

**What every Parent/Guardian should investigate prior to
agreeing to Discharge a Family Member from a Mental
Retardation Center.**

RIGHTS OF INDIVIDUALS

- NC GENERAL STATUTE 122C-2 "The policy of the State is to assist individuals with mental health, developmental disabilities, and substance abuse problems in ways consistent with the dignity, rights and responsibilities of all North Carolina citizens."
- NC GENERAL STATUTE 122C-51 "These (basic human) rights include the right to dignity, privacy, humane care and freedom from mental and physical abuse, neglect and exploitation."

DHHS Directive 61

Under the authority of NC General Statutes (NCGS 7B; NCGS 108A-80 Article 6 and NCGS 122C-66), the DHHS has established Directive 61 as rules with regard to the obligation to report abuse or neglect of juveniles and abuse, neglect or exploitation of disabled adults in need of protective services, who are receiving services from institutions of DHHS.

What every Parent / Guardian should investigate prior to agreeing to Discharge a Family Member from a Mental Retardation Center

The decision to discharge a resident from a Developmental Center to a community residential setting represents a significant transition for families as well as patients. The staff of the Center is required and wants to work with families to ensure that the transition from the Center to the community happens in an appropriate manner and to determine whether living in a particular community residential setting or living in a mental retardation center is the best setting for that person at this time.

The final decision regarding where a current resident of a Developmental Center lives belongs to that person, or, if that person has not been judged competent, to the parents or guardians of that person. "Only those who choose to do so will be considered for participation in community living alternatives and consideration will be regardless of severity or degree of disability." (The Comprehensive Plan for Services and Supports for Persons with Developmental Disabilities, Goal 20 E, page 25.)

Parent/Guardians should consult with the current residential placement regarding trial placement policies and admission procedures.

The questions below are some of the questions responsible parents/guardians should ask as they consider community placement. If appropriate, consider asking them of staff and residents to obtain a feeling for the place and its staff. These questions are not the only ones to ask. They do not presume to promote or discourage community placement or continued residence in a developmental center. Some community living settings have been and are appropriate for certain individuals while others may not be the best alternative. It is

Up to each parent/guardian with the support of the current team to decide what is best for their family member.

PART ONE: THE OVERRIDING CONCERN

1. Will my son, daughter, brother, or sister receive services and support systems in the community which are at least equal to, or better, in quantity and quality than those offered by the Developmental Center?
2. What are the safeguards to ensure that the family/guardian will not be the responsible care provider in the event that the placement disrupts?

PART TWO: MEDICAL, DENTAL, THERAPEUTIC, AND DIETARY CARE

1. Who will provide medical services for my family member? Name and availability of doctor. How experienced are these therapists/agencies in providing care to persons with mental retardation?
2. Are on-site nursing services provided? How often? Who administers medication? Is training provided for non-nursing personnel that administer medications? How frequent is that training?
3. How available and assessable is emergency medical care?
4. Does this medical facility have trained personnel to take care of persons with mental retardation and/or other developmental disabilities?
5. Who will provide dental care? How often do dental exams take place? What is the name and availability of dentist? Are they familiar with persons with mental retardation and other developmental disabilities?
6. What are the procedures when a resident needs immediate medical or dental attention?
7. Who are the persons responsible for obtaining the medical or dental care residents may need?
8. Will my brother, sister, son, or daughter receive the same kind of therapies given in the Developmental Center if the discharge team recommends them? What are the names of therapists or agencies providing therapeutic services? How experienced are these therapists/agencies in providing care to people with mental retardation?
9. How often will such therapies be given? Where?
10. How are the costs for medical and dental care, therapy, adaptive equipment, and prescriptions paid, and by whom? Will this affect me or put any additional burden of cost on me? Who will be responsible for processing the bills associated with these services?

11. How are the diets of each individual planned and monitored? By whom? What are the required experience and credentials associated with this position?

PART THREE: PROGRAMS OFFERED

1. Who coordinates the daily program of activities for my family member? What is the name of the responsible person? What are the required credentials and experience of this position?

2. Are there inter-disciplinary staff meetings that identify and monitor a set of educational and training goals for my family member if they are an identified need as noted in the discharge plan? How often do they meet? Can family members/guardians attend? May I see a typical report?

3. What kind of vocational training will he/she receive if recommended in the discharge plan by the current team? How often and where will training occur? Where? What is the name of person responsible? What are the required credentials and experience for this person?

4. What social and recreational programs are provided? By whom and how often are these programs offered? What are the required credentials and experience for this person?

5. Who monitors the implementation of these programs? What are the procedures to correct programs or the manner in which they are implemented if a deficiency or problem is identified?

6. How will the state track the quality of life for my family member for the rest of his/her life and make certain, by means of frequent personal contacts, that all services promised at the time of discharge from an Developmental Center are provided?

PART FOUR: STAFF TRAINING AND BACKGROUND

1. How long has the director been with this home? What are his/her credentials? Does this person make the decisions or is the team approach utilized?

2. What kind of staff training program have employees had and continue to receive? Does this include individual's rights training?

3. How long has each staff member worked in this community residential setting?

4. What has been the staff turnover rate each year for the last three years? (When visiting the facility, consider asking every employee how long he/she has worked at this home).

5. When employees cannot work as scheduled because of sudden illness, personal or family emergency, etc., how are the staffing needs of the home managed?

1. Have all employees had health examinations conducted by a physician or public health authority prior to employment by this facility? How

frequent are these checks updated (e.g. annual TB tests)?

7. Have all employees had police background checks prior to employment by this agency? If so, what kind of a check was made - local, regional, statewide, and nationwide? If not, why not? How frequent are these checks updated?

PART FIVE: HUMAN RIGHTS CONCERNS

1. How are parent/guardian concerns about the quality of care in this community residential setting addressed? Who is the person to contact when a family has questions or concerns? Is this person an employee of the facility providing care?

2. May our families talk to the parents/guardians of others who live in the proposed residential setting for my family member? Is there a parent support group?

3. May our family members visit this facility at any time - provided we have the proper identification from those who supervise the operations of this community residential arrangement - before and during placement of our family member in the home? If not, why not?

4. Does this facility provide a list of the basic human rights to residents and/or their families? See attachment for a summarized overview of the Basic Human Rights cited from the NC General Statute, 122 C-2, 122-51.

5. Does this facility have a human rights advocacy committee? How often does it meet? Who are its members? What were the dates of their last three meetings? If not, how are complaints handled?

6. How are aggressive and potentially harmful emotional and/or behavior problems managed for my family member or for others in that community residential setting during day and night shifts?

7. Has this facility been inspected by the local health department? What rating did it receive?

8. Did its report contain any violation of standards? If so, have they been corrected? Have these corrections been accepted by the Health Department?

9. When was this facility last inspected by the local Fire Department? Were any deficiencies reported? If so, have they been corrected and accepted as corrected by the Fire Department?

10. Is there a smoke detector in each bedroom and in other rooms in this facility? Where are fire extinguishers located? What plans exist if there is a fire? Are practice drills conducted?

11. What is the name of the Local Management Entity (formerly the local Mental Health Authority/ Area Program)? Does this agency oversee this facility? How is this monitored?

12. Does this agency conduct regular on-site inspection of this facility? What was the date of the last inspection? May parents/guardians see the report? If not, why not?

PART SIX: FINANCIAL CONSIDERATIONS

1. What is the name of the corporate entity operating this facility? Is it operated by the State of North Carolina, a non-profit organization, or a profit-oriented business?
2. Is the new provider of services mandated by law to notify the state of any changes such as change of location, ownership change, changes in the stated purpose of this facility, etc.?
3. What happens if funding is cut or if the ownership of the facility changes?
4. What happens if this facility closes? What happens to residents? Who decides where they shall be placed temporarily as well as long-term?
5. What contingency plans does the State have to accommodate residents of community facilities should the provider of that service suddenly become bankrupt or encounter other catastrophes, which would require large numbers of patients to be placed elsewhere?
6. Does each resident receive a clothing allowance? How much? Who is responsible for this?
7. Does each resident receive an activity allowance? How much?
8. Residents in family care centers, group homes, and other care facilities receive a modest monthly Social Security allowance to obtain personal items. If a resident is unable to manage this allowance, and if the management of the facility manages these funds for a resident, what kind of financial records are kept for this resident? Who reviews these expenditures? How frequent are these reviews? What external agency or advocacy group oversees the management of such funds?