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SELF-DETERMINATION: WHOSE DECISION IS IT ANYWAY?



Ideas to encourage
self-determination

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**Self-Determination:
Whose
Decision
Is It
Anyway?**

Prepared by Educated Transition Choices
A project of the Utah Parent Center
For the Utah Self-Determination Project
Division of Services for People with Disabilities
June 1999

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TASH, an international disability advocacy organization (formerly The Association for Persons with Severe Handicaps). The office of TASH is located in Baltimore, Maryland.

INTRODUCTION

Self-determination is about being in charge, making choices and accepting the consequences. It encourages people to make their dreams come true.

For Jed it meant leaving the institution. He moved back to a town near his family. He lives in his own apartment with some assistance and has two part-time jobs.

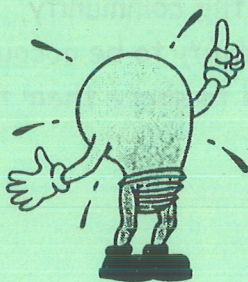
The process of self-determination gives people:

- the *freedom* to make choices,
- the *authority* to decide how their income and support funding are used,
- *support* from a network of natural resources in the community,
- and *responsibility* to be accountable for decisions and to share their talents.

Encouraging Self-Determination

- Treat your family member as capable by encouraging and supporting exploration and trying new situations.
- Increase his self-awareness by noticing and mentioning his strengths and things that make him special.
- Let her know you enjoy being with her, and really listen when she tells you things.
- Share stories about your family so he sees himself as part of a family circle.
- See that she interacts with people of all ages and different backgrounds to build social skills and confidence.

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- Help him experience success by having him do things he's good at.
- Praise her for trying to do things even if she does not always complete them.
- Have realistic expectations so he doesn't experience too many failures or lack challenges.
- Let her take responsibility for her actions and experience consequences.
- Include him in discussions and let him answer questions asked of him.

Adapted from "Suggestions for Parents: Helping Children Achieve Self-Determination" from NICHCY Transition Summary, Number 5, 1991, "Self-Determination"

Self-determination develops as individuals strive to take their place in the world. Sometimes their family members wonder if they will be safe as they find and make their own way. These concerns may lead to disagreements with parents or other authority figures.

This workbook offers some ideas to help families use the process, encourage self-determination and deal with risk.

Two companion booklets in the Self-Determination series are available from the Utah Self-Determination Project, Division of Services for People with Disabilities.

What Is It Anyway? talks about who is affected by self-determination and how it works. It tells where to find other resources in order to learn more.

Ask Your Questions Anyway! has answers to questions asked most often about self-determination. It also has definitions to help you learn the terminology.

SIX QUESTIONS TO ASK YOURSELF

- 1 Do I give the person with disabilities choices?
- 2 Do I do things for her that she could do herself?
- 3 Do I push him to try new things?
- 4 Do I model ways to cope with and learn from mistakes?
- 5 Do I allow more risk as my family member becomes more responsible?
- 6 Do I give her opportunities to learn skills of daily living?

① GIVING AND HONORING CHOICES

Good decision-making requires practice. Having choices means understanding the options, thinking about likes and dislikes, and expressing a preference. Giving choices can begin anytime, even at a very young age.

A simple choice between two different things could be:

Do you want an apple or an orange?

Adding a third choice makes the decision more difficult:

Which of these cereals would you like?

REMEMBER to respect the choice your family member makes even if you disagree or are inconvenienced by it!!



Let him choose whether or not to engage in an activity:

Do you want to go to the store or stay at home?

Or when to end an activity:

Let me know when you want to stop.

She can choose the order things are done in:

Do you want to eat first or take your bath first?

Or the amount of something:

How much milk do you want?

Open-ended questions can include conditions and give information:

We are going x, the weather will be y, and other people may be wearing z. What do you want to wear?

Rather than questioning the wisdom of a person's choice, spend more time bringing up other possibilities. When he makes an "unrealistic" choice, turn it into a learning experience:

So you want to be a rock star? What do you need to do to be a rock star? What can you work on now?

Let her help make family decisions like planning a vacation, choosing leisure activities, arranging furniture in the house, or selecting the meals for a week.

② DOING MORE THEMSELVES

Everyone needs to have things they do well.

Help them find things they can do more independently. Praise them for how well they are doing and how much they are learning. It will boost their self-esteem.



Here is a list of activities. Circle the ones your family member could do more independently and write your own ideas.

Make a checklist or picture list of things to try. Help only when needed. Things may be less tidy or less perfect, but it will help build healthy self-esteem and responsible behavior.

HOUSEHOLD MANAGEMENT

Plan meals, buy, prepare, clean, store food; buy, mend, wash, iron clothes; vacuum, sweep, empty garbage and:

HEALTH & PHYSICAL CARE

Hygiene, fitness, nutrition, make appointments with health care professionals and:

LEISURE SKILLS

Recreation and volunteer opportunities, movies, sports, games, exercise, music and:

MOBILITY

Ride the bus, read and understand schedules, call friends for rides and:

MONEY MANAGEMENT

Spend and save money, make/follow a budget, balance checkbook and:

SOCIAL INTERACTIONS

Start conversations, make phone calls, show affection appropriately and:

③ TRYING NEW THINGS

Good decision-making is dependent on having practice in making choices. Having different experiences gives a basis for choosing one thing over another.

It makes sense to build on the person's preferences.

For example, someone who likes country music might want to try line dancing and square dancing.



Trying new things is a good way to learn what we like and don't like. More experiences result in more informed decisions. By exploring lots of options, we have more ideas for jobs to try, ways to have fun and skills to learn.

This is an exercise in brainstorming. Involve the whole family in thinking of new things that everyone might like to try.

Some new things to try at home for fun are:

Some new things to try at home to learn daily living skills are:

Some new things to try for fun in the community are:

Some new things to try in the community to learn daily living skills are:

Some jobs to try are:

④ MAKING MISTAKES

Most of us have experienced "learning from our mistakes". Everyone makes mistakes. Making a mistake gives us a chance to figure out what went wrong and how to do it differently next time.



People with disabilities need to learn from their mistakes. No one makes the right choice every time, and no one does the right thing every time. Family members can turn mistakes into learning opportunities.

- LEARNING FROM MISTAKES

Making mistakes in a safe setting is a powerful way to learn. Experiencing the natural consequences of a mistake (unless outcomes are severe) can reinforce what is learned. Talk to your loved one about a mistake he made.

Find out what he learned from it.

Talk about what else he could have done in that situation.

- COPING WITH MISTAKES

One way we learn is by watching what other people do. Coping with mistakes is often done internally, through self-talk. To help someone else learn to cope with making mistakes, we can "show" them our self-talk. For instance, we could say:

"Oops, I screwed up. I lost my temper. I should have done...instead. Now I know what to do next time."

Treat the mistake as a problem to be solved not as a characteristic of the person.

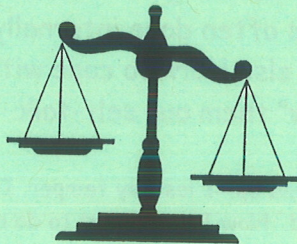
⑤ DEALING WITH RISK

Often the main concerns family members have are health and safety needs.

Dealing with risk is hard because often there is no certain way to decide which risk is okay and which isn't.

There is a degree of risk in any activity. Ask the question: If he didn't have a disability, would I let him do this? If the answer is yes, look for a way to manage the risk so he can participate.

Weighing risks and benefits



is a real balancing act.

Here's an example:

1. If it weren't too risky Janet could:

Ride the bus

2. What makes it risky?:

Someone might bother her. She might miss her bus and be late for work. She might get lost.

3. What are the benefits of the activity?:

I don't have to drive her. She will feel good about doing it on her own and be able to go more places.

4. What would make it less risky?:

Have her role play telling people to leave her alone. Teach her to move to the front of the bus by the driver. Teach her to ask for help, and to call if she is late.

Now try the process with your own situation.

1. Identify the risky situation: _____

2. Decide what it is that makes it risky: _____

3. What are the potential benefits for the individual:

4. Think about his capabilities and the options that could make the experience less risky: _____

⑥ DAILY LIVING SKILLS

Many say it's easier to do something themselves than to teach the skill(s) to others.

But when people take care of themselves and their surroundings, they are more likely to be perceived as competent, responsible adults who can contribute to others.

It also helps them to see themselves as capable of more independence.



By breaking a skill down into steps, it can be taught one step at a time. You can demonstrate how a skill is done or lead the person through the skill, telling them how to perform each step. Or you can do both. Sometimes picture cues or written instructions will help.

Hygiene activities are often the cause of disagreement at home. Motivating someone to learn how to keep themselves clean can be difficult, especially if they are withdrawn, isolated, or if they just started adjusting to living with a disability. Some are prompted by the possibility of social activities, making friends or moving to their own place.

What might motivate your family member to learn new skills? _____

Looking at the list of skills on page 9, decide what skill(s) your family member needs to work on first.

Remember:

- Social skills are vital to success.
- Networking opens many doors.
- Self-advocacy goes with self-determination.
- Building relationships leads to a fuller life.

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To get the companion booklets in the
Self-Determination series,
What Is It Anyway? and
Ask Your Questions Anyway!
contact the Utah Self-Determination Project,
Division of Services for
People with Disabilities,
120 N. 200 West, Room 411
Salt Lake City, UT 84103
(801) 538-4200

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