



# The North Carolina Relationships Initiative

Policy Recommendations to promote healthy social and emotional relationships for people with intellectual and developmental disabilities

February 2012



Human Services Research Institute  
7690 SW Mohawk Street  
Tualatin OR 97062  
[www.hsri.org](http://www.hsri.org)

# The North Carolina Relationships Initiative

**Policy Recommendations  
to promote healthy social and emotional relationships for  
people with intellectual and developmental disabilities**

**February 2012**

**Prepared for:**



North Carolina Council on Developmental Disabilities  
3125 Poplarwood Court, Suite 200  
Raleigh, NC 27604  
919-850-2901  
[www.nccdd.org](http://www.nccdd.org)

**Prepared By:**



Jaime Daignault, Yoshiko Kardell & Jennifer Negus  
Contributors: Monica J. Foster, Katherine McLaughlin &  
Paula Traverse-Charlton  
Human Services Research Institute  
7690 SW Mohawk St  
Tualatin, OR 97062  
503-924-3783  
[www.hsri.org](http://www.hsri.org)

This report may be cited as follows:

Daignault, J., Kardell, Y., Negus, J., Foster, M. J., Traverse-Charlton, P., & McLaughlin, K. (2012). *North Carolina Relationships Initiative: Policy Recommendations*. Tualatin, OR: Human Services Research Institute.

All opinions expressed herein are solely those of the authors and do not reflect the position or policy of the North Carolina Council on Developmental Disabilities or any other government authority.

## About the Authors

The Human Services Research Institute (HSRI) was founded in 1976 and is a non-profit, tax-exempt corporation. For over 30 years, HSRI has assisted states and the federal government to enhance services and supports to improve the lives of vulnerable citizens, such as those with developmental disabilities or mental illness, or low income families. HSRI has provided consultation in such areas as strategic planning and organizational change, funding, systems integration, quality management and assurance, program evaluation, evidence-based practices, family support, self-advocacy, self-determination, and workforce development. For more information, go to: [www.hsri.org](http://www.hsri.org).

HSRI has offices located in Cambridge, Massachusetts and Tualatin, Oregon. This report was prepared by the following three staff of the Oregon office and contributing consultants.

**Jaime Daignault, M.S.**, is a Policy Associate at HSRI. Her primary responsibilities involve project management and technical assistance to community organizations. She has contributed to several studies of disability service systems including state-level gap analyses and systems reform projects to improve self-determination. Working at the community level, she has provided training and technical assistance to local and statewide self-advocacy groups regarding strategic planning, peer support, and capacity building. She also oversees production of *The Riot* newsletter, a quarterly electronic self-advocacy and disability rights newsletter.

**Yoshiko Kardell, M.S.W.**, is a Policy Analyst at HSRI. She manages projects related to self-determination and resource allocation. She also coordinates development of *The Riot*. She has several years of experience working for people with disabilities including providing direct support and state level advocacy. She has a graduate degree in Social Work from Portland State University and an undergraduate degree in Social Work from the University of Nebraska – Omaha.

**Jennifer Negus** is a Policy Assistant at HSRI. She supports multiple projects and works directly with self-advocates on a variety of day-to-day tasks including off-site coordination in multiple states, event planning, production of user-friendly materials for self-advocates, tracks project budgets and coordinates both the production of *The Riot* and the National Conversation Series.

**Monica J. Foster** is a self-advocate living in North Carolina and the Chief Motivational Officer of BUTTERFLYWHEEL® Motivation, Advocacy & Consulting ([www.butterflywheel.com](http://www.butterflywheel.com)). She is a Certified Life, Life Purpose and Career Coach, Certified Vision Board Coach, and Certified Peer Support Specialist who specializes in working with other people with disabilities. In addition to running her business, Ms. Foster consults on several statewide and national

projects related to sexuality and disability. On this project, she served as the local project coordinator and educator. In this role, she provided education and support to local groups of self-advocates, helping them to identify and address barriers to relationships in their own lives and in their communities. At the national level, Ms. Foster contributes to national conversations and trainings on ways to help direct support staff, parents and self-advocates develop, customize, learn and support healthy, safe social skills and sexuality education.

**Paula Traverse-Charlton**, is the owner of Positive Behavioral Supports of Virginia, PLLC and has supported adults with intellectual disabilities for over 35 years. In the past few years, her focus has been on relationships and intimacy. While serving in the role of Service Director at Hope House Foundation, a residential not-for-profit agency in Virginia, she wrote policy regarding the provider role in supporting individuals with developmental disabilities to develop relationships. On this project, Ms. Traverse-Charlton assisted us to train project participants and develop policy recommendations that providers can implement.

**Katherine McLaughlin**, an expert on sexuality and developmental disabilities is a private consultant and teaches Human Sexuality at Keene State College in New Hampshire. She has trained nationally at conferences, developed and led parent workshops on *Talking to Your Kids with Disabilities about Sexuality*, and has trained staff on how to address sexuality with people with disabilities. She also co-authored two curricula for Planned Parenthood of Northern New England where she was a sexuality educator and trainer for over 20 years. Her curricula include *Sexuality Education for Adults with Developmental Disabilities* and *Sexual Violence in Teenage Lives*. On this project, Ms. McLaughlin taught relationships and sexuality education to people with developmental disabilities.

## Contents

About the Authors .....	i
Policy Recommendations to promote healthy social and emotional relationships for people with intellectual and developmental disabilities .....	<b>Error! Bookmark not defined.</b> 1
Position statement and policy recommendations .....	2
1. Align current practice with what people want .....	3
2. Promote self-determination .....	4
3. Utilize natural supports.....	6
4. Use guardianship with caution .....	6
5. Respect individual liberty and expression of healthy human sexuality with appropriate education and support and attention to health and safety. ....	7
5a. Provide comprehensive education and support.....	8
1. Comprehensive relationships and sexuality education .....	8
2. Consent.....	10
3. Sexual Advocacy .....	10
4. Sexual Contact and Intercourse .....	10
5. Pregnancy Prevention .....	11
6. Pregnancy.....	11
7. Sexual Orientation.....	11
8. Sexually Transmitted Infections .....	12
5b. Assure health and safety.....	<b>Error! Bookmark not defined.</b>
9. Reproductive Health.....	<b>Error! Bookmark not defined.</b>
10. Designated Safe Staff .....	<b>Error! Bookmark not defined.</b>
11. Abuse, Harassment and Exploitation .....	<b>Error! Bookmark not defined.</b>
12. Staff-Individual Contact and Boundaries.....	<b>Error! Bookmark not defined.</b>
5c. Provide opportunities to express healthy human sexuality..	<b>Error! Bookmark not defined.</b>
13. Privacy .....	<b>Error! Bookmark not defined.</b>
14. Cohabitation, Marriage and Unions .....	<b>Error! Bookmark not defined.</b>
15. Masturbation and Self-Stimulation .....	<b>Error! Bookmark not defined.</b>
16. Erotica.....	<b>Error! Bookmark not defined.</b>
Discussion.....	16

# **Policy Recommendations to promote healthy social and emotional relationships for people with intellectual and developmental disabilities**

---

The specific policy recommendations detailed below were developed to address barriers identified as a result of the North Carolina Relationships Initiative (NCRI) efforts. This project was funded by the North Carolina Council on Developmental Disabilities and implemented by the Human Services Research Institute and specialty consultants with expertise in disability, sexuality education and policy development. To read the full project report, visit the project webpage: <http://www.hsri.org/project/north-carolina-relationships-initiative>. This report is also available from the Council.

For the purpose of this project, we use the term “relationships” broadly to address a wide range of connections with others in our communities – primarily with people other than family members and paid staff. Consequently, when we refer to relationships, we mean connections with people with and without disabilities in communities where people live including recognition through association at places like a local coffee shop, grocery store, the bank, acquaintances, friendships, and emotionally intimate relationships including close friendships and love relationships, and sexually intimate relationships. We refer to this wide range of connections with others as social and emotional relationships.

As substantiated by NCRI findings, people with developmental disabilities in North Carolina face multiple barriers to experiencing healthy social and emotional relationships that are essential to human health. These relationships are typically accessible to others in the general population and include a wide range of connections to people. Yet, these connections are largely unavailable to people with developmental disabilities due to identified barriers.

The policy recommendations below address a range of topics related to supporting people with developmental disabilities to safely and responsibly experience healthy social and emotional relationships. As illustrated by the graphic below, we

## **Policy Recommendations**

1. Align current practice with what people want
2. Promote self-determination
3. Utilize natural supports
4. Use guardianship with caution
5. Respect individual liberty and expression of healthy human sexuality with appropriate education and support and attention to health and safety
  - Provide comprehensive education and support
  - Assure health and safety
  - Provide opportunities for individuals to express healthy human sexuality

believe that if implemented, opportunities for people with developmental disabilities to live full community lives will increase, yielding improved outcomes. Such outcomes may include increased community integration, reduced loneliness and isolation, and greater numbers of individuals living self-determined lives and experiencing healthy relationships they choose.



NCRI project staff worked with local Charlotte service providers, InReach, Developmental Disability Resources Inc. and Easter Seals/UCP, to develop the following recommendations. The purpose of these recommendations is urge policy makers, providers, family members and others to take action to promote healthy social and emotional relationships for people with intellectual and developmental disabilities in North Carolina. Below, our recommendations are organized according to five major themes: (a) assess current practice against what people want; (b) promote self-determination; (c) utilize natural supports; (d) use guardianship with caution; and (e) respect individual liberty to express sexuality with appropriate education, support and attention to health and safety.

## Position Statement and Policy Recommendations

Responding to our findings, we developed a position statement on social-emotional relationships. The position statement was developed with input from self-advocates, family members, service providers and others. The purpose of the statement is to increase awareness of loneliness and isolation experienced by people with developmental disabilities and to suggest what can be done to overcome barriers that contribute to this issue. To develop the statement, we conducted separate teleconferences with self-advocates and with a group of family members, provider agency staff and others to review an initial statement and gather feedback. Utilizing this input, we finalized the statement and created a second one-page version written in clear language for self-advocates and others (Appendix B). Later, we distributed a press release by email announcing both versions of the position statement to project participants.

Following release of the position statement, we worked with local Charlotte service providers, InReach, Developmental Disability Resources Inc. and Easter Seals/UCP, to develop

policy recommendations to address identified barriers. The policy recommendations address a range of topics related to supporting people with developmental disabilities to safely and responsibly experience healthy social and emotional relationships. These recommendations are detailed below and are available as a separate document.<sup>1</sup>

The position statement and the *Credo for Meaningful Relationships* contributed to our policy recommendations. Each seeks to increase awareness and describes the actions family members, service providers and others in North Carolina should take to reduce the impact of identified barriers on the lives of people with developmental disabilities. Meanwhile, our policy recommendations provide details about how such actions can be taken. As illustrated by the graphic below, we believe that if implemented, opportunities for people with developmental disabilities to live full community lives will increase, yielding improved outcomes. Such outcomes may include increased community integration, reduced loneliness and isolation, and greater numbers of individuals living self-determined lives and experiencing healthy relationships they choose.



Below, policy recommendations resulting from our efforts are organized according to five major themes: (a) align current practice with what people want; (b) promote self-determination; (c) utilize natural supports; (d) use guardianship with caution; and (e) respect individual liberty to express sexuality with appropriate education, support and attention to health and safety. Recommendations are detailed below according to each area.

## 1. Align current practice with what people want

**Belief:** As previously described, self-advocates themselves clearly articulate in the *Credo* what people with developmental disabilities want in regards to opportunities and support to experience healthy friendships and relationships. People with disabilities should:

- Be listened to and respected.
- Be recognized and treated as adults regardless of the challenges they face.
- Make their own decisions and learn from their mistakes.

---

<sup>1</sup> <http://www.hsri.org/project/north-carolina-relationships-initiative/overview/ncri-materials>



- Access people, places, and experiences in their own communities according to their interests and preferences.
- Choose their friends and who they want to spend time with.
- Experience safe and healthy friendships and intimate relationships with the people they choose, regardless of ability, gender, orientation, etc.
- Experience privacy in their homes and rooms to be alone, or with friends or dates.
- Receive comprehensive education about their bodies, sexuality, hygiene, appropriate public and private behavior, and how to protect themselves against abuse, unwanted pregnancy, and disease.
- Have access to open, honest and supportive conversations about making friends, dating, sexual health and safety.
- Be supported by staff and others who respect their right to live self-determined lives in every way possible.

### **Recommendations:**

Self-advocates have spoken – policy makers and service providers must listen. We urge state policy makers and local service providers to assess current practices and individual outcomes against the values laid out in the *Credo*. Questions policy makers and providers might ask include:

- Is the service system responsive to barriers that interfere with individuals achieving valued roles in the community such as neighbor, friend, employee, or spouse?
- Do staff provide ample opportunities for community integration and socialization according to individual goals, interests, and preferences with appropriate education and support?
- Are individuals satisfied with the number and depth of relationships they have with people other than family and paid staff?
- Are individuals satisfied with their ability to see or communicate with friends or significant others when they want to?

## **2. Promote self-determination**

**Belief:** Individuals with intellectual and developmental disabilities have the same human rights and dignity that all humans should expect. All individuals have the right to live self-determined lives according to the guiding principles of self-determination.

Self-determination has been defined many ways. According to self-advocates, “self-determination is a process that differs from person to person according to what each

individual determines is necessary and desirable to create a satisfying and personally meaningful life.”<sup>2</sup> Ideally, this process is based on the principles of self-determination. Five key principles are often used to guide self-determination policy and practice.<sup>3</sup>

- Freedom – with freely chosen family, friends and others – to plan a life with necessary supports rather than purchase a program.
- Authority to control a certain amount of dollars to purchase supports.
- Autonomy. The arranging of resources and personnel - both formal and informal - that will assist an individual with disabilities to live a full life rich in community affiliations.
- Responsibility. The acceptance of a valued role in an individual’s community through competitive employment, organizational affiliations, spiritual development, and general caring of others in the community, as well as accountability for spending public dollars in ways that are life-enhancing for persons with disabilities.
- Confirmation. The obligation to play an important leadership role in improving system policy and practice by providing feedback on their experiences or acting as mentors to peers.

### **Recommendations:**

- Staff should be trained to listen to and support each individual’s choices and preferences and offer appropriate choices and opportunities based on individual age, abilities, wants and needs, as well as concerns for health and safety.
- Educate families, staff, and other supporters about the importance of self-determination to address safety concerns and promote the independence of individuals receiving services.
- Treat all people with dignity and respect. Evidence of respectful treatment includes but is not limited to making eye contact, displaying social etiquette, including the person in conversations, showing common courtesy, acknowledging choice and preferences, allowing individuals to speak up for himself or herself, respecting an individual’s personal space and domain.
- Use person-centered planning methods to help individuals develop meaningful goals, and utilize self-advocacy skills to ensure access to available services and resources. Use this information to connect individuals with resources available in the community. This frequently requires a creative approach and thinking “outside the box.”

---

<sup>2</sup> The Self-Advocacy Association of New York State (SANYS): [http://www.sanys.org/determination/deter\\_3.htm](http://www.sanys.org/determination/deter_3.htm).

<sup>3</sup> The Center for Self-Determination is a working collaborative of individuals and organizations committed to the principles of self-determination. <http://www.self-determination.com>.

- Directly teach individuals choice-making, problem-solving, self-advocacy and leadership skills and provide opportunities to practice such skills in community settings in which they will be used.
- Provide structured opportunities for access to the community based on the interests and values of the individual.
- Provide ample opportunities for individuals to access the community independently and encourage direct interaction with other individuals in the community.
- Support individuals to become regularly attending and contributing members of groups that are formed around areas of interest.

### 3. Utilize natural supports

**Belief:** Natural supports are friends, family members and community members and are an important facet of individuals' lives. Natural supports provide connections, relationships, and safety while diminishing loneliness and isolation.

**Recommendations:**

- Train people providing services to develop and maintain natural support networks and relationships by assessing the existence of natural supports and the desire to build or maintain a network of natural supports that is satisfactory to each individual. Person-centered planning incorporates supports and resources closest to the individual such as family, friends, neighbors and co-workers who can offer assistance in natural ways, as well as other community resources (e.g., businesses, dance clubs, libraries, schools and colleges).
- Develop standard tools to assess the existence of natural supports and intimate relationships in people's lives and to ensure natural supports and intimate relationships exist at a satisfactory level.
  - Examples of these tools include the InReach Person Centered Plan Assessment and the Natural Support Analysis (available from InReach).<sup>4</sup>
- Include information collected with these tools in goals in the Person Centered Plan and in personal activities.
- Document progress toward achieving a satisfactory natural support network.

### 4. Use guardianship with caution

**Belief:** Effective guardianship involves the participation of the person to the highest degree possible when decisions are being made about the person's life or well-being.

Most of us (including people with and without disabilities) do not make big decisions without first consulting someone we trust. Guardianship should never be taken lightly and should only be accessed after alternatives have been explored and it is clear that a person cannot make safe, responsible decisions with support from people close to him or her.

---

<sup>4</sup> <http://www.inreachnc.org>

### Recommendations:

- Explore alternatives to guardianship including Power of Attorney, Living Wills, etc. Disability Rights North Carolina<sup>5</sup> is an excellent resource for this information.
- When necessary, support people to secure competent and responsive guardians to help them make informed decisions if this becomes necessary to ensure the health and safety of the individual. For example, if a guardian refuses to give consent for the individual to take a relationship and/or sex education class, the agency will advocate for the individual. The agency may also refer the individual for advocacy and/or legal services.
- Agency staff must understand North Carolina Guardianship laws regarding different types of guardianship and alternatives to guardianship. Disability Rights North Carolina is an excellent resource for this information.
- **Note:** North Carolina Guardianship Standards<sup>6</sup> do not specifically give the guardian authority of the individual's personal associations. These standards state that "to the maximum extent of his capabilities, an incompetent person should be permitted to participate as fully as possible in all decisions that will affect him."

## 5. Respect individual liberty and expression of healthy human sexuality with appropriate education and support and attention to health and safety.

**Belief:** Supporting people with developmental disabilities to safely experience the relationships they seek is a rewarding experience, yet can be a complex and challenging undertaking. While some people may feel satisfied with multiple friendships; others may choose to have a limited number of close friendships and intimate relationships – including sexual relationships.

### Recommendations:

Sexual relationships present a variety of risks and concerns for health and safety that must be addressed proactively. As a result, many of the following policy recommendations are focused on this topic. Our intention is not to promote sexual relationships. Rather, it is to promote individual rights to experience healthy expressions of human sexuality by: (a) providing appropriate and comprehensive education and support; (b) assuring health and safety; and (c) providing opportunities to express healthy human sexuality. The following recommendations are presented below according to these three categories.

---

<sup>5</sup> Disability Rights North Carolina is an independent, private not for profit organization designated by the Governor to ensure the rights of all state citizens with disabilities through individual advocacy and system change. Disability Rights NC (formerly Carolina Legal Assistance) is part of a national system of federally mandated independent disability agencies. <http://www.disabilityrightsn.org>.

<sup>6</sup> North Carolina Guardianship Standards 35A-1201(5). <http://www.ncids.org/Other%20Manuals/Guardianship%20Manual/Text.htm>.

Provide comprehensive education and support	Assure health and safety	Provide opportunities to express healthy human sexuality
<ul style="list-style-type: none"> <li>• Comprehensive Relationships and Sexuality Education</li> <li>• Consent</li> <li>• Sexual Advocacy</li> <li>• Sexual Contact and Intercourse</li> <li>• Pregnancy Prevention</li> <li>• Pregnancy</li> <li>• Sexual Orientation</li> <li>• Sexually Transmitted Infections</li> </ul>	<ul style="list-style-type: none"> <li>• Reproductive health</li> <li>• Designated Safe Staff</li> <li>• Abuse, Harrassment and Exploitation</li> <li>• Staff-Individual Contact and Boundaries</li> </ul>	<ul style="list-style-type: none"> <li>• Privacy</li> <li>• Cohabitation, Marriage and Unions</li> <li>• Masterbation and Self-Stimulation</li> <li>• Erotica</li> </ul>

## 5a. Provide comprehensive education and support

Comprehensive education and support would benefit people receiving and providing services, family members, agency staff and the broader community. Recommendations for comprehensive education and support cover eight topics including: (a) relationships and sexuality; (b) consent; (c) sexual advocacy; (d) sexual contact and intercourse; (e) pregnancy prevention; (f) pregnancy; (g) sexual orientation; and (h) sexually transmitted infections. Each topic is described below.

### 1. Comprehensive relationships and sexuality education

**Belief:** Pursuing relationships of choice is a basic human right. All persons have the need to develop and maintain personal relationships that are meaningful to them. They also have the right to obtain accurate, current and factual education regarding relationships and sexuality. The denial of sexual education to people with intellectual disabilities has contributed to exploitation, abuse and misinterpretation of behavior.

#### Recommendations:

- Provide comprehensive sexuality education to all individuals served and their families, staff and other supporters. Access additional resources and services when necessary.
  - This education should include but not be limited to interpersonal skills; communication, decision-making, assertiveness, sexual self-advocacy and refusal skills; sexual health and hygiene; and information related to sexuality and specific disabilities; education to help decrease the risk of victimization and abuse and reduce the risk of unwanted pregnancy and

disease; and actions that can be misinterpreted as behavior with a criminal intent.

- There are many curriculums available to choose from. Provider agencies should select a curriculum that best suits their needs or develop their own. The *Safe Sex Handbook* and the *Sexuality Education for Adults with Developmental Disabilities* curriculum were utilized during this project.
- Individuals may need other resources and services to develop and maintain healthy relationships. Agencies should access available community and other resources to address these needs. This requires agencies to maintain current knowledge of community resources.
- Other resources and services may include counseling, family planning, medical treatment, legal services, etc. as determined appropriate by designated staff according to individual circumstance.
- Provide education directly to people receiving and providing services and direct support for safe, legal and consensual relationships. Access additional resources and services when necessary.
- Provide support to individuals as they establish personal relationships with the people they choose.
  - This support may include creating partnerships, developing relationships, building bridges with other community organizations or individuals to create social opportunities in the community according to an individual's interests and preferences.
- Teach responsible behavior consistent with the norms of the communities in which individuals live.
- Develop procedures to gather information about current or potential personal and/or sexual relationships directly and respectfully from the individual to determine whether health and safety issues are present and what education, support, or additional resources (e.g., counseling, family planning, etc.) the individual needs to develop and maintain a healthy relationship. For example:
  - Privately discuss the relationship with the individual to determine the nature of the relationship including how they met; how the relationship has developed to date; where the individuals see the relationship going; and how roommates or family members feel about the relationship.
  - Meet the friend if the relationship is more than casual to assess safety.
  - Determine education or service needs to support healthy relationship development or other assistance as needed.
- Develop procedures for intervening respectfully when there are concerns for the safety of the person receiving services.

## 2. Consent

**Belief:** Any relationship, including a sexual relationship, must be consensual; that is, it must involve the willing participation of those in the relationship. A person's ability to understand the nature of sexual activity and the implications or consequences of that activity is a key component of consent. Due to the varying levels of cognitive ability, as well as the fact that people with intellectual disabilities have been denied sex education and have had few typical opportunities for a range of social and sexual activities, questions may arise concerning ability to give informed consent in social or sexual situations.

### **Recommendation:**

- Address the issue of consent through education to both people receiving and providing services, families and other supporters. Ensure that this education is tailored to the person receiving services receives and that he or she understands this education to the best of his or her abilities. Provide supports as needed.

## 3. Sexual Advocacy

**Belief:** Everyone has the right to advocate for themselves in areas that impact their lives. Relationships and intimacy are two critical areas in which people have the right to speak for themselves to get their needs met.

### **Recommendations:**

- Provide education directly to individuals with developmental disabilities regarding self-advocacy and sexual self-advocacy. This education is best provided by peers.
- Provide agency-wide support for an individual's right and need to speak for themselves concerning these subjects in any situation.
- Train direct service staff to support self-advocacy and sexual self-advocacy. Access additional resources and services when necessary.

## 4. Sexual Contact and Intercourse

**Belief:** Sexual contact and intercourse – defined as any physical contact between people that involves genital contact, or contact with breasts or buttocks, including oral, anal and vaginal sex – is a right of consenting adults regardless of sexual orientation, creed, color or disability. A sexually intimate relationship is recognized as an exciting and fulfilling time, and a significant developmental and lifestyle marker. With this experience comes the obligation to make responsible decisions.

Individuals should be fully informed and able to consent before they begin a sexual relationship. Unwanted pregnancy, disease and abuse are all legitimate concerns related to sexual contact. However, these risks should not automatically preclude individuals from experiencing sexual contact. Providing education and experience

regarding sexuality and relationships will help those who have historically been denied access to both to undertake responsible decisions.

**Recommendations:**

- Provide education to people receiving and providing services, families, and other supporters regarding how the agency supports individuals to make choices regarding sexual contact.
- Provide education, support and “Designated Safe Staff” (see below) to support healthy, consensual sexual contact. Access additional resources and services when necessary.

**5. Pregnancy Prevention**

**Belief:** For those who choose to engage in heterosexual behavior, pregnancy prevention is a critical issue. Everyone has a right to choose birth control options to prevent pregnancy.

**Recommendation:**

- Provide education regarding the importance of pregnancy prevention, and support the birth control method of choice for individuals through accessing medical and/or family planning services.

**6. Pregnancy**

**Belief:** The decision to become a parent and raise a child must be made with an understanding of the financial, emotional, and time commitments involved. The parent(s) should also be aware of the risks involved if these commitments are not met. However, having an intellectual disability does preclude people with developmental disabilities from being a responsible parent.

**Recommendations:**

- Provide education, counseling and support surrounding the decision of an individual woman with regard to pregnancy. Access additional resources and services when necessary.
- Provide similar information to any partner of the pregnant woman with regard to his or her role and responsibilities.
- Determine whether the agency is licensed to provide support to individuals under the age of 18 and communicate the agency’s position on supporting individuals to raise their children.

**7. Sexual Orientation**

**Belief:** People have the right to be in consensual relationships of choice with those of the same or opposite gender. Although sexual orientation is often subject to divergent attitudes, all individuals need to discover and express who they are free from external pressures, prejudices and discrimination. Regardless of orientation or gender, everyone has a right to intimacy within a consensual relationship.



**Recommendation:**

- Provide education and training to both people receiving and providing services, families and other supporters. Access additional resources and services when necessary.

**8. Sexually Transmitted Infections**

**Belief:** All those who are sexually active are at risk for Sexually Transmitted Infections or STIs (known diseases that can be transmitted through sexual contact and/or exchange of bodily fluids).

**Recommendations:**

- Support the use of condoms and dental dams as safe-sex practices.
- Provide education to prevent STIs. Access additional resources and services when necessary such as those offered through community health practitioners or Planned Parenthood.
- Train staff to treat people with STIs and/or HIV without discrimination.

**5b. Assure health and safety**

Recommendations related to assuring the health and safety of people receiving services address four areas: (a) reproductive health; (b) designated safe staff; (c) abuse, harassment and exploitation; and (d) staff-individual contact and boundaries. Each of these recommendations is presented below.

**9. Reproductive Health**

**Belief:** Everyone experiences some level of risk for disease or other health issues related to reproductive organs whether sexually active or not. Everyone has the right to education, information and resources to protect themselves, prevent disease and support a healthy life.

**Recommendations:**

- Provide age and gender-appropriate education and support to men and women with disabilities of all ages to prevent disease and health issues, recognize symptoms of problems, take care of one's own health (e.g., conduct breast exams) and access medical care when necessary.
- Support individuals to seek regular, medical check-ups including annual breast and pelvic exams for adult women, annual mammograms for women ages 40 and older, annual prostate exams men ages 50 and older, and assessment of risk for certain cancers (e.g., breast, prostate, etc.) and other life-threatening illnesses.

## 10. Designated Safe Staff

**Belief:** Everyone should have someone to communicate with who is trusted, safe, informed and concerned; and who is compelled to provide effective problem-solving support. This is especially important for people with disabilities who often do not have natural supports to fill this role.

### Recommendations:

- Train a team of Designated Safe Staff to provide accurate information and support related to general areas of relationship and sexuality. Access to Designated Safe Staff will also reduce the risk of sharing private and personal information with people with whom they are unfamiliar.
- Provide education to people receiving and providing services, family members and other supporters regarding the roles and responsibilities of Safe Staff, who an individual's Safe Staff is, and how and when to access them.
- Safe Staff will provide support limited to their scope of knowledge and will provide access to additional resources and services as needed.

## 11. Abuse, Harassment and Exploitation

**Belief:** Everyone has a right to be free from abuse, coercion, exploitation and harassment. People with intellectual disabilities are recognized as one of the most victimized groups in society, with those providing care the primary abusers. People with disabilities must be made aware of their rights to a safe place to live and to be supported by safe, respectful staff. They must also learn how to understand and report abuse.

### Recommendation:

- Provide education and support to people receiving and providing services, Designated Safe Staff, families and other supporters to address potential abuse, harassment and exploitation. Access additional resources and services when necessary.

## 12. Staff-Individual Contact and Boundaries

**Belief:** Touch and informal conversation may be easily misinterpreted by the people directly involved and/or observers. Understanding physical and emotional boundaries helps to ensure that people will develop and maintain effective relationships. This understanding also helps people recognize potentially unsafe contact and to avoid behavior that may be misinterpreted.

### Recommendations:

- People providing services will model socially acceptable touch and speech in every situation.

- Sexual contact between those providing and those receiving services is prohibited at all times.
- Provide education and support to staff providing services related to ethics regarding service relationships. Access additional resources and services when necessary.
  - For example, new staff should not provide assistance in the bathroom before the individual indicates this level of comfort with a direct support staff.
  - Develop a routine procedure for bathing and supporting an individual to use the bathroom. Educate people receiving and providing services regarding this standard to safeguard privacy and prevent inappropriate touch.

### 5c. Provide opportunities to express healthy human sexuality

Recommendations in this area are based on the assumption that sexuality is a natural part of human life and that all humans – including individuals with intellectual and other developmental disabilities – have the right to express sexuality with dignity, responsibility, and in ways that are healthy and respectful of the rights of others. Again, our intention is not to promote sexual relationships. Rather, it is to promote individual rights to experience healthy expressions of human sexuality. Topics in this area include: (a) privacy; (b) cohabitation, marriage and unions; (c) masturbation and self-stimulation; and (d) erotica.

#### 13. Privacy

**Belief:** Everyone is entitled to privacy regarding his or her body and personal space. This is critical to their mental and emotional well-being, and for understanding and maintaining a safe and healthy distance from others.

#### **Recommendations:**

- Provide education and direct staff support to ensure privacy. This includes ongoing evaluation of how staff balance human dignity with privacy and support in intimate areas (e.g., assisting an individual in the bathroom).
- Eliminate rules that restrict an individual's privacy to use the bathroom or be alone or with a friend or date in his or her own room or home.

#### 14. Cohabitation, Marriage and Unions

**Belief:** Everyone has the right to opportunities for consensual live-in partnership with the person of his or her choice. This is a significant developmental and lifestyle marker and one of the most important decisions a person can make.

**Recommendations:**

- Provide education to people receiving and providing services, families and other supporters regarding sexuality and relationships to help people undertake safe and healthy decisions regarding long-term partnerships.
- Provide education about the federal marriage penalty and how marriage can affect benefits. Access additional resources and services when necessary.

**15. Masturbation and Self-Stimulation**

**Belief:** Masturbation is a natural sexual exploration of one's own body that is acceptable when done in a safe, private place. An understanding of privacy, appropriateness, and gentleness is essential. Although people with intellectual disabilities are often misinformed about masturbation, and have been punished for practicing this form of sexual expression, everyone is entitled to an atmosphere of comfort and calm regarding this private sexual expression.

**Recommendations:**

- Support safe and private opportunities for masturbation. Access additional resources and services when necessary.
- Provide education to people receiving and providing services about safe and private places where this form of sexual expression is appropriate and not appropriate.

**16. Erotica**

**Belief:** A broad range of sexually explicit material is available. Therefore, adults may need assistance in accessing material that is enjoyable, respectful to human dignity and does not present sexual violence, illegal activity, or violate state or federal laws.

**Recommendation:**

- Provide support to an adult requesting access to use and own any legal erotic materials if they are used responsibly and privately, and without the potential for criminal behavior. For example, provide staff support to a person receiving services to access adult materials online or at a local adult shop.

## Discussion

Across the country, people with developmental disabilities frequently experience loneliness and isolation. This issue is also evident in North Carolina where multiple barriers described above prevent people with developmental disabilities from experiencing the healthy social and emotional relationships they seek.

We commend the North Carolina Council on Developmental Disabilities for addressing this complex and sensitive issue by funding the North Carolina Relationships Initiative. As a result of this project, North Carolina is poised to take intentional action to address this issue and produce better outcomes for people receiving developmental disability services. Outputs from our efforts include increased public discussion about this issue, a powerful *Credo for Meaningful Relationships* written by self-advocates, a position statement that describes actions stakeholders can take, and specific policy recommendations, which challenge disability service providers and others to change current practice.

We believe that future efforts taken by self-advocates, family members, service providers, policy makers and others will contribute to better outcomes including reduced loneliness and isolation, increased community integration, self-determination and reliance on natural supports, and increased opportunities for people with developmental disabilities to have people they care about in their lives. This initiative is just at its beginning. We urge the Council to continue addressing this issue and identified barriers with additional funding and/or partnerships with other organizations that have expressed interest in this project including InReach, Disability Rights North Carolina, the North Carolina Coalition Against Sexual Assault and others. Such initiatives or partnerships could include efforts to:

- Implement policy recommendations. This can be done by developing a community of practice that functions to create one or more pilot projects and supports each other to change service practices that act as barriers.
- Create a network of educators – including self-advocates as trained co-facilitators – to provide widespread and targeted education to people receiving services, people providing services, and family members around the state.
- Enlist local self-advocacy groups to present the position statement and *Credo for Meaningful Relationships* to press for systems change.

Given the increased awareness and momentum this initiative has generated, we believe many are prepared to take action to reduce identified barriers that lead to loneliness and isolation. Self-advocates, family members, provider agency staff and others who contributed to this project expect nothing less.