



N E T W O R K

Celebrating Over 50 Years of Hope and Excellence

CONSUMER RIGHTS ARE HUMAN RIGHTS WORKBOOK

To be used with Video

Annual Mandatory Training Manual

IMAGINE THIS IS YOUR LIFE

- You are born developmentally disabled.
- Your parents argue about how to best take care of you.
- Your mother ‘babies’ you; she’s afraid that you’ll get hurt.
- Your father withdraws from you; he’s embarrassed that you’re not ‘normal’.
- Your younger siblings learn faster than you. Before you know it they’re doing things that you’re not allowed to do.
- Your body is clumsy and slow; you have trouble remembering things.
- You look different than other children, they tease you, they don’t play with you.
- Nobody wants to be your friend.
- You learn pretty quickly that other people are smarter than you are; nobody trusts you to make good decisions – even yourself.
- Sometimes you have seizures and you lose control over your body; afterwards you feel funny and confused.
- You go to a special school; people there are pretty strange.
- You have trouble communicating what you need. Sometimes you freak out and lose control.
- You get sent to special doctors to ‘fix’ your problems.
- You don’t get many opportunities to explore on your own. Family and helpers are involved in all areas of your life (even the ones that you would rather keep private).
- Your family can’t deal with all of your special needs; you go to live in a residential school with other people who have problems.
- You move into a group home. You don’t have any choice about where you live or who you live with, you are told you are lucky.
- Sometimes the people that you live with have problems of their own – you don’t know how to cope with them.
- You have a counselor who is there to help you. You like having a counselor, but each time you get used to one, they leave. It’s hard to trust people.
- You go to workshop during the day – it is crowded and noisy.
- When there’s work, you get paid only a small amount of money – when there is no work, you sit around and do nothing.
- You have a girlfriend / boyfriend. It is hard to get to see him/her. Other people decide what you can and cannot do together.

YOU AND I

By Elaine Popovich, Direct Care Worker Lutheran Social Services,
Midland, Michigan

Consumer	STAFF
1. I am a resident.	1. You reside.
2. I am admitted.	2. You move in.
3. I am aggressive.	3. You are assertive.
4. I have behavior problems.	4. You are rude.
5. I am non-compliant.	5. You don't like being told what to do.
6. When I ask you out for dinner, it is an outing.	6. When you ask someone out it is a date.
7. I don't know how many people have read the progress notes people write about me. I don't even know what is in there.	7. You didn't speak to your best friend after she read your journal.
8. I made mistakes during my check writing project. Someday I might get a bank account.	8. You forgot to record some withdrawals from your account. The bank called to remind you.
9. I celebrated my birthday with five consumers and two staff members. I hope my family sends a card.	9. Your family threw you a surprise party. Your brother couldn't make it. It sounded wonderful.
10. My case manager sends a report every month to my guardian. It says everything I did wrong and no things I did right.	10. You are still mad at your sister for calling your mother after you got a speeding ticket.
11. I am on special diet because I am five pounds over my ideal body weight.	11. Your doctor gave up telling you to lose weight.
12. I am learning household skills.	12. You hate house housework.
13. I am learning leisure skills.	13. Your shirt says that you are a "couch potato."
14. After I do my budget tonight, I might get to McDonald's – if I have enough money.	14. You were glad that the new French restaurant accepted credit cards.
15. My (case manager, psychologist, RN, occupational therapist, physical therapist, nutritionist, and home staff) sets goals for me for the next year.	15. You haven't decided what you want out of life.
16. Someday I will be discharged. Maybe.	16. You will move onward and upward.

YAI

Residential Department

Consumer Rights and Responsibilities Fact Sheet

1. All people have the same rights to life, liberty and the pursuit of happiness.
2. OMRDD clearly states the no person shall be denied any rights solely because of the diagnosis of a developmental disability. In some states you cannot vote, cannot drive a car and cannot marry if you are diagnosed with a developmental disability. In New York State, a person's ability level is most important, not their diagnosis.
3. Because a person has rights it doesn't mean they can do whatever they want. They must assume the responsibilities that go with those rights.
4. If there is a need to limit a person's rights, the treatment team must submit their plan to the Human Rights Committee for approval. The consumer has a right to object to any of the findings and proper procedures must be followed.
5. In each individual's file there is a residence rights statement that should be read and reviewed.
6. No person should be denied any of their rights due to any discrimination, including their age, their race, or their sexual orientation.

INTRODUCTION

This training tape and workbook, *Consumer Rights are Human Rights*, is designed to assist you, the staff, in:

- ❖ Understanding the importance of the rights of people with developmental disabilities;
- ❖ What those rights are;
- ❖ A five step thinking strategy, the *Consumer Rights Assessment Strategy*, to utilize when evaluating a particularly difficult issue regarding consumer's rights.

This workbook is designed to be utilized only when viewing the Clients Rights are Human Rights training tape. **It is strongly recommended that staff do not view this tape alone; rather, this training tape should be viewed with an instructor running a formal group.**

HOW TO USE THE WORKBOOK

This training tape has STOP TAPE instructions at various segments. After each STOP TAPE, fill out the corresponding worksheet. When each worksheet is completed, discuss answer with the group, then continue to the next video segment.

THE IMPORTANCE OF CONSUMER RIGHTS

Please answer the following questions:

1. List 3 reasons why people with mental retardation/developmental disabilities require special consideration and protection regarding their rights.

1. _____

2. _____

3. _____

2. How can someone in the profound/severe range of mental retardation have their rights denied?

1. _____

2. _____

3. _____

3. How can someone in the mild/moderate range of mental retardation, or who is neurologically impaired, have his/her rights denied? List 3 ways:

1. _____

2. _____

3. _____

4. List 3 situations that could occur in your program where a person who is developmentally disabled could possibly have their rights denied?

1. _____

2. _____

3. _____

The following lists of Clients Rights are predominantly compiled from the New York State Department of Mental Retardation/Developmental Disabilities Regulations on the Rights of People with Mental Retardation/Developmental Disabilities. Please retain this list for future reference.

ENVIRONMENTAL/FACILITY

- ◆ The right to a safe and sanitary environment
- ◆ The right to privacy (sleeping, bathing, toileting)
- ◆ The opportunity to receive visitors at reasonable times, even without prior notice, and the opportunity for privacy during such visits
- ◆ The opportunity to visit others, including family and friends
- ◆ The opportunity to receive and send communications freely and uncensored
- ◆ Safe and accessible storage space for clothing and personal belongings

PROTECTION/HEALTH/SAFETY

- ◆ Freedom from physical or psychological abuse or pressure
- ◆ Freedom from unnecessary use of mechanical restraining devices
- ◆ Freedom from unnecessary or excessive medication
- ◆ Protection from commercial or other exploitation
- ◆ Confidentiality of all information contained in clinical records
- ◆ The right to appropriate and humane health care and to have input in the choice of health care provider, including the obtaining of a second opinion
- ◆ The opportunity to carry pregnancy to term
- ◆ The same access to abortion as any other person

- ◆ A balanced and nutritious diet served at appropriate times and normal manner, which is not altered or denied for behavior management purposes
- ◆ Individually owned and properly fitting clothing appropriate for age and season
- ◆ Individually owned grooming and personal hygiene supplies

CONSTITUTIONAL/INDIVIDUAL RIGHTS

- ◆ The opportunity to participate in the religion of his/her choice
- ◆ The opportunity to register and vote and to be educated as to his/her civic duties
- ◆ Respect for his/her cultural identity
- ◆ Regular notice of his/her financial status
- ◆ Use of his/her personal money and assistance in such use as appropriate
- ◆ The opportunity to request an alternative residential setting
- ◆ The opportunity to participate in the establishment of program rules
- ◆ The opportunity to express grievances without fear of reprisal
- ◆ The rights to participate, as an adult, if so desired, in consenting sexual activities, if time, place, and setting are appropriate
- ◆ The right to participate in activities that are valued by our society

CLINICAL SERVICES

- ◆ The right to a written individualized plan of services
- ◆ The opportunity to participate in the development of his/her service plan, to object to any provision within the plan, to appeal any decision made within the plan, and to appeal any decision, made with which she/he disagrees
- ◆ The right to participate in meaningful, productive, activities within his/her capacity
- ◆ The right to receive assistance and guidance from staff
- ◆ Access to clinically sound instructions on sexuality and family planning services
- ◆ The receipt of information prior to admission, and no less than biennially thereafter, of the supplies and services that the facility will provide

CONSUMER RIGHTS ASSESSMENT STRATEGY

You have just seen a model treatment team, utilizing the Consumer Rights Assessment Strategy (CRAS)

The CRAS is a concise tool that assists you, the staff, in helping to identify the essential issues that involve the rights of people with developmental disabilities

1. List five steps of the CRAS

1. _____
2. _____
3. _____
4. _____
5. _____

Compare your answers to the CRAS on the following page

THE CLIENT RIGHTS ASSESSMENT STRATEGY
1. Are rights involved?
2. Are health / safety issues involved?
3. Are the rights of others involved?
4. What is the least restrictive method of intervention?
5. Does it involve a dignity of risk issue?
6. Does the method of intervention need to be adapted to the individual's disability level?

In the model role-play, the treatment team utilizes the CRAS to resolve a complex issue regarding consumer's rights. Notice that the entire treatment team was involved in arriving at an agreement. Participation by every member of the treatment team further ensures that the rights of the individual with developmental disabilities will be respected and are not judged by any one person's value system.

IMPORTANT: Participation by the individual with developmental disabilities in treatment team discussions revolving around his/her rights is strongly recommended. The extent of participation by the individual is based upon the individual's functional abilities. Not only does participation by the individual's best ensure that rights are respected, but it also would help to achieve the desired results, since he/she is vested in the outcome.

How did the treatment team deal with this particular client right issue? On the following page, please note your observations, utilizing the CRAS.

HOW DID THE TREATMENT TEAM DEAL WITH THIS ISSUE

Model Role Play
“Messy Room”

CRAS	How did the treatment team deal with this issue?
1. Are rights involved?	
2. Health/Safety? Dignity of risk?	
3. Rights of others?	
4. Least restrictive intervention?	
5. Adapt to level of disability?	

The following three role-plays involve complex right issues. After each role play, STOP TAPE, when indicated, and applying the CRAS

HOW WOULD YOU DEAL WITH THIS ISSUE?

**ROLE PLAY #1
“More Food, Please”**

CRAS	How would you deal with this issue?
1. Are rights involved?	
2. Health/Safety? Dignity of risk?	
3. Rights of others?	
4. Least restrictive intervention?	
5. Adapt to level of disability?	

Discuss your answers with the rest of the group and compare to the recommended possible solutions.

Please review your answers to the role play conclusions with the recommended possible “solutions” on the following pages, after completion of your individual group discussions.

PLEASE REMEMBER

There is no one answer to a given situation involving a consumer right issue.

EXAMPLE OF AN APPROPRIATE RESPONSE

- ◆ Please note that other answers may also be appropriate. All answers should be carefully reviewed in your group.

ROLE PLAY #1
 “More Food, Please”

CRAS	How would you deal with this issue?
1. Are rights involved?	Yes. This particular individual’s rights issue falls under the consumers right category of Environmental/Facility. This category includes the right to nutritious and adequate meals.
2. Health/Safety? Dignity of risk?	It is possible that the individual’s health could be affected if he/she is defined by a doctor as ‘obese’. At this point, according to the individual’s recent medical report, the doctor has not indicated that he is becoming “obese”. Therefore, it does not seem that there is a risk to his/her health and safety. This issue could be further clarified with the doctor.
3. Rights of others?	The individual is not infringing on anyone else’s rights, assuming that there is enough food for everyone.
4. Least restrictive intervention?	If the doctor does indicate that the person has a health issue, then “seconds” would need to be the food determined non-fattening, yet at the same time filling, such as properly prepared vegetables.
5. Adapt to level of disability?	Since this individual has profound MR with poor impulse control, we would only want to give him appropriate portions of food (as approved by the doctor. Different foods, suggested by the doctor and selected according to the taste preference of the individual, will be provided as ‘seconds’.

**Applying the CRAS
HOW WOULD YOU DEAL WITH THIS ISSUE?**

ROLE PLAY #2
“Visitor”

CRAS	How would you deal with this issue?
1. Are rights involved?	
2. Health/Safety? Dignity of risk?	
3. Rights of others?	
4. Least restrictive intervention?	
5. Adapt to level of disability?	

Discuss your answers with the rest of the group and compare to the recommended possible solutions.

Please review your answers to the role play conclusions with the recommended possible “solutions” on the following pages, after completion of your individual group discussions.

PLEASE REMEMBER

There is no one answer to a given situation involving a consumer right issue.

EXAMPLE OF AN APPROPRIATE RESPONSE

- ◆ Please note that other answers may also be appropriate. All answers should be carefully reviewed in your group.

ROLE PLAY #2
“Visitor”

CRAS	How would you deal with this issue?
1. Are rights involved?	Yes. This individuals’ right issue falls under two categories of consumers’ rights. (a) Individual rights that includes the right to receive visitors (b) Environment/Facility that includes the right to privacy.
2. Health/Safety? Dignity of risk?	It is potentially dangerous to allow a stranger into one’s home. It is, therefore, standard operating procedure for many agencies to be familiar with the visitor in order to insure the safety of all participants and staff. There is a potential excessive risk of danger in allowing a stranger into one’s home.
3. Rights of others?	The rights of other individuals in the program/residence could be infringed upon by allowing the stranger into the program/residence. The ‘stranger’ could be a potential threat to their well-being, as well as to their possessions.
4. Least restrictive intervention?	Since the visitor is a stranger to all concerned, it is appropriate that he remain in the living room with the individual. The counselor should make every effort to familiarize herself with the visitor, and should remain nearby to ensure the safety of others in the residence. However, the counselor should not overly intrude on the visitation.
5. Adapt to level of disability?	Since the person on the role play is in the mild range of MR, she is capable of understanding residence rules as well as the reasons why those rules were created. Therefore, it is strongly recommended that residence rules be reviewed, understood and agreed upon. If the individual understands residence rules and their importance, such situations could be minimized.

**Applying the CRAS
HOW WOULD YOU DEAL WITH THIS ISSUE?**

ROLE PLAY #3
"Toothbrushing"

CRAS	How would you deal with this issue?
1. Are rights involved?	
2. Health/Safety? Dignity of risk?	
3. Rights of others?	
4. Least restrictive intervention?	
5. Adapt to level of disability?	

Discuss your answers with the rest of the group and compare to the recommended possible solutions.

Please review your answers to the role play conclusions with the recommended possible solutions on the following pages, after completion of your individual group discussions.

PLEASE REMEMBER

There is no one answer to a given situation involving a consumer right issue.

EXAMPLE OF AN APPROPRIATE RESPONSE

- ◆ Please note that other answers may also be appropriate. All answers should be carefully reviewed in your group.

ROLE PLAY #3
 “Toothbrushing”

CRAS	How would you deal with this issue?
1. Are rights involved?	We are all entitled to appropriate health & safety. In this case the health (dental health) of the individual is not being properly maintained.
2. Health/Safety? Dignity of risk?	Yes, this is a health and safety issue. Not brushing your teeth can result in numerous hygiene and ultimately, dental problems.
3. Rights of others?	The rights of other individuals in the program/residence could be infringed upon by allowing the ‘stranger’ into the program/residence. The ‘stranger’ could be a potential threat to their well-being, as well as to their possessions