

The image is a collage. The top right shows a close-up of hands pointing at an X-ray. The bottom right shows a doctor in a white coat with a stethoscope around his neck, looking at a clipboard. The bottom left shows a man in a grey hoodie sitting in a wheelchair, being assisted by a woman in a grey shirt. The background is a mix of blue and teal geometric shapes.

# Let's CHAT about Health!

Communication and Health Advocacy  
Training Partner Guide for Direct Support  
Providers and Family Members

Prepared by:  
The Partnership for People with Disabilities  
at Virginia Commonwealth University



*Virginia’s leaders with disabilities recognized the need for health advocacy training for people with intellectual and developmental disabilities and supported the development of Project CHAT (Communication and Health Advocacy Training). When CHAT was created, the project team reviewed other programs around the country and globally. An advisory board was formed that was made up of professionals, family members, and people with disabilities. They reviewed materials with the project team, and provided important feedback. The training was piloted with several disability support organizations before finalizing the sessions. This partner guide is intended to supplement “face-to-face” training provided to people with disabilities, so that their direct support providers and family members can be informed of how to support people with disabilities in use of the tools that are found in the CHAT training.*

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# Welcome to CHAT:

## Communication and Health Advocacy Training



The CHAT training teaches people with intellectual and developmental disabilities (IDD) how to become more involved in making decisions about their health. The training is about how to speak up if you do not feel well, and what to expect when visiting the doctor. Healthy habits are important to maintain good health, so CHAT also teaches people about why staying healthy is important in order to do the things that they want to do.

This guide was developed to assist family members and others who support people with IDD to become involved in supporting healthy choices. A central part of CHAT is filling out the *CHAT Health Passport*. The *CHAT Health Passport* was developed to assist people with IDD and their care professionals in having conversations about health. The *CHAT Health Passport* helps people to become more comfortable speaking with health care professionals. By completing the *CHAT Health Passport*, people with IDD will learn to:

- identify health priorities,
- speak up if they do not feel well and identify who to contact if they need help,
- determine what is important to them during medical visits,
- determine what support they would like when communicating with health care professionals,
- get ready for medical care visits,
- speak to health care professionals about their health priorities, and
- let others know how to identify the signs that they may not feel well.

You can help the people that you support to use the *CHAT Health Passport* by having conversations about their health with you and other people in their support networks, including health care professionals. This guide can be used with a person that you support who has received the training or as a stand-alone tool.

## How to Complete the *CHAT Health Passport*

Few people actually make important health-related decisions without talking to someone first. Usually, things are talked over with a family member, health professional or caring friend. Completing the *CHAT Health Passport* helps you and the person you support to have conversations about some of the choices and decisions involved in their health care.



People learn best when important information is reviewed several times in different ways. You can support people by listening to what is important to them about their health, and helping them make informed decisions. Part of being a good listener is making people feel welcome to talk to you. Encourage people to ask any questions they may have, and help them find answers to their questions. As a part of listening, you also need to be prepared to answer questions in a way that people with IDD understand, and you may need to repeat things more than once. A good way to determine if people have learned something is to ask them to explain it to you in their own words. Sometimes listening simply involves showing the person that you hear and/or understand what they are saying, rather than answering questions or sharing your opinion. Try repeating back to them what they told you, or acknowledge what they are sharing, by using phrases like, “It sounds like you are saying that you feel...?” or “That sounds really \_\_\_\_\_.”

The CHAT Health Power Statement was created to help people remember the things that are talked about in CHAT sessions. You can practice the power statement with the person you are supporting and talk to him or her about what it means.

### CHAT Health Power Statement

**I am in charge of my health!** – No one else knows how you feel. You are the only person who knows that.

**My doctor is my partner!** – Doctors and other health care professionals want to help us, but they cannot do that if they do not know what is wrong.

**If I have a question, I will speak up!** – It is important to say something if you have a question or if you are not feeling well.

**I can do this!** – If you are not used to taking charge when it comes to your health, it may take some practice, but you can do it!

## Who Completes the CHAT Health Passport?

In order to encourage people to be in charge of their health, it is important that they provide the information for their own health passport. Encourage people to write information in the passport if they are able, but you can help if a person needs assistance. Please review the **CHAT Health Passport** before helping someone fill it out. This will allow you to be familiar with the information.

Some things to consider when reviewing the health passport:

- **The most important thing about the passport is having a conversation about the topic that is on each page.** The pages of the passport were designed so that they would be easy to write on and identify by color.
- Many people prefer to write their own information into their own pages, even if it may be difficult for others to read or understand. The writing in the passport may look like scribbles to someone else, but that is okay. If additional health passports are needed to give to health care professionals, blank copies can be found at [Center for Disability Leadership website](#).

## What if People Use Communication Methods Other Than Speech?

It may be difficult to gather information for the *CHAT Health Passport* if you are supporting someone who does not communicate using speech. If you are completing the health passport with a person that you support, you know the person and their preferred method of communication well. If you are not a family member or close friend, and you do not understand the person's communication, try to find someone who *is* familiar with the person. You can also try other forms of communication that

the person prefers, such as American Sign Language, communication boards, iPads, etc. If needed, you can try to find someone who is skilled at using the alternative communication methods to help you communicate. If that is not an option, try to find other people in the person's life who know him or her very well.



This person may be able to provide insight on what the person would like in the passport based on their knowledge and history with that person.

## Why Is It Important to Stay Healthy? See CHAT Health Passport page 1

It is important to be healthy. People often forget, or have never been told, why being healthy is so critical. CHAT begins by asking people to think about the things that they like to do, and what parts of their body need to be healthy in order to do the activities that they like. For example:

- If you like to play videogames, not only do you need good vision, but you also need to keep score and keep your brain healthy by paying attention to blood pressure to keep the brain active.
- If you like to play sports, you need a healthy heart and lungs to be able to move quickly.
- If you like to dance, you need good ears to be able to hear the music and need a healthy body to move around.
- If you like to spend time outdoors, you need to move over grass and streets or uneven surfaces. You need to be able to navigate your surroundings to keep from falling or be able to help yourself get up.

The form is titled "What I Like To Do" and contains a rectangular box with the text "Insert Picture Here" inside it. The form has a blue border and a small number "7" in the bottom left corner.

CHAT reminds people that in order to do the things that they love to do, it is important to stay healthy. Below are some suggestions for starting this conversation with the person you support and completing the relevant page in the health passport.

### Conversation Starter:



- “Let’s talk about all of the things that you like to do. What are some of your favorite things to do?” You may need to remind the person of some of the things that you have seen him or her doing in the past few weeks.
- “Last week you played BINGO. Do you like BINGO?” or “I’ve noticed that you spend a lot of time outside. Do you like being outside? [If the person says yes] What do you like doing outside?” It is important NOT to assume what the person likes, or to tell them what he or she likes.
- **Do NOT** ask leading questions like: “You like Bingo, right?” or “You like to go outside? Let’s write that down.” Some people have a tendency to agree with what is said, so they may agree with a question even if the answer is not true. Asking in a different way may be necessary. For example, the person may repeat the last thing said or respond differently to the same question if it is asked in a different way.

## What Are My Health Priorities? See *CHAT Health Passport* page 2

If something is important to you, it is a **priority**. After someone tells you what he or she likes to do, have a conversation about what health priorities are important in order to keep doing that activity.

You should refer to page 1: “What I Like to Do” in the *CHAT Health Passport* to figure out the health priorities. For example, if people like to play BINGO, they have likely used their eyes, ears, etc. to do so. Keeping these body parts healthy are health priorities.



### Conversation Starter:



- “Let’s talk about how your health helps you do the things that you like to do. What body parts do you use to do [insert activity]?”
- Help the person identify how health impacts doing the things that he or she likes to do.

Remind the participant that sometimes they may not feel if something is not working the right way inside their body and sometimes the doctor may find that something is wrong that they do not know about. If the participant does not agree with a doctor’s recommendation, it’s important to ask what would happen if the doctor’s advice is not followed. That way, you both can look at the risks and benefits of the doctor’s suggestion. You may decide to add that to the person’s health priorities.

## Speaking Up if You Do Not Feel Well

Have you ever asked someone, “How are you?” and he or she always answers, “Fine.” Often, people tell us what they think we would like to hear because they do not want to be a bother or they do not know how to describe if something does not feel right. Or, sometimes people do not have the words to describe how they truly feel. It is important for people to speak up and let someone know when they do not feel well. If someone you support does not seem to be him or herself, you can help this person do a body scan, to ask what does not feel right. A body scan starts with the head and covers the whole body.

For example:

- Tell me about your vision.
- How does your head feel?
- How does your throat feel?
- Do you have pain on your face or teeth?
- How does your mouth feel?

- How do your neck and ears feel?
- How does your chest feel?
- How do your arms or shoulders feel?
- How does your stomach feel?
- Do you have pain in your abdomen?
- How are your legs?
- How are your ankles and feet?
- Tell me about your mood.
- Are you feeling sad?
- Are you feeling scared?
- Are you feeling stressed?

You may still need to ask more questions to get to the root of the issue. For example, if someone says yes to everything, you will need to find a way to figure out the real issue. This may take time. Remind people of who they might tell about how they are feeling when they are not with you.

Mental Health is a critical part of being healthy! Mental health and physical health are closely connected. If a person's behavior seems to have changed suddenly or the person seems constantly sad, he or she may be experiencing depression or have another mental health issue. If someone is depressed, the person may not recognize it at first, or know how to describe his or her feelings. Depression is not a temporary change in mood or a sign of weakness. It is a real medical condition with many emotional, physical,



behavioral, and cognitive symptoms such as aches, pains, and exhaustion. It may be difficult for people to seek help if they are experiencing depression, and therefore, they rely heavily upon people who know them well to seek help on their behalf. It is important that the person seek mental health support right away if you see:

- prolonged sadness or unexplained crying spells,
- significant changes in appetite and sleep patterns,
- irritability, anger, worry, agitation, anxiety,
- pessimism, indifference,
- loss of energy, lack of energy,
- feelings of guilt, worthlessness,
- inability to concentrate, unable to make a decision,

- inability to take pleasure in former interests, social withdrawal,
- unexplained aches and pains, or
- recurring thoughts of death or suicide.

For more information, please visit: [Government Find-Help National Helpline](#) and/or [Depression Hurts website](#).

## Being Honest with Your Health Care Professionals

Many preventable health issues occur because people are embarrassed or never mention an issue when communicating with a health care professional. Although people have been taught that some things are not polite to discuss, people need to understand that a health care professional is someone whom they should develop a positive relationship with and trust. Creating honest relationships can lead to better health outcomes. Remind people you support that they are the ones who truly know how they feel, and that no one else can help them unless they are aware of the health issue.

No one should feel embarrassed to speak with a health care professional about anything that is going on with their body. If you both feel comfortable, you can help the person by discussing sensitive issues, including sexual or related health issues with the person so that they do not feel embarrassed. Health care professionals really want to help, but there is nothing that they can do if they do not know about the issue. It is important to be honest with a doctor or other health care professionals if the person is unhappy or if anyone has hurt him or her. If a person truly feels too uncomfortable to mention a topic, he or she may be less anxious if you bring it up with the health care professional on their behalf. However, you should not do this without their permission unless it is an emergency. When the person observes the conversation, he or she may realize that it is okay to have frank and honest conversations with health care professionals about their health.



### Conversation Starter:

- “Tell me about how you are feeling.” Or, “I’m worried that you are not feeling well today. How do you feel? How does your stomach feel? How is your energy level?”
- **Do NOT** ask general yes or no questions like: “Do you feel okay?”
- **Do NOT** ask leading questions such as, “You look really tired. Are you tired?” Or, “You seem like you might have a stomach ache. Does your stomach hurt?”
- **Do NOT** assume that you know the cause of a physical complaint. Do not say, “That stomach ache is just gas. You will feel better soon.” Instead say, “Your stomach ache may be from gas. Let’s wait half an hour and see if you feel better then.”



### Telling Your Health Care Professional What You Want - See *CHAT Health Passport* page 4

Knowing how to be involved in a medical appointment is an important part of being a good health partner. The top of the form on page 4 allows you and your health partner to talk about how you can best support the person. Every appointment is different, so it is important to have a quick conversation before every appointment about how you should be involved in this visit. Everyone makes choices every day about things that they like and things that they do not like. When going to a medical appointment, it is okay to ask for things that might make the appointment go better. For example, if wearing hospital gowns makes someone cold or uncomfortable, he or she can ask the health care professional if it is okay to wear a sweater over the gown, or if a blanket is available. For some people, it is important to hear how they are going to be touched before an exam

A form titled "At the Doctor's Office..." with a purple border. At the top, it says "Unless I tell them differently, I want my health partner:" followed by four checkboxes: "To go with me to medical appointments", "To go with me to the exam room", "To be with me when I talk with the doctor/other professional", and "To help me remember what the doctor/professional said". Below these is a line for "Other:". The form is divided into two columns: "What I like:" with a smiley face icon and "What I don't like:" with a frowny face icon. The bottom right corner has a small number "4".

When helping someone, on page 4 of the *CHAT Health Passport*, ask people to think about the things that they enjoy about going to a medical appointment, and then to think about the things they do not like. Once you determine what someone dislikes about a medical appointment, help him or her to think of ways to ask for what they like and minimize what they do not like about going to medical appointments.

## Conversation Starter:



- “When we go to the doctor, how can I help you? Would you like me to wait in the waiting room when you go back? Is there anything that you would like to tell the doctor privately?”
- Allow the person to determine whether or not he or she would like someone in the examining room when the topic of discussion or exam is personal or intimate.
- Go through the list of options on page 5 of the CHAT Health Passport.
- It is important to ask and not assume how the person would like you to be involved.
- **Do NOT** say: “You don’t want to see the doctor by yourself, do you?” or “I’ll speak with the doctor about you while you wait outside.”

If the person that you support has preferences about the time of an appointment, being touched in a certain way, or needs other accommodations, the person making the appointment should ask for these accommodations at the time of making the appointment. It is important to listen to the preferences of the person that you support so you can reduce the stress of going to a medical appointment.

Medical offices have to meet certain accessibility requirements. Please visit this site for more information: [Access To Medical Care For Individuals with Mobility Disabilities](#).

You may call the U.S. Department of Justice for information about the Americans with Disabilities Act (ADA) through a toll-free Information Line: (800) 514-0301 (voice) or (800) 514-0383 (TTY)

When supporting people with IDD during medical appointments, encourage them to speak up and have open communication with health care professionals. Your support could include things like:

- helping the person prepare questions beforehand,
- offering privacy or supported communication,
- assisting with getting the attention of or time of the doctor,
- encouraging the person to share their preferences during the appointment by asking the person to share with the doctor what he or she told you yesterday,
- stating the preferences of the person during the appointment if the health care professional is not respecting those preferences, and
- empowering the person to know that they are in charge of their own health.

## Conversation Starter:

- “Is there anything you really like about going to \_\_\_\_\_? What are the parts that you don’t like about going to \_\_\_\_\_?”
- After identifying some things that the person does not like, ask, “What might be helpful the next time we go, that would make this go better?”
- You may want to suggest things based upon your past experience with the person, but do not ask leading questions.
- **Do NOT** say, “Everybody hates \_\_\_\_\_. You don’t like that, do you?” or “I don’t like anyone looking in my ears. You don’t like anyone looking in your ears, right?”



## How Do You Like to Communicate with Health Care Professionals? See *CHAT Health Passport* page 5

How would you feel if you went to a restaurant with a friend, and the server spoke only to your friend about what *you* would like to order? Would you feel unimportant and invisible? For many people with disabilities, that happens frequently. It is hard to speak up for yourself if you are not considered part of the conversation. Well-meaning health care professionals may overlook speaking directly to the person with IDD and speak to the family member or direct service professional who brought the person to the appointment. On page 5 of the *CHAT Health Passport*, have a conversation with the person you are supporting about communication preferences with health care professionals. Consider whether the person prefers assistance (e.g., translators). Regardless of the chosen communication method, in order to be in charge of his or her health, it is important that the patient be addressed directly. Even if a person does not make eye contact or seems like he or she is not listening, it is respectful to include the person in the conversation. If the health care professional does not appear to be addressing the person, you can give a reminder to speak directly to the person. If the person is able to communicate, you may look at them and say something like, “Let’s ask that question directly to Nancy. What do you think, Nancy?”

If someone does not easily communicate with words, needs to walk around the room, make sounds, or seems unengaged in the conversation, do NOT act as if the person is not there. Instead say, “Nancy, we are talking with the doctor about the best option of treatment for your health. The doctor is suggesting \_\_\_\_\_. Is that okay with you?” or “Will you let me know if that is not okay with you?”

**Talking with Me about My Health**



*Check as many boxes as you like and add your own!*

*Talk directly to me, not the person who is with me*

*Do not share information with the person who came with me*

*It's okay to share information with the person who came with me*

*Write instructions down so that I can review them later*

*Check with me to be sure that I understand what you are saying*

*Speak slowly and clearly*

*I may not understand your words or accent*

*It's okay to joke around*

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**5**

Some health care professionals may speak in a way that is difficult for the person to understand. If that happens, it is important for the person to ask health care professionals to speak more slowly, repeat their words, or help make notes about what is being said. If you think the doctor is speaking too quickly, but the person you support has not spoken up, you can encourage him or her to speak up by asking, “Nancy, do you need Dr. [insert name] to speak more slowly or to repeat what he just said?”

When people have not been given the opportunity to communicate independently, they have a tendency to ask others to take charge of life choices, including health care choices. However, in order to really help someone become more independent, it is critical that the supporter bring the person with IDD into the conversation and decision-making about his or her health care!

If people have legal guardians, they may not legally make the decisions about their own health care, but it is important that they **speak up** about what they would like, so that guardians and support providers are aware of their choices.

### Empowering Conversations with Health Care Professionals:

- “Let’s ask your question directly to Sam. Sam, what do you think about \_\_\_\_?”
- “Can you tell the doctor what you told me yesterday about your \_\_\_\_\_ (symptoms)?”
- “Would you like for me to leave the room so that you may speak to the doctor without me?”
- “Would you like me to help you talk to the doctor about \_\_\_\_?”
- “Would you like the nurse to speak more slowly?”
- “Would you like the nurse to tell you what he’s doing before he does it so that you aren’t surprised? Can you ask him that yourself?”

### Information About ME and MY HEALTH – A one-page health profile

Information from the first 5 pages of the *CHAT Health Passport* should be transferred to a one-page information sheet that may be copied and carried to health care appointments. An electronic version of this form is available on the [Center for Disability Leadership website](#) so that the form can be updated as the person’s choices and priorities change.

Take time to go through pages 1-5 of the *CHAT Health Passport* and review the information with the person you support before it is written on the one-page form called **Information About Me and My Health (One Page Health Profile)**. It is important that health care providers are able to read what is written on the page, but it may be difficult to write in the small spaces provided in the one-page form. You should ask the person if he or she would like to write it or want help with writing or typing it.

The form is titled "INFORMATION ABOUT ME and MY HEALTH". It has a header with "Name: \_\_\_\_\_" and "Date: \_\_\_\_\_". Below the header are several colored boxes for information:

- A red box labeled "My picture" with "Please call me \_\_\_\_\_" below it.
- A blue box labeled "What I like to do".
- An orange box labeled "My health priorities".
- A yellow box labeled "Talking with me about my health".
- A purple box labeled "What I like and don't like at the doctor's office", which is further divided into "Like 😊" and "Don't like 😞".
- A green box labeled "Who helps me make decisions about my health".

## How Others Know I Am Sick - See CHAT Health Passport page 6

Everyone behaves differently when they are sick or not feeling like themselves. Some may feel extremely tired or cold. Others may become easily frustrated, irritated, or sad. It may be hard to remember exactly how symptoms affect someone when he or she is not sick, and that is why there is a checklist on page 6 of the *CHAT Health Passport* that lists some common ways a person may show that he or she is not feeling well. If the person's symptoms are not listed in the checklist, there is room to include individualized information at the bottom of the page. One thing that would make this easier to complete would be to take notice of the next time the person you support becomes sick. Check in with him or her to describe how his or her body feels, or what their emotions are, when they are not feeling well. What are the behavioral or physical changes that you notice?

Emphasize that the person with a disability should try to speak up when not feeling well and should tell someone who is around them. Telling someone once may not be enough. If a person is unable to speak up, you can assist in telling medical staff that the person does not feel well and explain the person's symptoms.

### Conversation Starter:

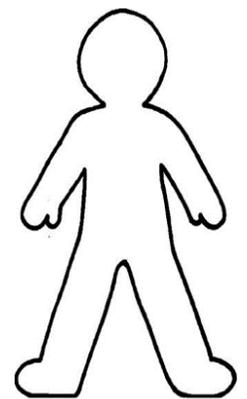


- “If you don’t feel well, you have to tell someone so that you can get checked out. How would someone know if you are not feeling well?”
- “Who would you speak to about this when you are at \_\_\_\_\_ (home, work, Special Olympics etc.).”
- “How will you let someone know? What if you need to use the telephone?”
- “If you tell someone and they don’t have time to listen to you, what are some things you could do?”

## Describing Your Symptoms: Where Do I feel Bad? See CHAT Health Passport page 7

### Describing Symptoms

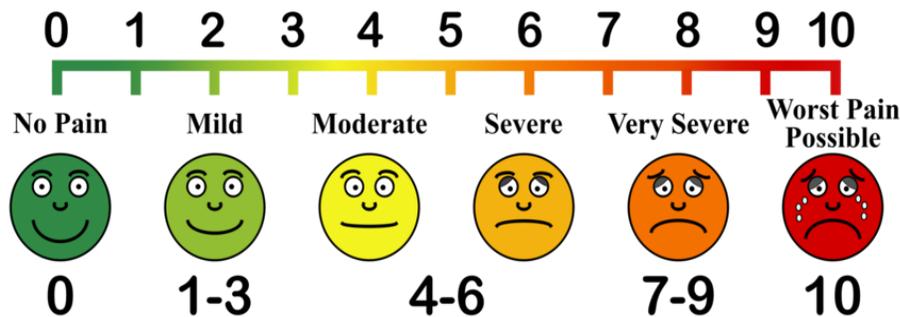
If you do not know the correct words, or do not communicate using words, describing exactly how you feel when you are not feeling well is difficult. For some, asking ‘yes’ or ‘no’ questions (Do you feel like you are going to throw up? Do you have a headache? Are you feeling sad or angry?) can be helpful, but you may not ask the right question and therefore may not receive critical information about what the person needs. Do not assume that someone understands the meaning of some words that describe symptoms such as nausea, heart burn, or constipation. Page 7 of the *CHAT Health Passport* shows a diagram of a person's body, and points out the major areas of the body. If describing the pain is difficult, the diagram provided on page 7 can help people describe where they may feel bad by pointing. Keep in mind



that they may not be feeling well because they may be feeling sad or stressed, so be sure to describe the role of the brain in your diagrams and discussions.

## How Much Pain? Do Symptoms Limit What You Can Do?

Not only is it important to describe where pain is felt, but also it is important to be able to tell someone how much it hurts. Page 8 in the *CHAT Health Passport* has a diagram of the **Wong Baker Faces Pain Rating Scale**. It is important that people understand the pain scale before they are in pain, so that it will be helpful when they need it. Some people will always indicate that their pain is a level 10, the worst possible pain. Therefore, you should review the pain rating scale with them and talk about what the faces describe. Explain the other levels of pain on the scale.



*Wong-Baker Faces Pain Rating Scale*

In addition to discomfort, pain and symptoms may impose limits on what people are able to do in their everyday lives. The tools on page 8 of the *CHAT Health Passport* can help people describe a pain level, or figure out how their activities may be limited because of the symptoms of their illness. Keep in mind that, if someone is feeling sad or stressed, their activities might be affected for reasons other than physical limitations.

## Talking About What Is Going On “Down There”: Abdominal, Digestive, and Genital Issues

Describing what does not feel right to someone is a very personal conversation. It is important to be able to describe or point out where pain or discomfort is coming from. As mentioned above, many preventable health issues occur because people are embarrassed or never mention an issue when they communicate. Women may not feel comfortable describing their symptoms to a male family or staff member, and the same is true of men describing something to a female



family or staff member. It is important to feel comfortable when describing issues surrounding menstruation, bowel movements, or issues which involve someone's genitals or anus. Digestive issues, skin irritations, urinary or bowel problems may be embarrassing to mention. If the person is not comfortable discussing these types of symptoms with you, it is important that he or she feel comfortable speaking with a health care professional or someone else.

## My Doctor Is My Partner

People should not feel afraid to have a conversation about anything with health care professionals. It is important to feel comfortable when describing issues surrounding menstruation, bowel movements, or issues that involve someone's genitals or anus. You can make someone feel more comfortable by asking frank and honest questions without becoming flustered or embarrassed. Reassure the person that everyone feels different and that his or her signs and symptoms may be different from other people, which is okay.

If a medical visit is scheduled, it will be important to be prepared to have an answer ready when the health professional asks, "What's wrong?". It is a good idea to practice how to answer that question and assure the person that it is okay if the doctor asks a lot of questions. The CHAT "My Doctor's Appointment" form provides an outline for what information should be easily provided, such as:

- what allergies the person has,
- current medications,
- symptoms that they currently experience,
- questions and concerns, or
- follow-up instructions.

## Moving Forward - Preparing for Future Medical Appointments

Communication is key to helping everyone speak up about their health to be their own health advocate. The information in this guide helps people with IDD take charge of their health and prepare for a medical appointment with someone who supports them, whether it is family, staff or a friend. Health communication is one of the key factors in preventing potentially serious medical issues from occurring.

Now that important information has been reviewed and written down, it's time to share it with the person's health care professionals. The information can be transferred on to the **CHAT One Page Health Profile**, which can be found on our website [Center for Disability Leadership](#), and on page 11 of this guide. When you visit the doctor, share a copy of this information, and be sure to update it as things change.

Thank you for helping someone who you care about become more empowered and advocate for their own health.

### CHAT Health Power Statement

- I am in charge of my health!
- My doctor is my partner!
- If I have a question, I will speak up!
- I can do this!

