Incapacity and People with Intellectual Disabilities
A Social Construction?

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History

- Congregation and segregation
- Control of reproductive capacity
- Religious perspective
- Deviancy and failure
Current Context

- Deinstitutionalisation - move from congregated settings

- Increased number of people with intellectual disabilities in the community

- Increased opportunities for relationships and for engaging in sexual intercourse

- Increased possibility of pregnancy (Gillberg & Geijer-Karlsson 1983)
• People with intellectual disabilities have been set up historically as deviants…
  – …different from others…in one or more dimensions…which are perceived as significant by a majority or ruling segment of society…who value this difference negatively
How Have they Been Marked Apart?
(Wolfensberger 1972)

- Relegated to low (‘deviant’) status
- Rejected, perhaps by family, neighbours, community, society, service workers
- Cast into multiple historic deviancy roles
- Symbolically stigmatised, ‘marking’, ‘deviancy-imaging’, ‘branding’
- Make to live in a state of multiple jeopardy
- Distanced: usually via segregation and also congregation
- Disempowered with loss of control, perhaps of autonomy and freedom
- Given lives of physical, social and relationship discontinuity
- Starved of natural/freely-given relationships with substitution of artificial/‘paid’ ones
- Deindividualised
- Made materially poor
How Have they Been Marked Apart?
(Wolfensberger 1972)

• Impoverished of experience, especially that of the typical, valued world
• Excluded from knowledge of/participation in higher-order value systems
• Made to have their lives wasted
• Brutalised
What has been the result of these processes?

Differentness

Deviation From the Norm

Deviant

Non-human
• Pre-human
• Sub-human

Menace, Evil, Object of Dread

Discardable

Object of Ridicule
What has been the result of these processes?

Differentness

Deviation
From the
Norm

Deviant

Object of Pity
Burden of Charity

Eternal Child
Holy Innocent

Client

Sick/Diseased
As Good as/
Better off Dead
What has been the result of these processes?

- Differentness
- Deviation From the Norm
- Deviant
- Disenfranchised
- Rights Violations
- Different Treatment
- Inhumane Treatment Justifiable
Significance of this for Rights and Equality

- Acceptance of the devaluation of people with intellectual disabilities has arguably become enshrined in society and in society’s response to these people.
Significance of this for Rights and Equality

Enshrining of the deviancy model of intellectual disability in society

**SERVICE DEVELOPMENT BASED ON PERCEIVED NEED**
- Led by professional experts
- Power-driven with denial of autonomy or capacity

**DEVELOPMENT OF DISABILITY THEORY AND CONTEXT**
- Perpetuation of theoretical context for control

**SOCIAL SUPPORT BASED ON MODEL OF DISABILITY**
- Model-making
- Definition of specialist roles
- Perpetuation of power in professionals/services
So…what is the experience of people with intellectual disabilities in Ireland today?

Where have we come from?
Institutionalisation
Institutionalisation with the ‘walls’
Community-Based Models
Independent Living Models
So…what is the experience of people with intellectual disabilities in Ireland today?

What is it like now?
A Strategy for Equality 1996

Criminal Offences Sexual Offences Act 1996

Modern Capacity Legislation

UN Convention on The Rights of People With Disabilities 2006

choose
...where normal life takes place...

...where people can have the ‘good things in life’...

Relegation to lower status
Rejection by society
Deviant-making
Marginalisation

Material poverty
Impoverished experience
Exclusion from value systems

Loss of control over life
Discontinuity
Deindividualisation
Congregation & regimentation

Dehumanisation
Life-wastage
Brutalization
Feeling of worthlessness

Society
• Inadequate access to health services
• Poor health outcomes

• Increased mental health problems
• Inadequate access to mental health services

society

…where normal life takes place…

…where people can have the ‘good things in life’…

• Inadequate access to education
• Inadequate access to work

• Presumed lack of capacity & loss of control
...where normal life takes place...
...where people can have the ‘good things in life’...

- Poor health outcomes
  - Specialist health practitioners

- Education/Work
  - Special Schools/Sheltered Workshops

- Inadequate access to mental health services
  - Specialist mental health practitioners

- Presumed lack of capacity & loss of control
  - Protective withholding of rights
...where normal life takes place...
...where people can have the 'good things in life'...

- Inadequate access to mental health services
- Specialist mental health practitioners
- Poor health outcomes
- Presumed lack of capacity & loss of control
- Protective withholding of rights

- Education/Work
- Special Schools/Sheltered Workshops
Nothing Changes!

• The problem is that health inequalities, work inequalities, educational inequalities, mental health inequalities are just that…

Inequalities!
Nothing Changes!

• The solution cannot be found in tampering with individual service approaches…

Inequality is a societal issue which must be addressed at that level
• Disabled people should ‘collaborate with God to avoid creating further pain and sorrow’ by sublimating their sexual urges into ‘friendship, or something more transcendental’.

• Parents of disabled ‘impure’
  – At a meeting in Sicily of 1,500 Opus Dei followers, Bishop Echevarria was quoted as saying that "according to scientific research" 90 per cent of handicapped people had been born to parents who had "not entered into marriage in a pure state".

  (12th April 1997) The Times
• Children with disabilities should be sterilised as babies
• What would be the product of persons with Down Syndrome?
• People with Down Syndrome cannot love and should not be allowed to have relationships.
• All people with severe learning disabilities should be sterilised.

Adrian Kennedy Phone Show – FM104 (22nd July 2009) – source BCC Complaints Decisions 2nd September 2009
Levels of Action

Specialist support

ACTORS

Healthcare
Education
Medical
Employment

MARGINALISED

MAINSTREAM SOCIETY

INEQUALITY

Political/Social action
Implications for this Conference

• Presumed incapacity suggests that there is no need to really *listen* to people with intellectual disabilities

• If we are to explore capacity, we (society) must divest ourselves of the historic contexts that have clothed our perspectives

• We must start out as humans and citizens and listen with openness to these people
IDRights: Human Rights and People with Intellectual Disabilities
An Inclusive, Participatory Action Approach
IDRights

Participation

Education

Campaigning

Action

Dissemination
IDRights

• Participation, Education and Action
  – Rights Day conferences in September 2009/2010
  • More than 300 people with intellectual disabilities attended along with their supporters
What did we find out?

Participants said that these were the important rights:

- To be able to work
- To be happy
- To be listened to by staff
- To choose where to live
- To be a parent
- To buy and choose my own clothes
- To be able to have respite
- To be able to vote
- To have my own bank account
- To be able to have education
IDRights

• Participation, Education and Action
  – Rights Day conferences in September 2011
    • More than 100 people with intellectual disabilities attended along with their supporters
    • The ‘Our Say, Our Rights’ Quilt Project
IDRights
What did we find?

These People want

- **CHOICE & NORMAL LIVING PATTERNS**

  Freedom and Change, Choice, Travelling on Buses, Going Out and About, To go to the Cinema, To Go for a Meal, To Make Music, To Make a Snowman, To Swim, To Colour, To Make Things, To Go to Concerts, Buying Clothes, To Go Shopping, To Go to the Aviva Stadium, Choose, Choice, My goals, pick my own clothes, choice, To Have a Life, To Party, To Have a Meaningful Day, Have Fun, activities, Holidays, to travel, to travel, To have a pet, to have a cat, to have a dog, leisure, religion
What did we find?

These People want

• FAMILY, FRIENDS AND RELATIONSHIPS
  Love, Marriage, Relationships, Friends, Family, meeting people, visiting home, friendship, friend

• TO BE HEARD
  Speaking Out, Standing Up, Having a Voice, Be Heard, to be listened to, to be heard, Vote, Ask Questions, on the committee

• HOME & PERSONAL SPACE
  Home, Personal Space, Privacy, House, home, house, Belonging
What did we find?

These People want

- **HEALTH & SUPPORT**
  Hospital treatment, Supports, Right to Green Environment

- **RESPECT & EQUALITY**
  Not to be Shouted at, Safety, Freedom from Abuse, Respect, Equality, same treatment, To be Happy, To Share, Fairness

- **WORK & MONEY**
  Employment, To Work in a Garden, To work, To work, to be a hairdresser, To be Paid Fairly, To have money, To Spend Money, to be a DJ
What have we learnt?

• We need:
  – To engage with people with intellectual disabilities in a context of equality…not in the context of service provision
  – To listen to…and to work with them
  – To amend our processes and languages to ensure that all can participate equally
‘…while both humanization and dehumanization are real alternatives, only the first is the people’s vocation.’

Freire 1996:25