



## *How Can I Have More Choice in My Life?*

NOTE: In addition to the person needing supports, “you” also refers to the family member or friend who will assist him or her to get the needed supports and services.

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### ***Why is Choice an Issue?***

Most of us make many choices each day throughout our lifetime but we don’t even think about them. We take for granted our ability to make choices. However, many people with developmental disabilities have not had the opportunity to make choices about things in their lives. In the past, other people have made choices for people who receive supports and services but change is happening now. People working in the mental retardation system have embraced the idea that all people should have choice about everything in their lives.

### ***Who Makes Choices About My Life?***

#### ***Choice belongs to you!***

The self determination movement, with individuals and families controlling their own lives, is changing the way choices are made. In *Everyday Lives: Making It Happen*, people said they want choice in all parts of their lives. This includes both small choices such as what to eat or wear and bigger choices such as where to live and work. You have the right to make choices and people who support you need to believe that you are capable of making choices, even though you might need support to do so.



Most of us do not make choices by ourselves. We talk with family, friends and loved ones to get information so that we can make better choices. Keep in mind that any choice requires responsibility and health and safety considerations and there are consequences to the choices we make. Choice belongs to you! Not just some choices, but all of the choices in your life.

### ***What Happens When Someone Is Concerned That I'm Making a Choice That Will Endanger My Health and Safety?***

If a family member or support person is concerned that you are making a choice that will harm you or another person, then they should explain to you why the choice might endanger your health and safety or another person. Since it is difficult to define what is meant by “endangering your health and safety,” a meeting of your support team should be called to discuss the particular issue that is causing concern. Your support team can help you to understand the consequences of your choice and you will be able to tell the others why you believe the choice makes sense for you. By taking the time to understand other people’s concerns and hopes for you and learning more about options that exist that you may not have known about, you will be better able to make an informed decision.

Working together, you with your support team ought to be able to find a satisfactory balance between the choices you want to make and maintaining your health and safety. For example, a gentleman wants to go to the local bar where his favorite kind of music is played. This is not a moral issue but there are medical reasons why he should not drink alcoholic beverages. His support team meets and decides that it is safe for him to go to the bar as long as he does not drink anything containing alcohol. They suggest that he order soda or non-alcoholic beer so he can still enjoy the music and being with the people there.

### ***What Might Limit My Choices?***

If you are supported with government funding, then the person or agency that provides your support is obligated to protect your health and safety but this should always be balanced with your choice.

Everyone has limits on choices that can be made. One of the main limitations is the cost of things we want. For example, if you want to live on your own in an apartment, you need to find one that you can afford with your income or else find roommates to share the cost.

Another limitation on choice is when you do things with other people. This happens in everyday lives. Sometimes you need to compromise or take turns with your friends in choosing things such as how to celebrate a special occasion or the restaurant where you and your friends will have dinner.

Having choice also means that you are responsible for the results of your choice. For example, a lady didn’t like going to the workshop because she didn’t have money to spend for things she wanted. She got a job in the community that paid her more money but at the job site she didn’t have friends like she had at the workshop. To solve this problem, she chose to work part time at the job to earn the money and go to the workshop part time. A gentleman in a similar situation made plans to meet his friends at a local diner so they could stay in touch. Things may not always work out this well for you. When you make choices that aren’t good for you, you have to take responsibility for the consequences. For example, when you choose to eat food that does not agree with you, then you need to recognize that it may make you sick. Or if you choose not to go to work when you don’t feel like going, you need to accept the fact that you may lose your job.

Concerns about safety might limit some of your choices. For example, two young ladies were sharing an apartment where they didn't feel safe because it was on a busy road and they were uncomfortable with some of the people who lived in the building. The busy road was a problem because they are watching their weight and need to walk for exercise in order to stay healthy. They moved to a condominium on a road that doesn't have much traffic so they can safely walk for weight control in addition to watching what they eat. The ladies understand that it is safer to walk during the day so one lady walks in the morning before going to work. The other lady walks in the afternoons.

### ***Where Does Choice Begin?***

Choice begins with you. Sometimes choice begins with knowing what you want and you just make a choice. An example would be that you choose to take a shower in the morning rather than showering at night. Having choice means that you have two or more things from which you can choose. Choice is not only, "what is available." You need to continually have the opportunity to try new things so that you will have more things from which you can choose.

You also have the right to refuse the things that are offered you. For example when asked if you would like to go shopping, if you use words to communicate, you can say, "I don't want to go shopping now. I'd rather stay home." If you do not use words, you might use body language to indicate that you do not want to go shopping. Your supporters could then ask if you would prefer to stay home. When you choose not to accept any of the things you are offered, the people who support you need to find other options for you. Regardless of how you communicate, choice begins with you.

### ***What Kinds of Choices Should I Have?***

No choice is too large or too small. Sometimes you will find yourself struggling with the small everyday choices and big life choices at the same time. For example, you chose to buy your own home and you also are choosing the color of paint for the rooms.

You should have choice about all parts of your life. This includes things such as choosing:

- Your Supports Coordinator, from those that are available
- How you communicate with other people
- How you spend your money
- Having a senior lifestyle when you are older
- What you want
- To have a key to your home, regardless of where you live
- Moving out of your family home and living independently
- Whether you live alone or with someone else
- The person or persons who live with you, if you choose to have roommates
- Who you allow into your home
- Who has a key to your home
- With whom you spend time
- To be alone at times
- To open your own mail
- To use a telephone in privacy



- To have privacy when friends or family visit
- To be alone with intimate friends or sexual partners
- What you do during the day-work, volunteer or other activities
- What supports and services should be paid for with your money, within limitations related to funding sources
- Whether an agency, individuals, or a combination of the two provide your supports and services
- Who provides your supports and services
- Who will assist you with personal care. Sometimes this will require trying several people and then choosing the one who works best with you.
- People who respect your modesty
- When and where you shop for things you want
- Your daily schedule
- A comfortable chair
- What you eat
- What you wear
- Relationships with friends, other than paid staff and relatives
- Whether you see your friends and family and when you see them
- To get married or not

- When and where you go for fun and with whom
- Where you go for vacation
- Whether you attend worship services or not and the place where you worship
- How you celebrate your birthday-going out for dinner, having a party, or doing something else that is meaningful to you. These would also include other choices such as who will celebrate with you, the restaurant or party food and decorations.
- Presents for holiday gift exchanges with friends and/or family
- Where and with whom you spend holidays
- To be your own boss and hiring your support people, if you want to do this
- To vote.

In addition to these choices, you probably will be making many other choices in your everyday life. The following are two examples of choices that some people have made.

We often take for granted that all people have keys to their homes but this is not true for many people who have a disability. You should have the choice of having your own key to your home, regardless of where you live. It doesn't matter if you live with your family, in an apartment or in a community home and whether or not you need people to assist you. Just tell the people who care about you that you want to have your own key.

Having a key to your home is part of having an everyday life and there are important reasons why you should have a key. One lady was out of her home and realized that medicine that she needed to take was left at home. Without a key, she would not be able to get into her home to get the medicine. There also could be a time when you are out and not feeling well so you would need to be able to go home. In another situation, a lady was in the community with her support staff and her mother found herself in a situation where she could not get home at the time she was expected to be there. The mother telephoned the support person and told her what was happening, told her that her daughter has the key to the house and requested that she stay there with her daughter until she could get home. Another time this young lady spilled a beverage on her clothing while she was out. This made her uncomfortable since it was a cold day and she was embarrassed and upset. Since the lady had the key to her home, she could return home and change her clothes before returning to her planned activities for the day. Having a key gives you more independence and allows you to better handle situations where things don't go the way you had planned.

Another choice is having a Pennsylvania Photo Identification card. This is an official ID card for people who do not drive, issued by the Pennsylvania Department of Transportation (PennDOT) for a fee. It contains your address and a picture of you.

You not only can choose to have a photo ID, but there are several reasons why you ought to have one and carry it with you all of the time. One lady chose to get an ID card so she could be like other people with their photo driver's licenses. She has used it several times. One time a medical provider asked for her

photo ID and she also was asked for it when she signed up to use a swimming pool in her community. Another time you would need to have an official photo ID would be if you plan to travel on an airplane, train or ship, since all passengers now must show a photo ID before boarding. You may also need to show a photo ID before entering some buildings.

If you should be in an accident and the other people with you could not identify you, then it would be useful to have an ID card. Another time that it would be useful would be if you were to get lost. In that situation, if you were carrying your ID card, then people could assist you in getting home.

If you want to have an official ID card, ask the people who care about you to help you to get one. After you get your photo ID, then it will be your responsibility to carry it with you at all times.

### ***How Can I Learn to Make Choices If I've Never Made Them Before?***

Having choice is important because it is a way for you to have control over your life. Making choices is a skill that is learned. Many children learn how to make choices as a natural part of being a child but sometimes people become adults without having learned the skill. It is never too late to learn to make choices about things that matter to you in your life. If you have not been given the opportunity to make choices in the past, then you probably will need to start with some basic choices like what you wear, your daily schedule and how you spend your free time.

As you begin to make choices and your choices are respected, you should find that you are making more and more choices. The more choices you make each day, the easier it will be for you to always be making choices.

Sometimes people who support you will need to ask you what you want and then listen carefully to what you tell them. You may be telling them with words but your actions will also tell them what you do and do not like. They also need to be patient and give you time to respond.

Several young adults have learned about making choices by being part of a self advocacy group where they learn from each other. In addition, these people chose to become part of a team that monitors the quality of mental retardation services in their county. While being involved in this project, they learned about options that are available to people and they learned to tell other people about the choices they want to make in their own lives. They also learned that people are different and even people who seem to be similar make different choices.

Even though you are an adult, sometimes your family may not recognize that you are able to make good choices without being reminded all of the time. A young lady knows that she needs to follow a healthy diet and exercise regularly in order to maintain good health. When she told her mother that her mother didn't have to mention her diet all of the time, her mother realized that her daughter understands what makes a diet healthy and said, "Perhaps parents need to make the choice to be quiet."

You might begin to tell other people about your choices by picking something that is important to you that you want to have in your life or something that bothers you that you would like to be changed.

### ***How Can I Make Choices If I Don't Talk or Use Words to Communicate?***

You do not have to talk or use words to be able to make choices. There are different ways that you might communicate your choices to the people who support you. When asked to make a choice, you might respond with a smile, nod, other head movement or a blink of your eyes. People who care about you and know you best will figure out how you communicate what you want and do not want. Your support people need to really get to know you so they will understand what you are communicating and this takes time. People who support you best will spend time just watching you so they will learn to read what you are saying by your actions. They may have to try several ways of communication before they find one that works for you.

If you do not use words to communicate, your supporters will have to make guesses about what your choices might be based upon what they know about you. They will have to ask if you are interested in several options so you can choose one of them. If your supporters haven't figured out what you are choosing, then they will have to try one of the options and observe your reaction to it. Your actions will communicate if you would choose this particular option or not. This process may have to be repeated several times in order to get a clear picture of what you want to choose.

There are various ways for you to choose things that you want or do not want. The following are some examples:

- When you are exposed to a new activity, your behavior often tells the people who support you whether or not you like the activity. However, they may have to try the activity several times to determine if you really like it or not since sometimes we're not sure how we feel about new things at first.
- One young lady looks at the items she chooses and looks away for things she does not want. For example, her support person lays two shirts or blouses on the bed and by looking at one of them, the lady chooses which one she wants to wear. When the lady looks at the item that is mentioned, then she is choosing to wear it that day. The same procedure is used in choosing the slacks she wears. If she looks away from both choices, then she is choosing not to wear either item of clothing. The person who provides support then needs to go item by item through the other things in her closet asking if she would like to wear each one.
- One lady chooses paid support staff who work with her, with assistance. She is involved in the interview process and later says "yes" or "no" on hiring the person by use of eye gaze—either looking directly at the person asking the question or away from the person.

- A gentleman, who needs much assistance, points to the foods in the kitchen that he wants for dinner. He chooses newspapers and magazines he wants to purchase by pointing to them. In addition, he uses pictures in a photo album to make choices about what he wants to do when he goes out.
- A lady who lives in a community home used to visit her family on one Saturday a month but her family and staff discovered that the schedule wasn't working well for the lady since she preferred to stay home and do fun things with her housemates on Saturdays. Now the lady selects the day from four or five days offered each month including Saturdays, Sundays and weekdays by looking at the support person for the time she wants.
- Another way you can choose things is by picking up the item you want. For example, you might be offered a carton of milk and a juice box of your favorite juice so you can pick up the one you want. If you don't pick one of these, then you are showing that you want another choice. Perhaps you would like water or a warm drink or you may not be thirsty. By watching what you choose and by providing many options, those who support you and care about you can help you have your choice.

- Pictures of things you might want can also be used to help you make choices of things that are in another place. Some examples would be photos of your favorite restaurants and other places you enjoy for fun, beverages and foods you enjoy, and people who are important to you whom you would like to visit.

- Generally going to the bathroom is a personal choice on the most basic level. In the past, because she didn't know how to communicate this need, a lady was unhappy when staff would take her to the bathroom when she didn't need to go. One day this lady who needs toileting assistance, tapped the hand of her support staff when they were sitting together at home. The support staff asked, "Do you have to go to the bathroom?" The lady looked directly at her support staff (this is her way of communicating "yes") and then she willingly went to the bathroom. This only happened through the staff getting to know the lady over a long period of time and learning the right question to ask. It takes time and commitment to develop this kind of understanding that the lady and staff have worked out but it is very exciting when it happens. The support person and the individual both benefit from developing this kind of relationship.

We never know what is possible as far as how you might communicate about the choices you want to make. Therefore, you need to continually have the support you need and be encouraged to make choices. This needs to happen every day, throughout the entire day, so you can continue to grow and learn.

### ***What Happens When I Change My Mind About a Choice I Made?***

People choose to make changes in their lives all of the time, usually leading to improvement. However, sometimes you may have to try several choices before you find the one that is right for you at the time. Just because you make a choice, it doesn't mean that you have to live with that choice forever.

Sometimes after a period of time you will change your mind about a choice you made. An example is a young gentleman who was living in a community home with two roommates. He has many skills, works at a part-time job and wanted to live alone in an apartment. After moving to his apartment, he found that he was lonely and decided that he wanted to have a roommate. He chose his new roommate and now he is happy living in his apartment. Another example is that you may want to have a pet dog. After having one for a while, you may discover that pets require a lot of work so you no longer want to have a pet but you had the opportunity to try the choice you made.

When we change our mind about a choice we made, sometimes we may need to do some things differently or we may need to plan and make arrangements for the change. Consequences and responsibility come with making choices. In the above example,

you would need to make other arrangements for the dog when you changed your mind about having a pet. In addition, until you could find someone who wants the pet, you would have to continue to care for the dog.

It is important for those who support and help you to recognize that just because you chose not to do something for a while, that doesn't mean you will always feel the same way about it. For example, for a while a gentleman chose to stay home rather than go out to eat and do other things in the community with his roommates. Now he is telling his support staff that he wants to go to a local dinner theater and they are making plans to do that.

### ***What If My Choices are Different From What My Family Wants For Me?***

You and your family may have differing ideas about some part of your life. Parents and other family members usually are acting out of concern for you and want to prevent bad things from happening to you. Following are some stories about adults who wanted choices that are different from what their families wanted for them.

A gentleman who is generally happy doing whatever other people choose, told his support staff many times that he wanted to go to the beach for vacation. His sister didn't think her brother would enjoy the beach and didn't want him to have a bad vacation so she had another idea. Staff used pictures of the beach and brochures from the place where he would stay at the beach, asking him many times if the beach trip was really what he wanted. Since the gentleman never changed his mind, his support staff advocated for what he wanted and were able to work out a compromise with the gentleman's sister so that he

got to do both things. He went on vacation to another place but also took a short trip to the beach to check it out. If this hadn't been worked out, an outside mediator could have been used to work with everyone involved so the gentleman and his sister could both be satisfied.

A lady comes from a religious Mennonite family but she doesn't want to wear the traditional Mennonite clothing, especially the black shoes. Her support staff respects both what the lady wants and her family's culture. A good relationship has been developed with the family and they have open communication where staff can explain how the lady feels to her family. Sometimes you might need another person to help you communicate with your family.

A gentleman had problems getting along with his brother and said he didn't like his brother telling him how to cut his hair and what to wear. When the brother did this, it would cause the gentleman to be upset and he would tell his support staff, "I wish he wouldn't come here" but the gentleman never told his brother directly how he felt. After observing this situation for a while, staff communicated about the problem with the gentleman's brother. The gentleman feels good that his support people are respecting his point of view. Even though he might not be happy, the brother now realizes that the gentleman is an adult and can make his own choices. This is an example of how choice can change a relationship and create a new level of respect between family members.

If your choices are different from what your family wants, you may want to gather a group of people to help you plan. You choose people who like you and know you well. Sometimes not all of the people in your group, including your family members, will agree on everything. The planning process looks at things in a variety of ways. Input from you, your family, friends and

the people who are paid to support you is gathered and valued. You contribute what is important to you. The other people contribute what they think is important to you and for you. Planning gives you an opportunity to discuss where you all agree and disagree and then decide on something that works for everyone and most importantly, it works for you. People planning with you need to really listen to what you are saying, not only with words but with your actions too. Listening is an important part of planning. Planning should help people who care about you understand why you are choosing the things you choose.

### ***What Happens If I Don't Make the Best Choice?***

We all try to make good choices but part of life's experience is that sometimes we make choices that perhaps are not the best ones in the long run. When we make the choices we have no way of knowing that they won't work out and hopefully we learn from the experience.

For example, a person who supports a gentleman planned a pre-paid vacation package for the gentleman that included a rental car. At home a van is used for transportation and there is no problem. On vacation the gentleman didn't want to ride in the car because he has a fear of sitting near a door in a vehicle. Through this experience the staff learned that next time they would have to rent a mini van.

In another case, a lady wanted to get married. Her family told her not to get married but she did it anyway. After being married a while, she learned that this was not a good choice. Now she lives independently and that is working well for her.

When a lady had some medical issues, she was told to quit her job that she loved. After a short time she realized that she missed the people at work and also missed earning money. The

lady called her employer and asked if she could return to work. Fortunately for her, she was able to return to her job.

In another situation, a gentleman was not so fortunate. He had a job in a restaurant but made the choice to quit that job so he could work in a factory where he could earn more money. Before long, the gentleman discovered that he didn't like the new job as much as he enjoyed working in the restaurant. When he called his previous employer to try to get his job back, he learned that the position had already been filled.

### ***I Live in a Community Home, What Kinds of Choices Can I Make?***

Choices should not be limited just because you live in a community home. However, remember that when you are being supported with government funding, there is an obligation not to jeopardize your health and safety or the safety of other people. People who are encouraged to have self determined lives are making choices every day.

You should be asked if you want particular staff people to work with you. The supervisors in your home can tell potential employees who come for interviews that this is your home and you and your housemates will hire the people who work there. After the interview, the supervisor can ask you and the other residents if you would like to hire this person. When all residents agree, the person should be hired.

When there is a vacancy for a resident in your home, you should be able to participate in interviews with potential housemates and have input into the choice of who will live with you. You should also choose the music you want to hear, the food you eat, the clothes you wear, how you spend your money

and whom you spend it on. You have the right to choose where you go for fun and with whom.

Your room should be furnished the way you want including the furniture in your room, the wall colors, the spread on your bed and pictures in your room keeping in mind that the items you choose will have to fit into your budget. You should also choose where things are hung on your walls and placed on your furniture. In addition, you have the right to choose the people who enter your room. If you are responsible for cleaning your room, you should be able to choose when you clean it.

You should choose your daily routine—the time you get up in the morning and go to bed at night; when you shower or bathe; the order in which you get ready for the day in the morning and prepare for bed at night. In addition, you should choose whether or not you attend religious services and where you go to do so.

If you feel that you no longer want to live in your community home, then you should talk to your friends and people who know and care about you about your desire to move somewhere else. There are some planning tools available that can help you figure out how to go about moving to another place. These are described in the Frequently Asked Questions pamphlet called, *What Should I Know About Person Centered Planning?* You can download a copy by going to the Department of Public Welfare, Office of Mental Retardation Web site [www.dpw.state.pa.us](http://www.dpw.state.pa.us), call your county Mental Retardation office or call the Pennsylvania Self Determination Consumer and Family Group at 1-800-459-1838.

## ***How Can Planning Help Me to Make Choices?***

If you feel you have not been making choices in your everyday life and want to, perhaps you should find someone to help you create a person centered plan. Person centered planning is a way for you to say what is important to you and what is important for you in your life. It also helps you figure out how to make the things you want in your life happen.

You choose whether or not people will be part of your planning group and who will attend meetings. Sometimes you may have a good reason to not want someone to participate in your planning meetings, even family members. One gentleman has a good relationship with his mother and wanted her to have input into his planning process but not by participating in his planning meetings. He asked her not to attend planning meetings and gave her the following reason. He uses an assistive device for communication and he discovered that when his mother is present, people look to her for responses rather than to him. At first his mother was surprised by his request but after she thought about it a while she said, “I was very proud of my son for making people listen to him, even though it takes longer.”

There are some times in your life when it is especially helpful to go through a planning process. Some of these are when you: want to change your job to one that better suits your interests; change where you live; or when you have a major conflict with agencies, your roommate or your family. It is also useful to plan before you are in a time of transition, such as when you leave high school and go to work in the community or when you retire from work.

When you communicate about the kind of job that is important to you and tell those who can help you make this choice happen, it can result in your being satisfied with your work. A

gentleman had a manufacturing job in a factory that was terminated. As part of his planning process, he expressed a desire to work around trains since he is very interested in them. He also collects baseball type caps. When he had to find a new job, the people who know and care about him helped him to find a job in the gift shop at a train museum where he stocks shelves with caps and other items. Planning helped him with his job choice and resulted in his finding a job based upon his interests that he really enjoys.

Most of us don't think about practicing a religion as needing to be a choice. At the personal care home where a lady lives, they have religious services but they are different from what she was used to all of her life before moving there. She made a choice that she didn't want to attend the services at the home but wanted to attend her old church. She communicated this choice with someone who could call the church to arrange for transportation. Now members of the congregation take her to her familiar church.

A lady wasn't happy going to the day program five days a week. Her planning support group assisted her to change her schedule so that she now goes to the program three days a week and spends the other two days building relationships in the community. This change took a while to accomplish but the lady seems happier with her new schedule.

Another young lady was very unhappy with the workshop she was attending. Her family worked with her to figure out what she could do instead. Using her individual budget, they changed her supports from a formal program to selecting her own support staff that assists the lady with being involved in community activities.

## ***What is Choice About?***

Choice is about you having the life that is best for you at any time. You are responsible for letting people who are supporting you know when your tastes change or when you are unhappy with some part of your life and you want to make changes. People who are close to you need to understand when you are not happy so they can help you to make your life better.

Typically at some point when people grow older, they need to have more space than just a room in the family house. For example, a young gentleman wants to live in his own apartment on his family's property and he communicated this choice to his family. They are now in the process of building a new family home that includes his apartment. Another gentleman decided that he needed more space in his parents' house so he asked if he could have another larger area of the house for his own. Realizing that he is now a young gentleman, his family is considering this possibility.

Just making choices is not enough. Your choices need to be respected by the people who support you.

**CHOICE BELONGS TO YOU!**

You can download a copy of this FAQ pamphlet and any other FAQ by going to the Office of Mental Retardation Web site [www.dpw.state.pa.us](http://www.dpw.state.pa.us)

This informational pamphlet was created by a work group of the Pennsylvania Self Determination Consumer and Family Group and the Pennsylvania Office of Mental Retardation.

For more information or other assistance from the Pennsylvania Self Determination Consumer and Family Group, call 1-800-459-1838.