

# **Where Human Rights Begin**

## **Human Rights and Guardianship for Individuals with Developmental Disabilities *In Plain Language***

**Editor-in-Chief: Joan Kakascik, Ed.D.**

**Associate Editor: Simon Azavedo, MSW, LCSW, CCBT, DAPA**

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**Jane Gildersleeve-Janoff**



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GANJI is proud to have partnered with the Arc of Essex County, New Jersey on the development of  
*Where Human Rights Begin*  
*The Arc of Essex County: For people with intellectual and developmental disabilities and their families*  
Since 1948

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2012

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## **FORWARD**

**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.**

**Yet 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***

**Speech before the United Nations  
NYC, 3/27/1958**

**10<sup>th</sup> Anniversary of the Adoption of the United Nations Declaration of Universal Human Rights  
12/9/1948**



# Where Human Rights Begin

## Human Rights and Guardianship for Individuals with Developmental Disabilities

*In Plain Language*

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# INTRODUCTION

*Human Rights are universal--the same for all people.*

*Human Rights apply to people with developmental disabilities whether or not the individual has a guardian.*

*Human Rights and Responsibilities should be taught and acquired by opportunities and practice learned through an individualized service plan and through daily life.*

*Human Rights should be a subject for staff training and for self-advocacy initiatives.*

## **PHILOSOPHY**

*Where Human Rights Begin* implements the words of Mrs. Eleanor Roosevelt quoted in the Forward: human rights apply to individuals “close to home” –neighborhood, school, and workplace. For individuals with developmental disabilities, human rights begin and continue in the home, school, group home, supervised apartment program, developmental center, supervised day program, skill sponsor home, recreation program, religious institution, nursing home, and on the job. Just as all citizens must do, persons with developmental disabilities must seek and be afforded opportunities to learn, to implement, and to advocate for their rights.

Human rights learning involves "my rights," "your rights," and "our rights." Implementing and advocating for the rights for self and others becomes a partnering for the good and just life for all, whether person-to-person, person-to-family, or person-to-community. Knowledge of rights and responsibilities is basic to self-advocacy initiatives as well as program/service initiatives.

While human rights benefit everyone, some individuals need certain protections. Legal protections, such as guardianship, are important for individuals who may be unable to make decisions in their own best interests, or, who may be vulnerable to exploitation. Powers of Attorney are more suitable for individuals who do not need a guardian.

## **PURPOSE**

TO PROVIDE individuals with developmental disabilities a unique, “hands-on,” interactive resource on human rights and surrogate decision making (guardianship and powers of attorney) written in plain language.

*Where Human Rights Begin* may be used in multiple ways, in whole or in part. It can be prepared as an individual's personal handbook, used as a supplement to the educational common core standards, and integrated into staff training. It may be helpful as a resource for self-advocacy training and a reference for families, professionals and caregivers.

TO OFFER suggestions for the families, staff, and professionals to facilitate self-direction and decision-making opportunities in the language of human rights.

TO OUTLINE surrogate decision making (guardianship and powers of attorney), pertinent law and case law.

*Where Human Rights Begin* is based on the *United Nations Declaration of Universal Human Rights* (1948), the *United Nations Rights of the Retarded* (1971), the *United Nations Rights of the Disabled* (2006), the *National Guardianship Association 'Rights of Individuals Under Guardianship'* (2004), and New Jersey case law, statutes, and regulations on surrogate decision-making and on the rights of the disabled as representative of similar laws in the other 49 states that we reviewed. A summary of key provisions in human rights documents, case law, statutes and regulations discussed above may be found in Appendix B.

The "plain language" text developed for each of the rights and sample responsibilities statements was determined through a pilot project that included collaboration with speech and language specialists, professionals who prepare service plans, direct care professionals, and individuals with developmental disabilities. The statements are considered easier to read than the original legal texts.

Members of the Guardianship Association of New Jersey, Inc. (GANJI), the staff of the Arc of Essex County, New Jersey, a faculty member of Raritan Valley Community College, disability advocacy consultants, attorneys, and family members contributed to preparing different parts of this book: the service plan goals and objectives, the staff training examples, suggestions for implementation into daily life, and a summary of guardianship. The volunteer members of each organization included: family members, special educators, social workers, attorneys, psychologists, program directors, and direct care professionals.

The National Guardianship Association (NGA) gave permission to print its document "*Rights of Individuals Under Guardianships*." GANJI gave permission to include its document "Frequently Asked Questions about Durable Power of Attorney and Medical Power of Attorney."

## **PART I: Self Determination: Human Rights and Sample Responsibilities**

Section A offers a summary chart of rights from law and standards from multiple sources: international, national, and (as example) the State of New Jersey. The rights statements are grouped into 5 areas for ease of reading, understanding, and learning.

Personal Rights  
Living Arrangements  
Health Care

Work/Habilitation  
Safe Environment

Section B provides two sets of the same 26 rights with sample responsibilities statements pages. The first set is personalized with photographs of “Jennie.” The pages with no photographs can be personalized for the individuals who may want such a handbook of his/her own. Photographs (pasted, Xeroxed, scanned-in) are recommended because clip art and drawings are too abstract for some to read and recognize as well as too impersonal.

Section C is particularly relevant to individuals under a guardianship. The section summarizes the rights of the individual who has a guardian appointed by the court. Guardians (legally appointed to be responsible for the care and management of the person and property of another—the ward) are expected to make sure that the “ward” (someone placed under the legal protection of a guardian) retains his or her rights as much as possible, consistent with the Court’s judgments and orders. An individual who the Court determined to be in need of a guardian does not lose his or her human rights.

Section D considers the legal alternative of Powers of Attorney (POA) for individuals with developmental disabilities who do not need a guardian. It offers Questions and Answers (Q&A) information about durable powers of attorney and medical powers of attorney.

## **PART II: Human Rights: Self Direction and Supported Decision Making**

Section A describes a Self-Direction Model of education and habilitation that moves forward from the prior models of medical and custodial care, of education and skill development, and of the habilitation model for adaptive living. The Self-Direction Model builds upon and represents a shift towards training that emphasizes purpose and meaning through recognizing a person’s rights, needs, strengths, and responsibilities as expressed in an increase in independence and functional abilities.

Section B offers a sample of service plans with illustrative goals and objectives that help an individual learn about human rights and responsibilities. Three examples of goals, objectives and techniques are provided for each of the 26 rights and responsibilities statements at 3 levels of cognitive ability (severe, moderate, mild cognitive limitations).

Formal habilitation objectives for individuals eligible for the federally funded Community Care Waiver (CCW; services run by the state and its contracted agencies) could pair rights education with the CCW requirements. Informally, rights education may occur through daily teachable moments where opportunities are provided to the individual for expressing preferences, identifying choices, or making decisions. With a personalized handbook, families and caregivers can assist the individual with a disability learn about and express his or her rights.

Section C provides discussion points for staff training programs about each right and responsibilities statement. Professionals and caregivers working with individuals with developmental disabilities must be knowledgeable about rights in order to provide daily-life opportunities for individuals to express rights for self and others.

Section D offers a personal perspective from families and professionals. The section offers reflection on the benefits of encouraging human rights experiences at home, in school, and in the workplace through opportunities for decision-making, self esteem, and autonomy.

Section E considers the role the ethical guardian in helping to develop the ward's independence and capacity.

### **PART III: Overview: Surrogate Decision Making (Guardianship)**

An individual who may lack the ability to make decisions for himself or for herself may need legal protections.

Section A offers summarized legal information about the guardianship process.

Section B outlines representative guardianship law.

Section C sites representative health-care statutes and case law.

### **PART IV: Appendices**

Appendix A Glossary

Appendix B Comparison of Legal Statutes, Declarations, and Standards

Appendix C References

### **CONCLUSION**

Human Rights is the cornerstone for setting equality for all human beings regardless of race, class, sex, nationality, religion, sexual orientation, and of course, disability. Only with this foundation can we begin to wholeheartedly address attitudinal, physical, and policy barriers. Learning about and honoring the human rights of all people, wherever they may be or wherever they may live, helps to ensure that human rights are respected. Human rights education and implementation have beginnings in daily life and continue throughout the lifespan for each of us.

*Where Human Rights Begin* is designed to be an interactive book where individuals may develop their own personal rights handbook. Training staff may bring human rights matters to annual service plan meetings. Families and caregivers can endorse a language and environment for "your rights, my rights, and our rights." *Where Human Rights Begin* is unique in its focus as a direct, hands-on resource for individuals with developmental disabilities. It uniquely considers Human Rights and Surrogate Decision Making: Guardianship and Powers of Attorney.

As Mrs. Eleanor Roosevelt said:

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

Joan Kakascik, Ed.D.  
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*Chester, NJ and Livingston, NJ  
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## **PART I**

### **Self Determination: Human Rights and Sample Responsibilities**

- A. Summary Chart of Rights and Sample Responsibilities
- B. Sample Handbook (Meet Jennie)  
Personal Handbook (“do-it-yourself”)
- C. Rights of the Individual under Guardianship
- D. Powers of Attorney: Questions & Answers
- E. The Ethical Guardian





# **PART I**

## **Self Determination: Human Rights and Sample Responsibilities**

**Joan Kakascik, Ed.D.**

**Simon Azavedo, MSW, LCSW, CCBT, DAPA**

- Learn about Your Rights! This is the beginning of Self-Advocacy.
- Learn about some of Your Responsibilities that may go with Your Rights!
- Learn about “Your Rights, My Rights, and Our Rights” at home, school, day program, work place, and self-advocacy meetings!
- If you have a guardian, talk to your guardian about your rights and responsibilities. Discuss with your guardian the chart of “Rights of the Individual Under Guardianship!”
- If you do not need a guardian, think about giving Powers of Attorney to someone who you trust!
- Talk to your staff or case manager about learning about rights and responsibilities through your service plan.

### **Section A**

#### **Summary Chart of Rights and Sample Responsibilities**

The Rights and Sample Responsibilities statements are written *in Plain Language* rather than in the legal terms. Each statement was reviewed by speech and language specialists, professionals who prepare service plans, direct care professionals and individuals with a developmental disability. The rights statements are grouped under the following topics:

- Personal Rights
- Living Arrangements
- Health Care
- Work and Habilitation
- Safe Environment

### **Section B**

#### **Sample Handbook (Meet Jennie)**

#### **Personal Handbook (do-it-yourself)**

Make Your own human rights handbook!

Place Your picture on the pages of Rights and Sample Responsibilities statements---like Jennie did.

## PART I, Section A

### SUMMARY CHART OF RIGHTS AND SAMPLE RESPONSIBILITIES

	<u><b>RIGHTS</b></u>	<u><b>RESPONSIBILITIES</b></u>
	<b>PERSONAL RIGHTS</b>	
1. RESPECT	<b>Right:</b> To be respected as a person with rights	<b>Sample Responsibilities:</b> 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	<b>Right:</b> To advocate for yourself	<b>Sample Responsibilities:</b> 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 when needed
3. RELIGION	<b>Right:</b> To freely go to the church, synagogue, mosque, or house of worship of your choice, or not go	<b>Sample Responsibilities:</b> 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
4. VOTE	<b>Right:</b> To register and to vote in elections, if you want to do so	<b>Sample Responsibilities:</b> To vote the way you want to vote at meetings, in organizations, and in

		<p>national, state and community elections</p> <p>To respect those who do not vote the way you vote or who choose not to vote</p>
<p>5. GUARDIAN</p>	<p><b>Right:</b> To have a limited or general guardian, if you need one</p>	<p><b>Sample Responsibilities:</b> To talk with your guardian, agent, or advocate what you are thinking about, what you want, or what you need</p> <p>To ask the judge to reverse your guardianship</p> <p>To appoint someone who you trust to be your Power of Attorney</p>
	<p><b>LIVING ARRANGEMENTS</b></p>	
<p>6. SERVICES</p>	<p><b>Right:</b> To have services that you need like a safe and clean place to live</p>	<p><b>Sample Responsibilities:</b> To follow safety rules</p> <p>To take care of your home</p>
<p>7. PERSONAL ITEMS</p>	<p><b>Right:</b> To have your own money, clothing, and personal items kept safe</p>	<p><b>Sample Responsibilities:</b> To take good care of your things</p> <p>To leave other people's things alone</p>
<p>8. MAIL</p>	<p><b>Right:</b> To send and receive unopened mail</p> <p>To ask someone to help you read or write your mail if you need help</p>	<p><b>Sample Responsibilities:</b> To respect another person's right to send unopened mail</p> <p>To respect another person's right to open and read his own mail</p>
<p>9. PHONE</p>	<p><b>Right:</b> To make phone calls and to receive phone calls from others during reasonable hours</p>	<p><b>Sample Responsibilities:</b> To follow the house rules for making and receiving phone calls</p> <p>To pay your phone bill</p>

	To have privacy for your phone calls	To respect another person's right to make and receive private phone calls
10. HEALTHY DIET	<b>Right:</b> To have a healthy, balanced diet	<b>Sample Responsibilities:</b> To help plan meals  To eat foods that you like and that are good for you  To follow the diet that your doctor says is good for you
11. RELATIONSHIPS	<b>Right:</b> To have relationships with girlfriends and boyfriends	<b>Sample Responsibilities:</b> To respect your friends  To learn how to behave at social events, at dances and on trips
12. VISITORS	<b>Right:</b> To have guests visit you during reasonable hours	<b>Sample Responsibilities:</b> To make plans for your guests to visit you during reasonable hours  To make sure that your guests follow house rules
13. ACTIVITIES	<b>Right:</b> To join social and recreational activities at your home, school, work place, or community when you want to participate in them	<b>Sample Responsibilities:</b> To follow the rules of the activity  To let others know if you want to go or not go to an activity
14. PRIVACY	<b>Right:</b> To have privacy when you want to be alone	<b>Sample Responsibilities:</b> To tell people when you want to be alone  To respect others when they want to be alone

	<b>HEALTH CARE</b>	
15. TREATMENT & THERAPY	<b>Right:</b> To get the treatment or therapy that you need	<b>Sample Responsibilities:</b> To go to treatment or therapy sessions  To follow the doctor's and therapist's directions
16. HEALTHY LIVING	<b>Right:</b> To practice healthy living and physical exercise	<b>Sample Responsibilities:</b> To take good care of yourself so that you stay healthy  To choose an exercise that you like, want, and can do
17. MEDICAL CARE	<b>Right:</b> To receive medical, dental, and other health care regularly and when you need it	<b>Sample Responsibilities:</b> To let people know if you are sick or if you are hurt  To talk to your doctors  To ask questions about your health, healthcare, and medications
	<b>WORK and HABILITATION</b>	
18. SCHOOL	<b>Right:</b> To go to school through age 21	<b>Sample Responsibilities:</b> To complete your education  To participate in school programs
19. WORK & PLAY	<b>Right:</b> To work  To get paid for what you do	<b>Sample Responsibilities:</b> To follow the rules of the workplace  To be a good co-worker  To pay your bills  To retire with things to do

20. JOB & PROGRAM	<b>Right:</b> To ask to go to another job, program, or place to live	<b>Sample Responsibilities:</b> To say what you like and what you do not like about a job, program, or place to live
21. SERVICE PLAN	<b>Right:</b> To participate in developing your service plan  To participate in your service plan meeting	<b>Sample Responsibilities:</b> To think about what you want and need  To let people know at your meeting, or before, what you want and need
22. PRIVATE INFORMATION	<b>Right:</b> To have files about you kept private	<b>Sample Responsibilities:</b> To give or not give permission for others to read your files  Do not read anyone else's files
<b>SAFE ENVIRONMENT</b>		
23. NO UNUSUAL TREATMENT	<b>Right:</b> To be free from unusual treatments and research unless ordered by the court and recorded in your medical record [shock treatment, psychosurgery, sterilization, and medical, behavioral, or pharmacological research]	<b>Sample Responsibilities:</b> To talk about any suggested unusual treatments with your family, guardian, advocate, agent, doctor, lawyer, case manager, or staff
24. NO RESTRAINTS	<b>Right:</b> To be free from restraints unless medically approved and recorded in your medical record [including time-out, mechanical, physical, medication, or chemical procedures]	<b>Sample Responsibility:</b> To talk about a behavior plan or protective device with your family, guardian, advocate, agent, case manager, or staff

<p>25. NO PUNISHMENTS</p>	<p><b>Right:</b> To be free from any kind of mental or physical punishment or abuse</p>	<p><b>Sample Responsibilities:</b> To tell someone <u>right away</u> if anyone punishes or abuses you</p>
<p>26. RIGHT TO HABEAS CORPUS</p>	<p><b>Right:</b> To have a lawyer represent you in court</p>	<p><b>Sample Responsibilities:</b> To tell the truth to your lawyer  To tell the truth to the judge  To have your guardian, if you have one, with you in court</p>





## Meet Jennie



*Jennie is the youngest of five children and the only girl. She was born in 1973 and started her path to independence at age 6 months with an infant stimulation program. After that, she continued with an early intervention program, then pre-school, special education classes, and finally high school graduation at age 21.*

*Jen was a typical teenager: dating, going to her proms, and having a special boyfriend whose name was Chris or affectionately Honey-poo! Chris passed away suddenly while Jennie was in her last year of high school. My daughter was devastated and she dropped out of all of her social programs for several years.*

*Jennie went right from high school to working in the community. She still works in community programs. She has grown up in the church where she volunteers and tithes regularly. Jennie is proud to write checks for the church and she enjoys being an active member.*

*Jennie has a debit card which she knows how to use. She also writes checks to pay for her hair and nail appointments. Jennie enjoys socializing and loves talking on her cell phone. She speaks regularly to family and friends.*

*Jennie has a particular gift that characterizes who she is. That gift is the blessing of caring. She worries about her friends when they are sick. She will always ask you how you are doing. Whenever I drive her to an activity or get her something as simple as a granola bar, she says “thank you!” Jennie is not perfect but that “thank you” makes me forget the difficult times.*

*Jennie is proud to have her pictures in this book. She understands her rights and can make reasonable choices about her meals, clothing, social and work activities. When it comes time to vote, we talk about the people and the issues so that she can make thoughtful choices.*

*Jennie and I do not always agree but I respect her choices. There are times though when I need to say “no.” When that happens, I give her two choices that I can live with.*

*Jennie’s guardianship papers are limited. This means that my powers as her guardian are limited. I must talk to Jennie about all options. I have the power to determine the use of major monies and she to determine use of her earnings. We have talked often and revisited where she wants to live when I pass. If there should be a major medical issue such as cancer, then it is my responsibility to present all of the different treatment options. In other words, Jennie is always part of the decisions that affect her life.*

*Jennie learns visually and so the pictures in this book have a special meaning for her. As we developed the book, Jennie helped to place her picture next to the correct “rights” statements. She now carries her “Human Rights” book with her everywhere to show her friends and family, and continues to learn about her rights from it by using it through her daily experiences.*

*By Her Mom, Jane Gildersleeve-Janoff*

## **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 at them**



## **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 when needed**



## **PERSONAL RIGHTS: RELIGION**

**Right # 3**    **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**





## **PERSONAL RIGHTS: VOTE**

**Right # 4** To register and to vote in elections, if you want to do so

### **Sample Responsibilities**

To vote the way you want to  
vote at meetings, in  
organizations, and in  
national, state and  
community elections

To respect those who do not  
vote the way you vote or  
choose not to vote



**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**



## **LIVING ARRANGEMENTS: SERVICES**

**Right # 6** To have services that you need like a safe and clean place to live

### **Sample Responsibilities**

To follow safety rules

To take care of your home





**LIVING ARRANGEMENTS: PERSONAL ITEMS**

**Right # 7** To have your own money, clothing,  
and personal items kept safe

**Sample Responsibilities**

To take good care of your  
things

To leave other people's  
things alone



**LIVING ARRANGEMENTS: MAIL**

**Right # 8**    **To send and receive unopened mail**  
**To ask someone to help you read or**  
**write your mail if you need help**

**Sample Responsibilities**

**To respect another person's**  
**right to send unopened mail**

**To respect another person's**  
**right to open and read his**  
**own mail**



## **LIVING ARRANGEMENTS: PHONE**

**Right # 9** To make phone calls and to receive phone calls from others during reasonable hours

**To have privacy for your phone calls**

### **Sample Responsibilities**

**To follow the house rules for making and receiving phone calls**

**To pay your phone bill**

**To respect another person's right to make and receive private phone calls**



**LIVING ARRANGEMENTS: HEALTHY DIET**

**Right # 10 To have a healthy, balanced diet**

**Sample Responsibilities**

To help plan meals

To eat foods that you like  
and that are good for you

To follow the diet that your  
doctor says is good for you





**LIVING ARRANGEMENTS: RELATIONSHIPS**

**Right # 11 To have relationships with girlfriends  
and boyfriends**

**Sample Responsibilities**

**To respect your friends**

**To learn how to behave at  
social events, at dances,  
and on trips**



**LIVING ARRANGEMENTS: VISITORS**

**Right # 12**      **To have guests visit you during reasonable hours**

**Sample Responsibilities**

**To make plans for your guests to visit you during reasonable hours**

**To make sure that your guests follow house rules**



## **LIVING ARRANGEMENTS: ACTIVITIES**

**Right # 13**    **To join social and recreational activities at your home, school, work place, or community when you want to participate in them**

### **Sample Responsibilities**

**To behave according to the rules of the activity**

**To let others know if you want to go or not go to an activity**



## **LIVING ARRANGEMENTS: PRIVACY**

**Right # 14**    **To have privacy when you want to be alone**

### **Sample Responsibilities**

**To tell people when you want to be alone**

**To respect others when they want to be alone**





**HEALTH CARE: TREATMENT & THERAPY**

**Right # 15**    **To get the treatment or therapy that you need**

**Sample Responsibilities**

**To go to treatment or therapy sessions**

**To follow the doctor's and therapist's directions**



**HEALTH CARE: HEALTHY LIVING**

**Right # 16**    **To practice healthy living and  
physical exercise**

**Sample Responsibilities**

**To take good care of yourself  
so that you stay healthy**

**To choose an exercise that you  
like, want, and can do**



**HEALTH CARE: MEDICAL CARE**

**Right # 17**    **To receive medical, dental, and other health care regularly and when you need it**

**Sample Responsibilities**

**To let people know if you are sick or if you are hurt**

**To talk to your doctors**

**To ask questions about your health, healthcare, and medications**



**WORK and HABILITATION: SCHOOL**

**Right # 18 To go to school through age 21**

**Sample Responsibilities**

**To complete your education**

**To participate in school  
programs**





**WORK and HABILITATION: WORK & PLAY**

**Right # 19 To work**

**To get paid for what you do**

**Sample Responsibilities**

**To follow the rules of the workplace**

**To be a good co-worker**

**To pay your bills**

**To retire with things to do**



**WORK and HABILITATION: JOB & PROGRAM**

**Right # 20**    **To ask to go to another job,  
program, or place to live**

**Sample Responsibilities**

**To say what you like and  
what you do not like about  
a job, program, or place to  
live**



**WORK and HABILITATION: SERVICE PLAN**

**Right # 21**      **To participate in developing your service plan**

**To participate in your service plan meetings**

**Sample Responsibilities**

**To think about what you want and need**

**To let people know at your Meeting, or before, what you want and need**



**WORK and HABILITATION: PRIVATE INFORMATION**

**Right # 22    To have files about you kept private**

**Sample Responsibilities**

**To give or not give permission  
for others to read your files**

**Do not read anyone else's files**





**SAFE ENVIRONMENT: NO UNUSUAL TREATMENT**

**Right # 23**    **To be free from unusual treatments and research unless ordered by the court and recorded in your medical record**

[shock treatment, psychosurgery, sterilization, and medical, behavioral, or pharmacological research]

**Sample Responsibilities**

**To talk about any suggested unusual treatments with your family, guardian, advocate, agent, doctor, lawyer, case manager, or staff**



**SAFE ENVIRONMENT: NO RESTRAINTS**

**Right # 24**

**To be free from restraints unless medically approved and recorded in your medical record**

[including time-out, mechanical, physical, medication, or chemical procedures]

**Sample Responsibilities**

**To talk about a behavior plan or protective device with your family, guardian, advocate, agent, case manager, or staff**



**SAFE ENVIRONMENT: NO PUNISHMENT or ABUSE**

**Right # 25**    **To be free from any kind of mental or physical punishment or abuse**

**Sample Responsibilities**

**To tell someone right away if anyone punishes or abuses you**





**SAFE ENVIRONMENT: RIGHT OF HABEAS CORPUS**

**Right # 26**    **To have a lawyer represent you in a court of law**

**Sample Responsibilities**

**To tell the truth to your lawyer**

**To tell the truth to the judge**

**To have your guardian, if you have one, with you in court**



***Where Human Rights Begin***  
**a**  
**Personal Handbook**  
**on**  
**HUMAN RIGHTS**

*From:*

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

*Editor-in Chief Joan Kakascik, Ed.D.*

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**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 at them**

**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 when needed**



**PERSONAL RIGHTS: RELIGION**

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**To talk about any suggested unusual treatments with your family, guardian, advocate, agent, doctor, lawyer, case manager, or staff**

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[including time-out and mechanical, physical, medication, or chemical procedures]

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To talk about a behavior plan or protective device with your family, guardian, advocate, agent, case manager, or staff

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**Sample Responsibilities**

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**To tell the truth to the judge**

**To have your guardian, if you  
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## *Part I, Section C*

# **Rights of Individuals Under Guardianship**

National Guardianship Association (NGA)

Excerpted with permission from “Fundamentals of Guardianship:

What Every Guardian Needs to Know,” Chapter 3, p. 17-18. [www.guardianship.org](http://www.guardianship.org)

Individuals retain human rights when under guardianship, except those rights which the court has granted to the guardian. The guardian’s responsibility includes insuring that the ward’s rights are not violated. The ward’s rights include all those guaranteed by federal and state constitutions and laws as well as the specific rights to:

<b>1. Be protected against abuse and neglect</b>
<b>2. Be treated with dignity and respect</b>
<b>3. A safe, sanitary and humane living, working and learning environment, which is the least restrictive environment for the ward’s needs and conditions</b>
<b>4. Privacy, including the right to bodily privacy and the right to private and uncensored communication with others by mail, telephone or personal visits</b>
<b>5. Religious expression in the manner of his/her choice</b>
<b>6. Interpersonal relationships and sexual expression</b>
<b>7. Exercise control over all aspects of life that the court has not delegated to the guardian</b>

<b>8. Appropriate services suited to the ward's needs and conditions, including mental health services</b>
<b>9. Have the guardian consider the ward's personal desires, preferences and options particularly in regard to ethnic, religious and cultural values</b>
<b>10. Exercise the option to procreate</b>
<b>11. Equal treatment under the law, regardless of race, religion, creed, sex, age, marital status, sexual orientation, or political affiliations</b>
<b>12. Have explanations for any medical procedures or treatment, including information about the benefits, risks, and side effects of the treatment, and any alternative procedures or medications available</b>
<b>13. Have personal information kept confidential including withholding certain information the ward may not want his/her family to know</b>
<b>14. Prudent financial management of property and information regarding how that property is managed</b>
<b>15. Notice of all proceedings related to the guardianship</b>
<b>16. Review personal records, including medical, financial, and treatment records</b>
<b>17. Speak privately with an attorney, ombudsman, or other advocate</b>

<b>18. Petition the court to modify or terminate the guardianship including the right to meet privately with an attorney or other advocate to assist with this legal procedure</b>
<b>19. Have the guardian available to meet the needs of the ward at all times</b>
<b>20. Not to be involved in research projects</b>
<b>21. Continuous review of the need for full or partial restoration of rights</b>
<b>22. Bring a grievance against the guardian or request the court to review the guardian's actions</b>
<b>23. Request removal and replacement of the guardian, or request that the court restore rights if it can be shown that the ward has regained capacity to make some or all decisions</b>

**The guardian also has a responsibility to request that the ward's rights be restored when there is evidence that the ward has regained capacity.**

See Appendix C for NGA information for guardians.

# PART I

## Section D

### Introduction

Usually many individuals with developmental disabilities are considered to require a general or limited guardianship for the protections that they need. It is not often that an individual with developmental disabilities negotiates Powers of Attorney: Durable or Medical. Negotiating Powers of Attorney with a lawyer may be an alternative for those individuals who are able to make decision in their own best interests, who have a strong support system (usually family) in place, and who have not been considered to be in need of a guardian.

Durable and medical powers of attorney are non-judicial procedures commonly used by people to legally designate a family member or other trusted person to make decisions (i.e., medical or financial) when he/she is unable to do so. Typically, a husband and wife name each other as an Agent in Power of Attorney. An older parent may identify a son or daughter as Agent for the Power of Attorney.

An individual with a developmental disability may need assistance in finding a lawyer or with making changes to an existing Power of Attorney. A family member, agency manager, case manager, social worker, or other interested person should REFER the individual TO A LAWYER. Names of lawyers are available from the following resources: Guardianship Association of New Jersey, Inc. 1-877-GUARDNJ; the New Jersey Bar Association 732-249-5000; County Legal Services. The Questions and Answers section below addresses some frequently asked questions about Powers of Attorney.

For convenience and clarity, the Case Manager (in public service or in the private sector) position is used in the Q&A document below as a representative professional person to whom an individual with a developmental disability may go to for information to include information about Powers of Attorney. Neither a state employee nor a provider agency employee is permitted to be appointed Agent for a Power of Attorney. It would be a conflict of interest.

### Questions & Answers

#### **DURABLE POWER OF ATTORNEY AND MEDICAL POWER OF ATTORNEY**

**Peggy Dervitz, MSW; Shashi Jain, Ph.D.; Daniel Jurkovic, Esq.; Joan Kakascik, Ed.D.;  
NJ Community Health Law Project: David Popiel, Esq.; Elizabeth Livingstone, Esq.**

Individuals with developmental disabilities who have been assessed by a physician or a psychologist as not in need of a guardian may wish to avail themselves of protection in the event that he or she may become incapacitated and need a surrogate decision maker. A **Durable Power of Attorney** and a **Medical Power of Attorney** are legal instruments that are available to all persons with capacity as a way of planning for such an event. The standard types of documents that attorneys use for the general population are written in such a way that they are often too complex and difficult for people with developmental disabilities to understand.

*Frequently Asked Questions about Durable Power of Attorney and about Medical Power of Attorney* follows. Sample legal documents are available for attorney consideration from the GANJI website: [www.ganji.org](http://www.ganji.org)

## **GIVING DURABLE POWER OF ATTORNEY TO SOMEONE**

### **Frequently Asked Questions**

#### **1.What is a Power of Attorney?**

Power of Attorney is a document that allows you to appoint an Agent to make financial and legal decisions on your behalf and access your financial and legal records.

#### **2.What is a Power of Attorney designed to do?**

A Power of Attorney is designed to allow your wishes with regard to financial and legal matters to be carried out or to be authorized by another person if you cannot authorize necessary financial and legal decisions yourself.

#### **3.What is a Principal?**

A Principal is the person giving authority to another person.

#### **4.What is an Agent?**

An Agent is the person you select to make financial and legal decisions for you if you are unable or unwilling to do so.

#### **5.Who is the Principal?**

You are the Principal.

#### **6.Who is the Agent?**

The Agent is the person with whom you share your authority.

#### **7.What can the Agent do?**

The Agent can access financial and legal records, talk with your financial and legal consultant(s) and collect information about your financial and legal affairs.

#### **8.Do I need to go to Court to execute a Power of Attorney?**

No. You do not need to go to Court.

#### **9.Do I need a lawyer to help me execute a Power of Attorney?**

It is strongly recommended that you seek the advice of an attorney. If you do not get help from an attorney, there is no guarantee that the document will be effective or honored by your financial and/or legal consultant(s).

#### **10.What do I do if someone advises me to sign a Power of Attorney?**

You should talk to your case manager and request assistance with a referral to the Community Health Law Project or a private attorney licensed to practice in New Jersey.

#### **11.How do I find a private attorney who is experienced in this work?**

There are organizations that can give you the names of private attorneys who can help you. You may call the Guardianship Association of New Jersey, Inc. at 1-877-GUARDNJ, the National Academy of Elder Law Attorneys at 520-881-4005, the National Elder Law Foundation at 520-881-1076, the New Jersey State Bar Association at 732-249-5000 or Legal Services in your county or you may visit their web sites.

**12.How much does it cost to execute a Power of Attorney?**

The Community Health Law Project does not charge a fee. The rates for private attorneys vary.

**13.What should I consider when selecting an Agent?**

You should select someone you trust, someone who will listen to you and honor and respect your wishes, someone who can help you understand your financial and legal needs. The person you select must be willing to act as your Agent.

**14.What should I do with the Power of Attorney after I sign it?**

You and the Agent should hold the originals. You should show the original to your financial and/or legal consultant(s) and ask the consultant(s) to make copies of it for your financial and legal files and then return the original to you. You should also give a copy to your caretaker and your case manager.

**15.Does designating a Power of Attorney take away my rights?**

No. A Power of Attorney helps ensure that your rights are protected and that you are able to exercise your legal rights.

**16.Can I change or revoke the Power of Attorney?**

Yes. If you want to change or revoke the Power of Attorney, talk with your case manager and request a Revocation of Power of Attorney form.

**17.Can my Agent make all financial and legal decisions for me?**

No. Your Agent should only make financial and legal decisions after consulting with you. If you are unable to be consulted, then your Agent should make financial and legal decisions that you previously expressed to him/her or that are in your best interest.

**18.What if my Agent does not consult with me?**

You should consider revoking the Power of Attorney and appointing a new Agent.

**19.What if my document is not honored?**

You should immediately talk to your case manager or the Law Project or your private attorney.

**20.What if my financial and/or legal consultant(s) only want to talk to my Agent?**

You have the right to have your financial and/or legal consultant(s) speak with you directly about your financial and legal affairs. If the consultant does not honor your right, you should talk to your case manager or the Law Project or your private attorney.

**21.What if my Agent dies, moves away or is no longer able to act on my behalf?**

You should talk to your case manager about executing a new document. Your case manager should advise your doctor and your caretaker that you have a new Agent.

**22.What if my Agent asks me for money?**

You should talk to your case manager about any financial arrangements between you and your Agent.

## **ACCEPTING A DURABLE POWER OF ATTORNEY FROM SOMEONE**

### **Frequently Asked Questions**

#### **1.What is a Power of Attorney?**

A Power of Attorney is a document that allows a person to appoint an Agent to make financial and legal decisions on his/her behalf and access his/her financial and legal records.

#### **2.What is a Power of Attorney designed to do?**

A Power of Attorney is designed to allow an Agent to carry out the wishes of a Principal with regard to financial and legal matters and authorizes the Agent to make necessary financial and legal decisions on behalf of the Principal.

#### **3.What is a Principal?**

A Principal is the person giving authority to another person.

#### **4.What is an Agent?**

An Agent is the person a Principal selects to make financial and legal decisions for him/her.

#### **5.Who is the Principal?**

The Principal is the person giving you this authority.

#### **6.Who is the Agent?**

You are the Agent. As the Agent, you share authority with the Principal.

#### **7.What can the Agent do?**

The Agent can access financial and legal records, talk with the Principal's financial and/or legal consultant(s) and collect information about the Principal's financial and legal affairs.

#### **8.Does the Principal need to go to Court to execute a Power of Attorney?**

No. The Principal does not need to go to Court.

#### **9.Does the Principal need a lawyer to help execute a Power of Attorney?**

It is strongly recommended that the Principal seek the advice of an attorney. If the Principal does not get help from an attorney, there is no guarantee that the document will be effective or honored by the Principal's doctor or medical facility.

#### **10.How much does it cost to execute a Power of Attorney?**

The Community Health Law Project does not charge a fee. The rates for private attorneys vary.

#### **11.What are the requirements for being an Agent?**

You should be someone the Principal trusts, someone who will listen to the Principal and honor and respect his/her wishes, someone who can help the Principal understand his/her financial and legal needs. You must be willing to act as the Principal's Agent.

**12.What should I do with the Power of Attorney after the Principal signs it?**

You and the Principal should hold the originals. The Principal should show the original to his/her financial and/or legal consultant(s) and ask the consultant(s) to make a copy of it for his/her file and then return the original to the Principal.

**13.Does a Power of Attorney take away the Principal's rights?**

No. A Power of Attorney is designed to help ensure that the Principal's rights are protected and that the Principal is able to exercise his/her legal rights.

**14.Can the Power of Attorney be changed or revoked?**

Yes. If the Principal wants to change or revoke the Power of Attorney, he/she should talk with his/her case manager and request a Revocation of Power of Attorney form.

**15.What do I do if I receive a Revocation?**

You must immediately cease making financial and legal decisions and accessing financial and legal information on behalf of the Principal. You can be held liable if you fail to honor the revocation once it has been provided to you.

**16.Can I make all legal and financial decisions for the Principal?**

No. You should only make financial and legal decisions after consulting with the Principal. If you are unable to consult with the Principal, then you should make financial and legal decisions that were previously expressed to you by the Principal or that are in the Principal's best interest.

**17.What if I do not consult with the Principal?**

The Principal should consider revoking the Power of Attorney and appointing a new Agent.

**18.What if I do not honor the document?**

The Principal should immediately talk to his/her case manager or the Law Project or his/her private attorney.

**19.What if the Principal's financial and/or legal consultant(s) only wants to talk to me?**

The Principal has the right to have his/her financial and/or legal consultant(s) speak with him/her directly about his/her financial and legal affairs. If the financial and/or legal consultant(s) do not honor this right, you should talk to the consultant and ensure the Principal's inclusion in discussions.

**20.What if I die, move away or am no longer able to act on behalf of the Principal?**

The Principal should talk to his/her case manager about executing a new document. The case manager should advise the Principal's financial and/or legal consultant(s) and caretaker that he/she has a new Agent.

**21.Am I permitted asks the Principal for compensation for my services?**

You should talk to the Principal's case manager about any financial arrangements between you and the Principal.



## **GIVING MEDICAL POWER OF ATTORNEY TO SOMEONE**

### **Frequently Asked Questions**

#### **1.What is a Medical Power of Attorney?**

A Medical Power of Attorney is a document that allows a person to appoint an Agent to make medical decisions on his/her behalf and access his/her medical records.

#### **2.What is a Medical Power of Attorney designed to do?**

A Medical Power of Attorney is designed to allow your wishes with regard to medical care to be carried out or to be authorized by another person if you cannot authorize necessary medical treatment yourself.

#### **3.What is a Principal?**

A Principal is the person giving authority to another person.

#### **4.What is an Agent?**

An Agent is the person you select to make medical decisions for you if you are unable or unwilling to do so.

#### **5.Who is the Principal?**

You are the Principal.

#### **6.Who is the Agent?**

The Agent is the person with whom you share your authority.

#### **7.What can the Agent do?**

The Agent can access medical records, talk with your doctors and collect information about your health.

#### **8.Do I need to go to Court to execute a Medical Power of Attorney?**

No. You do not need to go to Court.

#### **9.Do I need a lawyer to help me execute a Medical Power of Attorney?**

It is strongly recommended that you seek the advice of an attorney. If you do not get help from an attorney, there is no guarantee that the document will be effective or honored by your doctor or medical facility.

#### **10.What do I do if someone advises me to sign a Medical Power of Attorney?**

You should talk to your case manager and request assistance with a referral to the Community Health Law Project or a private attorney licensed to practice in New Jersey.

#### **11.How do I find a private attorney who is experienced in this work?**

There are organizations that can give you the names of private attorneys who can help you. You may call the Guardianship Association of New Jersey, Inc. at 1-877-GUARDNJ, the National Academy of Elder Law Attorneys at 520-881-4005, the National Elder Law Foundation at 520-881-1076 or the New Jersey State Bar Association at 732-249-5000 or Legal Services in your county or you may visit their web sites.

**12.How much does it cost to execute a Medical Power of Attorney?**

The Community Health Law Project does not charge a fee. The rates for private attorneys vary.

**13.What should I consider when selecting an Agent?**

You should select someone you trust, someone who will listen to you and honor and respect your wishes, someone who can help you understand your healthcare needs. The person you select must be willing to act as your Agent.

**14.What should I do with the Medical Power of Attorney after I sign it?**

You and your Agent should hold the originals. You should show the original to your doctor and ask the doctor to make a copy of it for your medical file and then return the original to you. You should also give a copy to your caretaker and your case manager.

**15.Does a Medical Power of Attorney take away my rights?**

No. A Medical Power of Attorney helps ensure that your rights are protected and that you are able to exercise your legal rights.

**16.Can I change or revoke the Medical Power of Attorney?**

Yes. If you want to change or revoke the Medical Power of Attorney, you should talk with your case manager and request a Revocation of Medical Power of Attorney form.

**17.Can my Agent make all medical decisions for me?**

No. Your Agent should only make medical decisions after consulting with you. If you are unable to be consulted, then your Agent should make medical decisions that you previously expressed to him/her or that are in your best interest.

**18.What if my Agent does not consult with me?**

You should consider revoking the Medical Power of Attorney and appointing a new Agent.

**19.What if my document is not honored?**

You should immediately talk to your case manager or the Law Project or your private attorney.

**20.What if my doctor only wants to talk to my Agent?**

You have the right to have your doctor speak with you directly about your healthcare. If the doctor does not honor your right, you should talk to your case manager or the Law Project or your private attorney.

**21.What if my Agent dies, moves away or is no longer able to act on my behalf?**

You should talk to your case manager about executing a new document. The case manager should advise your doctor and caretaker that you have a new Agent.

**22.What if my Agent asks me for money?**

You should talk to your case manager about any financial arrangements between you and your Agent.

## **ACCEPTING MEDICAL POWER OF ATTORNEY**

### **Frequently Asked Questions**

**1.What is a Medical Power of Attorney?**

A Medical Power of Attorney is a document that allows a person to appoint an Agent to make medical decisions on his/her behalf and access his/her medical records.

**2.What is a Medical Power of Attorney designed to do?**

A Medical Power of Attorney is designed to allow an Agent to carry out the wishes of a Principal with regard to medical care and authorizes the Agent to make necessary treatment decisions on behalf of the Principal.

**3.What is a Principal?**

A Principal is the person giving authority to another person.

**4.What is an Agent?**

An Agent is the person a Principal selects to make medical decisions for him/her if he/she is unable or unwilling to do so.

**5.Who is the Principal?**

The Principal is the person giving you this authority.

**6.Who is the Agent?**

You are the Agent. As the Agent, you share authority with the Principal.

**7.What can the Agent do?**

The Agent can access medical records, talk with the Principal's doctors and collect information about the Principal's health.

**8.Does the Principal need to go to Court to execute a Medical Power of Attorney?**

No. The Principal does not need to go to Court.

**9.Does the Principal need a lawyer to help execute a Medical Power of Attorney?**

It is strongly recommended that the Principal seek the advice of an attorney. If the Principal does not get help from an attorney, there is no guarantee that the document will be effective or honored by the Principal's doctor or medical facility.

**10.How much does it cost to execute a Medical Power of Attorney?**

The Community Health Law Project does not charge a fee. The rates for private attorneys vary.

**11.What are the requirements for being an Agent?**

You should be someone the Principal trusts, someone who will listen to the Principal and honor and respect his/her wishes, someone who can help the Principal understand his/her healthcare needs. You must be willing to act as the Principal's Agent.

**12.What should I do with the Medical Power of Attorney after the Principal signs it?**

You and the Principal should hold the originals. The Principal should show the original to the doctor and ask the doctor to make a copy of it for the Principal's medical file and then return the original to the Principal. The Principal should also give a copy to this/her caretaker and his/her case manager.

**13.Does a Medical Power of Attorney take away the Principal's rights?**

No. A Medical Power of Attorney is designed to help ensure that the Principal's rights are protected and that the Principal is able to exercise his/her legal rights.

**14.Can the Medical Power of Attorney be changed or revoked?**

Yes. If the Principal wants to change or revoke the Medical Power of Attorney, he/she should talk with his/her case manager and request a Revocation of Medical Power of Attorney form.

**15.What do I do if I receive a Revocation?**

You must immediately cease making medical decisions and accessing healthcare information on behalf of the Principal. You can be held liable if you fail to honor the revocation once it has been provided to you.

**16.Can I make all medical decisions for the Principal?**

No. You should only make medical decisions after consulting with the Principal. If you are unable to consult with the Principal, then you should make medical decisions that the Principal previously expressed to you or that are in the Principal's best interest.

**17.What if I do not consult with the Principal?** The Principal should consider revoking the Medical Power of Attorney and appointing a new Agent.

**18.What if I do not honor the document?**

The Principal should immediately talk to his/her case manager or the Law Project or his/her private attorney.

**19.What if the Principal's doctor only wants to talk to me?**

The Principal has the right to have his/her doctor speak with him/her directly about his/her healthcare. If the doctor does not honor this right, you should talk to the doctor and ensure the Principal's inclusion in discussions.

**20.What if I die, move away or am no longer able to act on behalf of the Principal?**

The Principal should talk to his/her case manager about executing a new document. The case manager should advise the Principal's doctor and caretaker that he/she has a new Agent.

**21.Am I permitted to ask the Principal for compensation for my services?**

You should talk to the Principal's case manager about any financial arrangements between you and the Principal.

## **PART II**

### **Human Rights: Self Direction and Supported Decision Making**

- A. Human Rights and a Self Direction Model of Education & Habilitation
- B. Sample Goals and Objectives for Service Plans
- C. Suggestions for Professionals and Caregivers
- D. Suggestions for Families



## PART II

### Section A

#### Human Rights: A Self-Direction Model for Education and Habilitation

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Melissa Soules

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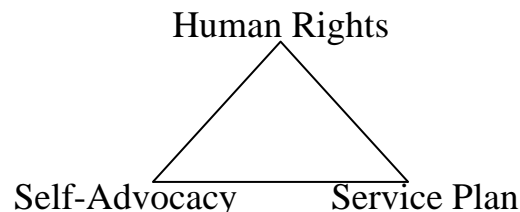
Maureen Murray

Christine Mc Evoy, MA

#### OVERVIEW

*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. We illustrate the Self-Direction Model in the language of human rights. Human Rights may be supplemental to at least two significant support program venues: the Annual Service Plan for the individual and Self Advocacy programs. Our focus is on the service plan.

The Self-Direction Model may be conceived as a triangle.



- Human Rights and Responsibilities should be taught and practiced
- Self-Advocacy encourages independence, responsibility, and self-expression
- Service Plans may include goals and objectives that can teach the fundamentals of human rights such as respect, privacy, and confidentiality, to name a few, through daily activities.

The “Rights and Sample Responsibilities” statements in this book may suggest content for personalized goals and objectives of a service plan. Please note that the service plan should be a plan of self direction and may be known at different times, in different places, by various titles with the over-all goal of assisting an individual with a disability acquire skills of independent living in the areas of activities of

daily living; domestic skills; and personal resources. Some other titles for the service plan may include: Individual Service Plan (ISP), Individual Habilitation Plan (IHP), Essential Lifestyle Plan (ESP), Individual Education Plan (IEP), or treatment plan. The methods in the plan may be called “goals, objectives, and techniques” or by terms such as “plan, outcome, and results.” The statements of rights and sample responsibilities are consistent with the plain language text in Part I, Sections A and B. All in all, the treatment plan, in any given State, such as already established in New Jersey, is a written legal document that is devised in such a way where it promotes the individual with a developmental disability to exercise his/her right to access quality supports and services in the community (i.e. day program, home, supportive employment, healthcare service, group home, school, faith-based facility where one chooses to learn and worship, etc.); to make it measurable; and to insure financial accountability. The "plan" maybe as general as "to exercise at the gym with a trainer," and "measurable" such as "three times a week for six months." Or it can be more detailed as we illustrate in the next Section (Part II Section B). The sample goals, objectives and techniques that we provide can still be adjusted to a different format of a treatment plan.

To illustrate implementing the Self Direction Model in an IHP format (which can be modified to an ISP), we offer:

- 3 examples of goals, objectives, and techniques for
- 3 levels of cognitive ability of each of the 26 rights and sample responsibilities statements in the following pages.

The levels of cognitive ability generally correspond to

- severe cognitive limitation,
- moderate cognitive limitation, or
- mild cognitive limitation.

The content of the examples reflects different settings: family home, community living arrangement, and workplace. The examples are representative, not all-inclusive.

The Self Direction Model of human rights training, may be included in staff training on service plan preparation. As always, an individual’s goals and objectives of the service plan are tailored to his or her needs, interests, and abilities.



The samples that we provide should be modified to meet the individual's needs. The 26 rights and responsibilities statements would be taught differently for individuals at various ages, ability level, and settings.

Educator Betty A. Reardon points out in her book Educating for Human Dignity, (1995, pages 15-16) that 'All have equal opportunity to learn (about human rights) and to be respected'. Learning about human rights prepares individuals for citizenship and for cooperation.

## **PART II**

### **Section B**

#### **Sample Goals and Objectives for Service Plans**

(section follows)

# 1 RESPECT

## RIGHT

To be respected as a person with rights

### Sample RESPONSIBILITIES

To talk to and act nicely to others as you want them to talk 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

### Sample Goals, Objectives, and Techniques

Level 1	Level 2	Level 3
<b>Goal:</b> Andre has the responsibility to respect others.	<b>Goal:</b> Monika has the responsibility to not hit people who don't show her respect.	<b>Goal:</b> Roger has the right to address disrespectful conduct of others: peers and staff.
<b>Objective:</b> Andre will shake hands instead of hugging when he meets peers and staff in the morning at the day program 4 of 5 days a week for 48 weeks.	<b>Objective:</b> When someone in her group home or day program calls her a "bad" name, Monika will tell that person not to call her names 100% of the time	<b>Objective:</b> Roger will learn how to use the grievance procedure by reviewing the grievance procedure with his self-advocacy group once a month for 12 months.
<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will role-play with verbal directions how Andre should shake hands in greeting.</li> <li>Staff will model "shaking hands behavior" with Andre.</li> <li>Staff will give verbal prompts to Andre to greet others of his choice at day program in the morning.</li> <li>When Andre arrives at day program, staff will initiate a handshake greeting.</li> <li>Staff will remind Andre not to hug others when he attempts to hug others.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will remind Monika not to hit someone when she is called a "bad" name.</li> <li>Staff will model what Monika should say to the person who is being disrespectful.</li> <li>Staff will verbally prompt Monika how to handle a disrespectful person.</li> <li>Monika will decide to give an appropriate verbal response instead of hitting the other person.</li> <li>Staff will praise Monika for speaking up for herself.</li> <li>Staff will tell Monika that it is staff responsibility to teach respect for others.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will teach and review the grievance procedure with Roger.</li> <li>Staff will remind Roger to review the grievance procedure the day before the advocacy meeting, if needed.</li> <li>Roger will tell the self-advocacy group about the grievance procedure.</li> <li>Roger will lead a discussion about what is and what is not a grievance.</li> <li>Roger will choose an example of a grievance to present to the self-advocacy group.</li> </ul>

### Other Sample Goals to consider:

- Introducing yourself ("Hello, my name is..."); saying "please", "thank you", "excuse me" and other civilities of polite speech
- Taking turns in a conversation
- Not interrupting others when they are talking
- Complimenting others; Accepting compliments from others
- Being polite in public settings like stores and movie theatre

## 2 SELF ADVOCACY RIGHT

To advocate for yourself

### **Sample RESPONSIBILITIES**

To learn about your rights and responsibilities

To speak for yourself

To get help when you need it

To meet with the Human Rights Committee when needed

### **Sample Goals, Objectives, and Techniques**

<b>Level 1</b>	<b>Level 2</b>	<b>Level 3</b>
<b>Goal:</b> Sam has the responsibility to tell staff what he wants.	<b>Goal:</b> Jane has the responsibility to get help from her staff and guardian when she needs it.	<b>Goal:</b> Laura has the right to advocate for herself.
<b>Objective:</b> Sam will make a choice between 2 objects or alternatives when the group home staff present them to him 3 out of 5 times a week for six months.	<b>Objective:</b> Jane will ask staff for help when she feels upset instead of breaking things in her apartment 100% of the time.	<b>Objective:</b> Laura will independently choose 2 human rights and responsibilities to discuss at the community meeting once a month for twelve months.
<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will provide Sam with a daily choice of two things: shirts to wear, sodas to drink, social activities.</li> <li>Staff will verbally prompt Sam to make a choice of the offered objects/activities.</li> <li>Staff will follow through on the choices that Sam has made.</li> <li>Staff will praise Sam when he has made a choice.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff and guardian will explain to Jane how to contact them when she begins to feel angry about something.</li> <li>Staff will talk to Jane about what is bothering her.</li> <li>Staff will offer to take a walk with Jane to help her feel better.</li> <li>Staff will ask Jane if she wants to call her therapist.</li> <li>Staff will praise Jane for deciding to call them to help her manage her anger.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will meet with Laura 1 day prior to the monthly community meeting to help her identify which 2 rights and responsibilities she thinks are important to discuss at the meeting on the next day.</li> <li>Staff may have to remind Laura to review her Rights and Responsibilities workbook.</li> </ul>

### **Other Sample Goals to consider:**

- Asking others for what you want and need
- Apologizing when you make a mistake
- Advocating for your rights;     Advocating for the rights of others
- Sharing your ideas and feelings
- Getting help when you need it
- Not interfering with things that do not concern you

### 3 RELIGION RIGHT

To freely go to the church, synagogue, mosque, or house of worship of your choice, or not to 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

#### **Sample Goals, Objectives, and Techniques**

<b>Level 1</b>	<b>Level 2</b>	<b>Level 3</b>
<b>Goal:</b> James has the right to become an active member of his religious faith.	<b>Goal:</b> Thomas has the right to become an active member of his church.	<b>Goal:</b> Susan has the right to practice her religious faith in her apartment.
<b>Objective:</b> James will wear the Star of David and a yarmulke as 2 symbols of his religion once a week for 12 months.	<b>Objective:</b> Thomas will be given the opportunity every Sunday to attend the First Presbyterian Church for 12 months.	<b>Objective:</b> Susan will plan her menu so that she can follow the weekly and holiday fasting periods according to the Orthodox Church 100% of the time for 12 months
<b>Techniques:</b> <ul style="list-style-type: none"> <li>• Staff will help James learn that the symbol for Judaism is the Star of David.</li> <li>• Staff will help James choose to wear the Star of David instead of other symbols and jewelry on religious holidays.</li> <li>• Staff will help James learn when to wear a yarmulke as directed by Rabbi Fishman.</li> <li>• James will select the Star of David and the yarmulke from other symbols and objects.</li> <li>• James will learn the sign for “Jew”</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>• Staff will assist Thomas to post the church service schedule on his calendar.</li> <li>• Staff will arrange for Thomas to go to church when he wants to attend.</li> <li>• Staff will verbally remind Thomas of the behavior expected of him in church and at coffee hour. (Fade to prompting)</li> <li>• Staff will help Thomas budget for his weekly church donation from his earnings.</li> <li>• As needed, staff will ask Thomas each week if he wants to go to church.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>• Susan will post the calendar of fast days.</li> <li>• Staff will help Susan to identify the foods she can and cannot eat during the fast.</li> <li>• Staff will encourage Susan to talk to Father David about what fasting is reasonable for her to do.</li> <li>• Staff will help Susan obtain fasting recipes from the church ladies and her mother.</li> <li>• Susan will decide on what recipes to prepare for fast days.</li> <li>• Susan will plan her menu once a week.</li> </ul>

#### **Other Sample Goals to consider:**

- Learning the names of the major religions and the religious stories as appropriate
- Learning about the religions of other people with whom you live
- Decorating for religious holidays
- Dressing properly for the religious service
- Respecting the wishes of people who do not want to participate in a religion or in religious activity
- Respecting the wishes of people who want to participate in a religion or religious activity

## 4 VOTE RIGHT

To register and to vote in elections, if you want to do so

### **Sample RESPONSIBILITIES**

To vote the way you want to vote at meetings, in organizations, and in national, state, and community elections

To respect those who do not vote the way you vote or choose not to vote

### **Sample Goals, Objectives, and Techniques**

<b>Level 1</b>	<b>Level 2</b>	<b>Level 3</b>
<b>Goal:</b> Edith has the right to vote at group home meetings.	<b>Goal:</b> Gloria has the right to vote at self-advocacy meetings and other groups.	<b>Goal:</b> Michael has the responsibility to be an informed voter.
<b>Objective:</b> Edith will vote by raising her hand in the weekly group home meeting for her choice of social activity.	<b>Objective:</b> Gloria will vote at her self-advocacy meeting for officers, activities, or refreshments once a month.	<b>Objective:</b> Michael will make a presentation once a month at his self-advocacy meeting about the politicians in the state who support disabilities issues.
<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will describe to Edith possible activities that will be discussed at the weekly meeting.</li> <li>Staff will ask Edith to think about what she might like to do.</li> <li>If needed, staff will remind Edith to attend the meeting.</li> <li>Staff will remind and verbally prompt Edith to raise her hand for the activity that she chooses to attend.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff and the Self-Advocacy Coordinator will explain the rules of the self-advocacy meetings.</li> <li>Staff and Self-Advocacy Coordinator will explain voting procedure: raise her hand once for the thing she wants.</li> <li>Staff will transport Gloria to the agency self-advocacy meetings when she decides to attend the meetings.</li> <li>Staff will give verbal directions to Gloria to vote only one time for what she wants.</li> <li>Staff will praise Gloria for voting.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will assist Michael to gather information about politicians and candidates from: newspapers, internet, newsletters</li> <li>Michael will visit and speak with local politicians and candidates.</li> <li>Michael will inform the self-advocacy group about what he has learned.</li> <li>Staff will ensure that Michael is brought to the polling place where he is registered to vote.</li> <li>Michael will decide whom to vote for and cast his vote.</li> </ul>

### **Other Sample Goals to consider:**

- Informing staff that you want to vote in elections
- Identifying candidates/parties/issues to be voted upon
- Indicating preferences about candidates/parties/issues
- Voting at the group home, day program or apartment
- Voting for officers in self-advocacy groups, organizations
- Registering to vote ; Voting at the polling place using the voting machine

## 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**

<b>Level 1</b>	<b>Level 2</b>	<b>Level 3</b>
<b>Goal:</b> Peter has the responsibility to communicate his wants and needs to his Bureau of Guardianship Services (BGS) worker (guardian).	<b>Goal:</b> Paul has the responsibility to discuss finances for activities with his guardian (his brother).	<b>Goal:</b> As a capacitated person, Mary has the right to appoint an agent for a Power of Attorney (POA) and Medical Power of Attorney (MPOA).
<b>Objective:</b> Peter will call his BGS worker (guardian) once a month for 12 months.	<b>Objective:</b> Paul will independently call his guardian/brother once a week to plan a trip and to attend activities for 12 months.	<b>Objective:</b> Once a week for 3 months, Mary will review information about POA and MPOA and then schedule appointments with her Community Law Project Attorney.
<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will verbally assist Peter to know the name of his BGS worker (guardian) and the name of his case manager.</li> <li>Staff will meet with Peter to review what he chooses to tell his BGS worker (guardian).</li> <li>Staff will physically assist Peter to dial his BGS worker's (guardian's) phone number.</li> <li>Staff will provide verbal reminders to Peter about what he wants to tell his BGS worker (guardian).</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will assist Paul to make a list of financial topics that he decides to discuss with his guardian/brother.</li> <li>Staff will review with Paul what he wants to tell his guardian/brother about his plans to save money and to go on vacation.</li> <li>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.</li> <li>Staff will provide privacy for Paul to talk to his guardian/brother.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Mary will review information from the pamphlet's "Frequently Asked Questions" about POA and MPOA provided by the Community Law Project.</li> <li>Mary will discuss the POA and MPOA procedures with her family, case manager, staff and others.</li> <li>Mary will decide whom to appoint as her POA and MPOA agent.</li> <li>Mary will talk to her proposed agent about her POA and MPOA.</li> <li>Staff will transport Mary to appointments with her attorney.</li> </ul>

### **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

## 6 SERVICES

### RIGHT

To have services that you need like a safe and clean place to live

### Sample RESPONSIBILITIES

To follow safety rules

To take care of your home

### Sample Goals, Objectives, and Techniques

Level 1	Level 2	Level 3
<b>Goal:</b> John has the right to live in a clean group home.	<b>Goal:</b> Paul has the responsibility to help plan activities at his group home.	<b>Goal:</b> Ringo has the responsibility to care for his apartment.
<b>Objective:</b> John will wipe the dinner table after each meal 3 of 5 days a week with verbal prompts.	<b>Objective:</b> Paul will plan, plant and care for his garden from April thru November, as needed, at least 1 time per week.	<b>Objective:</b> Ringo will independently prepare and implement a weekly schedule for cleaning his apartment.
<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will provide hand-over-hand assistance with fading to verbal prompts as John masters the task.</li> <li>Staff will verbally cue John to wipe the table.</li> <li>John will decide when he should wipe the table.</li> <li>Staff will praise John for his efforts.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will assist Paul to plan his garden for flowers and vegetables.</li> <li>Staff will help Paul budget his money in order to purchase plants.</li> <li>Staff will transport Paul to the local nursery to buy plants.</li> <li>Staff will encourage Paul to talk to the nursery people to learn when and how to plant.</li> <li>Staff will discuss with Paul when to plant, water, weed, and harvest his plants.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will assist Ringo to schedule his chores to fit around his employment schedule.</li> <li>Staff will help Ringo list the chores that need to be done: vacuuming, dusting, cleaning the bathroom, and others as needed.</li> <li>Ringo will follow his schedule of chores to be completed within the week.</li> </ul>

### Other Sample Goals to consider:

- Following safety rules within parking lots
- Participating in a variety of community activities
- Meeting social expectations for specific environments/activities
- Attending to safety matters in the home, i.e., floors clear of debris
- Requesting assistance as needed to remain safe and healthy
- Checking the schedule for changing batteries in alarms

## 7 PERSONAL ITEMS

### RIGHT

To have your own money, clothing, and personal items kept safe

### Sample RESPONSIBILITIES

To take good care of your things

To leave other people's things alone

### Sample Goals, Objectives and Techniques

Level 1	Level 2	Level 3
<b>Goal:</b> Serena has the responsibility to take care of her clothing.	<b>Goal:</b> Arthur has the responsibility not to wear his roommate's shirts or ties.	<b>Goal:</b> Maria has the right to have her money kept safe.
<b>Objective:</b> Serena will hang shirts in her closet after the laundry is completed once a week with 80% compliance for 12 months.	<b>Objective:</b> Arthur will wear his own coordinating shirts, ties and other clothing, 5 out of 7 days a week	<b>Objective:</b> Maria will independently place her personal needs allowance money in a locked box in her apartment weekly 100% of the time for 12 months
<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will put clean shirts on hangers for Serena to hang up.</li> <li>Staff will verbally ask Serena to hang the shirts up in her closet.</li> <li>Staff will move other clothes aside so there is room for the shirts to be hung.</li> <li>Serena will choose to hang the shirts where there is space.</li> <li>Staff will ask Serena to move other clothes aside to make room for her shirts, if necessary.</li> <li>Staff will praise Serena for hanging up the shirts.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will help Arthur arrange his wardrobe so that his clothing is not mixed in with his roommate's things.</li> <li>Arthur will have different colored hangers that are different from his roommate's hangers.</li> <li>Staff will provide verbal directions for Arthur to place his clothing on that color hanger.</li> <li>Staff will go shopping with Arthur and help him select coordinating shirts and ties.</li> <li>In the evening, Arthur will choose what he will wear the next day with staff assistance.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will shop with Maria to purchase a metal box with a lock, within 7 days of starting this goal.</li> <li>Maria will choose where to keep her lock-box key in a safe place, with staff assistance for ideas only.</li> <li>Staff will discuss safety measures to include not telling peers where her key is kept, being alone when accessing the lock box.</li> <li>Maria will decide where to keep her key safely and only tell the apartment manager about the location, within 10 days of purchase of lock box.</li> </ul>

### Other Sample Goals to consider:

- Taking care of personal items
- Not destroying things that belong to others
- Not taking things that belong to others
- Borrowing and returning items that belong to others



## 8 MAIL

**RIGHT:** To send and receive unopened mail

To ask someone to help you read or write your mail if you need help

**Sample RESPONSIBILITIES:** To respect another person's right to send unopened mail

To respect another person's right to open and read his own mail

### Sample Goals, Objectives and Techniques

Level 1	Level 2	Level 3
<b>Goal:</b> Joanie has the right to send cards to family members and friends.	<b>Goal:</b> Mitchell has the right to receive mail addressed to him that is unopened.	<b>Goal:</b> Robert has the responsibility to respect the privacy of others in the group home by not reading their mail.
<b>Objective:</b> Joanie will choose a card and send the card to a family member or friend once a week.	<b>Objective:</b> Mitchell will retrieve mail from the mailbox and ask staff to read his mail to him each time that he receives mail.	<b>Objective:</b> Robert will distribute mail to peers and staff without opening their mail on Tuesday and Thursday.
<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will take Joanie to the store to choose a card for a family member or a friend.</li> <li>Staff will read two different cards, appropriate for the occasion, to Joanie.</li> <li>Staff will prompt Joanie to choose which card she prefers by pointing.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will identify the mail that belongs to Mitchell and give his mail to him.</li> <li>Staff will verbally prompt Mitchell to open his mail if he does not open it after a reasonable amount of time.</li> <li>Staff will offer assistance to read Mitchell's mail.</li> <li>Staff will read the mail when Mitchell asks them to do so.</li> <li>Staff will wait for Mitchell to initiate a request for assistance to respond to his mail.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>If needed, staff will verbally prompt Robert when it is his turn to pick up the mail.</li> <li>Staff will prompt Robert to distribute mail to the appropriate recipients without opening the mail.</li> <li>Staff will remind Robert not to pick up other people's mail when they lay it down or put it on a desk.</li> <li>When Robert does not know which mail to open, he will ask the staff.</li> <li>Staff will fade prompts when Robert is able to respect other's privacy.</li> </ul>

### Other Sample Goals to consider:

- Sending mail: writing letter/card; addressing mail; proper postage
- Maintaining an address book
- Sharing your mail with housemates when you choose to do so
- Ordering items/subscriptions through the mail
- Asking for assistance with reading or writing mail

## 9 PHONE

### RIGHT

To make phone calls and to receive phone calls from others during reasonable hours

To have privacy for your phone calls

### Sample RESPONSIBILITIES

To follow the house rules for making and receiving phone calls

To pay your phone bill

To respect another person's right to make and receive private calls

### Sample Goals, Objectives, and Techniques

Level 1	Level 2	Level 3
<b>Goal:</b> Zachary has the right to place a phone call to a friend.	<b>Goal:</b> Amy has the right to phone her friends.	<b>Goal:</b> Archie has the responsibility to follow the house rules about phone use.
<b>Objective:</b> Zachary will ask for his friend when the phone call is connected once a week.	<b>Objective:</b> Amy will independently identify correct numbers from her phone book to call her friends twice a week.	<b>Objective:</b> Archie will independently follow house rules for phone call hours, length, and privacy daily.
<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will verbally prompt Zachary that it is Wednesday and to call H. if he chooses to do so.</li> <li>Staff will dial the phone number of Zachary's friend.</li> <li>Staff will hand the phone to Zachary once the phone starts to ring so that he may ask for his friend by name.</li> <li>Staff will remind Zachary to wait until someone answers the phone to say: "Hello, this is Zachary. May I speak to H.?"</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will help Amy organize her phone book with pictures of the people to be called along with name, address and phone number.</li> <li>Amy will decide whom she wants to call.</li> <li>Staff will assist Amy to dial the number of the person to whom she wishes to speak.</li> <li>By pointing to each large number on the phone, staff will direct Amy where to press the phone number or speed dial number.</li> <li>Staff will use verbal prompts if Amy goes to point at an incorrect digit.</li> <li>Staff will work with Amy until all of the correct digits are pushed and the call is placed.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will review the house phone rules with Archie when needed.</li> <li>Staff will remind Archie when he can and cannot make phone calls.</li> <li>Staff will remind Archie that he must limit his calls to the time agreed upon by all the group home members.</li> <li>Archie will choose whom to call during phone hours.</li> <li>Staff will prompt Archie to leave the phone area when others are using the phone.</li> <li>Staff will praise Archie for his cooperation with house phone rules.</li> </ul>

### Other Sample Goals to consider:

- Making a call and leaving a message; Answering a call and taking a message
- Taking messages and leaving messages on an answering machine
- Letting family and friends know of house phone rules

# 10 HEALTHY DIET

## RIGHT

To have a healthy, balanced diet

## Sample RESPONSIBILITIES

To help plan meals

To eat foods that you like and that are good for you

To follow the diet that your doctor says is good for you

## Sample Goals, Objectives, and Techniques

Level 1	Level 2	Level 3
<b>Goal:</b> Bob has the responsibility to select healthy food choices when ordering from a restaurant menu.	<b>Goal:</b> Alice has the responsibility to help plan the group home menu.	<b>Goal:</b> Linda has the right to order healthy foods that she likes and that are on her diabetes diet from a restaurant menu.
<b>Objective:</b> Bob will identify 1 healthy food item from a menu with verbal prompting from staff once a week for 3 months.	<b>Objective:</b> Alice will help to plan a balanced dinner meal with staff every Saturday for 12 months.	<b>Objective:</b> Linda will order a healthy, balanced meal from items on her doctor's list when she dines out twice a month for 12 months.
<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will take Bob out to a local restaurant of his choice once a week.</li> <li>Staff will remind Bob what healthy food choices are.</li> <li>Staff will read the menu to Bob.</li> <li>Staff will help Bob to identify a healthy food item from the menu.</li> <li>Staff will order what Bob selects from the menu.</li> <li>Staff will praise Bob for choosing a healthy food item.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will review the food groups with Alice.</li> <li>Staff will help Alice plan dinner meals based on the food groups and post the meal on the weekly menu.</li> <li>Staff will go grocery shopping with Alice to purchase the food items.</li> <li>Staff will ask Alice if she wants to purchase a few snack items in addition to the healthy food choices.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will review Linda's special diet food lists with her.</li> <li>Staff will take Linda to a local restaurant with a couple of friends.</li> <li>Staff will give verbal prompts to help Linda order healthy food selections and fade the prompts as Linda gains experience making her own healthy food choices.</li> <li>Linda will decide which foods on the menu are healthy for her diabetes diet.</li> </ul>

## Other Sample Goals to consider:

- Identifying healthy food choices; Identifying foods required for a special diet
- Naming foods associated with breakfast, lunch, dinner, snacks
- Identifying recommended portions
- Reading labels: calories, sodium, fat contents
- Shopping for healthy food items
- Identifying healthy snacks
- Listing healthy foods that you like
- Identifying foods that are not good for you

# 11 RELATIONSHIPS

## RIGHT

To have relationships with girlfriends and boyfriends

## Sample RESPONSIBILITIES

To respect your friends

To learn how to behave at social events, at dances, and on trips

### Sample Goals, Objectives and Techniques

Level 1	Level 2	Level 3
<b>Goal:</b> Jim has the right to develop relationships.	<b>Goal:</b> Peter has the responsibility to initiate and plan an outing with various family members.	<b>Goal:</b> Todd has the right to develop a friendship relationship with a member of the opposite sex.
<b>Objective:</b> Jim will invite someone to his group home once a month for 12 months.	<b>Objective:</b> Peter will socialize with family members once a month for 12 months.	<b>Objective:</b> Todd will go out on dates with female friends once a month for a year.
<b>Techniques:</b> <ul style="list-style-type: none"> <li>Jim will decide who he wants to invite to visit with him and call him (them).</li> <li>Staff will assist with the call, as needed.</li> <li>Jim will decide what refreshments he wants to serve.</li> <li>Staff will take Jim shopping for the refreshments.</li> <li>Staff will praise Jim for his efforts to socialize with others.</li> <li>Staff will arrange for Jim and his guest(s) to have some privacy.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>With verbal prompts, staff will assist Peter in identifying social activities to do with various family members.</li> <li>Peter will decide where to go with the family member.</li> <li>Staff will prompt Peter to call the family member and propose the activity (date, time, place, and event).</li> <li>Staff will assist Peter to prepare his social calendar.</li> <li>Staff will assist Peter to plan for any expenses that he might incur.</li> <li>Staff will provide transportation as necessary.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will help Todd learn how to ask a female friend out for an event.</li> <li>Staff will review the things to do before going out on a date: expense, phone call, identifies the destination and time, arrange transportation.</li> <li>If needed, staff will help Todd choose an event (movie, coffee, walk, etc.) for the date.</li> <li>Staff will provide transportation to and from the event for both Todd and his friend.</li> <li>Todd will decide to call a female friend for a date.</li> <li>Staff will arrange for Todd and his date to have privacy.</li> </ul>

### Other Sample Goals to consider:

- Identifying leisure activities in the local community
- Planning weekend leisure activities; Saving for expense of leisure activities
- Developing new friendships
- Inviting family and friends to visit you
- Learning about romantic relationships and sexuality
- Improving social skills (manners, greetings, small talk, board games)

# 12 VISITORS

## RIGHT

To have guests visit you during reasonable hours

### Sample RESPONSIBILITIES

To make plans for your guests to visit you during reasonable hours

To make sure that your guests follow house rules

### Sample Goals, Objectives and Techniques

Level 1	Level 2	Level 3
<b>Goal:</b> Matthew has the responsibility to help prepare his home for the arrival of visitors.	<b>Goal:</b> Mark has the right to have guests visit during visiting hours.	<b>Goal:</b> Luke has the responsibility to arrange for his guests.
<b>Objective:</b> Matthew will assist in weekly straightening of common areas prior to scheduled social events with verbal prompts.	<b>Objective:</b> Mark will plan an activity each time that he has guests during the month for 12 months.	<b>Objective:</b> Luke will prepare snacks for his visitor(s) once month with staff assistance, as needed.
<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will prompt Matthew to dust, fluff pillows, and set-up chairs in the living room for social events in the home.</li> <li>Staff will assist Mathew in deciding where to place snack bowls.</li> <li>Staff will praise Matthew for a job well done.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will discuss appropriate games, movies and other leisure activities that Mark can plan for his guests.</li> <li>Staff will show Matthew the various games and videos available for the social events.</li> <li>Staff will help Matthew make a choice on what activities he wants to do with his friends.</li> <li>Staff will praise Matthew for his planning.</li> <li>Staff will take Matthew to stores to obtain any videos or games that are needed.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Luke will tell staff what snacks he will serve to his visitors.</li> <li>Staff will help Luke make a shopping list.</li> <li>Staff will take Luke to the grocery store to purchase the snack items.</li> <li>Staff will provide Luke with suggestions for serving supplies: trays, plates, cutlery, and napkins.</li> <li>Luke will decide which snacks and serving items to use.</li> <li>Staff will supervise the preparation of snacks with assistance as needed.</li> </ul>

### Other Sample Goals to consider:

- Informing staff of visit
- Inviting visitors
- Preparing foods and beverages
- Sharing common area with others
- Discussing with housemates plans for your inviting guests to visit
- Reviewing visiting hours
- Cooperating when your roommate has guests

# 13 ACTIVITIES

## RIGHT

To join social and recreational activities at your home, school, work place, or community when you want to participate in them

## Sample RESPONSIBILITIES

To follow the rules of the activity

To let people know if you want to go or not to go to an activity

## Sample Goals, Objectives, and Techniques

Level 1	Level 2	Level 3
<b>Goal:</b> Alice has the right to participate in activities when she wants to do so.	<b>Goal:</b> Jennie has the responsibility to plan activities for herself.	<b>Goal:</b> Bernice has the responsibility to maintain a schedule of her social activities.
<b>Objective:</b> Alice will identify and participate in 1 special activity with a friend each month with staff assistance.	<b>Objective:</b> Jennie will independently plan a weekend social or athletic activity once a month.	<b>Objective:</b> On Sunday, Bernice will maintain her monthly social calendar of social activities and appointments.
<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will describe activities to Alice that she might like to do.</li> <li>Staff will present Alice with 2 choices of activities to do with a friend.</li> <li>Staff will allow Alice to choose between the alternate activities.</li> <li>Staff will arrange for Alice to go to the place of her choice with her friend.</li> <li>Staff will provide transportation and supervision during the outing.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will help Jennie look through newspapers and community listings to identify weekend social and athletic activities.</li> <li>After Jennie chooses her activity (s), staff will help her write her choices on her calendar.</li> <li>Staff will provide transportation and supervision as necessary.</li> <li>Staff will discuss Jennie's activity when she returns.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will provide transportation for Bernice to go to the mall to buy a personal date book.</li> <li>Bernice will choose a personal date book and decide which activities to note in it.</li> <li>Staff will review what Bernice schedules in her personal calendar: social activities, doctor's appointments, work schedule, etc.</li> <li>Staff will direct Bernice to look at her calendar when she is unsure of her activities and appointments.</li> </ul>

## Other Sample Goals to consider:

- Learning appropriate social skills for different events
- Selecting activities from different places
- Participating in activities selected
- Following the expectations of the event
- Dressing for the event
- Saying what you like or do not like to do
- Inviting people to go places with you

# 14 **PRIVACY RIGHT**

To have privacy when you want to be alone

## **Sample RESPONSIBILITIES**

To tell people when you want to be alone

To respect others when they want to be alone

### **Sample Goals, Objectives, and Techniques**

<b>Level 1</b>	<b>Level 2</b>	<b>Level 3</b>
<b>Goal:</b> Jack has the responsibility to allow others to have a private conversation.	<b>Goal:</b> Jill has the right to let peers and staff know when she wants to be alone in her room.	<b>Goal:</b> Hansel has the responsibility to respect the privacy of others.
<b>Objective:</b> Jack will calmly walk away from staff who are meeting for change of shift briefings and scheduled staff meetings daily.	<b>Objective:</b> Jill will tell peers and staff when she wants private time in her room for reading and resting after dinner daily.	<b>Objective:</b> Hansel will respect his roommate's need to sleep by watching TV in the living room after 10 p.m. daily.
<b>Techniques:</b> <ul style="list-style-type: none"> <li>• Staff will redirect Jack by reminding of him of his responsibility to give them privacy.</li> <li>• Staff will thank Jack for his cooperation.</li> <li>• Jack will choose where to wait if he wants to talk to staff after they finish their meeting.</li> <li>• Staff will address Jack's needs after completing the staff meeting.</li> <li>• When Jack's needs are urgent, staff will attend to them right away.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>• Staff will help Jill prepare a "Do Not Disturb" sign and a paper clock with movable hands to place on her door.</li> <li>• Jill will decide what time and for how long she wants to be by herself.</li> <li>• Staff will go over group home privacy rules with members of the home.</li> <li>• Staff will assist Jill fix the hands of the paper clock.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>• When Hansel chooses to watch TV after 10 p.m., he will watch it in the living room.</li> <li>• Staff will remind Hansel of the agreement that he and his roommate have made about the use of TV in the bedroom, if needed.</li> </ul>

### **Other Sample Goals to consider:**

- Identifying behavior when in private and public areas
- Planning activities that you can do by yourself
- Setting "quiet hours" for the house or apartment
- Thinking about the needs of others
- Working out how to get along with others

# 15 TREATMENT & THERAPY

## RIGHT

To get the treatment or therapy that you need

### Sample RESPONSIBILITIES

To go to treatment or therapy sessions

To follow the doctor's and therapist's directions

### Sample Goals, Objectives, and Techniques

Level 1	Level 2	Level 3
<b>Goal:</b> Peter has the right to attend speech therapy sessions as scheduled.	<b>Goal:</b> Bobby has the responsibility to participate in physical therapy (PT) sessions and follow-up exercises at home until discharged from therapy.	<b>Goal:</b> Greg has the right to schedule appointments with his psychotherapist.
<b>Objective:</b> Peter will attend 2 therapy sessions with Dr. Brady each month with staff support.	<b>Objective:</b> Bobby will keep track of his bi-weekly PT appointments and schedule his rehabilitation routine 4 days a week with verbal reminders from staff.	<b>Objective:</b> Greg will schedule weekly appoints with his psychotherapist.
<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will transport Peter to his therapy sessions.</li> <li>Staff will help Peter identify the date of his appointments using an appointment calendar.</li> <li>Staff will accompany Peter to the receptionist after each appointment to schedule his next appointment.</li> <li>Peter will practice daily his speech assignments with staff before or after dinner as he chooses.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will help Bobby mark on his wall calendar the date and time of his PT appointments.</li> <li>Staff will remind Bobby in the morning when his PT appointment is scheduled for that day.</li> <li>Bobby will tell his staff when he chooses to follow his therapy routine at 3 or 4 p.m. on Mondays, Tuesdays, Thursdays and Fridays.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Greg will decide to phone his psychotherapist or schedule appointments with the receptionist weekly.</li> <li>Staff will provide transportation for Greg to go to the psychotherapist's office.</li> <li>Staff will assist Greg to keep a schedule of appointments on a daily calendar.</li> </ul>

### Other Sample Goals to consider:

- Talking about the benefits of therapy
- Talking about how therapy helps you
- Talking to your therapist about your therapy goals
- Following therapist's recommendations
- Talking confidentially about therapy with your family, guardian, case manager, staff



# 16 HEALTHY LIVING

## RIGHT

To practice healthy living and physical exercise

### Sample RESPONSIBILITIES

To take good care of yourself so you stay healthy

To choose an exercise that you like, want, and can do

### Sample Goals, Objectives, and Techniques

Level 1	Level 2	Level 3
<b>Goal:</b> Lou has the right to participate in an exercise program.	<b>Goal:</b> Mary has the responsibility to take care of her personal hygiene.	<b>Goal:</b> Rhonda has the right to take good care of her skin.
<b>Objective:</b> With his doctor's approval, Lou will choose a sport to participate in for the Special Olympics and attend training twice a week for three months.	<b>Objective:</b> Mary will shower daily using soap and shampoo with verbal reminders from staff.	<b>Objective:</b> Rhonda will apply medicated skin cream, moisturizer and hand cream daily.
<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will review with Lou the choices of sports that the doctor has authorized for him.</li> <li>Lou will choose a sport that he is capable of doing and can afford.</li> <li>Staff will provide transportation to the recreation area where the training is held.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Mary will tell staff if she wants to shower in the morning or evening.</li> <li>Staff will remind Mary to bring her toiletries to the bathroom, as necessary.</li> <li>Staff will adjust the water temperature for Mary's shower.</li> <li>Staff will assist Mary as needed.</li> <li>Staff will praise Mary for taking responsibility for her personal hygiene.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Rhonda will decide when to have her medicated face cream prescription filled at the local drug store.</li> <li>Staff will remind Rhonda to have her prescription renewed, as necessary.</li> <li>Staff will help Rhonda budget to purchase moisturizer, hand cream and other skin care lotions.</li> </ul>

### Other Sample Goals to consider:

- Planning healthy meals for your restricted diet
- Dressing comfortably and according to the weather
- Administering your own medication
- Utilizing sleep apnea aids
- Maintaining a healthy weight
- Joining a health club or classes at the YMCA
- Installing a basketball hoop and buying sports equipment
- Taking hikes on Saturdays and Sundays

# 17 MEDICAL CARE

## RIGHT

To receive medical, dental, and other health care regularly and when you need it

### Sample RESPONSIBILITIES

To let people know if you are sick or if you are hurt

To talk to your doctors

To ask questions about your health, healthcare, and medications

### Sample Goals, Objectives and Techniques

Level 1	Level 2	Level 3
<b>Goal:</b> Shirley has the right to have medical care for her ear infections.	<b>Goal:</b> Lenny has the responsibility to talk to the nurse practitioner about his weight.	<b>Goal:</b> Kammy has the responsibility to tell staff when she feels ill.
<b>Objective:</b> Shirley will cooperate to see her Ear, Nose and Throat doctor every three months, or as determined by the doctor, to evaluate the status of her ear.	<b>Objective:</b> Lenny will meet with the nurse practitioner once a week to discuss his weight loss plan with staff assistance.	<b>Objective:</b> On a daily basis, Kammy will chart if she has headaches and/or blurred vision as well as notifying staff if she has these symptoms.
<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will contact Ear, Nose, and Throat doctor to make an appointment.</li> <li>The week of the appointment, staff will remind Shirley that she has an appointment in a positive manner, as something to look forward.</li> <li>Staff will discuss the reason why Shirley needs to see the doctor (so her ear won't hurt) and what the doctor will do during the visit (i.e. looking in her ears with a light, etc.)</li> <li>Staff will transport Shirley to the doctor's office along with any related medical records regarding her ears.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will take Lenny to his Weight Watcher's meetings each week.</li> <li>Lenny will choose recipes from his Weight Watcher's Cookbook that staff will help him prepare.</li> <li>Staff will transport Lenny to meet with the nurse practitioner as scheduled.</li> <li>Staff will maintain a log of Lenny's weight loss progress.</li> <li>Lenny will receive praise and encouragement from staff for trying to lose weight.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Kammy will set up a daily chart to mark occurrences of headaches and blurred vision, with staff assistance.</li> <li>Kammy will record her symptoms/lack of symptoms daily.</li> <li>Staff will maintain a log of Kammy's physical symptoms that Kammy reports to them.</li> <li>Kammy will decide if she can go to work, stay home to rest or go to the doctor based on her symptoms.</li> <li>Staff will take Kammy to the doctor, as needed.</li> <li>Kammy will show her chart to her doctor.</li> </ul>

### Other Sample Goals to consider:

- Following directions of doctors or dentist; Learning to take medications as prescribed
- Telling the doctor about the effects of your medication
- Attending men's and women's health discussion groups at self-advocacy meetings
- Asking for more information from your doctor or dentist about what you do not understand

# 18 SCHOOL

## RIGHT

To go to school through age 21

### Sample RESPONSIBILITY

To complete your education

To participate in school programs

### Sample Goals, Objectives, and Techniques

Level 1	Level 2	Level 3
<b>Goal:</b> Dorothy has the right to continue to attend school to participate in a life skills program because she does not turn 21 for another two years.	<b>Goal:</b> Rose has the responsibility to attend a transitional employment program provided by her school district.	<b>Goal:</b> Blanche has the right to attend community college courses that are within her cognitive abilities.
<b>Objective:</b> Dorothy will attend and participate in the life skills program at the special education school she attends that is funded by her town's school district.	<b>Objective:</b> Rose will work with her job coach on Mondays at job sampling activities until she finds competitive employment.	<b>Objective:</b> Blanche will attend courses at her local community college
<b>Techniques:</b> <ul style="list-style-type: none"> <li>The school district will provide transportation.</li> <li>Staff will work with the school in coordinating the activities of daily living skills that Dorothy is learning at school with her chores at home.</li> <li>Dorothy will plan with group home staff at-home activities.</li> <li>Dorothy will receive praise and encouragement from staff.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will transport Rose to/from her job assignment.</li> <li>The Job Coach will provide Rose with new job choices every 3 months.</li> <li>Rose will discuss with her job coach, which jobs she likes to do and can do.</li> <li>The job coach will assist Rose to look for competitive employment (newspaper, internet).</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Blanche will select courses that are of interest to her.</li> <li>Blanche will register for classes with staff assistance..</li> <li>Staff will assist Blanche in finding which bus goes to the college.</li> </ul>

### Other Sample Goals to consider:

- Planning for job changes
- Seeking competitive employment
- Choosing a new day program
- Planning activities around your work schedule
- Keeping track of your work hours
- Transitioning from school to work world

# 19 WORK & PLAY

## RIGHT

To work

To be paid for what you do

## Sample RESPONSIBILITIES

To follow the rules of the work place

To be a good co-worker

To pay your bills

To retire with things to do

## Sample Goals, Objectives, and Techniques

Level 1	Level 2	Level 3
<b>Goal:</b> Mark has the right to work at tasks to earn money at the work center.	<b>Goal:</b> Diane has the responsibility to behave as a good co-worker at the work program.	<b>Goal:</b> Joyce has the responsibility to accept her supervisor's directions at her competitive employment work site.
<b>Objective:</b> Mark will stay on task for 15 minutes at a time with staff direction and supervision.	<b>Objective:</b> Diane will participate in a weekly Job Club organized by staff.	<b>Objective:</b> Joyce will follow her work schedule daily.
<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will offer Mark the choice of tasks to do on the assembly line.</li> <li>Mark will choose which tasks he wants to work on for the morning and afternoon shifts.</li> <li>Staff will review with Mark the tasks he is to perform.</li> <li>Staff will refocus Mark to work steadily for 15 minutes at a time.</li> <li>Staff will let Mark know when he can take a scheduled work break.</li> <li>Staff will reinforce Mark's performance with verbal praise.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will teach about appropriate work behaviors (no arguing with boss or co-workers, being on time, dress, safety, etc.)</li> <li>Staff will teach about working productively.</li> <li>Staff will teach about how people earn money.</li> <li>Diane will tell the group how she did the past week about her work behavior (specific assignment).</li> <li>Diane will choose which appropriate work behavior to practice for the coming week.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Supervisor will meet with Joyce on Monday morning to discuss the work schedule.</li> <li>The job coach will meet with Joyce, as needed, to clarify what may be confusing to Joyce about the work schedule or the job.</li> <li>Joyce will decide when to call her job coach if she runs into difficulties.</li> <li>Joyce will tell her supervisor if she cannot perform a part of her assignment and explain why.</li> <li>Joyce will phone her supervisor by 8:30 a.m. if she will be out sick or late for work.</li> </ul>

## Other Sample Goals to consider:

- Researching career opportunities; Identifying work interests
- Completing a job application; Learning public transportation to get to work
- Knowing when to socialize on the job or not to socialize

## 20 JOB & PROGRAM RIGHT

To ask to go to another job, program, or place to live

### **Sample RESPONSIBILITY**

To say what you like and what you do not like about a job, program, or place to live

#### **Sample Goals, Objectives, and Techniques**

<b>Level 1</b>	<b>Level 2</b>	<b>Level 3</b>
<b>Goal:</b> Paula has the right to say what she likes and does not like about her day program.	<b>Goal:</b> Simon has the responsibility to ask for changes to the supervised residential program.	<b>Goal:</b> Randy has the right to move from the group home to a supervised apartment program.
<b>Objective:</b> Paula will tell staff and peers about her day program at dinner 5 days a week with verbal prompts.	<b>Objective:</b> Simon will chair the self-advocacy meeting to discuss reasons for changes 2 times a month.	<b>Objective:</b> Randy will prepare each week for his transition from the group home to an apartment in 6 months (May-October 20).
<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will encourage Paula to talk about her day program at the dinner table.</li> <li>Staff will ask Paula to say what was good about the day program today and what was not so good. (job she did, people she talks to, noise level, music, social activities, food).</li> <li>Staff will ask Paula what activities she chose to do at program.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will assist Simon to prepare the agenda for self-advocacy meetings.</li> <li>Staff will guide Simon about how to run the meeting.</li> <li>Simon will decide whose turn it is to talk at the meeting and make sure that everyone gets a chance to speak.</li> <li>Staff will help Simon obtain ideas about how to make the residential program better.</li> <li>Staff will assist Simon to write down people's ideas.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will transport Randy to various stores weekly to make purchases for his new apartment program.</li> <li>Randy will choose new furnishings and linens for his new apartment.</li> </ul>

#### **Other Sample Goals to consider:**

- Attending self-advocacy training
- Preparing to change programs or living arrangements
- Moving to another town or state
- Helping someone move to another program or living arrangement
- Phoning family, guardian or case manager to talk about your desire to move
- Calling an Interdisciplinary Team meeting to discuss your desire to move
- Discussing advantages and disadvantages of a move or change

## 21 SERVICE PLAN

### RIGHT

- To participate in developing your service plan
- To participate in your service plan meeting

### Sample RESPONSIBILITIES

- To think about what you want and need
- To let people know at your meeting, or before, what you want and need

### Sample Goals, Objectives, and Techniques

Level 1	Level 2	Level 3
<b>Goal:</b> Jan has the responsibility to let people know what she needs and wants to learn.	<b>Goal:</b> Cindy has the responsibility to request updates to her annual service plan.	<b>Goal:</b> Marsha has the right to give input at her annual service plan meeting.
<b>Objective:</b> Jan will identify persons from photos whom she wants to have at her quarterly IDT meetings.	<b>Objective:</b> Cindy will speak quarterly with her guardian and case manager to tell them what changes she wants for her service plan.	<b>Objective:</b> Marsha will contact her support broker once a month to plan for her annual service plan meeting 2 times a month for 6 months, prior to the annual plan date.
<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will help Jan organize a photo album of familiar people.</li> <li>Jan will point to pictures of people who she wants to attend her quarterly meeting.</li> <li>Staff will talk to Jan about her meeting before the meeting occurs.</li> <li>Staff will call the people who Jan chose from the photographs to invite to her quarterly meeting.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Cindy will call her guardian &amp; case manager to talk about her progress towards her service plan goals.</li> <li>The guardian &amp;/or case manager will ask Cindy if there are any changes she wishes to make for her goals and objectives.</li> <li>The case manager will call an IDT meeting when Cindy has identified some possible changes.</li> <li>Cindy will tell the IDT meeting what changes she wants.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Marsha will call her support broker to tell him how the plan is going so far.</li> <li>Marsha will discuss with her support broker about the things that she wants and needs.</li> <li>The support broker will look into any new requests and inform Marsha of his findings and alternatives.</li> </ul>

### Other Sample Goals to consider:

- Maintaining your personal progress diary
- Speaking at your meetings
- Reviewing your service plan
- Talking about changes in your guardianship status
- Talking about your thoughts about your future plans; Creating support circles

## 22 PRIVATE INFORMATION RIGHT

To have files about you kept private

### **Sample RESPONSIBILITIES**

To give or not give permission for others to read your files

Do not read anyone else's files

### **Sample Goals, Objectives, and Techniques**

<b>Level 1</b>	<b>Level 2</b>	<b>Level 3</b>
<b>Goal:</b> Herman has the right to keep his personal information kept private.	<b>Goal:</b> Marilyn has the responsibility to respect other people's private information.	<b>Goal:</b> Eddie has the responsibility to refrain from reading staff and consumer records.
<b>Objective:</b> Herman will talk with staff about the different people with whom he should discuss specific personal matters 2 times a month.	<b>Objective:</b> Marilyn will meet once a month with staff to talk about her health and not about anyone else's health concerns.	<b>Objective:</b> Eddie will avoid reading staff materials in the staff office that do not concern him for 30 days.
<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will remind Herman to talk to his parents/guardian, case manager and staff about his health and money.</li> <li>Staff will remind Herman not to talk to strangers.</li> <li>Staff will remind Herman not to tell his address to strangers.</li> <li>Staff will remind Herman not to talk to strangers about his medical information.</li> <li>Staff will remind Herman to stop talking to strangers when he starts to do so in the community.</li> <li>Herman will identify who are familiar people with whom he can talk about personal, private matters.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will discuss with Marilyn her health (or other concerns).</li> <li>Staff will remind Marilyn that they will not talk to her about her peers' health matters.</li> <li>Staff will review privacy of information at group home meetings.</li> <li>Marilyn will decide what information for her is private.</li> <li>Marilyn will identify what is private information for others.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Eddie will only enter the staff office when invited.</li> <li>Eddie will look at his records with a staff member.</li> <li>Staff will remind Eddie not to read over other people's shoulders or to read papers in the staff office.</li> </ul>

### **Other Sample Goals to consider:**

- Identifying types of information to be kept private
- Learning the meaning of "confidentiality" and "privacy"
- Asking for assistance to retrieve information about yourself
- Signing release of information papers
- Saying "no" to people who should not have your information

## 23 NO UNUSUAL TREATMENT RIGHT

To be free from unusual treatments and research unless ordered by the court and recorded in your medical record  
[shock treatment, psychosurgery, sterilization, and medical, behavioral, or pharmacological research]

### **Sample RESPONSIBILITY**

To talk about any suggested unusual treatments with your family, guardian, advocate, agent, doctor, lawyer, case manager, or staff

### Sample Goals, Objectives, and Techniques

Level 1	Level 2	Level 3
<b>Goal:</b> Roseanne has the right to be free from unusual restraints or procedures.	<b>Goal:</b> Tom has the responsibility to identify situations that involve unusual restraints and procedures to protect him.	<b>Goal:</b> Jack has the right to inform the agent for his Medical Power of Attorney (MPOA) about his healthcare treatments.
<b>Objective:</b> With staff presenting pictures and verbal descriptions, Roseanne will identify 3 different situations that involve unusual restraint or procedures for 48 weeks.	<b>Objective:</b> With staff presenting pictures and descriptions, Tom will identify 12 different situations that involve unusual restraints or procedures, once a week for 48 weeks.	<b>Objective:</b> Jack will meet with his doctor and agent at the medical center office every 2 weeks for 4 months for medical up-dates.
<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will present one at a time 6 different pictures, one-half depicting a situation involving unusual restraint or procedure and the other half depicting cooperative behavior.</li> <li>As each picture is presented, staff will read a shot description of what is happening in each picture.</li> <li>Staff will ask Roseanne if the situation involves “ok” behavior or “not right” behavior.</li> <li>Roseanne will answer “yes” or “no.”</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will present Tom with 24 different pictures of situations depicting unusual restraints and procedures or cooperative behavior.</li> <li>Staff will ask Tom to decide which pictures involve unusual restraint or procedures and why (i.e., hurts people).</li> <li>Staff will ask Tom to decide which pictures involve cooperative behavior and why (helps people).</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Jack will discuss the upcoming medical procedures at the hospital with his doctor and agent.</li> <li>Jack will inform his MPOA agent what health care treatment he wants or does not want.</li> <li>Staff/agency nurse will discuss with Jackie any unusual or unorthodox therapies that he considers.</li> </ul>

### Other Sample Goals to consider:

- Reporting violations or potential violations of rights to designated authorities



## 24 NO RESTRAINTS

### RIGHT

To be free from restraints unless medically approved and recorded in your case file  
[including time-out, mechanical, physical, medication, or chemical procedures]

**Sample RESPONSIBILITY:** To talk about a behavior plan or protective device with your family, guardian, advocate, agent, case manager, or staff

### Sample Goals, Objectives, and Techniques

Level 1	Level 2	Level 3
<b>Goal:</b> Jerry has the right to have an approved behavior management plan to help him live better.	<b>Goal:</b> Dan has the responsibility to discuss his behavior management plan.	<b>Goal:</b> Elaine has the responsibility to safely follow her approved behavior plan for severe head banging and seizures.
<b>Objective:</b> Jerry will reduce incidents of self injurious behavior within 6 months according to the attached behavior plan.	<b>Objective:</b> Dan will talk to his guardian and behaviorist about his behavior plan to change aggressive behavior once a month for the length of the plan (up to one year). (see attached plan)	<b>Objective:</b> Elaine will tell staff daily if her helmet is uncomfortable or tight.
<b>Techniques:</b> <ul style="list-style-type: none"> <li>Jerry's guardian and case manager will review his progress monthly with the behaviorist.</li> <li>Interdisciplinary Team meetings will be called as needed by the case manager for possible updates.</li> <li>Jerry will say how the behavior plan is to help him.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Dan will review the data from his behavior plan with the behaviorist to check his progress.</li> <li>Dan will review the monthly data with his behaviorist and guardian.</li> <li>The behaviorist will implement changes to the plan as needed.</li> <li>Dan will voice his opinion about the data and proposed changes.</li> <li>Dan will keep his own record on a behavior calendar to keep track of "good days" and "not so good days".</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Elaine will let staff know if she needs adjustments to her helmet.</li> <li>Staff will make the proper adjustments as medically prescribed and in accordance with the behavior plan. (See attached plan.)</li> </ul>

### Other Sample Goals to consider:

- Reporting abuse; Reporting physical restraints
- Reporting accidents
- Talking to the behaviorist about your plan

## 25 NO PUNISHMENT RIGHT

To be free from any kind of mental or physical punishment or abuse

### **Sample RESPONSIBILITY**

To tell someone right away if anyone punishes or abuses you

### **Sample Goals, Objectives, and Techniques**

<b>Level 1</b>	<b>Level 2</b>	<b>Level 3</b>
<b>Goal:</b> Lamont has the right to be free of any mental or physical punishment.	<b>Goal:</b> Hazel has the responsibility to learn the difference between punishing and non-punishing behavior toward self and others.	<b>Goal:</b> Lillian has the right to be free of any mental or physical punishment.
<b>Objective:</b> Lamont will point to 3 different situations, from pictures presented by staff, that involve physical punishment and those that involve praise 1 time per week for 48 weeks.	<b>Objective:</b> Hazel will meet with the Self-Advocacy group every two weeks for 6 months, with staff assistance.	<b>Objective:</b> Lillian will meet with the apartment program's assertiveness training group once a week for 6 months to learn how to protect herself from harm (verbal and physical).
<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will present 6 pictures to Lamont that portray punishment or praise.</li> <li>As each picture is presented, staff will read the brief description about punishment or praise depicted in the picture.</li> <li>Staff will ask Lamont if the situation is about punishment or praise.</li> <li>Lamont will indicate "not right" for punishment scenario and "yes, right" for praise scenario.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Staff will conduct self-advocacy training every two weeks (at the group home and at the day program).</li> <li>Staff will include training about rights and responsibilities.</li> <li>Staff will provide illustrations of punishment and non-punishment behaviors towards self and others.</li> <li>Hazel will verbally describe (from the illustrations) the behaviors that punish and the behaviors that do not punish at the self-advocacy meetings.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>The counselor and staff will train Lillian on 6 assertiveness skills.</li> <li>Staff will teach Lillian how to express herself to protect her rights.</li> <li>Staff will role-play situations of mental, verbal, and physical punishing behavior.</li> <li>Lillian will identify what the problem behaviors were.</li> <li>Lillian will decide which assertiveness skill to use in different situations.</li> </ul>

### **Other Sample Goals to consider:**

- Identifying situations involving mental or physical punishment
- Not punishing other people with words or actions
- Speaking up for yourself and others ; Talking to groups about the importance of being kind to people and not hurting them

## 26 RIGHT OF HABEAS CORPUS RIGHT

To have a lawyer represent you in court

### **Sample RESPONSIBILITIES**

To tell the truth to your lawyer

To tell the truth to the judge

To have your guardian, if you have one, with you in court

### **Sample Goals, Objectives, and Techniques**

Level 1	Level 2	Level 3
<b>Goal:</b> Robin's guardian and lawyer will represent her case at court.	<b>Goal:</b> Peter's court appointed lawyer and his guardian ad litem will present Peter's case at court.	<b>Goal:</b> John will talk to his attorney about a change in his guardianship status
<b>Objective:</b> Robin's guardian and lawyer will gather facts about the case.	<b>Goal:</b> Peter will provide information to those helping to present his case.	<b>Objective:</b> John will go to all appointments with his attorney
<b>Techniques:</b> <ul style="list-style-type: none"> <li>Robin will appear at court if requires and if medically approved.</li> </ul>	<b>Techniques:</b> <ul style="list-style-type: none"> <li>Peter will appear in court if required and medically approved.</li> <li>Peter's representatives will appear in court for him.</li> </ul>	<b>Technique:</b> <ul style="list-style-type: none"> <li>John will keep a record of his legal appointments</li> <li>John will visit the court house building before the court date.</li> <li>John will attend the court hearing when scheduled.</li> </ul>

### **Other Sample Goals to consider:**

- Privacy about legal matters
- Signing a contract for goods or services
- Community Health Law Project
- Talking to the police with your lawyer (and guardian)
- Going to court with your lawyer (and guardian)



## **PART II**

### **Section C**

#### **Suggestions for Professionals and Caregivers Discussion Points for Staff Training and Development**

**Karen Gutshall, Ph.D., L.S.W.**

#### **Overview**

Professional staffs of community services, private agencies, and residential facilities, who work with individuals with developmental disabilities, must know about human rights for themselves as well as for those with whom they work. Human Rights are available to all and are “learned,” not “earned.” They are the same for staff members and consultants as they are for consumers.

Discussion Points are identified for each of 26 rights and responsibilities statements for staff training consideration. The italicized “Rights and Sample Responsibilities” statements are the same statements used throughout this book. The 26 Rights Statements were developed from the representative state law and United Nations declarations and then written in plain language. Plain language was determined by a consensus of speech and language specialists, professionals who prepare service plans, direct care professionals, and consumers. The Discussion Points are written in ordinary language.

The Discussion Points are not intended to be conclusive. They are likely to lead to other considerations in the course of staff training programs. Human rights training will help prepare service professionals with the awareness needed to foster and to guard the rights of individuals with developmental disabilities. The training promotes the idea that responsibilities accompany rights and that responsibilities must be practiced to sustain the rights. This section supports Part II, Section B that offers illustrative service plan goals and objectives.

Discussion Points may be advantageous to families and to Self-Advocacy programs as human rights become a more widely understood consideration for daily life –at home and in programs.

## **PERSONAL RIGHTS**

### **1 RESPECT**

#### **Right**

*To be respected as a person with rights*

#### **Discussion Points**

- Respect is not something that an individual with a disability must “earn.” It is a right and an expectation that individuals with a disability should be treated in a polite and dignified manner at all times, not only by staff, but by family and friends as well.
- Being treated with dignity and respect includes being spoken to in a conversational tone of voice, not being shouted at or ordered around.
- Respect involves treating someone according to his/her chronological age. This includes tone of voice, activities provided, clothing choices, room décor, and form of address (i.e., Mr./Ms. Last name or by first name).

#### **Sample Responsibilities**

*To talk and act 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 yelling at, teasing, or hitting them*

#### **Discussion Points**

- Modeling respectful behavior demonstrates what is expected and how to do it.
  - Should an individual behave in a disrespectful manner to staff, family or friends, the response is NOT to be disrespectful in return. The objective is to have harmony among people.
- Human relationships work best when they are reciprocal. This means that people are expected to be courteous and respectful to one another. In this way the relationship is not “one-sided.”
  - In the “service industries,” whether in fast food, fine dining, or disability services, “the customer is always right.” The individual should be treated according to his or her status as someone “paying for a service.” This is not always the case between paid staff and the individuals with whom they work.
  - It is a human right to be treated with respect by others regardless of one’s ability to reciprocate, as might be the case with someone with a significant disability, challenging behavior, or poor communication skills.

### **2 SELF-ADVOCACY**

#### **Right**

*To advocate for yourself*

## Discussion Points

- Individuals with disabilities should be encouraged to speak up on their own behalf. This includes letting people (family, friends, and staff) know when the individual may not be happy with something or when he or she wants something in particular. Some “small” and “large” issues may concern a different style of clothing or changing a place of residence.
- Staff may need to encourage individuals to speak up for themselves, or even teach them what to say to help them be “heard.” Encouragement might include role playing, helping the person to get to self-advocacy group meetings, and having opportunities to learn from peers who may have already mastered positive self-expression.
- Asserting or speaking for oneself may be particularly difficult for some individuals with developmental disabilities. This may be especially true if the individual has never or infrequently spoken-up before such as expressing disagreement with a parent, staff member or other person in authority. Difficulties may be particularly true if the individual has been punished in the past for speaking out. Staff should never underestimate the perceived power that they hold over individuals with whom they work. Staff should provide reassurance and respect for the individual’s self-expression. Staff and family members should look for opportunities that allow the individual to assert his/her need(s) or desire(s). For example, waiting for the individual (if he/she has the awareness and capacity) to ask for a table napkin instead of “automatically” providing one.
- It is NEVER acceptable for staff, family, or friends to use their influence or perceived power to silence someone for sharing his or her views, advocating for himself or herself or otherwise expressing himself or herself, even if the view is unpopular.

### **Sample Responsibility:**

*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*

## Discussion Points

- Often parents, staff members, and others speak **for** a person with a disability because they do not think that the person can effectively speak for himself or herself. Regardless of how long it takes for the individual to express himself/herself, each person with a disability should be given the opportunity for self-expression..
  - Communication may be verbal or non-verbal. Non-verbal communication is communication without words and might require use of an alternative means of communication (write/print; pointing to words or pictures; use of computer; form of American Sign Language, or head or mouth pointers) Non-verbal communication may be as simple as smiling to indicate a positive preference when presented with a choice.

- Individuals should learn how to make choices and express them from a very early age, but it is never too late to start! Staff and families may look for and provide opportunities to facilitate self-expression—with prompts, if needed. The prompt could be: “Do you think you need a napkin?” Wait for the response and proceed to teach the individual to ask for the napkin. If possible, suggest that the individual get a napkin and use it. Realize the number of steps involved in the task and assess what part the individual can and cannot perform. Do not take an all-or-nothing approach. The more tasks an individual can accomplish, the greater the self-esteem. (See Part II, Section D for further discussion on self esteem.)
- At first, choices might need to be structured. For example, presenting 2 or 3 acceptable clothing options among which the individual can choose; only having healthy snack options available for the individual to freely access without “permission.”
- Role playing may be necessary for the individual with a disability to “rehearse” speaking up for himself/herself. Having someone present for encouragement and clarification may be useful and necessary. But, this is NOT a prerequisite to self-advocacy. It is a training issue, not a rights issue.
- When an individual is not expected to speak for himself/herself, the more likely it is that others (e.g., family, friends and the general public) will believe that he/she is incapable of speaking for himself/herself.
- When someone addresses a personal question to a staff member or other companion about the individual with the disability, the staff member should politely redirect the person to address the individual with the disability. Staff can model this by turning to the individual and repeating the question for him or her to answer directly.

### **3 RELIGION**

#### **Right**

*To go to the church, synagogue, mosque or temple of your choice, or not to go*

#### **Discussion Points**

- When it comes to religion in a program setting or activity program, the “majority” can NOT “rule.” “Freedom of religion” provides for each person to practice or not practice as he or she chooses.
- In a program or activity, even if “everyone is OK with prayers,” the prayers should not be lead by staff members. However, when approved, a staff member may teach prayers as part of a learning objective until the individual can perform the objective independently. Participation cannot be required by anyone choosing not to participate.



- If someone receiving services finds a religious practice in a program setting to be personally offensive, an alternative activity should be offered to the dissenter.
- Conversely, a religious practice should not be stopped if it is contrary to a staff member's personal beliefs or preferences. The right applies to the service recipients first and foremost. (The offended person may request a transfer to another situation that would be less offensive.)
- Even if one person's refusal to attend a religious program prevents others from attending, the individual should not be made to feel guilty about not going to the religious program.
- Scheduling should be done with planning to accommodate all religious preferences, to participate or not to participate.

### **Sample Responsibilities**

*To learn about and how to follow your religion*

*To respect the religion of others*

*To respect those who do not practice a religion*

### **Discussion Points**

- Staff members should provide assistance to individuals in learning about his or her own religion, if they choose to practice a religion.
- Individuals should be assisted in learning about the religious practices of others with whom they share space and activities in order to be respectful of their observances.
- Teasing about religious practices or attire constitutes a violation of Right # 3 and should be addressed by staff and caregivers.

## **4 VOTE**

### **Right**

*To register and vote in elections, if you want to do so*

### **Discussion Points**

- Individuals under guardianship, who have the right specified in the court's judgment, may vote as any other citizen.
- Individuals have the right to receive information and assistance in order to exercise their right to vote.
  - Individuals may require assistance to obtain and to complete voter registration forms in a timely manner.

- Individuals may need assistance with transportation to the voting place as well as a review of how to use the voting machines. Other individuals may need assistance with completing and submitting an absentee ballot in a timely manner.
- Individuals have the right to staff assistance in acquiring information, understanding the issues on the ballot and role playing the actual process of exercising one's right to vote.
- Every individual in a supervised setting has the right to vote about programs and activities.

### **Sample Responsibilities**

*To vote in the way you want to vote at meetings, in organizations, and in national, state, and community elections*

*To respect those who do not vote the way you vote or who choose not to vote*

### **Discussion Points**

- Individuals choosing to vote in a public election should be informed about opportunities to learn about the topic upon which they intend to vote and the candidate for whom they would be voting.
- Individuals must be free from undue influence of peers, family members, and staff in matters of voting, both in an organization setting as well as in community elections.

## **5 GUARDIAN**

### **Right**

*To have a guardian and/or advocate, if you need one*

### **Discussion Points**

- Guardianship is a legal action decided by the court where a person is declared to be incapacitated and a guardian is appointed to safeguard the ward's person and finances. [NOTE a more complete overview of guardianship is described in Part III of this book.]
- If a parent or other interested party seeks to be appointed a guardian of an individual, that person must consult an attorney or produce filings to the court independently.
- The individual alleged to be in need of a guardian will himself/herself be represented by an attorney, usually an attorney appointed by the court.
- The Judgment of Guardianship, prepared by the court, states the areas of responsibility of the guardian (general or limited). Staff should be familiar with the contents of the Judgment.

- If an individual has a guardian, that individual continues to have human rights. It is the responsibility of the guardian to involve the ward in decision making to the extent possible as well as to encourage the ward's decision making abilities.
- If an individual does not have a guardian, he or she may want to appoint an agent to have Powers of Attorney. [NOTE: Part III of this book offers a description of durable and medical powers of attorney.]
  - An agency or a staff member cannot be appointed as an Agent for an individual. It is a conflict of interest.
- The need for guardianship is reviewed during the annual Individual Service Plan meeting. Staff has the opportunity to "recommend" possible need of a guardianship, no need of a guardianship, or reversal of a guardianship. The recommendation involves obtaining legal advice and representation. The lawyer will then arrange for the proper assessments, as needed. The judge makes the ultimate decision about need of a guardian. [NOTE: The commonly used phrase "He's his own guardian." is incorrect. Are you "your own guardian?" No. Just say that the individual does not have a guardian! Then make recommendations as considered appropriate.]
- The parent of an individual with a developmental disability does not automatically become the legal guardian when that individual turns 18. Some families pursue guardianship when their son or daughter turns 18. If guardianship is not pursued, the individual is legally responsible for making his/her own decisions.
- The New Jersey Department of Human Service, Bureau of Guardianship Services, has been appointed to be a guardian for some individuals.
- Limited guardianship should always be considered, restricting decision making only where necessary.
- The guardian must be involved in program plans and, medical matters.

### **Sample Responsibilities**

*To tell your guardian, advocate or agent what you are thinking about, what you want, and what you need*

*To ask the judge to reverse your guardianship*

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

### **Discussion Points**

- Even if an individual is legally determined to be in need of a guardian, the individual should still be consulted and participate in decision making to the maximum extent of their ability.
  - This applies to representatives from the Bureau of Guardianship Services, family members or anyone acting in this capacity.

- The ward may consult an attorney for reversal of guardianship or change of guardian. The individual is likely to require assistance to locate an attorney in private practice or from the Community Law Project, if certain requirements are met.

## ***LIVING ARRANGEMENTS***

### ***6 SERVICES***

#### **Right**

*To have a safe, clean place to live*

#### **Discussion Points**

- Publicly funded housing must meet minimum standards of safety, cleanliness and overall quality.
- Individuals living with their parents or other family members have the right to “decent” housing as well, in accordance with family means and social norms.
- A failure to provide for a sanitary, safe living environment with adequate electricity, water and heat may constitute neglect.

#### **Sample Responsibilities**

*To follow safety rules*

*To take care of your home*

#### **Discussion Points**

- To protect one’s own safety as well as that of others, commonly agreed-upon safety rules should be followed. A failure to abide by common safety rules could result in injury to self or others.
- Individuals should be made aware of community dangers and actions to take to take precautions against harm.
- Each person has a responsibility to take care of his/her surroundings. This includes vacuuming, dusting, mowing the lawn, not intentionally destroying furnishings or the property of others, etc.
  - A person may be required to pay for damages caused by his/her actions or a failure to take proper care of their home or other property.

### ***7 PERSONAL ITEMS***

#### **Right**

*To have your own money, clothing, and personal items kept safe*

## **Discussion Points**

- Regardless of cognitive capacity, individuals have the right to a personal needs allowance, at a minimum. They have the right to make decisions about how to spend the funds available to them, with assistance if necessary.
  - Assistance might include physical assistance carrying money, handing it to a clerk, etc. or guidance with counting, budgeting, and comparison shopping.
  - If someone is unable to count change, for example, he/she may still carry money in his/her pocket, hand it over to the clerk and pocket the change while a staff member discretely monitors the transaction.
  - Some individuals may use a debit card for purchases. Training on the proper use of a debit card may be part of a service plan.
- Assistance with keeping one's money safe might include having a lock box with a key, or with staff having a key to ensure its safekeeping.
- Individuals should have the opportunity to purchase and select their own clothing. Clothing should not be shared unless it is the explicit choice of the individuals involved. "Congregate clothing" as was once common in institutional settings is unacceptable under any circumstances.
- Individuals should not take the property of others without permission and should expect staff assistance when necessary in protecting their belongings from others, including staff members.

## **Sample Responsibilities**

*To take good care of your things*

*To leave other people's things alone*

## **Discussion Points**

- As with the home and shared property, individuals should use items in the manner in which they were intended to be used. When necessary, staff members may need to instruct or assist individuals in properly caring for personal items.
- House rules or other means should be used to assist individuals in learning how to borrow things, with permission, and how to handle an individual's refusal to share a personal item, when asked.

## **8 MAIL**

### **Right**

*To send and to receive unopened mail*

*To ask someone to help you read or write your mail if you need help*

## **Discussion Points**

- Mail should not be screened by staff or opened by anyone other than the intended recipient unless such assistance is requested.
- Individuals have the right to have their mail read to them if they are unable to read it themselves and if they agree to have the mail read.
  - Mail should be read in a private place, when possible, to protect an individual's privacy.
  - Whatever is read should be treated confidentially by staff and not shared unnecessarily with others, including other staff members.
- Individuals with disabilities have the right to correspond with anyone of their choosing unless restricted by the service plan, legal agreement, or the explicit instructions of the guardian.
- Individuals may need to be encouraged by staff to correspond with others. Physical assistance in carrying out that choice may be required (i.e., help with writing a card or letter).
- Individuals need to be encouraged to seek assistance when necessary.
  - This may include learning to communicate an interest effectively and accepting assistance when it is available.
  - Individuals with limited communication or social skills may need suggestions and guidance in deciding what to write.

## **Sample Responsibilities**

*To respect another person's right to send unopened mail*

*To respect another person's right to open and read his own mail*

## **Discussion Points**

- Individuals may need training or guidance in identifying their own mail versus that of others to ensure everyone's privacy is honored.
- Mail delivery may require inconspicuous monitoring to ensure that individuals respect the privacy of others and read only their own mail.
- Individuals may need encouragement to ask for assistance with reading and writing when necessary.

## **9 PHONE**

### **Right**

*To make phone calls and to receive calls from others during reasonable hours*

## **Discussion Points**

- As with mail, telephone calls should not be screened by staff or intercepted by anyone other than the intended recipient unless such assistance is requested.
- An individual may request to have someone listen in or take notes for him/her if unable to write needed information down.
  - Whatever is heard while assisting someone with a conversation should be treated confidentially by staff and not shared unnecessarily with others, including other staff members.
- Individuals with developmental disabilities have the right to speak with anyone of their choosing unless restricted by the Individual Service Plan, legal agreement, the explicit instructions from the guardian, or in some other venue ceases the violation of the rights of others (e.g. prank calls, calls at unacceptable hours, repeatedly calling 911 for a non-emergency).
- Individuals may need to be encouraged by staff to contact family members, friends, or others. Physical assistance may be needed in initiating and carrying out such contact.
- A telephone should be available in a private place, or a cordless phone made available to allow for privacy during telephone conversations.
- Reasonable times may be interpreted differently in different settings and circumstances and is primarily at the discretion of the 2 parties involved as long as it does not interfere with the routines of others (i.e. sleep).
- An individual is responsible for paying for his or her private cell phone account as well as using the cell phone according to the guidelines of the home or work place.

## **Sample Responsibilities**

*To follow the house rules for making and receiving phone calls*

*To pay your phone bill*

*To respect another person's right to make and receive private calls*

## **Discussion Points**

- In congregate living arrangements it may be necessary to limit the length of calls of the times during which calls can be made and received. Otherwise the length, frequency and times of calls is between the caller and the recipient.
- In situations where rules are required due to shared usage or the expressed preferences of the person receiving the call, individuals should have the opportunity to participate in the formation of those rules. Once the rules are formed, all participants, including staff, should know those rules.
- Individuals should give each other privacy during calls, to include leaving an immediate area that is within ear-shot, if nicely requested to do so.

## **10 HEALTHY DIET**

### **Right**

*To have a healthy, balanced diet*

#### **Discussion Points**

- Individuals receiving services or residing with family members have the right to adequate nutrition.
  - The absence of a healthy diet, in extreme cases can constitute neglect.
  - Not providing a medically prescribed diet may constitute abuse, in some cases.
- Individuals with cognitive limitations that do not fully understand the consequences of poor nutrition have the right to guidance and training in this area.
- In some instances providing a healthy diet may be in conflict with an individual's personal preferences and require the intervention of the interdisciplinary team and/or legal guardian, along with a written medical prescription for a limited calorie diet and added to the Individual Service Plan.

### **Sample Responsibilities**

*To help plan meals*

*To eat food that you like and that is good for you*

*To follow the diet that your doctor says is good for you*

#### **Discussion Points**

- Individuals with cognitive limitations who do not reasonably understand the consequences of poor nutrition may need to be educated about good nutrition and the consequences of poor nutrition in order to make informed choices.
- Individuals should play an active role in meal planning and shopping for themselves.
- In group living situations, participation in meal planning may be conducted as part of house meetings or on a rotating schedule, but should always involve the residents.
  - The art of compromising and consensus building may need to be developed in this process.

## **11 RELATIONSHIPS**

### **Right**

*To have relationships with girlfriends and boyfriends*

#### **Discussion Points**

- Individuals with disabilities, like all human beings, generally desire to develop relationships with others. Relationships may encompass family members, friendships and romantic interests. This is a natural part of human development.



- Relationships with family and friends often require staff encouragement or prompting to develop and maintain.
- Individuals may need assistance with verbalizing their interests in personal relationships, initiating conversation, activities and dates.
  - Individuals often need staff guidance and support to “play host or hostess” and to develop social skills expected for their age and the occasion. Role playing, modeling and active training are often needed to promote and maintain mutually rewarding relationships.
- The natural course of many friendships and human development often results in a drive for sexual expression and romantic relationships.
- Despite concerns re: procreation, STDs (sexually transmitted diseases), and informed consent, many adults with disabilities do develop romantic and even sexual relationships.
  - The interdisciplinary team should always be involved in decisions about the role of staff and the mutuality of any sexual relationship between program participants.
  - Many agencies refer individuals to medical and/or community resources for training about sexual relationships.
- Sexuality education and relationships are among the most controversial and sensitive areas in the discussion of rights and responsibilities.
  - Family members often feel extremely protective and even controlling in this area.
  - Staff members are often uncomfortable providing information or training in this without guidance from the agency for whom they work.
  - Religious values about sexual expression may conflict among individuals and staff.
  - Agency policies should, but often do not, provide clarification for staff members as to their responsibilities in this area, and yet, it remains a basic right of individuals unless restricted by court order or the legal guardian.
- Every agency should have a sexuality policy in place to guide staff and individuals in their decision making when relationships between peers become more sexual. Sexual relationships between consumers and professional staff are not permitted.

### **Sample Responsibilities**

*To respect your friends*

*To learn how to behave at social events, at dances, and on trips*

### **Discussion Points**

- Relationships should be mutually respectful and free from yelling, teasing, or hitting.
- Individuals must respect the rights of others and refrain from unwelcome sexual overtures, conversations, or acts.
- Individuals may need formal instruction re: relationships and what behavior is considered appropriate in accordance with societal norms, especially outside of program areas. This

is especially true if the individual has had limited experience in the community or has not been held to social norms in the past.

- There are marriages between consenting adults who have developmental disabilities. For individuals under guardianship, permission from the guardian would be required unless permitted in the guardianship judgment.

## **12 VISITORS**

**Right:** *To have guests visit you during reasonable hours*

### **Discussion Points**

- “Reasonable” is dependent on the individual circumstance. An individual in his/her own home may choose to receive visitors at unusual hours, whereas individuals in group living situations or work centers must comply with the house and program guidelines.
  - Visitors may not be appropriate at a work site, unless others, including staff have visitors. The same rules and norms should be applied to everyone in the work setting.
  - Visitation may need to be scheduled in congregate living situations so as not to interfere with the routine, rights, and privacy of others.
- Individuals should have the opportunity to participate in determining the rules that define “reasonable.”

### **Sample Responsibilities**

*To make plans for your guests to visit you during reasonable hours*

*To make sure that your guests follow house rules*

### **Discussion Points**

- Individuals may need assistance in initiating plans or confirming arrangements with visitors that comply with stated guidelines.
- Individuals may need assistance planning things to do such as an activity or refreshments when expecting visitors.
- Individuals need to monitor the behavior of their visitors during visits, or have staff assistance in doing so. Ideally this can be done in such a way as to encourage rather than discourage future visitation, unless the circumstances warrant future limitation due to aggression, property destruction, personal harm, etc.

## **13 ACTIVITIES**

### **Right**

*To join social and recreational activities at your home, school, work place, or community when you want to participate in them*

#### **Discussion Points**

- Social and recreational activities are a critical part of good physical and emotional health and well-being. Activities should be encouraged and initiated, if necessary.
- Individuals should play an active role in planning and choosing activities through house meetings, voting, and asking for assistance in finding out about local activities.
- Regardless of staffing constraints, individuals in community living arrangements are expected to have access to activities in accordance with their IHP, personal preferences and societal norms.

### **Sample Responsibilities**

*To follow the rules of the activity*

*To let others know if you want to go or not to go to an activity*

#### **Discussion Points**

- Individuals may need instruction and guidance in following the rules of an activity.
- Individuals should be expected to follow the rules for everyone's enjoyment, unless an accommodation has been agreed upon.
- Individuals need to voice their opinion and level of interest when activities are being planned so that everyone knows what to expect. Staff may need to assist people in expressing their opinion and making informed choices.

## **14 PRIVACY**

### **Right**

*To have privacy when you want to be alone*

#### **Discussion Points**

- Individuals should have a designated place that he/she can go to be alone when he/she wants to.
- Individuals may need staff assistance to arrange this in congregate settings.
- Individuals may need guidance or training in identifying times or activities that should be addressed or conducted in private such as expressing themselves when they are upset, masturbating, and ill, etc.

### **Sample Responsibilities**

*To tell people when you want to be alone*

*To respect others when they want to be alone*

### **Discussion Points**

- Individuals may need to learn how to let someone know when they want to be alone.
- Individuals may need redirection from staff to ensure that the privacy of others is protected.
- Mutual respect for privacy may include staff members being considerate about invading the privacy of residents, even unintentionally in the course of fulfilling their responsibilities.
  - Everyone should learn to knock and wait to be invited in, regardless of their role.
  - Staff members, parents and others can be powerful role models, so consistency is critical.

## ***HEALTH CARE***

### ***15 TREATMENT AND THERAPY***

### **Right**

*To be referred for treatment or therapy if you need it*

### **Discussion Points**

- Individuals have a right to appropriate therapies, as needed. The therapies may include: mental health, occupational therapy, speech therapy, behavioral therapy, and/or psychiatric and other therapeutic care when necessary.
- Conditions, whether psychiatric or physical, should not be ignored due to limited financial or other resources.
- This often requires advocacy in locating a health care provider that participates in Medicaid.

### **Sample Responsibilities**

*To go to treatment or therapy sessions*

*To follow the doctor's and therapist's directions*

### **Discussion Points**

- Individuals may need staff assistance or prompting to ensure compliance with treatment requirements.

- Staff may need to find ways to explain why something is important and will be beneficial as it can be difficult for individuals with cognitive limitations to understand abstract concepts such as diet leading to good health, or exercises that hurt being necessary for the full recovery and use of a broken arm.
- Individuals often require staff assistance with transportation and moral support when keeping appointments with health care professionals.

## **16 HEALTH CARE**

### **Right**

*To practice personal healthy living and physical exercise*

#### **Discussion Points**

- Individuals may need assistance in identifying activities and practices that will contribute to good health, and assistance in carrying them out.
  - Staff members may need to organize activities for individuals and encourage their participation.
  - Staff should be a role model and participate in activities and exercises designed for the individual(s) with whom they are working.
- Multiple formats and opportunities for physical exercise should be available to accommodate individual differences in ability and interest.
- Training and guidance may be necessary, as well as ongoing supervision, for an individual to acquire good personal health habits such as regular teeth brushing, bathing, regular meals, etc.

### **Sample Responsibilities**

*To take good care of yourself and stay healthy*

*To choose an exercise that you like, want, and can do*

#### **Discussion Points**

- When opportunities are available for health care and recreation, an individual may need to be encouraged to learn about them and possibly to take advantage of interesting activities.
- Individuals should actively participate in identifying things that they would enjoy doing to promote good health.

## **17 MEDICAL**

### **Right**

*To receive medical, dental, and other health care regularly and when you need it*

## **Discussion Points**

- Individuals often rely on staff or family members to coordinate medical and dental appointments due to scheduling limitations, transportation, and insurance requirements.
- Advocacy is often needed to locate physicians and dentists who will accept Medicaid.
- Finding professionals with experience in treating individuals with complex or multiple disabilities may be difficult in certain communities, and extra vigilance is required to secure the necessary care.
- When possible, individuals should be taught to take an active role in keeping track of needed appointments and making the necessary arrangements.

## **Sample Responsibilities**

*To let people know if you are sick or if you are hurt*

*To talk to your doctors*

*To ask questions about your health, healthcare, and medications*

## **Discussion Points**

- Individuals may need staff assistance or prompting to ensure compliance with the healthcare directions they receive.
- Staff may need to find ways to explain, in accordance with the health care provider, why something is important and will be beneficial as it can be difficult for individuals with cognitive limitations to understand abstract concepts such as iron pills improving their energy level or that brushing 2-3 times a day will prevent gum disease.
- Individuals often require staff assistance with transportation and moral support when keeping appointments with health care professionals.
- Individuals may need encouragement to identify when they are ill or hurt and that it won't be perceived negatively.
- Individuals who are non-verbal may rely on alternate means of communication to express themselves. Staff may be required to help the physician or therapist understand the method of communication (i.e., communication board, head pointer, etc.).
- Role-playing and reassurance may be needed for those individuals who may be fearful of or intimidated by going to the doctor.
- Staff or family members should redirect healthcare professionals who speak to them instead of to the individual.
- Treatment information should not be relayed through others but communicated directly by the physician or other medical practitioner.

- Request a second opinion, as needed.

## **WORK & HABILITATION**

### **18 SCHOOL**

#### **Right**

*To go to school through age 21*

#### **Discussion Points**

- The Individuals with Disabilities Education Act (IDEA) [formerly Public Law 94-142, the Education of All Handicapped Children Act] guarantees the right to a free, appropriate public education, transition planning for students 14 years of age and older, placement in the least restrictive environment (LRE), and provision of the necessary supports and related services to ensure an opportunity to benefit from the educational experience.
- Transition planning includes aptitude assessment, job sampling in community employment sites, outreach (in New Jersey) to the Division of Vocational Rehabilitation Services, the Division of Disabilities, the Division of Developmental Disabilities, and adult provider agencies. Other states may have different names for similar governmental agencies.
- The principles of LRE means that a child should be in the classroom he or she would be in if they did not have a disability. According to the law, a child should not be placed in a special education setting without first attempting to implement a program with supports and services in the regular education classroom for all or part of the day.
- Some school districts may try to deny placement in the regular classroom or may not provide all necessary supports and services because these supplemental services can be costly. Regular education teachers may feel unprepared to deal with students classified for special education services, and/or a fear that learning for other students will be negatively affected, among other reasons.

#### **Sample Responsibilities**

*To complete your education*

*To participate in school programs*

#### **Discussion Points**

- Individuals should be encouraged to take advantage of their right to an education.
- The right to special education should include an opportunity to customize education plans to meet the needs of the individual through an Individualized Education Plan (IEP) and a Transition Plan in their later educational years.

- Transition planning might include employment evaluation, training in life skills, or other forms of community participation and support services. Day program placement, after completion of school, may include competitive employment, job sampling, job coach assistance, pre-vocational program or an adult activities center.

## **19 WORK & PLAY**

### **Right**

*To work*

*To get paid for what you do*

### **Discussion Points**

- Individuals should be encouraged to attend training programs that will promote their contribution to society and acquisition of functional job skills. The goal of such life experiences is increased independence.
- Individuals may need additional training and support in understanding the nature of the employer-employee relationship if all they have experienced is a client-staff relationship. The “rules” and expectations of the two relationships are very different.

### **Sample Responsibilities**

*To follow the rules of the workplace*

*To be a good co-worker*

*To pay your bills*

*To retire with things to do*

### **Discussion Points**

- Assistance should be provided to help an individual secure meaningful work in which he or she is interested and able to perform.
- Individuals need to have and be aware of avenues for expressing dissatisfaction with their program or work place in order to resolve problems rather than refusing to participate.
- When an individual reaches or approaches “retirement age” (i.e., 65), he or she should participate in transition planning with their support staff, interdisciplinary team, and family to identify meaningful things to do once retired.
- Individuals should be encouraged to remain active and to participate in generic senior citizen programs and other socially and culturally normative activities, with support, when necessary.

## **20 JOB & PROGRAM**

### **Right**

*To ask to go to another job, program, or place to live*



### **Discussion Points**

- Individuals may need encouragement and training in order to voice their desires for a change in program or employment situation.
- The options available may need to be explained and viewed by way of example to help someone in making an informed choice.
- Informed choice means knowing, to the best of a person's ability, the ramifications of their choice, such as lower pay, a longer ride, distance from family, higher cost, etc.
- Advocates and support agency personnel should do their best to honor such requests within the parameters of the resources and labor market forces.

### **Sample Responsibility**

*To say what you like and do not like about a job, program, or place to live*

### **Discussion Points**

- Individuals may need encouragement and practice to be able to identify why they might want a change in program, job, or living arrangement.
- Individuals may fear retaliation for sharing the real reason that they would like a change, especially if it involves mistreatment by agency personnel, parents, or others in perceived authority. Staff should be particularly sensitive to this possibility.
- Confidentiality should be available, if requested, unless the reasons for requesting change involve an abusive situation.
- An individual has the right to request a change even if he or she cannot voice a reason for the request (i.e. what they like or don't like).

## **22 PRIVATE INFORMATION**

### **Right**

*To have files about you kept private*

### **Discussion Points**

- Information about an individual should only be shared with others on a need-to-know basis. Need-to-know means that there is a useful purpose in sharing the information, such as to prevent harm, to obtain services, and upon the individual's request or permission.
- Written consent is required to disseminate information to other program providers.
- For an individual under guardianship, written consent of the guardian is required.
- Idle gossip or chit-chat among staff is a violation of an individual's right to privacy.

- Beware of discussing individuals with whom you work by name at trainings, in elevators, restaurants, etc. as someone in the vicinity might overhear you and know the person you are referencing.

### **Sample Responsibilities**

*To give or not give permission for others to read your files*

*Do not read anyone else's files*

### **Discussion Points**

- Individuals may need assistance in understanding why it might be important to share their personal information with others. Every effort should be made to provide a truthful and complete explanation.
- Individuals should be encouraged to cooperate with the sharing of information when it is being sought in order to improve their situation by obtaining resources, health care, etc.
- Individuals may need instruction and assistance to avoid looking into information that belongs to others with whom they may live or work. This is especially true if staff members or others are observed to be looking at confidential documents that may be left within eyesight or unattended.

## ***SAFE ENVIRONMENT***

### ***23 NO UNUSUAL TREATMENT***

#### **Right**

*To be free from unusual treatments and research unless ordered by the court and recorded in your medical record*

*[shock treatment, psychosurgery, sterilization, and medical, behavioral, or pharmacological research]*

### **Discussion Points**

- Unusual treatments, though once common, are rarely authorized by the court, unless all other alternatives have failed to prevent further harm to self or others.
- Less intrusive measures must always be attempted and the results documented in order to use more intrusive interventions (such as those identified above).
- Unusual or complicated treatments could be hard to explain to a person with developmental disabilities. It may be hard to comprehend that a treatment could be harmful. The guardian and staff will have to work together on the treatment matter.

### **Sample Responsibilities**

*To talk about any suggested unusual treatments with your family, guardian, advocate, agent, doctor, lawyer, case manager, or staff*

#### **Discussion Points**

- The individual should be encouraged and may need support in order to discuss matters of their own behavior and/or treatment options with persons in positions of authority.
- The individual should actively participate in treatment decisions regarding all and any life altering, irreversible procedures—at his or her level of ability.

## **24 NO RESTRAINTS**

### **Right**

*To be free from restraints unless medically approved and recorded in your medical record [including time-out, mechanical, physical, medication, or chemical procedures]*

#### **Discussion Points**

- Physical restraint includes any intervention or procedure which restricts or interferes with an individual's freedom of movement. This includes sedation that impedes one's ability to speak, move, or carry out typical personal functions.
- Time-out refers to the removal of stimuli from a public space as well as limiting one's sensory experience.
- Prohibiting someone from attending a recreational activity, sharing a meal, etc. may also be considered "time out" even if the individual remains physically in the same space. None of these procedures are permitted without proper documentation of the necessity for such measures. Documentation of previously failed less restrictive intervention plans must be provided. Refer to appropriate documents describing Behavior Management programs and Human Rights Committee.
- Behavior plans must be clearly written by those credentialed to do so that those responsible for implementing the plan can follow and document as required.
- Guardians must be involved with approval of behavior management therapies.

### **Sample Responsibility**

*To talk about a behavior plan or protective device with your family, guardian, advocate, agent, case manager, or staff*

### **Discussion Points**

- Individuals may need encouragement and support to discuss their own behavior and the interventions being proposed to address them.
- Individuals, and guardians, should always be present when their Individual Service Plan team meets to decide on the need for a behavior plan and its content, unless it is deemed detrimental to the individual to do so.
- A capacitated person (a person not under guardianship) must consent to the implementation of the behavior plan unless their right to do so is revoked by the court.

## **25 NO PUNISHMENT**

### **Right**

*To be free from any kind of mental or physical punishment or abuse*

### **Discussion Points**

- Punishment in any form is unacceptable in public programs and should be highly discouraged in family living arrangements as well.
- Punishment is considered “abuse” and is not an acceptable treatment option. This is even true if a parent is a legal guardian and thinks that they have the right to “discipline” their child with punitive measures.
- “Consequences” may be imposed as a result of destructive behavior as allowed by proper documentation in accord with guiding regulations.

### **Sample Responsibility**

*To tell someone right away if anyone punishes you or abuses you*

### **Discussion Points**

- Individuals may need training to identify what constitutes “punishment” and “abuse.” This may be especially true in an environment and/or when someone is used to being treated (and punished) like a child.
- Considerable support may be necessary for someone with a disability to be critical of a parent, guardian, sibling, staff member or share unacceptable treatment outside the home.
- Staff may assist the individual identify a trusted person to tell them what is wrong. Staff must avoid creating a dependent relationship with the individuals whom they serve. The issue is one of conflict of interest as well as privacy.
- An individual with a developmental disability may have difficulty understanding “punishing” behavior beyond physical punishment. Both the guardian and staff need to

discuss the matter at the person's level of ability as well as be advocates in the possibility of an individual being harmed or mistreated.

- Incident reports are required in any situation of harm.

## **26 RIGHT OF HABEAS CORPUS**

### **Right**

*To have a lawyer represent you in court*

### **Sample Responsibilities**

*To tell the truth to your lawyer*

*To tell the truth to the judge*

*To have your guardian, if you have one, with you in court*

### **Discussion Points**

- An individual has the right to be represented in court by a lawyer. He or she may need assistance in locating a private lawyer or a lawyer from a public law resource (i.e., Law Project; volunteer lawyers).
- If an individual has a guardian, that guardian must attend the court hearing with his ward and should participate in discussions with the lawyer.
- The individual must tell the truth to his lawyer, and, when in court, to the judge.



## Part II

### Section D

#### Suggestions for Families: Personal Points of View

**Sandra Ruth Pinkerton, Ed.D.**

Special Educator

**Jane Gildersleeve-Janoff, R.G.**

Parent

**B. J. Sancho-Duser**

Employment Specialist and Advocate

#### INTRODUCTION

##### COURAGE

*Parents, caregivers, and professionals have been committed for a long time to enhancing the quality of life of individuals with developmental disabilities. Strides great, small and insufficient have been made in providing care, protection, community inclusion, self-advocacy, skill training and growth towards independence. Is this enough? Of course it is not enough! Like housekeeping, advocating for the needs of individuals with developmental disabilities is constant and changing. Individuals with developmental disabilities must be taught, encouraged, and given opportunities to demonstrate more control, responsibility, and self-direction for their own lives to the extent possible. Increased self-control, personal responsibility and self-direction may be experienced and achieved through opportunities for decision making, for the development of self-esteem, and the experiences of autonomy at each stage of life—the components of a courageous life.*

#### **JANE: Some thoughts on Opportunities for Decision Making**

It is not easy! It is not easy to teach a child with a developmental disability about rights, responsibilities, and self advocacy. It is not so easy for parents to teach the same things to children without disabilities either (we had 4 boys plus Jennie). However, parenting a child with a developmental disability is a life-long task whether the child remains with you or lives in another supervised setting. The other children grow up and take the responsibility for their own lives in ways which Jennie is unable to do. But the most critical thing is to have the same expectations for the child with a developmental disability as you do for the other children in the family. Each child is important. Each child will have opportunities to grow, to develop, and to be good citizens within the family and within the community. Any child, with disabilities or not, has his/her own challenges, strengths, needs, abilities and hopes for the future.

The context of rights and responsibilities was not in my mind early on with Jennie. As I reflect back, my thinking was about providing my daughter with opportunities and choices. As a toddler, the most important thing was to create problem solving situations. I would sit Jennie in the middle of a maze made of pillows and place an object that she wanted out of the maze. Jennie had to figure out how to get what she wanted by going through the maze. There were

other “games” where I would hide things near her and she had to “seek” for them. Later, food choices were introduced---from foods that were on-hand! Offering two choices, I asked Jennie what she wanted for breakfast and lunch. An apple or an orange? A hot dog on a roll or a hot dog chopped with macaroni and cheese?

As a youngster in school, choices were expanded from food to clothing, especially what to wear for the weather. We listened to the weather station to find out what weather to expect on the weekends because the weather station came on after she left for school during the week. Usually I laid out the day’s clothes the night before so the choice involved the outer garment. I learned early—after much trial and error—that I had to take into consideration my daughter’s body temperature. Hers was not the same as mine. Where she could go out on a really cool day wearing a sweat jacket, I needed layers. My husband and I were learning just as she was.

Then came the teenage years, around age 16 and 17, when social activities, and “boys” were preoccupations. An agency for the general public in our area had a wonderful program of sexuality education. They taught facts on human sexuality and friendships (at Jennie’s level of understanding) and appropriate social behavior. How to act with a boyfriend? When to kiss? When to hold hands? How and when to socialize? It was good for Jennie to learn about sexuality from others not just her parents.

In the last couple of years in high school, Jennie had wonderful opportunities with job sampling. She liked the variety and knew that she did not want to work in the food industry such as a fast food restaurant. She was able to experience and to make informed choices about a wide range of work that she liked such as the cafeteria in the high school, cleaning service, and helping in a nursing home. Today Jennie continues to participate in a variety of jobs at a nearby vocational center. She also does volunteer work at a senior citizen center where they just love her friendly, helping disposition. Actually, socializing and helping others are her best skills and abilities. This is the best environment for her to thrive and to make her happy.

When Jennie turned 18, her father and I had to seriously consider guardianship for many reasons. Pursuing guardianship was very hard. For 18 years my husband and I did our best do to make Jennie the most independent and responsible person she could be. So had the schools and social programs! The legal system would consider her “incapacitated”—a difficult word for a parent to hear when our daughter could do so many things for herself and others! But that is the legal term. When we first pursued guardianship, the lawyer and the judge did not understand Jennie’s abilities to make certain decisions in her best interests. She could make decisions about day-to-day matters, not the complicated ones. As we learned about limited guardianship, we eventually pursued this with more comprehensive professional reports that an informed attorney placed before a judge for reconsideration.

When someone has the right to do something, it must be honored—unless there is some possibility of harm. When there is a disrespectful disregard of the stated right, the individual could become confused and angry. I recall the experience of a friend whose son came under guardianship. The judgment defined some particular rights for the individual with a developmental disability that included scheduled visits with a family member who proved to be irresponsible. The result was that the young man began to act out his frustration and was



considered a behavior problem in need of psychiatric/psychological treatment. No one understood that he was communicating a frustration about broken promises and his thwarted right established by the court (to have the visits on a regular basis). The matter was more a violation of a court order on the part of the family member. When the legal matter was straightened out, the acting-out behavior stopped. It really comes down to the fact that individuals with developmental disabilities want a say in their own life. Once an opportunity to make a decision about something is given, it is very important not to over ride it unless there may be harm.

Many of the rights will be difficult to explain to a person with developmental disabilities. For example, Jennie could never understand the possibility of a medical treatment harming her. She may not understand how a complicated health procedure may help her. It is sometimes very difficult to find the right words and assurances. In addition, in some cases, a particular procedure may not be an option or a matter of choice. Nothing is easy! Preparing this book has afforded Jennie and me with many opportunities for discussing rights. She liked the idea of using her picture. She was pleased to share the demonstration copy with her friends at the vocational center, at church, and with her family. Interesting discussions followed.

Ongoing opportunities for choices and for decision making is the cornerstone for developing a life plan.

### **SANDY: Some thoughts on Opportunities for Developing Self Esteem**

Self-esteem, the acceptance of and pride in one's self, starts with the parent's unconditional acceptance and love of the child, with or without a disability. An unconditional love sees the child as a person and not as a diagnosis, disability, or educational classification. As others do, individuals with a developmental disability continue to develop self esteem throughout the school years as well as through the later work years. A diagnosis and an educational classification are important since a diagnosis guides treatment with necessary supports and an educational classification identifies teaching practices and an approach to educational learning opportunities.

Encouraging an individual develops self-esteem and is a process during day-to-day life experiences. Self-esteem is acquired through fair praise, realistic evaluation, accepting the value of others, and setting goals that can be accomplished. This is true for the individual who may have multiple disabilities and be gifted with social awareness, smiles and attempts to help his/her caregiver, or, for the individual who is gifted with abilities to sight read words, handle a cell phone, and follow the routine of the work place. Below are some suggestions for encouraging self-esteem at home.

<b>Encouraging Self-Esteem</b>	<b>Examples</b>
<ul style="list-style-type: none"> <li>• Praise your child</li> <li>• Help the individual to evaluate realistically</li> <li>• Help the individual to set goals</li> <li>• Help the individual to praise himself/herself</li> <li>• Help the individual to praise others</li> <li>• Adults, don't forget to praise yourself</li> </ul>	<ul style="list-style-type: none"> <li>• You look beautiful in your prom dress.</li> <li>• Do you remember how hard it was for you when you first put dirty clothes in the hamper? (Discuss)</li> <li>• Now let's work on bringing the hamper into the laundry room when it is full.</li> <li>• I think you do a terrific job of choosing what to wear every day. What do you think?</li> <li>• What do you think of the picture that Susie drew for you?</li> <li>• I am a good mom/dad!</li> </ul>

Historically, persons with disabilities have been portrayed as dependent and "un-abled." This is a destructive and unhealthy picture. It is up to the family, the school, and the community to develop an "abled" portrait so that the individual with a disability feels that he/she belongs and is able to contribute; is able to realistically overcome the challenges of the disability, all resulting in the individual not defining himself/herself as a "disability." This portrait starts as early as possible and continues throughout life. Once the individual feels a sense of acceptance and belonging, he/she will reach out more to others, such as teachers, friends, and aides. Connecting with the people around them is the foundation upon which self-esteem develops.

In today's world, the needs of the individual are viewed more as human rights issues. Teaching human rights and responsibilities at his/her level of comprehension allows opportunities to express choices and make decisions thereby gaining self-confidence, and then feeling and being seen as capable and responsible. Following is a summary chart for parent—professional cooperation when changes are needed.

<b>Families need to:</b>	<b>Professionals need to:</b>
<ul style="list-style-type: none"> <li>• Make a list of questions when the needs of the individual have changed and/or when a program change will occur</li> <li>• Identify the individual with a disability likes/dislikes and strengths/weaknesses</li> <li>• Visit the types of programs that may be available</li> <li>• Provide the individual/family's preferred program or placement to the professionals</li> <li>• Provide the individual with a disability time to visit the various new settings</li> <li>• Identify any supports needed now or possibly in the future</li> </ul>	<ul style="list-style-type: none"> <li>• Recognize parent(s) devotion and knowledge of their child</li> <li>• Identify who's important in the family structure (siblings, aunts, uncles)</li> <li>• Identify the needs and supports for the individual/family</li> <li>• Identify the individual/family's priority for programs (educational) and for those that are older, placements (group home, supervised apartment, etc.) location, medical services, religious affiliation</li> <li>• Provide opportunities for individual/parents' to express child or adult likes/dislikes and/or strengths/weaknesses</li> </ul>

<ul style="list-style-type: none"> <li>• Provide professionals with any assistive technology devices the child may use in the home</li> </ul>	<p>(food, social, independent living skills, etc.)</p> <ul style="list-style-type: none"> <li>• Offer families support groups</li> <li>• Provide informational resources</li> <li>• Encourage families to ask questions and provide feedback through the process</li> </ul>
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But raising children in today's complex world is a very difficult task. A variety of issues such as safety, financial resources, time, etc. in the home, school and community is now questioned. However, parents assume that the child has opportunities to learn, make decisions and express choices that are age and cognitively appropriate. There may be a parental tendency to be overly protective. There is also a temptation to "do for" the individual because the parent (or other caregiver) can accomplish a task more efficiently and quickly. Some parents have difficulty with the teaching of skills with the goal of transitioning the child into adulthood. I would like you to think about two illustrative examples. One situation involves a child with cerebral palsy learning to put on a coat and the other an individual wanting to leave home for a community placement.

For some, watching an individual with a disability perform a task with difficulty is sometimes uncomfortable for the parent (and others). However, performing the task is very important, even though the parent could do it in a very short period of time. For example, an individual with cerebral palsy that effects the whole right side more than the left, struggles to put on a coat. He/she quickly learns that he/she must first put the right arm into the coat and bring it around to the left side. Allowing the individual to do it him/herself are steps that helps gain a sense of accomplishment and independence by doing the task. These tasks can increase an individual's self-concept and self-esteem. It is a task that also needs to be accomplished outside the home.

For many, one of the hardest situations for a parent is to prepare their child (now an adult) with a developmental disability to leave home. It is natural for children to leave home. It is natural for parent(s) to have time where they no longer care for children. Parents may feel no one can do a better job than them which can be true. Parents need to assess the individuals needs and the theirs. Parents need to view their child with a disability as an adult, even with their physical and/or cognitive challenges, and their particular level of need to receive support from others for overall care. Parents can remain active in their child's life, but the majority of care will be performed by the individual with support from others. Sons/daughters without disabilities naturally leave home, and yet some parents for whatever reason, prefer their child with a disability to stay home. In New Jersey (NJ), as part of a continuing and nationally evolving, growing movement, there are support services that offer the individual with a developmental disability to stay home with his/her parents. Nevertheless, parents with the individual, should explore all possible living arrangements to ascertain as to what is the best opportunity for growth for the individual as well as what he/she wants.

Legislation has promulgated that people with disabilities must be included in all aspects of community living. In many cases, the individuals have more opportunities than when they were in their family homes. They have to make decisions and are responsible for the outcomes of their decisions. It also needs to be noted that the individual with disabilities does not have to be

in the same environment for their entire life. Like everyone else, desires/needs occur throughout the lifecycle so the individual may need to change their residence or place of work later on.

The future lies in the hands of parents/guardians with collaboration from professionals and of course the involvement of the individual with the developmental disability. It lies in how the child/adult with a developmental disability has opportunities to live and work in the community as independently as possible with knowledge of his/her rights and responsibilities: “my rights”, “your rights,” and “our rights.”

### **B.J.: Some thoughts on Employment and Autonomy**

Jobs help define us and our dignity as citizens in the community. This is as true for you and me as it is for individuals among us with developmental disabilities. For an individual with a developmental disability to say “yes” to the question “Are you working?” and name of the place “Where do you work?” can provide a level of self-worth and feeling of integration within community life. The individual is a contributor to the common good and upholds, to his/her ability, service to his/her fellow man.

As I reflected on over 41 years in New Jersey (NJ) state service providing services to people with developmental disabilities, the one guiding principal for me had been that “all work is honorable.” Although I had not initially known that individuals with developmental disabilities as having the “legal” right to work and to receive payment for their labors, I did know that our programs offered individuals opportunities for work and pay as well as dignity, respect, skills acquisition and pride through the work programs. This was also true for individuals who lived and worked in the now closing NJ state developmental centers and in the partnering of state and private sector work programs in the community. Most of all, I have seen time and time again that individuals find a better and happier adjustment when performing work that suits their interests and abilities.

I think about the parents/guardians of individuals with developmental disabilities who I have known through the years. One of the most important things that they did was to expect that the individual with a developmental disability would work and have their own career. Within a family, siblings may go to college, trade school, or to the military. The siblings may work part-time or full-time. They probably date and marry. The life stage events can be emotionally difficult for the sibling with a disability when he/she compares himself/herself to the others. Was the individual with a disability being consigned to an eternal childhood? What was expected? Were the expectations found worthy? The sibling with the disability should have his/her own career plan and jobs as well as other aspirations. These career plans should be considered and celebrated as those are for the other siblings. Which brings me back to my first point: all work is honorable. Success is not measured by size of paycheck or title. I have seen individuals blossom as they gain confidence and a sense of autonomy through work experiences. For some, the work experience may be in a medical day program where the work is holding the napkins to be distributed at lunch or snack time. For someone in an adult training center, learning about the community becomes an important task to be mastered (i.e., knowing where the mail man works and where the mail is processed as well as expectation of behavior in

the work setting). For the older student or adult, support and direction from a job coach provides encouragement to stay on task and to follow the break schedule. For others with certain skills, the supervised, daily work setting may provide opportunities to use skill sets as well as to learn to work together with peers and a manager to meet work goals. Some will have a career path to competitive employment secured by the individual, their family or with the help of vocational rehabilitation services. There can be many career paths and opportunities.

Over the years, adult day programs for individuals with disabilities have become more work-oriented and community-centered. The more traditional programs may include contract work (i.e., packaging items) or food service assistance (i.e., setting tables, clearing tables), among other jobs. Some agencies have agreements with stores which enables job-specific task training at the agency setting to be followed by placement in the partnering stores. Some individuals will need 1-to-1 assistance in learning and carrying out a job. Others may require less supervision and follow-up. Some people may really enjoy working on a “crew” with peers to work in the community (i.e., landscaping or office clean-up). Individuals with challenging behavioral expression tend to find a more peaceful, cooperative life when performing the work tasks that were tailored for them in the community. It may be helpful for parents and individuals to visit the variety of work sites that may be possible as future work training and employment placements.

Adult training centers and supportive work centers should offer self-advocacy programs if they already do not have one. Here individuals can participate in acquiring the skills of speaking for one’s self as well as listening to others. Self-advocacy also helps individuals to understand their rights and responsibilities within a work setting.

In the end, what is work? Work is a variety of tasks to be undertaken as well as an independence (autonomy) booster. Work opens up the avenue for hopes to be explored and met. There are a variety of tasks for individuals with developmental disabilities to accomplish which, in the long run, contribute to the community at large. Some tasks may seem small and insignificant, but to the individual, it is his/her task to be completed and to be recognized. It is his/her career and his/her right to work and get paid for the work.

## **CONCLUSION**

As the discussions above affirm, the individual with a developmental disability must be part of, included in, and acknowledged to have the right to have a voice in all aspects of his/her life. Teaching about human rights at home, in school and in the work place fosters decision making, autonomy and self esteem. This process begins in childhood and continues through the life span. The individual with a developmental disability is a person. He or she is neither a diagnosis nor a disability. The individual is a son/daughter, brother/sister, uncle/aunt, friend and employee. Each individual is a person to be respected. Our culture holds the values of individualism, self-reliance, and cooperation. Implementing human rights education and training is essential to upholding these values.

## **Part II**

### **Section E**

#### **The Ethical Guardian**

**Peggy Dervitz, M.S.W.**

A Guardian is someone who is legally authorized to make decisions on behalf of another person—an awesome responsibility. But a good guardian, an ethical guardian, is more than that. An ethical guardian is a decision maker, a teacher, a counselor, an advocate and a facilitator of rights. The ethical guardian is constantly trying to achieve the proper balance between maximizing individual autonomy and protecting the individual from harm.

We live in a culture that has at its core a fundamental belief in individual autonomy. Every day, we read in newspapers and magazines how the social order is changing—how future generations will have to take ever-increasing responsibility for their career development, financial future and retirement planning, that government agencies will provide fewer guaranteed protections that they had in the past. In fact, the buzzword for the 1990s, as we “cross the bridge” to the 21<sup>st</sup> century is personal responsibility. How do we prepare all of our citizens, including those with disabilities, for a world in which more will be expected of them?

The journey toward independence for people with developmental disabilities has been a slow but steady one with gains made in education, training and habilitation. Helping people achieve a greater sense of personal freedom is the next step in that journey. The ethical guardian can and should take the lead by recognizing and creating opportunities that maximize the ward’s self-determination and self-direction.

In the name of benevolence, we developed systems of care for those less fortunate in which “we” know what is best for “them,” thus creating a culture of dominance and dependence that we are still struggling to overcome. Often we don’t realize that such a system dehumanizes both the care receiver by locking each into well-defined roles—the powerful and the powerless. We think that people with developmental disabilities are more independent because they live in the community and have mastered more habilitative skills, but so long as “we” continue to define “their” reality, we delude ourselves about what independence really means. The ethical guardian works in partnership with the ward paying

careful attention to his expressed needs, desires and preferences and advocates for opportunities in which he can express his autonomy and will.

Limited guardianship is a legal instrument in which the powers of the guardian are limited to only those areas that are absolutely necessary to protect the ward from harm. All other areas of decision making are retained by the individual. New Jersey has just begun its efforts at defining and implementing limited guardianship. However, whether guardianship is plenary or limited, the ethical guardian always practices limited guardianship.

The case of Eva illustrates how a limited guardianship helped Eva, now 34 years old, spent fourteen years in a developmental center before moving to a group home eight years ago. Since Eva was 18 years old, the state has been her guardian. Recently, Eva was reevaluated regarding her continued need for a guardian. It was concluded that Eva could benefit from a limited guardianship. The consent judgment granted the guardian authority to make decisions regarding serious medical problems and type of residential placement.

Eva retained authority to make decisions regarding vocational training as well as choices pertaining to her daily life, such as daily schedule, leisure-time activities, friends, food and clothing. Although the staff at the group home never denied Eva decision making in these three areas, they never encouraged her either, and Eva did not realize that she was allowed to think for herself and decide for herself in these domains. Instead, Eva would express her will by refusing to perform her daily routines if she doesn't want to, but she chooses to. It's her decision. As a consequence, power struggles are now a thing of the past. Eva is no longer considered "noncompliant" and staff do not have to "manage" her. Limited guardianship provided validation of Eva's autonomy. She feels a sense of freedom and free will that she never experienced before, and the staff her greater respect. The culture of dominance and dependence has been transformed to one in which Eva and the staff learn from each other and create a new and different reality for both. Eva teaches us that she suffered by feeling alienated from her own decision making. Eva wanted to act responsibly and did once her autonomy was affirmed.

For each of us, life's journey is to become more fully human—to define our own potential and to work toward making it a reality. That journey is no different for a person with a developmental disability. The job of the ethical guardian is to help the ward create his own reality, one in which opportunities for expression of freedom are maximized.





## **PART III**

### **Overview: Surrogate Decision Making (Guardianship)**

A. Judicial and Non-Judicial Surrogate Decision Making

B. Ethics and Guardianships

C. Health Care Decision Making: Statutes and Cases



## **Part III**

### **Overview: Surrogate Decision Making (Guardianship)**

The three sections in Part IV provide an overview of surrogate decision making to include the guardianship process, guardianship law, and case examples of health-care decision making.

The first section introduces family members, staff members, and non-lawyers to guardianship law and court procedures.

The second and third sections provide more technical information about the basic guardianship law in New Jersey as well as representative health-care decision making cases.

A. Non-Judicial and Judicial Decision Making

B. Ethics and Guardianships

C. Health Care Decision-Making: Statutes and Cases



## Part III

### Section A

## Non-Judicial and Judicial Surrogate Decision Making

Mary Ann Olsen, Esq.; Joan Kakascik, Ed.D.

(see [www.ganji.org](http://www.ganji.org) to download of pamphlet series on Surrogate Decision Making)

**GUARDIANSHIP** is a legal relationship in which one person is authorized to make decisions on behalf of another person. The court determines a person's abilities and incapacities and considers the individual's need for appointment of a guardian. An individual may be determined to be incapacitated if he or she is impaired by reason of mental illness or mental deficiency to the extent that he or she lacks sufficient capacity to govern himself or herself and manage his or her affairs. An individual under guardianship does not lose human rights.

**CONSIDERING GUARDIANSHIP** At age 18, each individual is presumed to have capacity and is able to assume the legal responsibilities of self-determination. For adults age 18 and over who may be incapable of making decisions in their own best interests, a petitioner (i.e., family member, friend, designated government agency) may seek to have the vulnerable individual declared incapacitated in a court of law. The court appoints a guardian (limited or general) if the person is judged to be incapacitated.

**GUARDIANSHIP STATUTES** New Jersey Statutes Annotated (N.J.S.A.) Title 3B states the duties and responsibilities of the Court and of the guardian. The provisions of the Statute are summarized in the Section B of Part III titled "Ethics and Guardianship."

### **PURSUING GUARDIANSHIP**

1. **Pro Se Filing** are "do-it-yourself" filings for guardianship. Documents for pro se filings are available from [www.judiciary.state.nj.us/prose/10558pdf](http://www.judiciary.state.nj.us/prose/10558pdf) Agencies such as SCARC Guardianship Services, Inc. at [www.scarcguardianship.org](http://www.scarcguardianship.org) and Plan NJ at [www.plannj.org](http://www.plannj.org) provide assistance with Pro Se filings at minimum to no cost. The
2. **Licensed Elder and Disability Law Attorney** Attorneys who specialize in Elder and Disabilities Law are familiar with matters relating to guardianship and estate planning. Contact the New Jersey Bar Association for names of attorney in your area: [www.njsba.com](http://www.njsba.com) The Guardianship Association of New Jersey, Inc. offers a list of member lawyers and other professionals: [www.ganji.org](http://www.ganji.org) In all guardianship proceedings, the court will appoint an attorney to represent the alleged incapacity person.
3. **Costs** Legal fees vary depending on services, complexity, and issues such as financial planning. There is a court fee for filing the action. A typical court fee of \$200, made payable to the County Surrogate, may be waived if the petitioner explains that he or she is at poverty level. Medical and psychological assessments usually incur fees. The court may or may not order fees for the attorney representing the alleged incapacitated person.

#### 4. **Court Procedures:**

- a. A **Complaint** is filed with the court through the County Surrogate's Office for a determination of incapacity and for the appointment of a guardian of the alleged incapacitated individual. The complaint must include reports and certifications affidavits of 2 physicians or 1 physician and 1 licensed clinical psychologist.
- b. **Assessments** are prepared by two physician(s) or a physician and a NJ licensed clinical psychologist to address decision-making abilities of the alleged incapacitated person. The assessments state the extent to which the alleged incapacitated person retains sufficient capacity to retain the right to manage specific areas, such as, legal, medical, financial, residential, educational and vocational decisions. Certifications based on the examination of the individual must occur within 30 days of the filing of the complaint.
- c. **Judgment** states the court's decisions about capacity and need and limits of guardianship services.
- d. The appointed guardian prepares an **Annual report to the Court** summarizing the ward's personal and financial status. See [www.njcourtsonline.com](http://www.njcourtsonline.com) "Legal Forms."

**PROTECTING BENEFITS AND ESTATE MATTERS** Consult an elder care and disabilities law attorney and a licensed financial advisor or certified public accountant (CPA) for estate planning. A person with developmental disabilities may require a Special Needs Trust to protect public benefits.

**CHANGE OF GUARDIAN AND RESTORATION TO CAPACITY** The court has the authority to change who has been appointed guardian. New Jersey Court Rule 4:87 and N.J.S.A. 3B:12-28 provide a procedure for restoring a person's rights where a determination is made that an individual has regained mental capacity. On the commencement of a separate summary action the ward has the right to challenge the guardian in a court of law, usually with legal representation. The court determines if the ward may change the guardian, be restored to limited capacity, or reverse the guardianship.

### **NON-JUDICIAL DECISION-MAKING**

**NON-JUDICIAL DOCUMENTS** do not need to be ordered by a judge. If an individual can understand what he or she is signing, these documents may prevent the necessity of court action for guardianship. See Part I, Section E of this handbook for basic information about Durable and Medical Powers of Attorney in a question and answer format.

- a. **Durable General Power of Attorney** may be limited or general and allows an individual to choose an agent to make financial and legal decisions as well as to access records.

- b. **Durable Medical Power of Attorney** may be limited or general and allows an individual to choose an agent to make medical decisions and to access records.
- c. **Advance Directive** (informally “living will;” usually in the same document as the Medical Power of Attorney) states the medical/mental health treatments a person would accept or refuse if or when unable to communicate choice.

## **JUDICIAL DECISION MAKING**

**JUDICIAL DOCUMENTS** must be ordered by a judge.

- a. **Conservatorship** is appointment of a person by a court to manage the financial responsibilities of an individual who requires assistance, is not mentally incapacitated, and consents to the conservatorship.
- b. **Limited Guardianship** recognizes that an individual may need assistance in only some areas. The guardian’s limitations are specified in the Court Order.
- c. **General Guardianship** applies to an individual who does not have the cognitive capacity to make decisions. The guardian is authorized to make legal, financial, personal, and medical decisions for the individual deemed by the judge to have mental incapacity.

## **PART III**

### **Section B**

## **Ethics and Guardianships**

**Sharon Rivenson Mark, Esq.**

### **INTRODUCTION**

Guardianship practice in New Jersey carries with it a responsibility to care for and to protect those individuals who cannot do so for themselves. The incapacitated individual may be indigent or may have substantial assets. Various ethical standards have been propounded in order to guide a guardian and those advising the guardian as to the proper management of the incapacitated person and the incapacitated person's assets.

The statutory duties and responsibilities of a financial guardian is codified in New Jersey law, in N.J.S.A. 3B:12-1, *et seq.*

The National Guardianship Association [NGA] has also published a manual entitled "Ethics and Standards for Guardians." The manual includes a model code that addresses the duties and responsibilities of a guardian for the ward's assets. The National Guardianship Association [NGA] is an organization dedicated to improving the quality of life for people in need of guardianship and other protective services. The NGA provides for the exchange of ideas, education, and communication between groups and individuals interested in providing or furthering guardianship services or alternative protective services to individuals in need of such services. The National Guardianship Association's website is <http://www.guardianship.org>

The New Jersey affiliate of the National Guardianship Association is the Guardianship Association of New Jersey, Inc. [GANJI]. The GANJI website is [www.ganji.org](http://www.ganji.org)

A "Manual for Guardians" was prepared by the Supreme Court Judiciary-Surrogates Liaison Committee and sets forth the responsibilities of a guardian of the property of an incapacitated person. The "Manual for Guardians" is available from the County Surrogates.

Adherence to these statutory rules and ethical standards will ensure the protection of the ward and the proper performance of a guardian's duties and responsibilities for the safekeeping and handling of the ward's assets.

### **GENERAL STATUTORY DUTIES AND RESPONSIBILITIES OF THE COURT AND GUARDIAN**



**N.J.S.A. 3B:12-1.1** details the power of the court to order a protective arrangement for the ward.

If it is established that a minor, an incapacitated person or an alleged incapacitated person or a person not yet in being has property or an interest therein which may be wasted or dissipated or that a basis exists for affecting the property or interest and affairs of a minor, an incapacitated person or an alleged incapacitated person or a person not yet in being or that funds are needed for the support, care and welfare of the minor, incapacitated person or alleged incapacitated person or those entitled to be supported by him, the court may, subject to the appointment of a guardian ad litem and upon notice to the guardian ad litem, without appointing a guardian of the estate, authorize, direct or ratify any single or more than one transaction necessary or desirable to achieve any security, service, care or protective arrangement meeting the foreseeable needs of the minor, incapacitated person or alleged incapacitated person or those dependent on him.

**N.J.S.A. 3B:12-36** details the authority of the court with respect to a ward's person and estate. If a guardian has been appointed as to the person of a minor or an incapacitated person, the court shall have the authority over the ward's person and all matters relating thereto; and if a guardian has been appointed to the estate of a minor or an incapacitated person, the court shall have authority over the ward's estate, and all matters relating thereto.

**N.J.S.A. 3B: 12-37** provides that the court may, at the time of appointment or later, limit the powers conferred upon the guardian, or previously conferred by the court, and may at any time relieve the guardian of any limitation. If the court limits any power conferred on the guardian, the limitation shall be so stated in certificates of letters of guardianship thereafter issued.

**N.J.S.A. 3B: 12-38** provides for title to a ward's property being vested in the guardian as trustee. The appointment of a guardian of the estate of a minor or an incapacitated person vests in his title as trustee to all property of his ward, presently held or thereafter acquired, including title to any property theretofore held for the ward by attorneys in fact. The appointment of a guardian is not a transfer or alienation within the meaning of general provisions of any Federal or State statute or regulation, insurance policy, pension plan, contract, will or trust instrument, imposing restrictions upon or penalties for transfer or alienation by the ward of his rights or interest, but this section does not restrict the ability of persons to make specific provision by contract or dispositive instrument relating to a guardian.

**N.J.S.A. 3B: 12-39** details delegation of a parent's or a guardian's powers regarding the ward's care, custody or property, and the limitations of that delegation. A parent, other than where custody of a minor has been awarded by a court of competent jurisdiction, with the consent of the other parent, if the latter is living and not an incapacitated person or a guardian of the person of a minor or an incapacitated person, by a properly executed power of attorney, may delegate to another person, for a period not exceeding six months, any of his powers regarding care, custody, or property of the minor child or ward, except his power to consent to marriage or adoption of a minor ward.

**N.J.S.A. 3B: 12-40** provides that if another person has been appointed guardian of the estate, all of the ward's estate received by the guardian of the person in excess of those funds expended to meet current expenses for support, care and education of the ward must be paid to the guardian of the estate, and the guardian of the person must account to the guardian of the estate for funds expended.

**N.J.S.A. 3B: 12-41** provides for the guardian of a ward's person entitlement to reimbursement for expenses and provides for payment to third persons. If another person has been appointed guardian of the ward's estate, the guardian of the ward's person is entitled to receive reasonable reimbursement and fees for his services and for room and board furnished to the ward, provided the same has been agreed upon between the guardian of the person and the guardian of the estate; and provided, further, that the amounts agreed upon are reasonable under the circumstances. The guardian of the person may request the guardian of the estate to expend the ward's estate by payment to third parties or institutions for the ward's care and maintenance.

**N.J.S.A. 3B: 12-42** provides that a guardian shall report at time intervals as ordered by the court, unless otherwise waived by the court, the condition of the ward and the condition of the ward's estate which has been subject to the guardian's possession or control as ordered by the court.

- a. A report of the guardian of the person shall state or contain:
  - (1) the current mental, physical and social condition of the ward;
  - (2) the living arrangements for all addresses of the ward during the reporting period;
  - (3) the medical, educational, vocational and other services provided to the ward and the guardian's opinions as to the adequacy of the ward's care;
  - (4) a summary of the guardian's visits with the ward and activities on the ward's behalf and the extent to which the ward has participated in decision-making;
  - (5) if the ward is institutionalized, whether or not the guardian considers the current plan for care, treatment or habilitation to be in the ward's best interest;
  - (6) plans for future care; and
  - (7) a recommendation as to the need for continued guardianship and any recommended changes in the scope of the of the guardianship.
- b. The court may appoint an individual to review a report, interview the ward or the guardian and make any other investigation the court directs.
- c. Agencies authorized to act pursuant to N.J.S.A. 52-27G-20 *et seq.*, N.J.S.A. 30:6D-23, *et seq.*, and N.J.S.A. 30:4-165.7 *et seq.*, and public officials appointed as limited

guardians of the person for medical purposes for individuals in psychiatric facilities listed in N.J.S.A. 30:1-7 shall be exempt from this section.

A guardian of the estate of a minor or incapacitated person may expend or distribute so much or all of the income or principal of his ward for the support, maintenance, education, general use and benefit of the ward and his dependents, in the manner, at the time or times and to the extent that the guardian, in an exercise of a reasonable discretion, deems suitable and proper, taking into account the requirements of the "Prudent Investor Act," N.J.S.A. 3B:20-11.1 et seq., with or without court order, with due regard to the duty and ability of any person to support or provide for the ward if the ward is a minor, and without due regard to the duty and ability of any person to support or provide for the ward if the ward is an incapacitated person, and with or without regard to any other funds, income or property which may be available for that purpose. [See N.J.S.A. 3B:12-43]

In making expenditures under N.J.S.A. 3B:12-43, the guardian of the estate of a minor or incapacitated person shall consider recommendations relating to the appropriate standard of support, education and benefit for the ward made by a parent and guardian of the person, if any. The guardian of the estate may not be surcharged for sums paid to persons or organizations actually furnishing support, education or care to the ward pursuant to the recommendations of a parent or guardian of the person unless the guardian knows that the parent or the guardian is deriving personal financial benefit therefrom, or unless the recommendations are clearly not in the best interests of the ward. [See N.J.S.A. 3B:12-44]

In making the aforesaid expenditures, N.J.S.A. 3B: 12-45 provides that the guardian of the estate of a minor or incapacitated person must expend or distribute sums reasonably necessary for the support, education, care or benefit of his ward with due regard to:

- a. The size of the ward's estate.
- b. The probable duration of the guardianship and the likelihood that the ward, at some future time, may be fully able to manage his affairs and the estate which has been conserved for him; and
- c. The accustomed standard of living of the ward and members of his household.

The guardian of the estate of a minor or incapacitated person may, pursuant to N.J.S.A. 3B:12-46, expend funds of the ward's estate for the support of persons legally dependent on the ward and others who are members of the ward's household who are unable to support themselves, and who are in need of support. In addition, funds expended by the guardian of the estate of a minor or incapacitated person, may, pursuant to N.J.S.A. 3B: 12-47, be paid by the guardian to any person, including the ward, to reimburse for expenditures which the guardian might have made, or in advance for services to be rendered to the ward when it is reasonable to expect that they will be performed and where advance payments are customary or reasonably necessary under the circumstances.

**N.J.S.A. 3B: 12-48** details the powers conferred upon a guardian. A guardian of the estate of a minor or an incapacitated person has all of the powers conferred upon the guardian by law and the provisions of this chapter except as limited by the judgment. These powers shall specifically include the right to file or defend any litigation on behalf of the ward, including but not limited to, the right to bring an action for divorce or annulment on any grounds authorized by law.

**N.J.S.A. 3B: 12-49** details the powers conferred upon the Court for the benefit of the ward. The court has, for the benefit of the ward, the ward's dependents and members of his household, all the powers over the ward's estate and affairs which he could exercise, if present and not under a disability, except the power to make a will, and may confer those powers upon a guardian of the estate. These powers include, but are not limited to, the power to convey or release the ward's present and contingent and expectant interests in real and personal property, including dower and courtesy and any right of survivorship incident to joint tenancy or tenancy by the entirety, to exercise or release the ward's powers as trustee, personal representative, custodian for minor, guardian, or done of a power of appointment, to enter in contracts, to create revocable or irrevocable trusts of property of the estate which may extend beyond the ward's disability or life, to exercise the ward's options to purchase securities or other property, to exercise the ward's rights to elect options and change beneficiaries under insurance annuity policies and to surrender the policies for their cash value, to exercise the ward's right to an elective share in the estate of the ward's deceased spouse or domestic partner as defined in N.J.S.A. 26:8A-3 to the extent permitted by law and to renounce any interest by testate or intestate succession or by inter vivos transfer and to engage in planning utilizing public assistance consistent with current law.

**N.J.S.A. 3B: 12-6** details the circumstances under which money may be paid or personal property delivered by a guardian. Any person under a duty to pay or deliver money or personal property to a minor may perform this duty, in amounts not exceeding \$5,000.00 per annum, by paying or delivering the money or property to:

- a. The minor, if married;
- b. A parent or parents of the minor;
- c. Any person having the care and custody of the minor with whom the minor resides;
- d. A guardian of the person of the minor; or
- e. A financial institution incident to a deposit in a federally insured savings account in the sole name of the minor and giving written notice of the deposit to the minor.

**N.J.S.A. 3B: 12-11** details the requirements for the content and filing of an affidavit or receipt for payment of money or delivery of property. The persons making payment of money or delivery of personal property as provided in this article shall obtain from the recipient thereof, if other than a financial institution or a married minor, an affidavit signed by the recipient acknowledging receipt of the money or personal property which shall set forth the recipient's status in relation to the minor and the purpose for which the money or personal property will be

used. The affidavit shall be filed in the office of the Surrogate of the county in which the minor resides or if the minor resides outside the State, the county which has jurisdiction of the property.

**N.J.S.A. 3B: 12-26** provides for procedures for an action against an incapacitated person when a guardian is newly appointed. No action shall be brought or maintained against an incapacitated person within one month after appointment of a guardian except by leave of the court wherein the action is to be brought or maintained.

**N.J.S.A. 3B: 12-27** provides for distribution of property of an incapacitated person as intestate property. If an incapacitated person dies intestate or without any will except one which was executed after commencement of proceedings which ultimately resulted in adjudicating a person incapacitated and before a judgment has been entered adjudicating a return to competency, the person's property shall descend and be distributed as in the case of intestacy.

**N.J.S.A. 3B: 12-56** details the powers, rights and duties of a guardian of the person of a ward generally:

- a. A guardian of the person is not legally obligated to provide for the ward from his own funds.
- b. A guardian of the person of a ward is not liable to a third person for acts of the ward solely by reason of the relationship and is not liable for injury to the ward resulting from the wrongful conduct of a third person providing medical or other care, treatment or service for the ward except to the extent that the guardian of the ward failed to exercise reasonable care in choosing the provider.
- c. If a ward has previously executed a valid power of attorney for health care or advance directive under N.J.S.A. 26:2H-53 et seq., or revocation pursuant to N.J.S.A. 26:2H-57, a guardian of the ward shall act consistent with the terms of such document unless revoked or altered by the court.
- d. To the extent specifically ordered by the court for good cause shown, the guardian of the person of the ward may initiate the voluntary admission, as defined in N.J.S.A. 30:4-27.2, of a ward to a State psychiatric facility, as defined in N.J.S.A. 30:4-27.2, or a private psychiatric facility. A ward so admitted shall be entitled to all of the rights of a voluntarily admitted patient, which rights shall be exercised on behalf of the ward by the guardian. The guardian of the ward shall exercise the ward's rights in a matter consistent with the wishes of the ward except to the extent that compliance with those wishes would create a significant risk to the health or safety of the ward. If the wishes of the ward are not ascertainable with reasonable efforts, the guardian of the ward shall exercise the ward's rights in a manner consistent with the best interests of the ward. Notwithstanding the provisions of this section to the contrary, if the ward objects to the initiation of voluntary admission for psychiatric treatment or to the continuation of that voluntary admission, the State's procedures for involuntary commitment pursuant to N.J.S.A. 30:4-27.1 et seq., shall apply. If the ward objects to any other decision of the guardian of the ward pursuant to this section, this objection shall be brought to the attention of the

Superior Court, Chancery Division, Probate Part, which may, in its discretion, appoint an attorney or guardian *ad litem* for the ward, hold a hearing or enter such orders as may be appropriate in the circumstances.

**N.J.S.A. 3B: 12-57 (f) and (g)** further details the powers and duties of a guardian of the person of a ward. In accordance with N.J.S.A. 3B: 12-24.1, a guardian of the person of the ward shall exercise authority over matters relating to the rights and best interests of the ward's personal needs, only to the extent adjudicated by a court of competent jurisdiction. In taking or forbearing from any action affecting the personal needs of a ward, a guardian shall give due regard to the preferences of the ward, if known to the guardian or otherwise ascertainable upon reasonable inquiry. **N.J.S.A. 3B:12(f)** states that, to the extent that it is consistent with the terms of any order by a court of competent jurisdiction, the guardian shall:

- (1) take custody of the ward and establish the ward's place of abode in or outside of this state;
- (2) personally visit the ward or if a public agency which is authorized to act pursuant to N.J.S.A. 30:4 to 165.1 *et seq.*, and N.J.S.A. 30:4-165.7 *et seq.*, or the Office of the Public Guardian pursuant to N.J.S.A. 52:27G-20 *et seq.*, or their representatives which may include a private or public agency, visits the ward not less than once every three months, or as deemed appropriate by the court, and otherwise maintain sufficient contact with the ward to know his capacities, limitations, needs, opportunities and physical and mental health;
- (3) provide for the care, comfort and maintenance and, whenever appropriate, the education and training of the ward;
- (4) subject to the provisions of subsection c. of N.J.S.A. 3B:12-56, give or withhold any consents or approvals that may be necessary to enable the ward to receive medical or other professional care, counsel, treatment or service;
- (5) take reasonable care of the ward's clothing, furniture, vehicles and other personal effects and, where appropriate, sell or dispose of such effects to meet the current needs of the ward;
- (6) institute an action for the appointment of a guardian of the property of the ward, if necessary for the protection of the property;
- (7) develop a plan of supportive services for the needs of the ward and a plan to obtain the supportive services;
- (8) if necessary, institute an action against a person having a duty to support the ward or to pay any sum for the ward's welfare in order to compel the performance of the duties;

- (9) receive money, payable from any source for the current support of the ward, and tangible personal property deliverable to the ward. Any sums so received shall be applied to the ward's current needs for support, health care, education and training in the exercise of the guardian's reasonable discretion, with or without court order, with or without regard to the duty or ability of any person to support or provide for the ward and with or without regard to any other funds, income or property that may be available for that purpose, unless an application is made to the court to establish a supplemental needs trust or other trust arrangement. However, the guardian may not use funds from the ward's estate for room and board, which the guardian, the guardian's spouse or domestic partner as defined in section 3 of N.J.S.A. 26:8A-3, parent or child have furnished the ward, unless agreed to by a guardian of the ward's estate pursuant to N.J.S.A. 3B:12-41, or unless a charge for the service is approved by order of the court made upon notice to at least one of the heirs of the ward, if possible. The guardian shall exercise care to conserve any excess funds for the ward's needs; and
- (10) If necessary, institute an action that could be maintained by the ward, including but not limited to, actions alleging fraud, abuse, undue influence and exploitation.

**N.J.S.A. 3B:12-57 (g)** states that in the exercise of the foregoing powers, the guardian shall encourage the ward to participate with the guardian in the decision-making process to the maximum extent of the ward's ability in order to encourage the ward to act on his own behalf whenever he is able to do so, and to develop or regain higher capacity to make decisions in those areas in which he is in need of guardianship services, to the maximum extent possible.

If the estate is ample to provide for the purposes implicit in the distribution authorized by **N.J.S.A. 3B:12-58**, a guardian for the estate of the incapacitated person may apply to the court for authority to make gifts to charity and other objects as the ward might have been expected to make.

**N.J.S.A. 3B:57-60** states that, upon the death of an incapacitated person, his guardian is required to deliver to the appropriate court for safekeeping any will of the deceased person which may have come into his possession, inform the executor or a beneficiary named therein that he has done so, and retain the estate for delivery to a duly appointed personal representative of the decedent or other persons entitled thereto.

**N.J.S.A. 3B:12-61** states that if within 40 days after the death of an incapacitated person, no other person has been appointed personal representative and no action for an appointment is pending in the Superior Court or Surrogate's Court of the county where the incapacitated person resided at his or her death, the guardian may apply to the Superior Court for authority to exercise the powers and duties of a personal representative so that the guardian may proceed to administer and distribute the decedent's estate without additional or further appointment. Upon application

for an order granting the powers of a personal representative to a guardian, after notice to all persons interested in the incapacitated person's estate either as heirs or devisees and including any person nominated executor in any will of which the applicant is aware, the court may order the conferral of those powers, upon determining that there is no objection, and may enter judgment that the guardian has all of the powers and duties of a personal representative. The making and entry of a judgment under N.J.S.A. 3B:12-61 shall have the effect of an order of appointment of a personal representative, except that the estate in the name of the guardian, after administration, may be distributed to persons entitled to the decedent's estate under his will or the laws of intestacy without prior retransfer to the guardian as personal representative.

In investing the estate, and in selecting assets of the estate for distribution under **N.J.S.A. 3B: 12-62**, in utilizing powers of revocation or withdrawal available for the support of the ward, and other powers exercisable by the guardian or a court, the guardian or the court should take into account any known estate plan of the ward, including his will, any revocable trust of which he is settlor, and any contract, transfer or joint ownership arrangement with provisions for payment or transfer of benefits or interests at his death to another or others which he may have originated. The guardian may examine the will of the ward.

**N.J.S.A. 3B:12-63** states that upon an adjudication that the ward has returned to capacity, the guardian, after the allowance of his final account, is required to pay over and distribute all funds and properties of the former ward.

**N.J.S.A. 3B:12-64** states that the authority and responsibility of a guardian of the person or estate of an incapacitated person terminate upon the death, resignation or removal of the guardian or upon the death of the incapacitated person or upon the entry of a judgment adjudicating the restoration of competency, but termination does not affect the guardian's liability for prior acts, or his obligation to account for funds and assets of his ward. Resignation of a guardian does not terminate the guardianship unless it has been approved by a judgment of the court.

**N.J.S.A. 3B: 17-3** states that a guardian or trustee shall settle his account in the Superior Court at intervals as the court may require. A guardian or trustee may settle his first account within one year after his appointment or as soon thereafter as may be practicable.

**N.J.S.A. 3B: 20-11. 1 et seq.** details the requirement of the Prudent Investment Act in the State of New Jersey for a fiduciary's investment and management of assets held in trust for beneficiaries.

**N.J.S.A. 3B: 12-41** states that for the guardian of a ward's person is entitled to reimbursement for expenses and provides for payments to third persons. If another person has been appointed guardian of the ward's estate, the guardian of the ward's person is entitled to receive reasonable reimbursement and fees for his services and for room and board furnished to the ward, provided the same has been agreed upon between the guardian of the person and the guardian of the estate; and provided, further, that the amounts agreed upon are reasonable under



the circumstances. The guardian of the person may request the guardian of the estate to expend the ward's estate by payment to third persons or institutions for the ward's care and maintenance,

## **MANUAL FOR GUARDIANS AND TRAINING RESOURCES**

The "Manual for Guardians" prepared by the New Jersey Supreme Court Judiciary-Surrogates Liaison Committee sets forth the responsibilities for a guardian of the person and/or of the property of someone who has been found to be incapacitated and unable to handle his or her personal or financial affairs. The "Manual for Guardians" states in the introduction:

'The State of New Jersey does not have a statewide adult guardianship training program. The following list of adult guardianship education and training videos, DVDs and movies from around the country was compiled by the American Bar Association Commission on Law and Aging.'

### **GENERAL GUARDIANSHIP VIDEOS and DVDs**

- a. What Do I Do Now? AARP, 8 minutes, 20 seconds. Actors portray duties involved in being a guardian. Designed as part of a series on practices for DC courts to use in a video kiosk in the clerk's area of the courthouse. Contact Pam Johnson at the National Training Project, AARP Foundation, 601 E Street N.W., Washington DC 20049, phone (202) 434-2118. The video is available for loan only.
- b. Adult Guardianship Mediation: An Introduction. The Center for Social Gerontology, 30 minutes. The video tells a story of a 75 year old man who lives in his own with his daughter and her two children. His son is concerned about his situation and his sister's management of financial matters. After consulting an attorney and realizing that a contested guardianship could destroy the family, the son decides to use mediation to resolve the problem. In the video, segments of the mediation sessions are shown step by step and illustrate the mediation process. This video is directed to attorneys, social workers and other professionals, but also is helpful in raising awareness of the mediation option for families. TCSG states that the video "can be shown by mediators, courts, attorneys, and others to people who are facing conflicts arising out of guardianship petitions and related matters. Although some Michigan terminology is used, the presentation is general enough to be of valuable use in other jurisdictions as well." To order the video see: <http://tcs.org/mediation/video.htm> Price \$50
- c. Guardianship Video Series—"Informing Families, Building Trust." Three videos, approximately five minutes each. These videos focus particularly on people with developmental disabilities. The presentations are dynamic, straight to the point and very clear, with a backdrop of music. The first part "What is Guardianship?" includes various speakers giving the basics. The second part "Guardianship and Alternatives to Guardianship" presents less restrictive options. The third part is about "Guardianship and Individual Rights," and emphasizes ways of enhancing the rights, choices and

participation of individuals under guardianship. The videos were released recently and are broadcast on You-tube at: <http://www.informingfamilies.org/Page.aspx?nid=72>

- d. Living Well: Guardianship and Probate Court. US Health Care Financing Administration (currently the Centers for Medicare and Medicaid Services in DHHS). This older video, featuring discussions on guardianship by nationally recognized experts, is a part of a five video set entitled “Living Well: A Guide to Healthy Aging.” The five-part set is endorsed by the National Institutes of Health and was a winner of the National Mature Media Award in 2000. The guardianship video is not available separately. Contact Mari-Lynn C. Evans, Evening Star Productions, 219 Overwood Road, Akron, OH 44313, phone (330) 867-7443 or e-mail [mlevansesp@aol.com](mailto:mlevansesp@aol.com) The set is available for \$29.00 plus shipping and handling.
- e. The Center for Guardianship Certification (CGC) has as its mission to enhance the quality of guardianship services by providing examination and certification of guardians and fiduciaries. The purpose of the CGC includes:
  - (1.)Developing and administering a credentialing process for guardians and guardianship agencies;
  - (2.)Addressing issues related to renewal, suspension and revocation of credentials for guardians and guardianship agencies;
  - (3.)Maintaining and up-dating rules and regulations for certification of guardians;
  - (4.)Encouraging, supporting, and fostering the work of the National Guardianship Association.
  - (5.)The CGC’s website is: [www.guardianshipcert.org](http://www.guardianshipcert.org)

#### **PROTECTING BENEFITS AND ESTATE MATTERS**

Protection of eligibility for needs-based benefits may be essential to the health and welfare of an individual. It is therefore very important to consult an attorney experienced in elder and disability law and public benefits eligibility for estate planning and for special needs trust information.

For further information about locating an elder and disability law attorney, contact:

New Jersey State Bar Association  
GANJI Professional Listing at [www.ganji.org](http://www.ganji.org)

## **PART III, Section C**

### **HEALTH CARE DECISION-MAKING: STATUTES AND CASES**

Sharon Rivenson-Mark, Esq.

#### **ADVANCE DIRECTIVES FOR HEALTH CARE - STATUTE**

**The New Jersey Advance Directives for Health Care Act** (N.J.S.A. 26:2H-53, et. seq.) states the rules for advance directives for health care in New Jersey. This Act states that a person, called a declarant, may execute a proxy directive designating a competent adult to act as his or her health care representative. It is important to note that an individual who has been adjudicated to be an incapacitated person cannot exercise the right to execute advance directives, pursuant to this advance directive statute. An adult with capacity, including, but not limited to, a declarant's spouse, adult child, parent, or other family member, friend, religious, or spiritual advisor, or other person of the declarant's choosing, may be designated as a health care representative. An operator, administrator or employee of a health care institution in which the declarant is a patient or resident is not permitted to serve as the declarant's health care representative unless the operator, administrator or employee is related to the declarant by blood, marriage, or adoption. This restriction does not apply to a physician, if the physician does not serve as the patient's attending physician and the patient's health care representative at the same time. A declarant may direct the health care representative to consult with specified individuals, including alternate designees, family members, and friends, in the course of the decision making process. A declarant shall state the limitations, if any, to be placed upon the authority of the health care representative including the limitations, if any, which may be applicable if the declarant is pregnant. A declarant may execute an instruction directive stating the declarant's general treatment philosophy and objectives, or the declarant's specific wishes regarding the provision, withholding or withdrawal of any form of health care, including life-sustaining treatment, or both.

#### **HEALTH CARE DECISION MAKING**

Significant case law has evolved surrounding health care and medical decision-making.

In **Matter of Roche**, 296 N.J. Super. 583 (Ch. Div. 1996), the Court emphasized that an incapacitated person's right to self-determination must be preserved to the greatest degree possible. In making decision on behalf of an incapacitated person as to whether to withdraw life-sustaining treatment, if some trustworthy evidence of the incapacitated person's intent can be found, but not enough to fully determine subjective intent, such evidence can be taken into account in determining the incapacitated person's best interests. A limited-objective test should be used, pursuant to which life sustaining treatment may be withdrawn if there is some trustworthy evidence that the patient would have refused treatment, and the decision maker is satisfied that it is clear that the burdens of patient's continued life with treatment outweigh the benefits of that life for him or her.

In **Matter of Quinlan**, 137 N.J. Super. 227 (Ch. Div. 1975), decision modified and remanded, 70 N.J. 10 (1976), a father sought to be appointed guardian of person and property of

his 21-year-old daughter who was in a persistent vegetative state and sought the express power of authorizing the discontinuance of all extraordinary procedures for sustaining daughter's vital processes. The court denied authorization for termination of the life-supporting apparatus and withheld letters of guardianship over the incapacitated person. The Supreme Court held that a decision by the daughter to permit a non-cognitive, vegetative existence to terminate by natural forces was a valuable incident of her right to privacy that could be asserted on her behalf by her guardian. The Supreme Court further held that the state of the pertinent medical standards and practices which guided the attending physicians who held the opinion that removal from the respirator would not conform to medical practices, standards, and traditions was not such as would justify the Court in deeming itself bound or controlled thereby in responding to the case for declaratory relief. The Supreme Court further held that upon the concurrence of guardian and family, should the attending physicians conclude there was no reasonable possibility of the daughter's ever emerging from her comatose condition to a cognitive, sapient state and that the life-support apparatus should be discontinued, physicians should consult with the hospital ethics committee and if the committee should agree with the physicians' prognosis, the life-support systems may be withdrawn and said action shall be without any civil or criminal liability therefore, on the part of any participant, whether guardian, physician, hospital, or others.

In **Matter of Grady** 85 N.J. 235 (1981) the parents of a noninstitutionalized daughter seriously afflicted with Down's Syndrome sought the appointment of a special guardian authorized to consent to sterilization of their daughter by tubal ligation. The supreme Court held that: (1) the right to be sterilized is included in privacy rights and protected by the Federal and State Constitutions; (2) an appropriate court must make a final determination as to whether consent to sterilization should be given on behalf of an incapacitated individual; (3) the provision within the "Bill of Rights for the Mentally Retarded" did not apply; (4) the public school, at which the daughter attended special education class, was not a "facility for the developmentally disabled" within the meaning of another statute; (5) the Chancery Division has inherent power under its parens patriae jurisdiction to decide whether to authorize sterilization for incapacitated persons; (6) if an application is made for authorization to sterilize an incapacitated person, the court should appoint an independent guardian ad litem as soon as possible; and (7) the trial court must not authorize sterilization of an incompetent unless persuaded by clear and convincing proof that sterilization is in such person's best interests.

In **Matter of Conroy**, 96 N.J. 321 (1985) the guardian of an incapacitated nursing home patient sought permission to remove nasogastric feeding tube, the primary conduit for nutrients, from the patient, an 84-year-old bedridden woman with serious and irreversible physical and mental impairments and a limited life expectancy. The application was opposed by the patient's guardian ad litem. The Supreme Court held that: (1) the death of the patient did not moot the case because it presented a substantial issue capable of repetition while evading review; (2) a competent adult generally has the right to refuse medical treatment and does not lose that right upon incompetency; (3) a surrogate decision maker for an incapacitated person may direct the withdrawal or withholding of life-sustaining treatment under certain circumstances if certain procedures are followed; (4) notification must be given to the Office of the Ombudsman for the Institutionalized Elderly; (5) there must be a determination that the incapacitated nursing home patient is incompetent to make the decision in question, and (6) the evidence in the instant case did not meet any of the three tests for termination of life sustaining treatment.

In **Matter of Farrell**, 212 N.J. Super. 294 (Ch. Div. 1986), judgment affirmed, 108 N.J. 335 (1987) a husband applied to be appointed special medical guardian for his wife, who had amyotrophic lateral sclerosis, including a request for express permission to remove a respirator. The Supreme Court held that: (1) the Supreme Court would render its decision on the merits although the wife had died while still connected to the respirator; (2) the right of the wife, who was a competent, terminally ill adult patient living at home, to withdraw the life-sustaining respirator outweighed the State's interests in preserving life, preventing suicide, safeguarding the integrity of the medical profession, and protecting innocent third parties; (3) the procedures that would be applicable when competent patients requested discontinuance of life-sustaining medical treatment were set forth; and (4) no civil or criminal liability would be incurred by any person who, in good-faith reliance on procedures established by the State Supreme Court, withdrew life-sustaining treatment at the request of an informed and competent patient who had undergone a required independent medical examination.

In **Matter of Jobes**, 210 N.J. Super. 543 (Ch. Div. 1986) judgment affirmed as modified, 108 N.J. 394 (1987), a husband brought suit seeking removal of a life-sustaining food nutrition system from his comatose wife. The nursing home moved for the appointment of a "life advocate." The Supreme Court held that: (1) the evidence supporting a finding that the patient was in an irreversible vegetative state; (2) the right of a patient in an irreversibly vegetative state to determine whether to refuse life-sustaining medical treatment may be exercised by the patient's family or close friend; (3) a surrogate decision maker who declines life-sustaining medical treatment must secure statements from at least two independent physicians knowledgeable in neurology that the patient is in a persistent vegetative state and that there is no reasonable possibility that the patient will ever recover to a cognitive, sapient state; and (4) the nursing home could not refuse to participate in the withdrawal of the system by keeping the patient connected to the system until she was transferred out of the facility.

In **Matter of Peter by Johanning**, 108 N.J. 365 (1987) a surrogate who the patient had authorized, by power of attorney, to make medical decisions on her behalf, filed a complaint seeking his appointment as guardian. After appointment, the surrogate requested that the Ombudsman for the Institutionalized Elderly approve the removal of the patient's nasogastric tube. The Ombudsman decided that a previous court ruling prevented him from consenting to removal of the tube. The Supreme Court held that: (1) the Conroy subjective test, under which life-sustaining treatment may be withdrawn or withheld whenever there is clear and convincing proof that if the patient were competent, he or she would decline treatment, is applicable in every surrogate-refusal-of-treatment case, regardless of the patient's medical condition or life expectancy and (2) the instrument which the patient executed shortly before she became incompetent, the surrogate's explanation that the patient had directed him to refuse life-sustaining treatment on her behalf, and nine reliable hearsay accounts of the patient's disinclination for type of the treatment that the surrogate was seeking to discontinue, established clearly and convincingly that the patient would, if competent, choose to withdraw the nasogastric tube which was sustaining her.

In **Matter of Moorhouse**, 250 N.J. Sup. 307 (App. Div. 1991) an application for emergent relief was brought after a chancery Division judge authorized removal of life support

from a resident of a state hospital who had been labeled “retarded” since birth. The Appellate Division, stayed the authorization to terminate life support and held that (1) the trial judge’s determination that clear and convincing evidence supported removal of the life support was not supported by sufficient credible evidence in the record and (2) the judge’s refusal to grant a stay pending emergent appeal and his failure to promptly issue an order memorializing his oral allowance of removal of the life support was improper.

In **Matter of Hughes**, 259 N.J. Super. 193 (App. Div. 1992) a Chancery Division judge entered judgment appointing a hospital administrator as guardian of a surgical patient, for the purpose of consenting to blood transfusions. The Superior Court, Appellate Division, held that the trial court did not commit error in making the appointment even though the patient had given written instructions prior to the operation that she was not to receive blood.

In **Matter of Schiller**, 148 N.J. Super. 168 (Ch. Div. 1977), a hospital filed a complaint asking that a special guardian be appointed to consent to the amputation of the leg of a patient who was alleged to be mentally incapable of giving consent to the operation. The Superior Court, Chancery Division, held that, in view of the testimony of a psychiatrist that the patient with a gangrenous foot was incapable of understanding his condition, that the amputation was a lifesaving technique, and that the patient was incapable of either consenting to or refusing to consent to amputation, the cousin of the patient would be appointed special guardian with authority to consent to the lifesaving medical treatment.

In **Matter of J.M.**, 2010 WL 3433050 (N.J. Super. Ct. Div. 2010), the Court in an unpublished decision, addressed a woman’s refusal of dialysis on religious grounds. The opinion dealt with determining a patient’s capacity to refuse a specific medical procedure, especially when she had capacity to make other medical decisions. The patient declined to appeal the decision. J.M. was determined to have lacked the capacity to decide, requiring the appointment of a special medical guardian. J.M. had consented to other medical procedures and executed a resuscitation order. J.M. was a single mother from Jamaica with a 17-year-old son and an eighth grade education. She refused dialysis for a variety of reasons, including fear of the dialysis machine and the anticipated loss of income that would result from time spent in dialysis several days a week. J.M.’s main objection was mainly religious. The Valley Hospital sought the appointment of a special medical guardian to consent to life-saving dialysis treatment. The court found by clear and convincing evidence that J.M. lacked capacity to refuse dialysis treatment because she demonstrated a lack of understanding of the high risk of death without dialysis and through her other medical choices had demonstrated an unequivocal desire to live. The court appointed a temporary special medical guardian.

In **Betancourt v. Trinitas Hospital**, 415 N.J. Super. 301 (App. Div. 2010) the daughter of a patient in a persistent vegetative state filed an action to enjoin a hospital from implementing a Do Not Resuscitate (DNR) order. Despite dismissing the appeal, the court discussed key issues in health care and end-of-life decision-making. The court recognized that determining what medical treatment should be provided to incapacitated or dying patients presents a matter of substantial public importance and that such matters are capable of evading judicial review. The court noted that court decisions have recognized the public interest in decisions regarding the termination of life-sustaining medical treatments.

## **OTHER SIGNIFICANT GUARDIANSHIP CASES**

In **Matter of M.R.**, 135 N.J. 155 (1994), the N.J. Supreme Court held that ordinarily, an attorney should abide by the client's decisions concerning the objectives of representation and act with reasonable diligence in representing and advocating on behalf of the client. In the context of a guardianship case, this requires that the court-appointed attorney must try to communicate with the client, the alleged incapacitated person, and present the alleged incapacitated person's opinions and preferences to the court, provided the opinions or preferences are not patently absurd or pose an undue risk of harm. Even if incapacity is uncontested, the alleged incapacitated person may want to contest other issues. Frequently an incapacitated person has the ability to understand matters affecting his or her own well being. These alleged incapacitated persons may express personal opinions and preferences, for example, about the identity of the proposed guardian or where they want to live. The task of the court-appointed attorney is to identify these opinions and preferences and convey them to the court. However, if a conflict between the preferences of the alleged incapacitated person and his or her best interests arise, the court-appointed attorney may wish to inform the court of the conflict and the possible need that a guardian *ad litem* be appointed.

In **Village Apartments of Cherry Hill, N.J. v. Novack**, 383 N.J. Super. 574 (App. Div. 2006), the Court held that in the absence of the tenant's guardian, lacked personal jurisdiction, who was incapacitated, to adjudicate summary dispossess action brought by landlord alleging that the tenant willfully, or by reason of gross negligence, caused or allowed destruction, damage or injury to premises; guardian was neither named as a party nor appeared at trial, guardian *ad litem* was not appointed when designated guardian did not appear, and although tenant was represented by attorney, attorney representation was insufficient.

In **Berberian v. Lynn**, 175 N.J. 549 (2003) the New Jersey Supreme Court ruled that a violent Alzheimer's patient did not owe a duty of care to a nurse whom the patient injured while he was in the nurse's care. The issue in this appeal was whether a mentally disabled patient, who does not have the capacity to control his conduct, owed his or her caregiver a duty of care. The New Jersey Supreme Court held that mentally incapacitated patients owe no duty of care to protect paid caregivers from injuries suffered while caring for those patients.

In **Matter of the Estate of Ann F. McNierney**, Docket No. BER-P-89-10 (Ch. Div. Bergen County), a Chancery Division Judge held, in an unpublished opinion, that a plenary guardian can control the visitation rights of their ward.

In **Matter of Queiro**, 374 N.J. Super. 299 (App. Div. 2005), family members brought an action seeking a judgment recognizing that mentally incapacitated adult continued to be an individual in need of a guardian over her person and confirming their appointment as testamentary guardians. The father filed a counterclaim seeking guardianship. The court held that a two-step analysis for situations involving a custody dispute between a third party and a parent was inapplicable in proceeding in which family members sought a judgment confirming their appointment as testamentary guardians of mentally incapacitated adult. The analysis was applied in situations involving a minor child, and these proceedings did not involve guardianship over a

minor child, but rather involved guardianship over an incapacitated adult.

In **Matter of Macak**, 377 N.J.Super. 167 (App. Div. 2005), an individual who had been adjudicated to be incapacitated filed a complaint seeking to re-open and set aside guardianship, restore him to legal capacity, and appoint a conservator for him. The court held that: (1) initial guardianship proceeding, in which a “settlement” was entered into by ward's attorney on ward's behalf, was fraught with error, mandating remand on issue of ward's capacity; (2) “settlement” failed to comply with procedures in place that were necessary to ensure ward's protection with respect to gifts that guardian was authorized to make to ward's daughter; (3) Order permitting guardian to serve without bond failed to protect ward's financial interests; and (4) ward was entitled to evidentiary hearing on his application to re-open and set aside guardianship. On remand, the court This court now found that Walter J. Macak is incapacitated based upon the clear and convincing weight of the evidence, that the mental and physical condition of Mr. Mack is such that he is unable to care for himself and manage his affairs, and the possibility of restoration to competency is virtually non-existent. A guardianship of the person and property of Walter J. Macak was determined to be appropriate and required. However, the guardianship was required to be defined and “limited” as required by the court's opinion, and included consideration of Mr. Macak's wishes and preferences, but not to be controlled by them. The court deferred to the judgment of the guardian to adopt such practices and procedures as are necessary and appropriate to protect the person and the property of Mr. Macak, without undue derogation of his human dignity and, under these circumstances, reserving to Mr. Macak a limited right of self determination by way of expressing his preferences, subject however to his guardians' authority.



## **PART IV**

### **Appendices**

Appendix A: Glossary

Appendix B: Comparison of Legal Statutes, Declarations, and  
Standards

Appendix C: References



## Appendix A: Glossary

**Advocate** – To assist, defend or plead for the benefit of another individual.

**Best Interest Standard** – A decision or plan that provides for what is in the best interest of the ward and the least restrictive course of action to meet the needs of the ward.

**Capacity** – A legal qualification of fitness to understand the nature and effects of one's actions: significant benefits, risks and alternatives.

**Emergency/Temporary Guardian** – A guardian who is appointed temporarily in an emergency.

**General (Plenary) Guardian** – Guardian delegated to exercise powers over the ward when the ward lacks capacity to care for his person and property.

**Guardian** – A person or organization named by court order to make decisions for the individual or the estate of the ward. Guardians are accountable to the court.

**Guardian *ad litem*** – Guardian appointed by the court to make decisions for a person in a particular matter during a stated time.

**Guardian of the Estate** – Guardian who has powers and rights over the ward's property.

**Guardian of the Person** – Guardian who has powers and rights over the ward's personal affairs.

**Incapacitated Person** – Any person who is impaired by reason of mental illness, mental deficiency, physical illness or disability, advanced age, chronic use of drugs, or other cause to the extent that the person lacks sufficient understanding or capacity to make or to communicate responsible decisions.

**Limited Guardian** – Guardian appointed to exercise specific rights and powers for the ward when the court finds that the ward has capacity to perform some but not all tasks needed to care for his person and property.

**Self-Determination** – A doctrine that states the actions of a person are determined by the person. It involves free-choice of a person's acts without external influence.

**Ward** – An individual for whom a guardian has been appointed.

## Appendix B: 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, <i>et.seq.</i>	UN Universal Declaration Human Rights	UN Rights of Persons with Disabilities	UN Rights of Mentally Retarded Persons	NGA Rights of the Individual under Guardianship
<b>PERSONAL RIGHTS</b>						
1.Respect	6D-2	3B:12-57	Articles: 1,2	Articles: 1,5	Paragraph 1	2
2.Self-Advocacy	6D-7 6D-8	3B:12-56	Articles: 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
<b>LIVING ARRANGEMENTS</b>						
6.Services	6D-3(b)	3B:12-57		Articles: 25, 28		
7.Personal items	6D-3(b)	3B:12-57	Article: 17	Article: 12(5)		4
8.Mail	6D-4c		Article: 12			
9.Phone	6D:4d		Article: 12			
10.Healthy Diet	6D:5(b)			Articles; 25, 28		6
11.Relationships	6D-4e		Article: 20			
12.Visitors	6D-4d		Article: 20			
13.Activities	6D-3b		Article: 24, 27	Article: 30		13
14.Privacy	6D-4d			Article: 22		8
<b>HEALTH CARE</b>						
15.Treatment & Therapy	6D-(3)	3B:12-57		Articles: 25, 28	Paragraph: 2	3
16.Healthy Living	6D-(3)					12
17.Medical Care	6D-5(b)	3B:12-56 3B:12-				

		57				
<b>WORK and HABILITATION</b>						
18.School	6D-5C	3B:12- 57	Article: 26	Article 24	Paragraph: 2	3
19.Work & Play	6D-6		Article: 23	Articles: 24, 26, 27	Paragraph: 2, 3	
20.Job & Program Choice	6D-6,7	3B:12- 57				15
21.Service Plan	6D-10	3B:12- 57				16
22.Private Information	6D-4f					20
<b>SAFE ENVIRONMENT</b>						
23.Free from unusual treatments	6D-5(2) (4)				Paragraph: 6	
24.Free from restraints	6D-5(3)				Paragraph: 6	1
25.Free from punishments	6D-5(1)		Articles: 6,7,8,10,11	Article: 12	Paragraph: 6	
26. The right to Habeas Corpus	6D-7	3B:12- 26				

## REFERENCES

1. New Jersey Administrative Code, N.J.A.C. 30:6D, Rights of the Developmentally Disabled
2. New Jersey Statutes Annotated, N.J.S.A. 3B:12-1, et.seq., Guardianship
3. United Nations Universal Declaration of Human Rights, Adopted and Proclaimed by the General Assembly, Resolution 217 (A), 10 December 1948
4. United Nations Convention of the Rights of Persons with Disabilities, Adopted by the United Nations General Assembly, 13 December 2006
5. United Nations Declaration on the Rights of Mentally Retarded Persons, General Assembly Resolution 2856, 20 December 1971
6. National Guardianship Association: Fundamentals of Guardianship: What Every Guardian Needs to Know, Chapter 3, 2004

## **Appendix C: References on Human Rights and Guardianship**

### **Human Rights**

#### **University of Minnesota Human Rights Resource Center**

229 19<sup>th</sup> Avenue South  
Minnesota  
MN 55455  
1-888-HREDUC8  
<http://www.hrusa.org>

#### ***Human Rights. Yes!/: Action and Advocacy on the Rights of Persons with Disabilities***

Human Rights Education Series, Topic Book 6  
Nancy Flowers, Editor (2007)  
University of Minnesota, Human Rights Resource Center

#### **Plain Language Association International**

<http://plainlanguagenetwork.org>

Articles, tutorials, and web links by Plain-Language Specialists

#### **Federal Government**

[www.ada.gov/cguide.htm](http://www.ada.gov/cguide.htm)

*A Guide to Disability Rights Laws*, U.S. Department of Justice, Civil Rights Division

Includes: *American with Disabilities Act*

*Americans with Disabilities*

*Individuals with Disabilities Education Act*

*General Resources of Disabilities Information*

#### **United Nations**

- [www.un.org](http://www.un.org) see Documents, Human Rights

#### **Young Adult Institute**

[www.yai.org](http://www.yai.org)

Training resources: DVDs, Manuals

#### **Professional Literature**

Azavedo, S. (2006) Needs of the Developmentally Disabled. *Annals of the American Psychotherapy Association*, Winter 2006/Volume 9, Number 4, p. 39-41.

Fowler, C.A. & Wadsworth, J.S. (1991) Individualism and equality: Critical values in North American culture and the impact on disability. *Journal of Applied Rehabilitation Counseling*, 22 (4), 19-23.

Wright, B. (1983) *Physical disability: A Psychosocial Approach* (2<sup>nd</sup> edition). New York: Harper& Row.

## **Guardianship**

### **Guardianship Association of New Jersey, Inc. (GANJI) [www.ganji.org](http://www.ganji.org)**

State affiliate member of the National Guardianship Association. Provides an Educational Institute for public education, an Annual Conference, Professional listing, publications, and quick response to general inquiries

### **National Guardianship Association (NGA)**

Further reading for guardians available from [www.guardianship.org](http://www.guardianship.org) or [info@guardianship.org](mailto:info@guardianship.org)

*NGA Fundamentals of Guardianship—What Every Guardian Needs to Know*

*NGA Standards of Practice*

*NGA Pamphlet Series*

*Guardianship of Developmentally Disabled Individuals*

*Guardianship and Conservatorship*

*Guardianship as Surrogate Decision Maker*

*Rights of the Individual Under Guardianship*

### **International Guardianship Network (IGN) [www.international-guardianship.com](http://www.international-guardianship.com)**

Provides support, information and networking opportunities for guardians and adults with disabilities worldwide

### **Mental Disability Advocacy Center (MDAC) [mdac@mdac.info](mailto:mdac@mdac.info)**

Provides rights information, legislation updates on the rights of the disabled in Europe

## **Professional Literature**

Dervitz, Jain, Kakascik. (2002) *Preference/Choice/Decision: A Model for Limited Guardianship*. GANJI Monograph

Dervitz, Jain, Kakascik. (2004) *Assessing Capacity for People with Developmental Disabilities: Implementing the Model for Limited Guardianship*. GANJI Monograph.

Dervitz, P. and Kakascik, J. (2005) *The Ethical Components of a Capacity Hearing*, *Ethics and Intellectual Disability*, Newsletter of the Network on Ethics and Intellectual Disability, Joseph P. and Rose F. Kennedy Institute of Ethics, Georgetown University.

Whelan, Donna. (2004) *Enhancing Communication with Non-Verbal or Communication Impaired People*. GANJI website.