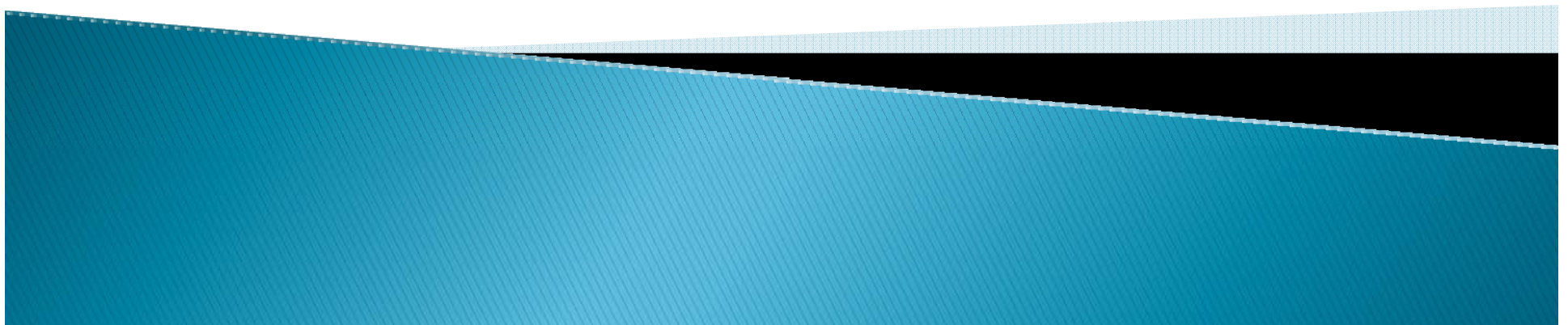# Friendships, Relationships, and Supports for People with Intellectual Disability

A Literature Review.
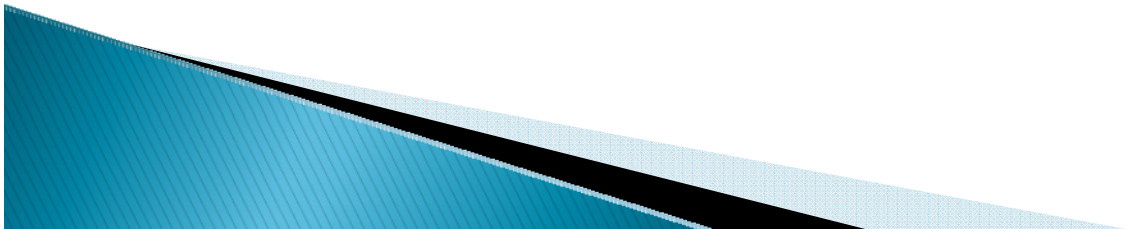
Orla Kelly

National Federation of Voluntary Bodies, 2010

# Agenda

- Themes

- Social Exclusion – Social Inclusion

- Institutionalisation Vs Community Living

- Construct of Disability?

- Methodology

- What matters?

# Themes

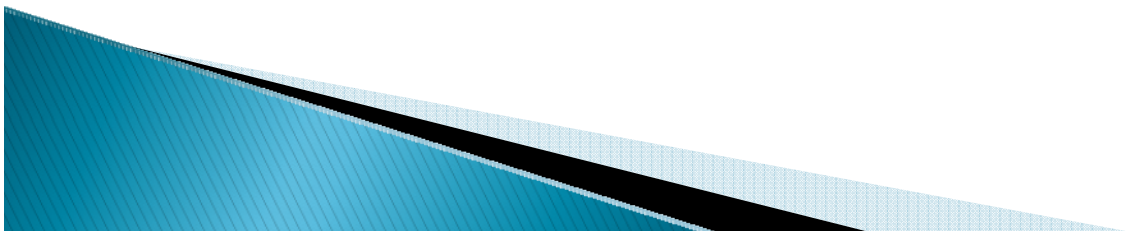- People with intellectual disabilities are not easily developing relationship networks

  (Whitehouse et al, 2001; McVilly et al, 2006)

- People with intellectual disabilities understand the importance of satisfying relationships to the quality of life and their social status but many do not participate

  (Chapell, 1994)

- People with intellectual disabilities have very few meaningful relationships with people who do not have intellectual disabilities, are not relatives, and who are not paid to support them
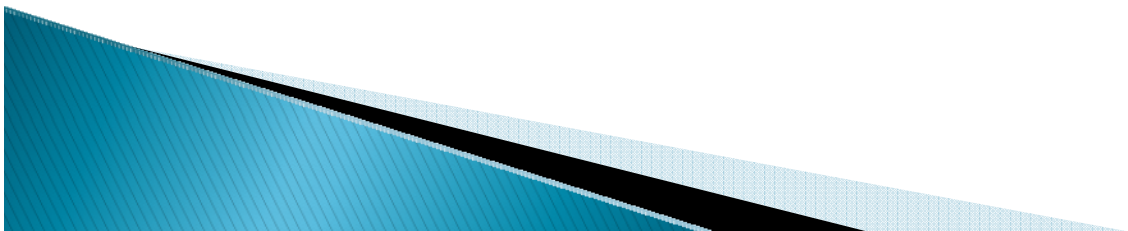
  (Robertson et al, 2001)

# Themes

▶ **Meaning of Friend:**

- A pivotal relationship
- A pervasive part of a person's life
- A sense of shared history
- An opportunity to share common interests
- A reliable but reciprocal source of support

➢ **Maintaining a Friend**

- Making arrangements
- Balancing other relationships
- Remembering and reminiscing
- Opportunities for autonomy
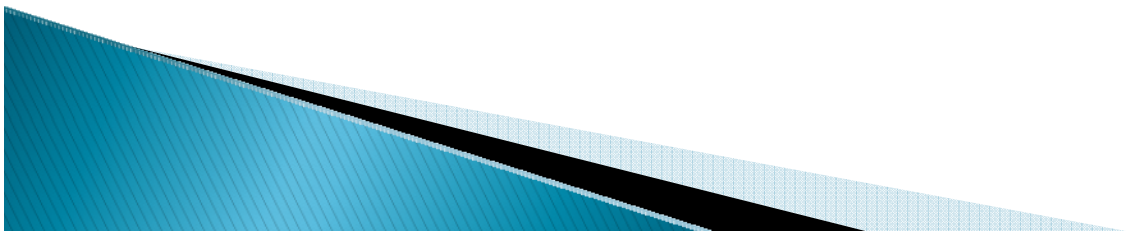- Living arrangements

(Knox et al, 2001)

# Themes

- ▸ **Meaning of a Boyfriend/Girlfriend:**
  - Characteristics of a boyfriend/girlfriend
  - Feelings of Intimacy
  - Physical Attractiveness
  - An expectation of relationship change

- ➤ **Maintaining a Boyfriend/Girlfriend**
  - Dating
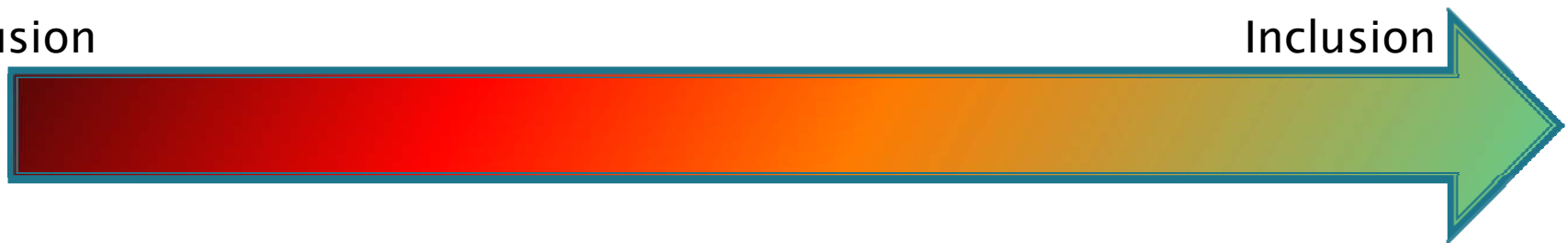  - Spending time alone
  - Planning for the future

(Knox et al, 2001)

# Social Exclusion –Social Inclusion
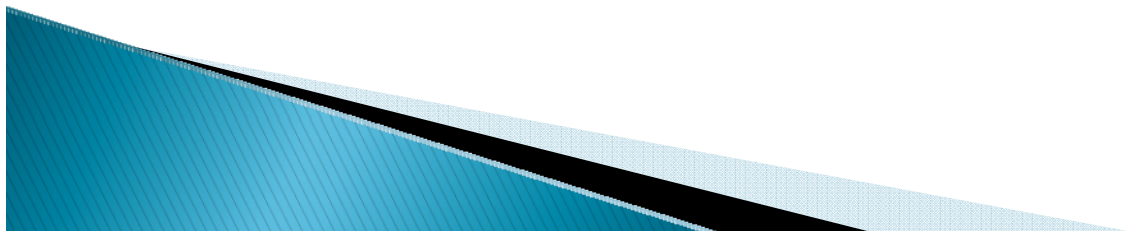
Social Exclusion

Social Inclusion

- Not being Listened to
- Having No Friends
- Finding it Difficult to do the things that People without Intellectual Disabilities do
- Being made that they have no Contribution to make, they are a Burden
- Feeling Unsafe, being Harassed, and Bullied
- Not having Control over Spending Money, not having Enough Money

*Morris, 2001.*

- Require more than just placing people in proximity to others.
- Means a sense of belonging that is fostered through the development of Valued Relationships
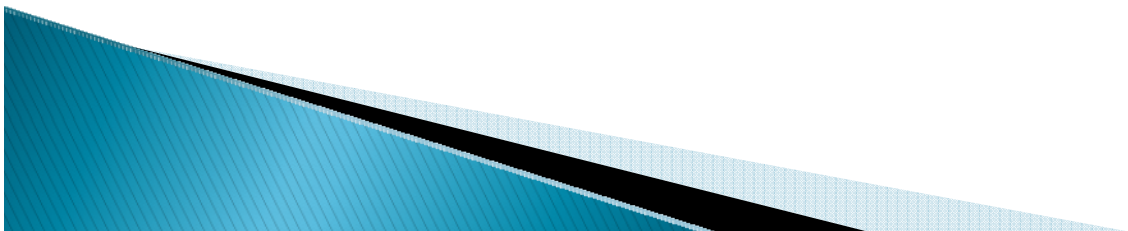
*Pockney, 2006.*

# Institutionalisation Vs Community Living

Community
Living

Institutionalisation

•Segregation
•'Distinct Social Space'
•Friendships with People
With Intellectual Disability,
Carers, Family .
•Asexual.

•Segregation
•'Distinct Social Space'
•Friendships with People
With Intellectual Disability,
Carers, Family .
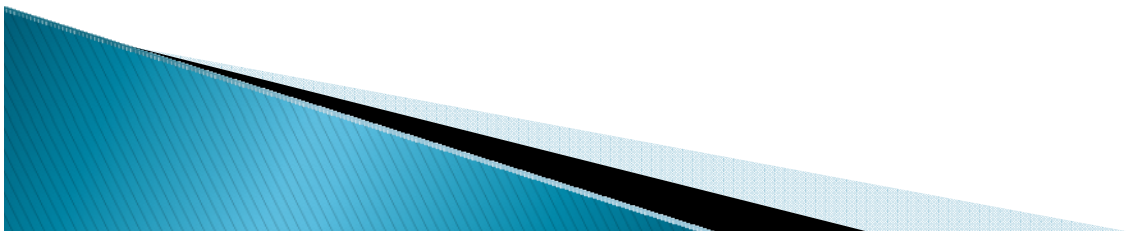•Community Presence
•May have Sexual Identity

# Construct of Disability?

People With Intellectual Disability

Community Integration

Staff & Families

Service Delivery & Priorities
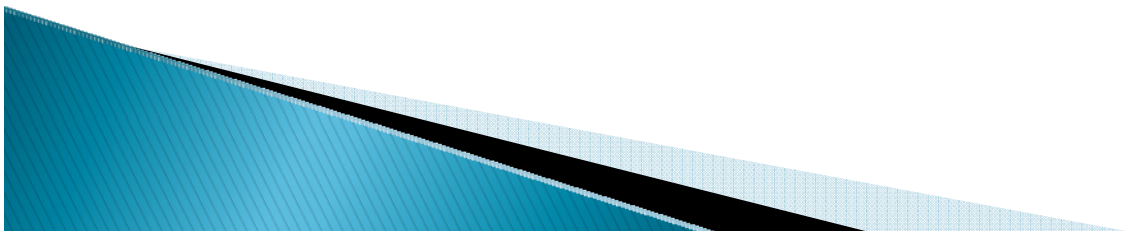
# Construct of Disability?

People With
Intellectual
Disability

⬇

A Lack of Social Skills
Behaviour & Communication Difficulties
(Forrester /Jones et al, 2006)

⬇

Development of Social Skills & Behaviour
Sex Education based on Biology, (Chivers et al, 2000)

# Construct of Disability?

Friendships for people with intellectual disabilities appear to count for little in the estimation of those who control their lives (Emerson & McVilly, 2004)
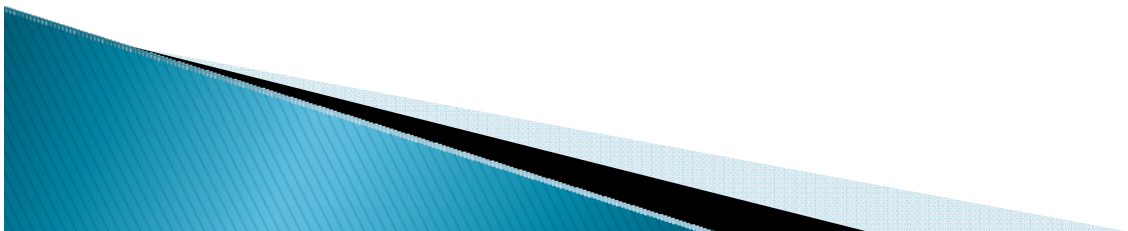
Staff felt that they needed to retain a degree of power if they were to adequately protect and provide (Pahl et al, 2000)

Staff fear of favouring one person over another – professional distance (Pockney, 2006)

Staff & Families

# Construct of Disability?

Tasks need to be done (Clement et al, 2009)

Parents hold more conservative views relating to sexuality than staff (Cuskelly & Bryde, 2004)
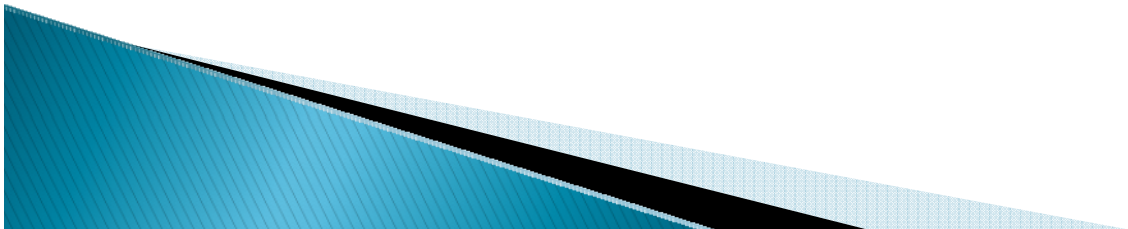
Staff do not feel confident working with gay/lesbian/bisexual (Abbott & Howarth, 2006)

Need for training, education and more information

Staff & Families
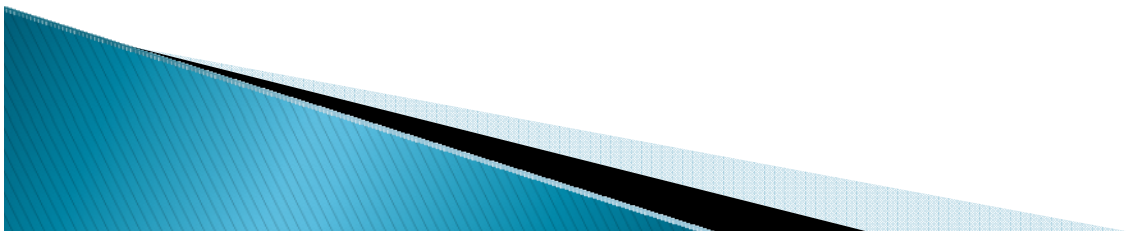
# Construct of Disability?

Examples of how Staff & Family support Friendships:

•Finding their Friends Phone Numbers
•Having Support to Exchange Cards at Birthdays
•To initiate contact and extend invitations
•Help identify Train and Bus routes

(McPilly et al, 2006)

Staff & Families
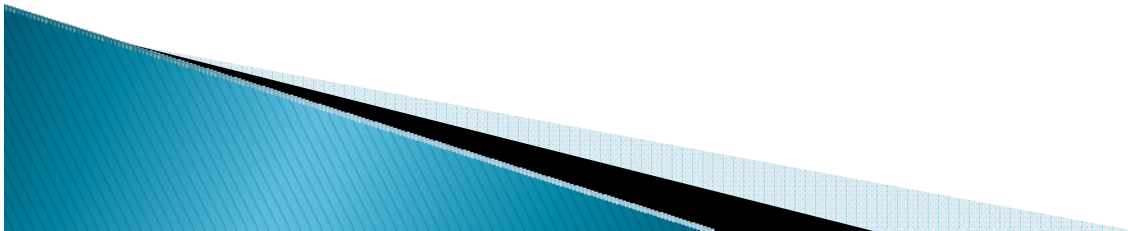
# Construct of Disability?

Economic, lack of transport, cuts in services, lack of access to one's money, organisation of staffing, poor access to resources, lack of autonomy, lack of privacy, personal info brought into public domain, residents publicly disciplined  (Abbott & McConkey, 2006; Chappell, 1994)

Barriers to making and maintaining friendships and relationships:

Service Delivery & Priorities

# Construct of Disability?

Positive outcomes derive from the absence of the overt subordination of residents to staff (Randell & Cumella, 2009)
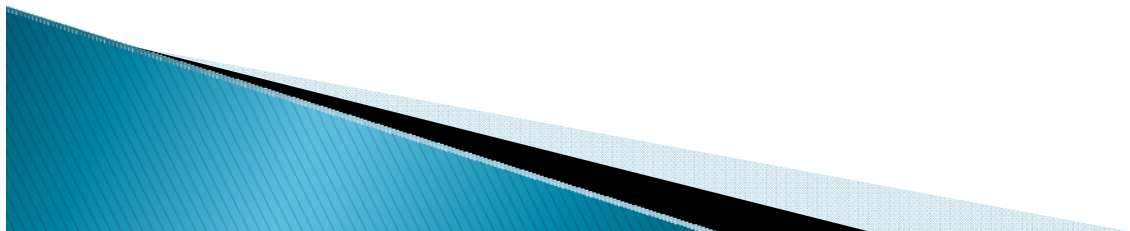
⬆

Need to listen to what people with intellectual disabilities want (Miller, 2008)

⬆

Need to intervene at a systems level (Emerson et al, 2004)

⬆

| Service Delivery & Priorities |

# Construct of Disability?

In times of spending restraint: 3 service goals to help focus costs on things that matter

Need to maintain or improve –
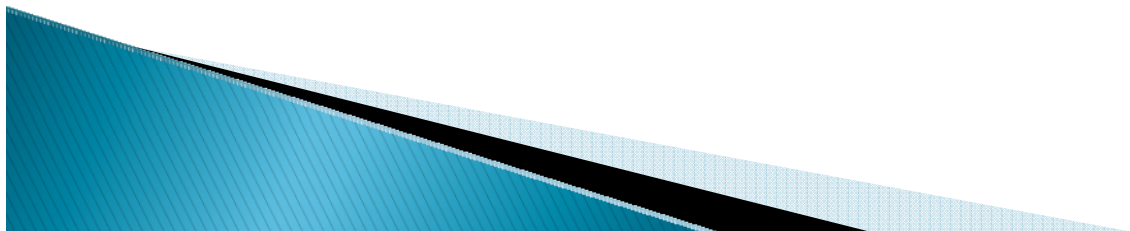1. good conditions of life
2. each person's happiness
3. the ways people have of becoming enabled to lead fulfilling lives of their own choosing

(Brown, 1999)

Service Delivery & Priorities

# Construct of Disability?

Mere community presence does not result in integration into the community (McVilly et al, 2006)
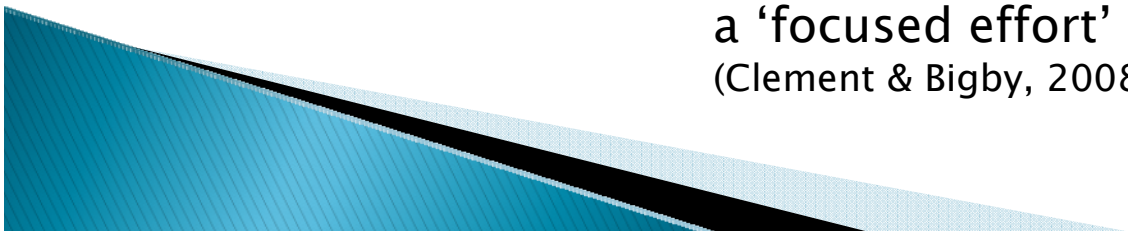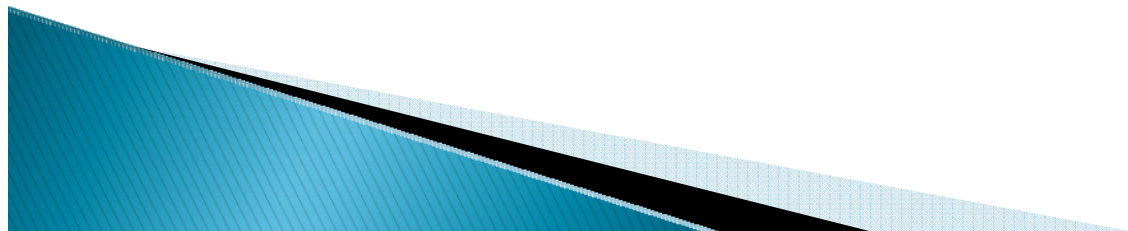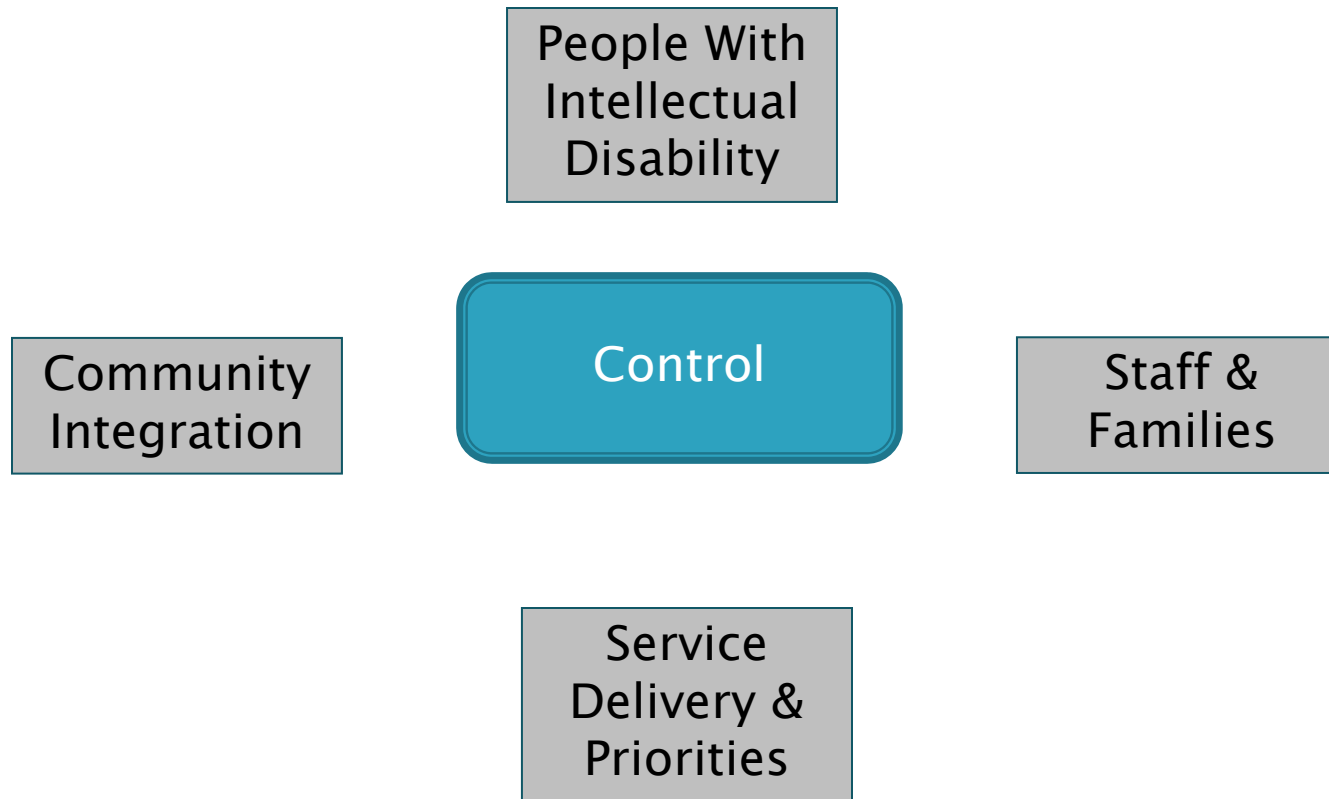
**Community Integration**

There needs to be an opportunity for social interaction – community activities around socialisation (Kampert & Goreczny, 2005)

There needs to be an examination of the importance placed on organisational tasks over a 'focused effort' for community participation (Clement & Bigby, 2008)

# Construct of Disability?

People With Intellectual Disability

Community Integration

Control

Staff & Families

Service Delivery & Priorities

# Construct of Disability?

The power that service workers have to support, enable or actively destroy an individuals relationships cannot be ignored (Knox & Hickson, 2001)

Control needs to be relinquished and people with Intellectual Disabilities need to be supported to take up this control

**Control**

We need to listen to what people want for themselves (Miller, 2008)
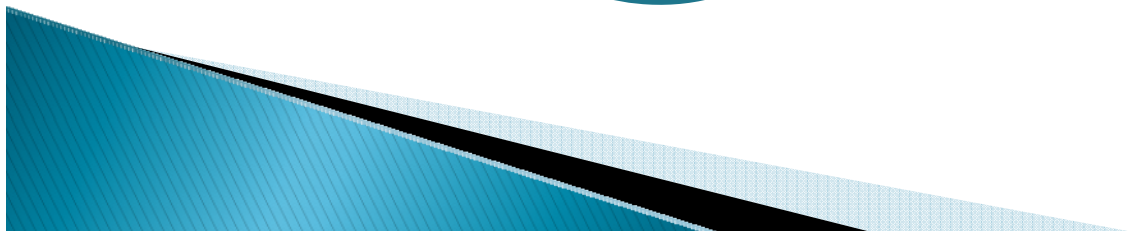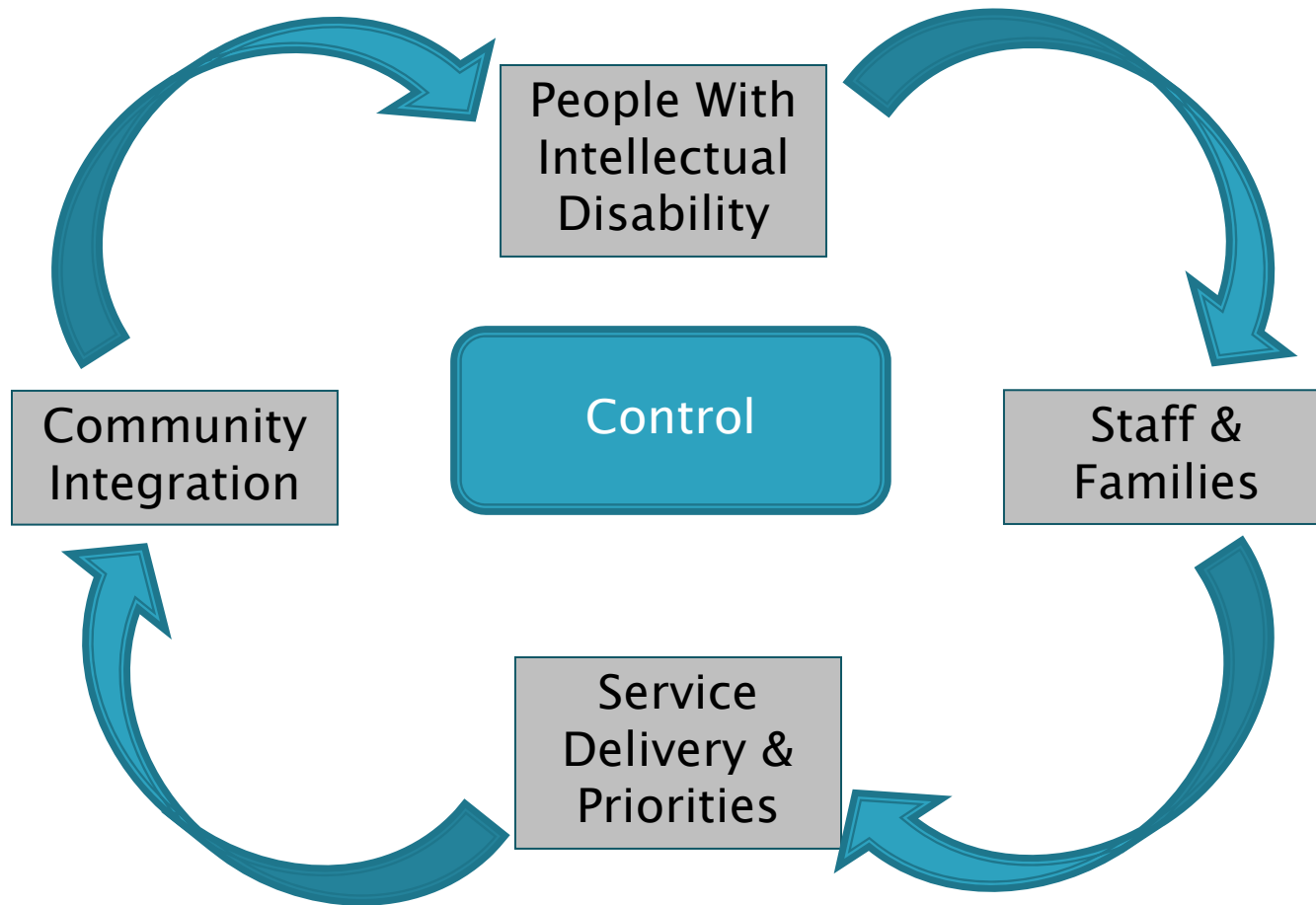
We need to "allow" people with Intellectual Disabilities to put their own meaning on friendship and how they wish to maintain them (Knox & Hickson, 2001)

We need to understand the importance of our friendship as staff members to people with Intellectual Disabilities and not devalue it

# Construct of Disability?

# Methodologies
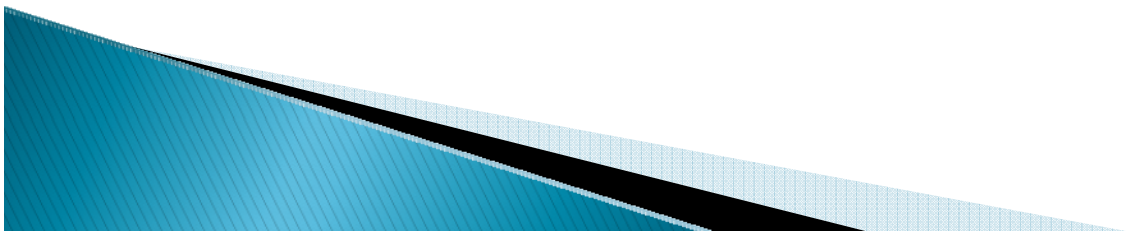
- Social Network Guide            (Forrester-Jones, 2006)
- Ethnographic Observations         Randell & Cumella, 2009)
- Longitudinal Study            (Jahoda et al, 2009)
- Quality of Life Questionnaire        (Miller, 2008)
- The Social Support Self Report       (Lippold et al,2009)
- The Social Inclusion Interview Schedule     (Pawson et al,2005)
- Personal Outcome Measures         (McCormack et al,2009)
- Workshops and Group Discussions      (Abbott & McConkey, 2006)
- Six Session Programme – Linking feelings with personal relationships
-
                                (Jobling et al, 2000)
- Participatory Research where consent was ongoing    (Knox et al, 2001)
- The Loneliness Scale            (McVilly et al, 2006)
- The Roommate Friendship Scale       (Wiltz et al, 2003)
- Sexual Attitudes Questionnaire  (Grieve et al,2008)
- Sexual and Mental Retardation Attitudes Inventory    (Bazzo et al, 2007)
- The Perception of Sexuality Scale      (Swango-Wilson,2008)
- SexKen-ID                 (McCabe et al, 1999)
- Assessment of Sexual Knowledge      (Galea et al, 2004)

# What Matters?

"Ultimately, it is not citizenship, but friendship that matters"

(Reinders, 2002)

# What Matters?

"What aspects of peoples lives facilitate or hinder friendships and participation in activities with friends"

(Emerson, 2004)