

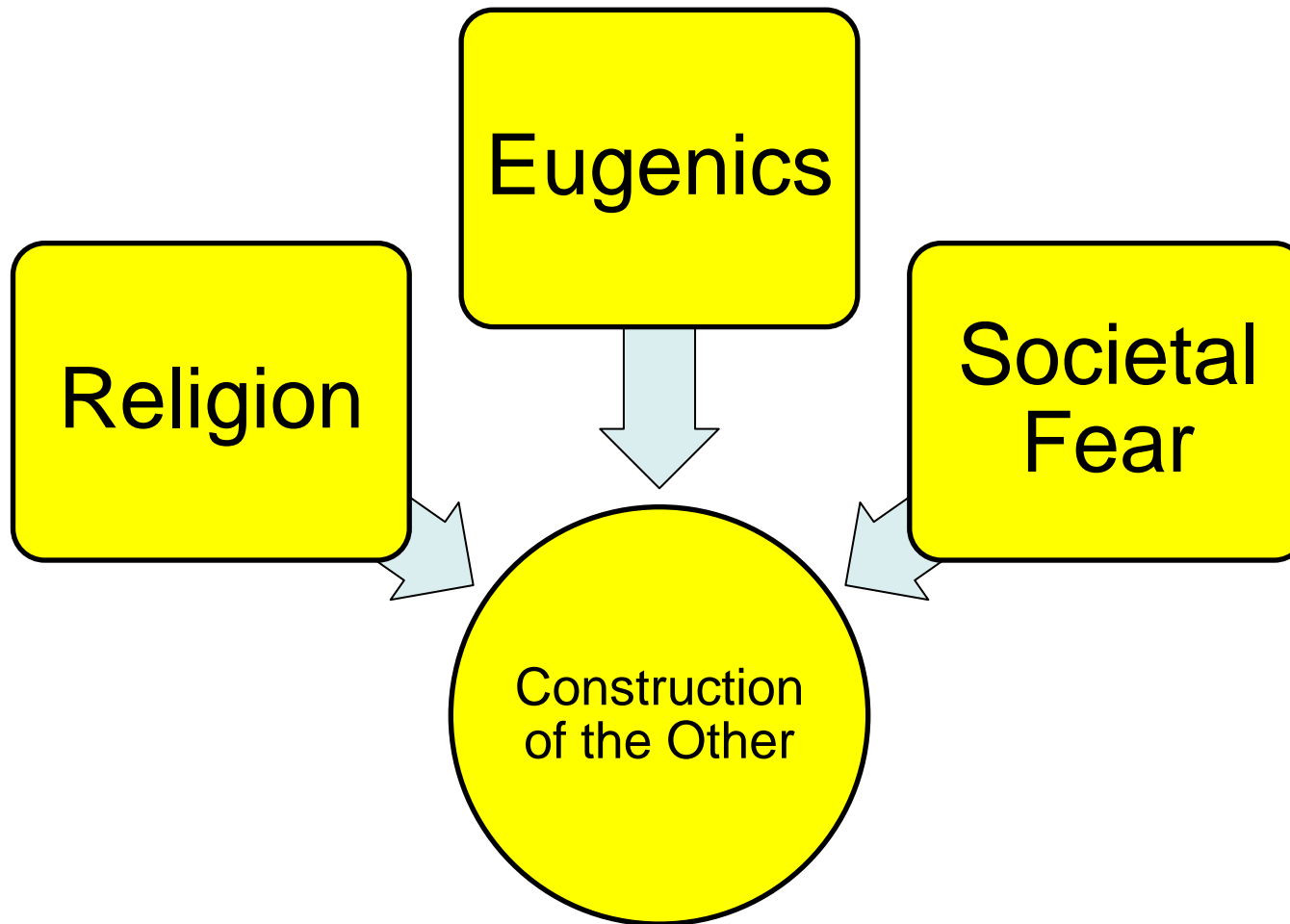
Incapacity and People with Intellectual Disabilities A Social Construction?

Dr. Fintan Sheerin

Lecturer in Intellectual Disabilities

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)

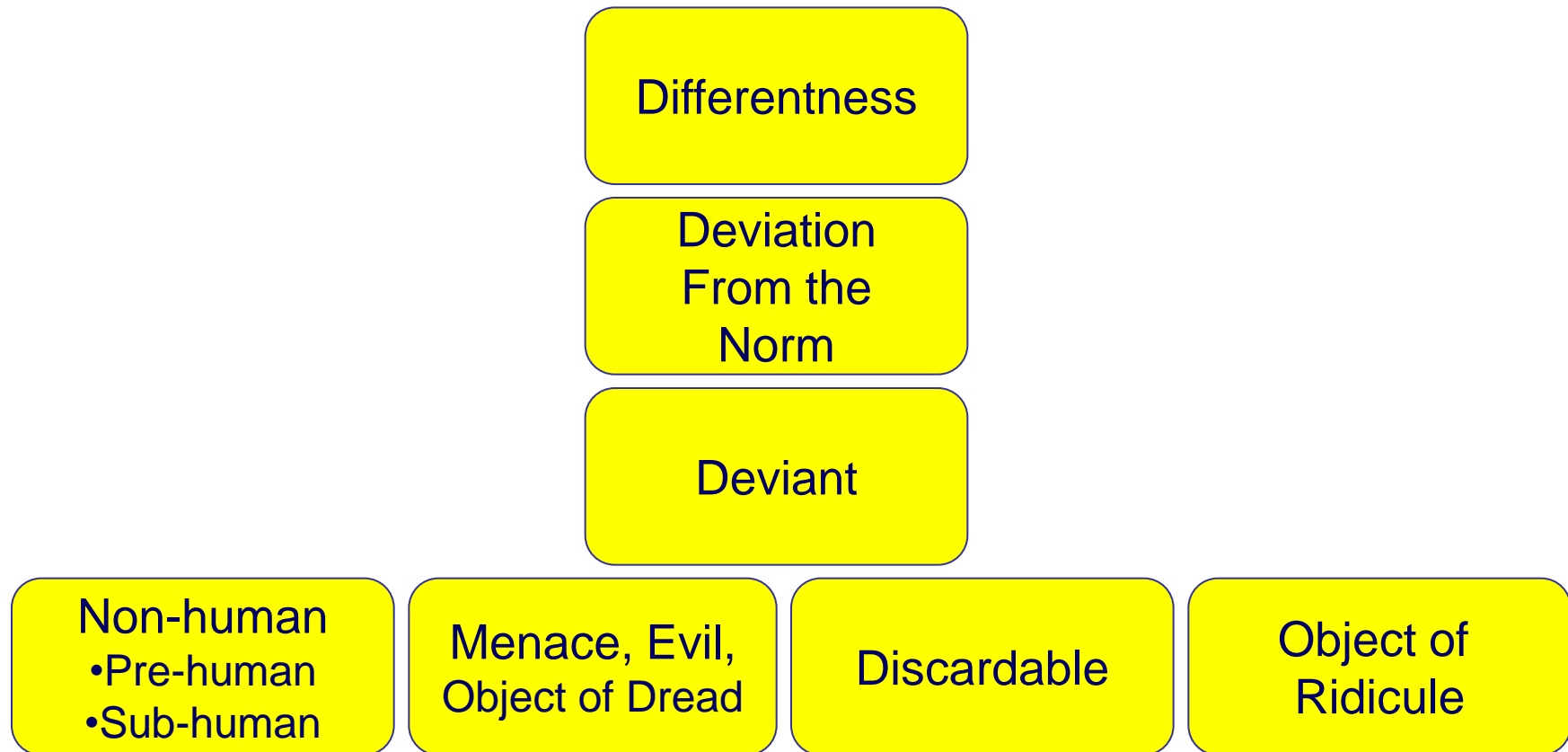
- Relegated to low ('deviant') status
- Rejected, perhaps by family, neighbours, community, society, service workers
- Cast into multiple historic deviancy roles
- Symbolically stigmatised, 'marking', 'deviancy-imaging', 'branding'
- Made to live in a state of multiple jeopardy
- Distanced: usually via 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?

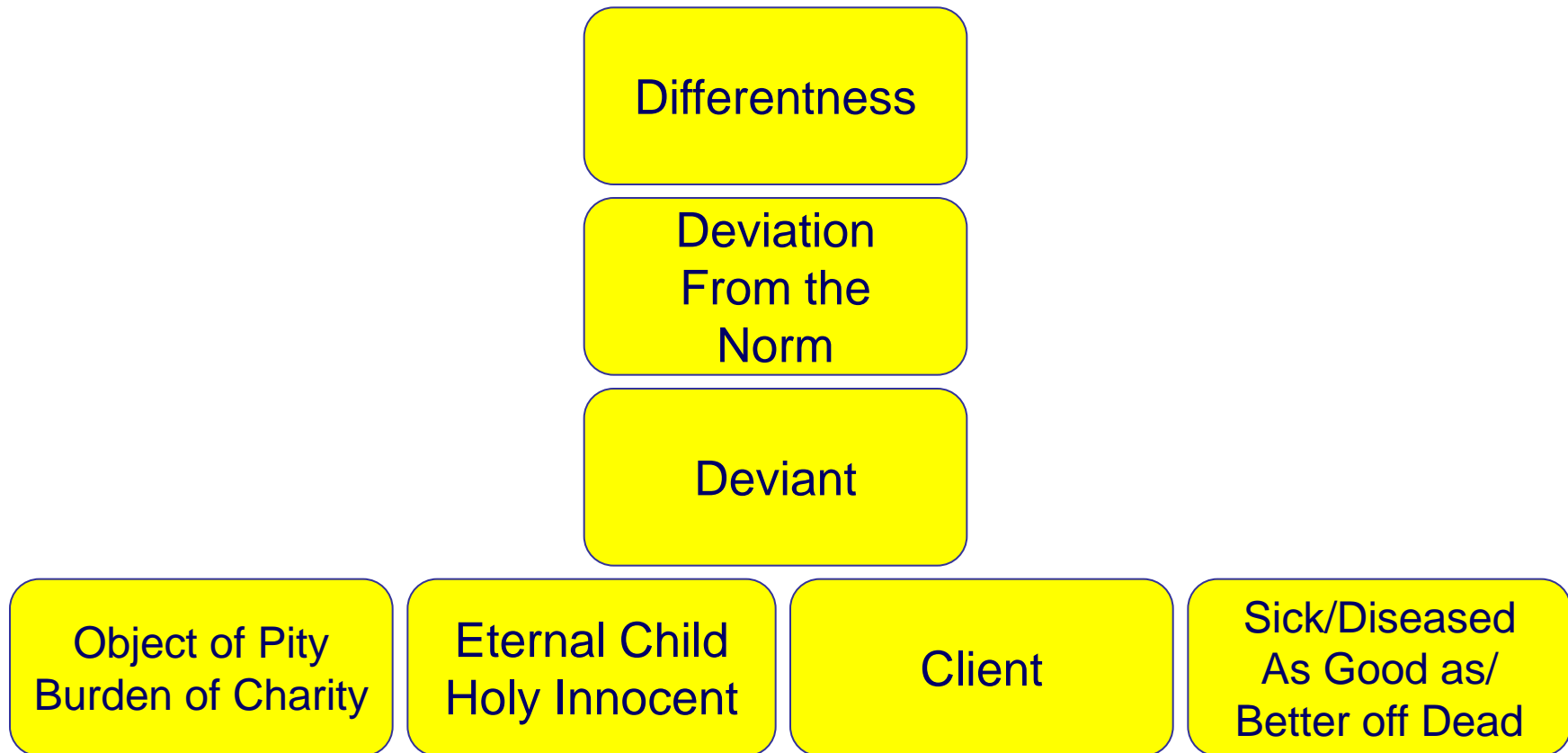
(Wolfensberger 1972)

- 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

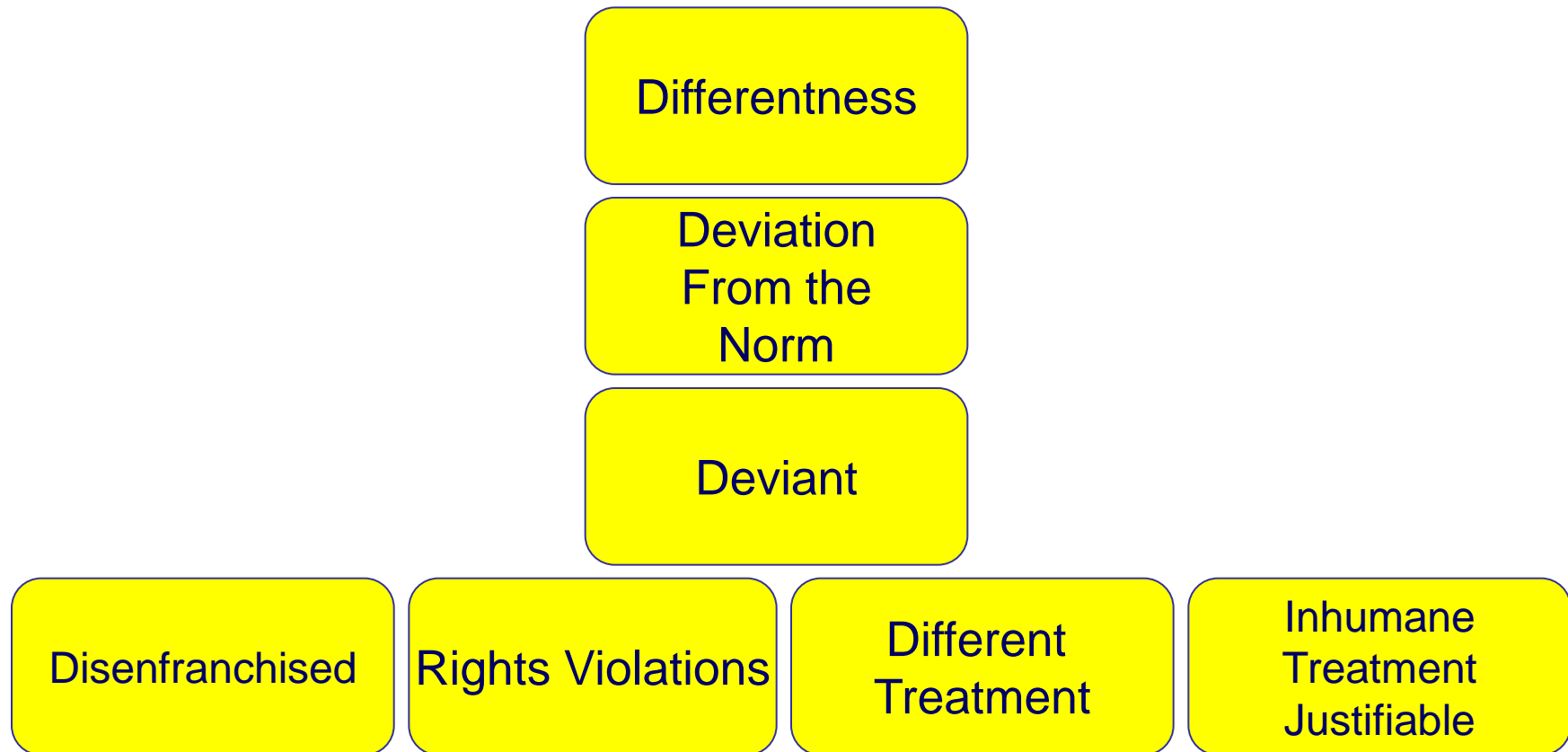
What has been the result of these processes?



What has been the result of these processes?



What has been the result of these processes?



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

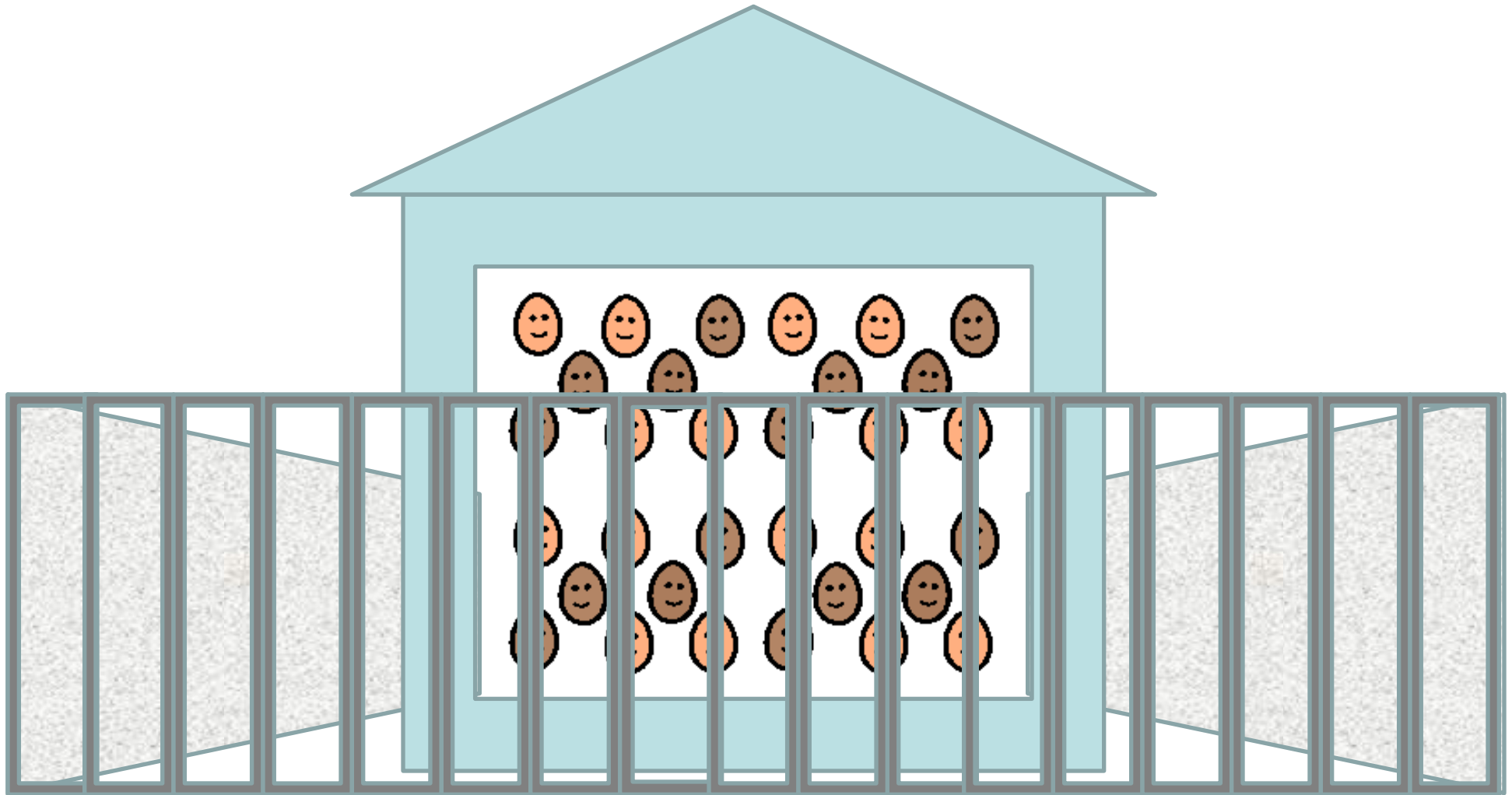
**SOCIAL SUPPORT
BASED ON
MODEL OF
DISABILITY**

- Model-making
- Definition of specialist roles
- Perpetuation of power in professionals/services

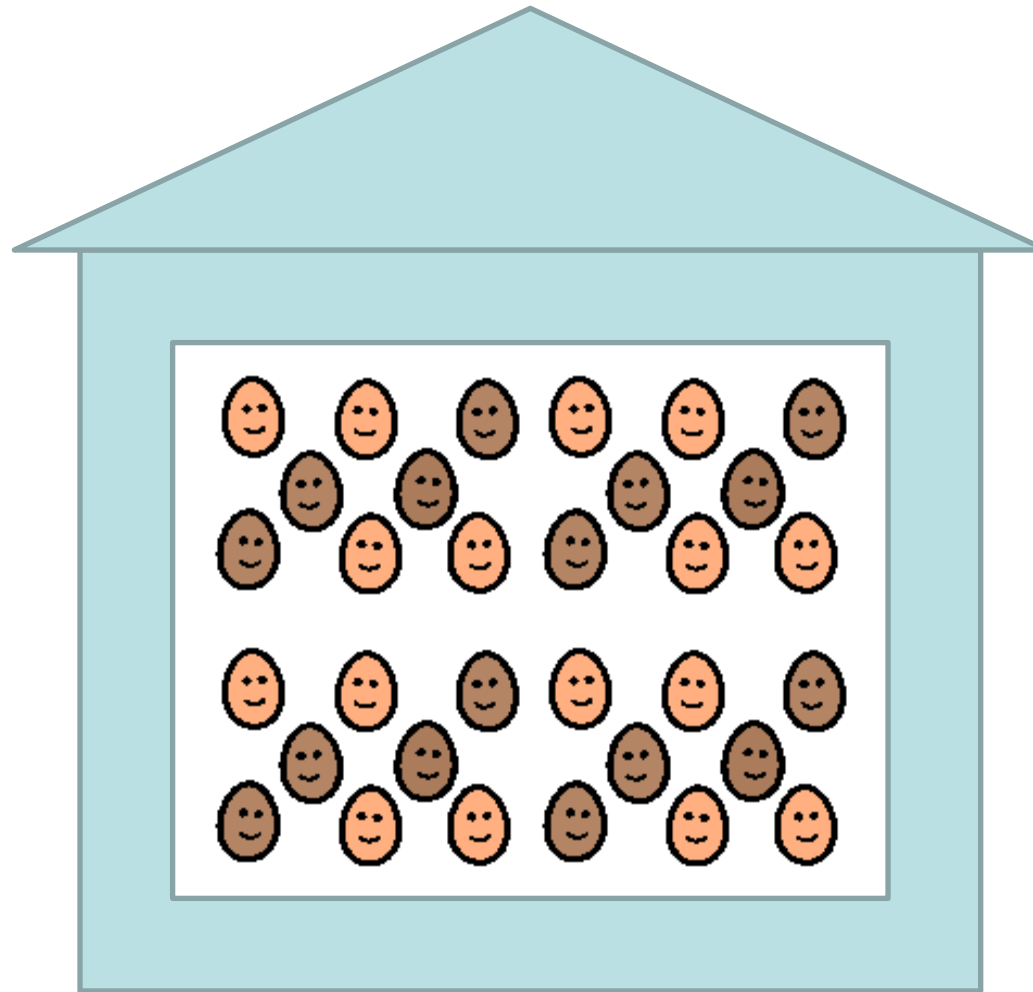
So...what is the experience of people with intellectual disabilities in Ireland today?

Where have we come from?

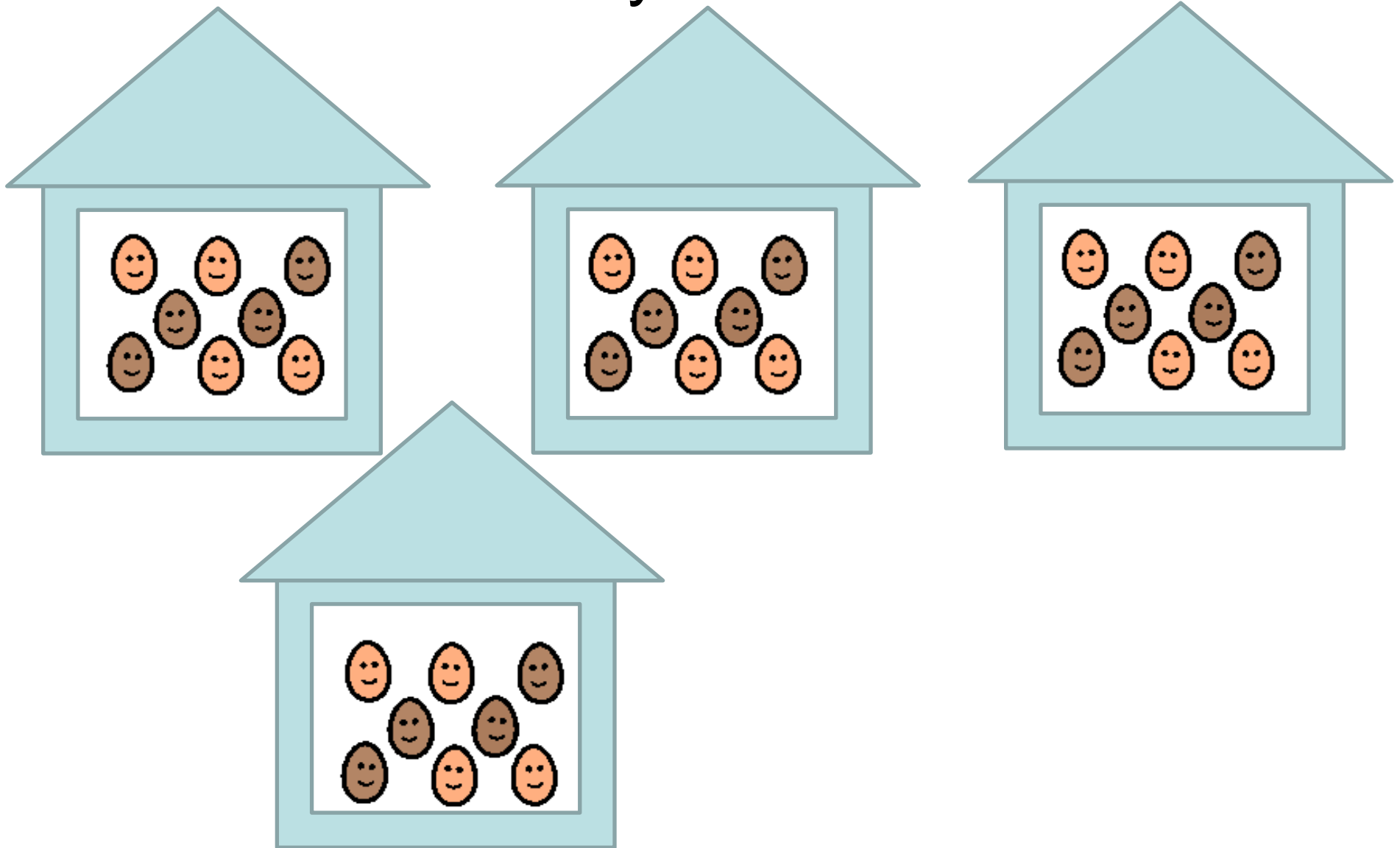
Institutionalisation



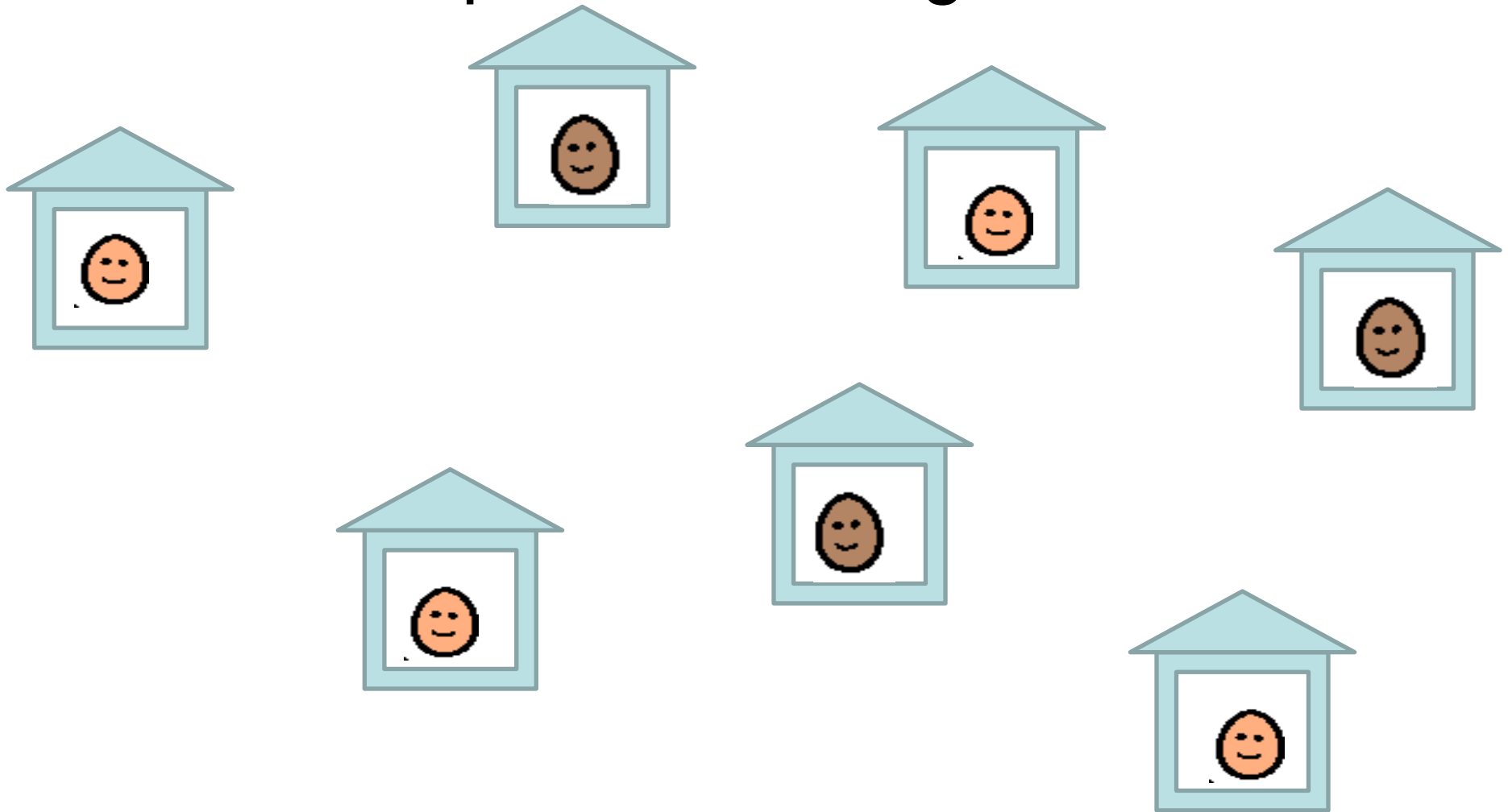
Institutionalisation with the 'walls'



Community-Based Models

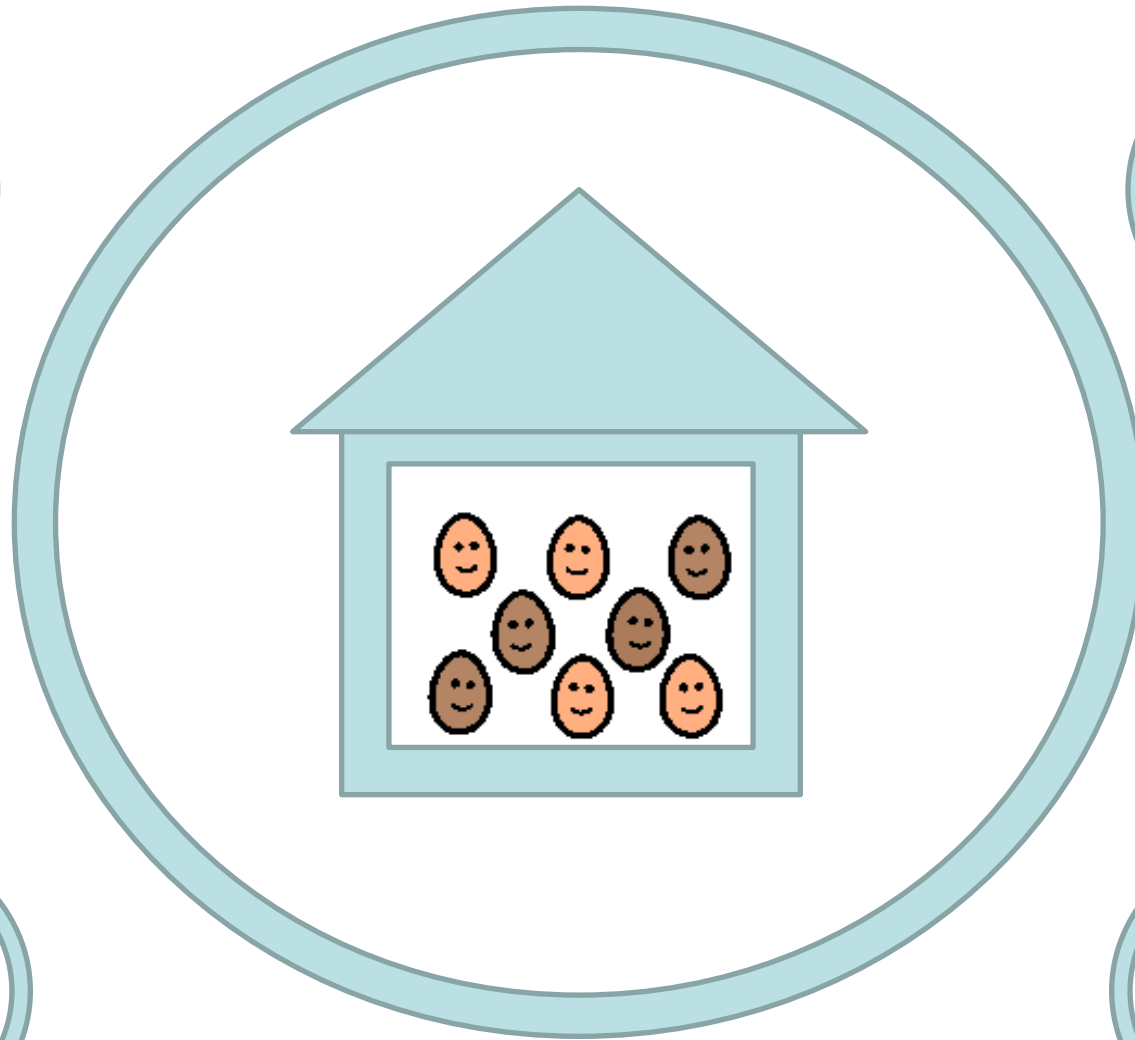
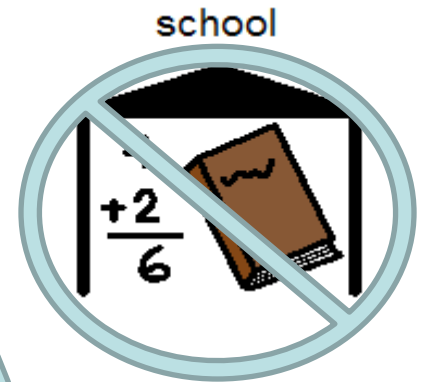


Independent Living Models

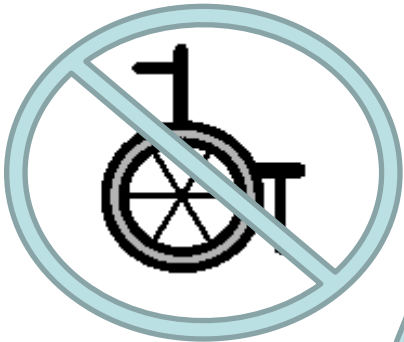


So...what is the experience of people with intellectual disabilities in Ireland today?

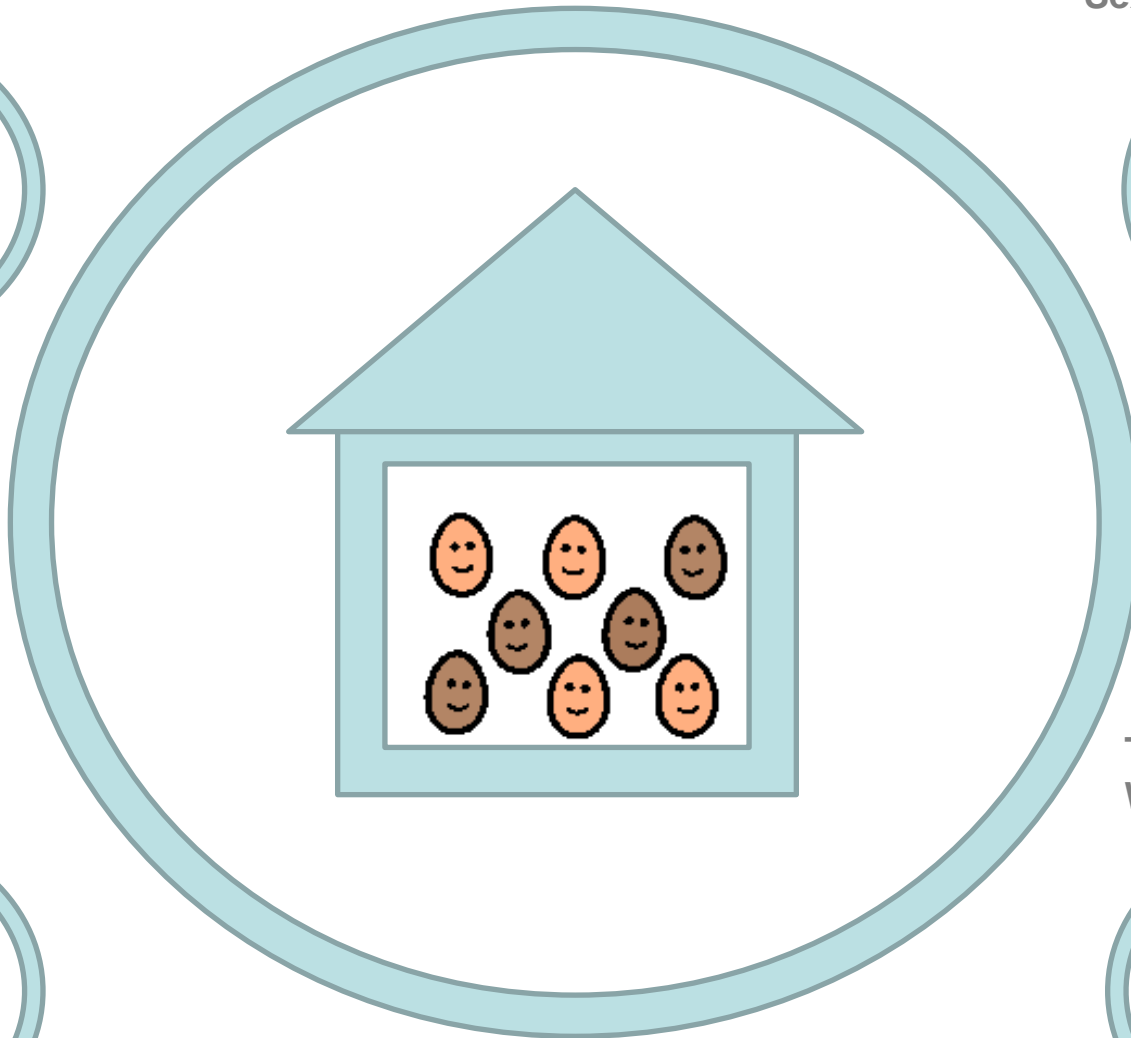
What is it like now?



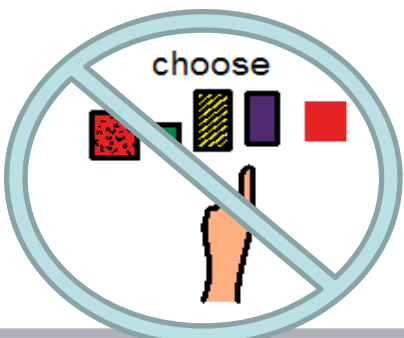
A Strategy for Equality
1996



Criminal Offences
Sexual Offences Act 1996

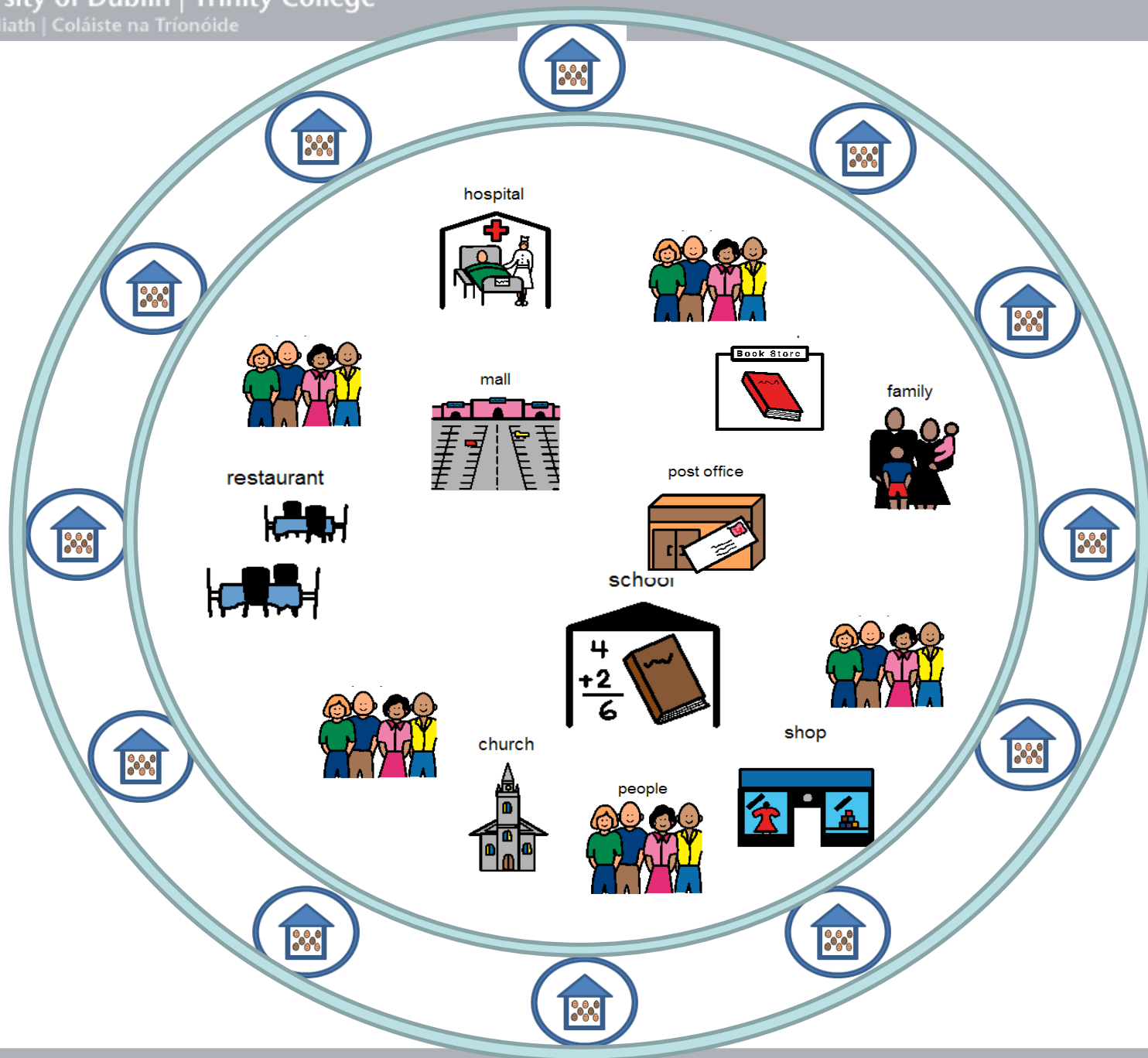


Modern Capacity
Legislation



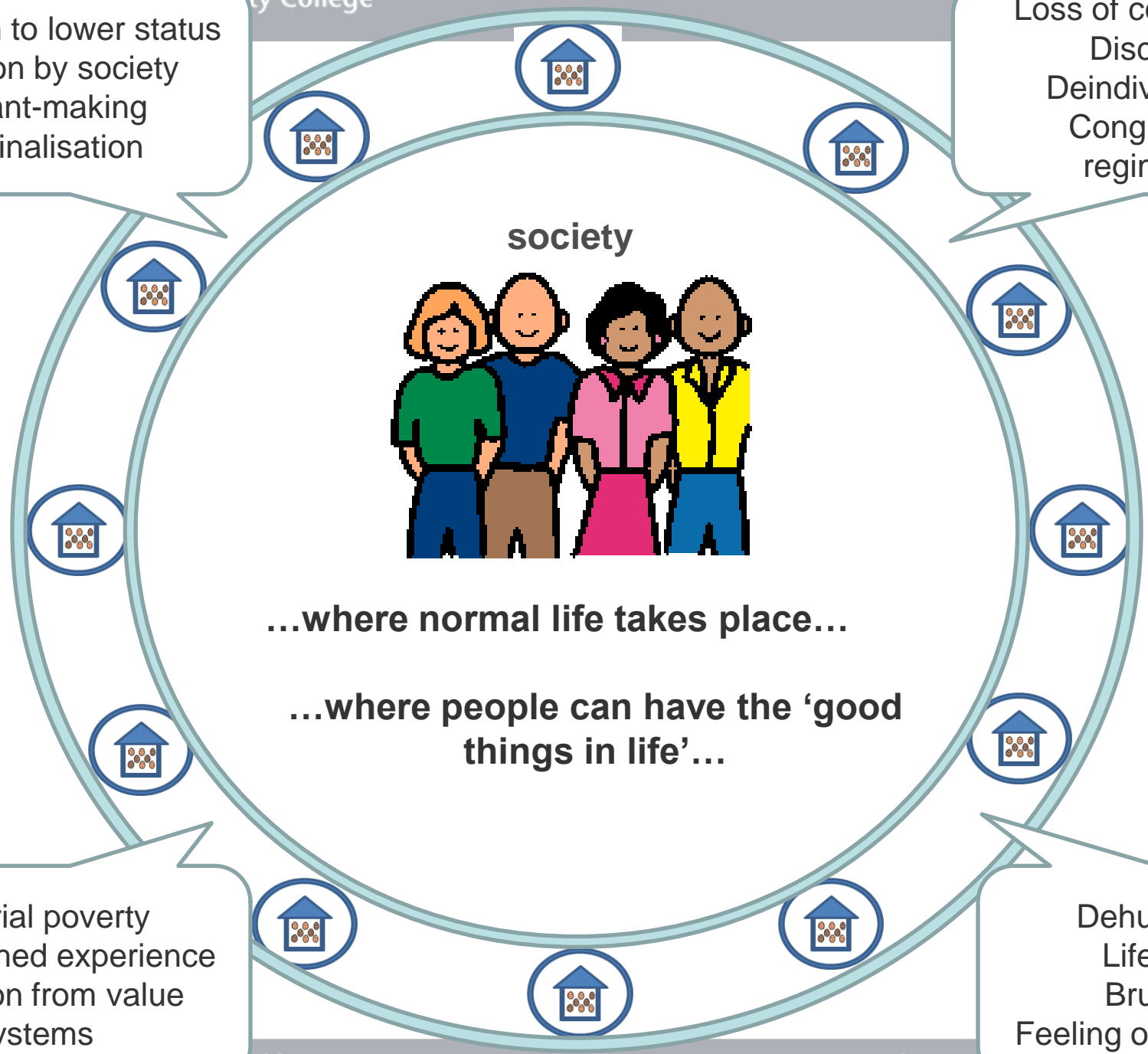
UN Convention on
The Rights of People
With Disabilities 2006





Relegation to lower status
 Rejection by society
 Deviant-making
 Marginalisation

Loss of control over life
 Discontinuity
 Deindividuation
 Congregation & regimentation

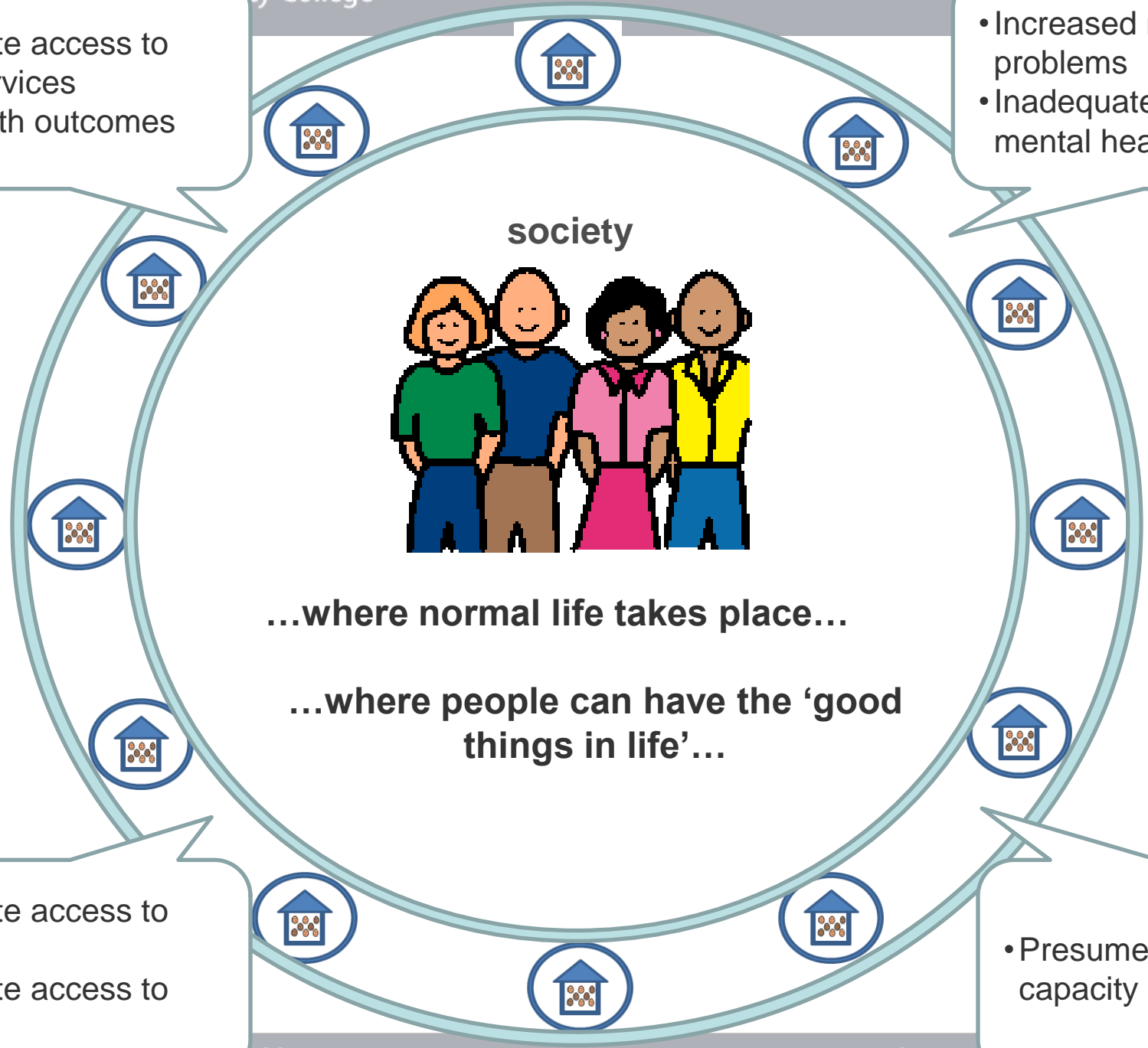


Material poverty
 Impoverished experience
 Exclusion from value systems

Dehumanisation
 Life-wastage
 Brutalization
 Feeling of worthlessness

- Inadequate access to health services
- Poor health outcomes

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

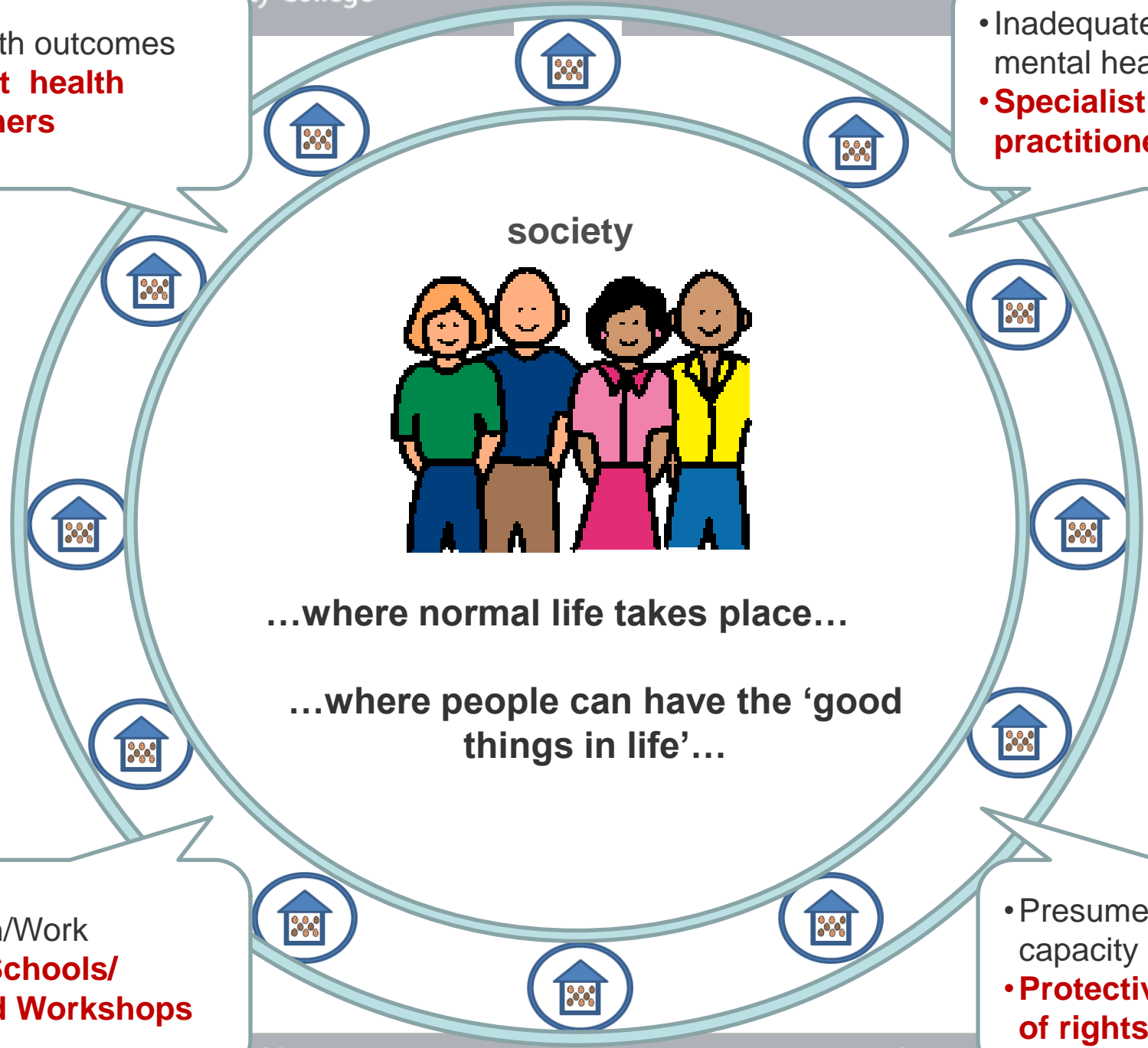


- Inadequate access to education
- Inadequate access to work

- Presumed lack of capacity & loss of control

- Poor health outcomes
- **Specialist health practitioners**

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



- Education/Work
- **Special Schools/ Sheltered Workshops**

- Presumed lack of capacity & loss of control
- **Protective withholding of rights**

outcomes

prac

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

For Many... Nothing has Changed!

society



...where normal life takes place
 ...where people can have the 'normal things in life'...

- Education/Work
- **Special Schools/ Sheltered Workshops**

- Prescribed capacity
- **Protective of rights**

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’.

Baldacci, M. (1997) The bioethics of sexual practice in people with genetically transmissible physical handicaps *Medicina e Morale*, 3, 503 - 532

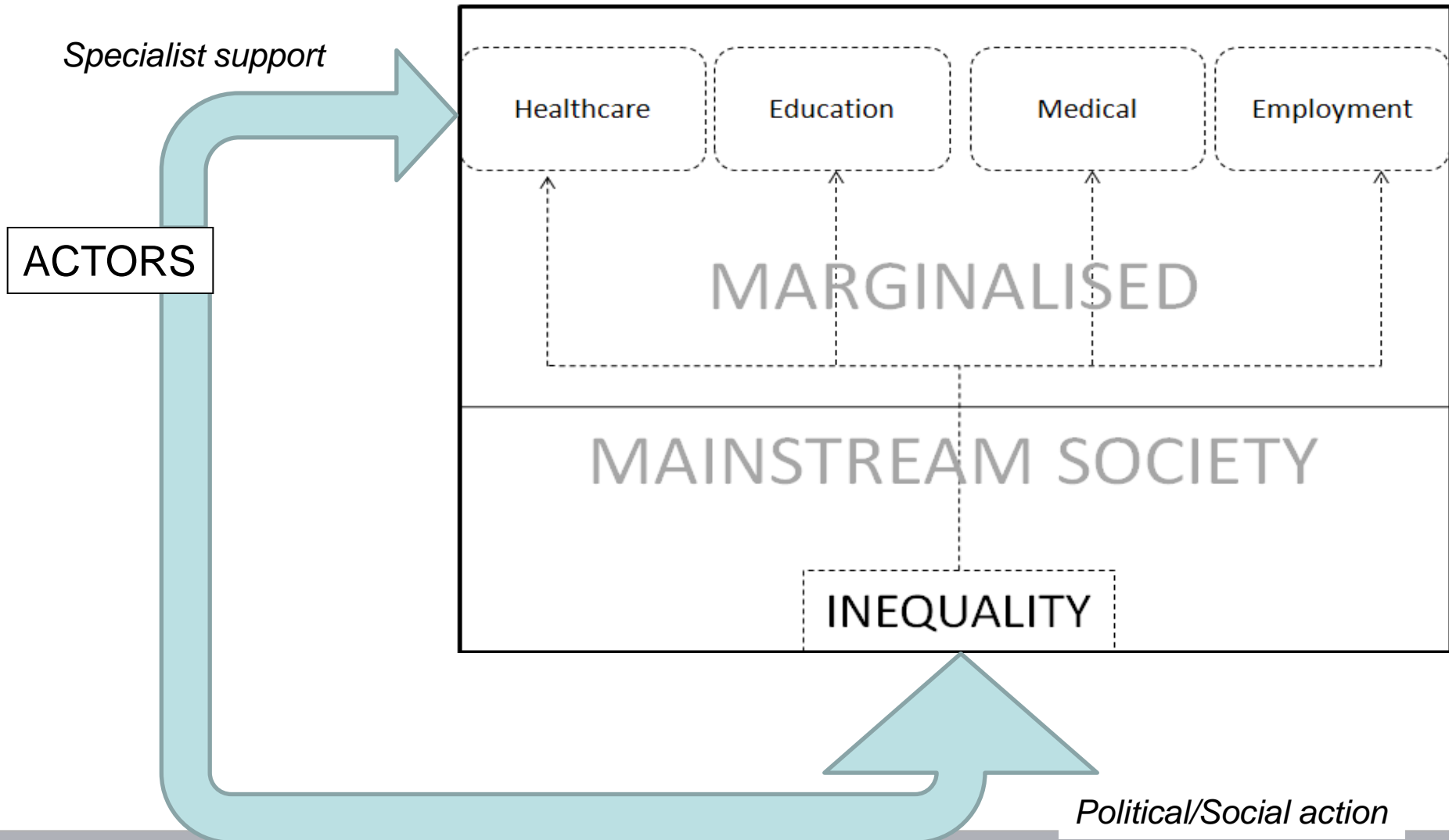
- Parents of disabled ‘impure’
 - At a meeting in Sicily of 1,500 Opus Dei followers, Bishop Echevarria was quoted as saying that "according to scientific research" 90 per cent of handicapped people had been born to parents who had "not entered into marriage in a pure state".

(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



Implications for this Conference

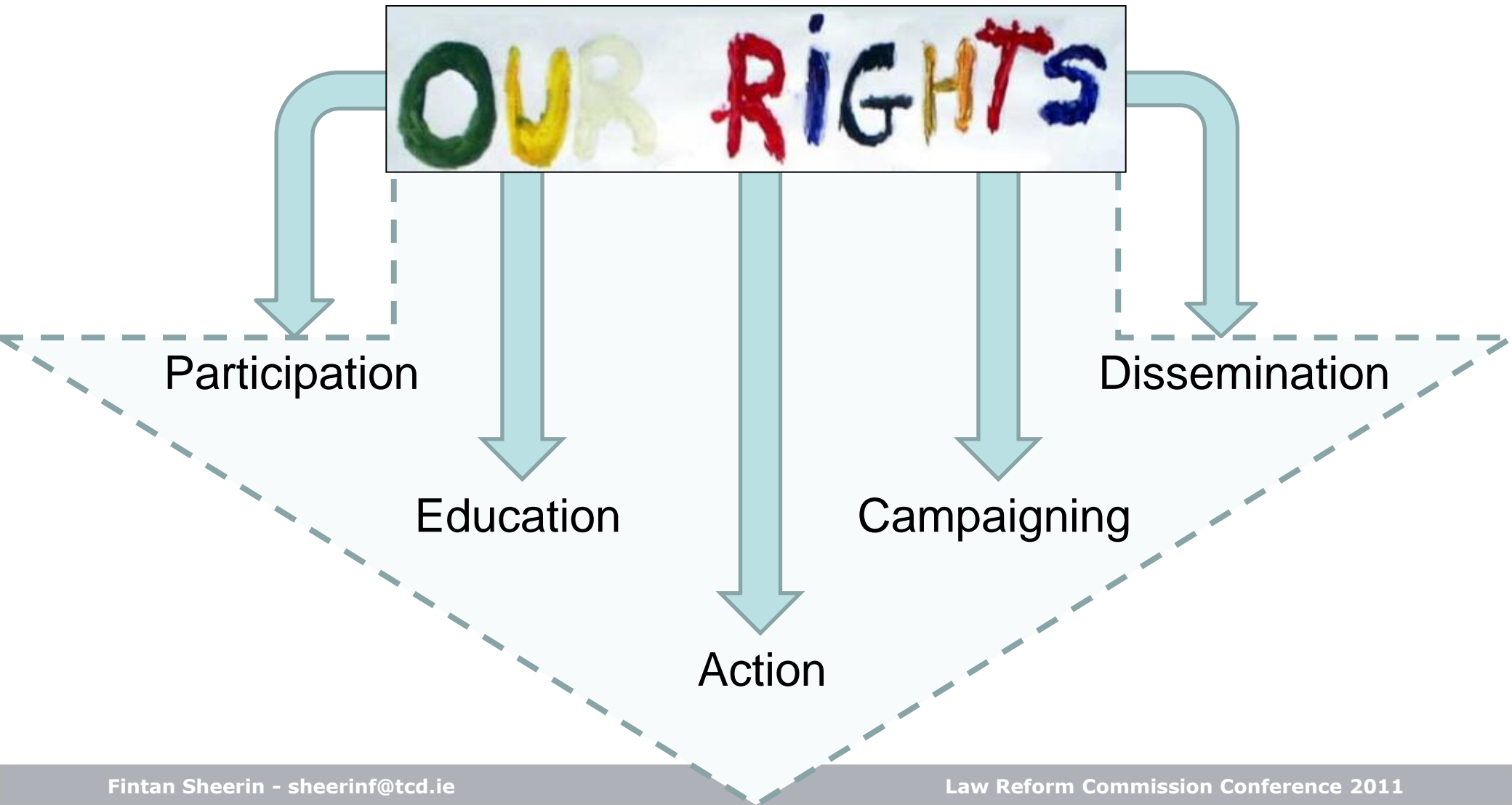
- Presumed incapacity suggests that there is no need to really *listen* to people with intellectual disabilities
- If we are to explore capacity, we (society) must divest ourselves of the historic contexts that have clothed our perspectives
- We must start out as humans and citizens and listen with openness to these people



IDRights: Human Rights and People with Intellectual Disabilities

An Inclusive, Participatory Action Approach

IDRights



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