WE ARE PEOPLE FIRST
WE ARE PEOPLE FIRST

A BOOK ON SELF ADVOCACY

DEVELOPED BY NEBRASKA ADVOCACY SERVICES
BY JOHN MCGILL

BASED ON "SELF ADVOCACY - YOU HAVE A
RIGHT TO SPEAK FOR YOURSELF" BY PATTY HENDERSON

AND

"LIFE, LIBERTY AND THE PURSUIT OF HAPPINESS"
BY BETTY HALGREN AND ANNETTE NORSEMAN
WE ARE PEOPLE FIRST.

Each of us is different. We all have certain strengths and weaknesses. We all have the right to be the way we are and become the way we want to be. Sometimes we think it is wrong to be different and try to be like another person or group of persons. Being different is good. It is easier to be ourselves than to try and be someone else.

We all have some handicaps. A handicap is only a part of our differentness. It is not the most important part of us. Sometimes people don’t understand this. They may put labels on us and treat us poorly. This is not because they are mean people. It is because they don’t understand. We can help teach them. Then the world will be a better place for all of us to live.
"We have the right to be treated like human beings, to be treated with respect and dignity."
-People First of Nebraska-
August 27, 1978

We all belong to the human family.

We are all members of the human family. We all have things that we can do well and those we do not. Sometimes we treat people based on the way they look or act. We should not make decisions about people without really getting to know them. We must accept others if we expect them to accept us.

Sometimes we are not treated fairly. People are sent to institutions; people are not paid enough for the work they do. These are just two examples of unfair treatment. You do not have to be treated that way. You can ask for better treatment if you don’t think it is good. You can stand up for yourself. You should let people know if your are not happy. This is called self advocacy.
"WE BELIEVE THAT WE HAVE TO FIGHT FOR OUR OWN RIGHTS, AND UNLESS WE DO, WE WON'T GET THEM."
- PEOPLE FIRST OF NEBRASKA - AUGUST 27, 1978

WHAT IS SELF ADVOCACY?

Self Advocacy Means to Stand Up For Your Own Rights. Self Advocacy Means to Speak For Yourself And To Look For Help When You Need It. It Is the Best Kind Of Advocacy Because It Means You Are Taking Charge Of What You Want To Do.

To Be a Good Self Advocate, You Need to Know More About Your Rights And Responsibilities. If You Know More About Your Rights, You Will Be A Better Self Advocate. If You Know About Your Responsibilities, You Will Be A Better Self Advocate Too.

This Book Will Tell You About Three Kinds Of Rights That You Have, It Will Also Tell You About Your Responsibilities. If You Study This Book, You Will Be A Better Self Advocate.
WHAT ARE RIGHTS?

The United States Constitution says that all people are created equal and all have certain rights which cannot be taken away. It doesn't mean that all people must be treated exactly alike, but it does mean we all have the same basic rights.

There are two kinds of rights. These are human and legal rights. Both kinds of rights are important. Our rights are the main thing we have in common with our fellow citizens. If you have a handicap, it does not matter, you still have the same rights.
Sometimes we take our rights for granted. Most of us don't think that having a name and a home, buying a new TV, or choosing our friends are all rights that we have. We are entitled to do these things because we have rights.

In the past, people with handicaps have had their rights denied. People have been sent to institutions or special schools for example. This book is to help you better understand your human and legal rights and how to use them in a responsible way.

Human rights are yours at birth. Because you are a person, you have human rights. We all have these rights. These rights have been written down in the Declaration of Independence.

Legal rights are the "laws of the land". If you have a handicap, there are laws to protect you from unfair treatment. There are penalties for violating these rights. These rights are written down in law books of the city, state, and county.

Rights are things we are entitled to because we are human beings and because of laws that we have made to protect us.
Human Rights are basic and very simple. They are yours at birth. These rights are important in being alive and living your life.

**Basic Human Rights**

The Right To Choice - To choose how you wish to live your life.
The Right To Life - To be alive.
The Right To Freedom - To move around as you wish and to be free from other people restricting your movement.
The Rights To Pursue Happiness - To learn about the world and to live in the world.

All human beings have these basic rights:

* The Right To Choose where you wish to live
* The Right To Choose the people you wish to be with
* The Right To Make up your own mind about what you want to do
* The Right To Say "No" when you don't want to do something
* The Right To Change things that you don't like
WHAT ARE RIGHTS OF LIVING

STOP HERE FOR A MINUTE AND THINK ABOUT THE FOLLOWING THINGS:

- Celebrating a special personal holiday, such as a birthday
- Going shopping with your own pocket money
- Selecting your own clothes to buy and wear
- Having friends away from home
- Dating people of the opposite sex
- Having a job and being paid a fair wage for a fair day's work
- Being spoken to when you are present
- Selecting the food you eat
- Going to church, or not going to church, as you wish
- Choosing your bed time
- Marrying and having children
- Going to school with other students your age
- Being able to leave your home to go into the community
- Not being ignored when you speak
- Going to the beach because you want to
- Doing nothing because you want to
- The right to choose what kind of life you want
SELF ADVOCACY IS

* Knowing Your Basic Human Rights
* Standing Up For Your Rights
* Taking Responsibility For Your Life
* Asking For Help Because You Want It Or Need It
LEGAL RIGHTS

As Human Beings, We Agreed on the Rights Which Belong to All of Us. We Also Made Some Rules and Said Exactly What We Needed to Do to Protect the Basic Rights of All People Living Together in This Country.

Legal Rights Are Those Which Have Been Given to You Because of Specific Laws. These Laws Are Clear Instructions As to How Your Rights Must Be Protected. There Are Penalties for Not Following the Law.

There Are Many Important Legal Rights. We Will Discuss Several of the Most Basic.
* Your Right to Equal Protection

All laws made for all people apply to you. You have the same or equal protection under the law just like any other person. You cannot be denied services that are available to other citizens, just because you have a handicap.

If you are put into an institution, just because you are mentally retarded, then your rights under the law are being violated.

If you are denied a job, for which you are qualified, just because you have epilepsy, then your rights under the law are being violated.

If you can't go to the school in your area, just because you have cerebral palsy, then your rights are being violated.

Equal protection means that you can demand the right to services which are being provided to all other citizens.
* Your Right to the Least Restrictive Environment

If you receive services, they must be provided in the "least restrictive" way necessary to help you. It means that no one should be cut off from the kind of life that others enjoy, just because of a handicap. Anyone who thinks that a person's special needs require services apart from the rest of us, must prove that it is the best for that person.

Learn - You have the right to go to school in the least restrictive school necessary to properly teach you.

Live - You have the right to live as independently as you can, in the community you choose.

Work - You have the right to work in a place that helps you be as productive as you can be.

Move - You have the right to move around in a society which is free from physical barriers -- like steps if you are in a wheelchair.

You have a right to live, learn, work, and move around in the place which restricts your freedom in the least possible way that is needed to help you.
**YOUR RIGHT TO INFORMED CONSENT**

Consent means to allow someone to do something. We give consent to be operated on by doctors, to be taught by teachers, or to allow our children to go on field trips. Informed consent simply means that you must be given all the information necessary so that you can give your consent.

Informed consent means that you do not have to agree to something unless:

1. It has been completely explained to you, or
2. To someone you trust and have chosen to help you decide, and
3. You have been given all the information about what other choices you have.

If you do not understand the program plan which has been developed for you, and you agree to it anyway, then you have not given informed consent.

If you agree to be sterilized even if you don’t understand what the operation does, you have not given informed consent.

If you agree to go to Goodwill because you are told it is the only place you can work, you have not given informed consent.

Informed consent means that you or someone you trust, must be given all the information including all of your options, before you agree to something. You can refuse if you want to.
YOUR RIGHT TO DUE PROCESS

Sometimes, a person’s rights are restricted, either for their own benefit or to keep them from hurting others. In order to restrict a person’s rights legally, due process must take place.

Due process means telling you what is happening before and while it happens. Here are the steps,

1. There must be strong evidence to prove that restricting the person is necessary to keep him or her from hurting themself or others.
2. Evidence must be presented at an open hearing or meeting.
3. The person must be allowed to attend and take part in the meeting.
4. If the person disagrees, they can appeal.
5. The restriction can only be for a certain amount of time. It must be reviewed to see if it is still necessary.

If you or your child is evaluated for special education and you are not told before the evaluation started, then you have not had due process.

If you are terminated from a program or service without knowing why, then due process has not been followed.

If you are moved from one place to another without having had a say, then you have not had due process.
* Your Right to Appeal

Sometimes you might disagree with what your caseworker wants you to do. When this happens, it is best to talk with him or her directly and find out their reasons. If you still don't agree, you have a right to appeal and ask to have the decision changed.

You may also appeal if you feel:

1. Information was withheld
2. You did not have a choice
3. Services were too slow
4. Your caseworker has been unfair
5. You don't have enough help

If you are moved into a boarding home and you don't want to be there, but no one in authority will listen to you, then you have not had your right to appeal.

If you are fired from your job and you feel it was unfair, but no one will listen to your concern, then you have not had the right to appeal.

If your child is placed in a special education class and you do not like the program, but the principal won't talk to you, then you have not had the right to appeal.

Appeals are ways of solving disagreements. You have a right to appeal something that you think is unfair.
SELF ADVOCACY IS
* Knowing Your Basic Legal Rights
* Standing Up For Your Rights
* Taking Responsibility For Your Life
* Asking For Help Because You Want It Or Need It

SELF ADVOCACY IS THE WAY IN WHICH YOU MAY PROTECT YOUR LEGAL RIGHTS.
SOME LAWS YOU SHOULD KNOW

In the past few years, there have been several laws passed which further protect your rights. They are very powerful. You can use them to fight discrimination. Discrimination is when you are treated differently or unfairly because of your handicap. Someone once said, "No people are free until all people are free." What does that quote mean to you?

* SECTION 504 OF THE REHABILITATION ACT OF 1973

This law states that you cannot be discriminated against simply because of your handicap. It says that you can fight back if you feel you have been treated differently or pushed aside because of your handicap. It requires that public places be accessible to you. It also says that you may not be isolated from your community simply because of your handicap.

SECTION 504 MAKES DISCRIMINATION ILLEGAL
* The Architectural Barriers Act of 1968

This law states that all new or remodeled public buildings must be accessible to all people. That means it is "barrier free." If you have a problem walking, stairs can be a barrier. If you are blind, smooth elevator buttons are a barrier. If you are deaf, fire alarms that ring are a problem. If you learn slower, signs that are hard to understand are a barrier.

The Architectural Barriers Act makes many inaccessible buildings illegal.

* Public Law 94-142

This law is also known as the Right to Education for All Handicapped Children Act. You can see why they shorten it to 94-142. This law requires all handicapped children to be in a public school program. Parents and students must be involved in the education process. Handicapped students must be with non-handicapped students as much as possible. The education must fit the student's needs.

94-142 makes it illegal for schools to refuse to teach children with handicaps.
* Public Law 94-103

This law was passed in 1975. It is also called the Developmental Disabilities Act. It means that all people in programs must be receiving an active treatment plan. This treatment must be made specifically for you, based on what kinds of help you need. It stresses that your rights must be protected.

94-103 means that putting people in places where they can't learn and develop is illegal.

* Urban Mass Transportation Act

This law is sometimes called UMTA for short. The law requires that special efforts be made so that persons with handicaps can use public transportation. If a person is in a wheelchair, they cannot use a regular city bus for example.

UMTA means that not providing transportation for all people is illegal.
SELF ADVOCACY IS:

* Knowing The Basic Laws Which Protect Your Rights
* Knowing These Laws Also Provide For Your Special Needs
* Standing Up For Your Rights
* Taking Responsibility For Your Life
* Asking For Help Because You Want Or Need It

SELF ADVOCACY IS USING THE LAW TO PROTECT YOUR BASIC LEGAL RIGHTS.
CAN MY RIGHTS BE TAKEN AWAY?

No. The rights of any person living in the United States of America may not be taken away — they may be restricted. This may be done to protect you, or to provide you with special help.

Any time any of your rights are restricted, due process must be followed.

The three major ways in which your rights may be restricted are:

* Restrictive Programs - If you are placed in a program which is specifically for developmentally disabled people, due process and informed consent must be followed.

Restriction from normal activities of everyday life is a restriction of your basic rights.

* Guardianship is a method by which the responsibility for your actions is given to someone else. The guardian is allowed to make decisions for you. Often, it is felt that this is your best interest.

Guardianship limits your ability to make decisions for yourself. Guardianship restricts your rights in being your own person.

* If you break a law, or violate the rights of other people, you may find your rights restricted through a court of law. Your rights may be restricted through confinement in a jail or other institution.

If you violate the rights of other people, your rights may be restricted.
WHEN RIGHTS OF HUMAN BEINGS ARE RESTRICTED

* Due Process Must Be Followed
* Informed Consent Must Occur
* You Have The Right To Appeal The Decision To Restrict Your Rights
* You Can Petition For Change

Anytime you think your rights are being taken away or restricted without due process, ask for help.

Self advocacy is standing up for your own rights.
"We should show the government that we can destroy any barriers that are put up in front of us and we should show them how we feel about being shut out."

- People First of Nebraska -
August 27, 1978

WHAT ARE RESPONSIBILITIES?

Responsibilities are things which others expect us to do. Being responsible means being trusted. Responsible people know what their own rights are and respect the rights of others. If you are responsible, it means that you care about other people's rights. It means that you try to do everything possible to make our community a good place for all of us to live.

Responsible people ask questions anytime they do not understand:

* What is happening
* What is being said to you
* What choices have been given to you
* What you have been asked to agree to or sign
WHAT SHOULD YOU DO?

If you feel that your rights are being taken away or are not being thought of...

If you feel that you are not getting the right information about the choices of services for you...

If you feel that you are being pressured into something, or are just not certain what to do...

Then you should:

* Get more information

* Ask for help from a helping agency or from a friend

* Think about what questions you need answered
STEPS IN SELF ADVOCACY

These steps are the same if you do it by yourself or if you have an advocate to help you.

You and your advocate work together

The first thing you need to do is to be able to explain what the problem is. Then you should set a goal to solve that problem.

Planning for self advocacy:

* Get your information together. Make sure it is true.
  Who you talked to - what they said - when you talked to them.
* If you have an advocate, make sure he or she knows the full story.
* Look at your facts. Look at your rights. Decide what you can do.
* If you need more information, find it out. Don’t take people’s word for things - you and your advocate need to get the information yourself from people you know.
* Figure out what the choices are - pick the best choice for you.
* Decide the steps you are going to take to reach your goal.
REMEMBER

* Anytime you begin to ask questions about the "status quo" about why things are being done a certain way - you are likely to feel some resistance.

* Advocacy involves being willing to continue your plans even though there is resistance.

* Try not to use pressure unless you need to - but make sure you have your information together so you can when you want.

* Write everything down - time, date, what happened, who it happened with - that is documentation.

IN ADDITION, YOU CAN...

* Use the "chain of command" and go to the person who is the main boss

* Find a friend of the person you are trying to convince - ask that person for help

* Have a back-up plan if the first one fails

* Call a meeting with all the people involved - make that someone is taking notes

* Agree on dates by which certain things are supposed to happen - make certain those things happen by those dates or find out why

* Know your rights both as a person and your legal rights as a person with a handicap.
SELF ADVOCACY MEANS...

* Getting All Of The Information
* Deciding What You Want To Do
* Finding Out What And Who Will Support You In Doing What You Want To Do
* Knowing Your Rights And Responsibilities
* Beginning To Change The Way Things Are

SELF ADVOCACY IS SPEAKING OUT ON BEHALF OF YOURSELF AND TAKING CHARGE OF WHAT YOU WANT TO DO.

SELF ADVOCACY IS THE BEST KIND OF ADVOCACY.

"If you think you are handicapped, you might as well stay indoors; if you think you are a person, come out and tell the world."

- Raymond Loomis -
REVIEW QUESTIONS

This review will give you an idea of how well you understood this book.

The page numbers to the left of each question tell you where to find more information.

The answers are on page 30.

Answer yes (you agree) or no (you don’t agree).

Pg. 1 1. We should try hard to be like someone else because being different is not good.

Pg. 2 2. We should not make decisions about people without really knowing them.

Pg. 4 3. All human beings have the same basic human rights.

Pg. 3 4. Self advocacy means letting other people make decisions for you.

Pg. 5 5. Legal rights are only given to people who vote in elections.

Pg. 9 6. Due process means telling you what is happening before and while it happens.

Pg. 12 7. Informed consent means that you have agreed to a decision even if you do not really understand what is happening.

Pg. 20 8. If you have a guardian, your right to make decisions on behalf of yourself is restricted.

Pg. 12 9. If you consent to being sterilized even if you don’t understand the operation, you do not have a right to change your mind.
10. If you live in an institution, you do not have a right to say what you want because your counselor always knows what is best.

11. If you apply for a job and you can do the work but are not hired because of your handicap, there is nothing you can do.

12. If you go to a public building and cannot get up the steps to the door and there is no ramp, your rights are being violated.

13. If you are not receiving a public school education, it is because the school can do nothing for you, and you have no rights under the law.

14. Responsible people know what their own rights are and respect the rights of others.

15. The first thing to do if you have a problem in getting services, is to threaten to sue the agency.

16. There will probably be some resistance when you try and change things that have been done a certain way for a long time.

17. The best type of advocacy is self advocacy.

18. Which of the following is self advocacy:

- Knowing your rights
- Taking responsibility for your life
- Asking for help if you want or need it
- Standing up for your rights
- Knowing the laws that protect your rights

[Answer choices: All, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 49, 50, 51, 52, 53, 54, 55, 56, 57, 58, 59, 60, 61, 62, 63, 64, 65, 66, 67, 68, 69, 70, 71, 72, 73, 74, 75, 76, 77, 78, 79, 80, 81, 82, 83, 84, 85, 86, 87, 88, 89, 90, 91, 92, 93, 94, 95, 96, 97, 98, 99, 100. All]