

WHEREAS

People with intellectual and developmental disabilities (IDD) want to have healthy social and emotional relationships with others, including romantic relationships. Yet, too often, we find that people with IDD regularly experience loneliness and isolation more than people without disabilities. These conditions increase the risk of experiencing disease, abuse, and neglect. Results from the 2008 National Core Indicators Survey show that about half of people with IDD in North Carolina surveyed are lonely at least some of the time. Additionally, about 1 in 4 said they have no one to talk to about personal matters.

Further, in focus groups and interviews conducted across North Carolina, people with IDD, family members, provider agency staff, and others report an absence of individual control over one's own life, and lack of support necessary for individuals with IDD to experience the healthy social and emotional relationships they seek.

People with IDD face a variety of barriers that prohibit them from experiencing healthy social and emotional relationships. Four primary barriers include:

- Genuine and sometimes overstated concerns for the health and well-being of people with IDD. Many are concerned about the health and well-being of people with IDD. Yet, such concerns are often taken too far. Guardians, family members, and staff though well-intentioned can easily over-reach individual choice and preferences to limit opportunities for relationship development.
- A system bias in policy and practice that discourages people with IDD from developing healthy relationships. Such biases are embedded within rules, regulations, and daily practice that minimize opportunities for individuals to experience a wide range of relationships with others in the community including people without disabilities.
- Enduring and outdated beliefs about people with IDD that suggest they are incapable of experiencing healthy relationships. For example, family members, staff, and others mistakenly believe that people with IDD are asexual or are not capable of handling an intimate relationship.
- Insufficient effort from policy makers, service providers, family members, and people with IDD to overcome these barriers. Many witness the barriers people with IDD face; yet seem content to allow the effects of these barriers to continue. This is unacceptable. We can do more.

WE BELIEVE ALL

People with intellectual and developmental disabilities (IDD) should be supported to pursue opportunities to develop a wide range of healthy social and emotional relationships with others based on individual interests, preferences, and desires to participate in community life.

The NCRI project is funded by the North Carolina Council on Developmental Disabilities. Learn more about NCRI at www.hsri.org/project/north-carolina-relationships-initiative.

NOW, THEREFORE, WE CALL ON

The North Carolina Department of Health and Human services and its divisions;

The North Carolina Council on Developmental Disabilities and its constituents;

North Carolina service providers and their trade associations;

Family members and their family advocacy associations;

Individuals with IDD, their local self-advocacy groups, and The Association of Self-Advocates of North Carolina

TO TAKE THE ACTION THAT EACH CAN TAKE

To overcome the barriers that keep people with IDD from experiencing healthy social and emotional relationships; and to assure that people with IDD receive the support they need to pursue opportunities they prefer to develop the relationships they seek.

EXAMPLES OF THESE ACTIONS INCLUDE

- Increase access to the community and opportunities for people with IDD to develop a wide range of relationships with others with and without disabilities living in their communities.
- Inspect and revise policies and practices that encourage and permit overstated and over use of guardianship.
- Clarify and reassert the rights of people with IDD to control their own lives, including the relationships they have with family members and guardians.
- Discover and eliminate unwarranted and silly rules created by well-intentioned staff and others that hinder the ability of people with IDD to experience healthy relationships.
- Provide appropriate education to providers, paid staff, family members, people with IDD, and others to recognize the capabilities of people with IDD to develop relationships and live a rich community life. Such education should include opportunities for people to learn from peers and practice what they have learned.
- Make a concerted effort to increase opportunities for people with IDD to interact with each other and others in the community with the support they need – including transportation.