

# **De-institutionalisation:**

Presentation to workshop EASPD Conference  
Skopje, Macedonia

**James Crowe**

7-8 October 2010



**Learning Disability Wales**

**Anabledd Dysgu Cymru**

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“Remove from an institution or from the effects of institutional life”

Ref: Oxford Concise Dictionary



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**‘Rob you of your identity,  
erase who you  
are....crush you and  
leave you a hollow  
shell, take away your  
face and replace it with  
a mask, the same as  
worn by everyone  
around....a permanent  
hell. Humans null and  
void.’**



**Ref: Humans, Null and Void ‘ Yana Buhrer Tavernier, 2010**

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**No longer optional or dependent on  
enlightened attitude / favours granted**

# UN Convention on the Rights of Disabled Persons 2006

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Institutions transgress many Convention articles

- 3: General principle of dignity and making own choices
- 10 & 14: right to life liberty and security of the person
- 17: respect physical and mental integrity
- 19: living independently and being included in the community



# UN Convention on the Rights of Disabled Persons 2006

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Institutions transgress many Convention articles

- 21: freedom of expression
- 22: respect for privacy
- 26: habilitation
- 29: participation in political and social life
- 30: participation in cultural life recreation, leisure and sport



# Convention

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- Signed by at least 28 EU states
- Ratified by at least 15 EU states



# Not just dogma!

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Closing the institution transforms lives and also transforms the  
working life of good staff

# The position in Europe

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Some 250,000 people with learning disabilities live in institutional accommodation.

Principles for transition have been set out.

Ref: 'Report of the Ad Hoc Expert Group on Transition from Institutional to Community Based Care' European Commission Sept 2009

# Opposition to closing an institution

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Almost inevitable that a toxic mix of interests will fight closure:

- managers/ staff of the institution
- parents/relatives
- funders

# Incremental Change

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- Redecoration/ changes to ward size
- Values training for staff

*Cosmetic – unlikely to reduce artificial nature of the accommodation or to provide sufficient challenge to inappropriate staff attitudes*

# Better outcome for service users

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## Review of 46 research studies 1980-94

Ref: 'Outcomes for Service Users: De-institutionalisation in UK and Ireland' Emerson and Hatton 1996

### Characteristics of Good Community Provision

- increased user engagement in ongoing activities
- increased contact from care staff
- increased use of community amenities
- increase in adaptive behaviour
- reductions in observed challenging behaviour
- increased opportunities for choice
- increased contact with families and friends
- better material standard of living
- increased acceptance by the community



# Wales Experience 1

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## 1983 All Wales Mental Handicap Strategy

3 Principles. People with a learning disability have a right to:

- An ordinary pattern of life
- Be treated as an individual
- Additional help and support in achieving their maximum potential



# Action for new models of support

- Closure of mental handicap hospitals completed by 2006
- Some progress on closing traditional large day centres

Year	Own Home	Family/ Foster Home	Lodgings/ Supported Living	NHS	LA	Private/ Voluntary	Other	Total 16-64 years	Total 65+ years	Total 16+ years
<b>1990</b>	<b>586</b>	<b>4,545</b>	<b>181</b>	<b>1,478</b>	<b>584</b>	<b>765</b>	<b>85</b>	<b>7,717</b>	<b>607</b>	<b>8,324</b>
1994	1,071	5,116	202	844	596	1,343	105	8,526	751	9,277
1998	1,168	5,239	276	469	428	1,572	57	8,251	860	9,209
2000	1,428	5,155	430	354	405	1,655	67	8,685	809	9,494
2003	1,980	5,049	724	218	322	1,752	80	9,284	841	10,125
<b>2005</b>	<b>1,904</b>	<b>5,120</b>	<b>1,372</b>	<b>168</b>	<b>256</b>	<b>1,529</b>	<b>101</b>	<b>9,524</b>	<b>926</b>	<b>10,450</b>

*Ref Statement on Policy and Practice for Adults with a Learning Disability  
WAG 2007*

# Wales Guidance on Community Living

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- Maximum of 4 residents
- Ordinary housing
- No 'core and cluster' or accommodation 'units'
- No congregation by 'label'
- Tenants rather than care home residents

Ref: 'Local Community Living: Accommodation and Support for adults with a learning disability' Welsh Assembly Government Circular 008/2010.



Llywodraeth Cynulliad Cymru  
Welsh Assembly Government

# Wales Experience 2

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Move away from one model: the 'group home'

- Person centred planning
- Emphasis on social connections and accessing generic services
- Adult placements
- 'Keyring'
- Direct payments
- Self directed support



# Steps to success

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- Strong policy leadership and direction
- Recruitment of new staff teams
- Bridging finance

