How to Identify Rights Violations

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Learning Objectives

• International statement of rights
• Rights in the Developmental Disabilities Act
• Rights in the new Home and Community-Based Services (HCBS) Settings Rule
• Right to be Free from Harm
• National Core Indicators Data on Rights
• How you can identify rights issues
Reflections on Rights

“Whatever is my right . . . is also the right of another; and it becomes my duty to guarantee as well as to possess.”
— Thomas Paine, Rights of Man

“…rights are not a guarantee of the good life, but an equal opportunity and responsibility to participate in producing the good life for oneself and for all.”
— Justin Dart, architect of the American’s with Disabilities Act

“To deny people their human rights is to challenge their very humanity.”
— Nelson Mandela

“This is my doctrine: Give every other human being every right you claim for yourself.”
— Robert G. Ingersoll, The Liberty of Man, Woman and Child
Where do Rights Come From?

- International treaties and declarations – Declaration of Human Rights, Convention on the Rights of People with Disabilities
- Federal statutes (Americans with Disabilities Act, Developmental Disabilities Act, Individuals with Disabilities Education Act) – right to public access, freedom from discrimination, right to education, right to habilitation
- Constitutional rights (Olmstead v. Georgia, Pennhurst, Wyatt) – right to live in the community with support, right to treatment
- State statutes – e.g., person centered planning requirements
- Federal and State Regulations (HCBS Settings Rules, Medicaid waiver assurances) – right to live and work in integrated settings, right to privacy, right to choose where you live
People are entitled to:

• Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independent of persons
• Non-discrimination
• Full and effective participation and inclusion in society
• Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
• Equality of opportunity
• Accessibility
• Equality between men and women
• Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their rights
Providing individuals with developmental disabilities with the information, skills, opportunities, and support to:

(A) make informed choices and decisions about their lives;

(B) live in homes and communities in which such individuals can exercise their full rights and responsibilities as citizens;

(C) pursue meaningful and productive lives;

(D) contribute to their families, communities, and States, and the Nation;
(E) have interdependent friendships and relationships with other persons;

(F) live free of abuse, neglect, financial and sexual exploitation, and violations of their legal and human rights; and

(G) achieve full integration and inclusion in society, in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of each individual.
New Federal Expectations for Community Services*
Requirements for HCBS Supported Community Services

- **Purpose:** Ensure people receiving federal funding for long-term services and have full access to the benefits of community living and opportunities to receive services in the most integrated setting appropriate.

- Includes services for aging, disability, and ID/DD

- Covers residential and day services

- Based on person’s choice

- Rule effective date March 17, 2014

Basis for CMS Settings Rule (2014)

- Normalization and the assumption that people with disabilities have the same rights to live normal lives in their communities as people without disabilities
- Landmark court decisions including the Olmstead case that required that people with ID/DD be supported in the community
- Wide variations in the size, quality and inclusiveness of community services
Community Services and Supports

- Are integrated in and support full access to greater community
- Ensure the person receives services in the community with the same degree of access as people not receiving federal Medicaid funding
- Provide opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources
Community Services and Supports

- Are chosen by the person receiving services from among residential and day options that include generic settings
- Respect the participant’s option to choose a private unit in a residential setting
- Ensure right to privacy, dignity and respect and freedom from coercion and restraint
- Optimize autonomy and independence in making life choices
- Facilitate choice of services and who provides them through supported decision making
Provider-Owned or Controlled Residential Settings

- **Person must have:**
  - A lease or other legally enforceable agreement to protect from eviction
  - Privacy in their unit including entrances lockable by the person (staff have keys as needed)
  - Choice of roommates
  - Freedom to furnish and decorate their unit
  - Control of their schedule and activities
  - Access to food at any time
  - Visitors at any time
  - Physical accessibility

- **Deviations from this rule (except accessibility) must be supported by a specific assessed need and justified in the person centered service plan (ISP-individualized service plan)**
Right to be Free From Harm

- People with ID/DD have the same basic legal, civil and human rights as ALL other citizens. They may need accommodation, protection and support to enable them to exercise these rights and they must be protected from harm/injury and must have the tools and supports so they can protect themselves. A recent Office of the Inspector General report found that states(1):

  - failed to ensure that group homes reported all critical incidents,
  - failed to ensure that all critical incidents reported by group homes were properly recorded,
  - failed to ensure that group homes always reported incidents at the correct severity level,
  - failed to ensure that all data on critical incidents were collected and reviewed, and
  - failed to ensure that reasonable suspicions of abuse or neglect were properly reported.

Facts About Abuse of People with Developmental Disabilities

Abuse and exploitation are constant dangers for people with developmental disabilities. They are four to ten times more likely to be abused than their peers without disabilities. Compared to the general population, people with developmental disabilities are:

• At greatest risk of abuse\(^1\).
• Tend to be abused more frequently.
• Are abused for longer periods of time.
• Are less likely to access the justice system.
• Are more likely to be abused by a caregiver or someone they know; many are repeatedly abused by the same person.
• Are more likely to remain in abusive situations.

2016-2017 Data Cycle
NCI is a voluntary effort by public developmental disabilities agencies to measure and track their own performance.

Collaboration began in 1997.

Currently 46 states and Washington D.C. represented plus 22 sub-state entities.

Coordinated by Human Service Search Institute (HSRI) and The National Association of State Directors of Developmental Disabilities Services (NASDDDS).
NCI Tools

- Adult In-person Survey*
- Family Surveys
- Staff Stability

*Formerly the Adult Consumer Survey (ACS)
NCI Adult Consumer Survey (2016-2017)

- People who receive at least one service beyond case management
- Face-to-face survey with the person receiving services
- Survey includes three main parts:
  - Background information – largely collected from state records
  - Section I – Subjective questions *only* the person can answer
  - Section II – Objective questions can be answered by a proxy when appropriate
- 462 valid surveys completed in Georgia

Two asterisks ** means that the data are significant at .01

Georgia Employment data comes from the NCI Adult Consumer Survey 2016-2017
Where Do People Live?

- Group residential setting: 25%
- Own home: 13%
- Parent or relative's home: 47%
- Foster care or host home: 14%

GA (N=455)
Rights and Privacy

Has a key to the home
- 41% GA
- 46% NCI

Others ask before entering the home
- 86% GA
- 90% NCI

Can lock bedroom**
- 73% GA
- 46% NCI

Others ask before entering the bedroom**
- 91% GA
- 84% NCI

**Sig. at .01
Rights and Privacy

Rights and Privacy by Residence

- **Has a key to the home**
  - Group residential setting (e.g., group home): 10%
  - Own home or apartment: 93%
  - Parents/relatives home: 50%

- **Others ask before entering home**
  - Group residential setting: 80%
  - Own home or apartment: 89%
  - Parents/relatives home: 85%

- **Others ask before entering bedroom**
  - Group residential setting: 93%
  - Own home or apartment: 94%
  - Parents/relatives home: 90%

- **Can lock bedroom**
  - Group residential setting: 71%
  - Own home or apartment: 90%
  - Parents/relatives home: 70%

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## Privacy in the Home

<table>
<thead>
<tr>
<th>Has a place to be alone in the home**</th>
<th>There are rules to having friends or visitors at home*</th>
<th>Can be alone with friends or visitors at home**</th>
</tr>
</thead>
<tbody>
<tr>
<td>- <strong>100%</strong> GA</td>
<td>- <strong>10%</strong> GA</td>
<td>- <strong>93%</strong> GA</td>
</tr>
<tr>
<td>- <strong>96%</strong> NCI</td>
<td>- <strong>35%</strong> NCI</td>
<td>- <strong>83%</strong> NCI</td>
</tr>
</tbody>
</table>

*GA is significantly lower than NCI Average  
**GA is significantly higher than NCI Average
Rights and Privacy

Rights and Privacy by Residence

- **Has a place to be alone in the home:**
  - Group residential setting (e.g., group home): 98%
  - Own home or apartment: 100%
  - Parents/relatives home: 100%

- **There are rules to having friends or visitors at home:**
  - Group residential setting (e.g., group home): 89%
  - Own home or apartment: 98%
  - Parents/relatives home: 90%

- **Can be alone with friends or visitors at home:**
  - Group residential setting (e.g., group home): 17%
  - Own home or apartment: 7%
  - Parents/relatives home: 10%

No sig, differences found
**GA is significantly higher than NCI Average**

- **Took part in last service planning meeting, or chose not to**: 100% (GA) vs 98% (NCI)
- **Understood what was being talked about at last service planning meeting**: 90% (GA) vs 83% (NCI)
- **Last planning meeting included the people the person wanted there**: 97% (GA) vs 94% (NCI)
- **Chose services included as a part of the service plan**: 88% (GA) vs 76% (NCI)
Self-Advocacy and Voting

Took part in a self-advocacy group meeting conference or event **

- 15% GA
- 25% NCI

Ever voted in a local, state or federal election

- 34% GA
- 39% NCI

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What Can You Do?

The Georgia Collaborative ASO
Ways to Ensure Rights Are Respected

- Make sure that people can exercise their rights as citizens including the right to vote, to be included in their communities, and to express their choices
- Ensure you understand the HCBS settings requirements
- Assist people to participate in self advocacy organizations like People First of Georgia and Sangha Unity Network, Inc.
- Learn a person’s preferences for exercising rights
- Provide continued information about how people receiving services and families can file grievances, and report abuse, neglect and exploitation
- Learn signs of abuse, neglect and exploitation and where to report
All through the Fall of 2016, Dan was excited to be able to vote for President. He had registered to vote for the first time in the Spring. He had just turned 21. As Election Day got closer, Dan got more and more excited and began to argue loudly with the other residents in the group home about his candidate. The staff became concerned that Dan was becoming overly excited. They were worried that if they took him to the polls, something might happen and Dan would have a behavioral episode. The staff met and decided that they wouldn’t take Dan to the polls on Election Day. Dan was really disappointed.

- **Question:** Were the staff abridging Dan’s rights?

- **Discussion:** Was Dan supported to exercise his rights?
Aubriana has lived in a group home for 5 years. She has a part-time job and takes the van to get there. Lately, there has been a new person driving the van. In the last month, Aubriana has lost several pounds and doesn’t have an appetite. She also is not sleeping well. As a rule she is warm and likes to get hugs. However, now she shies away and rejects any touching. Some of the staff think that she’s just depressed because her mother has been in the hospital. Another staff who knows her well, and understands her signs, is worried and thinks that something else is wrong. Unfortunately, Aubriana doesn’t use words to speak but has her own signs.

- **Question:** What should her staff or her case manager do?

- **Discussion:** These are signs of sexual abuse and an investigation should be initiated.
What can you do?

- **Report rights violations to:**
  - Provider agency
  - Support Coordinator
  - Constituent Services with DBHDD

- **Restrictive interventions in behavior support plans:**
  - Ensure behavior support plan has been approved by the person or guardian
  - Ensure behavior support plan is being monitored and assessed to adjust the restrictive intervention as needed

*Always refer to current DBHDD policy on reporting rights violations*
Questions and Feedback
Thank you

For Georgia Collaborative ASO general inquiry or questions please email:

GACollaborativePR@beaconhealthoptions.com