Caring Capacity in the Domestic Space: Current and Future Challenges

Irish Association of Social Workers and Social Care Ireland: 2017

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Some points of context

• After prolonged and intensive use of institutions, Ireland is entering a ‘post-institutional’ era

• The ‘The Community’ and ‘The Family’ are uncertain concepts in contemporary Ireland

• Caring capacity within the family / domestic setting is diminishing in contemporary Ireland

• This raises questions and challenges regarding the future provision of ‘care’ in Ireland
Island of Ireland 1840-1922
Population Trend and Total Number of "Mentally ill" Persons Resident in Institutions

Number of "Mentally ill" Persons Resident in Institutions
- Island of Ireland Population Trend (Total Population / 250)
Residential ‘Service Provision’ in Ireland

Republic of Ireland 1922-2000
Population Trend and Total Number of "Mentally ill" Persons Resident in Institutions

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of &quot;Mentally ill&quot; Persons Resident in Institutions</th>
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<tbody>
<tr>
<td>1920</td>
<td>19,000</td>
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<tr>
<td>1930</td>
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<td>1940</td>
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<td>1950</td>
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<td>1960</td>
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<td>1970</td>
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<tr>
<td>1990</td>
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<td>2000</td>
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Republic of Ireland Population Trend (Total Population / 250)
Residential ‘Service Provision’ in Ireland

Number of "Mentally ill" Persons Resident in Institutions Per 100,000 of Population 1850-2000

Island Of Ireland 1850-1922
Republic Of Ireland 1922-2000

Year
Number of "Mentally ill" Persons Resident in Institutions Per 100,000 of Population 1850-2000
Comparative Psychiatric Hospitalisation Rates

- England & Wales
- Scotland
- Ireland

Rates per 100,000

1889 1955 2001
<table>
<thead>
<tr>
<th>Ranked</th>
<th>Country</th>
<th>Number of Psychiatric Beds Per 100,000 of Population: WHO Annual Epidemiological and Vital Statistics Report for 1955</th>
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<tr>
<td>1</td>
<td>Ireland</td>
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<td>Sweden</td>
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<td>13</td>
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<td>Jamaica</td>
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Residential ‘Service Provision’ in Ireland

Number of "Mentally ill" Persons Resident in Institutions Per 100,000 of Population 1850-2000

Island Of Ireland 1850-1922
Republic Of Ireland 1922-2000
Number of "Mentally ill" Persons Resident in Institutions Per 100,000 of Population 1850-2000

Creation of a Tendency to Institutionalise
- Centralised Social Policy Planning for Asylums Expansion / Fragmentation of Local Demand, Payment and Control
- Dangerous Lunatic Acts 1838 & 1867
- Fragmentation of Judicial / Medical Control over Admission
- Medical Takeover of Asylums / Establishing of Inspector of Asylums
- All Encapsulating Diagnostic Criteria
- 1843 Asylum Rules
- Family Participation in Asylum Admissions
- Poverty / Local Economic and Social Dependency on Asylums

Interruption of Tendency to Institutionalise the ‘Mentally ill’
- 1945 Mental Treatment Act – Consolidated Medical Control of Admissions
- Introduction of Psychopharmacology / ECT and Psychological Interventions
- International Standardisation of Classification Systems
- European Convention on Human Rights & Fundamental Freedoms (1950)
- Increased Urbanisation/Industrialising & Contestation of ‘Traditional’ Family

Closure of Institutions
- 2001 Mental Health Act
- UN Principles for the Protection of Persons with Mental Illness (1991)
- Renewed System of Inspection / Mandatory Legal Advocacy
- End of Local Economic Dependency on Asylums
- Celtic Tiger and Full Employment
- Emergence Mental Health Promotion
- Sale of Asylum Buildings – Vision for Change
The Legacy of Irish Mental Hospitals

• No Comparable Redress / Recognition for Past Residents of Irish Mental Hospitals
• Expansion of Prisons
• Creation of New ‘Markets of Deviance’
• Continued Construction of ‘Others’ as ‘Mentally ill’
• Migration of Professional Practice
• Family and Community now ‘responsible for care’
Care and Capacity in the Domestic Space
The ID Context

• People with ID are living longer

• People with ID will need support as they age

• People with ID rarely form their own ‘traditional’ family structure

• Caring capacity within the family setting is diminishing
IDS-TILDA

Wave 1: 753 participants
10% representative of >40 yrs. people with ID

Wave 2: 95% retention rate
IDS TILDA & Family Carers Research

Family Carer Survey

Family Strategies

“Future Care Road Map”

IDS TILDA
Family Care Giving for Older People with an Intellectual Disability

Key research questions

• What are the experiences of family care givers?
• What family strategies best enable family care giving?
• How can long-term care needs be anticipated and planned for?
Family Strategies Study

To describe family strategies that enable long term and sustainable home environments for older people with an Intellectual Disability.
• Love, devotion, and commitment underpins caregiving

• However, many carers are under significant stress and experience poor health

• Most families feel that they represent the last remnant of family caregiving capacity

• Future care plans were not discussed between family members

I absolutely adore her, I love her and she is the grandparent that they didn’t have, that the kids didn’t have (Participant, Urban Focus Group)

What’s going to happen when we’re gone? Now the girls idolise him but it… it no way I think that they should have to have him

I assumed that once I made their decision to look after [sister’s name] that would be the end of the line. I never thought that there, that you know there might be another handover situation
Why is this research important?

• The family is identified as the main context of care provision in the ‘post-institutional’ era

• Socio demographic factors are diminishing caring capacity within the family

• Policy planning is required so as to avoid a resurgent demand for residential (institutional) care for older people with an ID
So what!!!

…Now That We Know That

What should we be doing?
A pilot study to enhance long term care planning for older people with an Intellectual Disability (ID) in Ireland and their families

The Development of “Future Care Road Map”
Emerging Issues

• Who is ‘Responsible’ for Caring in Irish Society?
  – The State
  – The Family
  – The Person who requires Care

• What are the ‘Deal Breakers’ that could Undermine the Sustainability of Family Care Provision?
New questions to be addressed

• How can family care giving be measured and costed?

• How can political choices and social policy maximise the care giving within families?

• How can the findings be applied to other fields (child care, life limiting / chronic conditions, mental illness, palliative care)?
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