3rd World Congress on Adult Guardianship May 30, 2014 Arlington, Virginia USA

Where Human Rights Begin: Human Rights and Guardianship for Individuals with Developmental Disabilities

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Introducing: Where Human Rights Begin—A Personal Handbook on Human Rights

Translation into several languages

PRESENTED IN PARTNERSHIP WITH



The Guardianship Association of New Jersey, Inc. (GANJI) an affiliate Member of the National Guardianship Association





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The Guardianship Association of New Jersey, Inc. (GANJI) is a not-for-profit organization of professionals, families, and individuals committed to supporting guardians and other surrogate decision makers in enhancing the lives of persons who require assistance. Our mission is to be a resource for guardians and advocates including families, professionals and concerned individuals who are involved in the lives of persons needing assistance. The organization provides education and a referral network and promotes ethical standards of practices.

www.ganji.org



The Arc of Essex County: For people with intellectual and developmental disabilities and their families Since 1948 www.arcessex.org



New Concepts for Living (NCFL) is a community non-profit organization committed to people with disabilities and their families. Inspired by the vision of families and people with developmental disabilities, New Concepts enables people to realize their dreams and to achieve their individual potential through quality community programs and services that include housing, vocational and day program training, recreation, advocacy and family education and support.

www.ncfl.net

Copies of the Human Rights book and USB are available for purchase from the GANJI and NCFL websites.

English and other language translations of the Personal Handbook are available at no cost by downloading from:

> www.ganji.org GANJI

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International Guardianship Network (IGN): International Resource Library info@nationalguardianshipnetwork.org

Part 1

Human Rights and Guardianship An Introduction to Supported Decision Making

Dr. Joan Kakascik Psychologist (USA)

Advocacy and struggles for Human Rights are woven through this 3rd World Congress on Adult Guardianship. The Guardianship Association of New Jersey, Inc. makes its contribution to this tapestry. Our contribution consists of personalized habilitation materials for direct use by individuals with developmental disabilities, their families, and the support staff. We are pleased to present a resource book on human rights and guardianship as well as introduce at this World Congress a personal handbook on human rights that has been translated into various languages.

Where Human Rights Begin, a practical, first-of-a-kind, personal handbook, was developed specifically for hands-on use by individuals with developmental disabilities and their families. It is inspired by Mrs. Eleanor Roosevelt's message to the United Nations, 3/27/1958, on the 10th Anniversary of the Adoption of the United Nations Declaration of Universal Human Rights, December 9, 1948.

Where, after all, do universal human rights begin?

In small places, close to home—so close and so small they cannot be seen on any maps of the world.

They are the world of the individual person;

the neighborhood he lives in; the school or college he attends; the factory, farm, or office where he works.

Such places where every man, woman, and child seeks equal justice, equal opportunity, equal dignity without discrimination.

Unless these rights have meaning there, they have little meaning anywhere.

Without concerted citizen action to uphold them close to home, we shall look in vain for progress in the larger world.

Mrs. Eleanor Roosevelt

[Chairman of the United Nations Human Rights Committee, 1948; Wife of US President Franklin Delano Roosevelt]

Where Human Rights Begin—Human Rights and Guardianship for Individuals with Developmental Disabilities—In Plain Language.

Supported Decision-Making and Human Rights

In supported decision-making, the individual is the decision maker. The support person(s) explains the issues and helps with interpretation of the preferences of the individual. *Where Human Rights Begin* suggests a way to implement and to encourage supported decision making through education about human rights and self-advocacy. The contents include:

- Supported decision making opportunities through a Self-Direction Model for learning;
- Examples of Service Plan goals and objectives;
- Suggestions for staff training;
- Considerations for the Ethical Guardian:
- Examples from one state (New Jersey) about its surrogate decisionmaking practices, ethics and guardianship, and health care decisionmaking.

Focus

The human rights book focuses on:

- PRESERVING the human rights of vulnerable people who are under guardianship whether the vulnerability may be due to dementia, developmental disability, mental impairment, or brain injury;
- ENSURING that vulnerable people know their rights and can advocate for themselves, to the extent possible;
- PRACTICING supported decision making.

Development

Development of *Where Human Rights Begin* followed a nation-wide literature search of state, agency, and publishing resources. Although there was much in the literature about laws, regulations, and teaching curricula, there were few "hands-on" materials in plain language available to individuals with developmental disabilities. There was little in the available literature that paired the rights of the individual with suggested responsibilities for those rights. Few publications considered human rights and guardianship.

Volunteer contributors to the book were people with long-time, hands-on, direct knowledge and experience. GANJI partnered with different people and groups to bring the human rights book to publication.

- The Arc of Essex County, New Jersey,--- to prepare sample Service Plan Goals and Objectives.
- The NJ Community Health Law Project -- to develop plain language Question & Answer information about powers of attorney.
- The National Guardianship Association to give permission to excerpt from a 2004 publication, *Fundamentals of Guardianship*.
- GANJI Attorneys to summarize NJ statutes and regulations as easy reference for the layman .
- Members of a Human Rights Committee to critically review materials.
- A professional researcher and advocate to volunteered his efforts.
- Experienced Contributors to volunteered to write about their work.
- Community members including Individuals with developmental disabilities, private advocates, provider agencies, law firms, and special educators to offer financial sponsorship.

The editors studied and integrated New Jersey law and statutes, UN declarations, and National Guardianship Association (NGA) materials to create a handbook that could be used by individuals with developmental disabilities and their caregivers, whether in a group home, supervised apartment program, work program, or at home. Its usefulness expands to families, to educators, and to service providers.

Key features of the publication include:

- Personal Handbook: with "your own" picture;
- Personal photographs instead of clip art (clip art and drawings are too abstract for many to read);
- Plain language guided by the Plain Language Association International Guidelines and vetted by clients, staff, and speech and language specialists;
- Convenient Format for use at: school, group home, supervised apartment, work setting and at HOME.

The handbook makes clear that just as every citizen must do, individuals with developmental disabilities must learn and advocate for their human rights. Individuals must know their human rights along with responsibilities for the rights. Families, guardians, professionals, and other support staff members must understand that a person with disabilities has legal and human rights which must be respected and protected. Advocates for individuals with developmental disabilities must insure that there are opportunities to learn and practice knowledge of human rights.

Where Human Rights Begin is one tool to encourage that these opportunities become a reality.

Purpose

The purpose of Where Human Rights Begin is 3-fold:

- 1. To provide individuals with developmental disabilities with a unique, "hands-on," interactive resource on human rights and surrogate decision making (guardianship; powers of attorney)---written in plain language;
- 2. To offer suggestions for families, staff, and professionals to help facilitate growth in self-direction and decision –making in the language of human rights;
- 3. To summarize representative New Jersey legislation and case law which may be similar to the legislation in your state or country.

Commitments

As citizens we must be committed to the ideas that;

- Human Rights are universal—the same for everyone;
- Human Rights and Responsibilities should be taught and acquired by opportunities and practice learned through an individual's service plan and through daily life;
- Human Rights should be a continuing subject for staff training and for self-advocacy initiatives;
- Individuals under guardianship retain their Human Rights.

Language Editions of the Personal Handbook

At present GANJI has partnered with New Concepts for Living (NCFL), Bergen County, New Jersey, to present several language translations of the personal handbook section. Some of the completed translations are in Arabic, Danish, English, German, Italian, Spanish, Thai, and Vietnamese. Further translations are under development and will be available from:

GANJI <u>www.ganji.org</u>
NCFL <u>www.ncfl.net</u>
IGN (International Guardianship Network)
International Guardianship Network Library
info@internationalguardianshipnetwork.org

In Conclusion

Human rights opportunities and education begin in daily life and continue throughout the life span for each of us—to include individuals with developmental disabilities or individuals who may have symptoms of dementia, mental illness, or brain injury.

Where Human Rights Begin uniquely considers human rights and surrogate decision making. It is a tool for implementing Supported Decision Making at the grass roots level..

In Part 2, <u>Mr. Simon Azavedo</u> will address learning opportunities and advocacy. His knowledge is founded on his direct experience with service plan development and position of leadership on a human rights committee.

Part 2

Human Rights and Guardianship

Self-Determination, Self-Direction, Habilitation and Staff Training

Simon Azavedo, MSW, LCSW, CCBT, DAPA Social Worker (USA)

To ensure excellence in guardianship, we must have knowledge about what one's human rights are and then to further teach self-advocacy—that is the foundation of what human rights and guardianship is all about. In the matter of a consumer with a developmental disability and his or her support people learning and implementing one's rights is essential. Two private provider agencies in New Jersey lead in this initiative. I am excited to tell you about them and about the excitement of the consumers.

Overview of Human Rights declarations and legislation

Human Rights are to be shared by everyone. There are common documents that articulate these rights. New Jersey law on the rights of the disabled was identified in 26 statements. Similar statements from other relevant documents were compared and integrated. The work was reviewed by GANJI lawyers for accuracy and consistency. *Where Human Rights Begin* is based on the following documents:

- United Nations Declaration of Universal Human Rights (1948)
- United Nations Rights of the Retarded (1971)
- United Nations Rights of the Disabled (2006)
- National Guardianship Association pamphlet—The Fundamentals of Guardianship (2004)
- New Jersey case law, statutes, and regulations on surrogate decision making and the rights of the disabled (representative of other USA State Laws)

Areas of Rights

The rights and responsibilities statements are easier to read, to comprehend, and to learn because the tenets of the documents were grouped under 5 subject areas and written in plain language. The subject areas are grouped as: Personal Rights, Living Arrangements, Health Care, Work/Habilitation, and Safe Environment.

A Summary Chart of the 26 Rights and Sample Responsibilities statements provides an introduction and overview. For consistency, the training materials follow the same order and use the same language as identified in the Summary Chart. Below is a sample of the first 3 rights statements.

SUMMARY CHART OF RIGHTS AND SAMPLE RESPONSIBILITIES

	RIGHTS	RESPONSIBILITIES
	PERSONAL RIGHTS	
1.Respect	Right: To be respected as a person with rights	Sample Responsibilities: To talk and act as nicely to others as you want them to be nice to you To tell your family, guardian, case manager, or staff if someone hits, teases, or yells at you To respect others by not hitting, teasing, or yelling at them
2.Self Advocacy	Right To advocate for yourself	Sample Responsibilities: To learn about your rights and responsibilities To talk for yourself To get help when you need it To meet with the (agency) Human Rights Committee when needed
3.Religion	Right: To freely go to the church, synagogue, mosque, or house of worship of your choice, or not go	Sample Responsibilities: To learn about and to follow your religion, if you choose to do so To respect the religion of others To respect those who do not practice a religion

Comparison Chart

Below is a small part of the full comparison chart documented in the Human Rights book and the shorter Personal Handbook illustrating how the United Nations, National Guardianship Association and New Jersey documents may be are inter-related. The comparison chart of laws and declarations follows the same subject areas as the Summary Chart.

Comparison of Legal Statutes, Declarations & Standards

Rights Topics	NJ Administrative Code N.J.A.C.30:6D (Rts. Of Dev. Disabled)	NJ Statute N.J.S.A. 3B:12-1, et.seq.	UN Universal Declaration Human Rights	UN Rights of Persons with Disabilities	UN Rights of Mentally Retarded Persons	NGA Rights of the Individual under Guardianship
PERSONAL RIGHTS						
1.Respect	6D-2	3B:12- 57	Articles: 1,2	Articles: 1,5	Paragraph 1	2
2.Self-	6D-7	3B:12-	Articles:			
Advocacy	6D-8	56	19,20			
3.Religion	6D-4b		Article: 18			5
4.Voting	6D-4a		Article: 21	Article: 29		
5.Guardian	6D-3b 6D-4d	3B:12- 37 3B:12- 48 3B:20- 11.1			Paragraph: 5	19

The 26 Rights Statements grouped in 5 subject areas

PERSO	NAL I	RIGH	ITS

- 1. Respect
- 2. Self-Advocacy
- 3. Religion
- 4. Voting
- 5. Guardian

WORK & HABILITATION

- 18. School
- 19. Work & Play
- 20. Job & Program Choice
- 21. Service Plan
- 22. Private Information

LIVING ARRANGEMENTS

- 6. Services
- 7. Personal Items
- 8. Mail
- 9. Phone
- 10. Healthy Diet
- 11. Relationships
- 12. Visitors
- 13. Activities
- 14. Privacy

HEALTH CARE

- 15 Treatment & Therapy
- 16. Healthy Living
- 17. Medical Care2

SAFE ENVIRONMENT

- 23. Free from Unusual Treatment
- 24. Free from Restraints
- 25. Free from Punishment
- 26. Right to Habeas Corpus

Where Human Rights Begin: Personal Handbook

PERSONAL RIGHTS: RESPECT

Right # 1 To be respected as a person with rights

Sample Responsibilities
To talk to and act as
nicely to others as you
want them to be nice
to you

To tell your family, guardian, case manager or staff if someone hits, teases, or yells at you

To respect others by not hitting, teasing, or yelling



The centerpiece of *Where Human Rights Begin* is a hands-on, personal handbook for the individual with developmental disabilities.

Each of the Rights and Sample Responsibilities Statements is illustrated by a personal photograph. The photographs are of Jennie Price-Janoff who made the decision to become a part of the GANJI project. On the previous page, Jennie is shown with Probate Judge Irvin Condon, North Carolina, and a Past President of National Guardianship Association (NGA).

The photograph illustrates Jennie and Right # 1: To be Respected as a person with the rights. While she has experienced respect from others over the years, Jennie came to understand her "rights" more personally and more fully through her experience with the human rights project. She began to talk about her "rights" and what they meant to her. Jennie's mother, Jane, said that there were many "interesting" discussions about rights as well as Jennie's sharing her knowledge about rights with others. Jennie proudly shows "her book" to her friends and relatives.

Where Human Rights Begin: Program Implementation

New Concepts for Living (NCFL), a New Jersey provider agency, has been holding **Human Rights Discussion Group Meetings** for the past several years. More recently the staff used *Where Human Rights Begin* to enrich discussions. Diana Germano Reinkraut, Director of Behavioral Services and group leader, developed a curriculum for the group and innovated a "comments section" for each page of the *Personal Handbook*.

The recorded comments allow insight into the individual's thinking about the particular right and responsibility. One young woman spoke about Right # 2: To advocate for yourself. She plans to take the responsibility to speak-up at her service plan meeting. She gave written permission to include her picture in the conference materials. The sample page follows. In the small group setting, discussions are lively. Popularity of the group has grown so that others want to participate. There is spontaneous discussion of rights among consumers, staff, families and guardians with active advocating occurring within the agency for rights as well. The activities of the NCFL human rights meetings, along with the personal and organizational follow-up, illustrates supported decision making and advocacy implementation.

PERSONAL RIGHTS: Self-Advocacy RIGHT #2 To advocate for yourself



Sample Responsibilities: To learn about your rights and responsibilities.

- To talk for yourself.
- To get help when you need it.
- To meet with the Human Rights Committee needed.

Comments:

- I would like to have 4 hours unsupervised only. I do not want 8 hours.
- I would like to stay in my apartment.
- I do not want a behavioral plan anymore.
- I will be advocating at my IHP meeting which I am very excited for.

Do-it-Yourself Handbook

While Where Human Rights Begin features Jennie's pictures, we purposefully created a section of the rights and sample responsibilities statements without a photograph. (See following page)

The pages without photographs are for <u>your</u> son, daughter, ward, or student's photograph in a personal handbook. Please insert photographs in the open spaces by scanning or pasting.

You may copy pages from the hard-copy book, or, you may down-load the pages from a flash drive of the book. The illustrated page without a picture is of Right # 5: To have a Guardian if you need one.

Foreign Language Handbook Supplement

GANJI and New Concepts for Living are partnering to create foreign language supplements of the Human Rights Summary Chart and the Do-it-Yourself handbook pages.

The following example of the text in Spanish illustrates the Right #5. To have a Guardian if you need one.

PERSONAL RIGHTS: GUARDIAN

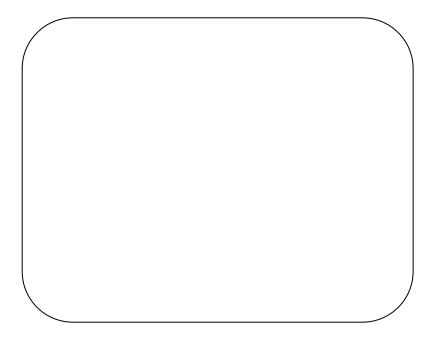
Right # 5 To have a limited or general guardian if you need one

Sample Responsibilities

To talk with your guardian, agent, or advocate about what you are thinking, what you want, or what you need

To ask the judge to reverse your guardianship

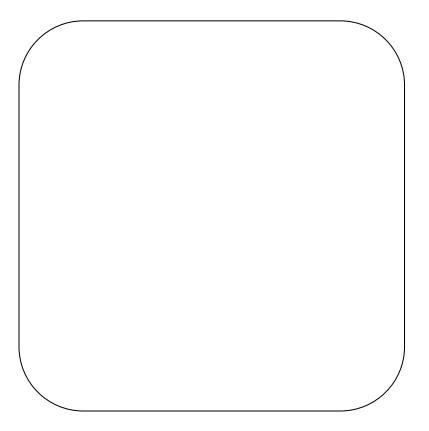
To appoint someone who you trust to be your Power of Attorney



DERECHOS PERSONALES: Guardián DERECHO # 5 Tener un tutor limitado o general si lo necesita

Responsabilidades:

Para hablar con su agente tutor o abogado acerca de lo que está pensando, lo que quiere o lo que necesita.



Self-Direction Model and Supported Decision Making

A personal human rights handbook is useful. However, human rights need to be learned and supported in daily life opportunities.

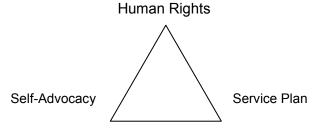
Without training and vigilance, a person's rights could be easily overlooked or actions taken that may not be in the best interests of the individual in ordinary, simple ways such as:

- Lack of opportunity to advocate for oneself;
- Unreasonable restrictions on social activities;
- Making medical changes without the permission of the individual and/or the guardian.

Education and Habilitation

GANJI's partnering with staff members from the Arc of Essex County, New Jersey, resulted in representative educational materials for schools, community living programs, and program work sites.

Where Human Rights Begin offers a Self-Direction Model of education and habilitation that emphasizes personal purpose and meaning through recognizing an individual's rights, needs, strengths, and responsibilities. The Self-Direction Model may be conceived of as a triangle.



Human Rights should be taught and practiced.

<u>Self-Advocacy</u> encourages independence, responsibility, and self-expression.

<u>Service Plans</u> may include goals and objectives that can teach the fundamentals of human rights through daily activities.

Samples are provided for each of the 26 rights statements with illustrative Goals, Objectives and Techniques. The sample plans suggest goals and objectives for three ranges of ability and may be incorporated into Individualized Education Plans (schools) and Service Plans (community).

5 GUARDIAN

RIGHT: To have a limited or general guardian, if you need one

Sample RESPONSIBILITY:

To talk with your guardian, agent, or advocate about what you are thinking, what you want, or what you need

To ask the judge to reverse your guardianship

To appoint someone you trust to be your Power of Attorney

Sample Goals, Objectives, and Techniques Level 2 Level 1 Level 3

Goal: Peter has the responsibility to communicate his wants and needs to his Bureau of Guardianship Services (BGS) worker (guardian).	Goal: Paul has the responsibility to discuss finances for activities with his guardian (his brother).	Goal: As a capacitated person, Mary has the right to appoint an agent for a Power of Attorney (POA) and Medical Power of Attorney (MPOA).
Objective: Peter will call his BGS worker (guardian) once a month for 12 months.	Objective: Paul will independently call his guardian/brother once a week to plan a trip and to attend activities for 12 months.	Objective: Once a week for 3 months, Mary will review information about POA and MPOA and then schedule appointments with her Community Law Project Attorney.
 Staff will verbally assist Peter to know the name of his BGS worker (guardian) and the name of his case manager. Staff will meet with Peter to review what he chooses to tell his BGS worker (guardian). Staff will physically assist Peter to dial his BGS worker's 	 Staff will assist Paul to make a list of financial topics that he decides to discuss with his guardian/brother. Staff will review with Paul what he wants to tell his guardian/brother about his plans to save money 	 Techniques: Mary will review information from the pamphlet's "Frequently Asked Questions" about POA and MPOA provided by the Community Law Project. Mary will discuss the POA and MPOA procedures with her family, case manager, staff and others.

- (guardian's) phone number.
 Staff will provide verbal reminders to Peter about what he wants to tell his BGS worker (guardian).
- and to go on vacation.
 Staff will verbally remind
 Paul to ask his
 guardian/brother to give
 him signed permission to
 attend overnight out-of state activities in the
 coming months.
- Staff will provide privacy for Paul to talk to his guardian/brother.
- Mary will decide whom to appoint as her POA and MPOA agent.
- Mary will talk to her proposed agent about her POA and MPOA.
- Staff will transport Mary to appointments with her attorney.

Other Sample Goals to consider:

- Identifying the roles of the guardian, case manager, family and staff
- Talking over important issues: medical, residential, financial, work, program
- Increasing opportunities for decision making; changing guardian; limited guardianship

Staff Training

Professor Karen Gutshall, Ph.D. from Raritan Valley Community College, New Jersey, developed staff training materials on human rights and guardianship for use in living arrangements, day programs, and work sites...

Human rights are <u>learned</u> not "earned." Human Rights training is not a behavior management matter. Human Rights are the same for staff members and consultants as they are for consumers. The chapter on staff training and development includes discussion points for each of the 26 rights and sample responsibilities statements. The Discussion Points are not intended to be conclusive and are likely to lead to further discussions.

The professional staff who work with individuals with developmental disabilities must know about human rights for themselves as well as for those with whom they work.

Surrogate Decision Making

Powers of Attorney Partnering with the New Jersey Community Law Project, "Frequently asked Questions", in a format of Questions &

Answers, were developed in plain language to inform about Durable and Medical Powers of Attorney. Sample legal documents are available from the GANJI website: www.ganji.org Not everyone with a developmental disability requires a guardian so powers of attorney may be an alternative.

Limited and General Guardianship GANJI attorneys Sharon Rivenson Mark, Esq. and Mary Ann Olsen, Esq., who both specialize in Elder Care and Disabilities Law, summarized the guardianship process as well as highlighted basic legal documents and case law for the lay reader. In New Jersey, Limited Guardianship must be considered in <u>all</u> cases involving guardianship (adult with cognitive decline, developmental disabilities, mental impairment, etc.).

In Conclusion

Human Rights education applies to people with developmental disabilities as well as to all citizens.

- Individuals with developmental disabilities must learn rights and responsibilities, to the extent possible.
- Human Rights can be a goal of a Service Plan.
- There must be a common language and understanding of rights in order to implement supportive decision making.

In Part 3, <u>Mrs. Jane Gildersleeve-Janoff</u> will comment on suggestions for family and staff based on her own experiences as a parent and as a leading advocate for guardianship in New Jersey and on the leadership tract for National Guardianship Association.

Part 3

Human Rights and Guardianship: Family, Caregivers and Community

Jane Gildersleeve-Janoff Family Guardian (USA)

My daughter Jennie and I have spent a lifetime of advocating and blazing trails for individuals with developmental disabilities. Our actions have taken us to meet some very interesting people and to participate in some very interesting places and events. We started with talking to the local school and now here we are—speaking to the "world."

The Family, the Caregivers, and the Community each play a significant role in advocating for individuals with disabilities.

The individuals with disabilities play a significant role in advocating for themselves and for others in the family, agency, and community.

Therefore, we can each be a part of a supportive community where each person benefits.

First, let me introduce Jennie.



<u>Jennie</u>

My daughter Jennie is the poster-girl for the GANJI Human Rights book—although it was not planned that way. Her role "developed" as the writing progressed over time. Jennie decided to allow her photos to be used to illustrate a personal handbook of human rights. She and I selected the pictures as well as the shooting locations. Because she is a visual learner, having her picture next to a rights statement was particularly important and beneficial. Interesting discussions followed.

Jennie is the youngest of 5 children and the only girl. Her pathway to independence started at age 6 months and included:

- Infant Stimulation Program
- Early Intervention Program
- Pre-school Education
- Special Education through high school and graduation at age 21

She was a typical adolescent and IS a typical adult.

Jennie enjoys:

- Social life activities and interests
- Dating and Love
- Work in the community (supervised)
- · Church attendance and tithing
- Volunteer work at church
- Cell Phone; Debit Card
- Her special gift is "caring about others"

Limited Guardianship

Jennie has a limited guardianship. We discuss all matters pertinent to her well being and desires. This is not always easy. It is her right to be informed and involved. She knows this quite well!

Suggestions for Families

Again----It is NOT easy!

- To teach a child with developmental disability about rights and responsibilities
- To teach the same things to children without disabilities

Parenting a child with a developmental disability is a <u>life-long task</u>, whether he/she lives with your or not. It is MOST CRITICAL to have the same expectations for all children, disabled or not. Each child has his/her own:

Challenges Abilities

Strengths Hopes for the future

Needs

Choices may be given and expanded. When a right is given to do something, it must be honored—unless there is the possibility of harm

Abilities, not Disabilities

Dr. Sandra Pinkerton, special educator and rights activist, pointed out that it is the abilities rather than the disabilities that are the defining aspects of a person. The family, school, and community need to develop a portrait of an "abled" person to help the individual feel included.

The portrait of ability starts as early as possible and continues throughout the life span. The family, school, and community needs to stem the temptations to "do for" the individual for expediency; to "make decisions" for the individual for convenience. The individual must be provided the opportunities to do things for himself/herself and to make choices and decisions in daily life matters. Practice, practice!

The fundamental needs of the individual are human rights. He or she must learn that rights include "my rights," "your rights," and "our rights."

Work is honorable

Elizabeth Sancho-Duser, former director of an adult training center and a case management supervisor, considered that it is vital for an individual's growth towards independence:

- To expect the person with a developmental disability to have his own career;
- To Celebrate the career plans and progress as you would celebrate those of other family members;
- To recognize that success is not measured by size of paycheck or title.

Many supervised day programs include <u>Self-advocacy programs</u> or <u>Human Rights programs</u> that help the individual to speak for himself/herself and to listen to others. Self-advocacy programs are fundamental to democracy and are based in human rights.

The Ethical Guardian

In her article on "The Ethical Guardian" in *Where Human Rights Begin*, Peggy Dervitz, MSW, retired supervisor with the NJ Bureau of Guardianship Services, wrote the following.

"An Ethical Guardian is a decision maker, a teacher, a counselor, an advocate and a facilitator of rights."

As a family guardian or professional guardian, it is vital to constantly try to achieve the right balance between maximizing your loved one's or your ward's autonomy, independence, and rights while protecting him/her from harm.

In Conclusion

Our culture holds the values of individualism, self-reliance, and cooperation.

Implementing human rights education and training—at home, in the school, in the community residence, and at the work place—is essential to upholding these values. The values underlie supported decision making.

Thank you for your interest in Human Rights and Guardianship as well as your support for the 3rd World Congress on Adult Guardianship.

I return the program to Dr. Joan Kakascik, past president of GANJI and co-author of monographs on limited guardianship and assessment of guardianship as well as a co-author of GANJI's pamphlet series on Surrogate Decision Making. Joan will direct the Question & Answer portion of this presentation.