

Using The Speak Up! Guide

This resource guide is divided into the following areas by chapters:

Chapter 1: Knowing Yourself

Chapter 2: Communication/Assertiveness

Chapter 3: Problem Solving

Chapter 4: Rules, Rights and Responsibilities

Chapter 5: Self-Advocacy and Self-Determination

Chapter 6: Starting a Self-Advocacy Group

Chapter 7: Being a Part of the Community

The Speak Up! Slide Show can be used to help present information in the Speak Up Guide. **Training scripts** for two activities in each chapter are also provided on this CD-ROM, to assist self-advocates in providing and leading their own training groups. The training scripts can also be used to accompany the Slide Show. Additional **role plays** for most chapters have also been developed and can be used to supplement the role plays in the Slide Show.

Speak Up! Guide

1: Knowing Yourself

Published by:
STIR – Steps Toward Independence and Responsibility
and
Shifting the Power,
projects of the
Clinical Center for the Study of Development and Learning, UNC-CH
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Speak Up! Guide

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RIGHT ON AND NO WAY!

Name: _____

Date: _____

Directions: Write a √ next to the activities that you like. Write an X next to the activities that you do not like.



☐ Camping
☐ Hiking
☐ Horseback Riding
☐ Swimming
☐ Walking
☐ Jogging
☐ Riding Bicycles
☐ Golfing
☐ Tennis
☐ Baseball
☐ Football
☐ Soccer
☐ Hockey
☐ Fishing
☐ Car Racing
☐ Having Pets
☐ Going to Church
☐ Babysitting

☐ Baking
☐ Cooking: _____
☐ Ice Skating
☐ Roller Skating
☐ Gymnastics
☐ Chess/Checkers
☐ Playing Cards
☐ Collecting Things (stamps, coins, dolls)
☐ Sewing
☐ Painting
☐ Pottery
☐ Gardening
☐ Watching TV/Movies
☐ Singing
☐ Dancing
☐ Writing stories/songs/poems
☐ Visiting with friends
☐ Hair Care and Make-up

Now, circle the three things you like the most.

Please list any other activities that you like:

LEISURE ACTIVITIES

- Activity A:** To encourage development of a sense of responsibility within individuals, leisure education sessions can be divided into two parts. One portion of the session could involve instruction to teach individuals how to participate in specific recreation activities (e.g., table games). The following portion would permit them to engage in socially acceptable activities of their choosing. During this time they would be in control and responsible for their participation. The amount of time individuals are placed in this situation would vary according to their skills.
- Activity B:** To help individuals focus on what makes them happy and could make them happy in the future, a learning activity could be conducted requiring participants to identify as many enjoyable recreation activities as possible. They could identify these activities by pointing to them in a book, verbalizing them, or drawing them. After they have completed this task, materials associated with one activity chosen by each person should be gathered. The participants can be encouraged to observe or join each individual participating in a chosen activity. Following demonstrations, participants' desire to learn any of the activities presented should be assessed. Exploration of what activities they have yet to master but are motivated to learn about is often helpful.
- Activity C:** To gain an awareness of leisure, it is useful for young adults to develop an understanding of the concepts of leisure and leisure lifestyle. When people understand these concepts, abilities to participate in recreation activities resulting in satisfaction and enjoyment will be enhanced. One way to help individuals gain an understanding of the difference between work and leisure may be achieved by dividing participants into two groups. One group is given paints and brushes and required to paint a specific object on a large piece of paper (e.g., a car). The other group can be provided with the same equipment and permitted to paint anything they like. After ten minutes, have the groups switch tasks. Questions and statements can be made about the differences between the activities and the role freedom plays in leisure participation.

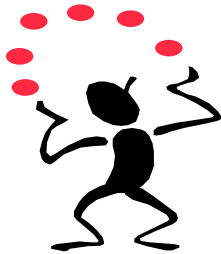
Activity D: To encourage the development of social integration skills, students can be instructed to participate in an activity to help them practice how to introduce themselves to a group. In turn, participants will communicate to the group their first name, and for 30 seconds share with the group positive information about themselves (e.g., accomplishments, desirable personal traits, friendships). Participants will be instructed to communicate only positive information about themselves during this time.

Activities A through J were developed by John Dattilo, University of Georgia, and Susan St. Peters, Pennsylvania State University. They were taken from a manuscript titled "A Model for Including Leisure Education in Transition Services for Young Adults with Mental Retardation", and are expanded upon in the book "Leisure Education Program Planning: A Systematic Approach".

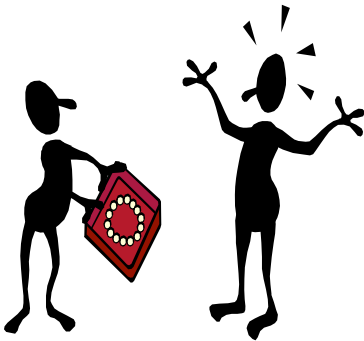
WHAT I HAVE TO OFFER



What I Know...gifts of my mind



What I can do...gifts of my hands



What I care about...gifts of my heart

PERSONAL STRENGTHS



Name: _____ Date: ____/____/____

Directions: Put a check (✓) next to any sentence that describes you. When you've finished put a star (*) next to the 3 sentences that best describe you.

- | | |
|--|---|
| _____ I'm reliable. | _____ I'm energetic. |
| _____ I'm friendly. | _____ I'm a good listener. |
| _____ I'm easy to get along with. | _____ I'm polite. |
| _____ I try to follow instructions. | _____ I'm honest. |
| _____ I like to do things with others. | _____ I'm hard-working. |
| _____ I like to do things on my own. | _____ I'm usually on time. |
| _____ I like to help other people. | _____ I'm serious. |
| _____ I like to keep things neat and organized. | _____ I'm generous. |
| _____ I like to have a good time. | _____ I'm proud of myself. |
| _____ I don't brag too much. | _____ I can keep a secret. |
| _____ I stick with things 'til they get done. | _____ I'm a good friend. |
| _____ I can work out my problems on my own. | _____ I'm a good student. |
| _____ I ask others for help when I need it. | _____ I'm musical. |
| _____ I can help others work out their problems. | _____ I'm artistic. |
| _____ I'm good with mechanical things. | _____ I'm creative. |
| _____ I have good common sense. | _____ I'm good with words. |
| | _____ I can "get to the heart of things". |
| | _____ I'm good with my hands. |

Use this space to write down your other strengths:

THINGS THAT MAKE YOU SPECIAL



Name: _____ Date: ____/____/____

List 25 things that make you special.

You might want to think about:

Your strengths

1. Things you know how to do well (your abilities/skills)
2. Things you enjoy doing
3. Things you have done of which you are proud
4. Your talents
5. Important things you have learned
6. Positive things about your personality

REMEMBER: YOU MUST HAVE 25 ITEMS ON YOUR LIST!

- | | |
|-----------|-----------|
| 1. _____ | 14. _____ |
| 2. _____ | 15. _____ |
| 3. _____ | 16. _____ |
| 4. _____ | 17. _____ |
| 5. _____ | 18. _____ |
| 6. _____ | 19. _____ |
| 7. _____ | 20. _____ |
| 8. _____ | 21. _____ |
| 9. _____ | 22. _____ |
| 10. _____ | 23. _____ |
| 11. _____ | 24. _____ |
| 12. _____ | 25. _____ |
| 13. _____ | |

Reprinted with permission from "A Student's Guide to the American with Disabilities Act", Hospital Industries Program,
Department of Rehabilitation Medicine, Maine Medical Center, Portland, Maine.

STRENGTHS

Mental Abilities

- Writing
- Reading
- Mathematics
- Foreign language skills
- Problem solving
- Complex thinking (ability to see a situation from many perspectives; to see the shades of gray between black and white)
- Abstract thinking (ability to see patterns and relationships; to see broad, overarching categories)
- Planning
- Understanding
- Teaching
- Computer skills
- Memory
- Other

Abilities in Specific Sports (with or Without wheelchair or assistive device)

- Basketball
- Baseball
- Football
- Tennis
- Swimming
- Track and field
- Weight lifting
- Aerobics
- Dancing
- Rugby
- Lacrosse
- Skiing (Downhill/Cross –country)
- Kayaking
- Sailing
- Fishing
- Volleyball
- Racquetball
- Hiking
- Mountain climbing
- Flying a plane
- Riflery
- Archery
- Other

Physical Abilities (General Abilities)

- Stamina/endurance
- Tolerance of pain
- Dexterity
- Upper body/lower body strength
- Quick reflexes
- Flexibility
- Eye-hand coordination
- Overall coordination of body
- Balance



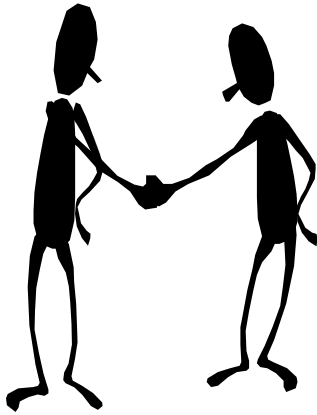
Personal Qualities

- Honest
- Dependable
- Sense of humor
- Caring
- Thoughtful
- Responsible
- Charitable
- Gentle
- Kind
- Self-confident
- Accepting of others
- Organized
- Patient
- Even-tempered
- Fun to be with
- Up-beat personality
- Other

STRENGTHS (*continued*)

Interpersonal Abilities

- Listening to others
- Sharing feelings with others
- Standing up for yourself
- Seeing where help is needed
- Putting others at ease
- Tactfulness
- Persuasiveness
- Comforting others
- Giving your time
- Giving your talent
- Giving your money
- Other

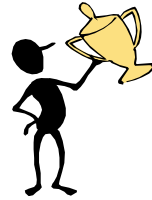


Specific Skills and Talents

- Telephoning
- Music (instrument, vocal, composing)
- Needlework
- Sewing
- Knitting
- Cross stitch
- Embroidery
- Gardening
- Raising Pets
- Computer games
- Collecting
- Telephoning
- Rocketry
- Photography
- Ham radio operating
- Model building
- Jewelry making
- Art
- Painting
- Sculpting
- Cartooning
- Calligraphy
- Chess
- Auto mechanics
- Other

Reprinted from Taking Charge: Teenagers Talk about Life and Physical Disabilities, by Kay Harris Kriegsman, Elinor L. Zaslow, & Jennifer D/Zmura-Rechsteiner. Copyright 1992 by Woodbine House. Reprinted by permission of Woodbine House, Inc. Publishers.

SKILLS



Name: _____ Date: ____/____/____

Directions:

Put a check (✓) next to all the things you are good at.

Then put a star (*) next to the 3 things you do best.

I'm good at:

____ Taking care of other people
____ Dealing with the public
____ Organizing things
____ Making change
____ Typing/filing
____ Answering phones
____ Using a computer
____ Waiting on tables
____ Construction/carpentry
____ Housepainting
____ Operating machines or tools
____ Fixing machines
____ Welding
____ Fixing cars
____ Logging
____ Gardening
____ Yard work

____ Reading
____ Writing
____ Math
____ Science
____ Social studies
____ Art
____ Sports
____ Music
____ Teaching
____ Babysitting
____ Cooking
____ Sewing or knitting
____ Cleaning
____ Hairdressing
____ Driving
____ Farming

Use this space to list other things you do well:

CHALLENGES

Social

- Relating to others
- Being at ease with others
- Introducing yourself and others
- Making others feel welcome
- Making others feel comfortable
- Carrying on a conversation
- Listening to others
- Helping others
- Sharing feelings
- Being dependable
- Standing up for yourself
- Taking on responsibility
- Seeing others' viewpoints
- Asking for help when necessary
- Other...

Physical

- Watching weight
- Exercising
- Strengthening
- Keeping in shape
- Not over-doing
- Personal hygiene
- Healthy diet
- Sticking to medical schedule (injections, pills if needed)
- Other...

Personal Development

- Having a sense of who you are
- Feeling good about yourself
- Forgiving yourself when necessary
- Accepting yourself
- Allowing yourself to be who you are
- Taking risks
- Taking care of yourself
- Taking responsibility
- Sticking to your principles
- Setting realistic goals
- Other...



HAVING YOUR STRENGTHS, SKILLS & CHALLENGES EVALUATED

Date: _____

Dear _____:

In order to know how I can contribute to my local community, I would like to develop a list of my strengths and abilities in all areas of my life. Because you know me well, I would like to have your help to complete the project. Would you please answer the following questions about me?

1. In your opinion, what are my abilities, skills, and talents?

2. In your opinion, what are my greatest strengths?

3. In your opinion, what are the areas I need to work on?

4. If an employer were to ask me the following question, how do you think I should answer? --- "Why should I hire you?"

I need this returned to me by _____. My address is _____.

Thank you very much for your help.

Sincerely yours,

ADDITIONAL STRENGTHS & CHALLENGES ACTIVITIES

Objective: Students will explore the challenges their disabilities present:

Activity A: Everyone deals with problems and challenges in different ways. The following Ways. The following activity will give students an opportunity to look at a variety of solutions to the same problem.

Ask students to consider the following scene and answer the questions.

You are being sent to live on a deserted island for one week.

1. What things would you need to take with you in order to survive on the island?
2. What things would you want to take to entertain yourself?
3. What would you take to make you feel safe?

Set up the scenario, making up a description of the island. Give students examples of things in each category (survival needs, entertainment, safety and security); i.e., water a portable radio, best friend. They may choose to bring a person with them.

When students have completed their lists, have them take turns sharing the items they identified. List their responses on the board in the three categories. If an item is listed by more than one student, put a check mark after the items each time it is mentioned.

When all answers are shared, discuss the areas that were identified that were common to everyone and those that are unique needs to individual students. Make a point that we all have common needs but we also have needs that are unique to us as individual

Activity B: Review the personal limitations listed on the Challenges worksheet. These include:

Social Abilities: the need to learn to respond to others more freely, to extend a hand first, to relate to others more positively.

Physical Abilities: the need to improve or develop new strengths or skills in your body.

Personal Development: the need to improve your personality and attitude toward yourself and others.

OK where I am: the feeling that there is no great need or urge to change.

Instruct students to identify their challenges or weaknesses. Have students place a blue ✓ mark next to the abilities they need to work on.

If they have trouble figuring this out, have students talk to someone with whom they are comfortable. Make sure the student really wants to know what they need to work on. Have them assure the person they talk to that their feelings won't be hurt if he or she is honest.

Activity C: Tell students that you understand that it is not easy for them to talk about their disability but, in order for the Americans With Disabilities Act to work, they may need to be able to tell an employer about their disability in a way that the employer will understand. The employer will not be interested in the name of the disability necessarily, but will want to know where it might cause problems on the job and what a person's needs are to be successful on the job.

(Note: No one has to tell an employer he/she has a disability by law. However, how can you talk about the accommodations needed without disclosing the disability?)

Have students write a paragraph about themselves that answers the following questions:

1. How do my disabilities or weaknesses challenge me?
2. Does it cause problems in my life (at home, at school)?
3. In which major life activities might it cause problems for me?

Activity D: Ask students if there is a relationship between their strengths and challenges. For example, is a particular weak point preventing them from making the most of a strong point?

Case in point:

Edward, for instance says his strengths are caring, being nice, and having a good personality. His weakness, he says, is that he is not outgoing and doesn't talk much to others.

Problem!	How are people going to know what a caring, nice guy Edward is if he doesn't talk with them?
----------	--

Idea!	In order to bring out his strengths, Edward might want to work on communicating with others. This is not always easy for someone who is shy, but can be done through practice.
-------	--

Activity E: Facilitate a discussion of how students cope with their disabilities or weaknesses. Ask each student to give an example of something he/she does to compensate. Ask them to share their strategies with the class. Help them to see that they all have many strategies that they use each day to compensate or to work around the difficulties that their disabilities present.

“WHO CHOOSES?” OBJECTIVE & ACTIVITIES

Objective: Students will identify those people, places, and activities that contribute to their sense of belonging and a feeling of continuity.

Activity A: Discuss the importance of basic support systems (including friends, family and community) in helping to cope with failure or disappointment.

(Refer to the article **Who Chooses?** By Bill Mitchell)

Activity B: Have students complete the **Islands of Calm** worksheet.

Activity C: Have students develop a **People Map**.

***A friend is like toothpaste;
She comes through in a squeeze.***

- Anonymous

“WHO CHOOSES?”

By Bill Mitchell

Parents are a strong, stabilizing force in a child's life and play an important role in helping the child develop self-confidence and a sense of independence. Parents of a child with disabilities typically want to protect the child, an instinct based primarily – but not exclusively – on a realistic knowledge of the child's limitations.

In this article that follows, the author discusses the need for young people with disabilities to be involved, as much as possible, in making decisions that affect their lives. He also discusses ways in which families affect their child's ability to take risks, make decisions, and live with the consequences.

Bill Mitchell works in the Governmental Affairs Office of the Association for Retarded Citizens (ARC) in Washington, D.C. Currently, he is involved in a project funded by the Department of Housing and Urban Development to provide technical assistance in the finance and design of housing for people with disabilities.

He came to Washington on a fellowship with the National Council on the Handicapped, during which time he wrote a paper on developing leadership in the disability rights movement.

Mr. Mitchell grew up in Atlanta, Georgia, where he attended public schools. He later graduated from Georgia State University with a Bachelors degree in Philosophy. Before coming to Washington, he worked as a counselor for students with disabilities at Georgia State University and as the staff advocate for the Georgia Advocacy Office.

Mr. Mitchell has mobility impairment.

The importance of receiving the message that those who are care about you have faith in your ability not only to succeed, but also to survive failure, cannot be overstated.

Historically, people with disabilities, both individually and in groups, have had few opportunities to exercise choices in their lives. In his book, *From Good Will to Civil Rights: Transforming Federal Disability Policy* (1984), Richard Scotch observes that “disabled people generally have not spoken for themselves, and public policies have typically dealt with their needs in ways shaped by stereotypes of dependency.”

The lack of involvement of people with disabilities in decision-making at the policy level has its roots in the lack of participation in decision-making at the individual level. Decisions affecting people with disabilities have frequently been made by others. Those disabled early in life have gone from having parents make decisions for them to having doctors, social workers, or rehabilitation counselors make decisions for them.

Those raised in segregated facilities have found their chances of making their own decisions restricted even further. No wonder then, that when confronted repeatedly with the message that they must learn to take responsibility, many people with disabilities feel confused and unprepared.

What are the barriers to exercising choices? Based on my observations and experiences with other people with disabilities, I have identified three barriers that I believe restrict opportunities for young people with disabilities to learn to make their own decisions:

1. Overprotection

Ironically, those who care most about individuals with disabilities may be among the obstacles to their gaining the experiences necessary to exert more control over their lives. Typically, most parents, but particularly parents of children with disabilities, feel the need to protect their children from the pain of failure and rejection. Yet, as they mature, children will be exposed to situations that require them to make choices and abide by the consequences.

As part of growing up, youngsters will be out in their environment – “hanging out” with the neighborhood kids, exploring the woods beyond the back yard, or stopping at the corner store on the way home from school – out from under the watchful eye of a parent or other authority figure. It is during these times that children begin to learn more about their own capabilities and limitations and to feel a sense of autonomy.

In some cases, the combined effect of parental concern and environmental barriers may lead to a situation in which a child with a disability is never out of the house unless in the presence of a parent or another adult. The natural tendency of parents to protect their children is reinforced by the reality of the difficulties present in the immediate environment. Parents of children with disabilities often do not have a basis of comparison for determining what are acceptable versus unacceptable risks in the environment, and consequently may lack the reassurance needed to be able to allow their children their own “space” to find their way in the world.

In my own experience as a child having mobility impairment and using a wheelchair, I got out a lot, explored my surroundings, and played with the neighborhood kids. These unsupervised experiences were among the most important in my life. I learned about relationships and about taking responsibility for my own actions, and generally broadened my perceptions of the world around me and how I fit into it.

Compare my experience to those of a child in a residential facility. One situation reflects the society we live in – the real world; the other reflects a society limited by restrictions that skew the child’s perception of the world. When I consider my experiences of growing up in my own community and attending a neighborhood school where I had the same restrictions as other children, and then compare them to the experiences of acquaintances who have spent a significant part of their lives in residential facilities, it is not hard to account for the uncertainty many of them feel when confronted with challenges and opportunities.

Unfortunately, for many adults with disabilities, decisions to take on new experiences are influenced more by the degree of risk involved rather than the opportunities afforded by the experiences. And while my observations are unscientific, there seems to be a direct correlation between the degree of restriction these adults had as children and their fear of taking risks as adults. If you have been told much of your life that there are so many things that are too hazardous for you to do so, and if you have never been given the opportunity to test the true limits of your capabilities, it wouldn't be surprising that you would be obsessed with security.

2. Low Expectations

Another barrier to the achievement of self-determination for many people with disabilities involves the low expectations that society has of them and consequently, that they have of themselves. As people with disabilities, we receive conflicting messages from different sources telling us: (1) that we are absolutely incredible for doing the most trivial of things; and (2) that whenever non-disabled people are around, we should let them help us do whatever we are doing because, surely, they can do it better. Instead of being encouraged to challenge ourselves to the point that we run a real possibility of failure, every effort is made to ensure that this doesn't happen. In the process, we are denied the thrill of a hard-earned success.

Such negative messages about the capabilities of young people with disabilities can be countered by conscious efforts on the part of parents or other adults. As I was growing up, and to my complete consternation at the time, I was constantly being challenged by my parents about whether I actually had done my best at different tasks. They attributed neither my successes nor my failures to my disability. In spite of what they may have felt inwardly, they never allowed me to feel that merely "getting by" was good enough. While psychologists may debate the effects of such an upbringing on the young psyche, it did lead me to expect more of myself: I chose either to keep working at something to make it better, or I chose to declare the deed done.

The importance of receiving the message that those who are about you have faith in your ability not only to succeed, but also to survive failure, cannot be overstated. However a "good" failure is something everyone should experience. To know that it is a normal part of life and that people still care about you and believe in you can encourage you to get up and try again. Another effect of this kind of early learning is a sense of feeling more in control of your own destiny.

The more significant a person's disability is perceived to be, the more urgent it is that he or she be given every opportunity to exercise choices. Whether children with disabilities indicate their decisions through verbal communication, or with the aid of a pointer, a micro switch, or a communication board, it is important that they exercise the right to make choices in matters in which they can see the effects of their decisions.

3. Lack of Stable Support Systems

The lack of basic support systems to help one cope with failure can be particularly difficult for persons with disabilities. Discontinuity in some of the basic necessities of life, such as home, community, or friends, especially during the formative years, can add an additional barrier to the disabled person's freedom to make autonomous choices. In some cases, the person's need for security and safety in the environment may outweigh the benefits of assuming a new role in the community or taking on a new job that might further his or her career. While it may seem contradictory to the earlier point about overprotection, having a sense of belonging and a feeling of continuity in your environment is an important element in being able to challenge your capabilities. To be comfortable in taking risks, it helps to know that you've got a place to come home to after it's all over.

For parents this means trying to provide stability and security for your children with disabilities to the greatest extent possible, while also giving them the freedom to explore. I believe that young adults with disabilities who are beginning to cope with increasing responsibilities and who are feeling overwhelmed by their choices can ease their anxiety by looking for small ways to bring stability to their world. For example, I love Mexican food, so at least once a week, even if the walls are crumbling around me, I go to the same familiar restaurant where they know me by name and always seem glad to see me. A small detail, perhaps, but it helps me gain perspective when other things are in flux. No matter how unstable an individual's circumstances may be, being able to find even one small "island of calm" that provides an anchor can do wonders for one's sense of stability.

I have listed three basic obstacles that young people with disabilities face as they strive to become adults with the confidence in their own capabilities necessary for exercising self-determination. All three barriers have the potential to limit opportunities in make choices. Parents can help their children to overcome these barriers by providing as many opportunities as possible that allow their children to take prudent risks and make decisions independently.

As I see it, there are two challenges to be addressed:

- How to expose children with disabilities to more opportunities to make choices for themselves
and to deal with the consequences of their choices; and
- How to support and encourage young adults with disabilities as they explore their capabilities
and options.

The answers that parents and other caregivers come up with today to these questions will determine the degree to which the next generation of young adults with disabilities is prepared to meet the challenges of a changing world.

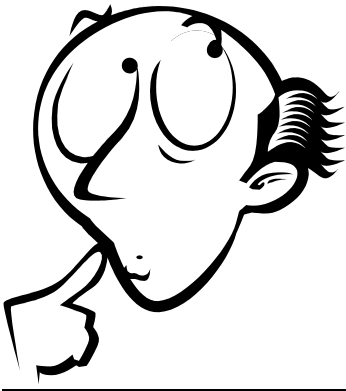
IDENTIFY YOUR “ISLANDS OF CALM”

Name: _____ Date: ____/____/____

Who are the people that help make you feel welcome, safe, “part of the gang”?

What are the environments that give you a sense of belonging and feelings of continuity?

What are the types of things you like to do in these environments?



People

Place

Activity

PEOPLE MAP

Name: _____ Date: _____

1. Divide the map into sectors for the Family, Service Providers (Staff), Friends, and Others.
2. Who are the people who are most important in this person's life? Put the most important people closest to the Focus Person (student).
3. Write down how often each person has contact with the Focus Person (student).
4. Indicate in green and/or plus signs who is most effective and/or has close ties with the Focus Person (student).

STAFF	Family
	
Community	Friends

This activity is part of the Personal Futures Planning Process developed by Dr. Beth Mount and was adapted from a mini-handbook on Personal Futures Planning written by Dr. Joe Patterson.

PEOPLE, ACTIVITIES, AND THINGS I NEED TO MAKE MY DREAMS COME TRUE

Name: _____

Date: _____

Directions: In the first column, list 3 of your dreams. Then list people, activities and things you may need to make these dreams come true:

Dreams	Needs		
	People	Activities	Things

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WHAT DO YOU KNOW ABOUT YOUR DISABILITY?

1. Do you know your diagnosis?
2. Do you know the possible causes of your disability?
3. What are the symptoms of your disability? How did your doctor reach his/her diagnosis?
4. Are there ways to manage the symptoms?
5. If you are taking prescribed medication(s), do you know the kind of medication(s) and dosage(s)?
6. Do you know the side effects of the medication(s) you may be taking?
7. Do you believe you will recover from your disability?
8. What possible treatment for your disability has been discussed by your doctor, treatment team, etc., with you? Do you understand what the Treatment Plan is?
9. What information would you like to have concerning your disability?

ACTIVITIES TO HELP YOU TELL OTHERS ABOUT YOUR DISABILITY

Objective: To become more comfortable with identifying yourself as a person with a disability and requesting individual accommodations.

Activity A: Discuss the pros and cons of disclosing one's disability, and the circumstances under which self-disclosure can help or hinder a person.

(Refer to the article **The Day of Reality** by George Ballard Jr.)

Activity B: Students complete the **Should I Tell?** Worksheet.

Activity C: At the beginning of the school year, have students attend classes for one week, then select the mainstream classroom teacher they feel most comfortable with. Ask students to then take a copy of their Individual Education Plan to that teacher, hand it to the teacher, and say "Mr./Ms._____, here is a copy of my Individual Education Plan, it lists the modifications I need in your classroom". To ensure the experience is a positive one, the student should initially role play the situation with the resource room teacher, and the resource room teacher should prepare the classroom teacher to expect the student's visit.

⊕**Activity D:** Have participants take part in role-play situations requiring them to ask for specific accommodations. Pair up so that one person is asking for the accommodations and the other is responding to the request. Each person should be allowed to select from a list of accommodations including: untimed tests, oral exams, use of a tape recorder, a tutor, different seating arrangement, etc.

Activities A & B were taken from "Self-Advocacy: A Resource and Training Manual for Mental Health Consumers, Ex Patients and Psychiatric Survivors", Connecticut Self Advocates for Mental Health, Inc. Activity C was developed by Dr. Patricia Phillips, East Lyme High School, East Lyme, CT.

THE DAY OF REALITY

George Ballard, Jr. is a third-semester student at Naugatuck Valley Community-Technical College in Waterbury, CT, working on his Associate Degree in Liberal Arts and Sciences. He plans to continue his studies in the areas of psychology and special education.

As I sat slouched at my desk listening to my new professor call attendance, I started to replay what the teacher had said at the beginning of the class and everything she had told us about the course. The class I was attending at the time was World Civilizations I. However, the one point that I kept pondering was that there was no use of tape recorders except for special circumstance. As the minutes dwindled and class ended, I felt nervous excited, and petrified all at the same time. As the other students left, I knew the time had come. It was the moment of truth. It was time for me to advocate for myself.

When I approached the professor, I cleared my throat and I spoke from my heart. To my surprise the words flowed naturally from my mouth. I told her first of all that I was real excited about the course and that I'd always loved history. Then I let her know that I have an auditory processing problem and how it affects my notetaking skills. That's why I need to be able to use a tape recorder. Also, I informed her that I have spatial orientation problems and written expression difficulties. After hearing this, she had a look of concern on her face as well as two additional recommendations. One was for me to use the tutors available and the other was to maybe think about taking the course in the summer instead when there would be less pressure on me. After having this meeting with the teacher, I felt good because I had advocated for myself, but, I felt that I didn't have support from the teacher and that she really didn't have an understanding of my learning disabilities or the fact that I had the skills and ability to pass her course with a decent grade. However, I was determined to do well and I knew I had a passion for history with an excellent capability for memorizing dates, places, and events. I also had a great understanding of concepts pertaining to history. The challenge was on! I was ready to prove that I could do it with little hard work and perseverance.

In order to meet this challenge, I knew I had to do my homework every night to the best of my ability. I also knew that in order to take good notes, I would have to use a tape recorder and in order to do that, I would have to go to every single class. And I did! No matter what time I went to bed or how sick or weak I was, I went. Using my tape recorder helped a lot. By using the tape-recorded classes and the homework I had done the night before, I could write down anything I might have missed from class or from the readings. A final strategy that helped me in the course was that I reviewed the material a couple of times a week.

The other way I met the challenge of taking this course was in the area of my spatial orientation. In the past I have had to take tests untimed and in a resource lab. This time was no different. The teacher let me take tests down in the resource center. I

arranged it this way because I didn't know what to expect from her and I didn't know if I was going to need extra time. However, I finished the exam in less than an hour, which is exactly what the rest of the students took. I knew I did well as soon as I turned in my test and it was great hearing my teacher say, "You did very well, George, and I don't think you need to take the test down in the learning center anymore." This was evident because I studied for each test from the homework sheets, disciplining myself to review and reflect upon the material. I was able to earn two "B+'s" and two "A's" on four tests ending up with an A- average for the course.

The most important thing that I accomplished in this course was that I changed a teacher's view on students with learning disabilities. I also heard from other teachers that my teacher was amazed by my accomplishments and that she never realized that a student with so many learning problems could do so well in such a difficult and demanding history course. Also it makes me feel good to know that my success changed her views on what students with learning disabilities could achieve and compensate for themselves. She also stated that in the future she would need to be more receptive to accepting and encouraging students with LD in her classes. One thought is nice to know is that instead of the teacher teaching the student, the student taught the teacher a little something for a change. Throughout life everyone learns a lesson. In my case I learned and taught someone else that just because a student has a learning disability doesn't mean that he or she can't use his or her talents or abilities to achieve a certain goal. When you combine that with a strong passion or desire for something, there isn't much that can stop you except giving up.

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SHOULD I TELL?

Name: _____ Date: ____/____/____

PROS

- + _____
- + _____
- + _____
- + _____
- + _____

CONS

- _____
- _____
- _____
- _____
- _____

Under what conditions and to whom should I self-disclose regarding my disability?

Under what conditions and to whom should I keep my disability to myself?

WAYS TO CONFRONT STIGMA

1. Learn about prejudice.
2. Network with other individuals and groups with whom you can address stigma/prejudice before opinion makers, public authorities, educators and others.
3. Write letters to public officials, news media, educators, human service professionals and others.
4. Give testimony at public hearings. Let people know that when others say something false, demeaning and discriminatory, it is harmful to everyone.
5. When you hear stories that reflect myths and misconceptions, make it known that they are untrue. Jokes which are frequently used in talking about people with psychiatric disabilities should be challenged.
6. Recognize and act upon the fact that all of us are entitled to fair and equal treatment and respect. Encourage others to do the same.
7. **Search your own beliefs** for your own prejudices toward others. The best way to overcome prejudice is to be willing to put yourself in someone else's shoes and get to know them.
8. **Role-play with others** the experience of discriminating against others as well as to learn how it feels to be discriminated against by others.
9. If you are a member of a group being discriminated against, do not allow yourself to believe you are immune from discriminating against others, even those within your own group. For example, the exclusion of people with psychiatric disabilities thought to be "low functioning" by others with psychiatric disabilities who believe themselves to be "high functioning" is not uncommon.

C.I.T.E. LEARNING STYLES INSTRUMENT

From the Center for Innovative Teaching Experiences
 Babich, A.M., Burdine, P. Allbright, L., Randal, Pl.
 Reprinted with permission from Wichita Public Schools
 Murdock Teacher Center

	Most Like me		Least Like me	
1. When I make things for my studies, I remember what I have learned better.	4	3	2	1
2. Written assignments are easy for me to do.	4	3	2	1
3. I learn better if someone reads a book to me than if I read silently to myself.	4	3	2	1
4. I learn best when I study alone.	4	3	2	1
5. Having assignment directions written on the board makes them easier to understand.	4	3	2	1
6. It's harder for me to do a written assignment than an oral one.	4	3	2	1
7. When I do math problems in my head, I say the numbers to myself.	4	3	2	1
8. If I need help in the subject, I will ask a classmate for help.	4	3	2	1
9. I understand a math problem that is written down better than one I hear.	4	3	2	1
10. I don't mind doing written assignments	4	3	2	1
11. I remember things I hear better than I read.	4	3	2	1
12. I remember more of what I learn if I learn it when I am alone.	4	3	2	1
13. I study best when no one is around to talk or listen to.	4	3	2	1

14. I would rather read things in a book than have the teacher tell me about them.	4	3	2	1
15. Speaking is a better way than writing if you want someone to understand what you really mean.	4	3	2	1
16. When I have a written math problem to do I say it to myself to understand it better.	4	3	2	1
17. I can learn more about a subject if I am with a small group of students.	4	3	2	1
18. Seeing the price of something written down is easier for me to understand than having someone tell me the price.	4	3	2	1
19. I like to make things with my hands.	4	3	2	1
20. I like tests that call for sentence completion or written answers.	4	3	2	1
21. I understand more from a class discussion than from reading about a subject.	4	3	2	1
22. I remember the spelling of a word better if I see it written down than if someone spells it out loud.	4	3	2	1
23. Spelling and grammar rules make it hard for me to say what I want to in writing.	4	3	2	1
24. It makes it easier when I say the numbers of a problem to myself as I work it out.	4	3	2	1
25. I like to study with other people.	4	3	2	1

C.I.T.E. LEARNING STYLES INSTRUMENT SCORE SHEET

Visual Language 5- 13- 21- 29- 37- Total ____ x2= ____ (score)	Social-Individual 4- 12- 20- 28- 45- Total ____ x2= ____ (score)	Auditory Numerical 7- 15- 23- 31- 39- Total ____ x2= ____ (score)
Visual Numerical 9- 17- 25- 33- 41- Total ____ x2= ____ (score)	Social-Group 8- 16- 24- 32- 40- Total ____ x2= ____ (score)	Kinesthetic-Tactile 1- 18- 26- 34- 42- Total ____ x2= ____ (score)
Auditory Language 3- 11- 19- 36- 44- Total ____ x2= ____ (score)	Expressiveness Oral 6- 14- 22- 30- 38- Total ____ x2= ____ (score)	Expressiveness-Written 2- 10- 27- 35- 43- Total ____ x2= ____ (score)

Score: 33 – 40 = Major Learning Style
 20 – 32 = Minor Learning Style
 05 – 20 = Negligible Use

C.I.T.E. DESCRIPTIONS (CONTINUED)

Individual Learner

-This student gets more work done alone. He or she thinks best and remembers more when the learning has been done alone. This student cares more for his or her own opinions than for the ideas of others. Teachers do not have much difficulty keeping this student from over-socializing during class.

Group Learner

-This student prefers to study with at least one other student, and, will not get much done alone. He or she values others' opinions and preferences. Group interaction increases his or her learning and later recognition of facts. Class observation will quickly reveal how important socializing is to this student.

Oral Expressive

-This student prefers to tell what he or she knows. He or she talks fluently, comfortably, and clearly. Teachers may find that this learner knows more than written tests show. He or she is probably less shy than others about giving reports or talking to the teacher or classmates. The muscular coordination involved in writing may be difficult for this learner. Organizing and putting thoughts on paper may be too slow and tedious a task for this student.

Written Expressive

-This learner can write fluent essays and good answers on tests to show what he or she knows. He or she feels less comfortable, perhaps even stupid, when oral answers or reports are required. His or her thoughts are better organized on paper than when they are given orally.

STUDY SKILLS SELF-EXAMINATION

Name: _____ Date: _____

This form will help you to better understand your study habits.

Check the study skills you practice regularly. Make sure you record your answer under the proper monthly heading.

I. Organization

Sept-Nov-Jan-Apr-June

1. I always carry a notebook to class _____
2. I always have a pen/pencil with me. _____
3. I always have an assignment pad. _____
4. I properly fill out an assignment pad to show all work. _____
5. I keep different sections in my notebook for each subject area. _____
6. I keep a section in my notebook where I keep handouts. _____
7. I keep a section in my notebook where I keep returned work, quizzes, and tests. _____
8. I arrange/clean my notebook each week. _____
9. I date all notes taken in class. _____
10. I always remember to go to my locker at the end of the day to get the proper materials for study at home. _____
11. I keep a monthly calendar of activities and long term school assignments. _____
12. I plan in advance to complete long term school work. _____
13. I keep up to date with the teacher charting and conferencing (if applicable). _____

II. Study Habits

Sept-Nov-Jan-Apr-June

1. I set aside a specific time every night for homework. _____
2. I study sitting at a table or desk. _____
3. I study in a quiet environment. _____
4. I study in 30-40 minute sessions without a break. _____
5. My breaks are only 10-15 minutes long. _____
6. I always remember to bring my assignment sheet home. _____
7. I always remember to bring the necessary books, workbooks, compasses, rulers, etc., home. _____

V. Report Writing

Sept-Nov-Jan-Apr-June

- 5. I can write a report based on my outline using:**
 - a. an introductory paragraph**
 - b. supporting paragraph**
 - c. a concluding paragraph.**
- 6. I am able to self-correct and revise my final draft:**
 - a. check for spelling errors**
 - b. correctly punctuate sentences**
 - c. check for capital letters**
 - d. indent for each paragraph**
 - e. use consistent verb tense**
 - f. ask for help whenever necessary.**
- 7. I know how to write footnotes and a bibliography.**

VI. Personal Assessment

Sept-Nov-Jan-Apr-June

- 1. I establish realistic goals for all classes.**
- 2. I chart goals on a weekly basis without constant reminders.**
- 3. I maintain a daily record of assignments.**
- 4. I am responsible for turning in all homework on time.**
- 5. I have a clear understanding of academic performance in all classes.**
- 6. I prepare for tests and quizzes by:**
 - a. re-reading all class notes**
 - b. reviewing past homework assignments**
 - c. reviewing/learning past tests and quizzes**
 - d. making up practice tests.**
- 7. I keep my parents informed of my progress.**
- 8. I am learning not to avoid difficult assignments or situations.**
- 9. I keep resource room teachers informed of my progress.**
- 10. I apply test taking techniques.**

INDIVIDUAL EDUCATION PROGRAM (IEP) ATTACHMENT

Student Name: _____ Date: ____/____/____

Class: _____

This student needs the following modifications to comply with his/her Individual Education Program (IEP).

Content Modification

- _____ Extra time to complete assignments and projects
- _____ Directions/instructions given orally and in writing
- _____ Long range projects broken down into short-term (small) assignments
- _____ Provide multi-sensory, hands-on instructions or activities
- _____ Modify reading assignments
 - _____ shortened length
 - _____ adapted reading level
 - _____ tape summary of reading material
- _____ Modify math assignments
 - _____ shorten length
 - _____ divide assignment into steps
 - _____ give assignments on appropriate level _____
- _____ Modify written assignments
 - _____ shortened length and requirements
 - _____ grammar, spelling, punctuation errors are noted but not evaluated
 - _____ extra time to complete written assignments
 - _____ allow someone to write answers for the student
 - _____ provide alternatives such as oral presentation, drawings, tape recordings, etc. _____
- _____ Other modifications
 - _____ provide a script/notes/study guide of lectures
 - _____ supplemental visual materials
 - _____ minimize memory demands
 - _____ vocabulary list prior to lesson
 - _____ repetition of explanation; practice

Environmental Modifications

- _____ Structured environment
- _____ Limited distractions
- _____ Consistent expectations and consequences
- _____ Preferential seating
- _____ Utilize techniques to increase productivity
- _____ Other _____

INSTRUCTIONAL MODIFICATIONS

READING

- Extended time
- Reader
- Taped textbooks
- Oral exams
- Taped exams
- Separate location
- Alternate test format
- Other:

WRITING/SPELLING

- Extended time
- Notetaker
- Tape recorder
- Oral exams
- Computer with spell-check
- Alternative demonstration of mastery
- Scribe
- Proofreader
- Other:

LANGUAGE

- Extended time
- Notetaker
- Tape recorder
- Oral exams
- Computer with spell-check
- Alternative demonstration of mastery
- Scribe
- Proofreader
- Other:

MATH

- Extended time
- Use of calculator
- Talking calculator
- Separate location
- Alternate test format
- Other:

AUDITORY

- Tape recorder
- Notetaker
- Visual clues
- Physical proximity study
- Other:

VISUAL/PERCEPTUAL

- Tape recorder
- Taped textbooks
- Auditory cues
 - Physical proximity
- Extended time
- Oral/taped exams
- Separate location
- Alternate test format
- Proofreader
- Other:

PROGRAM MODIFICATIONS

- Extended time to complete a program
- Adapting methods of instruction
- Course substitution
 - Part-time rather than full-time

ARE YOU READY TO MANAGE YOUR OWN HEALTH CARE?

- | | | | |
|-----|--|-----|----|
| 1. | I worry about my health. | Yes | No |
| 2. | My parents always take care of my health needs. | Yes | No |
| 3. | I would like to know more about my illness/disability. | Yes | No |
| 4. | I would like to be responsible for taking my own medications or doing my own treatments. | Yes | No |
| 5. | It is easy for me to talk with my doctor. | Yes | No |
| 6. | I feel I have little or no control over my illness/disability. | Yes | No |
| 7. | I would like to speak with my doctor alone during visits. | Yes | No |
| 8. | I would like to go to the doctor by myself. | Yes | No |
| 9. | Sometimes I get embarrassed if I have to take my medications in front of my friends. | Yes | No |
| 10. | If I follow my treatments and take my medications, my health is usually good. | Yes | No |
| 11. | My health needs will affect my future. | Yes | No |

“ADVOCATING FOR HEALTH CARE NEEDS”

Most teens agree that without self-advocacy skills, they cannot successfully plan for independence. LeAnne, a woman with cerebral palsy, describes her first attempts with advocating for her health care needs.

It was scary for me to start making my own doctor appointments. I feared that the receptionist wouldn't understand my speech, which is affected by cerebral palsy. Previously, my mother had done all the calling. Mom told me that I would have to be prepared to answer questions and that it would be wise to have my insurance card in front of me. At that time, I was still under my parents' coverage.

I remember making my first appointment. I felt out of breath, but the woman seemed very patient as she waited for me to tell her what I wanted. She asked the usual questions about health insurance, and I answered.

After I hung up the phone, I had a sense of achieving a small victory. Little did I know that in the next year I would have to learn to trust my own instincts in choosing the right doctor.

When my shoulders and legs started aching, I began to wonder if there was something wrong besides fatigue and tenderness due to cerebral palsy. I made an appointment with our family doctor.

After reading X-rays, the doctor said, “You have arthritis. And although you may be a little young, it's not unusual for people with cerebral palsy because of the wear and tear on your muscles.”

He advised me to rest more and take an over-the-counter medicine.

As the months went by, the pain and fatigue persisted. I finally made an appointment with a specialist. After several tests, she identified a condition that indicated I needed surgery.

I was really confused by the different information, and when it came time to make a decision, I elected not to have surgery. I felt I did not have enough information. Despite the pressure of the physicians, I decided to wait.

After some thought, I decided to get a second opinion. I called the local hospital and described what I wanted: “I am a 20-year old woman with cerebral palsy. I'm having stomach pains. I need to see a doctor who will listen to me and believe me.”

That day, I met the doctor who became my family physician. He discussed each of my concerns and offered detailed information regarding my condition. I began to believe and trust him. That made all the difference in the world. Eventually, I was able to make an informed decision about surgery.

HEALTH CARE SKILLS CHECKLIST

Skill	Performs Independently	Performs Parts Independently	Needs Practice	Plan To Start	Skill Accomplished
Describes chronic illness or disability					
Understands implications of chronic illness/disability on daily life					
Accesses medical records, diagnosis, information, etc.					
Prepares and asks questions for doctors, nurses, therapists					
Knows medications and what they're for, or carries information in wallet					
Is responsible for taking own medication					
Is responsible for doing own treatments					
Gets a prescription filled/refilled					
Calls to schedule own medical/dental appointments					
Keeps a calendar of medical appointments					
Knows transportation to medical office					
Knows height, weight, birthdate, or carries information in wallet					
Knows how to use and read a thermometer					
Knows health emergency telephone numbers, or carries information in wallet					

HEALTH CARE SKILLS CHECKLIST

[illegible]

Adapted from "Adolescent Autonomy Questionnaire" in West, Margaret A., (Editor) (1988) *Assessment for Adolescents with Special Needs: A Guide for Transition Planning*. University of Washington Press, Seattle, Washington. Reprinted from *Speak Up for Health Parent Handbook*, © 1993, with permission from PACER Center, 488 Chicago Av. S., Minneapolis, MN 55417; (612)827-2966.

INDEPENDENCE ACTIVITIES

Activity A: Discuss the fact that independence can be described in many ways. Some of these ways include:

- Freedom
- Making your own decisions
- Having control, power
- Choosing your own friends
- Deciding what to wear
- Doing what you want to do
- Doing things without our parents
- Taking care of yourself
- Paying your own way

Independence is also something that can be present to different degrees in different areas: mental, physical, or emotional. For example, you might feel that you are completely in control of your thoughts, but not of your body.

Limitations to your independence can come from two main sources:

- Other people, and
- Your own physical limitations

Activity B: Have students take a few minutes to think about the specific needs in their life that they feel hamper their independence. For example, some students may have to ask for help in brushing their hair or emptying their catheter. Some may need help in reaching dishes on a shelf or getting in or out of the car. Some may need help carrying a tray in the cafeteria. Some may need extra time changing classrooms at school.

Have students ask themselves:

- What does independence mean to me?
- How independent am I in my different activities at home, at school, in my extracurricular life?
- What things get in the way of my being as independent as I would like to be?
- How can I deal with the obstacles in my way? Is there any way to get over, around, or under them? Do I need help to do so?

Activity C: Present the following problem and idea to students.

Problem: If you need a lot of help because of your disability, how can you still be independent?

Idea: Think of yourself as one of those big executives who runs a conglomerate. The executive makes decisions and others execute them for him. He is independent; he is making the decisions and deciding they will be carried out. He is thoughtful and considerate of those who work for him. *You* are the executive of your life! It doesn't matter if you actually do the driving or comb your hair. *You* make the decisions regarding when and how those things are done in your life!

Learning when to be dependent and when to be independent – and that each is OK – is learning to be interdependent.

Activities A, B & B C were taken from the book Taking Charge: Teenagers Talk about Life and Physical Disabilities, by Kay Harris Kriegsman, Elinor L. Zaslow, & Jennifer D'Zmura-Rechsteiner. Copyright 1992 by Woodbine House. Reprinted by permission of Woodbine House, Inc., Publishers.

CHOICES

Made By Person	Made By Others

This activity is part of the Personal Futures Planning Process developed by Dr. Beth Mount and was reprinted from a mini-handbook on Personal Futures Planning written by Dr. Joe Patterson.

SELF-ASSESSMENT OF COMMUNICATION AND SOCIAL SKILLS USED IN GROUP SITUATIONS

Directions: Think of a group in which you are a member. Rate yourself on your ability to participate effectively in the group by marking “Always,” “Sometimes,” or “Never,” for each of the skills listed below.

When I am in a group, I:

Always	Sometimes	Never	
			1. Look at the person who is speaking.
			2. Keep my hands & feet to myself.
			3. Show others that I am paying attention to what is being said.
			4. Use a calm and quiet voice.
			5. Avoid “put-downs” or others.
			6. Avoid interrupting others.
			7. Ask others to explain if I don’t understand what is being said.
			8. Answer questions that are asked of me.
			9. Contribute at least 3 ideas to group discussions.
			10. Contribute more than 3 ideas to group discussions.
			11. Make people laugh when appropriate.
			12. Give others ideas on how to do things more easily.
			13. Like to participate in discussions.
			14. Like to notice what other group members are saying and doing.
			15. Like to keep track of the time.
			16. Like to write down the group’s ideas and plans.
			17. Like to lead group discussions.

Overall, this is how I feel about my skills as a group participant:

1	2	3	4	5
Not Good	Skills	Good	Very Good	Excellent
	Need Improvement			

The 3 skills that I would most like to work on in groups are:

RESPECT

**Behaviors and Roles you
think help you gain
respect?**

1. _____

2. _____

3. _____

4. _____

5. _____

6. _____

7. _____

8. _____

9. _____

10. _____

**Behaviors and Roles
respected by others:**

1. _____

2. _____

3. _____

This activity is part of the Personal Futures Planning Process developed by Dr. Beth Mount and was taken from a mini-handbook on Personal Futures Planning written by Dr. Joe Patterson.

ORIGINS OF ATTITUDES

There are many influences in molding people's attitudes. From a broad perspective society and the media, including TV, radio and newspaper, have an influence in determining attitudes. From a narrower aspect, family, friends, peers, and a person's own observations and life experience also add to a person's attitudes.

A young child tends to identify with the parent of the same sex excluding the other parent's career choice as a viable alternative for him. For example, a little girl whose father is a chef and whose mother is a teacher will not consider being a chef when she grows up. Or a little boy whose mother is a doctor and whose father is a teacher will not consider being a doctor.

The largest impact on shaping a person's attitude comes from within his own family. The family influence is so strong that a person may assume many of the attitudes he disagrees with on a subconscious level, at least. This does not occur through direct teaching from the person's parents or other family members, but rather the person picks up the necessary cues from observation. Children see and internalize much more than most realize from their families. They observe how their parents get along, how the parents treat the other children, how parents treat outsiders, what parents expect from every child in the family and, of course, how the individual is treated and what is expected from him.

Another person or persons who affect children's attitudes are the significant other adults in their lives. That may be a grandparent, an aunt or uncle, a cousin, a grown brother or sister or just a close adult friend.

All of the family influences occur primarily during the early years. As the individual grows older, into the teen years, the importance of family and its influence decreases and the influence of peers takes on greater significance.

The greatest impact on attitudes is from the family. Next is the impact from peers. And probably least significant is the influence from the media. However, all of these influences add up to be the sum total of the individual's attitudes.

MY FUTURE

Objective: Students will define “lifestyle” and describe their desired lifestyle.

⊕**Activity A:** Hold a group discussion about lifestyle: what it is, who and what influences our lifestyles, and how it impacts on the quality of our lives.

⊕**Activity B:** Have students describe their present lifestyle, and how they want it to look five years from now. Examine the differences between the two and discuss ways to bridge those differences over time. Which factors can they control and which are beyond their control? How important is money to their future lifestyle? Have leisure activities been added or deleted?

MY FUTURE

Objective: Students will identify help wanted ads of interest to them in the newspaper.

Materials Required: Multiple copies of a local newspaper.

⊕**Activity A:** Distribute copies of local newspapers to students. Have students turn to the “Help Wanted” section of the newspaper. Have them find 5 jobs in which they would be interested. Ask students to write the necessary information for applying for the job on a sheet of paper (position, place of employment, requirements, phone number, contact’s name, etc.). When students have identified 5 jobs, have them share with the class the ads they found most interesting.

Activity A was taken from the World Program, Jefferson County School District R-1, Colorado

PERSONAL PROFILE

My greatest strengths are:

My skills, abilities, and talents are:

My other qualifications are:

My learning style is:

Work Experience:

Licenses:

My disability is:

It causes these difficulties for me:

I think it can be accommodated in these ways:

Speak Up! Guide

2: Communication/Assertiveness

Published by:
STIR – Steps Toward Independence and Responsibility
and
Shifting the Power,
projects of the
Clinical Center for the Study of Development and Learning, UNC-CH
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Speak Up! Guide

Chapter 2: Communication/Assertiveness

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FEELINGS



Happy Questioning something Frustrated

Mad

Grateful

Disgusted

Amused

Bored

FEELINGS

What makes you upset?

What makes you happy?

What makes you angry?

What scares you?

What amuses you?

What makes you mischievous?

What makes you bored?

What makes you grateful?

What makes you disgusted?

What makes you secretive?

Let Your Body Say Positive Things About You

Before you even open your mouth, your body is announcing to others that you are either Showing confidence in yourself or not.

Showing confidence

1. stands straight and looks people in the eye when speaking with them
2. sits down in a relaxed, but businesslike manner
3. keeps eye contact with people when conversing with them
4. takes the initiative in greeting others at a meeting and in opening the conversation
5. is not afraid to sit next to the most powerful person in the room
6. doesn't wait for permission to speak before speaking up
7. is organized and carries a briefcase full of materials to meetings, spreads them on the table, and has the needed information at the fingertips
8. is dressed appropriately
9. is courteous and pleasant during discussion.

Not showing confidence

1. slumps when standing and seems afraid to look at you when talking to you
2. sits down as though sitting on eggs, too self-conscious to move
3. is uncomfortable looking at you for more than an instant
4. is afraid to take the initiative in greeting people and waits for others to give permission to say "hello"
5. sits inconspicuously – away from persons perceived as powerful or threatening
6. is afraid to speak unless spoken to and given specific permission to speak
7. seldom carries information or materials to meetings
8. is either under-or overdressed, for a picnic or a party
9. becomes unpleasant, argumentative or rude when expressing a viewpoint.



Good Ways to Tell People What You Want

Definitions

Listening is a communication skill that is as important as talking. Listening means that you show the person talking that you hear him or her. You also show interest in what the other person is saying. You show interest by looking at the person who is speaking. You show interest by nodding your head when you understand what the person is saying. You can also show you are interested by asking questions. You should ask questions so that you are sure you understand what was said.

Assertiveness is a style of communicating or talking with people. Assertiveness means telling people your needs or ideas clearly and directly. It means not being afraid or shy when you tell people what you want.

Negotiation is a skill that helps you to solve problems.

negotiation means taking to
other people in a way that
allows both people to get
more of what they want

Adapted from "A Self-Advocacy Curriculum for High School Students Who Have Been Labeled Learning Disabled and Educatably Mentally Handicapped" by J. Stephen Hazel, et. Al. Kansas: Kansas University, Draft Copy, 1987. Teachers' Manual, pp. 24 and 25.

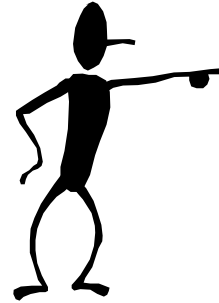
How to Talk to People

Three Styles of Communication:

Nonassertive



Aggressive



Assertive



In order to get what you want, you must be able to tell people what you want in a way that helps them to want to listen. How you say something, or your style of communication, is very important.

Let's look at three common styles of communication and see which one is best.

The following pages have been adapted from "The Assertiveness Program" Washington: People First of Washington, 1983, pp. 2 – 5.

Self-Advocacy Curriculum: Teaching Self-Advocacy to Adults with Disabilities, The Self-Advocacy Project, Alamance Community College, 224 E. Front St., Burlington, NC 27215.

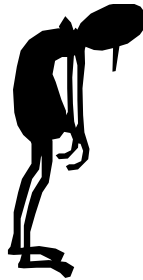
Non-assertive

You are being nonassertive when you:

- do not stand up for what is best for you
- do not let other people know what you need or want
- let other people decide what is best for you

When you are nonassertive:

- you stand or sit slumped down
- you look at the floor and your feet
- you mumble



After being nonassertive you feel bad:

- you feel controlled by other people
- you feel little
- you feel helpless

When you are nonassertive, other people see you as:

- little
- not able to make decisions
- always needing help
- childish

Being nonassertive is not a good way to communicate.

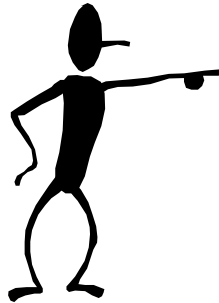
Aggressive

You are aggressive when you:

- want to win at any cost
- are pushy
- put down other people
- don't listen to or respect other people's feelings or ideas

When you are aggressive:

- you stand too close to people
- you clench your fists
- you talk too loudly or shout



After being aggressive you feel bad:

- you feel angry
- you feel alone
- you feel people don't like you
- people avoid you

When you are aggressive other people see you as:

- a loudmouth
- a troublemaker
- childish and immature

Being aggressive is not a good way to communicate.

Assertive

You are assertive when you:

- stand up for what is best for you
- make sure other people understand what you need or want
- openly and honestly express your ideas and feelings
- respect other people's rights and ideas
- listen to other people

When you are assertive

- you stand tall
- you look people in the eye
- you speak clearly
- you listen with interest



After being assertive you feel good:

- you feel honest and respected
- you feel proud

When you are assertive other people see you as:

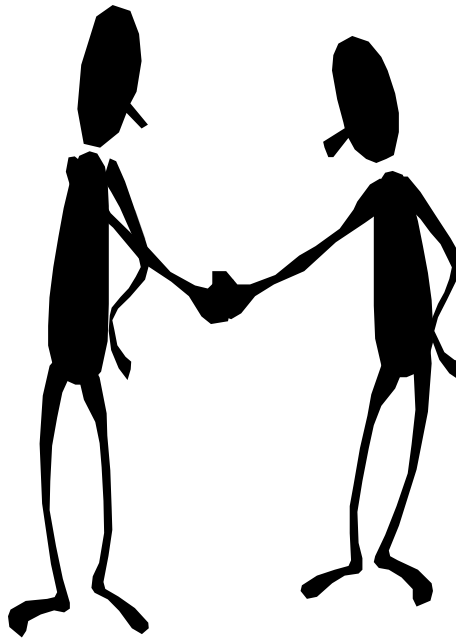
- an adult
- able to make decisions
- able to do things
- independent
- honest

Being assertive is a good way to communicate.

How to Talk to People

Basic Rules of Negotiation

1. Know what you want and why.
2. Plan what you will say.
3. Be truthful.
4. Don't give up.



Adapted from "A Self-Advocacy Curriculum for High School Students Who Have Been Labeled Learning Disabled and Educably Mentally Handicapped" by J. Stephen Hazel, et. al. Kansas: Kansas University, Draft Copy, 1987. Teachers' Manual, p. 24.

How to Negotiate

Negotiation Skill Steps

1. Face the other person.
2. Look in the eyes of the other person.
3. Use a good voice tone (not too loud or whiny).
4. Use a good facial expression.
5. Use good body posture (straight or relaxed).
6. Use good listening skills.
7. Ask for what you want.
8. State the reason why you want it.
9. Thank the other person if he or she agrees to the request.
10. Suggest a compromise if he or she does not agree.
11. Say thanks if the person agrees with your compromise.
Ask the other person for a solution if he or she does not agree with the compromise.
12. Say thanks if you agree with the other person's solution.
Suggest a different idea and keep on negotiating if you don't like the other person's solution.
If you need time to think about a solution, ask for it. Also ask the other person when you can talk with him or her again.

Adapted from "A Self-Advocacy Curriculum for High School Students Who Have Been Labeled Learning Disabled and Educably Mentally Handicapped" by J. Stephen Hazel, et. al. Kansas: Kansas University, Draft Copy, 1987. Teachers' Manual, pp. 24-26.

Negotiation Skill Steps Checklist

As each student completes a role-play, place a check mark by each skill step that was performed correctly.

Role Player's Name/Initials

DID PLAYER:

1. Face other person?

2. Look other person in the eyes?

3. Use good voice tone?

4. Use good facial expression?

5. Use good body posture?

6. Use good listening skills?

7. Ask for what he or she wants?

8. State reasons?

9. Say thanks or suggest compromise?

10. Say thanks or ask for a
different solution?

11. Say thanks or ask for time?

This form was adapted from one used in "A Self-Advocacy Curriculum for High School Students Who Have Been Labeled Learning Disabled and Educably Mentally Handicapped" by J. Stephen Hazel, et. al. Kansas: Kansas University, Draft Copy, 1987. Teachers' Manual, pp. 24-26.

Self-Advocacy Curriculum: Teaching Self-Advocacy to Adults with Disabilities, The Self-Advocacy Project, Alamance Community College, 224 E. Front St., Burlington, NC 27215.

CATEGORIES OF ASSERTIVE BEHAVIOR

1. **Refusal Assertiveness – How to say no at the right time and in the right way**
 - ◆ State your position – “No, I can’t.”
 - ◆ Explain your reason – “I have something else to do that day.”
 - ◆ Express understanding – “I hope you can find something else.”
2. **Expressing Feelings – telling people how you feel**
 - ◆ Express positive feelings – “You did a great job.”
 - ◆ Express negative feelings – “I am upset by what you did.”
3. **Request Assertiveness – To get information, clarification, and ask for what you want**
 - ◆ State the problem – “Boss, you have given two different instructions.”
 - ◆ Make a request – “Can you let me finish one project before starting the other?”
 - ◆ Getting clarification – “Can you explain what you want done again?”



TIPS FOR BEING ASSERTIVE

EYE CONTACT – Make sure the person is more interesting than what is on the floor. Look at the person most of the time. But, do not stare at people 100 percent of the time.

BODY POSTURE – Try to face the person. Stand or sit up tall. But, don't be a stiff board.

DISTANCE/PHYSICAL CONTACT – If you smell or feel the other person's breath, you are probably too close. Keep a comfortable distance.

GESTURES – Use hand gestures to add to what you are saying, but remember that you are not conducting an orchestra.

FACIAL EXPRESSIONS – Your face should match your emotion and what you are saying. Don't laugh when you are upset and don't have a frown when you are happy. A relaxed, pleasant face is best when you are happy. A relaxed, serious face is best when you are upset.

VOICE TONE, INFLECTION, and VOLUME – When you are making an assertive message, you want to be heard. In order to be heard you have to pay attention to the tone of your voice (happy, whiny, upset), the inflection of our voice (emphasis on syllables), and volume of your voice (whisper to yell).

FLUENCY – It is important to get out your words in an efficient manner. If a person stammers or rambles on, the listener gets bored.

TIMING – When you are expressing negative feelings or making a request of someone, this is especially important. Seven days later may be too long. Doing it right on the spot in front of people may not be the right time to do it. Do it as soon as there is a time for both parties to resolve their issues alone.

LISTENING – An important part of assertiveness. If you are making statements that express your feelings without infringing on the rights of others, you need to give the other person a chance to respond.

CONTENT – What a person says is one of the most important parts of the assertive message. Depending on what a person is trying to accomplish, the content is going to be different.

THE IMPORTANCE OF BODY LANGUAGE

Materials Required: Videotape, Behavior Observation Chart for Understanding and Using Body Language in “Tools for Transition” by Elizabeth Aune and Jean Ness. (Behavior Observation Chart is included here, the videotape is available for loan through the Special Education Resource Center (SERC), Middletown CT.)

Activity A: Ask students to walk up to a mirror in their usual, natural walk. Then have them stop and look at themselves. Ask students to determine if they are standing straight – with an air of self-confidence – or if their body is drooping, their shoulders slumping, and their head down. Ask them to study their face for a moment. Is it relaxed, smiling, cheerful – or is it taut, haggard, and unfriendly?

Activity B: Review the handout **Let Your Body Say Positive Things About You.**

Discuss the importance of body language in self-advocacy.

Activity C: Ask students to begin rehearsing a new way of walking, standing, sitting, and talking that demonstrates self-confidence.

Activity D: Show videotape segments 9 and 14 one at a time. Discuss the behavior shown on the video. Distribute the Behavior Observation Chart for Understanding and Using Body Language, and follow the activity format detailed in Section 2 of this curriculum in Activity E of the Objective: Students will develop skills in handling criticism assertively.

Activities A through C were taken from “How to Get Services by Being Assertive” published by the Family Resource Center on Disabilities, Chicago, IL, 1993. Activity D was taken from “Tools for Transition: Preparing Students with Learning Disabilities for Secondary Education”, © 1991, American Guidance Service, Inc., 4201 Woodland Road, Circle Pines, MN 55014 by Elizabeth Aune and Jean Ness. Reproduced by permission of publisher. All rights reserved.

Behavior Observation Chart

Assertive Behaviors	Situation 1	Situation 2	Situation 3

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Criticism

Criticism – Don't Let It Get to You

There are three ways to handle criticism assertively. Each way is designed to help you deal with the criticism so that you can make a decision about what behavior, if any, you will change.

Keep in mind that criticism deals with behavior – things you say and do – not your personality.

The three ways of handling criticism are:

1. If there is truth in the criticism, agree with it.

There is always the possibility that there is some truth in what others say about you. For example, somebody might say to you, "You are always minding everybody else's business." You might reply with, "Yes, sometimes I get too involved in other people's business."

2. If you have made a mistake, acknowledge assertively what you did.

Remember, you are only saying that you made a mistake and nothing about yourself as a person. For example, the teacher says "What's the matter with you, the assignment was supposed to be 13-D, not 13-C." You might say, "Oops, I made a mistake. I'll do the correct assignment."

3. If somebody continues to criticize you when it is not necessary, ask him what it is exactly that you are doing that bothers him.

For example, somebody has criticized your new jeans as being too short for you. You have agreed that the jeans are too short but the person continues to make a big deal out of it. At this point you might say something like, "I am not sure that I understand. What is it exactly about my short pants that you don't like?"

When you use any combination of the above three techniques for handling criticism assertively, then you are helping yourself get through an unpleasant situation without feeling guilty or dumb. Knowing that you handling criticism, as a responsible person will help you avoid shouting matches and name calling sessions. Dealing with criticism assertively will allow you to become closer to the person you want to be.

5. Tell observers to check off appropriate behaviors observed on the **Behavior Observation Chart**.
6. Ask observers to give feedback to the role players.

After the role-play, ask students to suggest other things the players might have done or said. As appropriate, have the volunteers reenact the scene using the suggestion.

You may wish to use a video camera to videotape the role-plays, so students can watch themselves and discuss their performance.

HANDLING CRITICISM ASSERTIVELY

Materials Required: Videotape and Behavior Observation Chart for Accepting Self in “Tools for Transition” by Elizabeth Aune and Jean Ness (Behavior Observation Chart is included here, the Videotape is available for loan through the Special Education Resource center (SERC), Middletown, CT.)

Activity A: To initiate a discussion on criticism, ask some of the following questions:

- a. How do you feel when somebody is criticizing you?
- b. How do you feel when criticizing others?
- c. How do you usually react when being criticized?
- d. How would you like to act when being criticized?

Activity B: Distribute the Criticism Student Handout, and review the three tips provided for handling criticism.

Activity C: Ask students to write down something for which they were recently criticized. Using the tips for handling criticism, have students determine if and how they handled the criticism assertively.

Activity D: To randomly assign students to groups of three for role-playing, have the students count off in three's. Assign an area of the classroom to each group.

Have each group create a situation in which one member of the triad is being criticized, one is doing the criticizing and the third is a coach. The student that is the coach will help the student being criticized remain assertive and avoid a name-calling or shouting match. Let groups practice, and then do their role-plays for the class.

Activity E: Show videotape segments 8 and 13 one at a time. Discuss the behavior shown on the video. Ask students to tell what was inappropriate and why. Have students brainstorm different behaviors they think would be more appropriate or better than those shown in the video segment. Write their ideas on the board.

Distribute the **Behavior Observation Chart for Accepting Self**. Ask students to write the appropriate behaviors in the “Appropriate Behaviors” column beside the skill name (Accepting criticism), as shown in the example below.

Behavior Observation Chart
Main Skill Area” Accepting Self

Skills	Check the Behaviors You Observed	Appropriate Behaviors – <i>What to look For in the role plays; What to do if You’re in this situation</i>
<i>Accepting Criticism</i>		<i>Stay calm – don’t get angry and upset.</i>
		<i>Ask what specific things I can do to improve my work.</i>
		<i>Thank the person for the feedback.</i>
		<i>Say that I will make the changes.</i>
<i>Taking Responsibility for One’s actions</i>		<i>Don’t blame someone else.</i>
		<i>Say that I made a mistake.</i>
		<i>Ask how I can correct it or say how I will correct it.</i>
<i>Being realistic About one’s Capabilities</i>		<i>Admit that there is a problem.</i>
		<i>Listen to advice from others.</i>
		<i>Say what I will do.</i>
		<i>Thank people who give me advice.</i>

Ask for volunteers to role-play the scene shown on the video showing one of the behaviors the group selected.

The following sequence for role-playing is recommended.

1. Describe the situation.
2. Encourage students to visualize what they will say and do (visual rehearsal).
3. Tell students to talk through what they will say and do (verbal rehearsal).
4. Have students act out the situation.

DEVELOPING EFFECTIVE LISTENING SKILLS

Activity A: Effective listening is an important part of assertiveness. It's also an important part of negotiation and communication.

To test listening skills ask students to:

1. Pair up with another person and have him/her speak to them nonstop for a full minute (about any subject matter).
2. Repeat – as closely as possible, what the speaker has just said to them.
3. Have the speaker make appropriate corrections.
4. Change roles – speaker is now the listener and vice versa.

Ask students if they listened intently enough to be able to repeat the speaker's statement reasonably accurately?

Or did they find it hard to concentrate, with their mind wandering and preparing what they should say next?

Students should practice this exercise before school meetings and negotiating meetings – so that they will be able to listen actively and get the most out of the meeting.

DEVELOPING EFFECTIVE COMMUNICATION SKILLS

Activity A: Have students 'act out' emotions non-verbally, while others identify which emotions are being demonstrated: shyness, sorrow, joy, suspicion, anger, happiness, fear, indifference, frustration, hope.

Activity B: Have students describe themselves to another, who then gives feedback on the way facial expressions, gestures, eye contact and posture were used; they then switch roles.

Activity C: Have students practice using brief verbalized expressions of interest and understanding: 'I see', 'Yes', 'Really', 'That's interesting', 'Great'.

Activity D: Have students practice phrases that indicate willingness to continue or expand a conversation: 'I'd like to hear more about that', 'What happened next?' 'What will you do about that?', 'Let's discuss that now'.

Activity E: Have students practice paraphrasing what someone has just said, to indicate that the communication has been understood: 'So you're getting a new job?', 'If you move into an apartment, you think you'll be happier', 'So John keeps annoying you, does he?'.

Activity F: Have students practice reflecting the mood of another person: 'You seem sad about that', 'You look angry', 'You seem tired', 'You sound very pleased with the way things have turned out'.

Activities A through F were taken from "We Can Speak for Ourselves", by Paul Williams and Bonnie Shoultz, Indiana University Press, Bloomington, Copyright 1982.

Speaking up for Yourself

Start thinking for yourself. It's important that you realize that you are unique, a one-of-a-kind person, an individual. Feel comfortable about the style in which you assert yourself. Some people speak very loudly and enthusiastically; people hear them clearly. Some people speak more softly and infrequently; they are heard equally clearly. Do not change your style. The key is to put into words exactly what you want or need.

Some general tips on being heard:

- Look the person you are talking to in the eye. If you are short or use a wheelchair, you will sometimes have to draw attention to yourself by speaking directly to the person. If he or she seems unwilling to look at you, you might find some clever – yet polite – way to say, “I’m right here!” How you do that will depend on your personality. For someone who is extroverted, that might mean carrying a red bandana to wave. For someone who is more introverted, that might mean speaking in a louder, stronger voice.
- Speak clearly and distinctly in whatever way you can. If you have a speech disability, calm your anxiety by trying to relax the muscles in your body, taking in deep breaths of air and exhaling slowly. Speak slowly and as distinctly as you can. Sometimes it helps to calm yourself by visualizing a soothing image, such as a mountain stream or a quiet meadow in springtime. You will find that your whole body will relax and that you will be able to focus on your thoughts and your message. If you are calm, the other person will relax and be able to concentrate on what you are saying. If you use a speech synthesizer to speak, you may want to give the person a little note explaining this device. You will think of other ways to communicate.
- Be courteous and polite; say “please” and “thank you.”
- Do not be overly polite (obsequious).
- If the person addresses everyone around you, but not you, tell the person nicely and firmly that you speak for yourself and that you would like to be addressed directly.
- Think about what you want to say and how you want to say it before you begin speaking.

Note: Assertiveness also means that you don't attack others in stating your needs. For instance, you don't berate the store clerk because the counters are too high for you to see over. That complaint will need to be given to the store owner/manager. Assertiveness means that you stand up for yourself in an adult, responsible way. It is not aggressive; it is not passive. Remember to keep the balance! And to be yourself!

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Activity A: Have students practice responding with a refusal to orders such as 'Go to the store!' or 'Take these out to the car!' Feedback is then given on whether the person appeared comfortable in refusing; whether he/she made eye contact; whether he/she hesitated; whether posture, gestures, tone, expression and volume were assertive, or too passive or aggressive.

Activity B: Have students practice positive assertiveness, with feedback. Students make positive statements such as: 'I like you', 'You look very nice', 'You're a nice person', 'I appreciate your patience', 'You work hard'. And they give positive replies such as: 'Thank you for saying so', 'I'm glad you think so', 'I'm happy you appreciate me', 'Working hard is important to me'.

Activity C: Have students responding to a salesman trying to sell them an encyclopedia they don't want, with feedback on their performance. Then students practice being the salesman, also with feedback.

Activity D: Ask students to visualize themselves in a situation where they are successfully using assertiveness techniques.

Activity D was reprinted with permission from "How to Get Services by Being Assertive" published by the Family Resource Center on Disabilities, Chicago, IL, 1993. Activities A through C were taken from "We Can Speak for Ourselves", by Paul Williams and

Bonnie Shultz, Indiana University Press, Bloomington, Copyright 1982.

Assertiveness Is...

Assertiveness Is Not...

What is assertiveness? There are many definitions and many examples of assertiveness. We offer the following as a sample.

Assertiveness is:

1. expressing your needs clearly and directly
2. expressing your ideas without feeling guilty or intimidated
3. sticking up for what you believe you need – even though professionals may not agree
4. knowing your rights and how to get them
5. documenting what you need and all facts pertaining to your case
6. collaborating with service providers and treating them like partners
7. effective communication
8. conveying your feelings of self-confidence when you communicate with others
9. advocating effectively on your own behalf
10. self-reliance and independence
11. persisting until you get all the services you need
12. analyzing a problem and pinpointing the area of responsibility before you act
13. agitating to get necessary legislation passed and implemented
14. organizing for change
15. having a positive attitude at all times
16. being strong when others are weak
17. joining others who are organizing for change
18. taking pride in your accomplishments
19. having the courage to dream and developing the skills to make those dreams come true

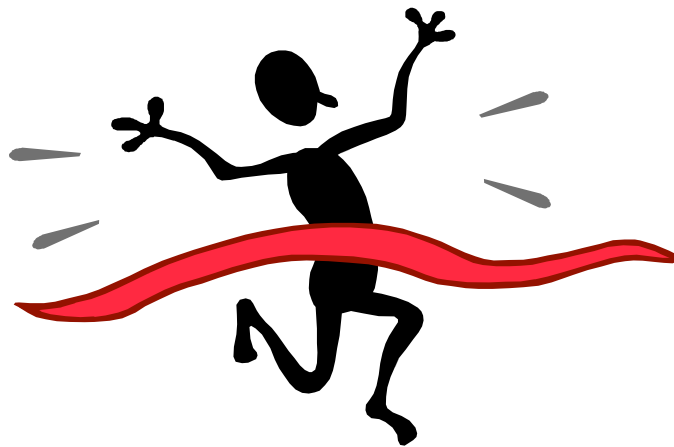
Assertiveness is not:

1. beating around the bush before stating your needs
2. feeling too guilty or afraid to express your needs
3. agreeing with professionals – no matter how you feel – because “professionals know what’s best”
4. ignorance about your rights
5. leaving everything to others because “they know how to do these things”
6. accepting inappropriate or inadequate services because it’s easier to let professionals handle things
7. ineffective communication
8. begging for what is legitimately yours by law
9. abdicating to others your right to self-advocate
10. reliance and dependence on others

Assertiveness Is...

Assertiveness Is Not...(continued)

- 11. giving up when you run into red tape
- 12. acting precipitously before you get all the facts
- 13. letting the politicians “take care of laws and all that political stuff”
- 14. accepting the status quo because “nothing can be done”
- 15. giving in to defeat
- 16. being swayed by others who have a “no win” attitude
- 17. acting “only” on behalf of yourself
- 18. being uncomfortable about your accomplishments
- 19. refusing to dream



Reprinted with permission from “How to Get Services by Being Assertive” published by the Family Resource Center on Disabilities, Chicago, IL, 1993.

Being Assertive Is Not My Style

If being assertive is not your style – What is your style?

Are you a:

1. **Nice Lady** – who is afraid to say anything or do anything that might offend anyone – especially bureaucrats, because they will call you other names instead of “nice lady”?
2. **Whiner** – who constantly whines and complains about:
 - a. The services you need and are not receiving?
 - b. How bureaucrats treat you when you ask for services?
 - c. How professionals treat you when you try to discuss your progress (or lack of progress)?
 - d. How bad everything is – but never does anything about it?
3. **Clinging Vine** – who clings to others and expects them to stick up for your rights and intervene on your behalf?
4. **Silent Victim** – who has resigned herself to lack of needed services because “there’s nothing I can do about it”?
5. **Fairy Princess** – who expects everything to happen, and every service to be delivered without any effort on your part.
6. **Waiter** – who waits for a miracle to happen, for something someone promised, who waits and waits and waits for someone else to do something.
7. **Bombshell** – who fires angry missiles sporadically, instead of calmly and methodically building a good case for what you need?
8. **Scaredy Cat** – afraid that “if I make trouble they’ll get back at me”?
9. **Appeaser** – who compromises your needs because “if I ask for too much they won’t give me anything”?
10. **Sellout Self-advocate** – who makes deals with bureaucrats to get services for himself and pressures others not to rock the boat?

Adapted and reprinted with permission from “How to Get Services by Being Assertive” published by the Family Resource Center on Disabilities, Chicago, IL, 1993.

DEVELOPING ASSERTIVENESS SKILLS

Activity A: Use the handout **Speaking Up for Yourself** to review with students various tips on being heard.

Activity B: Tells students that: “You are what you **think** you are. Start thinking Assertively and you **will** become the assertive person you want to be.”

Then go around the room, asking each student to complete the following sentence:

“I wish I were more...”

(*Example:* I wish I were more assertive; I wish I were more gutsy.)

Repeat the exercise with a new sentence:

“I can be more _____ by _____.”

(*Example:* I can be more assertive by being informed about my rights and insisting on what I’m entitled to.)

Activity C: Have students practice giving answers that are assertive, passive or aggressive in response to someone asking if they may smoke.

Activity D: Have students practice expressing the following statements in an assertive way, a passive way and an aggressive way: “It’s time for me to leave’, ‘No, I don’t want to join your club’, ‘It certainly is warm in here.’

Others Who Are Winning by Being Assertive

Assertiveness is not a new concept. People and organizations have won their objectives through assertiveness techniques for thousands of years.

All around you are examples of individuals and organizations who have “won” and reached their goals – by being assertive. For example:

- The Thirteen Colonies
- teachers
- U.S. Chamber of Commerce
- parent groups/coalitions
- government agencies
- nations
- political parties
- consumer groups
- trade associations
- professional associations
- student associations
- pressure groups

There are also many individual examples. Here are just a few (listed alphabetically):

- **Susan B. Anthony** – whose persistence in the long struggle for female suffrage won American women the right to vote in 1919.
- **Carol Mosely Braun** – who shook up Illinois politicians when she defeated the “undefeatable” Alan Dixon in the Illinois Democratic primary for U.S. Senate – and is predicted to become the first African-American woman in the U.S. Senate.
- **Jane Byrne** – (Chicago ex-mayor) whose outspoken assertiveness got her fired from her job in City Hall – but a year later, got her elected the head of City Hall.
- **Queen Esther** – whose courageous assertiveness saved her people from destruction at the hands of a cruel politician.
- **Betty Friedan** – whose 1963 book “The Feminine Mystique”, launched the women’s liberation movement.
- **Mohandas K. Ghandi** – who’s passive but determined assertiveness freed a nation and inspired subjugated people all over the world to emulate his nonviolent methods to gain their freedom.
- **Patrick Henry** – his assertive “Give me liberty or give me death” became the rallying cry of the American Revolution.
- **Jesse Jackson** – whose positive attitude overcame discrimination and poverty to become a powerful national leader.
- **Joan of Arc** – whose courageous assertiveness inspired a defeated French army to victory.

Others Who Are Winning By Being Assertive (continued)

- **Abraham Lincoln** – whose assertive refusal to allow the South to secede from the Union led to the Civil War and the emancipation of African-American slaves.
- **Martin Luther** – whose assertiveness against church corruption sowed the seeds that resulted in a new Church
- **Martin Luther King, Jr.** – whose nonviolent assertiveness inspired millions of American people.
- **Moses** – whose assertiveness in insisting, persisting, and persevering convinced the Pharaoh to finally “let his people go”.
- **Ralph Nader** – who has organized the strongest consumer movement in the nation, and has succeeded in making our politicians and our manufacturers accountable.
- **Florence Nightingale** – whose persistent assertiveness against British bureaucracies was responsible for professionalizing nursing.
- **Rosa Parks** – whose assertive refusal to give up her seat on a Montgomery, Alabama bus in 1954 sparked the citywide bus boycott, which propelled Martin Luther King and the Southern Christian Leadership Conference to national action and prominence.
- **Margaret Chase Smith** – who refused to listen to Maine politicians who proclaimed she couldn’t win, and subsequently became the first elected woman in the U.S. Senate.
- **St. Bernadette Soubiroux** – whose quiet and persistent assertiveness won over her detractors, who eventually proclaimed her a saint.
- **Harry Truman** – whose gutsy assertiveness got him the nickname “Give ‘Em Hell Harry,” and won him a presidential election many had predicted he would lose.

You will find that the people who stand out as doers and movers and achievers are all assertive people, Although they’re assertive styles may differ.

Reprinted with permission from “How to Get Services by Being Assertive” published by the Family Resource Center on Disabilities, Chicago, IL, 1993.

Speak Up! Guide

3. Problem Solving

Published by:
STIR – Steps Toward Independence and Responsibility
And
The Self-Determination Resource Center,
Projects of the
Clinical Center for the Study of Development and Learning, UNC-CH
For further information, please call Rebekah Pennell at (919) 966-5171

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1. **WHY DO WE NEED PROBLEM SOLVING?**

- **To be in control of what happens to us and not to allow others to decide for us.**

Example: Mary has planned to go out for lunch today since she has just received her paycheck. She asks Susan to join her but they have to decide where to go eat. Mary likes Mexican food but Susan wants to go to a fast food restaurant. Mary knows she might not be able to afford going out for a while and she feels she should go eat what she really wants. On the other hand she does not want to upset Susan who said she would not consider her a friend anymore if she does not go with her to McDonalds. Mary finally lets Susan decide where to go because she wants her to continue to be her friend.

- **To avoid the negative consequences of bad decisions.**

Example a: John accidentally bumped into Bill on the way to sharpen his pencil. Bill called John a name. John punched Bill in the nose. John is suspended for starting a fight.

Example b: The supervisor comes to check on the work of Mike who is stuffing envelopes. He discovers that Mike has been putting the wrong flyers in the envelopes and tells him that. Mike becomes upset because he has already done 200 envelopes and now he has to redo them and miss his lunch break. He yells and threatens the supervisor and leaves the workplace to outside for a break. The consequence might be that he does not get a raise or he might even be terminated for his impulsive behavior.

- **To attain your goals in spite of the barriers**

Example a: Betty needs a ride to go to work but Gary said he couldn't come anymore to pick her up. Betty is very concerned that she cannot get to work on time but she cannot think of anything she can do. She just sits there and cries when she could have checked the bus schedule or asked someone's help with getting there.

Example b: Francis goes to the movies but the person in front of her gets the last tickets for the movie she wants to see. The cashier tells her that all the tickets have been sold for that night but she can come back tomorrow.

Example c: Her supervisor at the fast food place gives Sue a task. After the boss leaves, Sue realizes that she does not remember exactly what

tables she has to clean and prepare for the new group that is to come. She wants to do her job but she forgot the instructions. As a result, she just sits there unable to do anything.

- **To make and maintain friendships**

Example a: Susan has moved to a neighborhood and does not know anyone. She wants to make friends because she does not have any in this new area. Problem solving can help her attain this goal.

Example b: Susan was on her way to class when Marci stopped to talk to her. She told her to wait so that she can tell her about the note she received from Justin before school. Susan stayed and listened because she did not want to hurt Marci's feelings. She was also anxious to hear the latest. As a result, Susan was tardy to her next class and had to serve detention.

- **To cope with difficult situations**

Example a: A co-worker tells Helen to help her clean the floors but the boss has told her to empty the garbage cans. Helen wants to be helpful to her friend but she does not want to disobey her boss and risk being fired.

Example b: A neighbor keeps borrowing money from Joe and he never pays him back. This way, Joe does not have enough money to buy things for himself and he would like this situation to stop.

Example c: Steve wants to watch a TV program but his roommate wants to watch another one. The roommate has been watching TV for the last hour and now Steve feels that it should be his turn to watch what he wants.

2. WHAT DO I NEED TO KNOW TO BE ABLE TO PROBLEM SOLVE?

- **Recognize feelings and how emotions can influence your decisions**
 - ◆ Exercise: Identify how you feel when you have a problem on Faces handout #1.
 - ◆ Exercise: Identify what emotions will make you take bad decisions on Faces handout #1.
- **Learn relaxation techniques**

In order to be able to make a good decision you should be calm, have a cool head, and have complete control over your behavior. That way you avoid impulsive decisions.

Brief demonstration of the relaxation procedure:

Remember when you are ready to relax, choose a place where you can concentrate and not be interrupted by other people or activities. Choose a quiet place and choose a chair with a straight back so you can sit up straight in a relaxed position with your feet flat on the floor. Sometimes it's hard to pay attention and do everything that is necessary to relax, so you might want to have someone sit and relax with you and help you remember to do the things that we talk about on this tape.

Now that you are ready to relax, sit in the relaxed position with your hands resting comfortably on your legs, close your eyes, and take a deep breath. Let it out slowly. Feel the way that your whole body begins to relax when you let out a breath. You're starting to feel better and you're starting to feel more relaxed already.

Now relax your shoulders. Let them droop down. Move your shoulders slowly so all of the tension goes away. Your shoulders are drooping down, and you feel so calm, and quiet, and relaxed.

Now this comfortable, relaxed feeling spreads down your arms all the way to your hands. Your arms and hands are resting on your legs, and they feel heavy and calm. Your whole body is feeling relaxed.

This warm, calm, comfortable feeling spreads down to your legs – all the way to your feet. Your feet are resting flat on the floor, and they feel heavy. Your whole body feels calm and relaxed.

Now take another deep breath and let it out slowly. Think about how good you feel. You are quiet, and calm, and rested. You feel so peaceful. It feels so nice, and you can remember this feeling so that any time you have a problem or start to feel upset, you can just take a deep breath and relax.

You've done a great job.

- **Learn to tell yourself positive self-statements** that increase your confidence in your ability to cope with the situation and make you feel good about yourself.

Positive self statements	Negative self statements
I can handle this	This can happen only to me
I will be calm	What a stupid thing to happen
Everything is going to be okay	I knew I was going to get in trouble
I can do this	This is more than I can stand
I can relax	I will never be able to do this

- **LEARN THE PROBLEM SOLVING STEPS**

Problem: John comes home from work and discovers that his CD player is broken. He knows Joe has been home all day and that he likes to listen to his CD player since he doesn't have one. Lisa and Steve are also living in the same house, but neither of them have expressed an interest in John's CD player. Thinking about how Joe could have broken his CD player, John starts to get angry but before going too far he remembers to use the problem-solving strategy. Instead of heading directly to where Joe is sitting and watching TV and screaming at him, he follows these steps:

STEP 1: Relax

John takes a deep breath and feels his tension going out when he lets the air out. He relaxes his muscles and he feels he is in control of his body as well as his actions.

STEP 2: Positive self statement

John says to himself, "I can remain calm" and he feels confident in his abilities to handle the situation without losing control.

STEP 3: Identify problem

John has to ask himself first "What is the problem? What makes me so upset?" Instead of identifying the problem by blaming Joe (e.g., Joe broke my CD player), John states the problem as being, "I found that my CD player is broken." John did the right thing because he has no confirmation that Joe actually broke his CD player.

STEP 4: Think of solutions

What are the different things you can do to solve your problem? What are the advantages and disadvantages of each one? What might be the good things and the bad things that might happen for each solution? Exercise: Use the Decision-Making Process worksheet for this step.

Problem: "I found that my CD player is broken." John's **goal** is to be able to listen to his CDs and the **barrier** is that his CD player is broken.

Possible solutions	Advantages (good things that might happen)	Disadvantages (bad things that might happen)
A. John might want to confront Joe about the CD player and ask him if he used it.	A. He will find out very quickly if Joe has broken it and can ask him to help pay for the repair costs.	A. He might upset Joe by seeming accusing and lose Joe as a friend
B. John might try to take the CD player to a repair shop or buy a new one	B. He will avoid showing his suspicions about Joe.	B. He will have to pay the whole cost of the repair.
C. John can listen to his music on cassettes or on the radio.	C. He will still enjoy listening to his music and still be friends with Joe.	C. John will still have a broken CD player to deal with later.
D. John can forget about music altogether and go watch TV with Joe.	D. He will still have Joe as a friend and find an enjoyable activity to do.	D. John will still have a broken CD player to deal with.

STEP 5: Choose and use the best solution

After carefully considering all options and their consequences, John chose to ask Joe if he knows that the CD player is broken. He will then take the CD player to the repair shop and, if it costs more money than he can spend, he will start saving some. This way, he will preserve his friendship with Joe while being able to repair something that he needs.

In summary the problem solving steps are:

- ❖ Relax (deep breath)
- ❖ Positive self statement (that makes you feel good)
- ❖ Identify problem (what is the problem?)
- ❖ Think of solutions (what can you do to solve the problem)
- ❖ Choose and use the best solution

3. WHAT ARE THE GENERAL CATEGORIES OF PROBLEM SITUATIONS?

- ❖ **Asking for information or favors from others** (e.g., asking for help)
- ❖ **Refusing unreasonable requests** (e.g., when someone asks to borrow your new baseball cap)
- ❖ **Dealing with criticism** (e.g., when your supervisor tells your work has not been done right)
- ❖ **Handling disagreements** (e.g., when your friend tells you that you are wrong)
- ❖ **Meeting new people** (e.g., when you want to make new friends)
- ❖ **Coping with objectionable behaviors from others** (e.g., when your co-worker teases you because you always bring carrots for lunch)

4. HOW TO MAKE PROBLEM SOLVING HAPPEN IN EVERYDAY LIFE SITUATIONS

How to make the problem-solving skills happen in different situations:

- Practice the same strategy for different situations
- Repetition of the same agenda every day
- Use the same pictures and reminders for all situations
- The strategy should be repeated every day, even several times a day during the learning period
- Use different problems while going through the same problem-solving steps.
- Use different actors to play the roles in various problems
- Use different settings in which the same problem is occurring

How to remember the problem-solving skills over time:

- Use natural reinforcers that they might be likely to encounter in the real world
- Use less and less reminders as the participants learn the steps
- Teach the participants to design their own reminders (cues)
- Hold sessions monthly or every other week to remind the participants of the problem-solving steps
- Pair persons who know the problem solving steps with those who are just learning them so that, by tutoring, they will keep the knowledge fresh.
- Let everybody know that you are learning and using the problem-solving steps so that they can remind you to use them in a situation when you forget.

For more information on the "Problem Solving for Life" manual and training audiotape contact Irina Paraschiv, Clinical Center for the Study of Development and Learning, CB # 7255, University of North Carolina, Chapel Hill, North Carolina 27599-7255, Phone: (919) 966-4846, Fax: (919) 966-2230, E-mail: iparaschiv@css.unc.edu, World Wide Web address of Learning for Life Program, <http://cdl.unch.unc.edu/lfi>

Name: _____

Decision Making Process

Problem to be solved Name the problem as it has been Identified	Possible solutions	Advantages (Good things that might happen)	Disadvantages (Bad things that might happen)
	A.	A.	A.
Barriers to solve the Problem	B.	B.	B.
Resources	C.	C.	C.
	D.	D.	D.

Problem Solving Steps

Step 1: Relax (Deep Breath)

Step 2: Positive Self-Statement

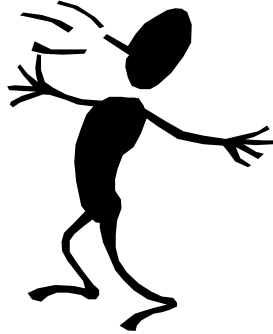
Step 3: Identify the Problem

Step 4: Think of Solutions

Step 5: Just do it!

Problem Solving Steps

Step one



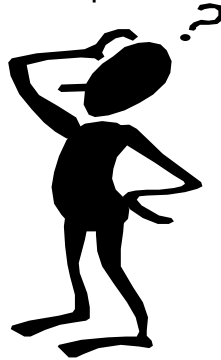
Deep Breathe

Step two



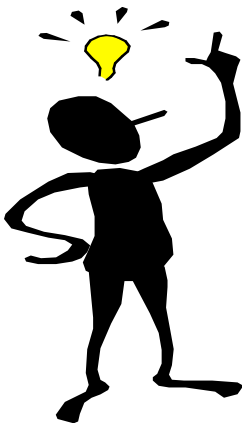
Talk to
Yourself
(you can do it!)

Step three



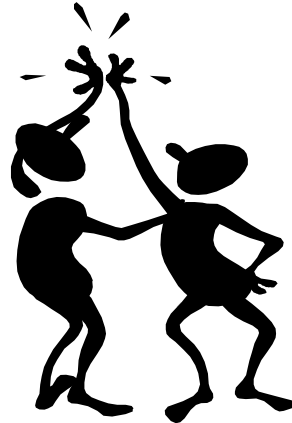
Identify the problem

Step four



Think of Solutions

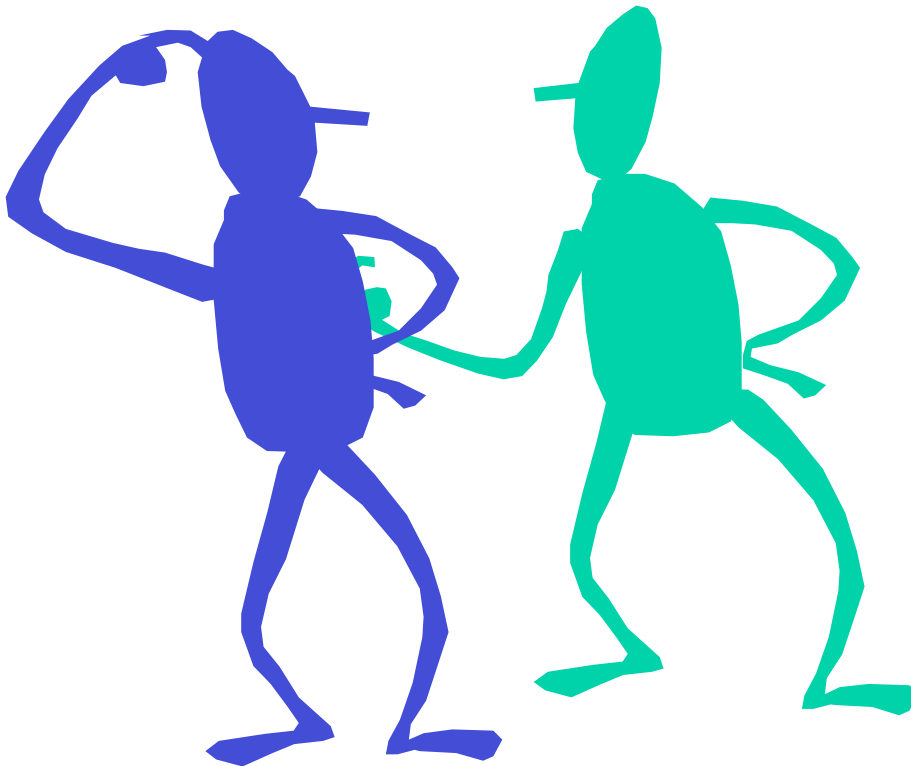
Step five



Just Do It!

Speak Up! Guide

We can do
What?



4: Rules, Rights and Responsibilities

Published by:
STIR – Steps Toward Independence and Responsibility
and
Shifting the Power,
projects of the
Clinical Center for the Study of Development and Learning, UNC-CH
For further information please call Rebekah Pennell at (919) 966-5171.

Speak Up! Guide

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...Choose How to Save or Spend Your Money	
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...Have a Place to Be Alone	
...Choose Your Friends	
...Call and Visit Family and Friends	
...Decide What You Want to Eat	
...Choose Where You Want to Live	
...Come and Go as You Wish	
...Have Visitors	
...Live in a Clean Furnished Home	
...Privacy And To Expect People To Knock Before Entering	
...Have Your Own Belongings	
...Do Group Activities or Do Things By Yourself	
...Get an Education	

- ...Choose Your Own Doctors and See Doctors When You Want
- ...Agree or Refuse to Participate in Research
- ... Have, Receive or Refuse Regular Therapy Services
- ...Not to Be Put Down by Words or Actions
- ... To Be Treated Fairly And With Respect
- ... Calm Yourself Down When You Are Upset Before Other Means Are Used
- ...Get Help
- ...Choose an Advocate
- ...Expect Public Places to Be Accessible
- ...Join Community Groups
- ...Plan and Enjoy Fun Activities
- ...Right to Vote
- ... To Decide If You Want Your Picture Taken
- ...Get Needed Services
- ...Request a Guardian
- ... Have Your Treatment Plan Written or Reviewed at
a Meeting with You
- ... Decide Who Can See Your Records and To Have Access To
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Additional Resources

Listed in this resource guide are agencies that Federal Laws mandate. These agencies can provide information and resources. Every state's agencies are listed in these directories. There is also a description of what the agencies' duties. Please take the time to look at each one. If you have a friend or relative in a different state please share the information for their state with them.

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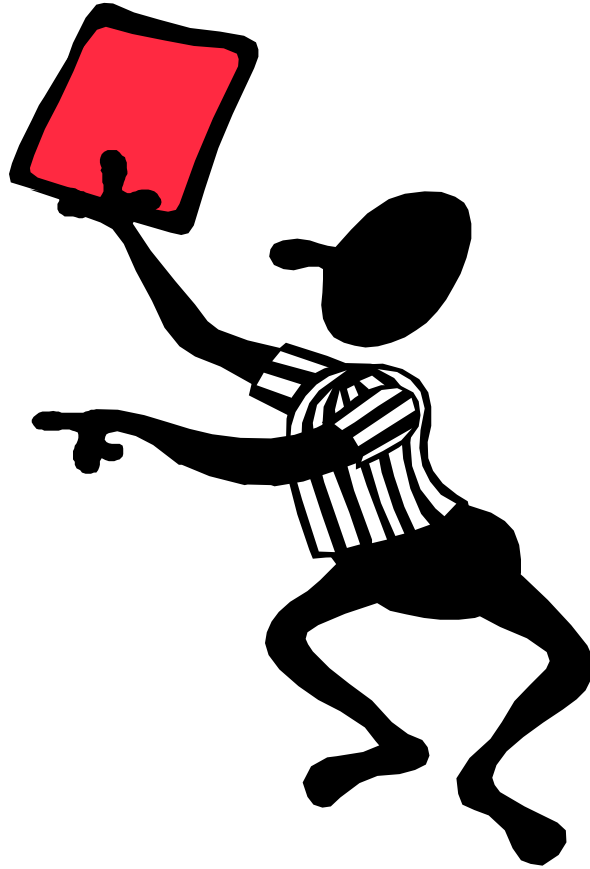
CHAPTER FOUR: RULES RIGHTS AND RESPONSIBILITIES

LEARNING OBJECTIVES

The objective of this chapter is to expose the trainees to some of the different laws that protect the rights of people with disabilities. It will also provide resources so you can find the information you need to advocate for yourself, or others.

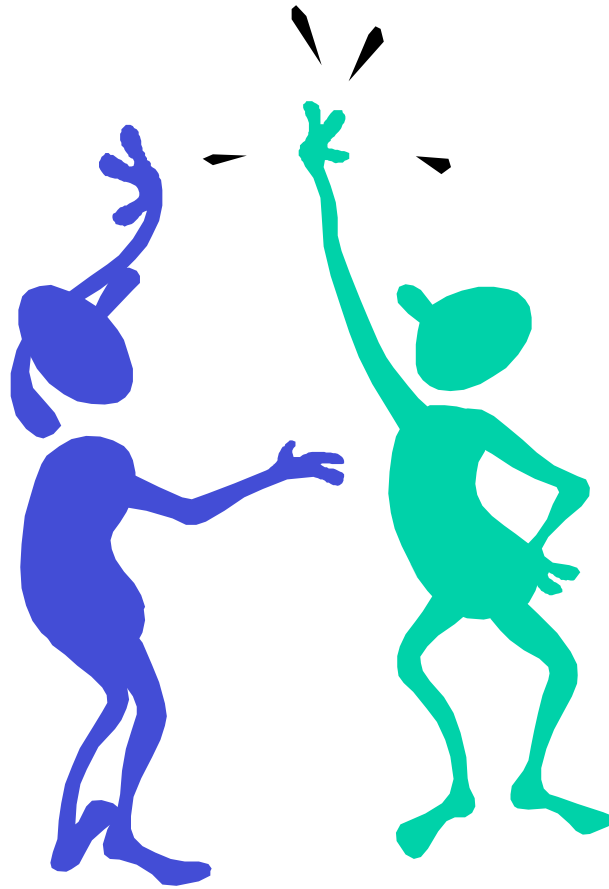
As you read and discuss the laws and information in this manual, keep in mind that laws continue to change and be updated. This manual provides you with agencies that can keep you up to date with current law. Some of the laws used in this chapter have already been updated and are used as examples.

Rules



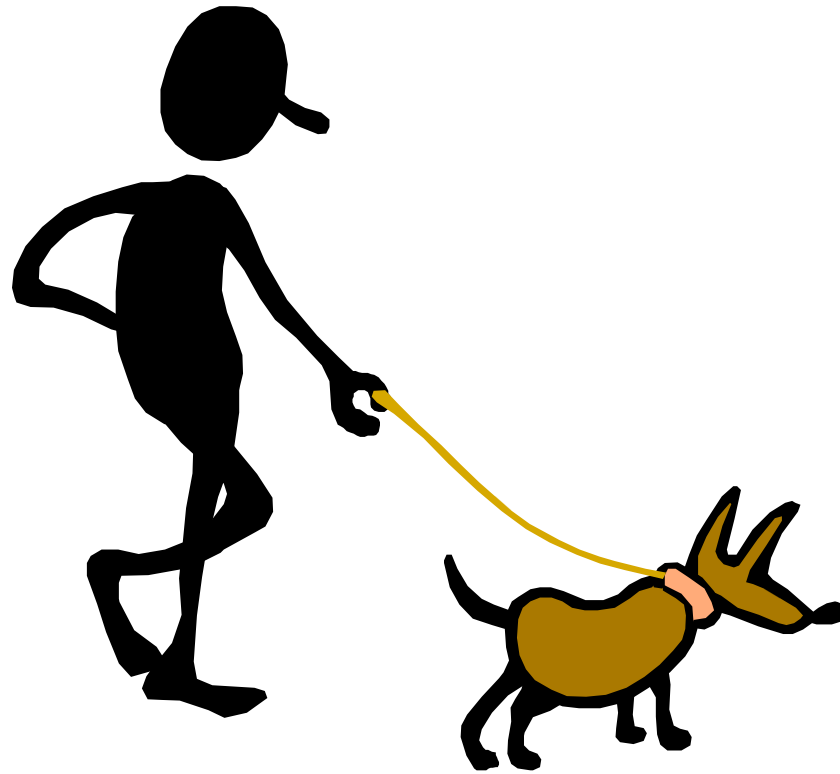
- Rules help us understand what we need to do to keep our rights.
- We all must follow rules.

Rights



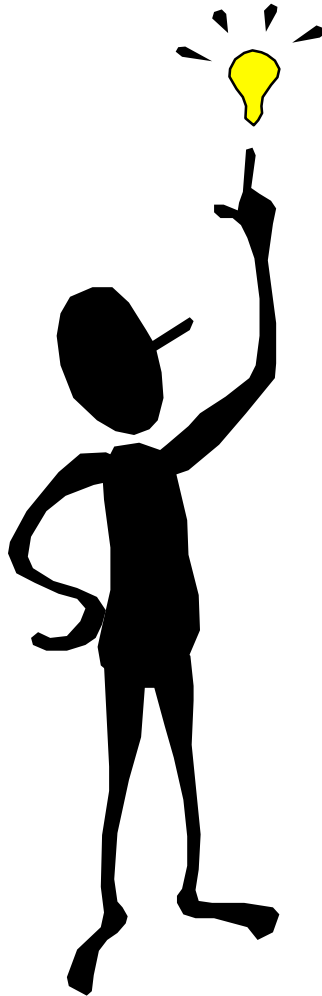
- Rights apply to everyone!
- Rights are Rules that help make people equal.

Responsibilities



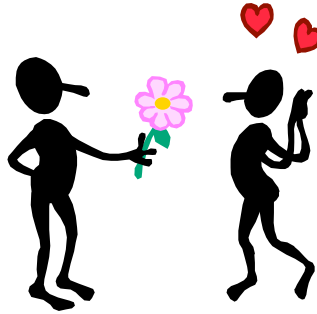
- To have our own rights respected, we must respect the rights of others.
- We must behave in a responsible way.

Rules and Laws



Rules and Laws both help us
know what our Rights and
Responsibilities are to
ourselves and others

You have the right to date



Responsibilities

- Treat other person with respect
 - Personal space issues
 - Intimacy issues
 - Say nice things
- Treat the other person kindly
- What does dating mean to you?
 - Holding hands
 - Meeting somewhere
 - Going to the dance

Role Play

Location: Group Home, where you live

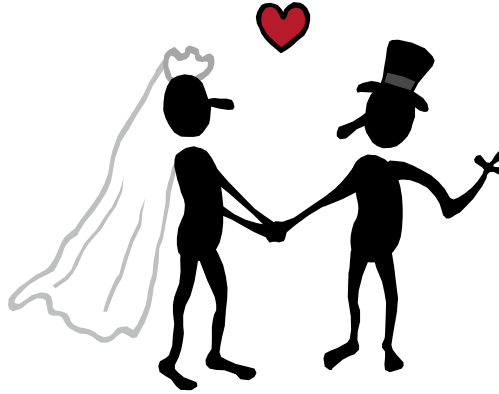
Situation: Two Friends are discussing dating after being told they have a right to date.

Role Play: What does dating mean?

How should you treat your date?

Where are you going to go and what do you want to do?

You have the right to get married



Responsibilities

- Treat spouse with respect
- Share responsibilities
 - Paying the bills
 - Household chores
 - Keeping a job
- Talk to each other about big decisions
 - Are you going to have kids?
 - Where are you going to live?
 - How are you going to spend your money?

Role Play

Location: Parents Home, where you live

Situation: A couple is discussing marriage with their parents.

Role Play: How will you support each other?

Will you share household duties?

Will you have children and
when?

You have the right to have children



Responsibilities

- Take care of your child
 - Doctors appointments
 - Getting baby shots
 - Feed them and clothe them
 - Provide a place to live
 - Give them love and affection

Role Play

Location: Doctors office

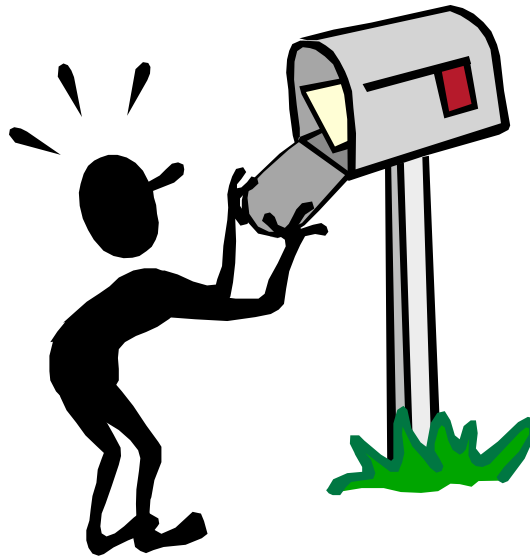
Situation: A newly married couple along with their parents and doctor are discussing the responsibilities of having children.

Role Play: What things do children need to be supported ?

How they will provide supports?

Do they even want children?

You have the right to open your own mail and packages and to send other people mail



Responsibilities

- ❑ Let others know not to open your mail unless you tell them it is O.K.
- ❑ Respect other people's mail
 - Do not open others' mail
- ❑ Let others know if you need help reading or responding to your mail

Role Play

Location: Group Home, where you live

Situation: Friends talking about wanting to open and send their own mail.

Role Play: How do the bring up the subject with the staff ?

Who do you ask for help if you need help understanding your mail?

You have the right to choose your job and to receive fair pay



Responsibilities

- ❑ Show up for work (on time)
- ❑ Do the best job you can while at work
- ❑ Call in if you can not show up for work
 - Sick
 - Doctor's appointment

Role Play

Location: Workplace, workshop, ect.

Situation: Two friends are discussing what they would really like to do for employment.

Role Play: What supports will they need to help them accomplish their goals?

What new skills may they need to learn?

You have the right to decide how to spend or save your money



Responsibilities

- ❑ Come up with a budget and spend within that budget
- ❑ Ask for help if you need it
- ❑ Know how much money you have
- ❑ Use the bank if needed

Role Play

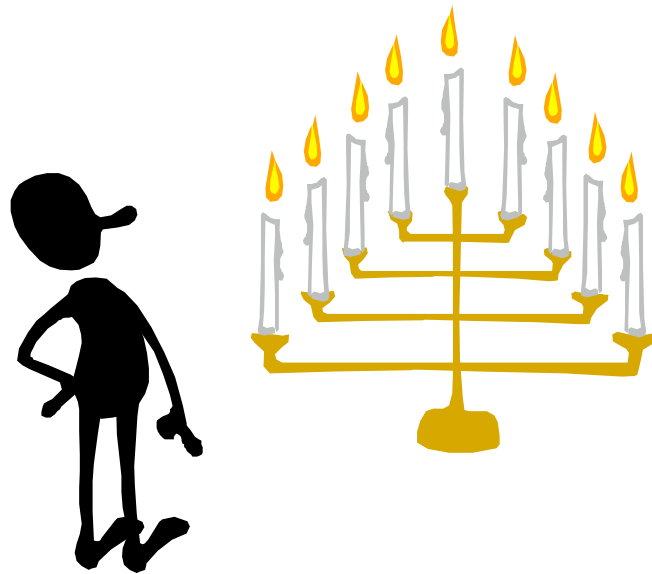
Location: Bank

Situation: You are speaking with a customer service representative about opening a savings or a checking account.

Role Play: What different types of accounts do they offer?

Is there a penalty for spending more money than you have in your checking account?

You have the right to choose where to worship and how to express your beliefs



Responsibilities

- Respect others' beliefs

Let some one know where and when you would like to worship.

Role Play

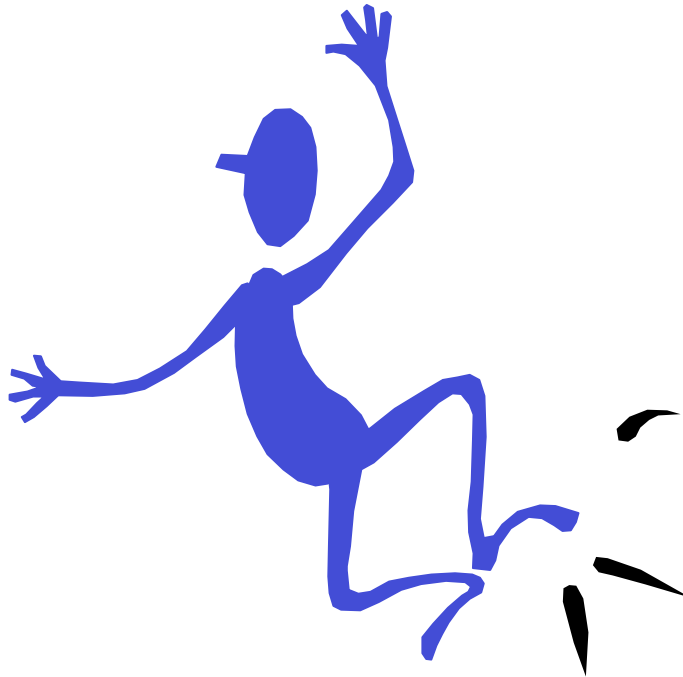
Location: Group home or where you live

Situation: You are talking to staff about were they are going to worship.

Role Play: You are expressing that they would like to continue worshipping at their own church.

You would like to attend a different church than what is offered / or no church.

You have the right to have a place to be alone



Responsibilities

- ❑ Respect other people's space
- ❑ Other people have the right to say "no"

Role Play

Location: Group Home or where you live

Situation: You are speaking to staff or your parents about having time to spend in privacy.

Role Play: You would like to listen to music without being disturbed.

You would like have a private place to make phone calls.

You have the right to choose your friends



Responsibilities

- ❑ How would you treat your friends?
- ❑ Where would you go to meet new friends?
 - Common interests
- ❑ How do you like to be treated by your friends?

Role Play

Location: Parents home, group home

Situation: A daughter or son speaking to parents, or resident to staff.

Situation: How do you treat your friends?

When you are with your friends do you act in a responsible way?

Where could you meet new friends?

Who is not a good friend?

You have the right to call and visit family and friends



Responsibilities

Visits

- ❑ Arrange visits ahead of time
- ❑ Respect your family and friends

Calling

- ❑ Respect other people's use of the phone
- ❑ Don't call other people too early or too late
- ❑ Let others know when you want to have privacy while on the phone

Role Play

Location: Group Home, where you live

Situation: You are talking to staff and friends.

Role Play: How are visits going to be arranged?

When is the best time for you to have phone calls or friends over?

Be a good friend and call or visit when you say you are going to.

You have the right to decide what you want to eat



Responsibilities

- Know what you can and cannot eat for health reasons such as...

Diabetes, high blood pressure, high cholesterol or if your doctor gives you a special diet

Role Play

Location: Restaurant, where you live

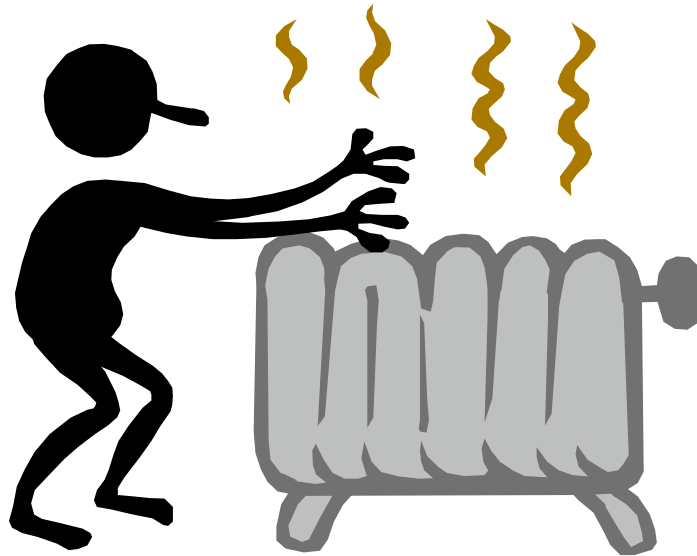
Situation: You are at a restaurant deciding what you want to eat. Or/ at home where ever you live.

Role Play: Do you have any thing you know you are not able to eat?

What would you like to eat?

Let others know what you want and like to eat.

You have the right to choose where you want to live



Responsibilities

- ❑ Choose a safe place
- ❑ Make sure your place is within your budget
- ❑ Check out the community
 - Public transportation
 - Shopping centers
- ❑ Let someone know if you want to move

Role Play

Location: Parents home, group home

Situation: You are talking about where you would like to live.

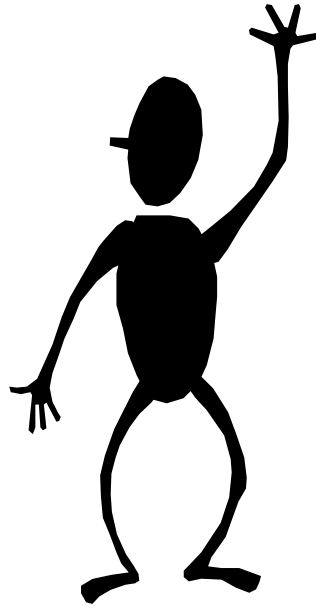
Role Play: Do you have enough money to live
own your own or with a room mate?

What supports will not need?

Where do you want to live?

Will you have transportation?

You have the right to come and go as you wish



Responsibilities

- ❑ Let others know where you are going and when you will be back
- ❑ Be back when you say you will be back or call and let someone know if you will be late

Role Play

Location: Home, where you live

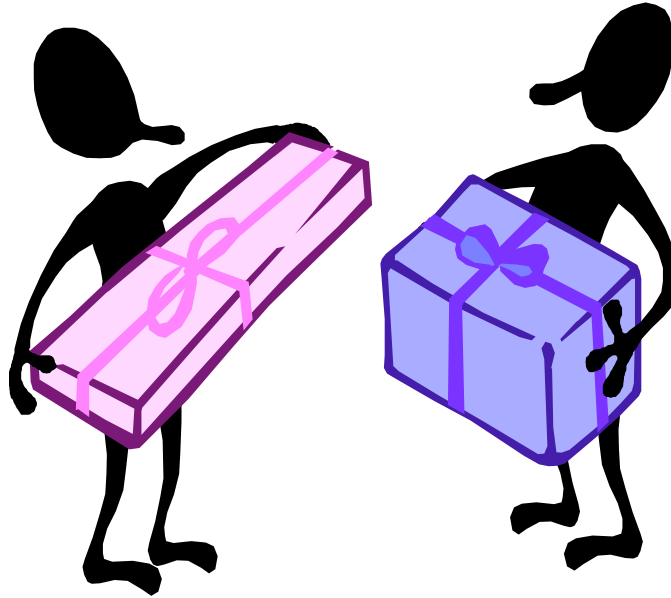
Situation: You are talking with staff or your parents about going somewhere.

Role Play: Make sure you let someone know where you are going to be, and how long you will be gone.

What you can do if you will be late?

Who you are going to be with?

You have the right to have visitors



Responsibilities

- ❑ Let others know when visitors will be coming
- ❑ Respect other people's space when you have visitors

Role Plays

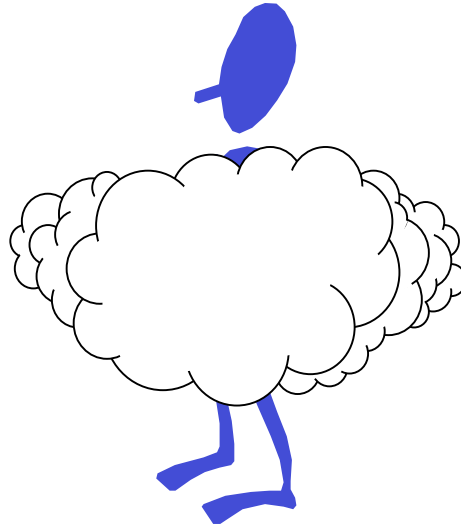
Location: Group Home, where you live

Situation: You are telling the staff or your parents that you are going to have visitors.

Role Play: Let the staff know who is coming to visit you and when you are expecting them to come.

If someone else is having company respect their privacy.

You have the right to live in a clean, furnished home



Responsibilities

- ❑ Keep your home clean
- ❑ Take care of your belongings
- ❑ Let someone know when things need to be fixed

Role Play

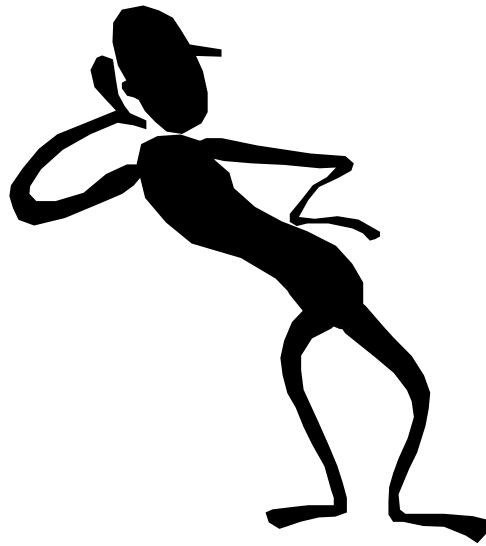
Location: Parents home, group home

Situation: You are moving into a new home, group home, supportive living, ect.

Role Play: How will you keep your home clean?

If when you move in, the home is dirty, how do you get help to clean it?

You have the right to privacy and to expect people to knock before entering



Responsibilities

- Respect others' rights to privacy
 - Knock before entering their home or bedroom
- Remind others to give you privacy

Role Play

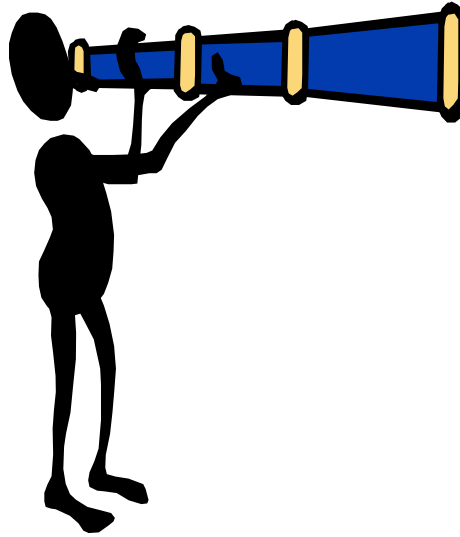
Location: Group home, parents home

Situation: You are in your room and someone just walks in without asking permission.

Role Play: How do you ask someone to please knock before entering your room?

If you are on the phone, how do you let them know you will be right with them?

You have the right to have your own belongings



Responsibilities

- Take care of your things
 - Clothes
 - Furniture
 - Jewelry

Role Play

Location: Group home, where you live

Situation: You and staff or your parents are talking about your belongings.

Role Play: You are responsible to keep your room neat and clean.

You have a right to have items that are just for you.

How do you take care of your favorite things?

You have the right to do group activities or to do things by yourself



Responsibilities

Group

- Work together with the group
- Respect others in your group

Alone

- Let others know when you would like to be alone
- Be safe when you are alone

Role Play

Location: Group home, or residence

Situation: The group is going to play basketball. Do you want to play? OR do something you want to do?

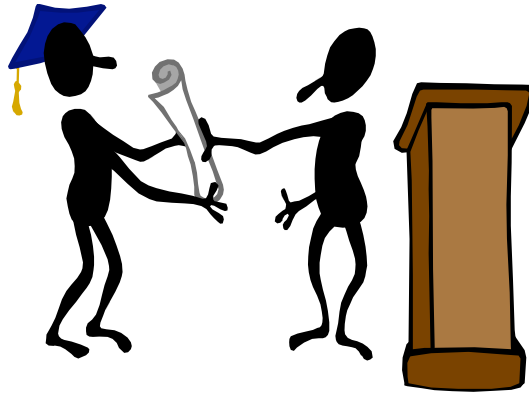
Role Play: Do you hate playing basketball?

Would you rather look at books?

Would you like to listen to your
music out side in the sun?

Would you like to take a nap?

You have the right to get an Education



Responsibilities

- What classes would you like to attend?
- Make sure you complete assignments.
- How will you pay your tuition and bills?
- Follow rules in the class.

Role Play

Location: Home, group home

Situation: You are talking to your parents or staff about education.

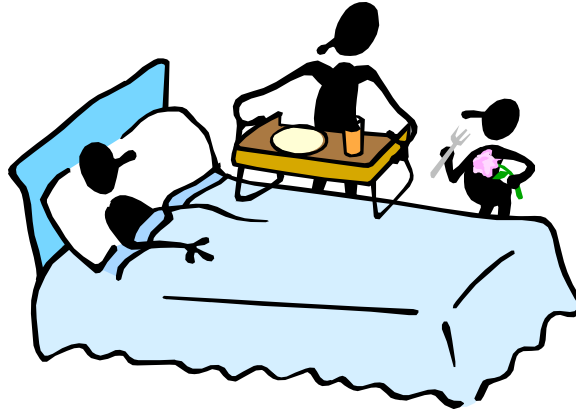
Role Play: Would you like to attend classes?

What are you interested in taking?

What rules do you need to follow?

Will you need help in class or with your assignments?

You have the right to choose your own doctors and to see the doctors when you want



Responsibilities

- ❑ Make appointments when needed
- ❑ Let someone know if you need help making appointments
- ❑ Show up for appointments
- ❑ Call your doctor if you cannot show up for your appointment
- ❑ Change your doctor if you want to
 - If you feel uncomfortable
 - If they are not helping you
 - If they are not answering your questions

Role Play

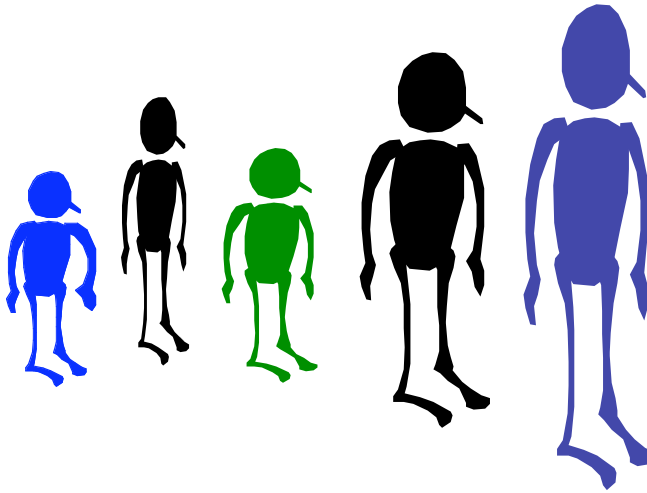
Location: Group home

Situation: You are sick and you want to go to a different doctor than you have been going to. You are talking to staff about your decision.

Role Play: How do you let staff know that you are uncomfortable with the old doctor?

How did you find the new Dr?

You have the right to agree or refuse to participate in research



Responsibilities

- ❑ Let others know when you do or do not want to participate
- ❑ If you do participate, you need to understand what the research is about.
- ❑ Make sure all of your concerns are addressed

Role Play

Location: Doctors office

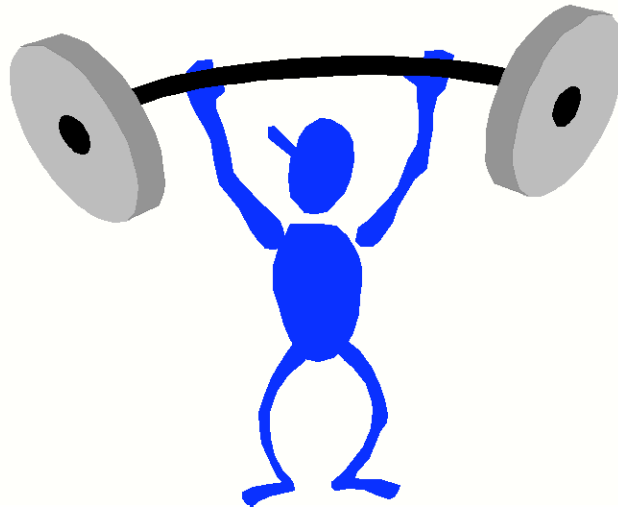
Situation: You have been asked to try a new drug they are working on for colds. It is in the testing phase and may not work.

Role Play: What information will you need before you make a decision to participate?

Could it make you sicker?

Do you understand the research?

You have the right to have, receive, or refuse regular therapy services



Responsibilities

- ❑ Let others know if you do or do not want the services
- ❑ Show up for all appointments
- ❑ Change services or providers if needed

Role Play

Location: Group home, doctors' office

Situation: You are not happy with the therapy you are receiving. You think you do not need it, or you think the therapist is not helping you.

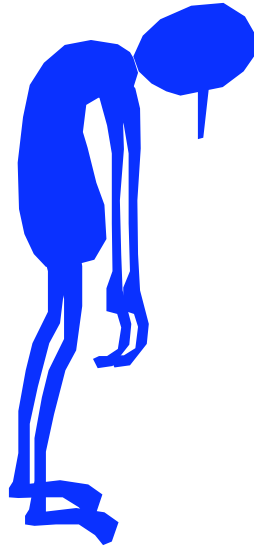
Role Play: Do you really need the therapy?

What will happen if you do not receive the therapy?

Will you find a different therapist?

How will you find a new therapist?

You have the right not to be put down by words or actions



Responsibilities

- ❑ Say “no”!
- ❑ Let others know when you feel upset
- ❑ Tell someone who can help you

Role Play

Location: School, work

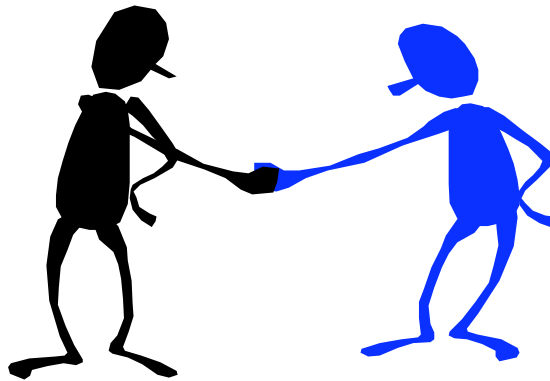
Situation: Someone just said something to you that was rude.

Role Play: What do you say back to that person?

Do you need to let someone else know about it?

How do you not take it personally?

You have the right to be treated fairly and with respect



Responsibilities

- ❑ Tell someone if you feel you are being treated unfairly
(Clients right committee)
- ❑ Treat others the same way you want to be treated

Role Play

Location: Group home

Situation: You have just moved in and one of the other house members is not being nice.

Role Play: Let the staff know how you feel.

How do you tell the person who is not being nice to stop!

How do you show respect for others and listen to how they feel?

**You have the right to calm yourself down
when you are upset before other means are
used**



Responsibilities

- ❑ Use your skills to calm yourself down
- ❑ Ask for help when you are upset
- ❑ Explain to others why you are upset

Role Play

Location: Hospital, work where you live

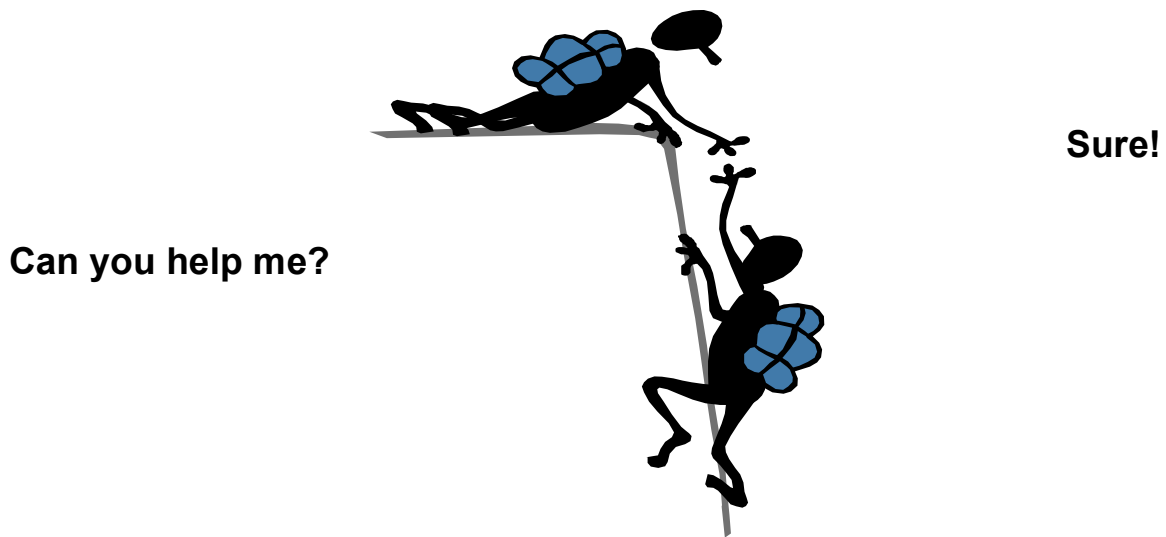
Situation: You are very upset. Someone has taken something that belongs to you.

Role Play: How can you calm yourself down
before someone gives you
medication to calm you down?

Will talking about it help?

Have you learned how to calm
down when you need to?

You have the right to get help



Responsibilities

- Ask for help if you need it
 - Policemen
 - Firemen
 - Lawyer
 - Advocate

Role Play

Location: You are in a new environment, home, work, school, shopping area.

Situation: You are with some friends and you find you need information about where you are.

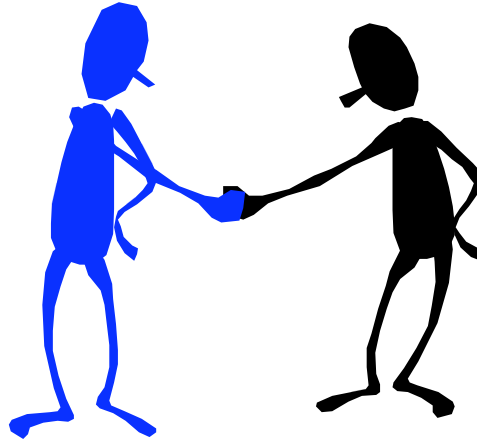
Role Play: Who could you ask for help?

How do you know who to ask for help?

What questions will you ask?

You have the right to choose an advocate

Would you be
my advocate?



Sure!

Responsibilities

- ❑ Let someone know when you need an advocate
- ❑ Let your advocate know what you need from them
- ❑ Let your advocate know when you need to see or talk to them

Role Play

Location: Where you live or work

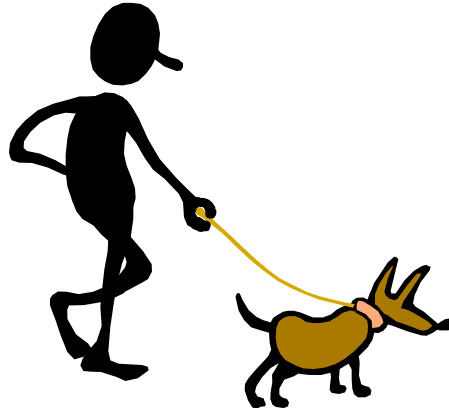
Situation: You have a problem you need help with.

Role Play: How do you find an advocate?

Will it cost you any money?

Express what your concerns are
and how you would like someone
to help you.

You have the right to expect public places to be accessible



Responsibilities

- ❑ Handicapped parking
- ❑ Braille
- ❑ Wheelchair ramps/curb cuts
- ❑ Elevators
- ❑ Accessible aisles
- ❑ Handicap restrooms
- ❑ Let others know if you need help

Role Play

Location: Restaurant, department store

Situation: You and your friend are on an outing; your friend has a guide dog.

Role Play: The restaurant manager will not let the dog come in his restaurant (it is the law, he must)

What are you going to do?

How can you change his mind?

You have the right to join community groups



Special Olympics
Bowling League

Athletic Booster
Church Group

Responsibilities

- ❑ Choose which groups you want to belong to
- ❑ Show up for scheduled meetings and/or events
- ❑ Respect others in your group

Role Play

Location: Community Center

Situation: You would like to participate in the play they are going to put on.

Role Play: Tell the director of your interests and what you like to do.

Will you need any supports to participate? (transportation, help learning your lines)

How often will they meet?

You have the right to plan and enjoy fun activities



Responsibilities

- ❑ Let others know what you would like to do
- ❑ Help plan for your activities
 - Get money if needed
 - Get equipment if needed
 - Get transportation if needed

Role Play

Location: Where you live or work

Situation: You and your friends are talking about starting a basketball team, or some other group activity.

Role Play: Who all would like to participate?

Will you need special equipment?

How often can you meet?

Will it cost anything?

You have the right to vote



Responsibilities

- ❑ Register to vote
- ❑ Learn about who you are voting for
- ❑ Do not let others tell you who to vote for
- ❑ Ask for help if you need it to understand the issues

Role Play

Location: Home, school, work

Situation: You and some of your friends would like to vote in the next election.

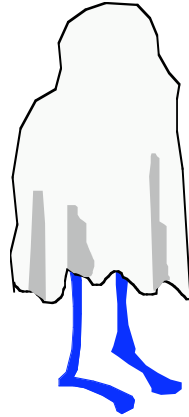
Role Play: Are you old enough to vote?

Do you understand the issues?

Is there someone who can help you understand the issues?

Will you need help getting to the voting place on election day?

You have the right to decide if you want your picture taken



Responsibilities

- ❑ Let other people know if you do not want your picture taken
- ❑ Let others know who can and cannot see your picture

Role Play

Location: Work, somewhere in the public.

Situation: Someone want to take you photo and use it in a book, new paper or on TV.

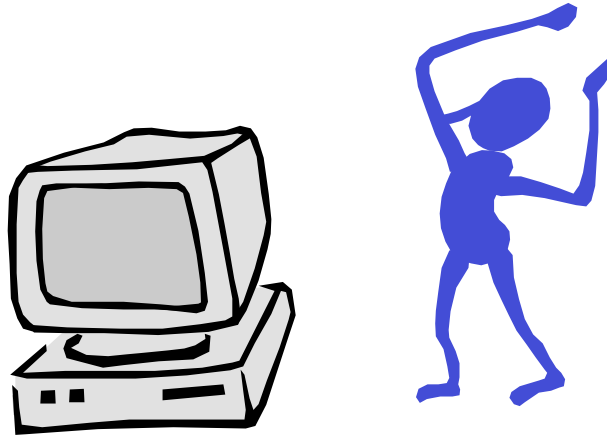
Role Play: Do you want your photo taken?

Do they need your permission to take your photo? (YES)

Will you be harmed or helped if they take your photo?

Do you hate to have you photo taken?

You have the right to get needed services



School

Case Management

Court House

Responsibilities

- ❑ Let someone know what services you need
- ❑ Give consent to release your information when needed

Role Play

Location: Group Home, parents home

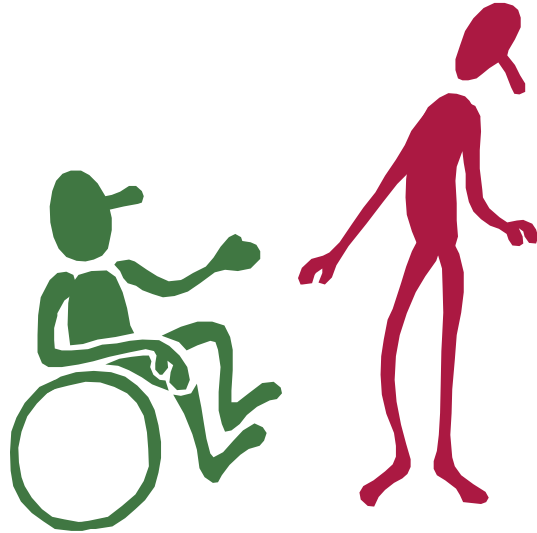
Situation: You are talking to your parents or staff, about needing some additional help.

Role Play: What type of help do you need?

Who do you think could help you get these services?

Will the services cost any money, and where will you get the money if they do?

You have the right to request a guardian



Responsibilities

- ❑ Let others know who you would like your guardian to be
- ❑ Talk to your guardian about your needs or wants
- ❑ Let other people know how you feel about your guardian

Role Play

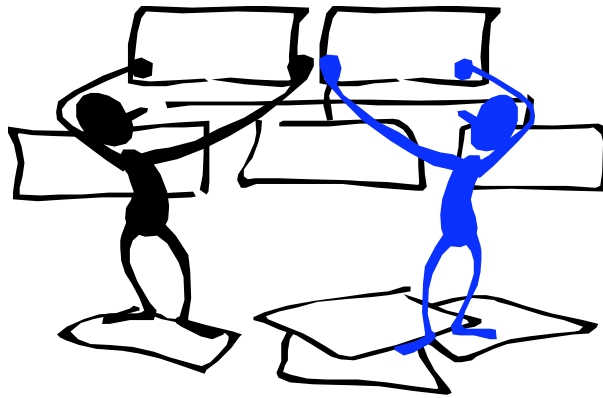
Location: Group Home

Situation: You are talking to staff. You are thinking you might benefit from the services of a guardian.

Role Play: What do you have to lose or gain from having a guardian?

Can you choose who you want?
Is there any cost involved?

You have the right to have your treatment plan written or reviewed at a meeting with you



Responsibilities

- ❑ Invite people you would like to be there
- ❑ Ask questions if you do not understand
- ❑ Show up at the scheduled time
- ❑ Give input about what you want and how you feel

Role Play

Location: Your parents home or group home

Situation: You are talking about your treatment plan with your case manager.

Role Play: You would like to participate in your treatment plan. There are things you would like to add and take off of it.

You would like a copy of your plan.

**You have the right to decide who
can see your records
and to have access to your records at all
times**



Responsibilities

- ❑ Let others know when they can or cannot look at your records (give consent)
- ❑ Ask questions if you do not understand your records
- ❑ Let others know when you would like to see your records

Role Play

Location: Group home or where you live

Situation: You are talking to staff or your parents.

Role Play: You would like to see your records.

Do you need help understanding
what some of the words mean?

You want to make sure that only
people who have your permission, or
your guardians permission, read you
records.

INTRODUCING THE CONCEPT OF BASIC HUMAN RIGHTS

Activity A: Define “rights” simply as the rules that help make people equal.

The need for agreement among lots of people in order for a right to be established can be discussed, and experiences can be recounted by individuals of attempts to take away their rights.

It can be pointed out that rights apply to everyone, by virtue of their being a human being and a citizen of their country, and they can only be taken away in very special and rare circumstances. Simply having a disability or being different is not a good enough reason on its own for a right to be denied to a person.

Activity B: Have students draw up their own list of rules that they would like to see adopted to help ensure equality between people with and without disabilities.

The list can then be reviewed to see what problems there might be in gaining general agreement to those “rights”. In the end a ‘Character of Rights’ might be drawn up, that the group is willing to work to get general agreement on and to see enforced.

To assist the group in deciding on important human rights, there are many sources of lists drawn up by others; some are declarations of the rights of everyone, some apply specifically to people with disabilities, and some apply to people in special circumstances like living in a hospital or residential establishment.

The *Self-Advocacy Workbook*, written by Nancy Gardener for the former TASA project based at the University of Kansas, gives this basic list.

- The right to life
- The right of choice
- The right to freedom
- The right to try to be happy
- The right to make up your own mind
- The right to choose the people you want to be with
- The right to be listened to
- The right to eat what you want
- The right to go to bed when you want

Playing a role in choosing the people who make decisions that affect our lives, and pass the laws that protect or restrict us, is one of the most important abilities that we have in democratic countries.

-Quote taken from “We Can Speak for Ourselves” by Paul Williams and Bonnie Shoultz

Activities A & B were taken from “We Can Speak for Ourselves”, by Paul Williams and Bonnie Shoultz, Indiana University Press, Bloomington, Copyright 1982.

DEVELOPING PERSONAL STRATEGIES FOR TACKLING INFRINGEMENTS ON RIGHTS

Activity A: Review the following strategies with students.

- Ask questions about why your rights are being limited. Keep asking questions until you understand what is happening.
- Write down the answers you are given, or get the answers on tape. Get as much information as you can. Make sure it is correct.
- Get a friend to help you if you want to. Some towns have services that can help you get a friend who knows about advocacy.
- Find out what all the choices are. Pick out the ones that are best for you.
- Decide what you think about what is happening. Decide what steps you need to take to reach your goal.
- Know who to talk to and who is in charge. Go to the person who makes the decisions.
- Know and use your rights. The main ones to remember when your rights are being limited are: the right to know all the information; the right to appeal and ask for a change in decision before you agree; the right to know what is happening all the time and why it is happening.

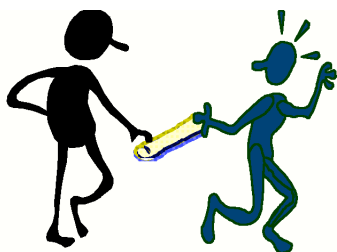
INTRODUCING THE CONCEPT OF RESPONSIBILITIES

Activity A: Discuss the fact that side by side with rights go responsibilities. The TASA Workbook uses the analogy that, just as we have to pay money for some things we want, we have to ‘do our duties’ to get our rights. One approach to teaching this concept might be to point out that if we wish to have our own rights respected, we must respect the rights of other people, and this involves behaving towards them in a responsible way. We must also not waste our rights by using them carelessly or without adequate preparation or information.

Examples in the *Workbook* include the responsibility to register as a voter ahead of time and to know who the candidates are, before exercising the right to vote; the responsibility to come to work every day, to be on time and to do the job as well as you can, when exercising the right to work and make money; and the responsibility to learn to wait at the right bus stop, have the money for the fare, and know how to get where you need to go, before exercising the right to use the public bus.

Responsibilities can also include more general aspects of behavior such as courtesy and consideration for others, and following rules of meetings.

Activity B: Have students generate their own list of responsibilities in relation to rights they wish to pursue. You may use the “Charter of Rights” developed in a previous activity.



Knowledge is

It has often been said that “knowledge is power”. This equation has even greater meaning for individuals with disabilities who are striving towards self-determination and empowerment.

Passage of the American with Disabilities Act, as well as recent amendments to the Individuals with Disabilities Education Act and the rehabilitation Act of 1973, all symbolize our country’s commitment to empowerment and equality. To ensure the individuals with disabilities are afforded due process and protection under the law, it is critical that students understand the major provisions of these acts.



This section focuses on empowering students with disabilities by providing them with information on basic human rights, as well as other rights under the law. It contains information and materials on various disabilities rights legislation (e.g. A.D.A., IDEA, and Rehab. Act of 1973) and includes specific information on rights in the mental health system and guardianship for person with cognitive impairments. This section contains information on voting and telephone rights, and addresses the fact that hand in hand with rights go responsibilities.



UNDERSTANDING YOUR RIGHTS UNDER THE AMERICANS WITH DISABILITIES ACT

Activity A: Distribute the **Americans with Disabilities Act Fact Sheet** and the article **What you should know About Disability Laws: An Interview with David Capozzi**. Review ADA's provisions for equal opportunity for individuals with disabilities in the areas of employment, public accommodations, transportation, state and local government services and telecommunications.

Activity B: Review the **Questions and Answers About the ADA** taken from "The Americans with Disabilities Act: Your Employment Rights as an Individual with a Disability".

Activity C: Review the importance of telling the employer about the need for an accommodation.

The ADA employment section states that all people must be considered for a job based on their qualifications. It says that the employer cannot refuse to hire a qualified person with a disability.

To make the ADA work, students must be prepared to do two very important things when they apply for a job:

1. Prove that they are the most qualified person.

Reinforce with the students that this is the same for everyone whether or not they have a disability.

2. Ask for a reasonable accommodation if they have a disability and think they will need one.

The employer is required to accommodate a disability only if they know about it. So, students will need to tell the employer if they need one. If students do not know what they need, they should work together with the employer to find the best accommodation.

Activities B & C were taken from "A Student's Guide to the Americans with Disabilities Act", Hospital Industries Program, Department of Rehabilitation Medicine at Maine Medical Center, Portland, Maine.

A Guide to Disability Rights Laws

The following section is provided

By the

U.S. Department of Justice

Civil Rights Division

Disability Rights Section

For persons with disabilities, this document is available in large print,
Braille, audiotope, and computer disk.

Reproduction of this document is encouraged
May 2000

Americans with Disabilities Act (ADA)

The ADA prohibits discrimination on the basis of disability in employment. State and local government, public accommodations, commercial facilities transportation, and telecommunications. It also applies to the United States Congress.

To be protected by the ADA, one must have a disability or have a relationship or association with an individual with a disability. An individual with a disability is defined by the ADA as a person who has physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such impairment, or a person who is perceived by others as having such impairment. The ADA does not specifically name all the impairments that are covered.

ADA Title I: Employment

Title I requires employers with 15 or more employees to provide qualified individuals with disabilities an equal opportunity to benefit from the full range of employment-related opportunities available to others. For example, it prohibits discrimination recruitment, hiring, promotions, training, pay, social activities, and other privileges of employment. It restricts questions that can be asked about an applicant's disability before a job offer is made and it requires that employers make reasonable accommodations to the known physical or mental limitations of otherwise qualified individuals with disabilities, unless it results in undue hardship. Religious entities with 15 or more employees are covered under title I.

Title I complaints must be filed with the U.S. Equal Employment Opportunity Commission (EEOC) within 180 days of the date of discrimination, or 300 days if the charge is filed with a designated State or local fair employment practice agency. Individuals may file a lawsuit in Federal court only after they receive a "right-to-sue" letter from the EEOC.

Charges of employment discrimination on the basis of disability may be filed at any U. S. Equal Employment Opportunity Commission field office. Field offices are located in 50 cities throughout the U.S. and are listed in most telephone directories under "U.S. Government." For the appropriate EEOC field office in your geographic area, contact:

(800) 669-4000 (voice) (800) 669-6820 (TTY)

[www. eeoc.gov](http://www.eeoc.gov)

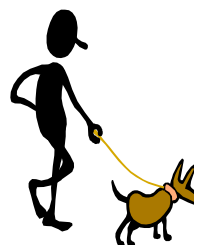
Publications and information on EEOC-enforced laws may be obtained by calling:

(800) 669-3362 (voice) (800) 800-3302 (TTY)

For information on how to accommodate a specific individual with a disability, contact the Job Accommodation Network at:

(800) 526-7234 (voice/TTY)

<http://janweb.icdi.wvu.edu/english>



ADA Title II: State and Local Government Activities

Title II covers all activities of State and local governments regardless of the government entity's size or receipt of Federal funding. Title II requires that State and local governments give people with disabilities and equal opportunity to benefit from all of their programs, services, and activities (e.g. public education, employment, transportation, recreation, health care, social services, courts, voting, and town meetings).

State and local governments are required to follow specific architectural standards in the new construction and alteration of their buildings. They must also relocate programs or otherwise provide access in inaccessible older buildings, and communicate effectively with people who have hearing, vision, or speech disabilities. Public entities are not required to take actions that would result in undue financial and administrative burdens. They are required to make reasonable modifications to policies, practices, and procedures where necessary to avoid discrimination, unless they can demonstrate that doing so would fundamentally alter the nature of the service, program, or activity being provided.

Complaints of title II violations may be filed with the Department of Justice within 180 days of the date of discrimination. In certain situations, cases may be referred to a mediation program sponsored by the Department. The Department may bring a lawsuit where it has investigated a matter and has been unable to resolve violations. For more information, contact:

Disability Rights Section
Civil Rights Division
U.S. Department of Justice
P.O. Box 66738
Washington, D.C. 20035-6738

www.usdoj.gov/crt/ada/adahom1.htm

(800) 514-0301 (voice)
(800) 514-0383 (TTY)

Title II may also be enforced through private lawsuits in Federal Court. It is not necessary to file a complaint with the Department of Justice (DOJ) or any other Federal Agency, or to receive a "right – to – sue" letter, before going to court.



ADA Title II: Public Transportation

The transportation provisions of title II cover public transportation services, such as city buses and public rail transit (e.g. subways, commuter rails, Amtrak). Public transportation authorities may not discriminate against people with disabilities in the provision of their services. They must comply with requirements for accessibility in newly purchased vehicles, make good faith efforts to purchase or lease accessible used buses, remanufacture busses in an accessible manner and unless it would result in an undue burden, provide paratransit where they operate fixed-route bus or rail systems. Paratransit is a service where individuals who are unable to use the regular transit system independently (because of physical or mental impairment) are picked up and dropped off at their destinations. Questions and complaints about public transportation should be directed to:

Federal Transit Administration
U.S. Department of Transportation
400 Seventh Street, S.W.
Washington, D.C. 20590

www.fta.dot.gov/office/civ.htm

(888) 446-4511 (voice/relay)
(202) 366-2285 (voice)
(202) 366-0153 (TTY)



ADA Title III: Public Accommodations

Title III covers business and nonprofit services providers that are public accommodations, privately operated entities offering certain types of courses and examinations, privately operated transportation, and commercial facilities. Public accommodations are private entities who own, lease to, or operate facilities such as restaurants, retail stores, hotels, movies theaters, private schools, convention centers, doctors' offices, homeless shelters, transportation depots, zoos, funeral homes, day care centers, and recreation facilities including sports stadiums and fitness clubs. Transportation services provided by private entities are also covered by title III.

Public Accommodations must comply with basic nondiscrimination requirements that prohibit exclusion, segregation, and unequal treatment. They also must comply with specific requirements related to architectural standards for new and altered buildings; effective communication with people with hearing, vision, or speech disabilities; and other access requirements. Additionally, public accommodations must remove barriers in existing buildings where it is easy to do so without much difficulty or expense, given the public accommodation's resources.

Courses and examinations related to professional, educational or trade-related applications, licensing, certifications, or credentialing must be provided in a place and manner accessible to people with disabilities, or alternative accessible arrangements must be offered.

Commercial facilities, such as factories and warehouses, must comply with the ADA's architectural standards for new construction and alterations.

Complaints of title III violations may be filed with the Department of Justice. In certain situations, cases may be referred to a mediation program sponsored by the Department. The department is authorized to bring a lawsuit where there is a pattern of practice of discrimination in violation of title III, or where an act of discrimination raised an issue of general public importance. Title III may also be enforced through private lawsuits. It is not necessary to file a complaint with the Department of Justice (or any Federal agency), to receive a "right to sue" letter, before going to court. For more information, contact:

Disability Right Section
Civil Rights Division
U.S. Department of Justice
P.O. Box 66738
Washington, D.C. 20035-6738

www.usdoj.gov/crt/ada/adahom1.htm

(800) 514-0301 (voice)

(800) 514-0383 (TTY)

ADA Title IV: Telecommunications Relay Services

Title IV addresses telephone and television access for people with hearing and speech disabilities. It requires common carriers (telephone companies) to establish interstate and intrastate telecommunications relay services (TRS) 24 hours a day, 7 days a week. TRS enables callers with hearing and speech disabilities who use telecommunications devices for the deaf (TDD's), which are also known as teletypewriters (TTY's) and callers who use voice telephones to communicate with each other through a third party communications assistant. The Federal Communications Commission (FCC) has set minimum standards for TRS services. Title IV also requires close captioning of federally funded public service announcements. For more information about TRS, contact the FCC at:

Federal Communications Commission
445 12th Street, S.W.
Washington, D.C. 20554

www.fcc.gov/cib/dro

(888) 225-5322 (voice)
(888) 835-5322 (TTY)



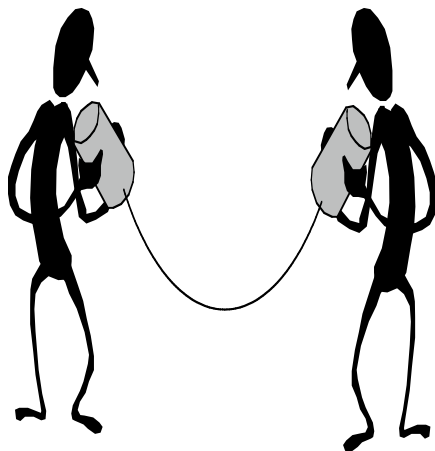
Telecommunications Act

Section 255 and Sections 251(a)(2) of the Communications Act of 1934, as amended by the Telecommunications Act of 1996, requires manufacturers of telecommunication equipment and providers of telecommunications services to ensure that such equipment and services are accessible to and usable by persons with disabilities if readily achievable. These amendments ensure that people with disabilities will have access to a broad range of products and services such as telephones, cell phones, pagers, call waiting, and operator services, that often inaccessible to many users with disabilities. For more information contact:

Federal Communications Commission
445 12th Street, S.W.
Washington, D.C. 20554

www.fcc.gov/cib/dro

(888) 225-5322 (voice)
(888) 835-5332 (TTY)



Fair Housing Act

The Fair Housing Act, as amended in 1988, prohibits housing discrimination on the basis of race, color, religion, sex, disability, familial status, and notional origin. Its coverage includes private housing, housing that receives Federal financial assistance, and State and local government housing. It is unlawful to discriminate in any aspect of selling or rent in housing or to deny a dwelling to a buyer or renter because of the disability of that individual, an individual associated with the buyer or renter, or an individual who intends to live in the residence. Other covered activities include, for example, financing, zoning practices, new construction design, and advertising.

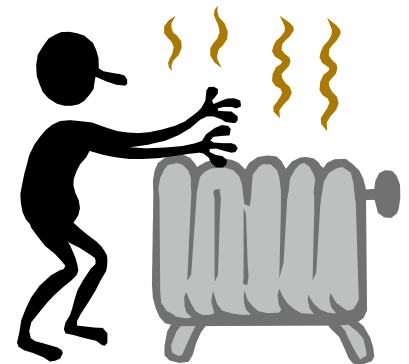
The Fair Housing Act requires owners of housing facilities to make reasonable exceptions in their policies and operations to afford people with disability equal housing opportunities. For example, a landlord with a “no pets” policy may be required to grant an exception to this rule and allow an individual who is blind to keep a guide dog in the residence. The Fair Housing Act also requires landlords to allow tenants with disabilities to make reasonable access-related modifications to their private living space, as well as to common used spaces. (The landlord is not required to pay for the changes.) The Act further requires that new multifamily housing with four or more units be designed and built to allow access for persons with disabilities. This includes accessible common use areas, doors that are wide enough for wheel chairs, kitchens and bathrooms that allow a person using a wheel chair to maneuver, and other adaptable features within the units.

Complaints of Fair Housing Act violations may be filed with the U.S. Department of Housing and Urban Development. For more information or to file a complaint, contact:

Office of Program Compliance and Disability Rights
Office of Fair Housing and Equal Opportunity
U.S. Department of Housing and Urban Development
451 7th Street, S.W. (Room 5242)
Washington, D.C. 20140

www.hud.gov/fhe/fheo.html

(800) 669-9777 (voice) (800) 927-9275 (TTD)



For questions about the Fair Housing Act, you may call the Office of Fair Housing and Equal opportunity at:

(202) 708-2333 (voice) (202) 401-1247 (TTY)

For publications, you may call the Housing and Urban Development Customer Service Center at:

(800) 767-7468 (voice) (800) 877-8339 (TTY)

Additionally, the Department of Justice can file cases involving a pattern of practice of discrimination. The Fair Housing Act may also be enforced through private lawsuits.

Air Carrier Access Act

The Air Carrier Access Act prohibits discrimination in air transportation by domestic and foreign air carriers against qualified individuals with physical or mental impairments. It applies only to air carriers that provide regularly scheduled services for hire to the public. Requirements address a wide range of issues including boarding assistance and certain accessibility features in newly built aircraft and new or altered airport facilities. People may enforce rights under the Air Carrier Access Act by filing a complaint with the U.S. Department of Transportation, or by bringing a lawsuit in Federal court. For more information or to file a complaint, contact:

Aviation Consumer Protection Division
U.S. Department of Transportation
400 Seventh Street, S.W.
Room 4107, C-75
Washington, D.C. 20590

www.dot.gov/airconsumer

(202) 366-2220 (voice)
(202) 755-7687 (TTY)



Voting Accessibility for the Elderly and Handicapped Act

The Voting Accessibility for the Elderly and Handicapped Act of 1984 generally requires polling places across the United States to be physically accessible to people with disabilities for federal elections. Where no accessible location is available to serve as a polling place, a political subdivision must provide an alternate means of casting a ballot on the day of elections. This law also requires states to make available registration and voting aids for the disabled and elderly voters, including information by telecommunications devices for the deaf (TDDs) which are also known as teletypewriters (TTYs). For more information contact:

Voting Section
Civil Rights Division
U.S. Department of Justice
P.O. Box 66128
Washington, D.C. 20035-6128

(800) 253-3931 (voice/TTY)

National Voter Registration Act

The National Voter Registration Act of 1993, also known as the “Motor Voter Act” makes it easier for all Americans to exercise their fundamental right to vote. One of the basic purposes of the Act is to increase the historically low registration rates of minorities and persons with disabilities that have resulted from discrimination. The Motor Voter Act requires all offices of State funded programs that are primarily engaged in providing services to persons with disabilities to provide all program applicants with voter registration forms, to assist them in completing the forms, and to transmit completed forms to the appropriate State official. For more information, contact:

Voting Section
Civil Rights Division
U.S. Department of Justice
P.O. Box 66128
Washington, D.C. 20035-6128

www.usdoj.gov/crt/voting

(800) 253-3931 (voice/TTY)



Civil Rights of Institutionalized Person Act

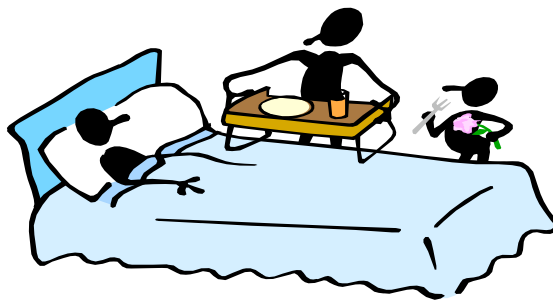
The Civil Rights of Institutionalized Persons Act (CRIPA) authorizes the U. S. Attorney General to investigate conditions of confinement at State and local government intuitions such as prisons, jails, pretrial detention centers, juvenile correctional facilities, publicly operated nursing homes, and intuitions for people with psychiatric or developmental disabilities. Its purpose is to allow the Attorney General to uncover and correct widespread deficiencies that seriously jeopardize the health and safety of residents of intuitions. The Attorney General does not have the thought under CRIPA to investigate isolated incidents or to represent individual institutionalized persons.

The Attorney General may initiate civil law suits where there is reasonable cause to believe that conditions are “egregious or flagrant” that they are subjecting residents to “grievous harm,” and that they are part of a “pattern of practice” of residence to resident’ full enjoyment of constitutional or Federal rights, including title II of the ADA and section 504 of the Rehabilitation Act. For more information or to bring a matter to the Department of Justice’s attention, contact:

Special Litigation Section
Civil Rights Division
U.S. Department of Justice
P.O. Box 66400
Washington, D.C. 20035-6400

www.usdoj.gov/crt/split/index/.html

(202) 514-6255 (voice/TTY)



Individuals with Disabilities Education Act

The Individuals with Disabilities Education Act (IDEA) (formerly called P.L. 94-142 of the Education for all Handicapped Children act of 1975) requires public schools to make available to all eligible children with disabilities a free appropriate public education in the least restrictive environment appropriate to their individual needs.

IDEA requires public school systems to develop appropriate Individualized Education Programs (IEP's) for each child. The specific special education and related services outlined in each IEP reflects the individualized needs of each student.

IDEA also mandates that particular procedures be followed in the development of the IEP. Each student's IEP must be developed by a team of knowledgeable persons and must be at least reviewed annually. The team includes the child's teacher; the parents, subject to certain limited exceptions; the child, if determined appropriate; and agency representative who is qualified to provide or supervise the provision of special education; and other individuals at the parents or agency's discretion.

If parents disagree with the proposed IEP' they can request a due process hearing and a review from the State educational agency if applicable in that state. They also can appeal the State agency's decision to State or Federal court. For more information, contact:

Office of Special Education Programs
U.S. Department of Education
330 C Street, S.W. (room 3086)
Washington, D.C. 20202

www.ed.gov/offices/OSERS/OSEP.index.html

(202) 205-8824 (voice/relay)



Rehabilitation Act

The Rehabilitation Act prohibits discrimination on the basis of disability in programs conducted by Federal agencies, in programs receiving Federal financial assistance, in Federal employment, and in the employment practices of Federal contractors. The standards for determining employment discrimination under the Rehabilitation Act are the same as those used in title I of the Americans with Disabilities Act.

Section 501

Section 501 requires affirmative action and nondiscrimination in employment by Federal agencies of the executive branch. To obtain more information or to file a complaint, employees should contact their agency's Equal Employment Opportunity Office.

Section 503

Section 503 requires affirmative action and prohibits employment discrimination by Federal government contractors and subcontractors with contracts of more than \$10,000. For more information on section 503, contact:

Office of Federal Contracts Compliance Programs
U.S. Department of Labor
200 Constitution Avenue, NW
Washington, D.C. 20210

www.dol.gov/dol/esa/public/ofcp-org.htm

(202) 693-0106 (voice/relay)

Section 504 of the Rehabilitation Act

Section 504 states that “ no qualified individual with a disability in the United States shall be excluded from, denied the benefits of, or be subject to discrimination under” any program of activity that either receives Federal financial assistance or is conductive by any Executive agency of the United States Postal Service.

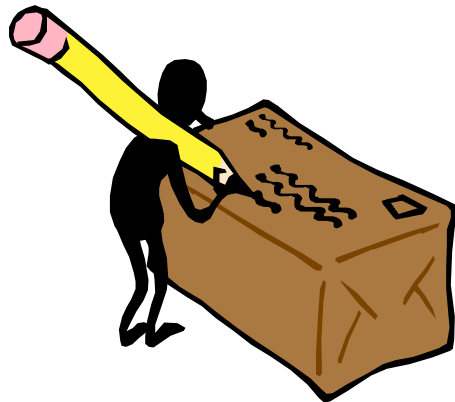
Each Federal agency has its own set of section 504 regulations that apply to it own programs. Agencies that provide Federal financial assistance also have section 504 regulations covering entities that receive Federal aid. Requirements common to these regulations include reasonable accommodations of employees with disabilities; program accessibility; effective communication with people who have hearing or vision disabilities; and accessible new construction and alterations. Each agency is responsible for enforcing it own regulations. Section 504 may also be enforced through private law suites. It is not necessary to file a complaint with Federal agency to receive a “ right to sue” letter before going to court.

For information on how to file 504 complaints with the appropriate agency, contact

Disability Rights Section
Civil Rights Division
U.S. Department of Justice
P.O. Box 66738
Washington, D.C. 20035-6738

www.usdoj.gov/crt/ada/adahom1.htm

(800) 514-0301 (voice)
(800) 514 0383 (TTY)



Section 508 of the Rehabilitation Act

Section 508 establishes requirements for electronic and information technology developed, maintained, procured, or used by the Federal government. Section 508 requires electronic and information technology to be accessible to people with disabilities, including employees and members of the public.

An accessible information technology system is one that can be operated in a variety of ways and does not rely on a single sense or ability of the user. For example, a system that provides out put only in visual format may not be accessible to people with visual impairments and a system that provides output only in audio format may not be accessible to people who are deaf or hard of hearing. Some individuals with disabilities may need accessible-related software or peripheral devices in order to use the system that complies with section 508. For more information on section 508, contact:

GSA Office of Government Wide Policy
Center for IT Accommodations (CITA)
1800 Street, N. W.
1801 Room 1234, MC: MKC
Washington, D.C. 204-0001

[Hppt://www.itpolicy.gasa.gov/cita](http://www.itpolicy.gasa.gov/cita)

(202) 501-4906 (voice)
(202) 501-2010 (TTY)

U.S. Architectural and Transportation
Barriers Compliance Board
1331 F Street, N.W. Suite 1000
Washington, D.C. 20004-1111

<http://www.aces-board.gov>

(800) 872-2253 (voice)
(800) 993-2822 (TTY)

Architectural Barriers Act

The Architectural Barriers Act (ABA) requires that buildings and facilities that are designed, constructed, or altered with Federal funds, or leased by a Federal agency, comply with Federal standards for physical accessibility. ABA requirements are limited to architectural standards in new and altered buildings and in newly leased facilities. They do not address the activities conducted in those buildings and facilities. Facilities of the U.S. Postal Service are covered by the ABA. For more information or to file a complaint, contact:

The U.S. Architectural and Transportation
Barriers Compliance Board
1331 F Street, N.W. (Suite 100)
Washington, D.C. 20004-111

www.access-board.gov

(800) 872-2253 (voice)

(800) 993-2822 (TTY)

General Sources of Disability Rights Information

ADA Information Line

(800) 514-0301 (voice)

(800) 514-0383 (TTY)

www.usdoj.gov/crt/ada/adahom1.htm

Regional Disability and Business

Technical Assistance Centers

(800) 949-4232 (voice/TTY)

www.adata.org



Statute Citations

Air Carriers Access Act of 1986

49 U.S.C. § 41705

Implementing Regulation:

14 CFR Part 382

Americans with Disabilities Act of 1990

42 U.S.C. § § 12101 et seq.

Implementing Regulation:

29 CFR Parts 1630,1602 (Title I, EEOC)

28 CFR Part 35 (Title II, Department of Justice)

49 CFR Parts 27,37,38 (Title II, III, Department of Transportation)

28 CFR Part 36 (Title III, Department of Justice)

47 CFR § § 64.601 et seq. (Title IV, FCC)

Architectural Barriers Act of 1986

42 U.S.C. § § 4151 et seq.

Implementing Regulations:

41 CFR Subpart 101-19.6

Civil Rights of Institutionalized Persons Act

42 U.S.C. § § 1997 et seq.

Fair Housing Amendments Act of 1988

42 U.S.C. § § 3601 et seq.

Implementing Regulation:

24 CFR Parts 100 et seq.

Individuals with Disabilities Education Act

20 U.S.C. § § 1400 et seq.

Implementing Regulation:

34 CFR Part 300

National Voter Registration Act of 1993

42 U.S.C. § § 1973gg et seq.

Section 501 of the Rehabilitation Act of 1973, as amended

29 U.S.C. § 791

Implementing Regulation:

29 CFR § 1614.203

Section 503 of the Rehabilitation Act of 1973, as amended

29 U.S.C. § 793

Implementing Regulation:

41 CFR Part 60-741

Section 504 of the Rehabilitation Act of 1973, as amended

29 U.S.C. § 794

Over 20 Implementing Regulations for federally assisted programs, including:
34 CFR Part 104 (Department of Education)
45 CFR Part 84 (Department of Health and Human Services)
28 CFR § § 42.501 et seq.

Over 95 Implementing Regulations for federally conducted programs, including:
28 CFR Part 39 (Department of Justice)

Section 508 of the Rehabilitation Act of 1973, as amended
29 U.S.C § 794d

Telecommunications Act of 1996
47 U.S.C. § § 255, 251(a)(2)

Voting Accessibility for the Elderly and Handicapped Act of 1984
42 U.S.C. § § 1973ee et seq.

The Americans with Disabilities Act Fact Sheet

Editor's Note: The following information on the Americans with Disabilities Act was provided to LDA by the National Organization on Disability, Washington, DC and is reprinted here with their very kind permission. Although not all of the information given here may apply to all individuals with learning disabilities, it is important for readers to understand the broad parameters of the Act. Therefore the entire Fact Sheet is reproduced here.

The Americans with Disabilities Act (ADA) furthers the goal of full participation of people with disabilities by giving civil rights protections to individuals with disabilities that are provided to individuals on the basis of race, sex, national origin and religion. It guarantees equal opportunity for individuals with disabilities in employment, public accommodations, transportation, state and local government services and telecommunications. President Bush signed the ADA into law on July 26, 1990. Highlights of the Act as set forth by the US Department of Justice are:

Employment

- Employers may not discriminate against an individual with a disability in hiring or promotion if the person is otherwise qualified for the job.
- Employers can ask about one's ability to perform a job but cannot inquire if someone has a disability or subject a person to tests that tend to screen out people with disabilities.
- Employers will need to provide *reasonable accommodations* to individuals with disabilities. This includes such steps as job restructuring and modification of equipment.
- Employers do not need to provide accommodations that impose *undue hardship* on business operations.
- Employers may reject applicants or fire employees who pose a direct threat to the health and safety of other individuals in the workplace.
- Applicants and employees who are current users of drugs have no rights to claim discrimination on the basis of their illegal drug use under the ADA. Drug testing is not prohibited by the ADA.
- Employers may not discriminate against a qualified applicant or employee because of the known disability of an individual with whom the applicant or employee is known to have a relationship or association.
- Religious organizations may give preference in employment to their own members and may require applicants and employees to conform to their religious tenets.
- ADA provides the remedies available under Title VII of The Civil Rights Act of 1964. They include back pay and court orders to stop discrimination.
- Complaints may be filed with the US Equal Employment Opportunity commission.

Who needs to comply?

- Employers with 25 or more employees must comply effective July 26, 1992.
- Employers with 15-24 employees must comply effective July 26, 1994.
- Regulations are due from the US Equal Employment Opportunity Commission by July 26, 1991.

Transportation

Public Bus Systems

- New buses ordered on or after August 26, 1990 must be accessible to individuals with disabilities.
- Transit authorities must provide comparable paratransit or other special transportation services to individuals with disabilities who cannot use fixed-route bus services unless an undue burden would result.
- New bus stations must be accessible. Alterations to existing stations must be accessible. When alterations to primary function areas are made, an accessible path of travel to the altered area (and the bathrooms, telephones and drinking fountains serving that area) must be provided to the extent that the added accessibility costs are not disproportionate to the overall cost of the alterations.
- Individuals may file complaints with The US Department of Transportation or bring private lawsuits.
- ADA provides the remedies available under Section 505 of the Rehabilitation Act of 1973.

Public Rail Systems

- New rail vehicles ordered on or after August 26, 1990 must be accessible.
- Existing rail systems must have one accessible car per train by July 26, 1995.
- New rail stations must be accessible. As with new bus stations, alterations to existing rail stations must be made in an accessible manner.
- Existing *key stations* in rapid rail, commuter rail and light rail systems must be made accessible by July 26, 1992 unless an extension of up to 20 years is granted (30 years, in some cases, for rapid and light rail).
- Existing intercity rail stations (Amtrak) must be accessible by July 26, 2010.
- Individuals may file complaints with the US Department of Transportation or bring private lawsuits.

Privately Operated Bus and Van Companies:

- New over-the-road buses ordered on or after July 26, 1996 (July 26, 1997 for small companies) must be accessible. After completion of a study the President may extend the deadline by one year, if appropriate.
- Other new vehicles, such as vans, must be accessible, unless the transportation company provides service to individuals with disabilities that is equivalent to that operated for the general public.
- Individuals may file complaints with the US Attorney General or bring private lawsuits under the public accommodations procedures.

The ADA requirements for privately operated bus and van companies becomes effective on:

- January 26, 1992 generally.
- January 26, 1996 (January 26, 1997 for small companies) for purchase of new over-the-road buses.
- August 26, 1990 for purchase or lease of certain new vehicles (other than over-the-road buses).
- Regulations are due from the US Department of Transportation by July 26, 1991.

Public Accommodations

- Public accommodations such as restaurants, hotels, theaters, doctors offices, pharmacies, retail stores, museums, libraries, parks, private schools, and day care centers may not discriminate, on the basis of disability, effective January 26, 1992. Private clubs and religious organizations are exempt.
- Reasonable changes in policies, practices, and procedure must be made to avoid discrimination.
- Auxiliary aids and services must be provided to individuals with vision or hearing impairments or other individuals with disabilities, unless an undue burden would result.
- Physical barriers in existing facilities must be removed if removal is readily achievable (i.e., easily accomplishable and able to be carried out without much difficulty or expense). If not, alternative methods of providing the services must be offered, if those methods are readily achievable.
- All new construction in public accommodations, as well as in *commercial facilities* such as office buildings, must be accessible. Elevators are generally not required in buildings under three stories or with fewer than 3,000 square feet per floor, unless the building is a shopping center, mall, or professional office of a health care provider.
- Alterations must be accessible. When alterations to primary function areas are made, an accessible path of travel to the altered area (and the bathrooms, telephones, and drinking fountains that serve that area) must be provided to the extent that the added accessibility costs are not disproportionate to the overall cost of the alterations.
- Entities such as hotels that also offer transportation generally must provide equivalent transportation service to individuals with disabilities. New fixed-route vehicles ordered on or after August 26, 1990 and capable of carrying more than 126 passengers, must be accessible.
- Public accommodations may not discriminate against an individual or entity because of the known disability of an individual with whom the individual or entity is known to have a relationship or association.
- Individuals may bring private lawsuits to obtain court orders to stop discrimination. But money damages cannot be awarded.
- Individuals can also file complaints with the US Attorney General who must file lawsuits to stop discrimination and obtain money damages and penalties.
- Regulations are due from the US Department of Justice on July 26, 1991 based on standards issued by the US Architectural and Transportation Barriers Compliance Board.

State and Government Operations

- State and local governments may not discriminate against qualified individuals with disabilities. All government facilities, services, and communications must be accessible consistent with the requirements of Section 504 of the Rehabilitation Act of 1973.
- Individuals may file complaints with federal agencies to be designated by the US Attorney General or bring private lawsuits.
- Regulations are due from the US Department of Justice on July 26, 1991.

Telecommunications

- Companies offering telephone service to the general public must offer telephone relay services to individuals who use telecommunications devices for the deaf (TDDs) or similar devices.
- Individuals may file complaints with the Federal Communications Commission.
- Regulations are due from the Federal Communication Commission on July 26, 1991.

All of the above information is available from the US Department of Justice in the following accessible formats: Braille, large print, audiotape, and electronic file on computer disk and electronic bulletin board. The electronic bulletin board phone number is (202) 514-6193.

The information on this Fact Sheet is taken from two US Department of Justice documents: **ADA Requirements Fact Sheet** and **ADA Statutory Deadlines**.

These documents are available at no cost from:

US Department of Justice
Civil Rights Division
Coordination and Review Section
P.O. Box 66118
Washington, DC 20035-6118
Phone: 11:00 A.M. – 4:00 P.M. Eastern Time
(202) 514-0301 (voice)
(202) 514-0381 (TDD)
(202) 514-0383 (TDD)

For additional information and answers to questions, contact the US Department of Justice at the address and telephone numbers above. Copies of the full 90-page Americans with Disabilities Act of 1990 may be obtained, at no cost, from:

US Senate Subcommittee on Disability Policy
113 Senate Hart Office Building
Washington, DC 20510
Phone:(202) 224-6265 (voice)
(202) 224-3457 (TDD)

WHAT YOU SHOULD KNOW ABOUT DISABILITY LAWS

An Interview with David Capozzi*

Ordinarily, you probably think of laws as rules telling you what you *can't* do: You can't drive through a red light, you can't help yourself to cookies in a grocery store without paying for them, you can't fudge your income on your federal tax return. But for young people with disabilities, some of the most important laws specify what you *can* do. In recent years, the federal government has passed a number of laws specifically aimed at benefiting people with disabilities. According to Mr. Capozzi, some of the most important are the IDEA, the ADA, the Rehabilitation Act of 1973, and the Air Carrier Access Act.

The IDEA (Individuals with Disabilities Education Act)

This is a new name for an old law: The Education for All Handicapped Children Act of 1975 (Public Law 94-142). If you have ever received physical therapy, occupational therapy, speech-language therapy, or any other special education service through your school, you have probably at least heard of this law. You may not be aware, however, of exactly what the IDEA means to you. Basically, it means that students with disabilities are entitled to receive a "free, appropriate education" in the "least restrictive environment". Furthermore, an "Individualized Education Program" (IEP) must be designed to meet each student's unique learning needs. Here's what these important provisions mean:

Free, Appropriate Education

The "free" in this expression means exactly what it sounds like. Students with disabilities are entitled to receive a public school education at no cost to themselves or their parents. If there is no public school available that can serve their needs, then the public school system must pay for them to attend a private school. The "appropriate" in this expression is a little harder to understand. Two common misunderstandings are: 1) that it means that students with disabilities are entitled to receive the best possible education; or 2) that students with disabilities should receive an education that is as good as students without disabilities receive. Unfortunately, neither of these things is true. What "appropriate" really means is that you must receive an education that is reasonable certain to give you some benefit. Fortunately, students and their parents have some say in determining what kind of education is appropriate and will provide them some benefit. This is where the concepts of least restrictive environment and the individualized education program came in. (See below.)

*David M. Capozzi is the Director of the Office of Technical and Information Services for the U.S. Architectural and Transportation Barriers Compliance Board. He has testified in support of the Americans with Disabilities Act (ADA) before the House Committee on Public Works and Transportation and was a member of the ADA "legal team" for the disability community that helped craft the legislative history and the final bill. As a member of a Federal Advisory Committee, he also helped negotiate regulations to implement the Air Carrier Access Act of 1986.

Least Restrictive Environment

This provision of the law requires that students with disabilities be mainstreamed as much as possible with non-disabled students. This means that if a student with a physical disability is capable of mastering the subjects taught in a regular classroom, he must be permitted to take his classes there. It also means that the school may have to make alterations to a classroom or provide special services to enable students with disabilities to be mainstreamed. For example, if a student with spina bifida wants to play trumpet in the band, but the band room is inaccessible to him because of the way the risers are placed, the school might have to build ramps. Or if someone who uses sign language to communicate is capable of learning calculus, but the only calculus teacher in the school can't understand sign language, the school would be required to find some way to allow the student to participate in class. The bottom line is that students with physical disabilities who have varying intellectual abilities cannot all be warehoused in the same classroom simply because other parts of the school building would require modification to be accessible.

Individualized Education Program

You are probably familiar with the basic elements of an IEP. To review, they include:

1. a description of your present level of achievement;
2. short-term and long-term goals of your educational program;
3. the specific educational services you will receive;
4. the date services will start and how long they will last;
5. the methods (such as tests) that will be used to determine whether you are meeting your goals;
6. the extent to which you will be mainstreamed.

After you reach sixteen, your IEP must also include a plan for helping you make the transition to work or college after graduation. This is a fairly new requirement, so you may find yourself asking for specific kinds of transition help that your school does not yet routinely provide. Types of transition services your school may be required to provide, if appropriate, include vocational training, training in independent living skills, and assistance in preparing for and making the transition to college. You, your parents, and school personnel should *jointly* decide what transition services you should receive, based on what you want to do after high school.

This brings up an important point: Transition planning is not the only way you can be involved in designing your IEP. Provided your parents consent you can take part in every annual meeting held to discuss your education program. You can tell the school staff *in person* about any problems you are having in school and also suggest strategies for solving those problems. Sometimes the IEP meeting may appear to be an adversarial process, because schools are cutting back on funding. But if you can give a good argument about why you *need* a particular service for example, a reader, a note taker, occupational therapy, or additional speech-language therapy – you just might get it. What if you or your parents request a particular service, but you are turned down? If you can show that this means you are not receiving an appropriate

education, you can fight the decision. The easiest way to resolve a dispute like this is for you and your parents to request a meeting with the IEP team, then try to work out a compromise. If the school staff won't budge you can request a due process hearing. During a due process hearing, both you and the school are given the chance to present your side of the story before an impartial hearing officer. You can bring witnesses (doctors, teachers, therapists), show the hearing officer medical records, hire a lawyer to argue your case, or otherwise try to convince the hearing officer that you need the educational program you are requesting. After both you and the school have presented your side, the hearing officer will decide which side has the stronger case. To request a due process hearing, one of your parents can send a letter to your school district's Special Education Director, briefly explaining the nature of the dispute.

The ADA (Americans with Disabilities Act)

After the IDEA, the Americans with Disabilities Act of 1990 is probably the single most important piece of disability legislation ever passed. Its purpose is to knock down virtually all remaining barriers that prevent people with disabilities from participating fully in their communities. There are provisions aimed at eliminating discrimination in employment, "public accommodations," telecommunications, and public transportation. Briefly, this is what these provisions cover:

Employment

As of July 26, 1992, companies with 25 or more employees are prohibited from discriminating against qualified individuals with disabilities. As of July 26, 1994, companies with 15 or more employees may not discriminate. This means that if you are qualified to do a particular job, an employer cannot refuse to hire you, train you, or give you a promotion simply because you have a disability. Furthermore, employers are required to make "reasonable accommodation" to permit you to do the job properly, unless it would cause them "undue hardship." "Reasonable accommodation" means taking steps to remove barriers that make it difficult or impossible for you to do the job. Reasonable accommodation might include making the workplace more accessible to you, modifying office equipment so you can use it, changing some job responsibilities that require more physical strength or agility than you have, or providing an interpreter.

Public Accommodations

This provision of the ADA prohibits discrimination by *any* business or facility that is open to the general public. Restaurants, hotels, theaters, parks, grocery stores, health clubs, hospitals, shopping centers, museums, bowling alleys – almost any business you can think of – must be open to individuals with disabilities under the same terms as they are open to individuals without disabilities. For example, a health club could not bar you from joining just because its locker room is not wheelchair accessible. (Instead, it might have to *make* the locker room accessible.) Or a restaurant could not refuse to let you use its dance floor because they think your wheelchair might get in the way of other dancers. Unless it would impose an unreasonable cost, every business that is open to the public must allow people with disabilities to use their facilities on an equal footing with others.

Telecommunications

By July 26, 1993, all telecommunications companies must make their services accessible to individuals with speech or hearing impairments. What this boils down to is that people who use a Telecommunications Device for the Deaf (TDD) must be able to communicate via telephone with people who do not have a TDD. The telecommunications companies will accomplish this via relay services. In addition, people with disabilities will not be charged any more to use telecommunications systems than people without disabilities.

Public Transportation

This provision of the ADA is designed to ensure that all types of public transportation will be accessible to people with disabilities. As of August 26, 1990, public bus and rail systems cannot buy new vehicles unless they are accessible. (Unfortunately, public school buses can still segregate students with disabilities from able-bodied students. We expect people with disabilities to enter mainstream society as adults, yet we still separate them on school buses as children and young adults. It doesn't make much sense.)

Making the ADA Work for You

The ADA is still relatively new, so it is difficult to tell how successful this law will be in creating a barrier-free society. In the meantime, what's the best way to use the ADA when you run up against a barrier? Mr. Capozzi suggests that you first make the manager or other person in charge aware of your problem in a nonthreatening way. For example, if there are steps leading into a restaurant where a ramp could easily be installed, politely tell the manager that this is a problem for people in wheelchairs. Second, tell him or her about the ADA. Explain that it is good business practice to make his restaurant accessible, because you and your family would like to spend your money here. And by not having a ramp, his business is excluding 43 million people with disabilities who could potentially be customers. Tell the manager that it is the right thing to do. You could also let him know that there are tax incentives for businesses that make themselves more accessible. As of 1992, a business that removes barriers to comply with the ADA can take a tax deduction of up to \$15,000 a year.

A number of agencies in the federal government can answer specific questions about the provisions of the ADA.

The Rehabilitation Act of 1973

Before the ADA was passed, discrimination against individuals with disabilities was only outlawed in certain instances. For example, section 504 of the Rehabilitation Act of 1973 prohibited discrimination by federally funded programs only. This law is still in effect. It requires that any program or activity that receives federal funds make itself accessible so that people with disabilities can participate. Federally funded agencies include not only federal agencies, but also many job-training programs, schools and universities, transportation systems, recreation programs, and housing programs.

This law will become increasingly important to you as you graduate from high school and move on to college. For example, if a college class you are scheduled to take is on the second floor, but there is no elevator, the school must make the classroom accessible either by moving the class downstairs or by installing some type of lift.

Air Carrier Access Act of 1986

This Act states in general that airlines may not discriminate against people with disabilities. In 1990, more specific regulations were created to give airlines and people with disabilities guidance. Now airlines cannot require a passenger with a disability to travel with an attendant. In addition, passengers with folding wheelchairs must be permitted to store them on board in the coat closet. If you do encounter a problem while traveling by plane, ask for the complaint resolution official with the airline for help resolving the problem. If you are still dissatisfied, you can file a formal complaint with the Department of Transportation. The address for Air Carrier Access Act complaints is: Consumer Affairs Department, U.S. Department of Transportation, 400 7th St., S.W., Washington, DC 20590.

Questions and Answers About the ADA

Q. Is an employer required to provide reasonable accommodation when I apply for a job?

A. Yes. Applicants, as well as employees, are entitled to reasonable accommodation. For example, an employer may be required to provide a sign language interpreter during a job interview for an applicant who is deaf or hearing impaired, unless to do so would impose an undue hardship.

Q. Should I tell my employer that I have a disability?

A. If you think you will need a reasonable accommodation in order to participate in the application process or to perform essential job functions, you should inform the employer that an accommodation will be needed. Employers are required to provide reasonable accommodation only for the physical or mental limitations of a qualified individual with a disability of which they are aware. Generally, it is the responsibility of the employee to inform the employer that accommodation is needed.

Q. Do I have to pay for a needed reasonable accommodation?

A. No. The ADA requires that the employer provide the accommodation unless to do so would impose an undue hardship on the operation of the employer's business. If the cost of providing the needed accommodation would be an undue hardship, the employee must be given the choice of providing the accommodation or paying for the portion of the accommodation that causes the undue hardship.

Q. Can an employer lower my salary or pay me less than other employees doing the same job because I need a reasonable accommodation?

A. No. An employer cannot make up the cost of providing a reasonable accommodation by lowering your salary or paying you less than other employees in similar positions.

Q. Does an employer have to make non-work areas used by employees, such as cafeterias, lounges, or employer-provided transportation accessible to people with disabilities?

A. Yes. The requirement to provide reasonable accommodation covers all services, programs, and non-work facilities provided by the employer. If making an existing facility accessible would be an undue hardship, the employer must provide a comparable facility that will enable a person with a disability to enjoy benefits and privileges of employment similar to those enjoyed by other employees, unless to do so would be an undue hardship.

Q. If an employer has several qualified applicants for a job, is the employer required to select a qualified applicant with a disability over other applicants without a disability?

A. No. The ADA does not require that an employer hire an applicant with a disability over other applicants because the person has a disability. The ADA only prohibits discrimination on the basis of disability. It makes it unlawful to refuse to hire a qualified applicant with a disability because he is disabled or because a reasonable accommodation is required to make it possible for this person to perform essential job functions.

Q. Can an employer refuse to hire me because he believes that it would be unsafe, because of my disability, for me to work with certain machinery required to perform the essential functions of the job.

A. The ADA permits an employer to refuse to hire an individual if she poses a direct threat to the health or safety of herself or others. A direct threat means a significant risk of substantial harm. The determination that there is a direct threat must be based on objective, factual evidence regarding an individual's present ability to perform essential functions of a job. An employer cannot refuse to hire you because of a slightly increased risk or because of fears that there might be a significant risk sometime in the future. The employer must also consider whether a risk can be eliminated or reduced to an acceptable level with a reasonable accommodation.

Q. Can an employer offer a health insurance that excludes coverage for pre-existing conditions?

A. Yes. The ADA does not affect pre-existing condition clauses contained in health insurance policies even though such clauses may adversely affect employees with disabilities more than other employees.

Q. If the health insurance offered by my employer does not cover all of the medical expenses related to my disability, does the company have to obtain additional coverage for me?

A. No. The ADA only requires that an employer provide employees with disabilities equal access to whatever health insurance coverage is offered to other employees.

Q. I think I was discriminated against because my wife is disabled. Can I file a charge with the EEOC?

A. Yes. The ADA makes it unlawful to discriminate against an individual, whether disabled or not, because of a relationship or association with an individual with a known disability.

Q. Are people with AIDS covered by the ADA?

A. Yes. The legislative history indicates that Congress intended the ADA to protect persons with AIDS and HIV disease from discrimination.

UNDERSTANDING YOUR RIGHTS UNDER THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA)

Activity A: Distribute the preceding article **What you Should Know About Disability Laws: An Interview with David Capozzi** and review the major provisions of **IDEA**.

Activity B: Distribute the handouts on the **Transition Amendments to the Individuals with Disabilities Education Act** and the **Connecticut Transition Legislation**. Discuss the impact of IDEA on the provision of transition services for students with disabilities, and emphasize the importance of student participation in the transition planning process.

Transition Amendments to the Individuals with Disabilities Education Act

PUBLIC LAW 101-476, THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA) – FORMERLY KNOWN AS P.L. 94-142 – WAS ENACTED IN 1990. A TRANSITION AMENDMENT WAS INCLUDED IN THE LAW AND WILL HAVE NATIONAL IMPACT ON THE PROVISION OF TRANSITION SERVICES FOR STUDENTS WITH DISABILITIES.

IDEA defines transition as:

“...A coordinated set of activities for a student, designed within an outcome oriented process, which promotes movement from school to post-school activities, including post-secondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation. The coordinated set of activities shall be based upon the individual student’s needs, taking into account the student’s preference and interests, and shall include instruction, community experiences, the development of employment and other post-school adult living objectives, and, when appropriate, acquisition of daily living skills and vocational objectives.”

IDEA further specifies that the Individual Education Program (IEP) shall include:

“...A statement of the needed transition services for students beginning no later than age 16 and annually thereafter (and when determined appropriate, a statement of the interagency responsible or linkages (or both) before the student leaves the school setting.”

And

“In the case where a participating agency, other than the educational agency, fails to provide agreed upon services, the educational agency shall reconvene the IEP team to identify alternative strategies to meet the transition objectives.

IDEA also requires that each statement of needed transition services or transition plan include 1) instruction, 2) community experiences, and 3) development of employment and other post-school living objectives, or specify why a given area of service is not needed. Additionally the statement or plan needs to address daily living skills (if appropriate), functional vocational evaluation (if appropriate), and linkages with adult services providers (if appropriate).

Transition Amendments to the Individuals with Disabilities Education Act (continued)

With regard to participants in meetings, IDEA states that:

“If a purpose of the meeting is the consideration of transition services for a student the public agency shall invite:

- i) The student and
- ii) A representative of any other agency that is likely to be responsible for providing or paying for transition services.

If the student does not attend, the public agency shall take other steps to ensure that the student’s preferences and interests are considered; and

If an agency invited to send a representative to a meeting does not do so, the public agency shall take other steps to obtain the participation of any other agency in the planning of an transition services.”

IN CONNECTICUT LEGISLATION REQUIRES THAT INTEGRATING TRANSITION GOALS AND ACTIVITIES IN THE IEP/ITP BEGIN NO LATER THAN AT THE ANNUAL REVIEW MEETING FOLLOWING A CHILD’S FIFTEENTH BIRTHDAY, THEREFORE CONNECTICUT LAW WILL SUPERSEDE THE FEDERAL AGE REQUIREMENT OF SIXTEEN. HOWEVER, IF IT IS DEEMED APPROPRIATE, TRANSITION GOALS AND ACTIVITIES SHOULD BE DEVELOPED AT AGE FOURTEEN OR YOUNGER.

CONNECTICUT TRANSITION LEGISLATION

P.A. 87-324

AN ACT CONCERNING INDIVIDUAL TRANSITION PLANS FOR STUDENTS REQUIRING SPECIAL EDUCATION

Be it enacted by the Senate and House of Representatives in General Assembly convened:

Section 1. Subsection (a) of section 10-76d of the general statutes is repealed and the following is substituted in lieu thereof:

(a) In accordance with the regulations and procedures established by the commissioner and approved by the state board of education, each local or regional board of education shall provide the professional services requisite to identification of school age children requiring special education, identify each such child within its jurisdiction, determine the eligibility of such children for special education pursuant to sections 10-76a to 10-76H, inclusive, prescribe suitable educational programs for eligible children, maintain a record thereof and make such reports as the commissioner may require. COMMENCING WITH THE 1988-1989 SCHOOL YEAR AND IN EACH SCHOOL YEAR THEREAFTER, AN INDIVIDUAL PLAN SHALL BE DEVELOPED FOR THE TRANSITION OF THE CHILD FROM SCHOOL TO ANOTHER PROGRAM OR COMMUNITY SETTING WHICH SHALL INCLUDE A STATEMENT OF THE NEEDED TRANSITION SERVICES FOR A CHILD REQUIRING SPECIAL EDUCATION. SUCH PLAN SHALL BE DEVELOPED NOT LATER THAN AT THE ANNUAL REVIEW OF THE PRESCRIBED EDUCATIONAL PROGRAM NEXT FOLLOWING SUCH CHILD'S FIFTEENTH BIRTHDAY AND SHALL BE INCLUDED AS PART OF SUCH PRESCRIBED EDUCATIONAL PROGRAM. TRANSITION SERVICES MAY BE INCLUDED AS PART OF SUCH PROGRAM PRIOR TO THE CHILD'S FIFTEENTH BIRTHDAY. SUCH STATEMENT SHALL IDENTIFY, WHERE APPROPRIATE, INTERAGENCY RESPONSIBILITIES BEFORE THE CHILD LEAVES THE SCHOOL SETTING. IF A PARTICIPATING AGENCY, OTHER THAN AN EDUCATIONAL AGENCY, FAILS TO PROVIDE AGREED UPON SERVICES, THE PLANNING AND PLACEMENT TEAM SHALL RE-CONVENE TO REVIEW THE INDIVIDUALIZED EDUCATION PROGRAM AND IDENTIFY ALTERNATIVE STRATEGIES TO MEET THE TRANSITION OBJECTIVES.

In the case of any meeting conducted by a planning and placement team established in accordance with the regulations issued by the state board of education, the parent or Guardian of a child for whom such meeting is conducted shall be given at least three school days prior notice of such meeting and shall have the right to be present at and participate in and to have advisors of their own choosing and at their own expense at and to participate in all portions of such meeting at which an educational program for such child is discussed, developed or written. Immediately upon the formal identification of any child as a child requiring special education, the responsible local or regional board of

education shall inform the parent or guardian of such child of the laws relating to special education.

Section 2. This act shall take effect July 1, 1987.

Amendments to this Act, published in the February 1992, Connecticut Education Laws, and incorporated federal transition requirements as defined in the P.L. 101-476 – The Individuals with Disabilities Education Act (IDEA).

Connecticut law has also incorporated the federal definition of “transition services” as specified in IDEA:

“Transition services means a coordinated set of activities for a student, designed within an outcome oriented process, which promotes movement from school to post-school activities, including post-secondary education, vocational training, integrated employment (including supported employment, continuing and adult education, adult services, independent living, or community participation.”

UNDERSTAND YOUR RIGHTS UNDER THE REHABILITATION ACT AMENDMENTS OF 1992 AND SECTION 504 OF THE REHABILITATION ACT OF 1973

- Activity A:** Distribute the summary of the **Rehabilitation Act Amendments of 1992** and the article titled **ADA is Cornerstone of New Rehabilitation Act**. Review and discuss the key changes in provisions related to employment, and discuss the Rehabilitation Act's focus on empowerment. Discuss Connecticut's new **Order of Selection** as it pertains to eligibility for services through the Bureau of Vocational Rehabilitation.
- Activity B:** Distribute **A Summary of Section 504 of the Rehabilitation Act of 1973** and **A Guide to Section 504**. Discuss Section 504, explaining its implications (particularly for students in postsecondary education), and asking questions to make sure students understand it.

Rehabilitation Act Amendments of 1992

Purpose:

The purposes of the Act are to empower individuals with disabilities to maximize employment, economic self-sufficiency, independence, and inclusion and integration into society.

Policies:

The policies include:

- Respect for individual dignity, personal responsibility, self-determination, and pursuit of meaningful careers, based upon the informed choice of individuals with disabilities
- Respect for the privacy, rights, and equal access of individuals with disabilities;
- Inclusion, integration, and full participation of individuals with disabilities;
- Support for the involvement of the family, advocates or authorized representatives, if desired or requested by the individual with a disability; and
- Support for individual and systemic advocacy and community involvement.

Title 1 – Vocational Rehabilitation Services Summary of Selected Sections

Determinations of Eligibility

A. Eligibility Criteria (See Connecticut’s rules for Order of Selection)

- The individual meets the definition of an “individual with a disability”, i.e., an individual who has a physical or mental impairment which constitutes or results in a substantial impediment to employment and can benefit in terms of an employment outcome from vocational rehabilitation services, and
- The individual requires vocational rehabilitation services to prepare for, enter, engage in, or retain gainful employment.

B. Social Security Presumption

An individual who has a disability or is blind as determined under title II or XVI of the Social Security Act, is to be presumed eligible for the purposes of the Vocational Rehabilitation Services.

C. Determination by Other Agencies

- Determination by other agencies, particularly education agencies, regarding whether an individual satisfies one or more factors relating to the determination that an individual is an “individual with a disability” or an “individual with a severe disability” are to be used to the extent appropriate, available and consistent with the requirements of the Act.

D. Presumption of Benefits

- The amendments make it clear that there is a presumption that an individual can benefit in terms of an employment outcome from vocational rehabilitation services. Thus all applicants for VR services are presumed to meet the second criteria for program eligibility unless the state agency can rebut this presumption.
- Prior to determining that an individual is incapable of benefiting from services due to the severity of the disability, the designated state agency must first conduct an extended assessment (evaluation).

E. Timelines

The state agency must make eligibility determinations:

- Within a reasonable period of time, not to exceed 60 days after the individual has submitted an application for services.
- Unless exceptional and unforeseen circumstances exist that are beyond the control of the state agency and the individual concurs with the extension, or an extended evaluation is required to determine eligibility.

Individual Written Rehabilitation Programs (IWRP's)

A. Joint Development and Agreement

The amendments require that an IWRP must be jointly developed (and amended, as appropriate), agreed upon, and signed by the individual with a disability or, as appropriate, a parent, family member, advocate or authorized representative and the counselor.

B. Contents

The IWRP must reflect:

- An employment objective consistent with the unique strengths, priorities, and capabilities of the individual;
- A statement of goals and intermediate rehabilitation objectives which are:
 - Based on the assessment determining eligibility and vocational rehabilitation needs, including the assessment of career interests, and

- To the maximum extent appropriate, include placement in integrated settings
- The specific services to be provided along with the projected dates for initiation and anticipated duration of each service, including:
 - If appropriate, a statement of the specific rehabilitation technology services;
 - If appropriate, a statement of the specific on-the-job and related personal assistance services, and, if appropriate and desired by the individual, training in managing, supervising and directing personal assistance services;
 - An assessment of the need for post-employment services or, if appropriate, extended services;
 - A re-assessment of the need for post employment services or, if appropriate, extended services prior to the point of successful closure;
 - A statement, if appropriate, as to how such post-employment or extended services will be provided or arranged through cooperative agreements with other service providers;
 - Objective criteria and an evaluation procedure and schedule to determine if the IWRP objectives are being achieved;
 - The terms and conditions under which goods and services are to be provided in the most integrated settings;
 - The identification of the entity or entities that will provide the services and the process used to provide or procure such services;
 - A statement by the individual in the individual's own words describing how he or she was informed about and involved in choosing among alternative goals, objectives, services, entities providing services, and methods used to provide or procure such services;
 - A description of the rights and remedies available to the individual;
 - A description of the availability of the Client Assistance Program (CAP); and
 - Information identifying other services and benefits from other programs to enhance the capacity of the individual to achieve the IWRP's objectives.

Vocational Rehabilitation Services for Individuals

The amendments clarify that services under Title I include:

- On-the-job training or other related personal assistance services provided while an individual is receiving services;
- Transition services that promote or facilitate the accomplishment of long-term rehabilitation goals and objectives;
- Maintenance payments only for additional costs incurred while participating in rehabilitation;
- Supported employment services; and
- Post employment services to assist individuals with disabilities to advance in employment as well as to maintain or regain employment.

Developed by Karen Palma-Halliday, Transition Coordinator, Connecticut Department of Education, Bureau of Special Education and Pupil Services. Reprinted with permission.

ORDER OF SELECTION

Order of Selection establishes the priority ranking by which eligible individuals are to be served in the event that case service funds are insufficient to meet the needs of all eligible individuals. All eligible individuals determined to have the most severe disabilities will receive the highest priority for services. (For a complete copy of the rules for Order of Selection, contact the Bureau of Rehabilitation Services at 298-2000.)

Policy

1. Individuals with disabilities shall be served in the following order of priority:
 - i. All eligible individuals determined to have a most severe disability.
 - ii. All eligible individuals determined to have a severe disability.
 - iii. All other eligible individuals.
2. All individuals shall be placed in the highest priority level for which they qualify.
3. Every individual within a higher priority level shall be served before individuals in the next lowest priority level are served.
4. Should funds become limited, the agency may need to limit services within a priority group. If this becomes necessary, services will be provided first to public safety officers in that group. The remaining individuals will be served chronologically on the basis of the date of eligibility determination (or, when applicable, the date of certification for established evaluation).
5. All eligible individuals, once under an Individualized Written Rehabilitation Program (IWRP), will continue to receive those services necessary, including Post Employment Services, until the attainment of their vocational goal and/or closure of their case.
6. The Bureau will periodically assess its ability to serve eligible individuals entering the system and declare what level in the Order of Selection the Bureau has the capacity to serve. All individuals who are in status 10 prior to June 30, 1994, and who are severely disabled, shall have their Employment Plans (IWRP's) developed and implemented. Individuals who are determined eligible on or after July 1, 1994, who are not in a priority group that is being served, will remain on a waiting list in Status 10 (or such other waiting list mechanism the Bureau may devise) until such time as the Bureau may be able to serve them. Individuals who choose not to wait may be closed in Status 30, Reason 11, "did not meet order of selection priority."

ORDER OF SELECTION (CONTINUED)

Requirements

1. All applicants must be informed of the Order of Selection at the initial interview.
2. Applicants, including individuals in extended evaluation, shall receive services necessary to determine their eligibility for VR services without regard to the order of selection, the extent that funds are available.
3. Each individual found eligible shall concurrently be placed in the appropriate priority level. The counselor is required to provide prompt written notice to the individual of both the eligibility decision and the priority ranking. Such notice shall include the right to appeal and the availability of the Client Assistance Program. Individuals shall have the opportunity to present additional functional information which may qualify them for a higher priority ranking. A priority ranking may be changed at any time based on new information or changes in functional limitations.

Definitions

Severe Disability:

An individual is considered to have a severe disability if:

(i) He/she has a severe physical or mental impairment which seriously limits one or more functional capacities (mobility, communication, self-care, self-direction, interpersonal skills, work tolerance, or work skills) in terms of an employment outcome;

AND

(ii) His/her vocational rehabilitation can be expected to require multiple vocational rehabilitation services over an extended period of time.

(Per Sec. 7(15)(A) of the Rehabilitation Act of 1973, as amended in 1992)

ORDER OF SELECTION (CONTINUED)

Most Severe Disability:

An individual is considered to have a most severe disability if:

- (i) He/she meets the definition of severe disability

AND

- (ii) a. He/she has serious limitations in a total of three or more functional areas (such as mobility, communication, self-care, self-direction, interpersonal skills, work tolerance or work skills) in terms of an employment outcome

OR

- b. Will require significant ongoing disability-related services on the job in order to maintain employment following VR closure from time-limited services.

Public Safety Officer:

Public safety officers are those individuals whose disability arose from an impairment sustained in the line of duty while performing as a public safety officer, and the immediate cause of the impairment was a criminal act, apparent criminal act, or a hazardous condition resulting directly from the officer's performance of duties in direct connection with the enforcement, execution, and administration of law, fire prevention, fire fighting, or related public safety activities.

It includes a person serving the United States, a State, or a unit of local government, with or without compensation, and any activity pertaining to:

- (i) the enforcement of the criminal laws, including highway patrol, or the maintenance of city peace by the National Guard or the Armed Forces,
- (ii) a correctional program, facility, or institution where the activity is potentially dangerous because of contact with criminal suspects, defendants, prisoners, probationers, or parolees,
- (iii) a court having criminal or juvenile delinquent jurisdiction where the activity is potentially dangerous because of contact with criminal suspects, defendants, prisoners, probationers, or parolees,

OR

- (iv) fire fighting, fire prevention, or emergency rescue missions

ADA IS CORNERSTONE OF NEW REHABILITATION ACT NEW REHABILITATION ACT FOCUSES ON EMPOWERMENT

On October 29, 1992, former President George Bush signed into law the Rehabilitation Act Amendments of 1992 (P.L. 102-569). The new law, which was enacted following two years of intensive involvement by people with disabilities, their advocates, and families, is built on the foundation of the Americans with Disabilities Act (ADA).

John Halliday, Director of the Bureau of Rehabilitation Services in Connecticut's Dept. of Social Services, said, "The Act brings us into a new level of partnership with individuals with disabilities and organizations as we move the system to its next phase. Philosophically, there is real meeting between the new Act and the ADA."

P.L. 102-569 begins with a new section, which lays out the purpose and policy intent of the Act. This section states in part, "Disability is part of the human experiences and is no way diminishes the right of individuals to live independently, enjoy self-determination, make choices, contribute to society, pursue meaningful careers, and enjoy full inclusion and integration in the...mainstream of American society...[A purpose] of this Act is to empower individuals with disabilities to maximize employment, economic self-sufficiency, independence, inclusion and integration into society."

Major changes have been made in both the independent living and employment-oriented sections of the Act. Some key changes in provisions related to employment are highlighted below.

Presumption of Ability

John Halliday observed, "People with disabilities have shown that they can work and participate in society." Under the new laws, the rehabilitation system's energies and resources will be focused on the strengths and needs of the individual and on providing or arranging for necessary services and supports.

The reauthorized Act changes the emphasis in accessing the system from the old "evaluation of rehabilitation potential" to an assessment of eligibility and rehabilitation needs. The law abandons "employability" and "feasibility" tests and focuses instead of serving people with severe disabilities who need rehab services.

John Halliday said, "We should be seeing a much smoother and shorter period of eligibility determination."

ADA IS CORNERSTONE OF NEW REHABILITATION ACT NEW REHABILITATION ACT FOCUSES ON EMPOWERMENT (CONTINUED)

Transition from School

P.L. 102-569 recognizes that many students with disabilities will require support from the rehabilitation system after they complete school. While the new law does not shift the responsibility for transition planning away from the education system, the Act does require state rehabilitation and education agencies to coordinate their policies so there is no gap in service for eligible students.

Rehabilitation Services

The scope of services available has been expanded and clarified in P.L. 102-569. Services specifically addressed in the new Act include rehabilitation technology, personal assistance services, and supported employment.

Rehabilitation Technology:

The 1986 reauthorization of the Rehabilitation Act placed considerable emphasis on the provision of technology services to assist individuals with disabilities in entering and maintaining employment. The new Act continues the emphasis with requirements that the technology needs of individuals must be addressed in Individual Written Rehabilitation Plans (IWRP) and that the rehabilitation system must provide technology services and devices to individuals who need them to achieve their rehabilitation goals. A broad range of rehabilitation technology services must be available across the state to people in all states of the rehabilitation process, and vocational rehabilitation counselors and other personnel must be provided with training in rehabilitation technology.

Personal Assistance:

P.L. 102-569 recognizes that without the availability of personal assistance services, a significant number of people with severe disabilities will be unable to maintain employment. Under the new law, the IWRP must include a statement of specific on-the-job and related personal assistance services to be provided.

Supported Employment:

With respect to supported employment, the reauthorized Act focuses on the importance of flexible, individually-designed services and on making supported employment available to those people who have the most severe disabilities. P.L. 102-569 acknowledges that supported employment can benefit a variety of individuals who have different types of disabilities and who need very different types of services and supports, including natural supports.

ADA IS CORNERSTONE OF NEW REHABILITATION ACT NEW REHABILITATION ACT FOCUSES ON EMPOWERMENT (CONTINUED)

Although supported employment services provided by state rehab agencies should be time-limited, it will be possible for a person to begin supported employment before a source of extended support is named, as long as there is a reasonable expectation that extended support will become available.

Additionally, state rehabilitation agencies will be able to provide supported employment services for a longer time than 18 months, when the person with a disability and his or her rehabilitation counselor agree to such an arrangement.

Empowerment and Choice

The Rehabilitation Act of 1992 is designed to increase the choice and control of individuals with disabilities over rehabilitation services, both individually and systematically. On an individual level, the IWRP will be jointly developed by the individual and his or her rehab counselor and must be consistent with the person's priorities, choices, strengths, and capabilities. Also, the new law empowers individuals to select their own services and service providers, as long as the services are part of the IWRP.

On a systemic level, the Act requires each state to establish a State Rehabilitation Advisory Council and a Statewide Independent Living Council. A majority of the members of both Councils must be people with disabilities.

Client Assistance Program

Under the reauthorized Act, the Client Assistance Program is given a stronger mandate to do individual and systemic advocacy. Additionally, State Rehabilitation Agencies will be required to inform people they serve about the availability of the CAP.

Next Steps

The federal government soon will be drafting regulations for P.L. 102-569. John Halliday advises, "Look for the federal regulations. It is very important to pay attention to the draft regulations and take the time to read and comment on them."

Effective October 1, 1993, states will be required to have developed a strategic plan for expanding and improving rehabilitation services. You are encouraged to watch for opportunities for public input while Connecticut's plan is being prepared.

A SUMMARY OF SECTION 504 OF THE REHABILITATION ACT OF 1973

Section 504 of the Rehabilitation Act of 1973 requires equal access to all programs and activities for all handicapped people and states that access should be offered in the most integrated and appropriate way. The handicaps included under Section 504 are mobility and sensory impairments, major physiological illness, emotional and psychological illnesses, learning disabilities, mental retardation, and chemical dependency. These conditions must be serious enough to reduce the quality of one's life.

Section 504 says: "No otherwise qualified handicapped individual shall, solely by reason of the handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance."

What this means for students: Any postsecondary institution receiving any type of federal assistance is required to ensure the rights of all handicapped students who enter postsecondary schools or risk losing all federal funding.

These regulations affect admissions, employment, student and staff services, and the curriculum. In postsecondary schools, Section 504 gives learning disabled students academic opportunities such as:

- changes in the length of time to complete papers, tests, and degree programs
- adapted arrangements for completing academic work
- access to and use of auxiliary aids: taped books, tape recorders, interpreters, note-takers
- waiver or substitution of required but nonessential courses

A Guide to Section 504

How it applies to Students with Learning Disabilities and ADHD

What is Section 504?

Section 504 is the section of the Rehabilitation Act of 1973 which applies to persons with disabilities. Basically it is a civil rights act which protects the civil and constitutional rights of persons with disabilities. Section 504 prohibits organizations which receive federal funds from discriminating against otherwise qualified individuals solely on the basis of handicap. Section 504 is enforced by the U.S. Department of Education, Office for Civil Rights (OCR).

How Does Section 504 Define “Handicap”?

A person is considered “handicapped” if he/she:

1. has a physical or mental impairment which substantially limits one or more major activities,
2. has a record of such an impairment, or
3. is regarded as having such an impairment

(In addition to school-age children who are eligible for special education services, this includes, for example, persons with communicable diseases, temporary handicapping conditions, attention deficit disorder (ADD), behavior disorders, chronic asthma & severe allergies, physical handicaps, and diabetes.)

What is a “Major Life Activity”?

Major life activities include such things as walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself, and performing manual tasks.

What Types of Discrimination Does Section 504 Prohibit

1. Denial of the opportunity to participate in or benefit from a service which is afforded non handicapped students.
 - Refusing to allow a student with an IEP the opportunity to be on the honor roll, denying credit to a student whose absenteeism is related to the disability, refusing to dispense Ritalin to a student with ADD (a school cannot require parents to waive liability as a condition of giving medicine, however, it is wise to get your physician’s prescription to back up medical accommodations).
2. Provision of opportunity to participate in or to benefit from a service which is not equal to that afforded others.
 - Determining sports eligibility on a student’s grades without regard to the student’s handicapping condition

A GUIDE TO SECTION 504 HOW IT APPLIES TO STUDENTS WITH LEARNING DISABILITIES AND ADHD (CONTINUED)

3. Provision of aids, benefits or services which are not as effective as those provided to others. Equally effective means equivalent, not identical, and must afford an equal opportunity, not equal results.
 - Placing a student with a hearing impairment in the front row instead of providing an interpreter.
4. Provision of different or separate benefits or services unless such action is necessary to be effective.
 - Separate classes, schools or facilities.
5. Aiding or perpetuating discrimination by providing assistance to an organization which discriminates.
 - Sponsoring a student organization which excludes persons with disabilities.
6. Denial of the opportunity to participate on a planning or advisory board because of an individual's handicapping condition.
7. Otherwise limiting the enjoyment of any right, privilege, advantage or opportunity enjoyed by others.
8. Selecting a site or location which effectively excludes persons with disabilities or subjects them to discrimination
 - Locating students with disabilities in inferior facilities due to a lack of classroom space.

What Does "Reasonable Accommodation" Mean?

A recipient of federal funds shall make reasonable accommodation to the known physical or mental limitations of an otherwise qualified person unless the recipient can demonstrate that the accommodation would impose an undue hardship on the operation of its program. Courts have required accommodations which achieve "meaningful equal opportunity." Accommodations need to take into account both the functional limitations of the individual and the alternative methods of performing tasks or activities, which would permit people of varying abilities to participate without jeopardizing outcomes. Some examples of reasonable accommodations are modified homework requirements, provision of readers, provision of taped textbooks, changes in the way tests are given, provision of a teacher's aide, or seating in the front row of the classroom.

1. Accommodations must be individualized.
2. The individual needs of the person with a disability should be met to the same extent as the needs of persons without handicapping conditions.
3. Modifications can be made to regular programs or the provision of different programs may be necessary.
4. Accommodations should place the student with a disability at an equal starting level with the non-handicapped student.

A GUIDE TO SECTION 504 HOW IT APPLIES TO STUDENTS WITH LEARNING DISABILITIES AND ADHD (CONTINUED)

How Does Section 504 Define “Appropriate Education”?

A free appropriate education is one provided by the public elementary or secondary school which includes regular or special education and related aids and services that (i) are designed to meet the individual educational needs of persons with disabilities as adequately as the needs of non handicapped persons are met, and (ii) are based upon adherence to evaluation, placement and procedural safeguard requirements.

Does Section 504 Require Evaluations?

Section 504 Regulation, 34 CFR Section 104.35(a) requires that a district evaluate “any person who, because of handicap, needs or is believed to need a special education or related services” (emphasis added). An evaluation is also required prior to any significant change in placement. Pre-screening methods which affect a student’s eligibility for special education may be considered “evaluations” and are *subject to proper notice requirements*. EHLR DEC.353.237 (1989).

Section 504 does not require that a district must carry out a full evaluation of a student simply because a parent requests it. However, refusal by the district to do so constitutes an official action with respect to the student’s evaluation and placement, and the district must provide that parent with procedural safeguards.

Does Section 504 Require an IEP?

Section 504 requires a written plan describing placement and services. Placement decisions must be based upon information drawn from a variety of sources and all information must be documented and considered. Although a formal IEP is not required, the placement decision must be made by a group of persons knowledgeable about the child, about the meaning of the evaluation data and about placement options.

What Procedural Safeguards do Parents Have?

To be in compliance with Section 504, school districts must:

1. Provide written assurance of nondiscrimination.
2. Designate an employee to coordinate compliance.
3. Provide grievance procedures to resolve complaints.
4. Provide notice of nondiscrimination in admission or access to its program or activities. Notice must be included in a student/parent handbook.
5. Annually identify and locate all qualified children with disabilities who are not receiving public education.
6. Annually notify persons with disabilities and their parents or guardian of the district’s responsibilities under Section 504.

A GUIDE TO SECTION 504 HOW IT APPLIES TO STUDENTS WITH LEARNING DISABILITIES AND ADHD (CONTINUED)

7. Provide parents or guardians with procedural safeguards:
 - a. Notice of their rights.
 - b. An opportunity to review relevant records
 - c. An impartial hearing – parents or guardians must be notified of their right to request a hearing regarding the identification, evaluation, or educational placement of persons with handicapping conditions.

How do I File an OCR Complaint?

Find someone in your regional OCR office who understands the application of Section 504 on education, and use that person as your contact. Explain the situation, specify the issue, and cite the area of discrimination. OCR should then send a representative to investigate the complaint.

What if I Don't Agree with OCR's Ruling?

Under the Freedom of Information Act ask for a copy of the investigation plan used by the OCR representative, a copy of the investigation report, and a copy of the school's documents. If you don't think that the investigation was a careful and thorough examination of the issue of complaint or the conclusions are wrong, write a letter of appeal saying you don't agree with the Letter of Finding and stating your reasons.

UNDERSTAND YOUR LEGAL RIGHTS IN THE MENTAL HEALTH SYSTEM

Activity A: Distribute a copy of **Your ‘Rights’ in a Psychiatric Facility: An Overview** and thoroughly review definitions, legal rights and complaint procedures.

Activity B: Distribute and discuss the handout **Access to your Medical, Psychiatric and Personal Records**.

Use the **SAMPLE letter** as a guide to assist students in writing to request a copy of their medical records.

Help students identify a person or persons who could assist them in understanding the content of their medical, psychiatric and personal records.

Activity C: Inform students that 2 years ago the legislature passed **An Act Concerning Outpatient Mental Health Treatment for Minors and Defining Community Health Centers**, a bill permitting minors to receive up to six sessions of mental health treatment without parental consent.

Review the sections of **Public Act No. 92-129** to inform students of their rights under this legislation.

YOUR “RIGHTS” IN A PSYCHIATRIC FACILITY AN OVERVIEW

WHAT IS A “MENTALLY ILL” PERSON?

According to Connecticut State law a “mentally ill person “ is someone who requires care and treatment due to an inability to live an active life (i.e., “gravely disabled”) as a result of a serious mental or emotional impairment or if that person is “a danger to him or herself or others.” The state’s definition is derived from the Third Revised edition of the American Psychiatric Association’s Diagnostic and Statistical Manual (DSM III-R).

WHAT DOES “DANGEROUS TO ONESELF OR OTHERS” MEAN?

The term “Dangerous to Oneself or Others...” has been interpreted to mean “if there is great risk of the individual causing physical harm to him/herself or upon another person.” [NOTE: *There is considerable debate among advocates, mental health professionals and legal experts over how clear this definition may actually be.*]

WHAT ARE “VOLUNTARY” AND “INVOLUNTARY” ADMISSIONS?

Any person who applies to a hospital or psychiatric facility of their own choice for observation, diagnosis or treatment because of symptoms of a mental disorder, is considered a “Voluntary” admission.

An “Involuntary” patient is anyone who has been admitted to a psychiatric facility or ward “at the request of...” someone other than the person considered the patient.

WHAT IS “INFORMED CONSENT”?

“Informed Consent” implies that a patient has an understanding of the nature and extent of his/her “illness”; has had the risks and benefits of all treatment options, medication uses and side effects explained clearly and understandably; and that she or he is able to make intelligent informed choices about whether she or he wishes to make use of those treatments and/or medications being recommended.

In practice, a psychiatrist and a patient’s “treatment team” may have decided to withhold some of the information described above on the basis that it would be harmful for the patient to be told this information at the time. In fact, there are some psychiatrists who may find that reading this may be deemed harmful to your health and may be able to legally prevent you from doing so on that basis. This is censorship, pure and simple, but citizens identified as mental patients are customarily censored. If they weren’t, there wouldn’t be a need for advocates, self advocacy or the mental health consumer movement.

CAN SOMEONE ADMITTED LEAVE A HOSPITAL FREELY?

A “voluntary” patient who wishes to leave a facility must sign a “Five Day Paper” to inform the facility he or she wants to leave. The hospital may choose to keep the person for up to five days after the request has been signed.

Hospital staff may apply to Probate Court to have a “Voluntary” patient civilly committed to the hospital. If this is done, it may take up to 15 days before the Probate hearing date, during which time the person would be required to stay in the facility. If the hospital *does not* file for a Probate Court hearing, the individual must be released within 5 days.

WHAT HAPPENS IF SOMEONE IS “PROBATED”?

The Probate Judge must give the patient, in writing, a “probable cause” hearing within 72 hours.

The hospital must inform the patient 24 hours before they file a commitment hearing request. Anyone wishing to avoid a civil commitment hearing must sign back in as a “Voluntary” patient and revoke their “5 day paper” request before the actual Probate hearing date.

IS A VOLUNTARY PATIENT REQUIRED TO TAKE THE MEDICATIONS OR TREATMENT GIVEN OR PRESCRIBED?

Legally, a “Voluntary” patient cannot have treatment or medication forced upon him or herself. Psycho-surgery (e.g., lobotomies) or Shock treatments cannot be given without written informed consent. As of October 1, 1993, a voluntary patient can be forced to take medication or treatment if found either to be: “1) incompetent by 2 physicians and the head of the hospital; or 2) at a significant risk of harm.” The hospital must either file a petition in Probate Court for a court order to medicate you or hold an internal hearing. This change in the law is important and too complex to explain further. If you have any questions or concerns, you should call an advocate immediately.

WHAT IS AN “EMERGENCY” PATIENT?

An “emergency patient” is one whom a physician has concluded is “dangerous to his or herself or others” or “gravely disabled.”

If someone is admitted as an “Emergency Patient”, a psychiatrist must evaluate that person within 48 hours of being admitted to a facility. That person may be kept up to 15 days without a court ordered decision. They may be kept in the hospital an additional 15 days if the hospital has applied for an involuntary commitment hearing.

An emergency patient cannot be held longer than 30 days if she/he has not been committed by the Probate Court.

WHAT IF THE PATIENT DISPUTES THE DECISION TO BE AN EMERGENCY PATIENT?

The patient or an Advocate representative may request, in writing, a Probable Cause Hearing. This is sent to the Probate Court serving the town where the hospital is located. The hearing must be held within 72 hours from when the Court has received this request.

The patient has the right to cross examine witnesses and to be represented by an attorney.

An outside doctor who the patient chooses may also be called in to testify.

WHAT DOES A CIVIL COMMITMENT MEAN?

A civilly committed patient must stay in a hospital because the probate judge has received:

- 1 – an application from the hospital requesting involuntary commitment, and
- 2 – sworn certificates from at least two doctors selected by the court, one of whom must be a psychiatrist. The probate judge will decide, based on evidence presented, whether or not a person will be committed.

The doctors testifying must report, in writing, what made them decide whether or not the patient was “a danger to him/herself or others” and/or “gravely disabled.” The doctor’s report must identify whether or not the patient’s condition has “seriously disrupted” his/her ability to live an active life; whether or not a less restrictive alternative (than hospital commitment) is recommended and available; and whether or not the person being probated is “capable of understanding the need to accept treatment” on a voluntary basis.

CAN AN INVOLUNTARY PATIENT REFUSE TREATMENT AND/OR MEDICATIONS?

Yes. An involuntary patient may refuse psychiatric treatment including drugs. It is against the law for any medical or surgical procedures to be performed without written informed consent. As of October 1, 1993, an involuntary patient can be forced to take medication or treatment of found either to be: “1) incompetent by 2 physicians and the head of the hospital; or 2) at a significant risk of harm.” The hospital must either file a petition in Probate Court for a court order to medicate you or hold an internal hearing. This change in the law is important and too complex to explain further. If you have any questions or concerns, you should call an advocate immediately.

CAN SOMEONE BE LOCKED IN SOLITARY CONFINEMENT OR PLACED IN RESTRAINTS?

Legally, no one can be placed in seclusion or mechanical restraints against their will. There are exceptions to this, however, and if it has been decided that a patient is “in imminent physical danger to self or others” a physician can order seclusion or restraints in writing.

Legally, seclusion and restraints cannot be used as substitutes for treatment. In practice, this can occur to individuals who do not conform to the rules of the “therapeutic environment.”

In clinical records it may appear as if the use of mechanical restraints and seclusion is declining. In practice, this may reflect the fact that the language of reporting has changed. Seclusion, for instance, is now more commonly referred to as “Time Out.” In practice, the physician’s signed order for requiring restraints may have been written up hours after the actual use of restraints has occurred.

DOES A CITIZEN LOSE HIS OR HER CIVIL RIGHTS ONCE IN A PSYCHIATRIC FACILITY?

In theory, NO ONE in any public or private hospital should be deprived of any personal, property or civil rights, "including the right to vote, hold or convey property and contract except in accordance with due process of law" or unless one has been declared legally incompetent in a court of law. In practice, the civil and human rights of citizens placed in psychiatric facilities can be, have been and continue to be violated.

WHAT RIGHTS DOES A "MENTAL PATIENT" HAVE WHILE IN A FACILITY?

There are numerous rights a patient retains, including the right to communicate by sealed mail with any individual, group or agency; the right to receive visitors at regular hours, to have access to private, individual storage space, to wear one's own clothes, etc.

In practice, the rights of any patient may be denied them if the head of a hospital OR his/her authorized "representative" has decided that it would be harmful for the patient to exercise his or her rights.

HOW CAN COMPLAINTS OF VIOLATIONS OF INDIVIDUALS BE ADDRESSED?

There are "Complaints Procedures" for resolving patients' rights complaints at state operated facilities. These include the following:

- A. Forms and envelopes for filing a complaint are available to patients on the ward. Complaints may also be filed verbally.
- B. Contact the Legal Rights Advocate of the Facility.
- C. DMH's Affirmative Action Officer may be contacted on your own. You may also wish to contact the DMH Director of Consumer Education at 1-800-446-7348.
- D. The Superintendent or Director of the facility may be contacted.
- E. File a complaint directly with the DMH Commissioner's office: 90 Washington Street, Hartford, CT 06106.
- F. Contact the Office of Protection and Advocacy at 1-800-842-7303; TDD (203) 566-2102.

ACCESS TO YOUR MEDICAL, PSYCHIATRIC AND PERSONAL RECORDS

Introduction

Since the issue of access to records is often raised by individuals considered to be “mentally ill”, PAIMI has developed this general guide to understanding your rights in gaining access to your records. Please note that there are several different laws that may apply, depending on the circumstances. Therefore, you need to know the following:

1. What type of document(s) you want (e.g., medical, psychiatric).
2. What person (doctors, therapists) and/or facility (public or private hospital, outpatient clinic, Department of Mental Health facility) has the records.
3. Whether the records can be released to you.
4. Whether the records can be released to your authorized representative.

Please remember that this is merely a guide to assist you in evaluating your legal rights. It is not intended to answer all your legal questions. If you believe that your rights have been violated, you should consult with an attorney.

I. Access to Psychiatric Records From A Psychiatric Facility

What are psychiatric “facilities”?

A psychiatric “facility” is any inpatient or outpatient hospital, clinic, or other facility for diagnosis, observation or treatment of the mentally disordered. The facility can be either public or private.

How do I obtain access to my records?

You have the right, upon written request, to inspect all of your hospital records and to make copies.

When can I obtain access to my records?

If your request is in connection with legal action related to your hospitalization, you or your attorney can have access to your records during or after your hospitalization. Otherwise, you may have access to your records only after your discharge from a facility.

Can the facility refuse my request?

So long as your request is not made in connection with litigation related to your hospitalization, the facility may refuse to disclose any portion of your record which the facility determines:

1. Would be medically harmful to you:
2. Would constitute an invasion of privacy of another person; or
3. Would violate an assurance of confidentiality furnished to another person.

Can I appeal a facility's refusal to disclose my records?

Yes. If you wish to contest a facility's refusal to disclose your records, a motion may be filed in superior court. The court then sends a notice of a hearing date and an order to have the records brought to court. The judge may review the records in private when deciding whether they should be disclosed. The judge will release the records to you if she or he decides in your favor. You can attempt to bring this action yourself but it is always better to consult with an attorney first.

II. Access to Hospital Records**How do I obtain access to my hospital records?**

After your discharge from a private or public hospital, you or your physician or attorney may examine and make copies of your hospital records. Be sure to make your request in writing and to keep a copy of your letter. Your right to access your records only applies after discharge and only to hospitals receiving state aid.

How do I know whether the hospital I was in received "state aid"?

"State aid" refers only to appropriations by the legislature. This does not include tax exemptions, welfare reimbursements, or payments under other contracts with the state. To find out if the hospital you were discharged from receives state aid you can ask for a copy of its annual report or contact the Commissioner on Hospital and Health Care.

What are hospital records?

Hospital "records" include the history, bedside notes, charts, pictures and plates kept in connection with your treatment at the hospital.

Can I appeal if the hospital refuses my request?

Yes. If your request for records is denied, you may file a motion for disclosure with a judge of the superior court. The court sets a hearing date and orders the hospital to bring the records to the court. If the hospital refuses to produce the records, the judge can impose a fine of no more than \$100.00 or imprisonment for not more than 6 months, or both. Again, you can attempt to do this yourself, but it is better to consult with an attorney first.

If I was in a hospital that did not receive state aid, do I have the right to obtain my records?

Yes. There is a law that requires health care institutions licensed by the state to provide you access to your records.

What are health care “institutions” licensed by the state?

Health care institutions licensed by the state include, for example, hospitals, nursing homes, mental health facilities, and alcohol or drug treatment facilities. Health care institutions include state agency facilities except state facilities for persons with mental disabilities or substance abuse problems. Since practically all state agency facilities will be covered by the rules discussed in the next section on “personal data”, look to that section for guidance in dealing with state operated facilities.

III. Access to Personal Records

Can I have access to records containing personal information about me?

Yes. You are entitled to access personal data by public agencies.

What is “personal data”?

“Personal data” is any information about your education, finances, medical or emotional condition or history, employment or business history, family or personal relationships, reputation or character.

What is a “public agency”?

A public “agency” is any state or municipal board, commission, department or officer which maintains a personal data system. This would include the Department of Mental Health, for example.

What specific rights do I have regarding my personal data?

Public agencies must allow:

- (1) you to contest the accuracy, completeness or relevancy of your personal data;
- (2) the personal data to be corrected upon your request when the agency concurs in the proposed correction;
- (3) you to add your own statement which shall become a permanent part of the record, when you believe the agency maintains inaccurate or incomplete personal data;
- (4) you access, upon written request, to all your personal data.

Can the agency refuse my request for access to my personal data?

Yes, the agency may refuse disclosure but only:

1. If the agency determines that disclosure of medical, psychiatric or psychological data concerning you would be detrimental to you; or
2. Not disclosing such information is permitted or required by law.

What can I do if the agency refuses my request for disclosure?

If an agency refuses to disclose personal data, you may request that a qualified medical doctor be permitted to review the data to determine if it should be disclosed. If disclosure is recommended by your medical doctor, the agency must disclose the data to you. If, however, your medical doctor does not recommend disclosure, the agency cannot disclose the data but must inform you of your right to appeal in court.

What is the process for filing an appeal?

Within 30 days of the agency's refusal, you must petition the superior court where you reside for an order requiring the agency to disclose the personal data. The court, after a hearing and a private review of the records, will order the disclosure unless it determines that such disclosure would be detrimental to you or is otherwise prohibited by law. We advise you consult with an attorney prior to initiating any action.

Also if you are aggrieved by an agency's decision, you may bring an action in court for an injunction, declaratory judgment, mandamus or a civil action for damages.

All of these terms are difficult to explain. You should contact an attorney for assistance in this area.

IV. ACCESS TO MEDICAL RECORDS FROM HEALTH CARE PROVIDERS

Who are health care providers?

Health care providers are individuals licensed to provide health care services (for example, medical doctors, doctors of osteopathy, chiropractors, podiatrists, physical therapists, occupational therapists, substance abuse counselors, midwives, nurses, etc.).

Are there any exceptions to the law covering records maintained by health care providers?

Yes. It does not apply to:

- a. Information in records relative to any psychiatric or psychological problems or conditions and;
- b. Personal data maintained by any public agency.

How do I obtain access to my records from a health care provider?

Once you make a request, a provider is required to supply you complete and current information concerning your diagnosis, treatment and prognosis. Such information shall also be supplied to any person you designate as your representative. You may request and receive this information orally. If you want a copy of your record, the request must be in writing. In furnishing you a copy of the health record, the provider cannot charge more than 25 cents a page and the cost of first class postage, if applicable.

Can the health care provider deny my request?

Your request may be denied if the provider determines:

- 1. the information is detrimental to your physical or mental health; or
- 2. is likely to cause you to harm yourself or another.

Can I appeal the provider's refusal to disclose my record?

Yes. If disclosure is denied by a provider, you may, within 30 days of the refusal, petition the court for an order of disclosure. The court after a hearing and a private review, will order disclosure unless it determines that disclosure would be detrimental to your physical or mental health or is likely to cause you to harm yourself or another.

We urge you to contact an attorney prior to initiating any appeal of this kind. Attached is an example of a letter of request. You must first determine which section applies to your individual situation prior to writing the letter.

These laws are complex. They may be difficult to understand and apply. There are a number of legal resources available to you for free consultation. All requests and information is confidential.

PAIMI – Protection and Advocacy for Individuals with Mental Illness
Office of Protection and Advocacy for Persons with Disabilities
60-B West Street, Hartford, CT 06120
Phone: 297-4300; 1-800-842-7303; TDD 566-2102

Connecticut Bar Association
101 Corporate Place
Rocky Hill, CT 06067
Phone: 721-0025

Legal Aid Society of Hartford County, Inc.
80 Jefferson Street
Hartford, CT 06106
Phone: 541-5000; TDD 541-5069

Connecticut Legal Services
P.O. Box 841
Middletown, CT 06457
Phone: 344-0447

SAMPLE

Connecticut Valley Hospital
P.O. Box 351
Eastern Drive
Middletown, CT 06470
Attn: Medical Records Dept.

December 1, 1992

RE: Medical Records of John Doe

Dear Records Department:

I am writing to request a copy of (or the opportunity to inspect my records) maintained by Connecticut Valley Hospital. I was a patient at the hospital from approximately June 1, 1990 to April 1, 1991.

Please send a copy of my records to the address printed below at your earliest convenience.

Thank you for your prompt attention to this matter.

Sincerely,

John Doe
1 State Street
Hartford, CT 06111
Phone: 555-1000

SUBSTITUTE SENATE BILL NO. 94
PUBLIC ACT NO. 92-129

**An Act Concerning Outpatient Mental Health Treatment for Minors
And Defining Community Health Centers**

Be it enacted by the Senate and House of Representatives in General Assembly convened:

Section 1. (NEW) (a) For the purposes of this section, "outpatient mental health treatment" means the treatment of mental disorders, emotional problems or maladjustments with the object of (1) removing, modifying or retarding existing symptoms; (2) improving disturbed patterns of behavior; and (3) promoting positive personality growth and development. Treatment shall not include prescribing or otherwise dispensing any medication which is a legend drug as defined in section 20-184a of the general statutes.

(b) A psychiatrist licensed pursuant to chapter 370 of the general statutes, a psychologist licensed pursuant of chapter 383 of the general statutes, an independent social worker certified pursuant to chapter 383b of the general statutes or a marital and family therapist certified pursuant to chapter 383a of the general statutes, may provide outpatient mental health treatment of a minor without the consent or notification of a parent or guardian at the request of the minor if (1) requiring the consent or notification of a parent or guardian would cause the minor to reject such treatment; (2) the provision of such treatment is clinically indicated; (3) the failure to provide such treatment would be seriously detrimental to the minor's well-being; (4) the minor has knowingly and voluntarily sought such treatment and (5) in the opinion of the provider treatment, the minor is mature enough to participate in treatment productively. The provider of such treatment shall document the reasons for any determination made to treat a minor without the consent or notification of a parent or guardian and shall include such documentation in the minor's clinical record, along with a written statement signed by the minor stating that (A) he is voluntarily seeking such treatment; (B) he has discussed with the providers the possibility of involving his parent or guardian in the decision to pursue such treatment; (C) he has determined it is not in his best interest to involve his parent or guardian in such decision; and (D) he has been given adequate opportunity to ask the provider questions about the course of his treatment.

(c) After the sixth session of outpatient mental health treatment provided to a minor pursuant to his section, the provider of such treatment shall notify the minor that the consent, notification or involvement of a parent or guardian is required to continue treatment, unless such a requirement would be seriously detrimental to the minor's well-being. If the provider determines such a requirement would be seriously detrimental to the minor's well-being, he shall document such determination in the minor's clinical record, review such determination every sixth session thereafter and document each such review. If the provider determines such a requirement would no longer be seriously detrimental to the minor's well-being, he shall require the consent, notification or involvement of a parent

or guardian as a condition of continuing treatment. No provider shall notify a parent or guardian of treatment provided pursuant to this section or disclose any information concerning such treatment to a parent or guardian without the consent of the minor.

- (d) A parent or guardian who is not informed of the provision of outpatient mental health treatment for his minor child pursuant to this section shall not be liable for the costs of the treatment provided.

Sec. 2 (NEW) As used in sections 17-314k, 17-314i, 19a-7b, and 19a-59b of the general statutes and section 18 of public act 91-11 of the June special session, "community health center" means a public or non profit private medical care facility which (1) is not part of a hospital and is organized and operated to provide comprehensive primary care services;

(2) is located in an area which has a demonstrated need for services based on geographic, demographic and economic factors; (3) serves low income, uninsured, minority and elderly persons; (4) provides, on an ongoing basis, primary health services by physicians and, where appropriate, mid-level practitioners, diagnostic laboratory and x-ray services, preventive health services and patient care management; (5) maintains an ongoing quality assurance program; (6) is a participating Title XIX and Medicare provider; (7) has a governing board with authority and responsibility for policy and conduct of the center, the majority of whom are active users of the center, and of the nonuser board members, no more than half may derive more than ten per cent of their annual income from the health care industry; (8) is open at least thirty-two hours per week; and (9) has arrangements for professional coverage during hours when the center is closed.

GUARDIANSHIP AND SELF-DETERMINATION

Objective: Students will understand the implications of guardianship.

Activity A: Review the Connecticut statute on guardianship. Discuss the fact that at age 18, the State of Connecticut considers individuals capable of making their own decisions unless determined otherwise by Probate Court. Highlight the importance of decision-making and accountability.

Activity B: Review the article on **Guardianship and Self-Determination** by David Flower. Debate the need for guardianship and discuss the idea proposed in this article that legal guardianship is increasingly a thoughtful attempt to promote self-determination, rather than a simple taking away of rights.

GUARDIANSHIP FACT SHEET

CONNECTICUT ADULTS WITH MENTAL RETARDATION

(CONNECTICUT GENERAL STATUTES 45A-668 TO 45A-684)

Under Connecticut Law an Adult with Mental Retardation is Deemed Competent to Make Their Own Decisions Unless Determined Otherwise by Probate Court.

Connecticut law assumes adults with mental retardation, age 18 and over, are capable of making their own decisions. However, when a probate court determines that an individual adult with mental retardation is not capable of making a particular decision or decisions in general, the judge can appoint a guardian to act in any of three capacities.

Plenary Guardian

Makes all decisions requiring consent for an adult with mental retardation. Usually, only appointed for someone with profound mental retardation.

Limited Guardian

Makes decisions in any one or a combination of specific areas assigned by the court, such as:

1. Place of abode
2. Habilitative and Educational Programs
3. Release of Clinical Records and Photographs
4. Behavioral Intervention Programs
5. Medical and Dental Treatment
- 6.

Temporary Limited Guardian

Makes decisions in any one or a combination of specific areas assigned by the court as above for a temporary period of time (within 60 days). Used most often for specific surgical, medical or dental treatment.

Process for Appointing a Guardian

Any adult person, whether family or not, may petition the court asking that a guardian be appointed for an adult individual with mental retardation. A hearing is held by the court serving the town where the individual lives or where his/her legal residence is; for example, the town where involved parents live. The judge decides whether to appoint a guardian by gathering information from an assessment team designated by the Department of Mental Retardation. The judge pays particular attention to what the individual's strengths and weaknesses are. She/he may also listen to others such as parents, teachers and social workers.

For a guardian to be appointed the court needs to find, by clear and convincing evidence, that the individual is not able to make any, or some, informed decisions about matters related to his/her care.

(For a complete copy of the statutes contact the Department of Mental Retardation at 566-3680)

GUARDIANSHIP AND SELF-DETERMINATION

BY DAVID FLOWER

The idea of legal guardianship understandably tends to raise mixed feelings in persons concerned with self-determination. Guardianship is, after all, based on two premises seemingly irreconcilable with the ideal of self-determination. The first premise is that some people are not able to make competent decisions. The second premise is that those persons' legal rights to make certain choices should therefore be removed and given to another to exercise on their behalf. The dilemma concerning guardianship and self-determination is therefore quite clear: Guardianship is a legal relationship that attempts to insure that potentially vulnerable persons' best interests and rights are protected, but at the expense of the right to self-determination.

Guardianship law, like our society in general, has traditionally been reluctant to view persons with developmental disabilities as capable of self-determination. There is a growing recognition, however, that historical assumptions about the capacities of individuals with developmental disabilities are simply not accurate. Legal systems are perhaps slower to change. Nonetheless, conceptions of "legal competence" and the roles and functions of guardians are also changing. The premises underlying guardianship are likewise changing in ways that may allow legal guardianship and self-determination to more peacefully coexist.

Guardianship laws increasingly recognize that individual capacity is not an all or nothing affair, to be determined simply by looking at a disability label. In the past, "competence" was often determined as if it were some inherent, global trait that most people were blessed with and some completely lacked. Most state guardianship statutes now require some degree of functional assessment of a person's capabilities and skills, rather than relying almost solely on a disability label to reach a conclusion of legal incompetence. Furthermore, most guardianship laws now acknowledge that decisional capacity is not global, but that a person may be able to make decisions in some areas or situations even if lacking capacity in others. Most states accordingly provide for limited guardianships, where the guardian is not automatically vested with plenary power, but may have a limited area of authority while the person under guardianship retains other decisional rights.

This increased focus on functional definitions of legal competence should also force courts to more clearly face the question of whether certain people need any sort of guardian at all. Indeed, the possibility of varying levels of need in regard to substitute decision-making relationships has brought increased interest to crafting a continuum of alternatives, including guardianship. Full guardianship should be seen as one option among many, including limited guardianship, alternative legal arrangements such as trusts and power of attorney, formal supports such as case management, and informal social supports. In this evolving view, guardianship is seen much as any other service: it may not be needed at all, and if it is needed it should be provided in the most appropriate and least restrictive manner.

GUARDIANSHIP AND SELF-DETERMINATION (CONTINUED)

There is also a growing understanding that not only is the ability to exercise personal control not a global, inherent trait, but that it is largely dependent on individual opportunity, social support, and personal growth. As people with developmental disabilities become part of communities, experience true opportunities for choice, and are supported in their choices, “legal competence” increases hand-in-hand with functional competence. To the extent that a person’s choices and wishes are heard, valued, and supported by the larger community, there is less need for protective arrangements. Specific support tools such as personal futures planning reach toward this same end. The principles of support not supervision; communication, not paternalism; and choice, not helplessness are coming to be valued in the practices of guardianship as they are in the ideal of community inclusion.

In this same vein, the role of legal guardians also seems to be undergoing some evolution. There is a move away from conceptions of guardianship as a custodial relationship, toward a view that guardians should serve primarily as “substitute decision-makers.” In broad terms, of course, guardians have always been substitute decision-makers. Where the field of guardianship is truly changing is in a greater focus on the principles and processes of ethical decision-making. Substitute decision-making is seen less often as a paternalistic decision on behalf of the person, and more as a determination and advancement of the person’s wishes. To some degree, the ideal role of guardians is converging on the role of advocates. Like advocates, when guardians truly hear and work to support a person’s wishes, individual choice is supported. A guardian or advocate may be the only person who truly does hear and value those wishes, and can be instrumental in bringing them to a service system or community that may otherwise ignore them.

The changing nature of the services available to persons with developmental disabilities demands that we confront the dilemma of guardianship. The number and variety of options for work; community living, and provision of support services continue to increase. Service and support systems increasingly are taking on a market orientation, and state governments are encouraging privatization of services and emphasizing consumer choice. Given this trend, it is vital that important individual decisions do not devolve onto service providers or others who have no such legal or ethical authority. The first preference is always that the individual concerned should have true opportunity to make those decisions, and that individual autonomy receive support.

Most people with developmental disabilities can indeed exercise autonomy – a basic fact too long ignored. On the other hand, many do not exercise autonomy because of an inability or unwillingness of others to learn to communicate with them, a historical and still present unwillingness to offer the opportunity for choice making, and/or through the lack of community or social support. Legal guardianship is increasingly a thoughtful attempt to promote self-determination, rather than a simple taking away of rights.

GUARDIANSHIP AND SELF-DETERMINATION (CONTINUED)

Like our communities in general, guardianship is an imperfect system that often serves to devalue and exclude some members of society. Like our communities, it is also a system in transition, and is slowly beginning to search for ways to support inclusion, autonomy, and dignity of all persons.

David Flower is a graduate student in Educational Psychology and a law student at the University of Minnesota, Minneapolis. Reprinted with permission from IMPACT, Institute on Community Integration, College of Education, University of Minnesota, Volume 6(4), Winter 1993/94.

VOTING

Objective: Students will demonstrate knowledge of their right to vote.

Activity A: Make copies of the handout **Voting** for your students, or purchase brochures from the ARC at \$13 per hundred. The student brochure answers questions about voting: What is voting? Who can vote? When and how can I vote?, etc.

Activity B: Review the videotape **You Can Vote**, sponsored by Awareness Communication Team, which encourages people with disabilities to vote and helps them overcome barriers to voting.

Activity C: Assist students with registering to vote.

About half the states require registration in person, and half allow it by mail. Obviously, mail-in registration offers the advantage of convenience. Both types of registration, however, can be done in class if the registration clerk's office agrees to send someone to the class to register the students. Such a visit offers the advantage of having a guest speaker on the subject of voting procedures. Registration deadlines vary from a few days to a month before the election.

Activity D: Have a student call your city or county clerk for voter registration information, and ask about rules for helping a voter read the ballot. The student can report this information back to the class.

Activity E: Discuss the importance of making wise choices. Encourage students to ask questions of parents, teachers, friends and neighbors concerning political parties and candidates. It is best to get more than one point of view. Call the candidates' local offices and ask one of their representatives to visit the class for a short talk and question/answer period.

Activity F: A total language approach can be taken to voting instructing. A notebook of news and magazine items, pictures, letters written, and notes taken from class discussions will keep attention focused on the election. It is a good idea to hold a mock election in class, selecting a person to go perform a duty that involves the whole class. For example, hold an election to choose one person to decide on a special activity for the class. One candidate might campaign for a picnic, another for a field trip, etc. Such an activity will demonstrate the will of the majority, wise choices, and campaign speeches.

Picture code the issues on sample ballots, and then discuss their meanings and potential impact on the community. Hold mock debates by class members who present both pro and con opinions. Take a class trip to look at a bridge that proposed taxes are needed to strengthen. Then put a picture of a bridge by that item on the sample ballot. Stress, however, that the picture will not appear on the official ballot.

Activity G: Give students the opportunity to go to the polls or vote absentee. Polling places that utilize voting machines will often allow training sessions with the machines. One alternative to hands-on training would be to visit the site yourself and take pictures of the machines for a small teacher-made training booklet for classroom use.

VOTING

WHAT IS VOTING?

Voting means making choices. Citizens of the United States must choose which people they want to make decisions for them. Obviously, we can't all go to Washington to run our own government. We can't all go to city hall to make decisions for ourselves. For that reason, we vote. We choose people to decide for us. This is a big, important job. We must choose well. We want to be happy with our choices. We make choices that will affect the whole United States. Voting is a serious responsibility.

United States citizens vote by marking ballots. Ballots are pieces of paper with the choices listed on them. Some people use voting machines to mark their ballots.

WHO CAN VOTE?

In the United States, citizens 18 and over can vote.

Where you born in the United States?

Are your parents citizens? Or

Did you take a test to become a citizen?

If you answered "yes" to one of these questions, then you are a citizen, and you can vote.

WHAT IS A CITIZEN?

A citizen is a person who lives in a country and enjoys its privileges. A good citizen is concerned about his country. A United States citizen enjoys special freedoms.

What do you have to do to enjoy freedom? Citizens have duties. Some of the duties of United States citizens are:

Citizens are expected to obey the laws.

If they don't like the laws, they can vote to change them.

Citizens over age 18 are expected to vote.

Any citizen of the United States 18 years old or older can vote.

HOW AND WHEN CAN I VOTE?

All states require voters to register. To find out how and when to register to vote, call the city or county clerk or the League of Women Voters, listed in the telephone directory. Also, the National Organization on Disability will help you. Call it at (202) 293-5960, TDD (202) 293-5968. When you call the city or county clerk, ask them whether they will allow someone to help you read the ballot. Ask them also whether they will allow you to register by mail.

National elections take place every two years. Members of Congress and one-third of the Senators are elected then. The President is elected every four years. The date for national elections is always on the first Tuesday after the first Monday in November.

VOTING (CONTINUED)

Some cities have chosen to hold their elections at other times. You can ask the city clerk about your particular city.

WHO CAN HELP ME IF I DECIDE TO VOTE?

Your teacher is a good person to ask for help.

A parent is also often eager to help.

Who takes you to the doctor? Maybe that person is the one to ask.

Neighbors or friends sometimes help.

Call the League of Women Voters for help. It is an organization that helps people

vote. It is listed in the phone book.

Get some phone numbers to call for a ride at the last minute, in case your helper can't take you to vote.

WHAT IF I CAN'T READ VERY WELL?

Ballots are often hard to read. However, most polling places will let you take someone with you to read for you.

HOW CAN I DECIDE ON MY CHOICES?

Voting requires some study. Sometimes you will vote on new laws for your community. Other elections are about choosing the right people as leaders. You may need some help making your decisions. There are many places to get help. Don't forget that every citizen must make his/her own choices. Another person cannot make you vote for something or someone you don't like.

Here are some ways you can learn whom and what you want to vote for.

Talk to teachers, parents, friends and neighbors about their choices.

Listen to television and radio news.

Look at the people running for office (called candidates).

Listen to what they say.

Keep a notebook about voting and candidates.

REMEMBER: CITIZENS VOTE TO KEEP THEIR FREEDOM. VOTING IS A SERIOUS DUTY AND PRIVILEGE. ASK SOMEONE TO HELP YOU TO PREPARE TO VOTE.

USING THE TELEPHONE

Objective: Students will be provided with information on their telephone rights.

Activity A: Distribute the **Telephone Support Project** handout, and discuss telephone rights.

Activity B: Invite a representative from the telephone company to further discuss telephone rights, consumer responsibilities, and special services for individuals with disabilities.

TELEPHONE SERVICE INFORMATION

Some people lose their telephone service because they cannot pay their bill. There are a few money saving ideas that you may not be aware of.

Money Saving Tips

It costs more money to have extra services on your phone. Some examples are:

- Call Waiting
- Call forwarding
- Three way calling

You might be spending \$3.00 or more each month that you do not need to. If you do not need these services, **don't get them**

There is a charge every time you use call trace. (*69)

It costs money if you dial 900 numbers.

It may cost you more money to make long distance calls during the day. You may want someone to help you find out what your service plan prices are for day, evening, and weekend calling.

Find out when is the best time to make all long distance.

To keep this information handy, cut it out and keep it with your phone book.

Know Your Telephone Rights and Responsibilities.

If a consumer cannot see, read or use a phone book because of a disability, he or she may ask the local phone company not to charge for calls to Directory Assistance, to obtain local numbers (555-1212). You may be asked to fill out an application; however, a doctor's signature is not required.

Some local areas have special 3 digit numbers for local information.

When you call directory assistance they will offer to place the call for you, this service **IS NOT FREE**.

Everyone can make two directory assistant calls per month for free. If you tell the operator at the beginning of the call, you may be able to get 2 numbers per call. **After that you will be charged for each number that you request.**

Consumers should call their local phone company's consumer help line for more information.



ADDITIONAL RESOURCES

Developmental Disability Councils

Protection and Advocacy

University Centers for Excellence

**Parent Training and Information
Centers**

NICHCY

Central Directory of Resources

LISTING OF NATIONAL ORGANIZATIONS

NATIONAL ASSOCIATIONS STATE COUNCILS ON DD

CONSORTIUM OF DEVELOPMENTAL DISABILITIES COUNCILS (CDDC)

2102 Weatherton Dr.
Wilmington, DE 19810
Phone: (302) 529-7270
FAX: (302) 529-7271
E-Mail: INFO@cddc.com
Web Page: <http://www.cddc.com>
Consortium Director:
Phyllis Guinivan, Ph.D.

Office of Governmental Relations
296 Dover Road
Warrenton, VA 20186-2308
Phone: (504) 428-1095
Director of Government Relations:
Ed Burke
E-Mail: epbcddc@aol.com

NATIONAL ASSOCIATION OF DEVELOPMENTAL DISABILITIES COUNCILS (NADDC)

1234 Massachusetts Ave. N.W.
Suite 103
Washington, D.C. 20005
Phone: (202) 347-1234
FAX: (202) 347-4023
E-Mail: NACCD@naddc.org
Web Page: <http://www.naddc.org>
Executive Director:
Mrs. Donna Heuneman
E-Mail: dheuneman@naddc.org

NATIONAL ASSOCIATIONS PROTECTION AND ADVOCACY AGENCY

National Organization
National Association of Protection and Advocacy Systems (NAPAS)
900 2nd Street, N.E., Suite 211
Washington, D.C. 20002
Phone: (202) 408-9514
FAX: (202) 408-9520
E-Mail: vicki@napas.org
Web Page: <http://www.protectionandadvocacy.com/>
Executive Director: Curtis Decker
E-Mail: curtis@napas.org

NATIONAL ASSOCIATIONS UNIVERSITY CENTERS

American Association of University Affiliated Programs
Suite 410
Silver Spring, MD 20910
Phone: (301) 588-8252
FAX: (301) 588-2842
E-Mail: thosinski@aaup.org
Web Page: <http://www.aaup.org/>
Executive Director:
Dr. George Jesien

WHAT IS THE COUNCIL ON DEVELOPMENTAL DISABILITIES?

What is the Council on Developmental Disabilities? The North Carolina Council on Developmental Disabilities (DD Council) is part of a national network of organizations that assist people with developmental disabilities. In each state, federal law (PL 106-402), the Developmental Disabilities Assistance and Bill of Rights Act or DD Act) creates a planning council, such as the DD Council, a protection and advocacy system, and a university affiliated program. Together, these three organizations work to promote the "independence, productivity, integration and inclusion into the community" of people with developmental disabilities and their families.

Like all DD Councils and their partners, we are funded through the US Administration on Developmental Disabilities (ADD). The NC DD Council receives approximately \$1.8 million in federal funds, through the NC Department of Health and Human Services. Our 32 members, appointed by the governor, decide how those funds will be used, based on a three-year State Plan. We are proud that 60% of our members are people with developmental disabilities or family members of people with developmental disabilities.

The DD Council's role in NC's ADD network is to promote a community service delivery system that is personalized to meet the unique needs of each individual with a developmental disability. We do this by funding community partners to conduct activities, across the state, that advance innovative, cost-effective ways of providing services. We share information about the best of what's happening across the nation and advocate for changes to make NC communities more welcoming to and supportive of people with disabilities. The DD Council is strongly committed to supporting leadership roles for people with developmental disabilities and families in all the work that we do.

In our state, there are over 118,000 North Carolinians affected by developmental disabilities. Under the DD Act, the Council advises all state agencies in North Carolina that receive federal funds used to assist people with developmental disabilities. Under state law, we have a special advisory role to the NC Department of Health and Human Services (see NCGS 143B-177-179).

How do I contact the Council? You may reach us by mail, telephone, fax and e-mail:

The North Carolina Council on Developmental Disabilities
1001 Navaho, Suite GL-103
Raleigh, NC 27609
(919)-850-2833 (voice/tdd)
(800)-357-6916 (voice/tdd)
(919)-850-2895 fax
www.nc-ddc.org
Council Chair: William B. Morris, III
Executive Director: Holly Riddle, J.D., M.Ed.

Customers. Our customer is anyone with a developmental disability or a member of that person's family (see [definition of DD](#)). Our customers are people who experience a wide range of disabilities--intellectual, physical or both--but they have much in common with each other and with everyone else. Like people not affected by a disability, our customers tell us they want to live full, productive lives. They want the rights and responsibilities of full citizenship. They want to choose and have control over the services and supports that will enable them to be respected, contributing members of their families, communities, state and nation.

Mission. Our mission is to ensure that people with developmental disabilities and their families participate in the design of and have access to culturally competent services and supports, as well as other assistance and opportunities, that promote inclusive communities.

We describe our mission as "building bridges to communities." We envision inclusive communities to be those where people with developmental disabilities and their families are valued and respected. In these communities, people with developmental disabilities live, go to school, work, play and retire, side by side with others. In inclusive communities people with disabilities can exercise the rights and responsibilities of full citizenship. They have access to the specialized services--provided by those of their choice--when, where and how they want them. They also have access to community services and informal supports. We are dedicated to promoting, through partnership and collaboration the way to service delivery systems and communities that afford each person with a developmental disability the opportunity to live a self-determined life in an inclusive community.

The DD Council is committed to partnership. Our partnership is led by people with disabilities and their families. Together, we work with policy makers, legislators, professionals and other community members to meet the shared need of those with developmental disabilities for a personalized, coordinated array of services and supports provided in the community.

The Council itself is comprised of 32 members appointed by the governor. Sixty percent of our members are people with developmental disabilities or family members of people with developmental disabilities. Others include representatives from major state agencies serving people with developmental disabilities, legislators and community representatives. The Council is an independent entity, directed by its members. All of our meetings are open to the public. We encourage you to attend and share your concerns or ideas with us during the public comment period of each Council meeting.

Philosophy. The Council on Developmental Disabilities recognizes that all people with developmental disabilities:

- are unique, have value and must be afforded dignity and respect
- can contribute to family and society ("contribution"), provided the necessary services and supports ("no more and no less than what is needed")
- can lead self-determined lives when given freedom, responsibility, support and control over their lives ("self-determination," "family support")
- have the right to participate fully in developing the unique services and supports that allow them to pursue their dreams, hopes and desires ("person-centered planning")
- can benefit from the on-going support of family and friends ("circle of supports")
- have a right to the same life choices as others ("dignity of risk")
- have a right to be safe and free from harm
- can, with support, participate fully in society ("full citizenship") and should not be expected to earn that right by progressing through a "continuum of care"
- must have ready access to vital services and supports, including accessible transportation, affordable housing and health care, competitive work, inclusive recreation and leisure opportunities, and specialized services, as well as those services generally available to all who reside in a community
- have the right to belong to and be included in all aspects of society ("community inclusion") while retaining their own cultural and ethnic heritage ("cultural competence")
- benefit from inclusive communities, just as society benefits ("mutual interdependence") from the contributions and economic productivity of those with disabilities

Responsibilities. The Developmental Disabilities Bill of Rights and Assistance Act (PL 106-402) states that Councils, through members, staff, consultants, contractors, or grantees shall have specific responsibilities, as defined in the federal law. Some of our responsibilities are:

- Systemic change, capacity building and advocacy
- Examination of priority areas
- State plan development, implementation and monitoring
- Demonstration of new approaches
- Outreach
- Training
- Supporting communities
- Interagency collaboration and coordination
- Coordination with related councils
- Barrier elimination, systems design and citizen participation
- Public education and coalition development
- Informing policymakers
- Prevention
- Other activities consistent with the DD Act

ADD network partners. The DD Act (PL 106-402) provides the DD Council with two partners, 1) the protection and advocacy system: The NC Governor's Advocacy Council for Persons with Disabilities; and 2) Centers for Excellence in Developmental Disability Research, Education and Service: In NC, the Center for Development and Learning. Together, these three agencies make up North Carolina's "Administration on Developmental Disabilities (ADD) Network." Our state ADD network is administered through the Region IV Administration on Children and Families ADD office in Atlanta: telephone: 404-562-2911.

The Governor's Advocacy Council for Persons with Disabilities (GACPD) is charged with protecting the legal and human rights of people with developmental and other disabilities. Its address is 2113 Cameron Street, Suite 218, Raleigh, NC 27605-1275. The toll-free number for GACPD is 1-800-821-6922. The GACPD Website is <http://www.doa.state.nc.us/doa/gacpd/gacpd.htm>.

The Center for Development and Learning (CDL) is charged with 1) the preparation of students, fellows and other leadership personnel; 2) community training and technical assistance for or with people with developmental disabilities, professionals, paraprofessionals, students and volunteers; and 3) dissemination of information and research findings. The address for the CDL is Campus Box 7255, University of North Carolina, Chapel Hill, NC 27599-7255. Its Website is <http://cdl.unch.unc.edu>.

State partners. The Council has many partners. Some are represented on the Council itself: people with developmental disabilities or family members of people with developmental disabilities; the public at large; non-governmental agencies; local governmental agencies; the Office of the Secretary of the Department of Health and Human Services (DHHS); the NC General Assembly; the Division of Mental Health, Developmental Disabilities, and Substance Abuse; the Division of Aging; the Department of Public Instruction, Division of Exceptional Children; the Division of Social Services; the Division of Vocational Rehabilitation; the Division of Medical Assistance; the Division of Maternal and Child Health; and the Department of Corrections, Mental Health and Psychological Services.

The Council is a member of numerous advisories, task forces, committees, councils, and consortia, including the NC Developmental Disabilities Consortium and the Coalition 2001.

Becoming part of the DD Council family. The 32 members of the DD Council are appointed by the governor and serve on a voluntary basis. Each year, the Council advertises for new members, who serve a four-year term. We review all applications and make recommendations to the governor for his consideration. The Council holds public meetings four times a year and welcomes guests. Each meeting closes with a "public comment" period. If you are a person with a disability and would like to attend a meeting, please let us know in advance of any accommodation you may require.

STATE COUNCILS ON DEVELOPMENTAL DISABILITIES

State Councils on Developmental Disabilities Program

Under Part B of the Act, the State Councils on Developmental Disabilities program provides financial assistance to each State to support the activities of Developmental Disabilities Council in that State. Councils are uniquely composed of individuals with significant disabilities, parents and family members of people with developmental disabilities, and representatives of State agencies that provide services to individuals with developmental disabilities. Together, this group of individuals develops and implements a statewide plan to address the Federally-mandated priority of employment, and optionally any of three other Federal priorities (case management, child development, and community living) as well as one optional State priority.

The emphasis of the Councils is to increase the independence, productivity, inclusion and integration into the community of people with developmental disabilities, through a variety of systemic change, capacity building, and advocacy activities on their behalf, including development of a State Plan, which lays out activities for demonstration of new approaches to enhance their lives; training activities; supporting communities to respond positively; educating the public about their abilities, preferences, and needs; providing information to policy-makers to increase their opportunities; and eliminating barriers.

Fiscal Year 1999 appropriations provided \$64,803,000 to support these activities.

This program is authorized under Part B of the Act.

LISTING OF STATE COUNCILS ON DD

ALABAMA

STATE COUNCILS ON DD
Alabama State Council for DD
RSA Union Building
Halcyon
Post Office Box 301410
Montgomery, AL 36130-1410
Phone: (334) 242-3973
Toll Free: (800) 846-3735
FAX: (334) 242-0797
Web Page: <http://www.acdd.org>
Executive Director:
Sheryl Matney
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Chair: Elizabeth Prince
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ALASKA

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And Special Education
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Executive Director:
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AMERICAN SAMOA

STATE COUNCILS ON DD
American Samoa
Developmental Disabilities Council
P.O. Box 194
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Phone: (011-684) 633-5908
FAX: (011-684) 633-2919
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Henry Sesepasara
Chair: Lu Tagisia Faumuina

ARIZONA

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Governor's Council on
Developmental Disabilities
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Phoenix, AZ 85007
Phone: (602) 542-4049
FAX: (602) 542-5320
Executive Director:
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Chair: Josephine Frampton
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ARKANSAS

STATE COUNCILS ON DD
Governor's Developmental
Disabilities
Planning Council
Freeway Medical Tower
5800 West 10th, Suite 805
Little Rock, AR 72204
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TDD: (501) 661-2736
FAX: (501) 661-2399
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CALIFORNIA

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California State Council on
Developmental Disabilities
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TDD: (916) 324-8420
FAX: (916) 443-4957
Executive Director:
Judy McDonald
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COLORADO

STATE COUNCILS ON DD
Colorado Developmental Disabilities
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Web Page:
<http://www.cddpc@state.co.us>
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FAX: (720) 941-8490
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COMMONWEALTH OF THE NORTHERN MARIANA ISLANDS

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CNMI Governor's Developmental
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U.S. Northern Marianas
Saipan, MP 96950-2565
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TDD: (670) 322-3014
FAX: (670) 664-7030
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<http://www.cnmiddcouncil.org>
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CONNECTICUT

STATE COUNCILS ON DD
Connecticut Council on
Developmental Disabilities
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Phone: (860) 418-6160
TTY: (860) 418-6172
Toll Free: (800) 653-1134
FAX: (860) 418-6003
Web Page:
<http://www.state.ct.us/ctcdd/>
E-Mail: maggie.carr@po.state.ct.us

Executive Director: Edward T.
Preneta
E-Mail: ed.preneta@po.state.ct.us
Chair: Margaret M. Cohan

DELAWARE

STATE COUNCILS ON DD
State of Delaware
Developmental Disabilities Council
Margaret M. O'Neill Building, 2nd
Floor
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DE 19901
Phone: (302) 739-3333
Toll Free: (800) 273-9500 (Out-of-
state)
Toll Free TDD: (800) 464-HELP (In-
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FAX: (302) 739-2015
Executive Director:
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STATE COUNCILS ON DD
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GOV'T OF FEDERATED STATES OF MICRONESIA

STATE COUNCILS ON DD
Gov't of Federated States
of Micronesia
Department of Education
Palikir, Pohnpei, FM 96941
Phone: (691) 320-2609
FAX: (691) 320-5500
Executive Director: Yosiro Suta

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FLORIDA

STATE COUNCILS ON DD
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FAX: (850) 922-6702
Web Page: <http://www.fddc.org>
Executive Director:
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Chair: Linda Merrell

GEORGIA

STATE COUNCILS ON DD
Governor's Council on
Developmental Disabilities for
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Atlanta, GA 30303
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HAWAII

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Hawaii State Planning Council
on Developmental Disabilities
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Honolulu, HI 96814
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FAX: (808) 586-7543
E-Mail: hiddc@pixi.com
Executive Director: Diana C. Tizard
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IDAHO

STATE COUNCILS ON DD Idaho
State Council on
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TDD: (208) 334-2179
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FAX: (208) 334-3417
Web Page:
<http://www2.state.id.us/icdd/>
E-Mail: icdd@icdd.state.id.us
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ILLINOIS

STATE COUNCILS ON DD
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Illinois Council on Developmental
Disabilities
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Chicago, IL 60601
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FAX: (217) 524-5339
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INDIANA

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FAX: (317) 233-3712
Executive Director: Suellen Jackson-
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IOWA

STATE COUNCILS ON DD
Governor's DD Council
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KANSAS

STATE COUNCILS ON DD
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915 S.W. Harrison, Room 141
Topeka, KS 66612-1570
Phone: (785) 296-2608
FAX: (785) 296-2861
Web Page:
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Executive Director: Jane Rhys, Ph.D.
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KENTUCKY

STATE COUNCILS ON DD
Kentucky Developmental Disabilities
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100 Fair Oaks Lane, 4th FL.

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Toll Free: (877) 367-5332
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LOUISIANA

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Louisiana State Planning Council
on Developmental Disabilities
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Executive Director:
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MAINE

STATE COUNCILS ON DD
Maine DD Council
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MARYLAND

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MASSACHUSETTS

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Massachusetts DD Council
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MICHIGAN

STATE COUNCILS ON DD
Michigan D.D. Council
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MINNESOTA

STATE COUNCILS ON DD
Governor's Council on Dev.
Disabilities Minnesota Dept. of
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658 Cedar Street
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Toll Free (877) 348-0505
TDD: (651) 296-9962
FAX: (651) 297-7200
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Web Page: <http://www.mnddc.org>
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MISSISSIPPI

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FAX: (601) 359-6295
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MISSOURI

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TDD: (573) 751-8611
Toll Free: (800) 500-7878
FAX: (573) 526-2755
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<http://www.modmh.state.mo.us/mrdd/moplan/moplan.html>
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NEBRASKA

STATE COUNCILS ON DD

Governor's Council on DD
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NEVADA

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FAX: (775) 687-3292
Executive Director: Ken Vogel
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Chair: George Brown

NEW HAMPSHIRE

STATE COUNCILS ON DD
New Hampshire DD Council
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Toll Free TDD: (800) 735-2964
FAX: (603) 271-1156
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NEW JERSEY

STATE COUNCILS ON DD
New Jersey DD Council
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Trenton, NJ 08625-0700
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FAX: (609) 292-7114
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STATE COUNCILS ON DD
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Toll Free: (800) 395-3372
FAX: (518) 402-3505
Web Page:
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NORTH CAROLINA

STATE COUNCILS ON DD
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Toll Free: (800) 357-6916
FAX: (919) 733-1863
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NORTH DAKOTA

STATE COUNCILS ON DD
State Council on Developmental
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ND Dept. of Human Services
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FAX: (701) 328-8969
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STATE COUNCILS ON DD
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Planning Council
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FAX: (614) 466-0298
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OREGON

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Chair: Paul O'Hanlon

PUERTO RICO

STATE COUNCILS ON DD
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Ethel M. Torres Arroyo
Chair: Vicente Sanabria Acevedo,
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RHODE ISLAND

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SOUTH CAROLINA

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<http://www.sccddc.state.sc.us>
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Chair: Ms. Mildred Lilley

SOUTH DAKOTA

STATE COUNCILS ON DD
SD Governor's Council on
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TENNESSEE

STATE COUNCILS ON DD
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TDD: (615) 741-4562
FAX: (615) 532-6964
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TEXAS

STATE COUNCILS ON DD
Texas Council for DD
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Toll Free: (800) 262-0334
FAX: (512) 424-4097
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Web
Page: <http://www.rehab.state.tx.us/tpcdd/>
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Chair: Jan R. Newsom

UTAH

STATE COUNCILS ON DD
Utah Governor's Council for
People with Disabilities
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TDD: (801) 533-4128
FAX: (801) 325-5826
Web Page:
<http://www.gcpd.state.ut.us>
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VERMONT

STATE COUNCILS ON DD
Vermont DD Council
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FAX: (802) 241-2989
Web Page:
<http://www.ahs.state.vt.us/vtddc/>
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Chair: David Sagi
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VIRGINIA

STATE COUNCILS ON DD
VA Board for People with Disabilities
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202 North 9th Street, 9th Floor
Richmond, VA 23219
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TDD: (800) 846-4464
Toll Free TDD: (800) 846-4464
FAX: (804) 786-1118
Web Page:
<http://www.cns.state.va.us/vbdp/>
Executive Director: Brian S. Parsons
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WASHINGTON

STATE COUNCILS ON DD
Washington State DD Council
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TDD: (800) 634-4473
FAX: (360) 586-2424
Web Page: <http://www.wa.gov/ddc>
Executive Director: Edward M. Holen
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Chair: George Walker

WESTERN CAROLINA ISLANDS

STATE COUNCILS ON DD
Trust Territories of the Pacific
Trust Terr. Hlth. Cncl.
MacDonald Mem. Hosp. KOROR
Palau, WCI 96940
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MD

WEST VIRGINIA

STATE COUNCILS ON DD
West Virginia DD Council
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FAX: (304) 558-0941
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<http://www.state.wv.us/ddpc/>
Executive Director: Steve Wiseman
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WISCONSIN

STATE COUNCILS ON DD

Wisconsin Council on DD
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FAX: (608) 267-3906
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Executive Director: Jennifer
Ondrejka
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WYOMING

STATE COUNCILS ON DD
Wyoming Council on DD
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FAX: (307) 777-5690
Executive Director: Brenda Oswald
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Chair: Barbara Weston
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PROTECTION AND ADVOCACY (P&A)

P&A are Federally mandated systems in each state and territory. They provide protection of the rights of persons with disabilities through legal based advocacy. P&A's were established to address public outcry in response to the abuse, neglect, and lack of programming in institutions for persons with disabilities. Congress has created distinct statutory programs to address the needs of different populations of persons with disabilities.

The Protection and Advocacy for Persons with developmental Disabilities (PADD) Program was created by the Developmental Disabilities Assistance and Bill of Rights (DD) Act of 1975. P&A's are required by the Act to pursue legal, administrative and other appropriate remedies to protect and advocates for the rights of individuals with developmental disabilities under all applicable federal and state laws.

The governor in each state designated an agency to be the P&A system, and provided assurance that the system was and would remain independent of any service provider. 1994 amendments to the DD Act expanded the system to include a Native American P&A program.

Administration for Children Youth and Families, Administration on Developmental Disabilities (ADD) administers the PADD program.

The Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program was established in 1986. Each state has a PAIMI program that receives funding from the national Center for Mental Health Services. Agencies are mandated to (1) protect and advocate for the rights of people with mental illness and (2) investigate reports of abuse and neglect in facilities that care for or treat individuals with mental illness. Agencies provide advocacy services or conduct investigations to address issues that arise during transportation or admission to, the time of residency in, or 90 days after discharge from such facilities. The system designated to serve, as the PADD program in each state and territory is also responsible for operating the PAIMI program.

Substance Abuse and Mental Health Services Administration, Center for Mental Health Services (CMHS) administers the PAIMI program.

The Protection and Advocacy for Individual Rights (PAIR) Program was established by Congress as a national program under the Rehabilitation Act in 1993. PAIR programs were established to protect and advocate for the legal and human rights of persons with disabilities.

Although PAIR is funded at a lower level than PADD and PAIMI, it represents an important component of a comprehensive system to advocate for the rights of all persons with disabilities. The system designated to serve, as the PADD program in each state and territory is also responsible for operating the PAIR program.

Office of Special Education and Rehabilitative Services, Rehabilitation Services Administration (RSA) administers PAIR. **The Client Assistance Program (CAP)** was established as a mandatory program by the 1984 Amendments to the Rehabilitation (Rehab) Act. Every state and territory, as a condition for receiving allotments under Section 110 of the Rehab Act, must have a CAP.

CAP services include assistance in pursuing administrative, legal and other appropriate remedies to ensure the protection of persons receiving or seeking services under the Rehab Act.

Rehabilitation Services Administration also administers CAP.

The Protection & Advocacy for Assistive Technology (PAAT)

Program was created in 1994 when Congress expanded the Technology-Related Assistance for Individuals with Disabilities Act (Tech Act) to include funding for P&A's to "assist individuals with disabilities and their family members, guardians, advocates and authorized representatives in accessing technology devices and assistive technology services" through case management, legal representation and self advocacy training.

Originally passed by Congress in 1988, the Tech Act set up a lead agency in each state to coordinate activities to facilitate access to, provision of and funding for assistive technology devices and services for individuals with disabilities.

Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR) administers PAAT.

Eligibility & Priorities

The DD Act requires that **PADD** clients meet the definition of developmental disabilities as defined in the Act as chronic and attributable to mental and/or physical impairments which must be evident prior to the age of twenty-two. They tend to be life long and result in substantial limitations in three or more the major life areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency.

Individuals eligible for **PAIMI** must have significant mental illness or emotional impairment and reside in residential facilities. These facilities, which may be public or private, include hospitals, nursing homes community facilities, board and care homes, homeless shelters, jails and prisons. PAIMI may address issues, which arise during transposition or admission to, the time of residency in, or 90 days after discharge from such facilities.

Persons eligible for **PAIR** are individuals with disabilities who are not eligible for the PADD or PAIMI programs, or whose issues do not fall within the jurisdiction of CAP.

Individuals eligible for **CAP** are those persons who are seeking or receiving services from a Rehab Act project, program or community rehabilitation program.

In addition, P&As develop priorities, after receiving public comment, which establish case selection criteria. Priorities must insure that the most vulnerable populations or those with complex advocacy needs are served before less vulnerable populations. P&As must reach out to unserved or underserved populations. The need to prioritize is necessary as the demand for representation often exceeds the resources of the P&A system.

Legally based advocacy for persons with disabilities based on the following principles:

Equality, Equity and Fairness - People with disabilities are full and equal citizens under the law. They are entitled to equal access to the same opportunities afforded all members of society. People with disabilities are entitled to be free from abuse, neglect, exploitation, discrimination, and isolation, and to be treated with respect and dignity.

Meaningful Choice and Empowerment - People, regardless of age, type and level of disability have the right to make choices both with respect to daily routines and major life events.

Supports and Participation - Services and supports are shaped by the unique needs and preferences of each individual, and assure and enhance opportunities for integration in all aspects of life. Services are age-appropriate and premised on the fact that people with disabilities, continue to learn, change and develop throughout their lives. For children such growth is best accomplished within families, and for adults, within integrated communities, rather than institutions.

Independence - Advocacy services are based on a philosophy of equal access, peer support and self-determination to be achieved through individual, professional and system advocacy. Services are delivered in a manner that maximizes leadership, independence, productivity and integration of individuals with disabilities.

Cultural Competency - Advocacy services reflect, and are responsive to, the diverse cultural, ethnic and racial composition of society.

Activities of a P&A System include: Investigating, negotiating or mediating solutions to problems expressed by persons with disabilities eligible for P&A and CAP services;

- Providing information and technical assistance to individuals, attorneys, governmental agencies, services providers and other advocacy organizations;
- Providing legal counsel and litigation services to eligible persons and groups who satisfy the established priorities for the provision of services; and
- Providing education and training for their staff, governing boards, advisory councils, volunteers, service delivery professionals, constituency groups and the community.

In addition, P&A systems interact with elected and appointed officials to share information which will assist policy makers in making legislative and administrative changes which benefit persons with disabilities.

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NAPAS, is the voluntary national membership association of protection & advocacy systems and client assistance programs, assumes leadership in promoting and strengthening the role and performance of its members in providing quality legally based advocacy services. NAPAS has a vision of a society where people with disabilities exercise self-determination and choice and have equality of opportunity and full participation. NAPAS believes this vision will be realized through the enactment and vigorous enforcement of laws protecting civil and human rights.

NAPAS was created to: facilitate coordination of its members; represent the needs of members before federal agencies and Congress; and provide technical assistance and training to member agencies, which enhance their effectiveness on the state and local level.

NAPAS has daily contact with P&As and CAPs nationally and has provided training and technical assistance to its members since its inception. NAPAS' goals and activities are based on its understanding of the needs and capacities of the P&A/CAP network.

NAPAS is a non-profit membership organization chartered by the State of Florida in 1983. It is exempt from federal income taxes under section 501 (3) of the Internal Revenue Code.

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NATIONAL NETWORK OF UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES EDUCATION, RESEARCH, AND SERVICE.

The University Centers is a discretionary grant program providing for operational and administrative support to University Centers in the States as part of a national network to support interdisciplinary training, exemplary services, technical assistance, and information/dissemination activities.

The mission of University Centers is to serve as liaisons between academic expertise and institutions of higher learning and service delivery systems so as to positively affect the lives of individuals with developmental disabilities and their families by increasing their independence, productivity, and integration into communities.

The University Centers have evolved considerably during their history since 1963. Fifiield and Fifiield, in their 1995 historical survey of University Centers, consider their evolution to have occurred within three periods. The first period (1963-1974) emphasized the construction of institutions, closely associated with Universities, and predominantly serving persons with mental retardation, at which clinical services, diagnosis and treatment, and the training of personnel and centralized expertise were provided. The second period (1975-1986) emphasized community-based service, developmental concepts, providing services through a person's full life span, and emerging environmental concerns. This period included the expansion of the definition of developmental disabilities to include autism and learning disabilities. It also saw the creation of the three major components of the present developmental disabilities system: State Developmental Disabilities Planning Councils, Protection and Advocacy Agencies, and University Centers. The third period (1987 to present) has emphasized a consumer focus, as exemplified by the completion of an extensive national consumer satisfaction evaluation study ("The 1990 Report"), and brought the issues of consumer empowerment, independence and inclusion into major focus.

Currently, University Centers engage in four broad tasks: conducting interdisciplinary training, promoting exemplary community service programs, providing technical assistance at all levels from local service delivery to community and state governments, and conducting research and dissemination activities. UAPs provide community training and technical assistance to family and individual support service organizations, working with individuals with developmental disabilities, family members of these individuals, professionals, paraprofessionals, students, and volunteers. Direct exemplary service programs and the provision of training and technical assistance may include activities in the areas of family support, individual support, personal assistance services, clinical services, prevention services, health, education, vocational and other direct services. The University Centers continue to contribute to the development of new knowledge through research, development and field-testing of models, and the evaluation of existing as well as innovative practices.

Over the past decade, the network of University Centers has increased from 40 at the time of the 1987 reauthorization to its present total of 61, with 60 additional training initiative projects in the areas of early intervention, community services, positive behavioral supports, assistive technology, community transition, the Americans with Disabilities Act, aging, and special concerns. Fiscal year 1995 marked the completion of the legislative mandate that every State and Territory be served by at least one university affiliated program, and saw the addition of the Guam University Center. This expansion and development of new programs is concurrent with an increased impetus for excellence, accountability and involvement of consumers and consumer organizations.

Fiscal Year 1999 appropriations provided \$17,461,000 to support these activities.

This program is authorized under Part D of the Act.

LISTING OF UNIVERSITY CENTERS

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TECHNICAL ASSISTANCE ALLIANCE FOR PARENT CENTERS

What Is the Alliance?

The Technical Assistance Alliance for Parent Centers (the Alliance) is funded by the U.S. Department of Education, Office of Special Education Programs, to serve as the coordinating office for the Technical Assistance to Parent Projects beginning October 1, 1997. The Alliance is a new innovative project which focuses on providing technical assistance for establishing, developing, and coordinating Parent Training and Information Projects under the Individuals with Disabilities Education Act. The Alliance offers a variety of resources to assist the Parent Centers as they move into the 21st Century. This will further strengthen the Parent Centers' ability to effectively serve the families in their community whose children have disabilities.

What Are Parent Training and Information Centers?

Parent Training and Information Centers (PTIs) in each state provide training and information to parents of infants, toddlers, children, and youth with disabilities and professionals who work with children. This assistance helps parents to participate more effectively with professionals in meeting the educational needs of children and youth with disabilities.

How Will PTIs Benefit?

PTIs, will benefit from the following:

1. Computerized, user-friendly linkages with one another, including Web sites;
2. Increased opportunities to network and coalesce with one another around issues which impact children, students, and families in special education;
3. Opportunities to apply to be a center of expertise; and
4. Collaborative activities with larger constituencies in the public and private sectors, including businesses and direct access to teams of experts.

Who Is a Part of the Alliance?

The Alliance is a partnership comprised of a coordinating office located at PACER Center in Minnesota and four regional centers located in New Hampshire, Ohio, Texas, and California. Alliance partners are as follows:

Alliance Coordinating Office:

PACER Center

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Minneapolis, MN 55437-1044
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(952) 838-0190 TTY
(952) 838-0199 fax
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Director

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Sue Folger, TA Project Administrator

Dao Xiong, Multicultural Advisor

Jesús Villaseñor, Multicultural Advisor

Northeast Regional Center

Parent Information Center
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Concord, NH 03302-2405
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(603) 224-4365 fax
E-mail: picnh@aol.com
Judith Raskin, Regional Director
Lori Salvi, TA Coordinator
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TA Coordinator
Covering: CT, DE, DC, ME, MD, MA,
NH, NJ, NY, PA, PR, RI, VT, USVI

Midwest Regional Center

Ohio Coalition for the Education of
Children with Disabilities (OCECD)
Bank One Building
165 West Center Street, Suite 302
Marion, OH 43302-3741
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Dena Hook, TA Coordinator
Gloria Mitchell, Multicultural TA
Coordinator
Covering: CO, IL, IA, IN, KS, KY, MI,
MN, MO, NE, ND, OH, SD, WI

South Regional Center

Partners Resource Network, Inc.
1090 Longfellow Drive, Suite B
Beaumont, TX 77706-4819
(409) 898-4684 voice & TDD
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E-mail: path@partnerstx.org
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Coordinator
Covering: AL, AR, FL, GA, LA, MS,
NC, OK, SC, TN, TX, VA, WV

West Regional Center

Matrix Parent Network and Resource
Center
94 Galli Drive, Suite C
Novato, CA 94949
415-884-3535
415-884-3555 FAX
E-mail: matrix@matrixparents.org
Deidre Hayden, Regional Director
Nora Thompson, Technical
Assistance Coordinator
Patricia Valdez, Multicultural TA
Coordinator
Covering: AK, AZ, CA, Department
of Defense Dependent Schools, HI,
ID, MT, NV, NM, OR, Pacific
Jurisdiction, UT, WA, WY

How Will the Alliance Reach Its Goals?

The Alliance will achieve several of its goals by building the technological capacity of the parent centers. Over the next five years the Alliance will provide sufficient funds to insure that federally funded Parent Training and Information Centers and funded Community Parent Resource Centers have technology for on-line access. This network will provide a user-friendly, national communication network for the timely delivery and collection of information for PTIs.

Technical assistance information, training, and publications will cover a wide range of topics including management and education. Through annual needs assessments, the Alliance will address those topics which have merited the greatest attention from PTIs and will provide this information in a current and timely manner. The Alliance will develop standardized curricula that can be adapted by PTIs to meet the needs of families they serve and arrange for teams of experts to address priority topics from PTIs.

Networking and collaborating with a variety of multicultural, limited English proficiency, and literacy organizations will serve to increase cultural competency and accessibility in publications and technical assistance activities. Each regional center has a Multicultural Technical Assistance Coordinator. The staff will provide technical assistance that can readily and easily be accessed by the PTIs and Community Parent Resource Centers. The Alliance will establish a central translation service to assist centers in the translation of written materials. Each year, one of the topical institutes will focus on meeting the needs of multicultural populations.

What Is Scope of the Alliance?

The Alliance will establish collaborative relationships with national clearinghouses, regional resource centers, and national dissemination projects concerned with the education of youth with disabilities (e.g. NICHCY, ERIC, assistive technology projects) to identify strategies and best practices for working with parents, families, teachers, and schools. The Alliance will disseminate the information through collective activities including joint publication efforts, Web links, and conferences. In addition, the Alliance will establish collaborative activities between parent centers and stakeholders on the issues of systems change and school reform.

The Alliance has joined forces with several representatives from the business and media communities. These collaborations will assist parent centers in building relationships with representatives of the business community. These leaders are willing to share their expertise in order to help parent centers cultivate needed technology, media, public relations, administrative, management, and fiscal skills.

Federally Funded Parent Projects:



Alabama

Special Education Action
Committee Inc.
Carol Blades, Director
P.O. Box 161274
Mobile, AL 36616-2274
334-478-1208 Voice &
TDD
334-473-7877 FAX
1-800-222-7322 AL only
seacofmobile@zebra.net
[home.hiwaay.net/~seachs
v/](http://home.hiwaay.net/~seachs/v/)

Alaska

PARENTS, Inc.
Faye Nieto
4743 E. Northern Lights
Blvd.
Anchorage, AK 99508
907-337-7678 Voice
907-337-7629 TDD
907-337-7671 FAX
1-800-478-7678 in AK
parents@parentsinc.org
www.parentsinc.org

American Samoa

American Samoa PAVE
Fa' Anati Penitusi
P.O. Box 6844
Pago Pago, AS 96799
011-684-699-6946
011-684-699-6952 FAX
[SAMPAVE@samoatelco.c
om](mailto:SAMPAVE@samoatelco.com)
[www.taalliance.org/ptis/am
samoa/](http://www.taalliance.org/ptis/am
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Arizona

Pilot Parents of Southern
Arizona
Lynn Kallis
2600 North Wyatt Drive
Tucson, AZ 85712
520-324-3150
520-324-3152
ppsa@pilotparents.org
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Southern AZ

Arizona

RAISING Special Kids
Marta Urbina
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Hwy, Suite 101
Phoenix, AZ 85017-3621

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TDD
602-242-4306 FAX
1-800-237-3007 in AZ
Central and Northern AZ
[raisingspecialk1@qwest.n
et](mailto:raisingspecialk1@qwest.net)

Arkansas

Arkansas Disability
Coalition
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1605
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TDD
501-614-9082 FAX
1-800-223-1330 AR only
adc@alltel.net
www.adcpti.org
Statewide
With FOCUS AR

Arkansas

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Ramona Hodges
305 West Jefferson Ave.
Jonesboro, AR 72401
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870-931-3755 FAX
888-247-3755
focusinc@ipa.net
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California

DREDF
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Berkeley, CA 94710
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510-841-8645 FAX
1-800-466-4232
dredf@dredf.org
www.dredf.org
Northern California
With Parents Helping
Parents, Santa Clara

California

Exceptional Family
Support, Education and
Advocacy Center
Debbie Rowell

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Paradise, CA 95969
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Fresno, CA 93726
559-229-2000
559-229-2956 FAX
epu1@cybergate.com
[www.exceptionalparents.o
rg](http://www.exceptionalparents.org)
Central California

California (CPRC)

Loving Your Disabled
Child
Theresa Cooper
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Los Angeles, CA 90043
323-299-2925
323-299-4373 FAX
lydc@pacbell.net

www.lydc.org
Most of LA County

California

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Northern California
With Parents Helping
parents, Santa Clara

California

Parents Helping Parents of
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2416
415-841-8820
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Nine counties in the San Francisco Bay area

California

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408-727-5775 Voice / 408-727-7655 TDD
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Northern California
With Matrix and DREDF

California (CPRC)

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With Loving Your Disabled Child

California

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Juno Duenas
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Southern California

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California (CPRC)

Vietnamese Parents of Disabled Children Assoc., Inc. (VPDCA)
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With Loving Your Disabled Child

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719-531-9400 voice / 719-531-9403 TDD
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1-800-284-0251
info@peakparent.org
www.peakparent.org

Connecticut

Connecticut Parent Advocacy Center
Nancy Prescott
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860-739-7460 FAX (Call first to dedicate line)
1-800-445-2722 in CT
cpacinc@aol.com
members.aol.com/cpacinc/cpac.htm

Delaware

Parent Information Center of Delaware (PIC/DE)
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366-0178 (TDD)
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picofdel@picofdel.org
www.picofdel.org

District of Columbia

Advocates for Justice and Education
Bethann West
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www.aje.gpg.com/
District of Columbia

Florida

Family Network on Disabilities
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1-800-825-5736 FL only
fnd@fndfl.org
fndfl.org

Florida (CPRC)

Parent to Parent of Miami, Inc.
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Georgia

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Hawaii

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dotty@hawaii.edu;
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Idaho

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ipul@rmci.net
home.rmci.net/ipul

Idaho

Native American Parent
Training and Information
Center
Chris Curry & Susan
Banks
129 East Third
Moscow, ID 83843
208-885-3500
208-885-3628 FAX
famtog@moscow.com
Nation-wide resource for
Native American families,

tribes, and communities as
well as parent centers and
others needing information
on this subject.

Illinois

Designs for Change
Donald Moore
29 East Madison, Suite 95
Chicago, IL 60602
312-236-7252 voice / 312-
857-1013 TDD
312-857-9299 FAX
markse@designsforchange.org
www.dfc1.org

Illinois

Family Resource Center
on Disabilities
Charlotte Des Jardins
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Room 300
Chicago, IL 60604
312-939-3513 voice / 312-
939-3519 TTY & TDY
312-939-7297 FAX
1-800-952-4199 IL only
frcdptiil@ameritech.net
www.ameritech.net/users/frcdptiil/index.html

Illinois

Family T.I.E.S. Network
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830 South Spring
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217-544-6018 FAX
1-800-865-7842
ftiesn@aol.com
www.taalliance.org/ptis/fties/

Illinois

National Center for Latinos
with Disabilities
Everado Franco
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Chicago, IL 60608
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666-1788 TTY
312-666-1787 FAX
1-800-532-3393
ncld@ncld.com
homepage.interaccess.com/~ncld/

Indiana

IN*SOURCE
Richard Burden
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219-234-7101
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219-234-7279 FAX
1-800-332-4433 in IN
insourc1@aol.com
www.insource.org

Iowa

Access for Special Kids
(ASK)
Jule Reynolds
321 E. 6th St
Des Moines, IA 50309
515-243-1713
515-243-1902 FAX
1-800-450-8667
ptiowa@aol.com
www.taalliance.org/ptis/ia/

Kansas (CPRC)

Families ACT
Nina Lomely-Baker
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Wichita, KS 67203
316-685-1821
316-685-0768 FAX
nina@mhasck.org
www.mhasck.org
Sedgwick County and
Outlying area

Kansas

Families Together, Inc.
Connie Zienkewicz
3340 W Douglas, Ste 102
Wichita, KS 67203
316-945-7747
316-945-7795 FAX
1-888-815-6364
fmin@southwind.net
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Kentucky

Special Parent
Involvement Network
(SPIN)
Paulette Logsdon
2210 Goldsmith Lane,
Suite 118
Louisville, KY 40218-1038
502-456-0923
502-456-0893 FAX

1-800-525-7746
spininc@aol.com

Kentucky

FIND of Louisville
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502-584-1261 FAX
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Louisiana (CPRC)

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Louisiana

Project PROMPT
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504-888-0246 FAX
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[fhfno@ix.netcom.com](mailto:fhfqno@ix.netcom.com)
www.projectprompt.com

Maine

Special Needs Parent Info
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Janice LaChance
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207-582-3638 FAX
1-800-870-7746
jlachance@mpf.org
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Maryland

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Massachusetts

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Richard Robison
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Massachusetts

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Michigan

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info-cause@voyager.net
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Michigan

Parents Training Parents
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Southfield, MI 48075-3745

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248-557-4456 FAX
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ucp@ameritech.net
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Wayne County

Minnesota

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pacer@pacer.org
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Mississippi

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arcpti@parentpartners.org
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Mississippi (CPRC)

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1-800-337-4852
empower@tecinfo.com

Missouri

Missouri Parents Act
(MPACT)
Janet Jacoby, Executive
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302
Kansas City, MO 64111
1-816-531-7070
1-816-531-4777 fax
1-800-743-7634
ptijci@aol.com
www.crn.org/mpact/

Montana

Parents Let's Unite for
Kids
Dennis Moore
516 N. 32nd Street
Billings, MT 59101
406-255-0540
406-255-0523 FAX
1-800-222-7585 in MT
plukinfo@pluk.org
www.pluk.org

Nebraska

Nebraska Parents Center
Glenda Davis
1941 South 42nd St., #122
Omaha, NE 68105-2942
402-346-0525 Voice &
TDD
402-346-5253 FAX
1-800-284-8520
gdavis@neparentcenter.org
www.neparentcenter.org

Nevada

Nevada Parents
Encouraging Parents
(PEP)
Karen Taycher
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702-388-8899
702-388-2966 FAX
1-800-216-5188
nvpep@vegas.infi.net
www.nvpep.org

New Hampshire

Parent Information Center
Judith Raskin
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Concord, NH 03302-2405
603-224-7005 (Voice &
TDD)
603-224-4379 FAX
1-800-232-0986 in NH
picnh@aol.com
www.parentinformationcenter.org

New Jersey

Statewide Parent
Advocacy Network (SPAN)
Diana MTK Autin
35 Halsey Street, 4th Floor
Newark, NJ 07102
973-642-8100
973-642-8080 FAX
1-800-654-SPAN
span@spannj.org
www.spannj.org

New Mexico

Parents Reaching Out,
Project ADOBE
Larry Fuller
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Los Lunas, NM 87031
505-865-3700 Voice &
TDD
505-865-3737 FAX
1-800-524-5176 in NM
nmproth@aol.com
www.parentsreachingout.org

New Mexico

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New York

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advocacy@frontiernet.net
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Statewide except for NY
city.

New York

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212-947-9779
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aespada@advocatesforchildren.org
www.advocatesforchildren.org
Five boroughs of New
York City

New York

Resources for Children
with Special Needs, Inc.
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New York, NY 10003
212-677-4650
212-254-4070 FAX
info@resourcesnyc.org
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New York City (Bronx,
Brooklyn, Manhattan,
Queens, Staten Island)

New York

Sinergia/Metropolitan
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Director
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212-496-5608 FAX
dalsinergia@worldnet.att.net
www.sinergiany.org
New York City

New York (CPRC)

United We Stand
Lourdes Revera-Putz
312 South 3rd Street
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718-302-4315 FAX
uwsofny@aol.com
www.taalliance.org/ptis/uw/s/

North Carolina

ECAC, Inc.
Connie Hawkins
P.O. Box 16
Davidson, NC 28036
704-892-1321
704-892-5028 FAX
1-800-962-6817 NC only
ECAC1@aol.com
www.ecac-parentcenter.org/

North Dakota

ND Pathfinder Parent
Training And Information
Center
Kathryn Erickson
Arrowhead Shopping
Center
1600 2nd Ave. SW, Suite
19
Minot, ND 58701-3459
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837-7501 TDD
701-837-7548 FAX
1-800-245-5840 ND only
ndpath01@minot.ndak.net
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Ohio

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Ohio

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165 West Center St., Suite
302
Marion, OH 43302-3741
740-382-5452 Voice &
TDD
740-383-6421 FAX
1-800-374-2806

ocecd@gte.net
www.taalliance.org/PTIs/re/gohio/

Oklahoma

Oklahoma Parents Center,
Inc.
Sharon Bishop
4600 Southeast 29th
Street, Suite 115
Del City, OK 73115-4224
405-619-0500
405-670-0776 FAX
1-877-553-IDEA
okparentctr@aol.com

Oregon

Oregon COPE Project
Anne Brown
999 Locust St. NE
Salem, OR 97303
503-581-8156 Voice &
TDD
503-391-0429 FAX
1-888-505-COPE
orcope@open.org
www.open.org/~orcope

Pennsylvania (CPRC)

Hispanos Unidos para
Niños Excepcionales
(Hispanics United for
Exceptional Children)
Liz Hernandez
Buena Vista Plaza
166 W. Lehigh Ave., Suite
101
Philadelphia, PA 19133-
3838
215-425-6203
215-425-6204 FAX
nuneinc@aol.com
City of Philadelphia,
occasional service to
surrounding counties

Pennsylvania

Parent Education Network
Louise Thieme
2107 Industrial Hwy
York, PA 17402-2223
717-600-0100 Voice &
TTY
717-600-8101 FAX
1-800-522-5827 in PA
1-800-441-5028 (Spanish
in PA)

pen@parentednet.org
www.parentednet.org

Pennsylvania

The Mentor Parent
Program
Gail Walker
P.O. Box 47
Pittsfield, PA 16340
814-563-3470
814-563-3445 FAX
gwalker@westpa.net

Puerto Rico

APNI
Carmen Sellés de Vilá
P.O. Box 21280
Ponce de Leon 724
San Juan, PR 00928-1301
787-763-4665
787-765-0345 FAX
1-800-981-8492
1-800-949-4232
apnpr@prtc.net
Island of Puerto Rico

Rhode Island

RI Parent Information
Network
Cheryl Collins
175 Main Street
Pawtucket, RI 02860
401-727-4144 voice / 401-
727-4151 TDD
401-727-4040 FAX
1-800-464-3399 in RI
collins@ripin.org
<http://www.ripin.org/>

South Carolina (CPRC)

Parent Training &
Resource Center
Beverly McCarty
c/o Family Resource
Center
135 Rutledge Ave., PO
Box 250567
Charleston, SC 29425
843-876-1519
843-876-1518 FAX
mccartyb@musc.edu
Tri-county: Charleston,
Berkeley, and Dorchester

South Carolina

PRO-PARENTS
Mary Eaddy
2712 Middleburg Drive,

Suite 203
Columbia, SC 29204
803-779-3859 Voice
803-252-4513 FAX
1-800-759-4776 in SC
proparents@aol.com
community.columbiatoday.com/realcities/proparents

South Dakota

South Dakota Parent Connection
Bev Petersen
3701 West 49th St., Suite 200B
Sioux Falls, SD 57106
605-361-3171 Voice & TDD
605-361-2928 FAX
1-800-640-4553 in SD
bpete@sdparent.org
www.sdparent.org

Tennessee

Support and Training for Exceptional Parents, Inc. (STEP)
Nancy Diehl
424 E. Bernard Ave., Suite 3
Greeneville, TN 37745
423-639-0125 voice / 636-8217 TDD
423-636-8217 FAX
1-800-280-STEP in TN
tnstep@aol.com
www.tnstep.org

Texas (CPRC)

El Valle Community Parent Resource Center
Laura Reagan
530 South Texas Blvd, Suite J
Weslaco, TX 78596
956-969-3611
956-969-8761 FAX
1-800-680-0255 TX only
texasfiestaedu@acnet.net
www.tfepoder.org
Cameron, Willacy, & Starr Counties.

Texas (CPRC)

The Arc of Texas in the Rio Grande Valley
Parents Supporting Parents Network

Larry Zuniga
601 N Texas Blvd
Weslaco, TX 78596
956-447-8408
956-973-9503 FAX
1-888-857-8688
lzuniga@earthlink.net
www.thearcoftexas.org

Texas

Partners Resource Network Inc.
Janice Meyer
1090 Longfellow Drive, Suite B
Beaumont, TX 77706-4819
409-898-4684 Voice & TDD
409-898-4869 FAX
1-800-866-4726 in TX
txprn@pnx.com
www.PartnersTX.org

Texas

Project PODER
Yvette Hinojosa
1017 N. Main Ave., Suite 207
San Antonio, TX 78212
210-222-2637
210-475-9283 FAX
1-800-682-9747 TX only
poder@tfepoder.org
www.tfepoder.org
San Antonio, Hondo, & Castroville. Cameron, Hidalgo, Willacy, & Starr Counties.

Utah

Utah Parent Center
Helen Post
2290 East 4500 S., Suite 110
Salt Lake City, UT 84117-4428
801-272-1051
801-272-8907 FAX
1-800-468-1160 in UT
upc@inconnect.com
www.utahparentcenter.org

Vermont

Vermont Parent Information Center
Connie Curtin
1 Mill Street, Suite A7

Burlington, VT 05401
802-658-5315 Voice & TDD
802-658-5395 FAX
1-800-639-7170 in VT
vpic@together.net
homepages.together.net/~vpic

Virgin Islands

V.I. FIND
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St. Thomas, US VI 00802
340-774-1662
340-774-1662 FAX
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www.taalliance.org/ptis/vifind/
Virgin Islands

Virginia (CPRC)

PADDA, Inc.
Mark Jacob
813 Forrest Drive, Suite 3
Newport News, VA 23606
757-591-9119
757-591-8990 FAX
1-888-337-2332
webmaster@padda.org
www.padda.org

Virginia

Parent Educational Advocacy Training Center
Cheri Takemoto
6320 Augusta Drive
Springfield, VA 22150
703-923-0010
703-923-0030 FAX
1-800-869-6782 VA only
partners@peatc.org
www.peatc.org

Washington (CPRC)

Parent to Parent Power
1118 S 142nd St.
Tacoma, WA 98444
253-531-2022
253-538-1126 FAX
yvone_link@yahoo.com

Washington

PAVE/STOMP
Heather Hebdon
6316 South 12th St., Suite B
Tacoma, WA 98465

253-565-2266 Voice &
TTY
253-566-8052 FAX
1-800-572-7368
hhebdon@washingtonpave.org
washingtonpave.org
U.S. Military installations;
and as a resource for
parent centers and others
needing information on
this subject.

Washington

Washington PAVE
Joanne Butts
6316 South 12th St., Suite
B
Tacoma, WA 98465-1900
253-565-2266 (Voice &
TDD)
253-566-8052 FAX
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West Virginia

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Clarksburg, WV 26301
304-624-1436 Voice &
TTY
304-624-1438
1-800-281-1436 in WV
wvpti@aol.com
www.iolinc.net/wvpti

Wisconsin

Native American Family
Empowerment Center
Don Rosin
Great Lakes Inter-Tribal
Council, Inc.
2932 Highway 47N, P.O.
Box 9
Lac du Flambeau, WI
54538
715-588-3324
715-588-7900
1-800-472-7207 (WI only)
drosin@newnorth.net

Wisconsin

Parent Education Project
of Wisconsin

S. Patrice Colletti, SDS
2192 South 60th Street
West Allis, WI 53219-1568
414-328-5520 Voice / 414-
328-5525 TDD
414-328-5530
1-800-231-8382 (WI only)
PMColletti@aol.com
members.aol.com/pepofwi/

Wisconsin (CPRC)

Wisconsin Family
Assistance Center for
Education, Training and
Support
Janis M. Serak
2714 North Dr. Martin
Luther King Dr., Suite E
Milwaukee, WI 53212
414-374-4645 / 414-374-
4635 TTD
414-374-4655 FAX
wifacets@execpc.com

Wyoming

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5 North Lobban
Buffalo, WY 82834
307-684-2277 Voice &
TDD
307-684-5314
1-800-660-9742 WY only
tdawsonpic@vcn.com
www.wpic.org

**(CPRC)=Community
Parent Resource Center**



NICHCY

The NICHCY State Resource Sheet for your state will help you locate organizations and agencies within your state that address disability-related issues. Included on NICHCY state sheets are:

- state senators
- state governors
- state agencies serving children and youth with disabilities
- state chapters of disability organizations and parent groups
- parent training and information projects

These state level agencies and organizations can often refer you to local sources of information and assistance. Some state departments of education serving general and special education have web sites. The [National Association of State Boards of Education \(NASBE\)](#) provides links to sites.

NICHCY updates these State Resource Sheets regularly; however, the addresses and telephone numbers of these groups are constantly changing. If you find that an address or number has changed or is incorrect, please e-mail us at nichcy@aed.org and let us know. Your contribution to helping keep our State Resource Sheets current will be greatly appreciated by all who use them!

About NICHCY

NICHCY is the national information and referral center that provides information on disabilities and disability-related issues for families, educators, and other professionals. Our special focus is children and youth (birth to age 22).

[Hablamos español.](#)

NICHCY provides information
and makes referrals in areas related to:

Specific disabilities
Early intervention
Special education and related services
Individualized education programs
Family issues
Disability organizations
Professional associations
Education rights
Transition to adult life, and much, much more!

NICHCY's Services Include:

Personal Responses to Your Specific Questions--

Our information specialists are available to speak with you about your area of interest or concern. Call us at **1-800-695-0285**, or e-mail nichcy@aed.org.

NICHCY Publications--

NICHCY makes available a wide variety of [publications](#), including fact sheets on specific disabilities, state resource sheets, parent guides, bibliographies, and our issue papers, "News Digest" and "Transition Summary." Most publications can be printed off the Internet. You may also request documents in print. Our publications are also available in alternative formats upon request.

Referrals to Other Organizations and Sources of Help--

We can put you in touch with [disability organizations](#), parent groups, and professional associations at the state and national level.

Information Searches of Our Databases and Library--

We can provide an information search to your unique needs and concerns.

Materials are also available in [Spanish](#), on disk, and as camera-ready originals.

Contact NICHCY

NICHCY
P.O. Box 1492
Washington, DC 20013
1-800-695-0285

If you have any remarks, suggestions, or corrections regarding the material that NICHCY has made available at this Web site, please send them to nichcy@aed.org.

The Central Directory of Resources

The Central Directory of Resources is a computerized database of agencies, organizations, services, and literature relevant to families of children with special needs living in North Carolina. Caring and knowledgeable Resource Specialists know the ins-and-outs of services and supports for children with special needs and their families. They take the time to identify each caller's needs and refer them to resources in their community or at the state or national level. One of our Resource Specialists is fluent in Spanish.

Our database houses information on developmental disabilities, physical disabilities, chronic illness, and rare diseases. This information is cross-referenced by county, so that when a parent or professional calls, we can let them know about resources that are available in their area. As well as providing information about services and resources by phone, we have family-friendly printed information that we mail to callers. We have literature on specific diagnoses and disabilities, transitioning between services, and parenting concerns along with other topics. Information is mailed to callers free of charge.

The Individuals with Disabilities Education Act, or [IDEA](#) requires that each state provide a Central Directory of Resources on public and private early intervention services and resources available in the state. Family Support Network provides this service for North Carolina. See our [Mandates](#) to learn more.

The Central Directory in your state should be a good resource for locating services and support in your area. We are currently developing a listing of the various state CDR's and plan to have it online by Spring 2001.

The National Information Center for Children and Youth with Disabilities (NICHCY) provides [resource sheets](#) for all 50 states (as well as Puerto Rico and the Virgin Islands) listing disability-related public agencies.

National organizations that provide information, support and advocacy on issues related to disabilities or chronic illness can be accessed by [searching the Central Directory of Resources](#) or by visiting our [links](#) page.

You may obtain a list of the Central Directory of Resources from

NICHCY
P.O. Box 1492
Washington, DC 20013
1-800-695-0285

Speak Up! Guide

5: Self-Advocacy and Self-Determination

Published by:
STIR – Steps Toward Independence and Responsibility
and
Shifting the Power,
projects of the
Clinical Center for the Study of Development and Learning, UNC-CH
For further information please call Rebekah Pennell at (919) 966-5171.

Speak Up! Guide

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SELF-ADVOCACY DEFINED...

Self-advocacy is having the opportunity to know your rights and responsibilities stand up for them, and make choices about your own life. Self-advocacy allows people with disabilities to **speak out for themselves**. By doing these things, the quality of life for people with disabilities is vastly improved.

The self-advocacy movement began in Sweden in the 1960's when a group of people with mental retardation drew up a list of requests about how they wanted services delivered and what they wanted from their service providers. Back then; what these pioneers did was a novel idea, but not any more. Now, this idea has taken the shape of an international civil rights movement by and for people with developmental disabilities.

The self-advocacy movement is closely related to the self-determination movement. The self-advocacy movement emphasizes self-advocates speaking out for themselves and learning about their rights and responsibilities. The self-determination movement also does these things, plus it focuses on the important components of system changes, legislation, policy, etc.

RESOURCES FOR FINDING OUT MORE ABOUT SELF-ADVOCACY...

- ◆ <http://www.self-advocate.org>
- ◆ <http://web.syr.edu/~thechp/moretho.htm>
- ◆ <http://www.customcpu.com/np/alaskapf/default.htm>
- ◆ <http://thearc.org/misc/sadescr.html>
- ◆ http://cnet.unb.ca/cap/partners/chsptf/bc_advocacy.html
- ◆ <http://www.wf.net/~thearc/people.html>
- ◆ http://www.villagelife.org/news/archives/11-4-97_selfadvocacy.html
- ◆ <http://web.syr.edu/~thechp/samoveta.htm>
- ◆ <http://thearc.org/posits/selfadv.html>
- ◆ <http://thearc.org/misc/sabib.html>
- ◆ <http://www.ohsu.edu/selfdetermination/proclamation.shtml>
- ◆ <http://www.nami.org/youth/selfadv.htm>
- ◆ http://cnet.unb.ca/cap/partners/chsptf/bc_advocacy.html
- ◆ <http://www.people1st.net/>

SELF-ADVOCACY: WHAT IT IS...

SELF-ADVOCACY IS...

People speaking-up for the things that they see as important for themselves

Informed individuals expressing themselves

Something everyone is capable of

Here to stay, Change

A Revolution

People taking control over their own lives...for their decisions and also for the consequences

A process

A way of life

An inclusive, ALL encompassing, on-going learning experience for everyone involved

Creating a new "System" (we won't do it the same anymore...the "old way" stunk!)

Acknowledging anger and working it through

The means...a tool or vehicle for change

Learning to trust

Taking risks

Going after your dreams

Making mistakes...and learning from them

Asking questions

...WHAT IT ISN'T

SELF-ADVOCACY IS NOT...

People sitting around and complaining

A token way for an agency to say that it "includes" the people it offers services to

Only for a select group

A fad

Stagnation

A Revolt

A program for John to make an independent choice for 3 out of 4 consecutive trials of success

A product

An activity

A skills training class to meet a GSP goal

Turning "The System" upside down (i.e.: "we'll do to them what they've always done to us!")

Staying angry

The end

Living in fear

Passive

Living in a padded room

Sleeping through your dreams (or having a recurring nightmare!)

Playing it safe

Being questioned

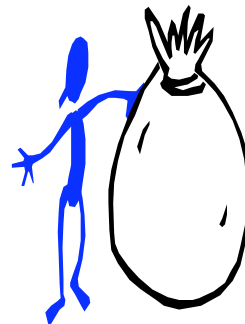
SACK OF DREAMS

What is **one** of your future goals (one dream)?

- ❖ Put your face and your dream on the outside of a paper sack
- ❖ Write and or use index cards to draw some answers to these questions. Put them in the sack:

- 1) What are your strengths? What are you good at?
- 2) Who are some friends you know will be able to help you reach your dream?
- 3) Who do you get support from (an agency and/or staff people)?
- 4) What are your “resources” – i.e.: how much of a budget do you have?
- 5) What is available in the community? (Groups you could connect with, free things that agencies might offer, public meetings, special classes, etc., etc.)

As questions arise about making your dream come true, think about how you can answer them with the resources in your sack.



AN “ABOUT ME” BOX

Have you ever been frustrated because you wanted to say something, tell a friend about your recent vacation, or describe how you felt when you heard a new song, but you couldn't put it all into words? This activity will help.

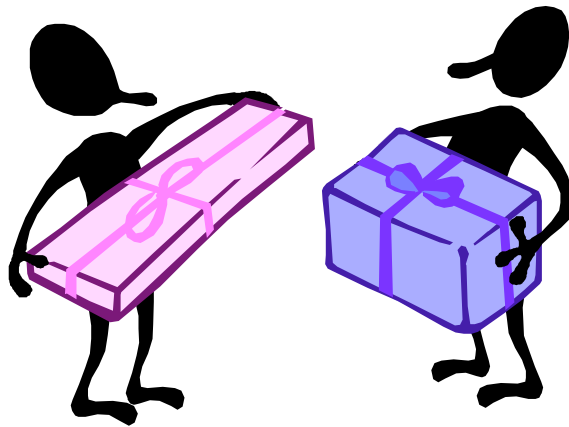
Someone once said that a picture is worth a thousand words. For this exercise, you will use pictures, objects, and other things to tell people about yourself. Follow the steps below.

(1) MAKE YOUR BOX:

Decorate the container of your choice in a way that tells others something about you. Be creative! You can use different containers (a plant pot, a Kentucky Fried Chicken Bucket, a beach bucket, a shoe box with comic strips on it, etc.).

(2) FILL YOUR BOX:

Pick different things that answer the questions below. These can include objects, pictures, music, food, aromas, things that have a certain texture, things that feel a certain way, like sand paper being scratchy and cotton being soft, and more!



QUESTIONS TO ANSWER:

**Use this sheet to take notes on your answers if you need to.
Get a friend to help you write things down if you want – or you can draw pictures!**

(1) Who is your family?

(2) Who are your friends?

(3) Where do you spend your time during the day (work, volunteer, at home, etc.)?

(4) Where do you live?

(5) What is one thing you are good at – or one thing you are proud you have done?

(6) What do you dream about doing / want to do one day??

REMEMBER: THERE ARE NO WRONG ANSWERS!!!

CHEAT SHEET!!

Confused?? Here are some examples to help

- a family photo “talks” about your family
- a card from a friend “talks” about your friend
- a coffee mug from the restaurant where you work “talks” about your job
- a house key “talks” about your apartment
- a trophy, medal or newspaper story written about you “talks” about something you’re proud of
- a bag of play money “talks” about your dream of getting a good job one day that pays well

Thanks to the following people for helping develop “About Me Boxes”:
Lynda Kahn, Deb Griffin Knew, Jo Krippenstapel, Tim LaFazia,
Doreen McConaghy, Angela Semonelli & Carol Wilson

SELF-DETERMINATION DEFINED...

Ultimately, self-determination means that people with disabilities will be in charge of their own services and in control of money to make their desires and dreams real. Self-determination involves people with disabilities claiming their basic civil rights including all of the freedoms guaranteed by our Constitution and Bill of Rights. Self-determination is the freedom to make individual choices about one's own life and the opportunity to fail, just like any other person. In order to achieve these goals, there will have to be major changes in social attitudes and policy. Self-determination is going to require a lot of very hard work and a collaborative effort among *all* people with disabilities and advocacy groups.

Some thoughts from Ellen Cummings (a national consultant on Self-Determination)... "One of the most important things about self-determination is its power shift. Self-determination without the ability to control the resources is fantasy, and that's what makes self-determination different from anything else we have done." Self-determination means that people have authority over how, where, and with whom their lives will be lived. It means that people have control of the resources needed for their support and responsibility for their decisions and actions.

Self-determination refers to "acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference" (Wehmeyer, 1994).

RESOURCES FOR FINDING OUT MORE ABOUT SELF-DETERMINATION...

- ◆ <http://www.self-advocate.org>
- ◆ <http://www.self-determination.org/>
- ◆ <http://www.rwjf.org/>
- ◆ <http://www.uncc.edu/sdsp/>
- ◆ <http://www.libertynet.org/>
- ◆ <http://www.pbrookes.com>
- ◆ <http://www.iod.unh.edu/projects/rwj.htm>
- ◆ <http://www.ohsu.org/selfdetermination/index.shtml>
- ◆ <http://www.ohsu.edu/selfdetermination/natcent.shtml>
- ◆ <http://www.napanet.net/business/personal/ASA/selfdetermine.html>
- ◆ <http://www.mcare.net/overview.html>
- ◆ <http://www.mcare.net/beyond.html>
- ◆ <http://www.thearc.org>
- ◆ <http://www.rfgeen.com/sdsp/right.htm>
- ◆ <http://www.state.nh.us/sdp/princ.html>
- ◆ <http://www.vcu.edu/rrtcweb/sec/feb5.html>
- ◆ http://www.libertynet.org/speakng/learning_p.html
- ◆ <http://www.ohsu.edu/selfdetermination/selfdet.shtml>
- ◆ <http://www.ohsu.edu/selfdetermination/alliance.shtml>
- ◆ <http://www.aamr.org/ShapingOurDestiny/ProviderGuide.html>

WHAT IS SELF-DETERMINATION?

Self-Determination: what a complex word to explain such a basic concept.

Across the country, the idea of self-determination is changing the way people with developmental disabilities live their lives. It also spells change for how public services are designed and delivered to meet these individuals' needs. In North Carolina, four projects are demonstrating how this idea can be put to work to change people's lives. Meanwhile interest is growing across the state among self-advocates and parents to make self-determination work statewide.

It can be as simple as being able to choose extra sauce on your pizza or as complex as choosing to live in your own apartment with the services and supports you need.

Self-determination simply is the freedom and right to make choices about one's life, the same choices that people without disabilities take for granted. People with disabilities deserve the right to determine what services and supports they need, and who will provide them. How and when they use their resources are decisions that people with disabilities should have the power to make.

The constitution of the United States guarantees to all citizens: the right to life, liberty and the pursuit of happiness. Without self-determination those rights are taken away.

Today self-determination is just a dream for most people with disabilities. Decisions are made for them; where and with whom they will live, where and when they will work, when to get up and when to go to bed, what time of day to take their shower or bath are usually the decisions someone makes for them. When you are part of a group the groups needs come before the individual's.

Sheltered workshops and group homes were considered innovative ideas in their time, however today they are outdated and provide little or no opportunity for individuals to fulfill their dreams for life. How long could you work in the same room or building with little or no access to the real world? Would you be happy performing the same job day after day? Could you enjoy a job that you did not choose, but one that the system chose for you?

How would you like to live in a home with a group of people you did not choose to live with, or eat from a menu that was prepared by a stranger who did not take into consideration your likes and dislikes? Do you really think that people who live in-group homes all want to go see the same movie or all want to go bowling on the third Saturday of the month? If given the opportunity to decide what they would like to do, each one might have a different idea of what would be fun to do that day.

We seem to have a great misconception that if someone does not look like us, they are somehow different. That idea is far from the truth. A person's ability to walk does not affect their ability to think. Many people who have physical limitations when given the chance to learn and communicate their dreams successfully fulfill those dreams. They are able to work in the community, attend social functions, and receive an education to the best of their abilities.

Citizens with limited cognitive abilities also have dreams the same as you and I. They want to live in a loving, supportive, family environment. They deserve the right to work at a job that they enjoy and chose, not a job that was picked for them. Even taking part in deciding where they would like to go for a vacation is self-determination.

There is an ever-growing cry from people with disabilities and their families to gain the control of their lives that we take for granted. People with disabilities need and want to be contributing members of our communities.

No one is independent of others. We are all interdependent. Utility companies provide our electricity, water, and phone services. The media provides us the news. We rely on farmers to grow the food we eat and sanitary workers to take away our leftover trash. We rely on friends and family in times of crisis. Our neighbors come to our aid when they see we are in need of help.

Every one of us has different abilities and interests. Some of us require help in accomplishing daily tasks that others take for granted. People with disabilities are part of our system already, and contribute a great deal to our lives through their participation in our work places, communities, and families. More individuals want that chance!

We all have dreams for our future. People with disabilities have those same dreams and are willing to work towards their goals just like you and I. Yes people young or old with disabilities do want control of their lives.

Self-Determination is just a simple concept, the basic right to fulfill one's dream for their future. Please help us make it a reality for all people.

Written By
Rosemary Livingston Bernauer
For my son Andrew and people with disabilities everywhere

FACT SHEET: SUMMARY OF SELF-DETERMINATION

What Self-Determination Is and What it Is Not

- ✂ Self-Determination is NOT a model or a program with a predetermined menu of available services and a set way of delivering them.
- ✂ Self-Determination IS a process that differs from person to person according to what each individual determines is necessary and desirable to create a satisfying and personally meaningful life. Persons with disabilities no longer have to receive services as determined by the traditional model. They are free to “order off the menu,” including those services they desire to be provided in ways that meet their needs.
- ✂ Self-Determination is both person-centered and person-directed. It acknowledges the rights of people with disabilities to take charge of and responsibility for their lives. In Self-Determination, the individual, not the service system, decides where he or she will live, and with whom; what type of services he or she requires, and who will provide them; how he or she will spend his or her time, which may include the type of vocational or educational opportunities he or she wishes to engage in, and how he or she will relate to the community, which may include joining in community events, taking part in civic groups, and developing and maintaining relationships with others in the community.

The Principles of Self-Determination

- ☆ Freedom – The ability for an individual together with freely chosen family and friends to plan a life with necessary support rather than purchase a program.
- ☆ Authority – The ability for a person with a disability (with a social support network or circle if needed) to control a certain sum of dollars in order to purchase services.
- ☆ Autonomy – The arranging of resources and personnel—both formal and informal—that will assist an individual with a disability to live a life in the community rich in community affiliations.
- ☆ Responsibility – The acceptance of a valued role in a person’s community through competitive employment, organizational affiliations, spiritual development, and general caring of others in the community, as well as accountability for spending public dollars in ways that are life enhancing for persons with disabilities.

PRINCIPLES OF SELF-DETERMINATION

People with developmental disabilities have:

FREEDOM

The *freedom* to develop a personal life plan.

People with developmental disabilities have the freedom to make life decisions. Self-Determination recognizes that this is an ongoing and dynamic process. The work of those committed to persons with disabilities is to assist the individual when she or he needs assistance in exercising this right.

THIS MEANS

You must plan your own life. Your plans must fit your budget. If you want to change your plan, you can do it. You can do the things you want to do, but you must know what you want to do and when you want to do it.

Different people make different choices. Some people choose to have an apartment of their own. Others choose roommates. Some buy houses or condos to live in. Other people get married and find their own apartment. Some people get vans and adapt them for their disability. People can shop where they like. They can buy and wear their style of clothes. They can buy the food they enjoy and go out to eat when they want as long as it all fits in their budget. They can find a good job, and hire the people they like to help them when they need help.

AUTHORITY

The *authority* to control a targeted amount of resources.

The resources are under the control of the individual and freely chosen family members and friends. This means that the resources are portable. They can be re-configured; priorities can be changed and the dollars follow the individual as his or her priorities change. Public dollars are used wisely to buy supports and services the person wants and needs.

THIS MEANS

Every person will have their own special government money account. People who need a lot of help will get more money than people who only need a little help. An agency acts like a bank. You can change agencies if you want to. When you need money to pay someone who works for you, you and your circle of support tell your agency who they should pay and how much they get. The agency will pay for all the expenses you budget for such as programs, transportation, community activities, schools and maybe rent.

SUPPORT

The *support* needed to obtain personal goals.

Those supporting individuals with disabilities also much be free to provide the desired assistance, either as employees of service agencies or when hired by the individual, to achieve the variety and intensity of supports an individual may desire.

THIS MEANS

You will have to find a group of family, friends, community members, and professionals

to help you decide what supports you need to live responsibly in the community. You will decide, but other people who you trust will help you think about it. This group is called your **circle of support**.

You can hire your own staff, people you like to help you, either from an agency or someone you know and trust in your neighborhood. If you need a lot of help, you may want to hire someone who spends the night with you or lives with you. If you need less help, perhaps people can come a few hours a day. They can help you with your medication. You can hire people who are good at math to help you with the bills, or a good cook to teach you how to cook. An aide could help you with dressing and cleaning if you can't do that yourself. You can hire someone to help you find the job you want. You must plan on enough supports to keep you safe and healthy. It all depends on what you need and want.

DO YOU WANT TO BE IN SELF-DETERMINATION?

Do you like where you are living now, or do you want to live somewhere else? Do you have a job? One that you like? Do you earn some money? Do you get to go to places you like to go? Can you and your friends get together when you want to?

Self-Determination can help you to answer these questions with a **big YES!**

HOW DOES SELF-DETERMINATION WORK?

People that choose the Self-Determination process may have an agency helping them. If they live in an agency house, they will have to follow the agency rules. If they rent or own their own place, they make their own decisions.

You need a plan for your life. A service coordinator or a service broker can be paid to help you develop your plan. They can also help you put your plan into action. You need to find your family, friends, community friends and staff people who are willing to become part of your **circle of support** to help you.

You need to find out more about Self-Determination. Call your Self-Advocacy Association or your DDSO.

RESPONSIBILITY

The responsibility for contributing to one's community and using public dollars wisely.

They have the ordinary obligations associated with freedom in America. These are obligations of citizenship and include the obligation to spend public dollars in ways that are life-enhancing and cost-effective. This obligation includes engaging other social, business, and religious organizations in ways that help redefine and build community for all of us. The individual also has the responsibility to give back to the community through paid and volunteer work whenever possible. This includes seeking jobs in the community, and using supports to find and keep employment.

THIS MEANS

Earning your own money is important. You should try to find a way to get a paying job. You can use some of your government money to help you do this. Money that comes from the government has to be spent according to certain rules. You will have to spend your government money that the agency takes care of wisely. You can spend money you earn on the things you want. Of course, you will have to pay for your food and rent first.

You will also want to make more friends in the community. One of the best ways of doing this is to belong to clubs, churches and service organizations like the “Y”, the Moose, the Lions or other fine organizations. You can find ways to help them with their projects in your free time.

VALUES SUPPORTED BY SELF-DETERMINATION

⇒ **Respect** – Self-Determination, by its nature, recognizes that persons with disabilities are valuable, capable persons who deserve to be treated with respect. Respect is more than politeness and paying lip service. It is acknowledging the individual's value as a person, seeing his or her strengths and abilities, granting him or her the same consideration we each desire, and holding him and her in esteem.

⇒ **Choice** – Choice is central to Self-Determination. Many times people with disabilities have very limited choices. They often cannot choose very important aspects of their lives, such as where they live, with whom, how they will spend their time and their money, and sometimes even what they eat. At other times, selections are limited. For instance, individuals may be able to choose who their roommate will be, but not whether or not they will have one. True choice is being able to pick from the same wide variety of lifestyles, goals, and individual preferences most people enjoy.

⇒ **Ownership** – Self-Determination not only supports persons with disabilities to have more choices in their lives, but ownership of their lives. Ownership implies more than just decision-making. It means that the individual is the final and total authority—the boss. While most people are supported in the decision-making process by a circle of support, Self-Determination gives the person the final say. Ownership allows him or her control over his or her life and services. He or she may hire, manage, and if necessary, fire those who provide services. It also gives him or her control over the management of his or her financial affairs. Ownership also means that the individual accepts the responsibility for his or her actions and decisions, including spending public monies conservatively.

⇒ **Support** – Support is a keystone to making Self-Determination work. Most people have some type of support network in their lives that they turn to when they must make an important decision or take a step forward in their lives. Persons with disabilities are no different. However, before Self-Determination, those persons who helped establish goals and devise plans were mostly paid workers who in many instances were assigned rather than chosen. In Self-Determination the individual selects and invites each member of his or her circle of support. They can be family members, friends, and people from the community—anyone that the person desires. Most importantly, they are people with whom the individual has or wishes to build a trusting relationship.

⇒ **Opportunity** – Many persons with disabilities have had only limited opportunities to experience many aspects of life. Self-Determination expands those opportunities allowing and encouraging individuals to explore the possibilities that are present in their communities. Since they are able to spend their funds in ways that they now choose, they are able to take part in events and activities that previously were unavailable. When someone has had limited experience, it may be difficult for others to allow him or her to take risks. However, opportunity also includes the ability to take risks, to make mistakes, and to grow from them.

Self-Determination Calls for a Systems Shift

If Self-Determination is going to be successful, it requires that those who supply services and fund them make certain changes in both the way they think about persons with disabilities and the way they serve them. Without a shift in the service system, no philosophy can truly support persons with disabilities to become self-determining individuals. In order for Self-Determination to happen, the system must shift:

- From seeing persons with disabilities as having limitations that prevent them from participating fully

in life to seeing them as valuable citizens who have many talents, strengths, and abilities to contribute to their communities.

- From seeing persons with disabilities as service recipients to seeing them as individuals with rights and entitlements.
- From providing agency-controlled services to supporting person-directed services.
- From systemic and agency control of financial resources to individual control.
- From control to empowerment.

A Final Thought

“Self-Determination is what life is all about. Without it, you might be alive, but you wouldn’t be living—you would just be existing”

(M. Kennedy, “Self-Determination and Trust: My Experiences and Thoughts,” In Sands & Wehmeyer, Self-Determination Across the Life Span, 1996, p. 48).

Prepared by Michael Kennedy & Lori Lewin, Staff Associates

The preparation of this fact sheet was supported in part by the Center on Human Policy, School of Education, Syracuse University, through a subcontract with the Research and Training Center on Community Living, University of Minnesota, supported by the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR), through Contract No. H133B980047, and in part by the National Resource Center on Supported Living and Choice, Center on Human Policy, School of Education, Syracuse University, through the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR), through Contract No. H133A990001. Members of the Center are encouraged to express their opinions; however, these do not necessarily represent the official position of NIDRR and no endorsement should be inferred.

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MACROW

SELF-DETERMINATION CHECKLIST

**VERSION 3.3
(Revised 3.12.01)**

Developed to Assist Self-Advocates, Family Members, Personal Agents, Case Managers, Support Coordinators, Service Coordinators, Support Brokers, Fiscal Intermediaries and Circle Members in Developing Person Centered Plans and Individual Budgets
Based on the Principles of Self-Determination

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PREFACE

This checklist is intended to be a barometer to indicate if you are setting a course that will ultimately support individuals with disabilities in “getting a life.” Many individuals have, through conversation, presentations, publications or sharing life experiences contributed to this checklist. Periodically it will be revised to incorporate current feelings, needs, dreams and views of individuals with disabilities, their families and friends. The checklist is not intended to replace or be used as a personal “outcomes” evaluation tool.

The reference to the “Personal Life Quality Protocol” (Center for Outcome Analysis) and the “Planning Guide for Paid and Unpaid Companions” (Cummings and Crowley) are suggestions only. Other tools serving the same purpose may be available. The Principles of Self- Determination and Principles for Action are provided as reminders to those completing the checklist.

[NOTE: The following pages are adapted from several publications authored by Ellen Cummings, Thomas Nerney, James W. Conroy, Anita Yuskauskas, Robert P. McCaffrey and Richard F. Crowley.]

DEFINITION OF SELF-DETERMINATION

“A national movement to redesign long-term care for individuals with disabilities that eschews the traditional program models and facility placement approaches ...Self-determination insists that public dollars be seen as an investment in the lives of people with disabilities. Public dollars need to be used strategically to support existing family and community relationships as well as to help create them where they do not exist.”

Tom Nerney, 1998

PRINCIPLES OF SELF-DETERMINATION

The following principles are meant to provide a philosophical foundation for substantive system and cultural change that incorporates values deeply held by persons with disabilities, families, friends and advocates:

- ☐ **FREEDOM:** to choose a meaningful life in the community
- ☐ **AUTHORITY:** over a targeted amount of dollars
- ☐ **SUPPORT:** to organize resources in ways that are life enhancing and meaningful to the individual with a disability;
- ☐ **RESPONSIBILITY:** for the wise use of public dollars and recognition of the contribution individuals with disabilities can make to their communities
- ☐ **AFFIRMATION:** of the important leadership role that self advocates must play in a redesigned system and support for the self advocacy movement

PRINCIPLES FOR ACTION

Self-Determination is another way of saying *freedom*. It is a fundamental human right that *affirms* the leadership role self advocates and family members and empowers people to have *authority* over how their lives will be lived, where and with whom. It means that people have control of the resources needed for their *support*, as well as having *responsibility* for their decisions and actions. It *affirms* the emerging leadership role that self-advocates and family members have in guiding systems change.

☐ **DIGNITY AND RESPECT**

All people have an inherent right to be treated with dignity and to be respected as a whole person with regard to mind, body, and spirit. Most of life's greatest lessons are learned when we make choices that we later realize were mistakes. All people have the right to the dignity of risk. The network of support makes risk possible by weaving a net, which provides safety and supports growth.

☐ **RELATIONSHIPS**

Supporting people in developing and maintaining relationships is an on-going process. A relationship must be treasured, nurtured and protected. Those with whom the individual has real relationships provide the strength assistance and security, which ensure each person's well being.

☐ **CHOICE**

People have a right to choose what they do with their lives where and with whom. When people need help, it is friends and family closest to them who can assist in broadening their experiences and exercising their right to choose. A personal network or circle of support chosen by the person ensures freedom of choice.

☐ **CONTROL**

People have the power to make decisions and truly control their lives, including their resources and finances. If support must be purchased, the people buying it, with assistance from family and friends when necessary will determine which supports will be purchased and when. People must have control of hiring those who will provide support.

☐ **DREAMING**

All people have dreams and aspirations that guide the actions that are most meaningful to them including commitment to helping people create their dreams, respecting those dreams and helping make them come true is crucial.

☐ **CONTRIBUTION AND COMMUNITY**

Everyone has the ability to contribute to his or her community in a meaningful way. Giving of ourselves helps us establish a sense of belonging and identity. Community membership includes having the opportunity to be truly involved in the routines of the community and to make a difference in the lives of others.

❑ FISCAL CONSERVATISM

The services the present systems provide are often expensive and often do not meet the needs of those they are intended to support. Making things happen does not always require money. If people have, opportunities to make real choices, and control over those choices, they will purchase support in a way that will allow them to get what they need, and pay only for what they receive. Make real investments, spend money more efficiently and make adjustments when needed. They are also responsible to contribute to their support from all financial resources at their disposal. To find the best quality for the most reasonable price, people must be free to purchase in and out of the system.

❑ CHANGING ROLES OF PROFESSIONALS

Individuals, as they take control authority over their lives and resources, will assume responsibility for their decisions and actions. Professional and staff work for the individual rather than for the system. Families, friends and staff assist people to create more meaningful relationships, link them with needed supports, remove barriers, develop safety networks, and help dreams come true - while never forgetting who is charge

❑ WHATEVER IT TAKES

Having an attitude that nothing is impossible. As long as it is legal and causes no harm is required. "No we can't" as an answer is replaced with "How can we make this happen?" Those who work in the system become barrier removers.

MACROW SELF-DETERMINATION CHECKLIST

Individual: _____ **Date:** _____

Name of person completing the checklist: _____

Relationship to Individual: _____

Please answer each question to the best of your knowledge

0 = No

1 = Rarely

2 = Sometimes

3 = Frequently

4 = Most of the time

5 = Yes

0 - 5

Score

1. Did the individual choose their personal agent? _____
2. Was the Personal Agent (Case Manager, Support Coordinator etc.)
trained to facilitate the PCP and individual budgeting process? _____
3. Did the Individual with disability agree to participate? _____
4. Did the Personal Agent & individual hold a pre-planning meeting? _____
5. Was a "targeted" individual budget amount available and used? _____
6. Were members of the circle solely invited by the individual? _____
7. Did individual choose the time, place and date of PCP meeting? _____
8. Did the process of dreaming, identifying needs/wants occur? _____
9. Were current and future supports determined using the a Planning
Guide For Paid and Unpaid Companions (or similar guide?) _____
10. Were all housing options and needs/desires addressed? _____
11. Were professional and clinical needs addressed? _____

12. Were employment/day needs & desires addressed? _____
13. Were all transportation options and needs addressed? _____
14. Was a Personal Quality of Life Protocol completed prior to the PCP? _____
15. Did the Personal Agent participate in helping recruit circle members? _____
16. Do circle members understand their roles and responsibilities? _____
17. Do circle members follow through on their commitments? _____
18. Does the circle understand that the PCP is dynamic and the individual may request meetings, changes in the plan, circle composition or budget at any time? _____
19. Did the individual (or designee) approve and sign the final budget in the presence of the Personal Agent? _____
20. Were current (actual) revenue and expenses determined before a "target" figure was established? _____
20. Did the individual receive a copy of the final budget? _____
21. Was a Fiscal Intermediary used? _____
22. Was the Fiscal Intermediary selected by the individual? _____
23. Does the individual receive a monthly financial statement? _____
24. If the individual moves - does the funding follow? _____
25. Does the individual have access to cash or use an ATM card, credit card or personal checking/savings account? _____

TOTAL SCORE

\$\$ SELF-DETERMINATION MONEY \$\$

“Show Me the Money”

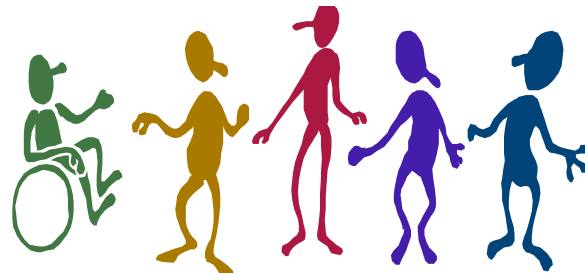
Self-Advocates who have heard about Self-Determination as well as customers involved in the Self-Determination process have heard that they have control over the money that they can use, but are often mystified by the fact that they do not have the money in hand. This exercise will help them learn where the money comes from and how they can control it.

Materials needed:

- A large stack of Self-Determination \$1000 bills.
- Signs for all the players to wear, so that we all know their roles.

Players:

FOCUS PERSON Self-Determination Participant
TAXPAYER
SSI/SSA
OMRDD State DD Agency
BOSS or ENTERPRISE
FISCAL INTERMEDIARY
LANDLORD
BANK
SUPERMARKET/SUPERSTORE
TRANSPORTATION - CAR/BUS/TRAIN
TAX COLLECTOR
SERVICE COORDINATOR
SUPPORT STAFF
JOB COACH
SUPPORT BROKER
SERVICE COORDINATOR
CIRCLE OF SUPPORT



The process leader chooses the focus person, the taxpayer, the state agency, the fiscal intermediary, and the tax collector.

The Focus Person chooses his or her circle of support, a Boss or business, a service coordinator, a service broker, a job coach, support staff, transportation, a supermarket/superstore, and a landlord or a bank for the mortgage.

The process leader hands out Self-Determination money to everyone including extra to the Boss. Each person gets to keep one bill, but the tax collector collects the rest and gives it to the State Agency (OMRDD) and SSI/SSA.

The Focus Person has met with his or her circle of support and has a budget of their income and expenditures.

The State agency gives the Fiscal Intermediary part of the money for the use of the Focus Person. It is the amount listed on the budget.

The Focus Person with the help of the Circle of Support decides how to spend the money. They have listed the expenses on the budget.

Now we will spend the money. The Focus Person serves as the delivery service to get the money to the right place.

The SSI/SSA \$\$ go to the Bank (personal account).

The Boss pays the Focus Person and those \$\$ go to the Bank (personal account).

Exception: OMRDD pays the Service Coordinator. (Not the Focus Person)

The Fiscal Intermediary with the Focus Person pays the Support Staff, the Support Broker and the Job Coach.

The Focus Person goes to the Bank and gets money from the personal account for the supermarket, the landlord, the mortgage, property taxes and transportation.

If more money is needed, the Focus Person applies to OMRDD.

SELF-DETERMINATION BUDGET WORKSHEET

SUMMARY

(Sample) 9/20/99

Name: John Demo
Address: 10 Garden Lane, Beautiful, NY
Phone: 914-000-000
Social Security #: 000-00-000 TABS # 000000

Guardian: _____
Advocate: Mrs. Demo-Mother
DDSO: Taconic
CIN# 000000 Date: 10/20/99

EXPENSES

1. <u>Supports-Individual, program purchase, one time expenses</u>	3100	37200
2. <u>Housing-(Rent, mortgage, taxes, utilities, furniture, supplies)</u>	572	6864
3. <u>Personal-(Food, clothing, recreation, meals out, education, dues)</u>	675	8100
4. <u>Transportation-(Taxi, bus, subway, auto, insurance)</u>	500	6000
5. <u>Fixed Monthly Costs- (Health & life insurance, loans, spend down, prescriptions)</u>		
6. <u>Miscellaneous- (Medical/Dental, taxes)</u>	250	3000

TOTAL EXPENSES

5097 61164

NOTE:

The Personal Resource Account (PRA) covers both Medicaid HCBW funds and 100% State dollars. Medicaid waiver funds for eligible participants may be used to fund any needed supports and services consistent with ISP goals and the approved HCBS waiver agreement. These include but are not limited to staff, e-mods, adaptive equipment, and community participation costs. Any supplement needed for living costs (room and board), elective divisional costs not related to ISP goals and any expenses for HCBW ineligible persons must come out of 100% State funds.

COMMENTS:

John lives with a disabled friend, sharing an apartment. He wants to control his own life. He needs support at home, at his job and to negotiate the community. He lives in a small town without access to public transportation and uses a leased car and qualified staff for transportation. He hires his own staff and pays them through a fiscal intermediary.

INCOME**MONTHLY** **ANNUAL**

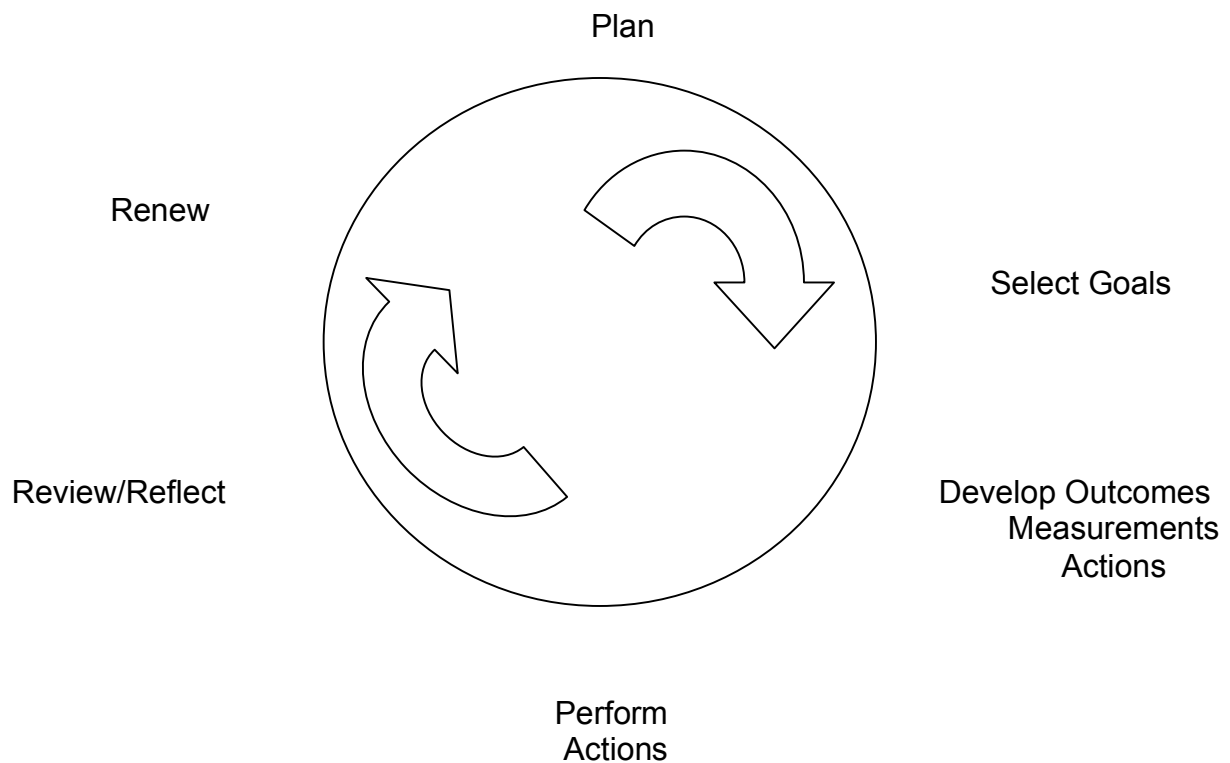
1. Employment	375	4500
2. Public Assistance	0	0
3. Social security- (SSI & SSDI)	662	7944
4. Other Benefits: VA, Black Lung, Railroad, etc.	0	0
5. Food Stamps	10	120
6. HEAP	0	0
7. HUD Subsidy	0	0
8. HCBW-Consolidated Supports (CSS)*	3500	42000
9. OMRDD Supports- (100% State funds)	300	300
10. Medicaid- (Other State Plan)	250	3000
11. Medicare	0	0
12. Private Health Insurance	0	0
13. Other Insurance: Life, Burial, etc.	2000	2000
14. Pre-paid Burial Plan	0	0
15. Bank Accounts	350	350
16. Other Assets	0	0
17. Other Loans and Liabilities	0	0
18. Pending Litigations and Judgments	0	0
<u>TOTAL INCOME</u>	<u>5097</u>	<u>61164</u>

Note:

CSS plus 100% State funds make up
the Personal Resource Account (PRA)

**A QUALITY ASSURANCE
TOOL KIT
FOR
THE SELF-DIRECTED SUPPORTS PROGRAM**

By Pat Tangeman,
Support Team Member



TOOL KIT

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1. Quality Assurance: What is it and Why do it?
2. Goal Selection Process
3. Developing the Plan:
Outcomes, Measure and Actions
4. Action Planning Process
5. Reviewing, Reflecting and Renewing the Plan

QUALITY ASSURANCE WHAT IS IT? AND WHY DO IT?

Quality Assurance System

A quality assurance (QA) system is a way to measure the success of a program in meeting its intended goals and purpose. It also provides a way to find out what changes need to be made in the program to keep success occurring or to make improvements as needed.

For the Self-directed Supports statewide change, the QA system intends to find out whether the plan that each local team has developed has helped families and self advocates to chart a more self-directed path for themselves. It will help to ask whether the components of the plan really do encourage the values that were described by each local steering committee. Questions asked in the QA review process will help local teams determine what changes are needed to move plans closer to the overall goals and 3 year state guidelines.

Why do this?

A systematic review of each county's program can guide the future development of the plan.

The review will promote continuous program development and improvement.

Why not let some experts do the evaluation and QA?

Leaders in the field of developmental disabilities and self-determination suggest that local teams define their own QA systems especially if the overall vision of the program is the charting of self-directed paths. You developed the plan and program. You designed the program. You ought to evaluate it and make the improvements.

Who should develop the QA plan?

The local group who is responsible for monitoring the plan should develop and carry out the QA plan. This group needs to have the gratification of success and the responsibility for making the necessary changes.

GOAL SELECTION PROCESS

Where to Start?

Start by asking the question, what important aspects of the program do you need to monitor or track? What information do you need to know to move towards a complete three year plan? How will you maintain continuous improvement of your service?

These questions could be answered by a small working group of your steering committee or could be brainstorming questions that are put to the whole group.

The intended purpose for the program – that people with disabilities and their families are defining their goals and moving towards those goals using self-directed supports would be a most likely area to monitor.

Aspects of the plan and program that you feel may need adjustments such as community outreach and linkage, selection criteria, or the accessibility of your program may be important areas to track.

As you start this process, it is recommended that you choose only a **few** areas that are **doable or achievable**. Your plans include many actions. You do not need to set up a QA tracking system for each action.

Written standards sometimes can help to define your goals. Laurie Powers, PhD., the principal investigator for the Oregon Self-determination Project, that helped to define many of the concepts necessary for self-directed supports programs and the staff of Self Directed Supports, Incorporated (SDRI), a project that is providing self-directed supports in some parts of the state have developed some standard indicators (see Appendix A). These indicators are based on their experiences with self-directed support systems. Their standards could be goal standards or outcome statements. The state guidelines could act as goal standards. Your own county standards could be goals. What is most recommended is that you select goals to be monitored that are **important** to your local team and that the tracking of progress towards these goals will give you real information that will either indicate your success or need for improvement.

DEVELOPMENT OF THE QUALITY ASSURANCE PLAN

Components of the Q.A. Plan:

1. **Outcomes:** Visions of the results that you want for each goal area.
2. **Measurement:** A way to know if you are making progress toward that outcome or result.
3. **Actions:** What you will do to get to your outcome.

(Gosh, this looks like things that we have already done for the plan development)

Right! Just choose the goal areas that you want to track!

Process: How to develop the components of the plan

Once you have chosen your goal areas, a small group could develop the outcomes, measures and actions and bring a draft to the large group. For smaller counties, this activity could be done in the whole group led by the facilitator, however some preparation ahead of time with a small group would make the process go smoothly.

Outcomes or visions for what you want: **why do this?** Why not just use the goal statements? People who have studied creative thinking have found that if individuals or groups can learn to be more **results** oriented and spend time **visualizing** the benefit or result for themselves or others, there will be a tension between what is and where you want to go. This tension can provide both a **pull** towards the **outcome** and a **focus** for knowing when you get there. Outcomes are written in the present tense and describe future behaviors or program characteristics.

Some sample outcomes:

- | | |
|-----------------|---|
| Goal: | Improve the ability of people with disabilities to direct their own lives. |
| Outcome: | Families and people with disabilities use self-directed supports to realize their own individual goals. |
| Goal: | Make sure that the program is accessible to all families and self-advocates across the county. |
| Outcome: | Families and people with disabilities who need and desire supports know about the program and how to access the |

program.

Goal: **Community linkages will be developed, nurtured and maintained.**

Outcome: Families and people with disabilities know about services available in our community and use county self-directed supports to become a part of the community service system.

Measurement or how you will know when you are making progress.

When you choose a way to know when you are making progress, you usually need to **observe** some change. For something to be observable, you usually need to either count a change, see a change or see a difference. These are called **quantifiable** ways to measure progress. Quantifiable measures should also be **achievable or doable**.

People who study changes in program development or individual growth have learned that something else is needed. Sometimes change in systems just needs to be talked about or described. These ways of measuring progress are called **qualitative measures**. Ways to describe change include phone interviews about satisfaction with a program, satisfaction surveys, focus groups, and just group discussions.

To measure program results, then, it is a good idea to use both **observable** ways and **descriptive** ways. Measurement samples for the outcomes mentioned earlier follow. Appendix B contains some sample satisfaction surveys that have been used successfully by Self Determination Resources Inc.

Samples:

Outcome #1: Families and people with disabilities use self-directed supports to realize their own individual goals.

Measurements/How will you know when you are making progress?

1. Using the SDRI Individual Satisfaction form, 75% of people who have received services indicate that the program is doing a good job in helping individuals and families obtain the supports they want and that people with disabilities and families have achieved at least one of their goals.
2. Our service records indicate that we were able to find supports for 100% of people requesting this service.

3. Using random phone interviews, most people described the ability to meet their own individual goals.
4. A focus group of families and individuals who have used self-directed supports describe positive experiences and movement towards reaching their goals.

Outcome #2: Families and people with disabilities who need and desire supports know about the program and can access services easily and efficiently.

Sample Measurements:

1. Families and individuals with disabilities describe their positive experiences accessing the Self-Directed Supports program in focus groups.
2. Random phone calls to people who have used the Self-Directed Supports Program indicate positive experiences in accessing the program.
3. The results from the SDRI satisfaction survey indicate that 75% of people using the services did not have difficulty accessing the service.

Outcome #3: Families and people with disabilities know about the services available in our community and use county self-directed supports to become a part of the community service system.

Sample Measurements:

1. Selected satisfaction surveys indicate that families and people with disabilities use community services.
2. Focus group interactions describe how people use self-directed supports to access community services to meet their goals.

Actions: The action statements are what you will do to move towards the outcome. Your plan document most likely contains many of the actions steps you would use for the QA plan.

Outcomes = results you want to create

Measures = how you know you are progressing

Action = what you will do

ACTION PLANNING PROCESS

Action Planning

Process: A clear action plan prepares the program to move forward by designating responsibility for actions, determines when the review meeting will occur and when particular measurement activities will occur. The action plan becomes a reminder for all team members and staff and indicates a commitment to the process.

Action	Responsibility	Timeline
1. Schedule QA review meeting for Sept. governing body meeting	Chair	August reminder
2. Send out satisfaction surveys monthly	SDS Coordinator	Begin in April
3. Conduct focus groups in July	Parent Group	Plan in June

QUALITY ASSURANCE PLAN WORK SHEET

County: _____

Date: _____

Quality Assurance Criteria Goal: All possible efforts will be made to ensure that the Self-Directed Supports Services are accessible to all families and self-advocates across the county.

What will you do to make this happen? <i>(ACTION STEPS)</i>	What will be the benefit to families and Self advocates? <i>(OUTCOMES)</i>	How will you know you are making Progress? <i>(MEASUREMENT)</i>

What kind of help do you need? _____

Plan Review Date: _____

Review: _____

Notes: _____

QUALITY ASSURANCE PLAN WORK SHEET

County: _____

Date: _____

Quality Assurance Criteria Goal: Improve the ability of people with disabilities to direct their own lives.

What will you do to make this happen? (ACTION STEPS)	What will be the benefit to families and Self advocates? Or results you want (OUTCOMES)	How will you know you are making Progress? (MEASUREMENT)
1. Educate SDS staff about the role of personal support agents 2. Provided workshops to inform community about self-directed supports and how they can help individuals and families meet their needs. 3. The SDS coordinator assists individuals who want to hire personal support agents with names of people and helps them set up the system.	1. Families and people with disabilities use self-directed supports to realize their own individual goals.	1. Using the SDRI Individual Satisfaction form, 75% of people who have received services indicate that the program is doing a good job in helping individuals and families obtain the supports they want and they are reaching their goals. 2. Our service reports indicate that we were able to find self-directed supports for 100% of people requesting this service. 3. Using random home interviews, most people described positive experiences in using self-directed supports. 4. A focus group of families and individuals who have used self-directed supports describe positive experiences.

What kind of help do you need? _____

Plan Review Date: _____

Review: _____

Notes: _____

REVIEWING REFLECTING AND RENEWING THE PLAN

Review, reflect and renew

Process: The review, reflect and renew process takes place during a decision making meeting that should end with a celebration and action planning for the next meeting. Full attendance and preparation of all members of the team is necessary for this meeting to be effective. Copies of the QA plan, the action plan and the purpose of the meeting need to be sent out to all members of the review team.

The meeting needs to be structured by goal area with a report from each person who was responsible for bringing information. Many of you have been to these kinds of review meetings. Without an exchange of information and reflection time, the meetings can be uninteresting and without a sense of completion. To encourage reflection, the facilitator can structure a discussion after each report by asking and recording: **What went well?** **What could be better?** The facilitator encourages members of the group to listen and ask questions. Next, the group leader asks the question: What are some conclusions about our progress? What changes need to be made, if any to the plan? Do additional actions need to be taken? Are the measures getting the information we need? Is this an area that we need to continue to track? Record decisions on an action plan chart or on the QA form.

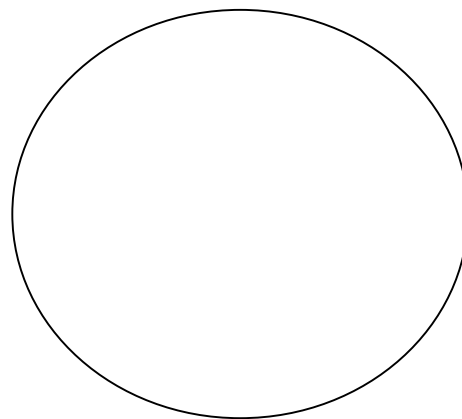
Each goal area is reviewed the same way. At the end of the review, the leader asks if there are other emerging areas that require a review. Conversations with families and individuals with disabilities may have indicated other areas that need to be monitored. A small group may develop the plan for these areas or the large group may decide.

At the end of the review, the facilitator can ask for another reflection: What went well? What might we change the team chooses a way to **celebrate** their successes and **determines** the date for the next meeting!

Celebration

Conversation

Continuous Learning



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ASSIST CUSTOMERS TO FIND AND SET UP SUPPORTS

Self-Directed Support Programs assist customers to find or create supports, to make support agreements with existing or new providers, including personal support agents, and to work with funders and customers' friends and families to set up supports that match what the customers want. The focus is on helping the customer to set up individualized supports in the community rather than 24-hour, traditional services.

This checklist shows what Self-Directed Support Programs do to assist customers to find and set up their supports. It can be used as a guide to design or evaluate the Program's activities.

Key Activities	Is It Happening?		What will we do to make it happen?
	YES	NO	
Assistance is given to customers who want to hire personal support.			
Personal support agents can be relatives, friends, neighbors, providers or anyone else the customer chooses.			
The Program offers regular help to customers and the people who assist them to find and set up their supports.			
Customers can find and set up their own supports, if they choose.			
Program staff also are available to directly assist customers to find and arrange their supports.			
Supports are set up that match only what the customer wants.			
Customers can choose to use existing providers and/or to creatively set up new supports.			
The Program helps customers match their support plan with their budget.			
The Program assists customers to find funding from traditional and nontraditional sources.			
The Program assists customers to make support agreements with existing or new providers.			

FISCAL INTERMEDIARY AND EMPLOYMENT SUPPORTS

Self-Directed Support Programs assist customers to hire and supervise their personal support providers and/or to set up contracts for their support with existing organizations. They also assist customers with the paperwork that has to be done to be an employer and they help customers to track their personal support budgets. The Self-Directed Support Program works with the customer and does not have a close relationship with the support providers and support agencies that the customer manages. The Program is not the employer of record for a customer's support providers.

This checklist shows what Self-Directed Support Programs do to assist customers to manage their budgets and support providers. It can be used as a guide to design or evaluate the Program's activities.

Key Activities	Is It Happening?		What will we do to make it happen?
	YES	NO	
Customers put in writing exactly which fiscal intermediary services they want to use from the Self-Directed Support Program.			
The Program has policies that say its goal is to assist customers who want to direct their support, its primary allegiance is to the customer, not the support provider, and it is not the employer of record for the customer's support providers.			
The Program assists customers to be the employers of record for their support providers and/or it assists customers to set up agreements with other organizations who will be the employers of record.			
John Descriptions are written for each customer's support provider.			
Support providers are chosen and supervised by customers.			
No (or minimal) limits are placed on who customers can hire to be their support providers.			

(Fiscal Intermediary, continued) Key Activities	Is It Happening?		What will we do to make it happen?
	YES	NO	
Agreements are written between each customer and his or her support provider or the organization that will provide the customer's support.			
The Program has little direct contact with the support provider unless it is with the customer.			
Benefits are available to the customer's support providers.			
The Program can process employment taxes, FICA, worker's compensation, etc. for customers, and issue W-2 forms.			
Customers approve in writing the payment of all bills for their support and they are given regular budget reports.			
Checks are sent to customers to give to their support providers.			
Checks can be issued within 24 hours, if needed by a customer.			
The Program can get the funds for the customer's supports from the agencies or other sources that are paying for it.			

ASSIST CUSTOMERS TO MONITOR QUALITY OF THEIR SUPPORT

Self-Directed Support Programs assist customers to monitor the quality of the support they receive. Customers are assisted to monitor the quality of their supports through periodic check-ins, satisfaction surveys or postcards, and Quality Gatherings. A Quality Gathering is a group of customers who meet together to give feedback to the Program about how their supports are working and ways they could be improved.

This checklist shows what Self-Directed Support Programs do to assist customers to monitor the quality of their supports. It can be used as a guide to design or evaluate the Program's activities.

Key Activities	Is It Happening?		What will we do to make it happen?
	YES	NO	
Customer support plans clearly show their support goals.			
Customer agreements with support providers show when they will review the quality of their support with the providers.			
Customers get the assistance they want to evaluate the quality of their supports and to identify areas that need improvement.			
Customers get the assistance they want to have regular meetings with their providers to review the quality of their support.			
Customers regularly evaluate the quality of the assistance they get from the Self-Directed Support Program.			
Customer satisfaction is regularly reviewed by the governing Board for the Program.			
Individual customers are regularly invited to share their ideas for ways to improve the Program.			
There are regular Quality Gatherings where customers share their experiences and ideas for improving the Program with each other, the governing Board and the Program Director.			
Customers are provided with the assistance they want to fire support providers who do not provide quality support and to find new providers.			

Customers are given the name and phone number of a person in the community to contact if the Program does not improve its services within a reasonable amount of time.		
--	--	--

CUSTOMER EDUCATION

Customers may want new information or skills in order to take charge of their supports. The Self-Directed Support Program helps customers to get the information and skills they want by offering individual education, workshops, and contact with mentors, or other customers who have experience and are willing to share.

This checklist shows what Self-Directed Support Programs do to assist customers to get the information and education they want to direct their supports. It can be used as a guide to design or evaluate the Program's activities.

Key Activities	Is It Happening?		What will we do to make it happen?
	YES	NO	
Customers are given information about what self-directed support is and the ways the Self-Directed Support Program can assist them.			
All customer support plans list the information, skills and experiences that customers want to choose and direct their supports.			
Customers get ongoing education and assistance to manage their support budgets and to choose and direct their supports.			
Workshops are conducted on topics picked by customers.			
Individuals with disabilities and family members help to plan and conduct workshops.			
Customers are invited to have mentors and/or to be mentors for others.			
Mentors are given training and ongoing assistance.			
Customers are assisted to participate in other advocacy, educational or leadership activities.			
Customers are assisted to use the world wide web, public libraries or other information resources in the community.			
The Self-Directed Support Program has a library of resource information for customers.			

CONSUMER GOVERNANCE

Self-Directed Support Programs are led by a governing group of community leaders, at least 51% of whom are individuals with disabilities and family members. The governing group is responsible for making sure that the Self-Directed Support Program does its job of helping customers to determine and direct their supports. The governing group oversees the quality of the Program's work in carrying out each of its functions, and develops goals and policies to improve the Program.

Key Activities	Is It Happening?		What will we do to make it happen?
	YES	NO	
The focus of the governing group is to oversee and maintain the mission of the Self-Directed Support Program.			
The governing group does careful planning for the Program's future.			
The governing group develops policies and reviews the performance of the Program Director or Manager.			
The governing group regularly reviews how well the Program is doing its job and decides what needs to be improved.			
The role and authority of the governing group is well-defined.			
If the Self-Directed Support Program is part of a larger agency, there is a direct link between the governing group of the Program and the governing body of the agency (ex. a member of the governing board of the Program is a member of the governing body of the agency).			
More than 25% of the members of the governing group are individuals with disabilities and more than 25% are family members of individuals with disabilities.			
The governing group matches the diversity of the community.			
The governing group meets regularly and has a structure (ex. chairperson, president, secretary, etc.).			
The governing group has a pool of people who are interested in being members.			

There is an orientation program for new members.		
Information and written material for the governing group is presented in easy-to-understand language, pictures, etc. to make it understandable.		
Pre-meetings are held for members who want more time and assistance to review the agenda and the last meeting's minutes, and to figure out their viewpoints and questions for the upcoming meeting.		
Assistance is provided to increase the participation of members in meetings (e.g. yes/no question-asking, taking time to review hard to understand information, notes on an easel, using straightforward language, etc.).		
Support is given to make sure that members can attend meetings (e.g. respite, transportation, personal assistance).		
The governing group regularly evaluates its leadership and support for members.		
Members have opportunities to take part in activities to increase their knowledge and leadership skills.		

COMMUNITY BUILDING

The Self-Directed Support Program conducts forums and workshops in the community to educate people about self-directed support and to increase the number of self-directed support providers. Staff also work with other organizations to increase the support options available in the community.

This checklist shows what Self-Directed Support Programs do to build community supports. It can be used as a guide to design or evaluate a Program's activities.

Key Activities	Is It Happening?		What will we do to make it happen?
	YES	NO	
Training is given to people who want to be personal support agents.			
A registry of personal support agents is kept for customers.			
The Program does regular workshops about self-directed support for agencies, organizations and community members.			
The Program does projects with other organizations and agencies to increase the self-directed support options in the community.			
The Program shares information and resources with other organizations that can assist customers.			
The Program builds relationships with foundations and organizations that give grants in order to increase their understanding and funding of self-directed support.			

CUSTOMER SATISFACTION SURVEY

Our records show that you recently met with a support broker at Self-Determination Resources, Inc. (SDRI). The Board of Directors at SDRI wants to know how satisfied you are. Please complete and mail back this postcard. Your individual answers will not be shared with the staff. We encourage you to tell SDRI staff when they are doing a good job or that you want better services.

1. My broker listened to my needs and understands me.

Great job Good job Needs work Help!

2. I got the information and help I need to make decisions.

Too much Right amount Not enough Confusing

3. The plan we developed is what I want.

Exactly Close Needs work Help!

4. I would recommend SDRI to a friend.

Yes No

Comments:

OPTIONAL

If you would like to talk with someone about your experiences at SDRI, please

Write your name and phone number below.

Name: _____

Phone: _____

QUALITY QUESTIONS FOR INDIVIDUAL AND FAMILY CUSTOMERS OF SELF-DIRECTED SUPPORT

It is important that you have the support you need to be safe and to live the way you choose. **You are in charge of deciding whether you are receiving the support that you need.** Please answer the following questions that ask about the quality of your life and support. Feel free to write any comments or ideas. If you need assistance to answer these questions, please call _____.

YOUR GOALS

Listed below are the goals you had the last time you planned your supports. For each goal, circle whether you achieved it, you're making progress, you're stuck, or it's not important any more.

Goal: _____

Achieved it
Anymore

Making Progress

I'm Stuck

Not Important

Goal: _____

Achieved it
Anymore

Making Progress

I'm Stuck

Not Important

Goal: _____

Achieved it
Anymore

Making Progress

I'm Stuck

Not Important

YOUR SATISFACTION WITH LIFE AND THE SUPPORTS OR SERVICES YOU GET

Parts of life	Are you satisfied? (Circle Yes or No)		Are you getting the support or services you need? (Circle Yes or No)		Put a check (✓) if you want To change or improve something.
Where you live	Yes	No	Yes	No	
Your job or day activity	Yes	No	Yes	No	
Your medical care	Yes	No	Yes	No	
Your opportunities to have fun and meet friends	Yes	No	Yes	No	
Transportation	Yes	No	Yes	No	
Other area of life (write it in)	Yes	No	Yes	No	

Do you have a personal agent (someone who works for you to arrange the support you need)? Yes No

If yes, are you getting the help you want from your agent? Yes No

Are there supports or services that you need and you don't get? Yes No

What additional supports do you need?

Are there times when you don't feel safe? Yes No

SUM IT UP

Look over your answers. Do you want to change anything to safe or happy? Yes No

What would you most like to change or improve?

We want to help. Would you like some assistance to change or improve anything? Yes No

THANKS FOR DOING THIS QUESTIONNAIRE. PLEASE MAIL IT BACK IN THE ENCLOSED ENVELOPE. IF YOU HAVE ANY QUESTIONS, PLEASE CALL _____

HOW'S OUR BOARD DOING?

Our Mission and Goals

1. The overall mission or purpose of our Board is clear to members.

_____ yes

_____ no

2. We are making progress in achieving our goals.

_____ yes

_____ no

3. Our meetings are productive.

_____ Always

_____ Sometimes

_____ Rarely

4. Our Board is strong.

_____ yes

_____ on our way

_____ no

What could be done to help clarify or move forward the mission and goals of our Board, to make our Board stronger?

Program Management

5. We understand what our Program does for customers.

_____ yes
_____ no

6. Our program policies are adequate.

_____ yes
_____ no

7. We are able to adequately oversee and guide the work of our Brokerage Manager.

_____ yes
_____ no

Suggestions for ways to improve our Board's management of the Program.

On a Personal Level

8. I feel good about my contribution to the Board.

_____ yes
_____ no

9. I feel like the effort I put into the Board is worth it.

_____ yes
_____ no

10. I have the information I need to fulfill my Board role.

_____ yes
_____ no

11. I have the skills and support that I need to fulfill my Board role.

_____ yes
_____ no

What do you need to increase your effectiveness/satisfaction on the Board?

THERE'S NO PLACE LIKE HOME

Some things to think about when deciding where to live.

Developed by Deb Griffin Kney
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DID YOU KNOW

◆ Rhode Islanders who have a developmental disability live in lots of different places around the state.

some live with their family and some live in group homes. Others live in their own apartment. Some also own their own home.

◆ You don't have to live alone. You could have a roommate.

If you move into a place with a roommate who also needs support. You can "share" a staff person to, help cover the hours that each of you might need them to be there.

◆ If you don't know how to do some things it may take to live in your own home (like pay bills, clean or cook), you can get help to learn

◆ You don't need to know how to do everything before you move into your own home.

◆ You could live in something called a subsidized apartment. This means the Government will help you pay your rent.

You have to apply for a subsidized apartment by filling out some paperwork. Many service providers can help you do this.

QUESTIONS TO ASK YOURSELF and YOUR ANSWERS

✓ Where do you want to live? Country or city? On the bus line? In a house or apartment? Who do you want to live with? Write a few of your ideas:

✓ Are you living in a decent and safe place? Is it clean? Is it comfortable?

YES -or- NO

If you answered the last question “NO”, explain why you think your home is not clean or safe. What do you want to see different? _____

- ✓ If you're thinking about moving, do you have enough money to do it? Rent or a mortgage, food and utilities are some of the things you will have to pay for. Can you think of some other things you will have to pay for? Write them here:

- ✓ Some people decide to have roommates to help share expenses or to keep them company. Have you thought about having someone as a roommate? What qualities do you want in a roommate? Here is a list of some. Check off the ones that are important to you and add others:

My roommate ...

- ☐ ... needs to be the same sex as me
- ☐ ... needs to have some support staff hours so we can share
- ☐ ... needs to be able to pay: \$_____ for rent and utilities
- ☐ ... needs to be able to do their share of the housework
- ☐ ... needs to be someone close in age to me
- ☐ ... needs to give me “my space” – and not expect to do everything together
- ☐ ... needs to _____

- ✓ Where do you want to live? Near your job? Near family? Near friends? In the country? In the city? On the bus line? In a house? In an apartment? List your answers:

DECISIONS!

Moving is a BIG decision! If you are thinking about getting your own place, be ready to tell friends and family why you want to do it. Is it ***the most important thing*** that you want? Why? Write your answer:

Now that you've found out about housing, and asked yourself some important questions, you may have decided to move, or to ask for more support where you live right now. Whatever you decide that you want and need, **GO FOR IT!!** Here is a list of some possibilities. Check off the ones that are most important to you. Don't be afraid to dream! Things don't need to happen overnight!

- ☐ Learn how to do different things I'll need to live on my own. Here is a list of some things to learn. Circle your top three or add others:

COOKING

CLEANING

SHOPPING

BANKING

**TAKING A BUS
MEDICINE**

USING THE PHONE

TAKING

YARD MAINTENANCE

- ☐ Move to my own place to live. Here are some things to do first. Circle all that you need and write others. I need to:

- ◆ Find an agency to help me
- ◆ Learn the right questions to ask landlords
- ◆ Decide how much I can afford
- ◆ Find a roommate
- ◆ Look for a place to live
- ◆ Get furniture, towels and dishes
- ◆ Apply for subsidized housing
- ◆ Move my belongings
- ◆ Other:

- ❑ My parents/family that I live with are getting old and it is hard for them to help me like they used to at home. I need someone to come to my home and help me so I can continue living with them. The things I need help with at home so I can keep living there are:

- ❑ I want to make some changes to my home so I can get around easier. Some changes people make are: a ramp, hand bars in the bathroom, and wider doorways. The changes I need to make are:

CHANGE TO MAKE	REASON I NEED TO MAKE IT
For example: I need a new ramp	My father used to carry me into the house because I couldn't get my wheelchair up the stairs. He can't do it any more. I need to get in my house!

- ☐ I need extra emergency help to live in my home. Right now I call this person/number if there is an emergency:

I need someone else to call.

- ☐ I need to learn to use 9-1-1 for emergencies when I can't reach family, friends, or my staff support.

- ☐ I need a person to help me with personal care in my home. Some of the things I need this person to help me do are:

HELP ME TO TAKE A
SHOWER OR BATH

HELP ME
IN THE BATHROOM

HELP ME WITH THESE
MEDICAL ISSUES:

OTHER THINGS:

Other things I think I need or want that will help me to live in the place that I want, with the people that I want are: _____

Are you making some decisions about housing? You can call or write the Division of Developmental Disabilities, or any of the other Resource Networks listed at the back of this book for help. They can give you more information. They can also help you walk through this booklet to make some decisions if you aren't sure. Either way, call or write today.

THINKING ABOUT MOVING

Objective: Get people brainstorming ways to overcome some “obstacles” to moving/living on their own (also helps promote teamwork!)

What to do:

- ❖ Number 8 ½ x 11” pieces of paper 1-50
- ❖ Tape/place paper on floor – connecting pieces in a “trail” to make a large “game board”
- ❖ Divide class into 2 teams – one person from each team is the game marker for their team
- ❖ Decide who goes first and give that team an “obstacle card”
- ❖ Team will work together to brainstorm a solution. Then they share the solution and spin to move ahead. The game marker moves ahead that many spaces.
- ❖ Each team gets one turn – brainstorms until they come up with a solution – if they “give up” they don’t move. (Don’t EVER give up!)

Nope, there isn’t much “strategy” to this game – just a roll of the dice! *But ...* the life size game board and interactive players as game pieces – plus each team brainstorming solutions makes it FUN!

Developed by Deb Kney, PAL
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Phone: 401-785-2100/508-252-5601, fax: 401-785-2186, email: debg@ids.net

These are some Obstacle Cards – You can make others. Ask the class members what types of obstacles they have faced or think about facing in regards to moving.

**YOU DON'T KNOW HOW TO
READ THE APARTMENT ADS
IN THE NEWSPAPER**

**YOU ONLY HAVE A BEDROOM
SET. YOU DON'T HAVE ANY
OTHER FURNITURE FOR YOUR
NEW HOME**

**YOU DON'T HAVE ANY
KITCHEN UTENSILS.**

**DON'T KNOW HOW TO
HANDLE MONEY**

**STAFF AT YOUR WORKSHOP
TELL YOUR PARENTS YOU
AREN'T "READY" TO MOVE
BECAUSE YOU CAN'T COOK**

**YOU WANT TO MOVE, BUT YOU ARE
AFRAID TO LIVE ALONE**

**YOU DON'T THINK YOU CAN
AFFORD AN APARTMENT ON
YOUR OWN**

**YOUR PARENTS TELL YOU
THEY ARE AFRAID YOU MIGHT
GET HURT IF YOU MOVE INTO
YOUR OWN APARTMENT**

**YOU COULDN'T GET IN THE
DOOR OF THE APARTMENT
YOU WERE GOING TO LOOK
AT BECAUSE THERE WASN'T
A RAMP.**

**YOU DON'T KNOW HOW TO DO
LAUNDRY**

Speak Up! Guide

6: Starting a Self-Advocacy Group

Published by:
STIR – Steps Toward Independence and Responsibility
and
Shifting the Power,
projects of the
Clinical Center for the Study of Development and Learning, UNC-CH
For further information please call Rebekah Pennell at (919) 966-5171.

Speak Up! Guide

Chapter 6: Starting a Self-Advocacy Group

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PEOPLE FIRST – NEW ULM OVERVIEW

I. How Our Group Got Started

In 1993 MBW Company made a commitment to assist people they support in having a self-advocacy group in New Ulm. We started with staff researching what self-advocacy is and presented the idea to the people we thought would be interested. We found about ten people who said they wanted to find out more about this.

The next thing we did was to set up an information meeting. We had two speakers who were in self-advocacy come talk with us. We talked about what self-advocacy means and what would make our lives better.

In our beginning meetings we all agreed that we wanted a better transportation system and better working conditions at our sheltered workshop. These two issues helped bring people together and created the enthusiasm and commitment we have today.

II. Election of Officers

We used the officers' handbook to help us elect officers. We talked about what officers need to do and what type of person we want as an officer. We reviewed the role of each officer. We then voted who we thought would do a good job.

(Role of officers from packet)

III. People First Meetings

Our group meets one time each month. Before each meeting we have an officers meeting. We decide on our agenda, what announcements to make, what program we want, what old or new business to talk about. We make a lot of decisions that is why it is important to elect responsible officers.

The Big Monthly Meeting

At our self-advocacy meetings we present what is on our agenda.

What we have done:

- ❖ We like to have speakers for our program on topics of interest.
- ❖ We have speakers from our workshop, the bus and our recreation service to talk about making the services better for everyone.
- ❖ Sometimes we do a survey before the speaker comes to help us know what questions we want to ask.
- ❖ Sometimes we do social stuff such as parties, picnics, dances.

Wilbur Neushwander-Frink and People First of New Ulm, Minnesota

Speakers we have had and topics:

- ❖ Ombudsman
- ❖ Fire marshal
- ❖ Sexual harassment
- ❖ First aid
- ❖ How to vote
- ❖ Videos
- ❖ Small group discussions
- ❖ Skits – riding the bus
- ❖ Rodonna's story

IV. Setting Goals

Goals give us direction on what we want to do for the year.

Every December we fill out a questionnaire on what we want for goals.

We put everyone's ideas together on a big piece of paper.

What I like about the meetings

What I want to do

What I want to change

We then set goals and we come up with projects from our goals.

V. Committees

After deciding on projects we set up committees to work on them. Ask for volunteers and a guide to help with each. Committee members report at the meetings.

Our committees are:

Newsletter – puts out quarterly newsletter

Presentation – presents history of self-advocacy to community

Social – plans social events

Fundraising – plans fundraisers

Recognition committee – helps recognize people's efforts by sending cards, planning celebrations. Features an advocate in the newsletter and helps close the meeting with motivational activities

Common vision -

Recycling -

Renters -

We do most of our work in our committees.

Goals Accomplished Since 1993

Fundraising Committee

Rummage sale
Hot dog stands
Candy bar sales
organizations
Cookbooks

Tupperware
Bowl-A-Thon
Letters to businesses and

Educate Community

MNASH conference presentation on SA
Scarecrow contest – banner
Set up new groups
Presentation – David Minge, MBW staff
Conference

parades
SA welcome booklets
Newspaper articles and pictures

Letter to MRCI requesting changes
ARS requesting input
Heartland

State convention
Educate direct care staff to SA
needs
Newsletter

98 presentations at AARM conference and Watonwan County

Educate ourselves

Workshops on leadership
Conferences
Partners in policy making
People First MN board membership
Voting
Ombudsman
Officers training
Sing
Open meetings

Training on labels
4 easy pieces
Rights
Sticks and Stones video
Dance
Retreats with ACT
Play – Let Heaven and Nature

Work with community organizations

ARS board membership
Community ed committee membership
Members of QA team
Heartland Express
Remembering with dignity video
MRCI board membership

Cab service – started coupon
system
Work with ACT – story to close
institutions

Service to community

Volunteer
Start new group – Mankato
Walk for Justice
German Park project
Recycling project at Flandrau Park

Nursing home party – bingo and
pie
Mentoring
Clean up Flandrau Park

PART I

SHARED VISION - BUILDING AN ORGANIZATION MISSION STATEMENT

What is vision? A picture that shows what the group is, where the group or a person wants to go, the “Big Picture” of Purpose and Meaning for a person or group.

For James, a vision may be a house of his own, a job and being a contributing citizen of the community.



Visions create the SPARK – the excitement that moves a person forward.

Imagine that you can achieve the things you want in life. What would that look like to you? What words would you use? Or pictures? Why do you want to do these things? Or be that kind of person?



Your own apartment or house

A Job working at the local store!

Having a pet....

Taking care of you own house plants

Going to the movie of your choice.

Shopping

Swinging at the park

Wilbur Neushwander-Frink and People First of New Ulm, Minnesota

Personal Vision

With a partner, describe your personal vision.

Self-Image: What kind of person do you want to be? Describe these qualities.

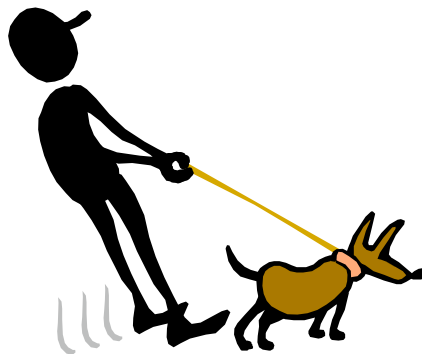
Example: James wants to be kind, hard working, and independent



How about you? Why do you want to be that kind of person?

Things you would like to own: What types of things would you like to own?

Example: James would like a dog.



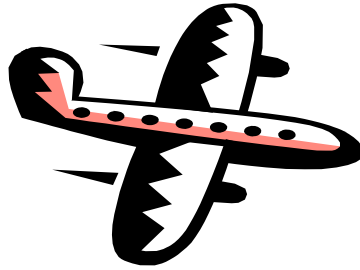
How about you?

Personal Vision

Personal learning

What would you like to learn or do?

Example: James would like to learn how to dance and travel to Las Vegas.

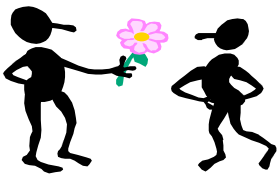


How about you?

Why would you like to do those things?

Community: What would you like your community to look like where you live?

Example: James would like to have friendly neighbors and join a musical group.



How about you? Why do you want that for your community?

Personal Vision

Home: What would be your ideal living situation?

Example: James would like a two-bedroom home in a friendly neighborhood.



How about you? Why would that be your ideal living situation?

Health: What is your ideal desire for health and fitness.

Example: Jane would like to have fewer seizures and go to the fitness center two times a week.



Look at me, only one seizure
last month. I take my pills
and see the doctor regularly.

Personal Vision

How about you? Why do you desire, and why?



Vision

When you look at what's important to you, it makes you feel good. It gives you a clearer picture of where you would like to go.

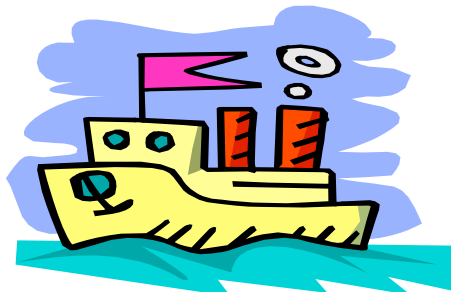


James without a vision



James with a vision

A vision is like a rudder on a boat. It keeps you moving on the right course.

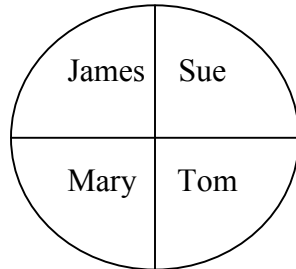


James is moving in the right direction. He is steering the boat!

PART II

SHARED VISION – BUILDING AN ORGANIZATIONAL MISSION STATEMENT

We have looked at our own personal vision. When we are a part of a group, we bring our vision to it. It is a part of a greater whole.

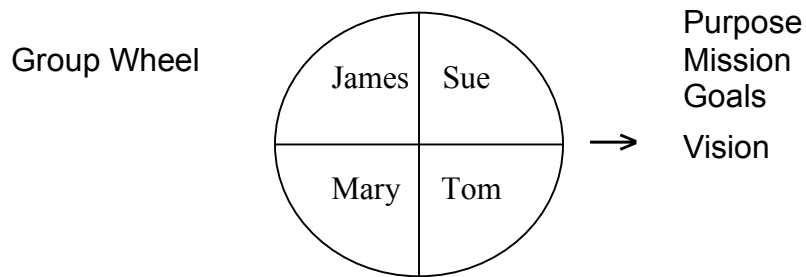


Group=Wheel

Individual=Spokes

The group is like a wheel and all the members are spokes. When we put all the spokes together, we get a functioning wheel. It is whole. It will roll forward.

When the whole wheel is together it will work and the group can do things and really “go places”.



The Group Now

Where the group wants to go.

Where do the group visions come from?

Each member of the group (a spoke) brings its vision to the group. Groups usually form for a common reason.

Shared Vision

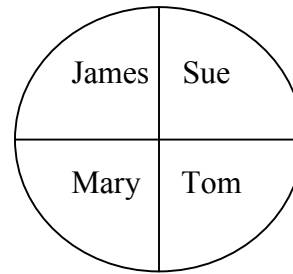
James



James



Group

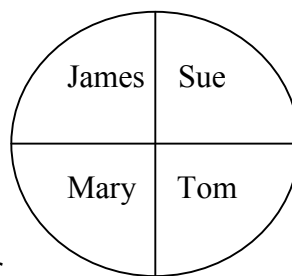


Group with a common purpose,

James wants to learn how to speak up for her rights as a person with disabilities. She wants to learn how to be a leader.

(Use cardboard cutout or wheel with broken spoke to illustrate)

When groups form for a common reason, they can create a tremendous amount of energy together to move forward towards a shared vision.



⇒ Common or shared vision

Group moving together

What does it mean to share a vision?

A vision is to have a common cause, or reason to move forward as a group.

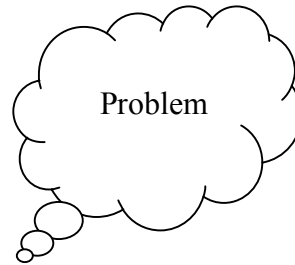
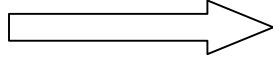
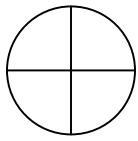


James, Kevin, and Mike want to learn to speak up for the rights of people with disabilities.

(use connecting paper people to illustrate)

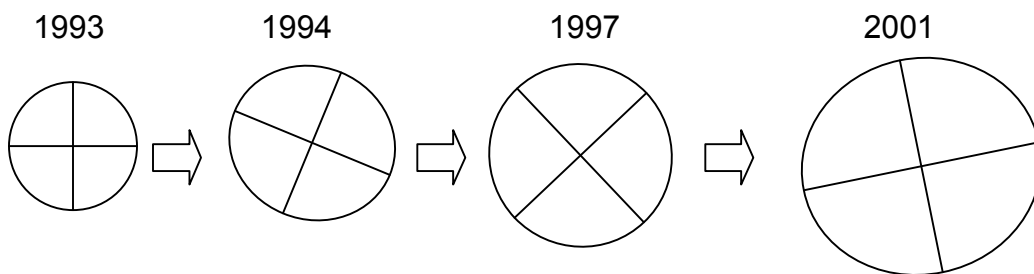
Shared Vision

Shared vision helps us to solve problems.



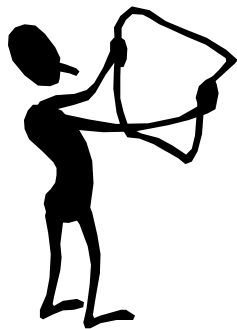
Shared Group Vision

Shared vision takes time to grow.



The shared vision growing.

Building shared vision requires careful listening so that individual vision can be built into the group.



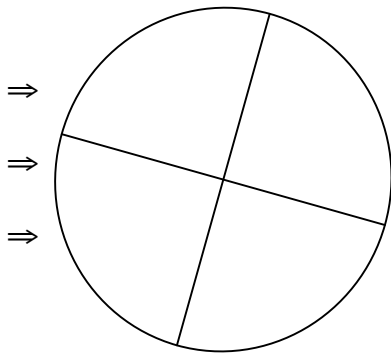
James is talking about his personal vision to learn how to speak out about the rights of people with disabilities.



Kevin listens carefully.

Shared Vision

A shared vision can create energy and hold people together so they can achieve the vision of the group.



“Shared Group Vision”

Shared Visions:

- 1) Do not come from “on high” – do not give them to you.
- 2) Are ongoing and never-ending. It is part of what the group does with every action it takes.
 - * Leaders must help design and nurture the vision. Leaders must share their personal vision.
- 3) It is not a shared vision until it connects with all of the personal visions of the group – such as with Jane, Kevin, and Mora wanting to learn how to speak up for the rights of people with disabilities.

(Give everyone a triangle piece).

Shared Vision

It is important to write down what your vision is.

Why?

- 1) So all members of the group know what it is at all times.
- 2) So other people will know what your group is all about.

The Mission or Vision Statement of People First

- This is called a vision or mission statement of your group.
- The statement is usually short and put into words or pictures that the whole group can understand.
- The statement is a constant reminder of your shared reason or purpose in coming together.

How can we start to write this vision statement?

Let's work together in steps to get to it.

Vision Statement

PART III

SHARED VISION – BUILDING AN ORGANIZATIONAL MISSION STATEMENT

Writing a Statement

Let's Brainstorm



- Throw out words and pictures to describe People First of New Ulm.

Person Centered

innovative

Grassroots

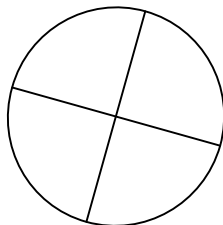
- What words or pictures would describe the purpose of People First of New Ulm?

Self-determination

Choice

Self-advocacy

- Let's build a wheel structure to start to put together a statement.



Let's take from our lists and put what you see as "most important".

(Everyone will put one word or a short sentence on the wheel or do it in groups if more than 8 people)

Writing a Statement

- How does the wheel look? Does it say what the group is all about? Purpose?

- Ask the group

Would you like to leave it in the shape of the wheel?

Or

Write a statement based on the words in the wheel.

- Ask the group to re-visit statement at next meeting.

Who will present it?

Take a vote on it.

Project Notes

08-25-98
Meeting 1
Contract

Today was the first meeting of the project. The officers/mentor group met to discuss the project contract and sign it. We reviewed the following items: Terms of the contract, this writer's role as coach/ally for the project, setting a time to set a budget for the next year and discussing times to meet.

The group asked thoughtful questions about the project. They were concerned about recruiting more advocates and guides to participate in the project.

People attending decided to present a short information session at the next People First general meeting. This would give all members an opportunity to hear about the project and have a chance to volunteer. After a list of volunteers is collected, a task breakdown meeting will be held to give people more information. It will be an opportunity for people to volunteer for various activities within the project.

A budget meeting/dinner will be held on September 2 to set a budget for project monies received. After this meeting, the People First treasurer and this writer will meet with an accountant to set up a _____ and accountability of monies received.

This first meeting was an excellent learning experience. As a coach, it is not my place to do the work and make decisions. One must provide information and guide people in the thought process of making important decisions. I recognize that I need to work on this. I saw that I was able to give information and let them process it. My challenge will be to guide in thoughtful decision-making without swaying the decision or making it.

Project Notes

09-03-98
Meeting 2
Budget

This week's meeting focused on establishing a budget for the funds for the project. The officers and mentors for People First of New Ulm were present at the meeting.

The following items were considered for the budget. The group needed to plan for \$9,000.00. The group set a budget for mileage reimbursement, wage replacement when working at the retreats and traveling to work with other groups, materials, parties and celebrations, video resources, tuition for People First members attending the retreat, meals, accountant fees, facilitator's wage, and phone usage.

People First of New Ulm members decided to not use a fiscal beneficiary to handle the project money. With the assistance of their coaches and an accountant, the group will handle project monies received.

The group spent approximately two hours in its initial planning process. Considerable dialogue was spent on topics such as wage reimbursement and a facilitator's wage. The group opted to pay both of these out at minimum wage for now.

The group will have a second budget meeting in October to revisit the accounts and budgets. The treasurer and Project coach will meet with the accountant in two weeks to discuss how we will document on the money spent. We will need to develop a system of accountability for project monies. We will also need to discuss the accountant's fee.

The group needed some coaching to work through this part of the project. Many members have only minimal experience with budget establishment. This writer used large poster paper to show the group how much we had to work with and what areas needed to be considered in the budget. This process worked well as visual guides are helpful. We will ask the accountant to help us develop a computerized pie graph to visualize amounts for the group.

Project Notes

09-23-98

Meetings 3 & 4

Retreat training

Accountant

The retreat facilitators prepared for the second retreat, which will focus on power relationships and organizing around issues. People First will present a summary on the leadership aspects of the last retreat. We will also show the video "The People's Firehouse". This video focuses on a real-life example of grass roots organizing. We will show the video and then ask retreat participants to discuss the various aspects of the video. We will try to focus on the organizing efforts and leadership demonstrated in the video.

The two People First facilitators enjoy the process of working on retreats. They actively participate in planning related to the retreat. It is wonderful to see how people have grown in confidence and in their own leadership skills. I think it is important for people to have meaningful participation in order to see true growth and development. I will address this issue in a separate paper on participative or shared leadership.

Members of the group met with the accountant who will be assisting us with our financial accountability. We reviewed the budget prepared for incoming project money. The accountant _____ computerizing our quarterly statements, and will meet with us quarterly to review ledger statements.

Two People First members will be actively involved in the financial aspects of the project. They will attend all financial meetings and keep track of the ledger system.

The project is up and running. It truly is a process. We don't have prior history of experience with anything of this scope. People are flexible, however, and willing to learn as they go along. Our challenge this year is to discover ways in which a variety of people can be involved in meaningful ways. This will require flexibility and creativity. This will be addressed at our next leadership meeting in early October 1998.

Power and Organizing

Retreat #2

Sept. 25 & 26, 1998

The second retreat focused on power, leadership, and organizing. Anne, Rodonna, and I participated in this two-day retreat with those from Advocating Change Together.

Anne, Rodonna, and I focused on the first half-day as a summary on leadership and the viewing of a film called "The People's Firehouse". We reviewed points on leadership focusing on the idea of shared leadership and leadership skills. We approached the process of leadership as a journey that we take. We talked about how it starts with someone having a vision. They have seen a place they want to share with others. They share in this visioning process by including others and accepting them for who they are at that moment. As people take this leadership journey they may discover as they go talents and skills. These skills are within them and they can learn how to use them as they take the leadership journey.

We shared a story about how geese conduct shared leadership. We asked people to close their eyes and imagine the geese as we read about their "leadership" skills.

We also discussed the relationships of power as they were illustrated in the video "The People's Firehouse".

With power issues, we discussed how power changes as one exercises leadership skills. Retreat participants shared personal experiences related to power issues in their own lives.

It was interesting to note how confident Anne, Rodonna, and Jenny were at this retreat. They readily shared ideas and opinions. They also actively engaged people in conversation. As their confidence has grown they are willing to speak with others in an open and honest way. They have grown as leaders.

At this retreat we networked with other group members and exchanged information on what our group could do to assist them. We concluded the retreat with a visioning of the future for self-advocacy. The next grouping of retreats will be in the winter.

Project Notes

10-12-98

The group is now actively engaged in Part II of the Common Vision project – technical consultation. Our first consultation will be in Windom with a group of people interested in starting a self-advocacy group.

The officer and mentor group has been brainstorming on how to assist other People First members in becoming involved in the project. At their general meeting on October 14, Anne and Mike will present on the project. They will invite people to join them for a special in-service and volunteer session on October 28.

The project participants would like to start five small work groups where volunteers could work with trained people. Each group will focus on one area from around South Central Minnesota. These work groups will personally connect with the group assigned to them. They will have an opportunity to assist other groups in starting up self-advocacy organizations. They will also learn to assist these groups in how to organize around issues important to them.

We are not sure if this process of work groups will be helpful to people. We will need to _____

The project members also started a checking and savings account today. They were excited about this and also about getting paid for their work as facilitators. The pride in their work was quite evident. It was a pleasure for this writer to see and makes the hard work of the project enjoyable.

Project Notes

10-26-98

Participants from the project traveled to Windom on 10-19-98 to talk with people from Windom and Marshall on self-advocacy. There were approximately 25 people in attendance for this gathering.

Anne, Rodonna, and Jenny presented a short history on when People First – New Ulm started. They gave a few personal stories on how self-advocacy has helped them grow as leaders. The participants then assisted people attending in how to start meetings, elect officers, set agendas, set goals, and how to fundraise. We also role-modeled a mock meeting for attendees to view.

We ended the gathering by asking people attending to gather in a circle, hold hands, and join us in our closing words, “Together we’re a team, Let’s do it!” We had time to network with people informally and share phone numbers.

Anne, Rodonna, and Jenny agreed that this first gathering was successful. We decided to polish up our notes and posters prior to our next gathering.

On 10-26-98, this writer met with the guide leader to work on a proposed agenda for the educational meeting for the membership of People First – New Ulm. The meeting will provide people with more information on the project and invite people to be more active participants in the project. We will look at a variety of volunteer opportunities available for people to participate in. We will invite people to become a part of one of the five work groups working with regional groups. The hopeful outcome will be for the Common Vision project to include a wider circle of people.

Jenny, the project treasurer and this writer will meet on 10-27-98 to begin her system of accounting for the project. Various bills will be paid and tracking of money will occur. Jenny and this writer will meet with our accountant in November to review the process.

An evaluative summary for the first quarter was completed and sent to our partnership organization in St. Paul. This summary will be included in a report to the State of Minnesota’s Department of Economic Security. A copy of the summary is included with the project report.

Project Notes

11-02-98

Common Vision General Meeting

The core group of people working in the project had decided to have a general informational meeting to inform more people about the project. General members of People First – New Ulm were invited to an informational meeting on October 28, 1998.

Approximately 25 people attended the meeting that afternoon. Mike and Anne presented an overview of Common Vision. They used large poster paper to illustrate their points. After this basic informational session, people were invited to volunteer for a variety of activities. These activities ranged from general committee work to specific Common Vision work groups.

There was quite a bit of energy and excitement around volunteering. People wrote their own names on the sign-up sheets and chose their own committees. All the available spots for Common Vision work groups were signed-up for.

The core members of the group did a fine job at presenting material and describing volunteer activities. Their growth as leaders increases daily. I am in awe of the experience these people bring to the group as a whole.

The next step in the process is to meet with individual work groups assigned to regions. This writer will be guiding two work groups and assisting the other three as needed.

This writer's plan is to have a large work group meeting in early December. This meeting will focus on the basics of leadership and community organizing. The group will have an opportunity to develop individual leadership posters and learn about the spiral model of organizing.

COMMON VISION PROJECT – PEOPLE FIRST

MONTHLY CASH DISBURSEMENTS

4TH QUARTER 1998 SUMMARY

	October	November	December	Total
Consulting Fees/Retreats	\$ 428.00	\$ 152.60	\$ 100.00	\$ 680.60
Accounting/Legal Fees	25.00	25.00	25.00	75.00
Mileage Reimbursement	-0-		56.70	56.70
Office Supplies	68.31			68.31
Reference Materials	-0-			-0-
Tuition – Retreats	496.00			496.00
Lodging	-0-			-0-
Meals	47.91			47.91
Celebration Expense	12.80			12.80
Telephone Charges	-0-			-0-
Videos	196.00			196.00
Totals:	\$1274.02	\$ 177.60	\$ 181.70	\$1633.32

COMMON VISION PROJECT – PEOPLE FIRST

MONTHLY CASH DISBURSEMENTS

October, 1998

Date	Check No.	Check Issued To	Consul.Fee s/ Retreats	Acctg./ Legal Fees	Mileage Reimb.	Office Supplies	Reference Materials	Tuition/ Retreats	Lodging	Meals	Celebration Expense	Telephone Charges	Videos	Total
10/27/98	109	Current-Labels				9.45								9.45
10/27/98	108	Chris Janns Accountant		25.00										25.00
10/27/98	107	Anne Roop	184.00											184.00
10/27/98	106	Rodonna F.	184.00											184.00
10/27/98	102	Rita Werner	20.00							26.56				46.56
10/27/98	104	Advocating Change						496.00					196.00	692.00
10/27/98	101	D.F.N.U.									12.80			12.80
10/27/98	105	Jenny Bauer	20.00											20.00
10/27/98	103	Wilbur Frink	20.00			6.70				21.35				48.05
10/27/98	110	Kmart				30.18								30.18
10/28/98	111	MBW, Co.				21.98								21.98
		Totals:	428.00	25.00	-0-	68.31	-0-	496.00	-0-	47.91	12.80	-0-	196.00	1254.02

Problem Solving – Relaxation

What do you need to know so you can solve problems in your life? You need to know about three things:

- 1. How you feel.**
- 2. How to relax.**
- 3. Problem solving steps.**

In order to make a good decision you should be calm, have a cool head, and have complete control over your behavior. Remember, when you are ready to relax, choose a place where you can concentrate and not be interrupted by other people or activities. Choose a quiet place and choose a chair with a straight back so you can sit up straight in a relaxed position with your

feet flat on the floor. Sometimes, it's hard to pay attention and do everything that is necessary to relax, so you might want to have someone sit and relax with you and help you remember the things that we talk about today.

Now that you are ready to relax, sit in the relaxed position, with your hands resting comfortably on your legs, close your eyes, and take a deep breath. Let it out slowly. Feel the way that your whole body begins to relax when you let out a breath. You're starting to feel better and you're starting to feel more relaxed already.

Now relax your shoulders. Let them droop down. Move your shoulders slowly so all of the tension goes away. Your shoulders are drooping down, and you feel so calm and quiet and relaxed.

Now this comfortable, relaxed feeling spreads down your arms all the way to your hands. Your arms and hands are resting on your legs and they feel heavy and calm. Your whole body is feeling relaxed.

This warm, calm, comfortable feeling spreads down to your legs --- all the way to your feet. Your feet are resting flat on the floor and they feel heavy. Your whole body feels calm and relaxed.

Now take another deep breath and let it out slowly. Think about how good you feel. You are quiet and calm and rested. You feel so peaceful. It feels so nice and you can remember this feeling so that anytime that you have a problem or start to feel upset, you can just take a deep breath and relax.

You've done a good job.

Problem Solving – Steps

- STEP 1: Relax**
Take a deep breath and let the air out.
- STEP 2: Say something positive.**
Saying something positive gives you confidence and makes you feel good about yourself because it helps you remain in control. Say, “It’s ok. I can figure this out.”
- STEP 3: Identify the problem.**
Ask yourself, “What is the problem?”
- STEP 4: Think of solutions.**

What can you do to solve the problem?

STEP 5: Choose a solution and just do it!

Problem Solving – Role Plays

Watch as we show you some role plays. We're going to act out a few scenes and ask for your help to go through the problem solving steps.

Role Play 1: The Soda Machine

You are at work and it's time for your break. You decide to go and get a soda. You put your money in the machine, and push the Coke button but nothing comes out.

Role Play 2: The Phone Call

You need to make an emergency phone call and you are waiting in line to use the phone. The person in front of you finished their phone call when someone cuts in front of you and begins making a call.

Role Play 3: The Library

You are in the library studying for a big test that is on the next day. There is someone studying at the table beside you. Another person comes and sits down and starts talking loudly with the person at the table beside you.

Activity found in Chapter 3, pgs 6-7

Speak Up! Guide

7: Being a Part of the Community

Published by:
STIR – Steps Toward Independence and Responsibility
and
Shifting the Power,
projects of the
Clinical Center for the Study of Development and Learning, UNC-CH
For further information please call Rebekah Pennell at (919) 966-5171.

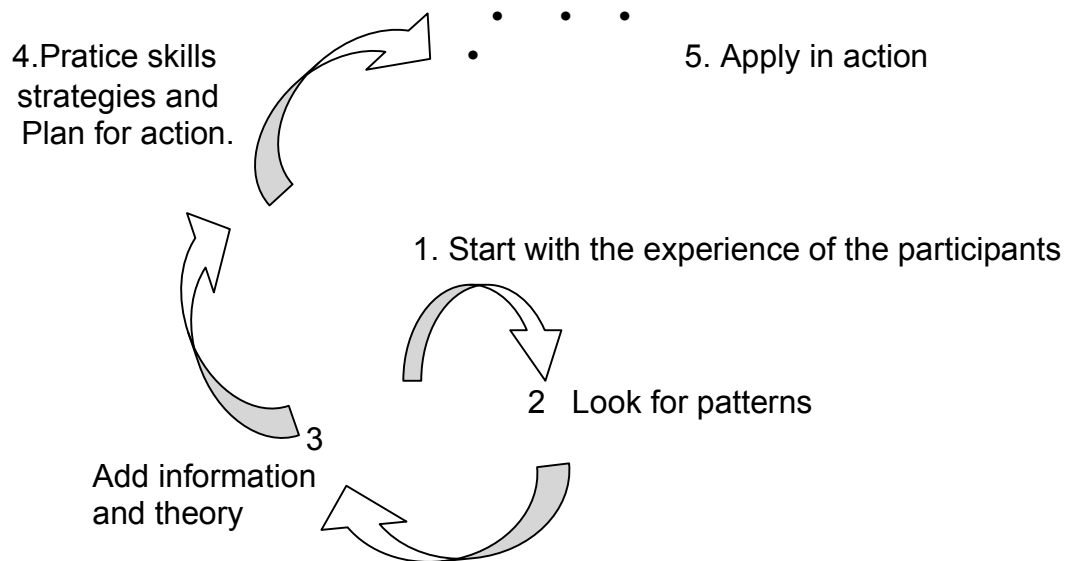
Speak Up! Guide

Chapter 7: Being a Part of the Community

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Spiral Model



This model suggests that:

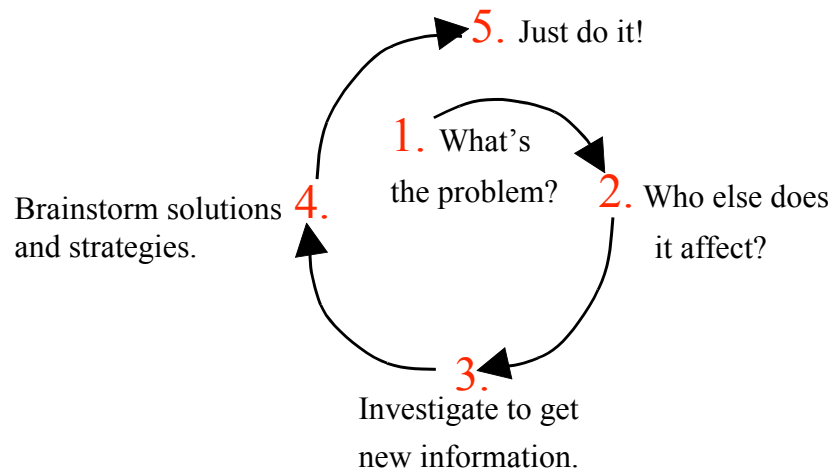
1. learning begins with the experience or knowledge of participants;
2. after participants have shared their experience, they look for patterns or analyze that experience (what are the commonalities and what are the differences?);
3. to avoid being limited by the knowledge and experience of people in the room, we also collectively add or create new information or theory;
4. participants need to try on what they've learned: to practice new skills, to make strategies and plan for action;
5. afterwards, back in their organizations and daily work, participants apply in action what they've learned in the workshop.

ACT

Advocating Change Together

Courtesy of Doris Marshall Institute

The Spiral Model



The Spiral Model

1. What is the problem?
 2. Who else does it affect?
 3. Investigate to get information
 4. Brainstorm solutions and strategies
 5. Just Do It!
 - Choose the strategy
 - Do it!
 - Did it work? If not, try another strategy
-

CHOOSE IT OR LOSE IT

Time: 30-45 minutes

Goal: to provide a framework for choosing issues.

Materials: blackboard or flip chart and markers.

Description:

This exercise helps participants understand the significance of choosing the right issue for their group. Participants consider the overall makeup of their group and practice selecting issues that address their beliefs as self-advocates and benefit their group in the long-term. In analyzing who they are as a group, participants learn the value of choosing issues that build lasting leadership, on both a personal and group level.

Directions:

Read the following profile of a self-advocacy group: it states who they are, what their goals are, and what issue they are currently working on. (If all participants are from one group, they may choose to use their own group profile for this exercise.) One person from each table must act as facilitator and read the profile aloud. Have participants pretend that this is their group. These are their goals, and everyone must act as if they are working on this issue. When they've gone through who they are and what they are working on, use the Issue Checklist to determine if this issue is a good fit for their group. Ask each group to report their findings to the larger group when they're finished.

Group Profiles

- 12 year old People First group
- Staff support of 10 hours per week through a parent advocacy organization
- Office space at the Arc with access to a photocopy machine, a telephone, and a fax machine
- You have 25 members – some very active, some not
- Your group meets once every week
- You have a track record of success with small issues, such as getting a microwave in your lunchroom at the workshop
- \$10,000 annual budget through small grants
- Members participate in statewide self-advocacy every year
- A newer member has personal connections with a local reporter
- Most members work at the workshop or get SSDI

Goals of the group:

- Bring in new members
- Make sure everyone feels welcome
- Raise \$5,000 through a fundraiser
- Make more connections to the larger disability community
- Break away from the parent advocacy group and become an independent organization
- Have new leaders to work on issues
- Increase visibility in community as a “real” organization
- Do more work together with other social change, social justice, and neighborhood groups
- Have fun!

Current Issue: Make our neighborhood safer

Additional information:

- Two members assaulted recently
- Poor lighting on streets
- Bus stop is a hang-out for teenagers
- Drugs being sold at vacant parking lot
- Neighborhood safety group interested in working together
- Media is somewhat interested in safety issue
- Your group has had success at working with city to increase police patrol

Is this a good issue for your group? Why?

Checklist for choosing a good issue:

Will the issue:

- | | |
|--|--------|
| - Result in meaningful change for people? | YES |
| NO | |
| - Give people a sense of their own power and leadership? | YES |
| NO | |
| - Build your organization? | YES |
| NO | |
| - Change the relations of power? | YES |
| NO | |
| - Be winnable in your own terms? | YES |
| NO | |
| - Be easy to understand? | YES |
| NO | |
| - Involve new people in your organization/group? | YES |
| NO | |
| - Be consistent with your values and vision? | YES NO |

Take a few minutes at the end of this exercise to go over the group's responses. Can participants think of other issues that would be a good fit for their profile? When considering issues for new groups, encourage participants to look for issues that can be realistically achieved. A track record of success, even small successes such as getting a microwave oven at the workshop dining room, will lead to greater success in the future.

Action Step: Working in groups, ask participants to name an issue they have worked on and evaluate it through the Issue Checklist. Have the larger group discuss whether this was a good issue for the group.

ORGANIZING FOR CHANGE

Time: 30-45 minutes

Goal: to give participants experience in choosing issues, developing strategies, and selecting tactics.

Materials: blackboard or flip chart and markers

Description:

This exercise provides scenarios where self-advocacy groups are faced with the need to make important decisions. Through choosing issues, making plans, and selecting tactics, participants are encouraged to consider how their decisions and actions will affect their group, and their community, in the long term. They will also consider the consequences of other groups developing goals and strategies for them.

Directions:

Read the following scenarios and choose an issue that best meets the needs of your group. You may choose an issue from the stories below, or use one of your own. Read the checklist carefully and make sure all group members are comfortable with the issue they choose.

Facilitator's Tip:

The group should agree on time to be spent on an activity. It is respectful to the group to keep track of this time agreement and let participants know where they are in the allotted time. It is okay to go slightly overtime, but anything more than this should be arranged by group agreement.

Part One: Identifying the Problem and Choosing an Issue

SCENARIO ONE

You work with a disability rights organization that has been around for twelve years. Your group is small but very strong, with a lot of community support. Since your group started, it has helped people learn to speak for themselves and stand up for their rights. For the past three months, you have worked with other community members in making your neighborhood safe. This has been important to your group because two of your members were assaulted over the past year.

Recently, a government agency – the Planning Department – has started providing “self-advocacy training” to individuals with disabilities. Although your organization has a good track record for doing this kind of work, the Planning Department claims that they are better qualified to do this, since they have a large professional staff and financial resources. You know and even like many of the people in the Planning Department, but you feel their new direction may undermine your organization. When your group discusses this concern with the Planning Department, they offer to use a few of the more experienced members of your group in their trainings. They even offer to pay a \$25 stipend to each person who assists them.

Some of the members of the group want to work with the Planning Department, especially if it means earning \$25. Other members worry about being used by the Planning Department, about being treated as tokens. Larry, a quiet member of the group who usually doesn’t speak much, says “I thought our mission was to help people with disabilities. I don’t care if we do trainings or if they do them, as long as we’re helping people.” But some people disagree with Larry.

SCENARIO TWO

Your self-advocacy group has been around for over ten years. There are over 25 members, four full-time staff, and dozens of volunteers. Over the years, your group has had many victories as you’ve responded to problems in the community. You have helped people with disabilities get better jobs, you’ve made the community more accepting of people, and you’ve helped people to take control of their own lives. But now, after all these years, your group is getting a little tired. The same people in your group have been making all of the decisions and the others feel left out.

Recently, there has been a lot of news coverage of people with disabilities working for low wages in workshops. One of your members was even featured in a newspaper article, talking about working long hours and only making \$2.00 per hour. Most of the group members are excited about this, but the group leaders – the ones who make most of the decisions – are not very interested, and the others are not comfortable speaking up.

During your last meeting, the group decided to plan what they would be working on for the next year. Some suggestions the group raises are 1. Fighting discrimination against all persons with disabilities, 2. Raising the minimum wage, 3. Closing all institutions in the United States, 4. Creating better job opportunities in the community, and 5. Using technology. Which issue, if any of these, will you choose.

- As a group, describe the problem.

- Describe your group: What are your strengths & weaknesses?
What kind of support do you have in your community?
- What will happen if you ignore the problem?
- What would you like to have happen?
- What issue will you work on?

Go through the following checklist for choosing an issue:

Will the issue:

- Result in meaningful change for people?
- Give people a sense of their own power and leadership?
- Change the relations of power?
- Be winnable in your own terms?
- Be easy to understand?
- Have clear goals and objectives?
- Involve new people in your group?
- Be consistent with your values and vision?

Facilitator's Tip:

It is more important that everyone shares their perspectives than that everyone agrees. If differences of opinion arise, it can be helpful to explore or at least note them. It is important, however, that conflicts not become personal or attacking. If this happens, restate the need for respect of differences or any related group rules.

Part Two: Planning a Strategy and Choosing Tactics

Now that you've chosen an issue, you have to plan a strategy to map out where you're going, and choose tactics in order to get there.

Like planning a trip, planning a strategy begins with the knowledge of where you are and where you want to go. You need to know where your starting point is: the strengths of your group, what skills and abilities you have, what resources you have, and who your friends are. A good strategy involves considering a variety of tactics, or steps, for moving an issue forward.

Begin by thinking of as many tactics as you can. Even if they seem silly or impossible, list as many tactics as you can think of. Sometimes the most creative tactics come from people who have never before organized around an issue.

Now that you have a list of possible tactics, decide which ones are the best fit for your issue and your organization. Use the following checklist to help you pick the best tactics:

Does our organization have the ability to do this?

Does it affect a lot of people?

Does it bring people closer together?

Does it really involve the people in your group, and others you may join in the issue?

Do people feel strongly about the tactic?

Is the tactic simple and easy to understand?

Does the tactic build your organization? Will working on this tactic in any way help you in the future?

Is this tactic fun? Will your group enjoy working on it?

After you've considered your strategy and picked your tactics, share your plans with the whole group. Tell others how you are going to pursue your issue and what you think it will do for your group and for the community.

Supporting Individuals With Developmental Disabilities And Family Members On Governance Boards

Strategies for Making it Work

By
Jill Flynn
Laurie Powers, Ph.D.

Published by the Oregon Self-Determination Project
June 1999

Supporting Consumers on Governance Boards

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What is consumer governance?

A board makes decisions about the direction of an organization. Consumer governance means that people who receive services have meaningful roles in the decisions made about how services are offered. Consumer governance must include people who might qualify as consumers, or users of that service. As we talk about Self-Directed Supports, consumer board members are individuals with development disabilities or family members who want to be involved in governing the program.

??

Why have consumers involved in governance?

The word consumer implies a person has choices and some control over the way resources are spent. While we have been using this term for years, the choice of services has not been terribly extensive, and the power of individuals to control how services would be provided has been minimal. Individuals with disabilities and their family members “must have meaningful voices in their own affairs and decisions made for them as citizens” (From Not Another Board Meeting). Any board that serves individuals should include the very people they serve as their members.

One crucial thing to remember is that this will only work if an organization sincerely believes people with disabilities and family members have the right to be at the table and active in discussions. Governing boards which have successfully supported consumer members have set up a “culture of support” which makes meetings more accessible for ALL its members. An organization must sincerely “buy-in” to this goal of creating a culture where members feel respected and safe to speak up. This means that the organization has truly asked itself questions like the following:

?? “How will we – personally and as a group – continually challenge our own and others’ misconceptions and stereotypes about people with disabilities?”

?? “How will we improve the way we communicate to all board members?”

?? “What will our commitment to support individuals with disabilities and family members as group members *really* look like?”

It is important for us to benefit from the experience of individuals with disabilities and family members. Yet, to benefit from their expertise requires an investment. Whether that is an investment in time, or in dollars for transportation, respite, or personal assistance, the investment will be worthwhile.

Organizations do not have any business inviting people onto governing boards if they are not committed to supporting members who need assistance. This support takes time and is most successful when based on the general roles and responsibilities of being a board member. It is critical to take time to establish a relationship of respect between those staff in the organization who are doing the supporting and those members who require assistance to fulfill their duties.

QA

Quality Assurance

How can a governing group make sure that they are on track? How can they measure how well they are doing in ensuring the meaningful involvement of individuals and families at the same time they measure how well they are getting their work done? We have put together two tools to help board members measure their progress.

First, board members fill out an evaluation of their board process on how productive they have been and where they need to improve. This gives them the opportunity to look at what they are doing in the big picture, getting away from the details they work with each meeting. The next tool is a checklist of things that should be in place if a consumer board is working well. These Quality Indicators should be reviewed honestly by the board, as a way of evaluating how well the organization is working for its customers. Samples of both tools are found at the end of this document.

Successful Strategies To Recruit, to Orient & Train, and to Support Consumer Boards

Recruiting

Recruiting board members who know everything about your organization is basically impossible, so there is always a need to inform people about what it is you do. The best way to do this is to hold regular, informational forums about the organization, a couple of times each year. Invite a broad group of people to attend, making sure to send information about the forum to parents and self-advocacy groups.

Customers of the organization are also a good source for board members. After all, they know what you do and they are likely to be invested in making sure you do a good job. Having customers on the board is not a conflict of interest as long as they act in the best interest of the organization as a whole. This means that they care about the organization, are loyal to the decisions made by the board, and follow the rules of the board process.

To keep a board strong, it is necessary to do ongoing recruitment. Do not wait for vacancies on the board. Instead, build a pool of people who are interested in joining when an opening comes up. To do this requires regular forums, sending information to customers and contacting specific people who you want on the board in the future.

The board members you want are people who are interested in the work of the organization. You want people who can understand the mission, figure out what that means to them and then figure out how they can support that mission for the good of the customers served by the organization. Members must be willing to actively participate in a governing group that is responsible for making sure the program follows its mission.

Many of us have had the experience of being on boards where some people are “token” members. We may even have been those “tokens” ourselves because we have a characteristic, like disability, that is needed on the board, but we are not listened to and we do not actively participate. Boards and their members cannot allow this to happen. Everyone on the board must have responsibilities and the organization must give support to make sure each member has a fair chance to participate and do their jobs as board members.

KEYS TO A SUCCESSFUL RECRUITMENT

1. **Determine what the strengths and weaknesses of your current board are.** Determine what qualities of skills in board members would strengthen the group. If a lawyer or an accountant is something you are looking for, find one who has experience with disabilities, whether through themselves, as a family member, or as a friend or colleague. It may be a customer of your organization whose perspective is needed to round out your board.
2. **Come up with an initial list.** Then be creative and go beyond that first list of potential members, since those people are usually busy already. In every community, there are leaders every group wants to get involved. Keep your eyes open for the budding leaders who, with a little experience, mentoring and support, could emerge as extremely valuable board members.
3. **Talk about the expectations you have for board members up front.** Send potential board members a letter with general information about your organization, the length of a board member's term, and an invitation to call if they have questions. This, of course, must be done in easy to understand language. Invite them to attend a board meeting to see how it works.
4. **Hold informational meetings or Forums.** Share information about your organization and activities and the expectations for board members. Then invite all still interested to apply. Offer assistance in filling out applications and supply it as needed. Keep the applications simple (see samples). Make these meetings fit the character of your community. In some communities, this has been done as a potluck or a barbecue.

ORIENTATION

Process:

Set up a way of giving an Orientation to new members.

This might look different in various groups.

- One-on-one meetings, or a full day meeting, if a number of new members will come on at the same time.
- Consider filming a video presentation with key information for new members to view.
- Have a consistent policy, with who does what clearly laid out.

Information:

However you do it, there are things to include in your Orientation of new members.

- The mission of the organization and its goals and activities (a brief history of the board, including past minutes and a timeline of events).
- Also, provide a short discussion (and info sheet) on the board's current or upcoming issues.
- Clarify the role of the board (as a policy making group) and the role of the organization's lead staff (as manager of the organization). Also, clarify other staff roles.
- An organizational chart, show the board's committee structure.
- A Who's Who On the Board info sheet, with short biographies (maybe even photos) of each board member.
- Provide a cheat sheet of acronyms specific to the issues of this governance board.
- Board member responsibilities: attendance expectations, how to handle conflict of interest, legal responsibility as a board member, asking for supports or information when it's needed, and financial responsibilities and the impact of the board's fiscal decisions. Provide a Board Member Position Description (see sample).
- It is important the board realizes how what they do impacts the customers served by the organization. This can be done by a series of customer profiles (written or on video), to show how the process works, what it means to different customers, what it is like being a customer coming in for service.
- Don't forget the basic details like the layout of the office, and where the bathrooms or the coffee are found. How can they get reimbursed for their expenses and when? These questions answered up front will strengthen open communication later.

A special note on Orientation & Training: Organizations may need to make extra efforts to increase the meaningful involvement of consumer members in these two areas of key responsibility:

- Budget discussions.
Make this mean something to members.

- Strategic planning for the group
-

TRAINING

All boards can benefit from training now and then. Staff to consumer boards need to spend additional time in this area, in order to give individuals and families more background information or training in skills which they may not have had the opportunity to learn yet.

Consider these training sessions for all or some of the board members:

- Simply, “How Meetings Work” – not everyone will be familiar with the rules to follow in meetings or with meeting etiquette. This can be a formal training or a facilitated discussion.
- A discussion about what supports are or are not working (general and personal supports).
- How to be more assertive.
- Interpersonal communication, or Communicating when you disagree.
- Dealing with the media: who does it and when? What is each board member’s responsibility?

Build in opportunities for board members to get involved.

- Giving board members opportunities to build upon their skills and information is one of the best ways to make them effective and motivated members of the board. Many consumer members have not had access to diverse opportunities.
- Have board members attend workshops or conferences where they can learn new information and act as a representative of the organization.

Supporting Board Members

Every board member has support needs, and each person (not just those who have disability labels) is responsible to let their support needs be known. The organization, in turn, is responsible for making sure that board members get the support they need to actively contribute to the board. Support needs take different amounts of time, energy and attention by the person who is doing the supporting.

The group must build a culture of support, one in which ALL members feel free to ask for the assistance they need, and one in which ALL feel responsible to help each other. By building a “culture” on your board where people support each other, all members can be more effective.

On the following pages are some strategies which can be used to promote this “culture of support”. These are suggestions which have worked exactly as written in some cases. In others, variations were made when it made sense for the individuals who requested support or for a particular board’s way of doing things. Be flexible.

WAYS TO PROMOTE A CULTURE OF SUPPORT:

- Pair new members, or those who need more support, up with a mentor, another board member who can assist them when they have questions.
- Provide orientation, in the form of materials *and* training.
- Hold pre-meetings for those who want to spend extra time to understand the agenda topics or organization's activities, so that everyone can feel more confident in the meeting.
- Go through the "Support Needs Checklist" with every new board member, and review it from time to time. (From Not Another Board Meeting: Guides to Building Inclusive Making Groups)
- Use easy-to-understand language: in materials and during board discussion, all members should avoid using jargon without explaining what it means (including acronyms). It is amazing the effect this can have on ALL involved in enhancing meaningful discussion around the table.
- Have frequent phone calls with board members, and have one-one meetings with them occasionally, as this is where mutual respect and contributions might become apparent.
- Think about ways to make the actual meeting more accessible.
 - Record the meeting on a cassette, so it could be reviewed at home.
 - On a flip chart, write key words of discussion topics during the meeting, so people can follow the train of thought.
 - Put the budget into an image (like a gas tank) so a general idea of the organization's money can be grasped before getting to the specifics. (See sample.)
 - Before a vote on a serious issue, go around the table, one by one, and give everyone a chance to ask a question, express a concern, to bring up a point for others to consider when voting. This can slow the tempo of the meeting down enough to let everyone put a word in. It also supports educated decision-making, which is a responsibility of every board member.
- Frequently ask (both individually and as a group) board members these questions: (see sample board evaluation)
 - "Are you receiving information in a way you can understand?"
 - "Are you confident in your skills as a board member or are there areas you need more training in?"
 - "What's working for you on the board, and what's not?"
- Get the agenda, minutes and materials out in a timely manner. (Using consistent symbols or colors of paper might assist non-readers)
- Provide time for board members to get to know each other and learn more about their individual interests and experiences.

WHAT DOES IT TAKE?

- Hold meetings when individuals with developmental disabilities and family members can attend.
- Provide reimbursements for Transportation, Personal Assistance or Respite Care so individuals and families are able to attend meetings.
- Have a specific contact person on the staff to provide general support, in addition to the mentor pairings.
- The sincere belief that it can work.
- Time.

RESOURCES:

© 1994. Oregon Developmental Disabilities Council. \$10.00 plus shipping. 503-945-9941 for flyer. **Strongly suggested reading for a full discussion tool and a valuable resource for any board.**

TOOLS:

- Application for board membership. Two samples of easy-to-understand applications are enclosed.
- “Checklist of Support Needs” from Not Another Board Meeting, a walk-through tool to use as you set up a support relationship with a board member, to determine what they need assistance with and what they will do themselves.
- Chart for Board room of Mission and main goals/tasks of board, see example, which is blown up and posted onto the wall of the board room for easy viewing.
- Visual image to help explain general budget information (see example of gas tank).
- Board self-evaluation, to be filled out at least yearly, so that board members and staff can see where they need work and can address problems in their governing process.
- Quality Indicators: a checklist the board can go through to measure how well they are overseeing the work of the organization.

SELF-DETERMINATION RESOURCES, INC. APPLICATION FOR THE BOARD OF DIRECTORS

*If you need assistance to apply for this Board, please contact
Jill Flynn or Mary Anne Seaton at (503) 364-9943*

Name _____	
Address _____	
City/State/Zip _____	
Home Phone _____	Work Phone _____
Email _____	Fax _____

1. Are you a family member representing a child adolescent, or adult?
2. Are you a person with a disability? yes no
3. Why are you interested in being on this Board?

4. Please check which areas interest you.

_____ **Policy Development.** Set up policies to make Self-Determination Resources, Inc., an organization that really helps people to control their lives and get the support they want.

_____ **Financial Operations.** Develop the budget for the organization and oversee how the money is spent.

_____ **Community Resource Development.** Develop plans for the organization to educate customers about directing their supports, to educate other people about the best ways to help customers, and to get more people in the community involved.

_____ **Quality Assurance.** Monitor the quality of services the organization is providing to customers and set goals to improve the services.

5. Please list organizations that you are currently or have been involved in (for example, neighborhood associations, school boards, People First, fraternal organizations).

Are you now or have you ever been a member of a board of directors?

yes no

What is/was your role on the board? _____

6. What types of skills and experiences would you bring to this Board?

7. What is your paid or volunteer work? What do you do?

8. Are you a customer or user of developmental disability services?

yes no

If yes, what services do you receive?

9. Do you see yourself as a future customer of this organization? yes no

10. Can you make a commitment to attend one or two Board meetings every month and to do committee work? yes no

If yes, which days couldn't you meet?

During the development of the board and activities related to the brokerage, limited funds for family support services or personal assistant services and mileage or transportation costs will be available to allow board members full participation at scheduled meetings.

Additional Information/Comments

**SELF-DETERMINATION RESOURCES, INC.
BOARD OF DIRECTORS
APPLICATION FOR APPOINTMENT**

Please type or clearly print information and return form to:
SDRI, P.O.Box 82746, Portland, OR 97282

Name: _____

Occupation: _____

Address:

Home Phone: _____ Work Phone:

Reason for applying:

Availability for meetings:

Membership Category: *Circle One*) Parent Professional Other

Applicant's Signature

Date

Do Not Write Below This Line – Board Use Only

.....

Date Received by Board of Directors:

Appointed by the SDRI Board of Directors on

Board Signature:

SELF-DETERMINATION RESOURCES, INC. MEMBERSHIP CRITERIA FOR THE BOARD OF DIRECTORS

The Board of Directors consists of people with disabilities, active family members and community members. People with disabilities and active family members comprise at least 51% of the Board. The following criteria guide the selection of the Board of Directors.

1. Commitment to promote the mission of Self-Determination Resources, Inc.
2. Willingness to regularly attend Board and Committee meetings and to actively participate in decision-making.
3. Current or potential customers of Self-Determination Resources, Inc.
4. Consumer members that represent people of diverse ages and disabilities.
5. Geographic representation from the various neighborhoods and communities in Multomah County.
6. Cultural and ethnic diversity.
7. Community representatives who are active in education, employment, and community living programs that involve people with disabilities.
8. Community representatives who are involved in community employment, housing and recreation activities aimed at the general community.
9. Community representatives who have technical skills, such as accounting, law, fundraising or public relations.

HOW'S OUR BOARD DOING?

Our Mission and Goals

1. The overall mission or purpose of our board is clear to members.

_____ Yes

_____ No

2. We are making progress in achieving our goals.

_____ Yes

_____ No

3. Our meetings are productive.

_____ Always

_____ Sometimes

4. Our Board is strong.

_____ Yes

_____ On our way

_____ No

What could be done to help clarify or move forward the mission and goals of our board to make our board stronger?

Program Management

5. We understand what our Program does for individuals and families.

_____ Yes

_____ No

6. Our program policies are adequate.

_____ Yes

_____ Some, but not others

_____ No

7. We are able to adequately oversee and guide the work of the Brokerage Manager.

_____ Yes

_____ No

Suggestions for ways to improve our Board management of our Program:

Community Education/Systems Change

8. Our board is helping to educate the community about the needs of families and individuals with developmental disabilities.

_____ Yes

_____ Somewhat, but I wish we could do more

_____ Not really

9. Our Board is helping to influence services for individuals and families in our community.

_____ Yes

_____ Somewhat, but I wish we could do more

_____ Not really

Suggestions for improving our ability to do community, education and advocacy.

On a Personal Level

10. I feel good about my contribution to the Board.

_____ Yes

_____ No

11. I feel like the effort I put into the Board is worth it.

_____ Yes

_____ No

12. I have the information I need to fulfill my Board role.

_____ Yes

_____ No

13. I have the skills I need to fulfill my Board role.

_____ Yes

_____ No

What do you need to increase your effectiveness/satisfaction on the Board?

CONSUMER GOVERNANCE

Self-Directed Support Programs are led by a governing group of community leaders, at least 51% of whom are individuals with disabilities and family members. The governing group is responsible for making sure that the Self-Directed Support Program does its job of helping customers to determine and direct their supports. The governing group oversees the quality of the Program's work in carrying out each of its functions, and develops goals and policies to improve the Program.

This checklist describes the key features of consumer-led governing groups. It can be used as a guide to organize and evaluate such groups.

Key Activities	Is it Happening?		What will we do to make it happen?
	YES	NO	
The focus of the governing group is to oversee and maintain the mission of the Self-Directed Support Program.			
The governing group does careful planning for the Program's future.			
The governing group develops policies and reviews the performance of the Program Director or Manager.			
The governing group regularly reviews how well the Program is doing its job and decides what needs to be improved.			
The role and authority of the governing group is well-defined.			
If the Self-Directed Support Program is part of a larger agency, there is a direct link between the governing group of the Program and the governing body of the agency (ex. a member of the governing board of the Program is a member of the governing body of the agency).			
(Consumer Governance, continued)			
Key Activities	Is it Happening?		What will we do to make It happen?
	YES	NO	
More than 25% of the members of the governing group are individuals with disabilities and more than 25% are family members of individuals with			

disabilities.		
The governing group matches the diversity of the community.		
The governing group meets regularly and has a structure (ex. chair, president, secretary, etc.)		
The governing group has a pool of people who are interested in being members.		
There is an orientation program for new members.		
Information and written material for the governing group is presented in straightforward language, pictures, etc. to make it understandable. Pre-meetings are held for members who want more time and assistance to review the agenda and the last meeting's minutes, and to figure out their viewpoints and questions for the upcoming meeting. Assistance is provided to increase the participation of members in meetings (e.g. yes/no question-asking, taking time to review hard to understand information, notes on an easel, using straightforward language, etc.). Support is given to make sure that members can attend meetings (e.g. respite, transportation, personal assistance).		
The governing group regularly evaluates its leadership and support for members.		
Members have opportunities to take part in activities to increase their knowledge, and leadership skills.		

WHAT'S OUT THERE?

Churches

Libraries

Civic Groups

Town Council

County Board

Neighborhood Associations

Hospitals

JOINING A GROUP OR COMMITTEE

Find out who can attend the meetings.

Find out when and where the meetings are held.

Attend several meetings as a visitor to decide if you want to be a member of the group.

Find out how to become a member.

Become a member.

NEXT STEPS

What is the thing you would like to do for yourself or your community?

Write down what you've decided to do.

Figure out the first steps you should take (talk with your group to figure it out).

Share your goal and steps with others.

Decide if you would like our team to call you to help with ideas to reach your goal.

HERE ARE SOME GENERAL STEPS TO HOW **LAWS** ARE MADE:

LAWS are rules that everyone has to follow.

- 1) An idea for a **LAW** goes to the State House
- 2) The idea is present as a **Bill** and gets sent to a Committee
- 3) The **Committee** hears the **Testament** of anyone who wants to talk about the bill

LIST SOME WAYS YOU CAN TELL THE COMMITTEE HOW YOU WANT THEM TO VOTE ABOUT A BILL:

- 4) The **Committee** votes on the **Bill**

VOTE

NO = stops the bill

YES = Bill goes to full House and Senate

5) The House and Senate vote on the **Bill**

VOTE

NO = bill does NOT become a law

YES = bill goes to Governor

6) If the Governor votes **NO** it is called a **VETO**. A vetoed bill does **NOT** become a law.

If the Governor votes **YES**, the bill becomes a law.

Bill

VETO

Law

LIST SOME WAYS YOU CAN TELL THE GOVERNOR HOW YOU WANT HIM/HER TO VOTE ABOUT A BILL:

_____	_____
_____	_____
_____	_____