they wipe it?

Unless the Medicaid employee has a disability themselves, they will NEVER understand what the life of a PWD is like in terms of not having the lifestyle which abled people take for granted.

That PWDs are as a class are generally repressed, uneducated and downtrodden, which as a result most are not good self/lay advocates, but that does not mean they are wrong and your (HCPF) job to make sure clients get what they need, when they need it, and should get it with respect and without undue burdens or barriers as has been the culture in the Dept

Families of people with disabilities are not "moochers" or "freeloaders" or a drain on the system. We are human beings with real needs and need to be respected and given the dignity we deserve. Nobody would go through this system unless they had real need!

That we aren't looking for "handouts" for our kids. We are just trying to raise them & get the best care for them so that they can be just as productive as any other citizen.

Caring and concern for all of their needs. Again try to put yourself in each person's shoes and to think about what you would do if you were in their place.

## UNDERSTANDING AND EMPATHY -45

The degree of pain and/or discomfort the individual has to deal with on a daily basis, and how long they have been afflicted with their condition.

They are people like everyone else.

That there is a necessity for the programs that our loved ones are in need of and that it is their job to make sure the needs are met....not to safeguard the system!!!

Parents have an almost undoable job - they tend to put things in a better context than they really are and need to be reminded that it's okay to describe their child as s/he is on their worst day because that is the reality. They need to be believed, not patronized. They need to be respected and their dignity validated. No one knows their child as well as they do.

(see above) Plus training in practicing REFLECTIVE communication, repeating what the customer says until the customer confirms that they have been understood correctly.

That we are not all trying to scam the asystem but are actually seeking their expert assistance.

patience and try to understand from our perspective

Pay attention

Do NOT assume that PWDs or their guardians don't show up for meetings because they are not interested. Their lives are sometimes chaotic and they often have little or no spare time; people who do have not experienced disabilities and/or chronic illness don't understand this.

Some parents are extremely tired and attempting to cope with years of sleep deprivation and/or ongoing very high stress levels. With appropriate sleep and respite, we could be more concise and clear with our communications. That isn't available for most of us, so learning to deal with people who are hyperactive and disorganized is critical.

While interacting with individuals with disabilities, employees must be aware that no one plans to be disabled, however, a willingness to adapt includes all circumstances.

We are just trying to make life as good as possible for the people with disabilities we support.

Disabilities are not cattle. They are real live human beings with feelings, needs, desires, and most of all need love and understanding. Some are difficult because what they have had to experience. WE WOULD BE TOO. On the other hand we don't need to make them so spoiled and demanding that no one can stand them. We need to treat them like we would a family member.

They should have shadowed a disabled client for at least a week. they should try and live on the monthly medicaid stipend.

## UNDERSTANDING AND EMPATHY -45

That individuals with disabilities and/or parent/guardian/representatives are people and should be treated as such.

One of the common problems with most disabling diseases is extreme fatigue that interferes with all functions of life: personal, relationships, and most of all with the loss of ability to work.

I would like them to know that just trying to go through a day, doing the things that everyone else does seamlessly, we encounter numerous barriers that have to be navigated.

Please listen to the person with the disability, if they are able to express themselves. They know their limitations.

Understand who they serve

How to "talk" to clients in simple and clear ways and give timelines.

This is 24-hour-7 days a week life that others may take for granted. We do not. Everyday is made special to give our people self-worth. So listening to our needs will be helpful.

Please don't take it personally if we sound irritated on the phone. Let us know that you are interested in helping us get from point A to point B, not in figuring out more ways to make things difficult for us.

Keep the big picture of all individuals involved not just a select few.

We have lived with this their whole lives we know their risks and issues as well as what they need better than you ever will.

Please remember that if you are employed with Medicaid that you don't have 'customers' or 'clients' - you have PATIENTS. Medicaid and those programs alike are crucial for people with disabilities and please remember that Medicaid isn't the only program that they have to stay on top of or communicate regularly. As you get frustrated with the patients, they can be equally as frustrated with hoops they themselves have to jump through on a regular basis.

Speak directly and use words that makes sense to the layman

Being Disabled does not equate being sick. They need to study at least a basics of the history, from being hidden in closets, to Large state run institutions, to moving back into homes and schools with PL94142 and Definitely Ed Roberts and others who fought to live in their own homes, go to school and have jobs

I would like for them to know that making the process more difficult by not clearly communicating makes life hard for people with disabilities.

## **UNDERSTANDING AND EMPATHY -45**

We live the experience EVERYDAY. We can help you help persons with disabilities because we are disabled or around it. It's our life.

Just what a quagmire it is...finding therapies, decent doctors, know what services are available, etc. There is so much out there and you usually have to find out what you need from other parents. That this is NOT something we choose. A lifetime with a disabled child is a lifetime for the rest of the family...especially the caregiver to give up their life.

## **KNOWLEDGE 18**

It is very frustrating when speaking with someone that is supposed to be informative and a support to learn that they don't know the difference in disabilities, not to mention cross disability or a case with a multiplicity of disability.

In my attempt to do the best for my daughter, it helps when I interact with people who look at me when they are talking to me or I'm talking to them. I feel like I'm being heard and that can ease my burden as much as having a need approved.

The person will want to learn and understand, and work towards benefiting the disabled

Your more experienced colleagues give out misinformation a great deal of the time. Please take everything you think you know with a grain of salt, and if a parent says they've been told otherwise, ALWAYS respond with a reference to an exact law, policy or regulation number along with the website it is located on. Your own supervisor/trainer may have accidentally misinformed you.

We need your help; you have the power to make a positive difference in our lives.

As parents, even though we are exhausted, most tend to under-report the struggles. It becomes the "new normal" for us and we lose track of what a typical life looks like, making the exhaustion worse because we beat ourselves up for not being able to do it all, day in and day out. Please prompt us a bit to get at some of the underlying struggles, because they are layer upon layer that needs to be teased out.

Spend actual time with consumers receive personal assistance services and meeting with the key community organizations serving persons with disabilities, including: CCDC, Family Voices, P2P, the ILC's and ARC's.

**KNOWLEDGE 18**

That these are not entitlements, they save lives, they rebuild lives and give hope, that they keep people independent and vibrant in community. That common sense and choice trump regs and bureaucrats-so pay attention. Also, the things we need and the form we access them in, are often better for us and the budget--i.e. snf vs community living with hcbs

make sure that you know as much as you can about medicaid before you start to go back to work. Talk with your caseworker about what medicaid has to offer when you do go back to work. It is hard the world is having a hard time adapting to the needs of the disabled community. For the disabled its harder to find jods, find housing, getting transportaion, and just plain old living in general is harder then an abled body person.

Not every treatment or method is black and white. One treament may work with one client where another may reject it or they just plain cannot deal with whatever the med/equipment/therapy, ect. Getting the resaources needed to function is absolutely essential to daily life, i.e., preferred size of gauze for g-tube fed individuals or replacement parts of wheelchairs for more active clients, ect. If they need it....allow it.

Parents and individuals with disabilities have years and years of interacting with all kinds of professionals, each time having to educate that person about their circumstances, and receiving different responses and understanding.

We often show up when we are desperate or worse and we do not know how to obtain benefits. It is all new to us and it is not obvious what we need to do.

Most parents, guardians, and host providers are natural solution seekers but may experience "battle fatigue" over the course of years of dealing with high rotating staff turn overs in CCBs- so be patient when explaining your agency policies and be prepared to direct them to a person who can really be part of the solution, not a transfer for convenience sake.

How to speak effectively about their program and what is available to the Medicaid family

Deinstitutionalization was hoped to be best for all persons with DD in the 1980's, not the case, and as such, placement options are limited and success does not look the same as a person who utilizes home health to a near complete recovery. DD population all have medical issues and more tech dependent folks cost more. DD status is Habilitation, not Re-habilitation so solutions to quality life look very different case by case & most PASAs do not have a knowlegable nurse in their employ to help weed through rules.

**KNOWLEDGE 18**

I think, as much as possible, new Medicaid employees need to understand the very basic needs of consumers. I think a new employee should trail several CNA's and/or CDASS/IHSS Attendants for several hours. They should also spend some time in a nursing home and assisted living. In addition to hands on (or close to being on), I think it would be wise to have a DVD giving new employees an overview of the independent living movement, why living independently and having choices over one's life is so very, very important to persons with disabilities, particularly those who need assistance with activities of daily living. I think too it would be good to let new employees know that not all persons with disabilities can live independently, particularly consumers with pronounced developmental disabilities. However, those individuals need resources and services that will enhance the quality of their lives and those of family members.

Medicaid employee needs to understand we don't all speak medicaid ease, the employee should make sure their information is easy to understand, concise and most important accurate

. Educate yourself before making assumptions - otherwise you become a hindrance and not a help to increasing the individual's ability to live as independently as possible and be a contributing member to their community. Remember the Olmstead Act and respect the civil rights of individuals with disabilities to live in their own chosen community.

**PERSON CENTERED - 14**

**Person-Centered!!!**

The main thing to remember is you are representing someone with a disability and you have to listen closely to what they say. In order to provide service for the individual you have place yourself in the person's shoes in order to understand the needs and services required for that individual.

**Serve PEOPLE, not SYSTEMS**

Understanding language and vocabulary choices to ensure person-centered approach and implementation of services

Communicate with us -- join with us in making things work for the people with disabilities, not just for the system!

Patience, listening and hearing, guide questions to get to the help the client is asking for there assistance on.

To ask about our circumstances. Not assume they understand it all because they see the "history" on paper.

**Person-Centered!!!**

The main thing is you have to learn to listen to individuals. Some individuals have problems with motor and/or speech skills due to the disability.

people first.

That people with disabilities have an opinion about their care.

**PERSON CENTERED - 14**

LISTEN we know the diagnoses and needs. we need help locating resources and navigating paperwork. we DON'T need Medicaid workers telling us their opinions.

We are people not forms, listen to us, know us, take your lead from us--we usually drive our life better than you assumptions about them.

**SYSTEM - 15**

That I am frustrated with the slowness of how things change for my child to be included. My irritation is sometimes with you, but mostly it is with a system that moves slow, is very complicated, and doesn't really meet my child's needs, but I depend on it anyway. And I work to make it better. I am not your enemy, I am an ally.

It seems like there is an enormous amount of paperwork and waiting. It is very helpful for a parent or an individual with a disability to understand the process and know what steps need to be taken and when. Then it's important to know that the paperwork will be taken care of in a timely manner. Many times things seem to get "lost" on someone's desk and oh, by the way, now they are gone on vacation for two weeks and no one else can take care of it.

We as parents of children with disabilities, spend a great amount of time on the phone with insurance people of all varieties. We often have to explain our child's disability and its medical consequences. It is helpful if we can talk to a person in a timely manner and not a machine. It is helpful if the Medicaid person listens and hears our problem and remembers each of our children are unique, their needs are unique, and they do not fit into a box. Sometimes we all have to think out side of the box to meet each chid's particular medical needs.

Required attendance at training (before employment and annually thereafter) actually experiencing a variety of disabilities (w/c use, non-verbal communication, blindfolded, hearing blocked, having your "advocate" MISREPRESENT your needs, etc.

The vulverability of people with disabilities necessitates a high level of responsiveness in whatever capacity that person presents- whether through application or through requested services

**SYSTEM - 15**

The complexity and difficulty of coordinating and understanding the various programs and requirements.

I think that PPL needs to have the option for benefits for employees. I have been with CDASS when it was a pilot program and have slowly seen the applicants interested in full-time hours dwindle since the option was discontinued.

Understand that we are probably working with multiple agencies, doctors, therapists, organizations and sometimes it's hard to keep everything straight. Working with one person at an organization who is able to answer all the questions without being routed to a different person all the time is very helpful.

When the person with the disability is assessed, they are nervous and often omit all of the care needs that affect their daily lives. The ULTC 100.2 and care plan questions aren't the only things you may need to ask questions about. Explain to them verbally and in writing how their care needs are funded in addition to what things they are responsible for knowing and complying with in order to remain qualified for continued funding. .

They need to understand that the system is very confusing and difficult to understand for individuals with disabilities especially those with brain injury.

Listen to the parent. Hear what the exact medical problem is, be willing to work on solving the problem. If there is any way to streamline the paperwork each year, so that the kids on Medicaid have their own paperwork, unique to their situation, and different from the general population applying for aid, it would help all of us as parents of special needs children.

Life is so different from that of friends and relatives. There is still a lot of stigma and very few understand the isolation and exhaustion in families with a member having a disability. Inclusion and acceptance and respect are so necessary, but only doled out in safe, small amounts from people who don't understand. Plus, with few services, the isolation only gets worse. Day programs mostly take those who are mildly impacted. Where do the ones with severe disabilities go? Nowhere because day programs can't afford to offer such individualized services that take a real low staff to client ratio. If you can get in with the right people, you might have a chance, but you have to get lucky.

## SYSTEM - 15

Be nice. The process of applying for Medicaid and all human services is difficult and the intake workers make it very hard to find resources for help, long wait times, and grouchy intake worker who make people wait for hours and often send them home for more information, making them come back numerous times for a decision. Please treat all people with respect, and understand that before they get to you, they have had to wait months and even years for help. Health care is expensive. Exchange preventative care with ER visits.

## HISTORY - 10

People with disabilities have always had to fight to get what they currently have---its been a long hard journey

where it all started

The disabled have been fighting for equality for over 20 years & we still hear things like "that dog can't come in here".

general history of the disability movement is maybe important (you need to know where you have been in order to know where you are going. It is important they understand and appreciate parents, representatives have a lot on their plate don't make them jump through extra hoops.

Who was Ed Roberts, Justin Dart, Wade Blank, Barry Rosenberg and what roles did they play in the early disability movement, which began in Berkeley? What do they know about ADA and its passage? What experiences have they had with people with disabilities -- especially developmental disabilities -- have they spent any time in their homes and/or with the parents?

New employees need to understand the history of the disability advocacy movement, not only the past, but the present. Why there are groups out there still advocating and pushing for change.

I have been a caregiver for 16 years to a grandchild with a severe disability - hopefully a new Medicaid employee would be a compassionate person and be willing to learn all about the history of the disability movement and why it was started

## **HISTORY - 10**

That the current rights individuals with disabilities have were hard fought and hard to retain - these are civil rights, like any person without a disability expects to have - paid employment (at least at minimum wage), adequate and appropriate food/nutrition, appropriate health care, education, the right to live freely in the community of their choice. Every day individuals with disabilities fight hard to ensure they retain these rights and that the bureaucracy that is suppose to support these rights do not make it difficult, and sometimes impossible, to hold onto these rights.

That we have historically been systematically excluded from community, relationships and wealth by a well-meaning service system that has too often reinforced negative stereotypes about us.

Utilizing a wheelchair to get around brings a better understanding of being a person with a disability, and employees should know the history of the ADA.

## **LAWS AND RIGHTS - 8**

That the ADA was fought for by families and those who care about the disabled....and that the ADA is to be honored by those who work in the system that serves them. The employee needs to study the ADA and see it as if they themselves were the person with the disability, as some day they themselves could become disabled.

Understand the ADA.

These programs are in place to equalize the playing field for people with disabilities, not "enhance." Treat individuals from the faciliator perspective.

It is about basic civil rights. An individual with a disability has the same rights and values as the next person.

I think its important for new Medicaid employees to understand that the ADA is about preventing discrimination against people with disabilities and assuring that people with disabilities have equal access to government services, employment, public places, etc. The ADA does for people with disabilities what other laws have done to protect against discrimination on the basis of race and gender.

how to keep up with all the rules and regulations is important not only to you but to the client as well.

That the prupose of Medicaid services for those with disabilities is to allow people to access the supports they need to live heathly, independent lives.

## LAWS AND RIGHTS - 8

Effective communication with an individual with a disability is highly individualized, requires an interactive process, and that employees may need to provide reasonable accommodations to effectively interact with individuals with disabilities.

## SERVICES - 6

The State employee is there to facilitate services not figure out how to deny. These programs are in place to use not minimize.

I don't know a lot about the disability movement except that it has been long and hard. Trying to get what is needed for my daughter can sometimes feel futile and hopeless. I keep trying and do the best I can for her.

Availability of services. Understanding that what type of services are needed on an individual basis.

I have called the employee because of what I consider a problem. It concerns me -- my health, at times my living situation. It is a timely call about an important --at times, scary-- problem. A. Answer the message (employees that I've dealt with seldom answer their own phones, & a machine takes the message. B. Answer it in a timely manner (within the day -- next day later, max) C. Be polite, and at least ACT caring.

This seems unimportant. What is happening now and what we are moving toward is more important.

Do not assume that they have all the answers always ask if they would like additional information about programs, figures etc.

## MEDICAL MODEL CONCERNS - 6

The necessity to focus on goal and dream acquisition, rather than medical model of rehabilitation

The difference between the civil rights and medical models of disabilities, and how they interact with respect to Medicaid. (Anyone want to write a thesis?)

To understand that the "medical model" of services should be discarded for an enlightened view of that consistently results in the provision of Medicaid services to support us in our goals to engage in a life that is characterized by the same aspirations that more "typical" community members have: to live, love, work and participate in society as each individual sees fit.

to avoid the medical clinical therapy labeling categorizing trumping approach to communication

## MEDICAL MODEL CONCERNS - 6

There is a vast (almost yawning) difference between the Medicaid services that are needed to ensure a healthy and inclusive life and those services needed in acute care settings.

The label/diagnosis does not equate to the need for support for adults or intervention for children. Each individual has different strengths/needs. It is very different from the acute care medical model where you get a diagnosis, prescribe a treatment and you are done.

## ADVOCACY - 4

Persons with disabilities and their family members have typically had to advocate strongly for many of the same things that non-disabled community is granted with ease. Over time, the result is that members of the disability community are burnt out, have less ability to keep fighting for their rights, and are often forced to "pick our battles". Please keep this in mind when a person backs off from an issue and don't assume that they agree with the outcome. It may be that they just can't advocate for that issue any longer. In some cases, they are facing another battle at that point that is a higher priority.

some of us parents have been fighting for our children's rights for many years and we're tired but we're not going away and we need to be heard. Being a parent of a child who is disabled is very difficult and we need to be part of the decision making about what works.

If you win 90% of the time you choose to argue, that behavior is going to be reinforced. If I continue to challenge you to get my son's needs met it's not because I'm trying to make your life difficult, it's because it works. The only way to prevent that is to make the right decision the first time: the decision that won't be overturned by a supervisor or judge later.

Most of us have been advocating for years for our children. It starts when they are diagnosed and we are told what they can't do, then we fight with insurance or in our case, we go to the community to do fundraising wheelchairs, therapy and communication devices. Then, we advocate in the schools, then fight for the few resources in the adult community. We get tired. We don't know the system as well as you might, or in some cases, we know it better. Simply put, we both need to suspend judgement and work together for the good of the client. Most important part...we are not out to cheat the system, just make it work for us.

<b>LEAST RESTRICTIVE ENVIRONMENT - 2</b>
that segregation (nursing homes, group homes, regional centers) and lack of interaction with the general public is a danger to health and can lead to abuse and neglect
That choice to make decisions regarding who, when, where and how their care needs will be provided. This will mean increased independence and a more healthy, happy life style opposed to having to live the rest of their days in a LTC institution.

<b>OTHER -10</b>	
See next answer.	
How to clearly communicate in writing.	
See above	
I have no idea	
not sure	
I have no idea	
See above.	
Already said in number 3.	
people first	
help us get birth cert for all.	