The College of Psychiatry of Ireland
Coláiste Síciatrachta na hÉireann

Excluded, Expelled and Exported:

The citizens we've ignored and those we've exiled

A report on the 5th Anniversary of *A Vision for Change*

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Introduction

It should not need stating that the rights of an individual with an intellectual disability are the same as those of any other member of society and that best practice in the provision of mental health services for people with intellectual disability[1] is the same as those for all mental health services: citizenship, inclusion, access and community-based services[2].

An intellectual disability [synonymous with 'learning disability'] is not a mental illness. However, the two often co-exist and intellectual disability "can be thought of as a risk factor for mental illness".[3] Studies of the relationship between mental health and intellectual disability estimate that 50% of people with severe and profound intellectual disabilities will have a mental health problem at some point in their lives, as will 20–25% of those with mild and moderate intellectual disabilities[4].

Intellectual disability services in Ireland provide a level of multidisciplinary person centred care that is focused on the social, vocational, educational and residential needs of the individual with intellectual disability. In general, such services do not deal with specialist mental health needs[5].

Gaps in current service provision were recognised in *A Vision for Change*, which noted amongst other things that "significant funds have been expended by health boards in recent years on inappropriate short-term placements for individuals with intellectual disability and

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[1] Intellectual disability is the presence of a significantly reduced ability to understand new or complex information and to learn new skills, with a reduced ability to cope independently, which starts before adulthood and has a lasting effect on development. The presence of low intelligence (IQ below 70) is not, of itself, a sufficient reason for an individual to require health and social care support. Need is determined by an assessment of social functioning and communication skills. [*A Vision for Change*, page 124].

[2] *A Vision for Change*, page 124.

[3] Bernal J, Hollins S. Psychiatric illness and learning disability: a dual diagnosis. Advances in Psychiatric Treatment 1995; 1: 138-145.

[4] International Association for the Scientific Study of Intellectual Disabilities (IASSID) (2000) *Mental health and Intellectual Disabilities: Addressing the mental health needs of people with intellectual disabilities.* Report by the Mental Health Special Interest Research Group of IASSID to the World Health Organisation.

[5] *A Vision for Change*, page 126

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severe mental health problems, or by "exporting the problem' to providers outside of the State"[6].

In 2011, 5 years after the launch of *A Vision for Change* and midway through the 10-year implementation timeline, we turn our attention to developments in the provision of mental health care for those with intellectual disability.

A Vision for Change 2006: Key Recommendations in relation to mental health needs of people with intellectual disabilities

A Vision for Change recommended that mental health services for people with intellectual disability[7] should be provided by a specialist mental health of intellectual disability (MHID) team. It was envisaged that 2 multidisciplinary MHID teams for adults with ID should be provided per 300,000 population [total of 26 teams nationally] and 1 MHID team per 300,000 population for children and adolescents with intellectual disability [total of 13 teams nationally].

The recommended composition of each of these teams is one consultant psychiatrist, one doctor in training, two psychologists, two clinical nurse specialists, two social workers, one occupational therapist, and administrative support staff, with a clearly identified team leader, team co-ordinator and practice manager. The annual cost of such a team would be in the region of €725,000.

In addition, *A Vision for Change* also recommended the provision of five acute in-patient beds, ten rehabilitation beds and one day hospital with ten places per 300,000 adult population.

A Vision for Change 2011: The gap between what is needed and what exists

A Vision for Change recommended that there should be 39 MHID teams nationally. Five years on, two Dublin-based MHID teams exist. Even these are not yet staffed at the level envisaged in *A Vision for Change* [detailed above]. Those 2 MHID teams came into existence after the publication of *A Vision for Change*, emerging from generic intellectual disability teams.

[6] *A Vision for Change*, page 127

[7] The National Disability Database had 25,443 people registered in 2008 [latest] of which 308 people [1.2%] were in psychiatric hospital care, and 188 people of these were felt to be suitable to move to the community.

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However, in neither case was additional funding or other resourcing provided to allow adequate development of a MHID team; in fact, resources have been lost in the interim, resulting in marked understaffing of such key disciplines as occupational therapy, nursing and social work. The Faculty of Learning Disability Psychiatry has confirmed to the authors of this report that the only members of the Cheeverstown and Stewart's Hospital MHID teams who are permanently dedicated to mental health are the psychiatrists, and other disciplines such as they are, provide input on a part-time basis. That is to say, even these teams, nominally the only adult MHID teams in Ireland, do not have the range of fulltime allied health professional members of the multidisciplinary team assigned purely to mental health care.

Elsewhere in the country, there are approximately 20 consultant psychiatrists who work in the ID services but also without the staffing mix essential to providing an optimal service of prevention and mental health promotion; early detection of mental health problems; specialised mental health service management and support and crisis management for mental health problems and challenging behaviours.

Approximately half of those consultants psychiatrists are employed in a temporary capacity and in some instances the incumbents are not on the Medical Council's Specialist Register but are employed on contracts of indefinite duration assigned to intellectual disabilities services. The ability of those holding temporary posts to advocate or influence on behalf of their patients may be diminished by virtue of their temporary status.

There is no MHID team for children and adolescents operating anywhere in the country.

Many ID services in Ireland operate without any specialised mental health input at all, although these services are responsible for the care of adults, children and adolescents with mental illness, epilepsy and challenging behaviour,[8] many of whom are prescribed psychotropic medications that require regular physical monitoring.

[8] Challenging behaviour(s) is / are culturally abnormal behaviour(s) of such intensity and frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour that is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.

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The proposals relating to dedicated inpatients beds for those with acute mental health disturbance have not been acted on. It had been planned to develop such a unit in the new Beaumont Hospital Psychiatric Unit but those plans[9] were scrapped in early 2010 – lack of funds due to the economic downturn being cited. A ten-bedded national forensic unit for those with ID was also recommended, but no progress has been made.

The failure of *A Vision for Change* implementation: implications for people with intellectual disability who are placed outside the State

Most people with intellectual disability live at home and in their communities. This is also true of those with an intellectual disability and a co-existing mental illness such as major depression or schizophrenia. However a fraction of people with intellectual disability require long-term residential placements, often because they exhibit challenging behaviour that makes it impossible for their families or ordinary community facilities to provide adequate and safe care and/or they require clinical support in a specialist therapeutic environment.

Dozens of such persons are currently placed outside of Ireland because therapeutic residential services appropriate to their needs have never been developed within the Irish State. Of those who are currently placed outside of Ireland, some have been excluded from Ireland for almost thirty years.

Placements outside of the State dislodge vulnerable people with intellectual disability from their families and local communities, and some placements cost the state hundreds of thousands of euro per year. The issue of how a relatively low technology care environment, adapted for the MHID needs of these vulnerable people, is not being provided in Ireland needs to be addressed. It remarkable that so many of our citizens are placed in specialist residential settings in several facilities in the North of Ireland while the Republic of Ireland, with 3 times the population of Northern Ireland, has never developed its own regional high level [but low tech] care settings. Quite apart from the moral imperative to provide services that maintain people within their communities as much as possible, could one also make the economic case that continuously part-funding several facilities in the NHS represents a leaching of our own meagre resources?

[9] These were at a relatively advanced stage and much professional time involved in their development.

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In 2006, *A Vision For Change* reported that 35 people with ID were placed out of state and the 2007 Royal College of Psychiatrists paper "*Persons with a Learning Disability who offend*: *forgiven but forgotten?*" reported that 8 people were placed in Forensic Services outside the State.

The HSE has now indicated, in response to an FOI request, that 55 people with intellectual disability were placed outside the state as of 2010.[10] This represents an increase of 20 people [or 57%] since *A Vision for Change* was published. Some had been recently placed, and some decades earlier. The longest placement reported is of a person who has been in the United States since 1981. Some people who were initially placed abroad due to lack of national services have chosen not to return to the local services in Ireland, as emerged in a survey of such placements carried out by the College of Psychiatry of Ireland in 2010. Except for two individuals (who we have not included in the 55 discussed here), the FOI document did not include information on people who had previously been placed out of state but who had returned during or prior to 2010.

In addition to these 55 individuals, it is estimated by Irish psychiatrists specialising in ID and local health managers who participated in the College's survey that 137 persons with ID who require specialist services cannot avail of them, either in Ireland or abroad. This is an enormous and unacceptable unmet need representing more than two and a half times the number currently placed abroad. As the rate of response to the College's survey was low, at 36%, this is likely to be a considerable underestimate of the level of unmet need.

As we export people with intellectual disability for placement and treatment, individual people and their families may get a service, but no level of national expertise builds up. Even if exporting Irish citizens with intellectual disability and challenging behaviour were a rational and humane way of providing a service to them and their families, it would not be sustainable. Clearly, it is not rational or humane but rather *ad hoc* and inequitable and clearly, many people get no service at all.

[10] The title of the FOI document seen by the College was "Clients placed out of state in 2009", but there were several references throughout the document to placements that continued or ended in 2010, so that it was clear despite the title that information up to 2010 was included. The FOI request was granted in November 2010.

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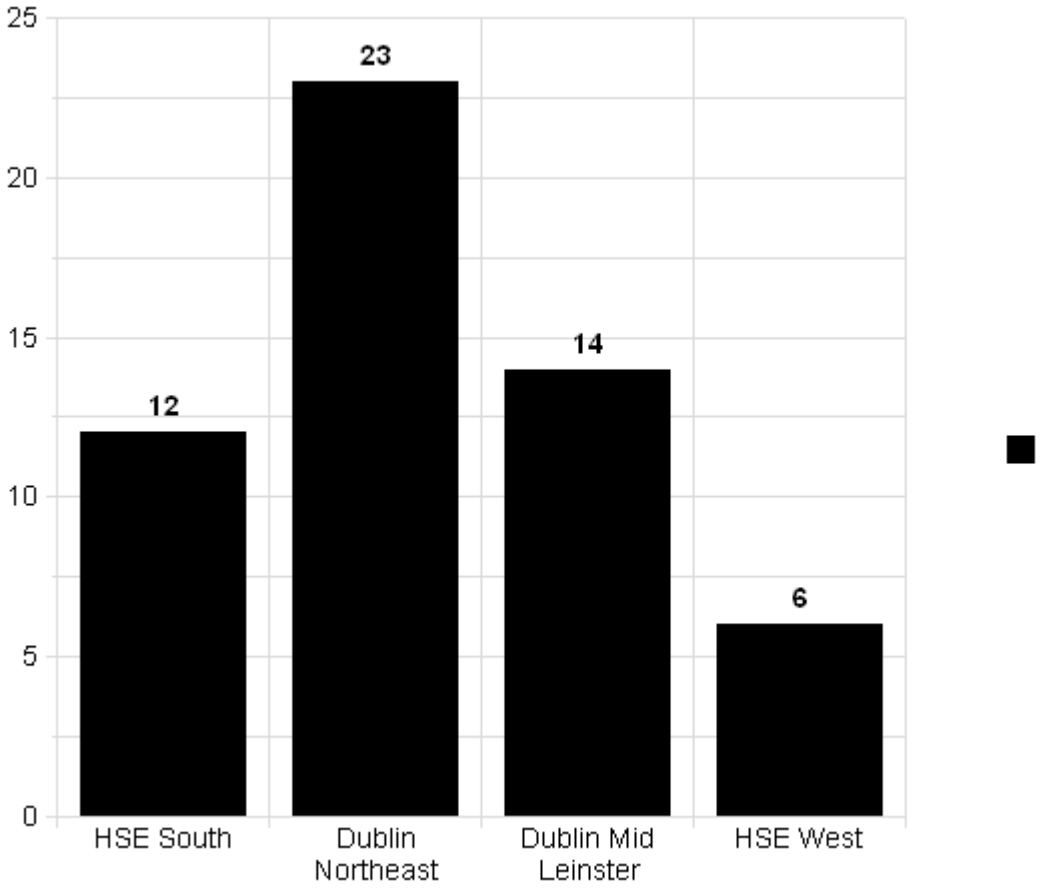
Results

i. HSE area of origin of people with ID placed out of state, 2010



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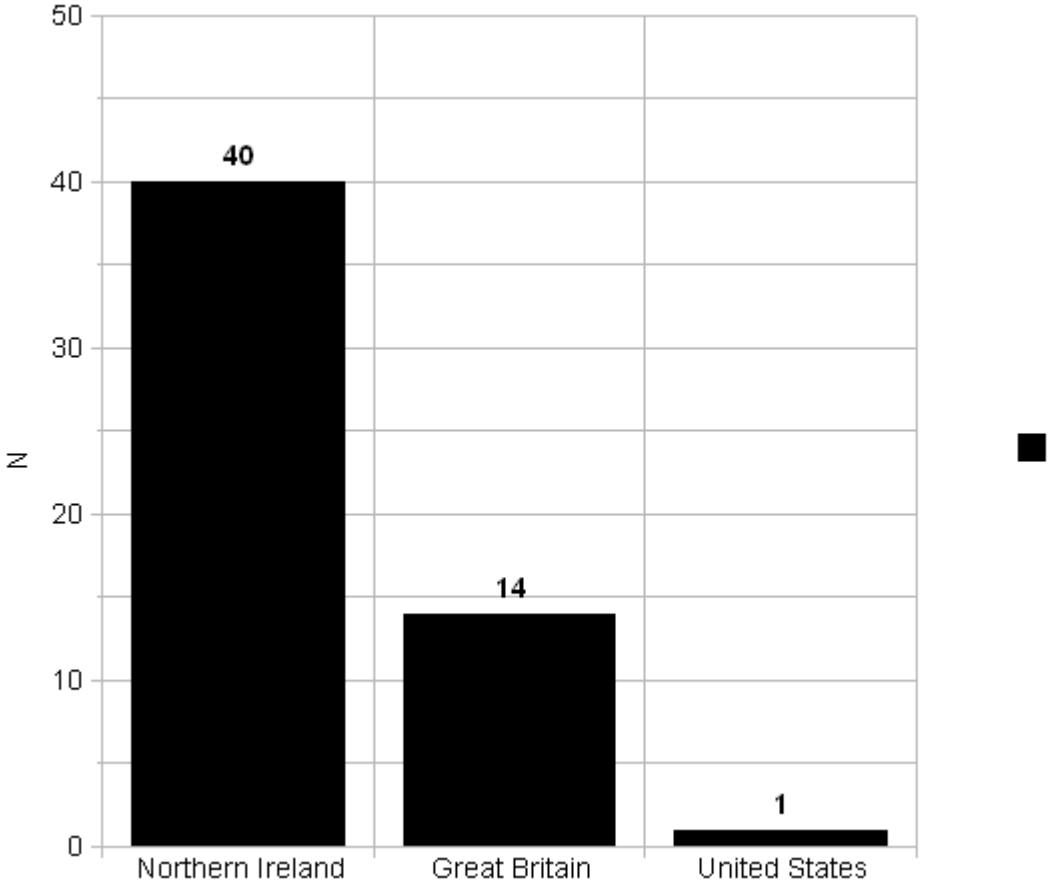
ii. Current location of people with ID placed out of state, 2010



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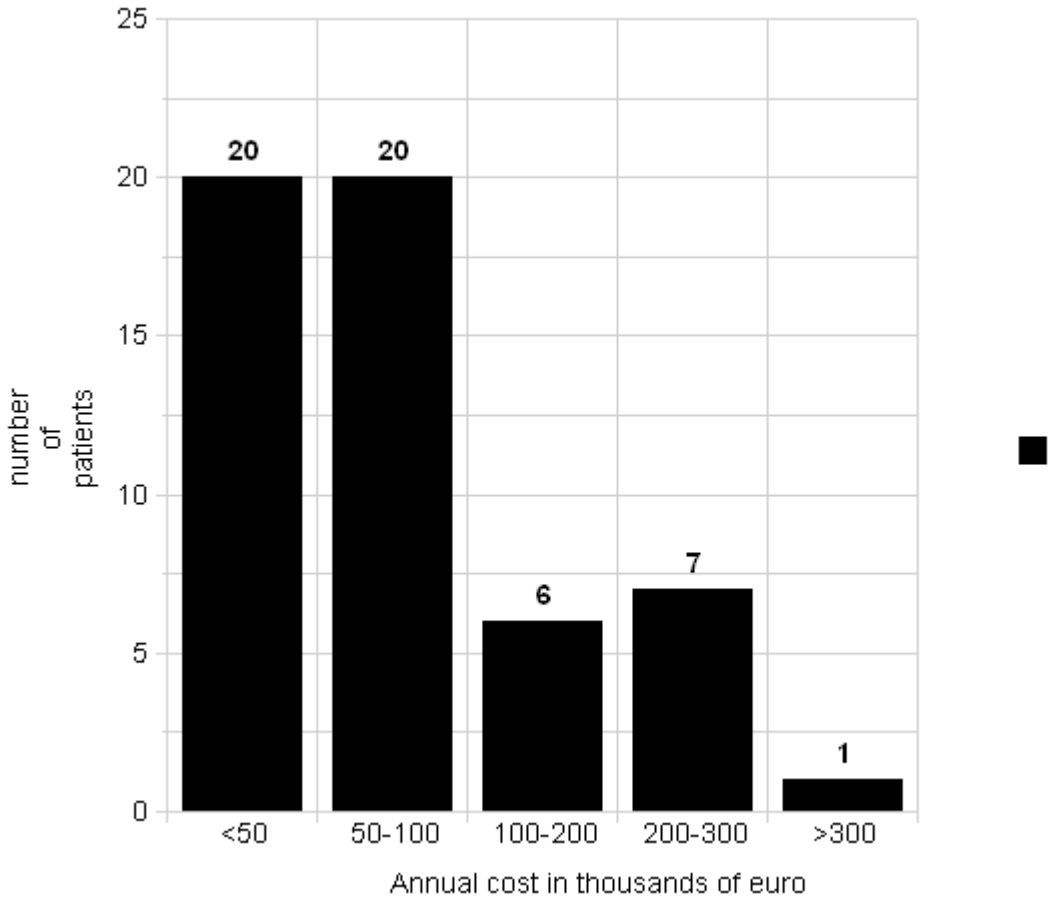
iii. Annual cost of placements in euro for those currently out of state*



*N=54 as data not available for one patient from Dublin South West

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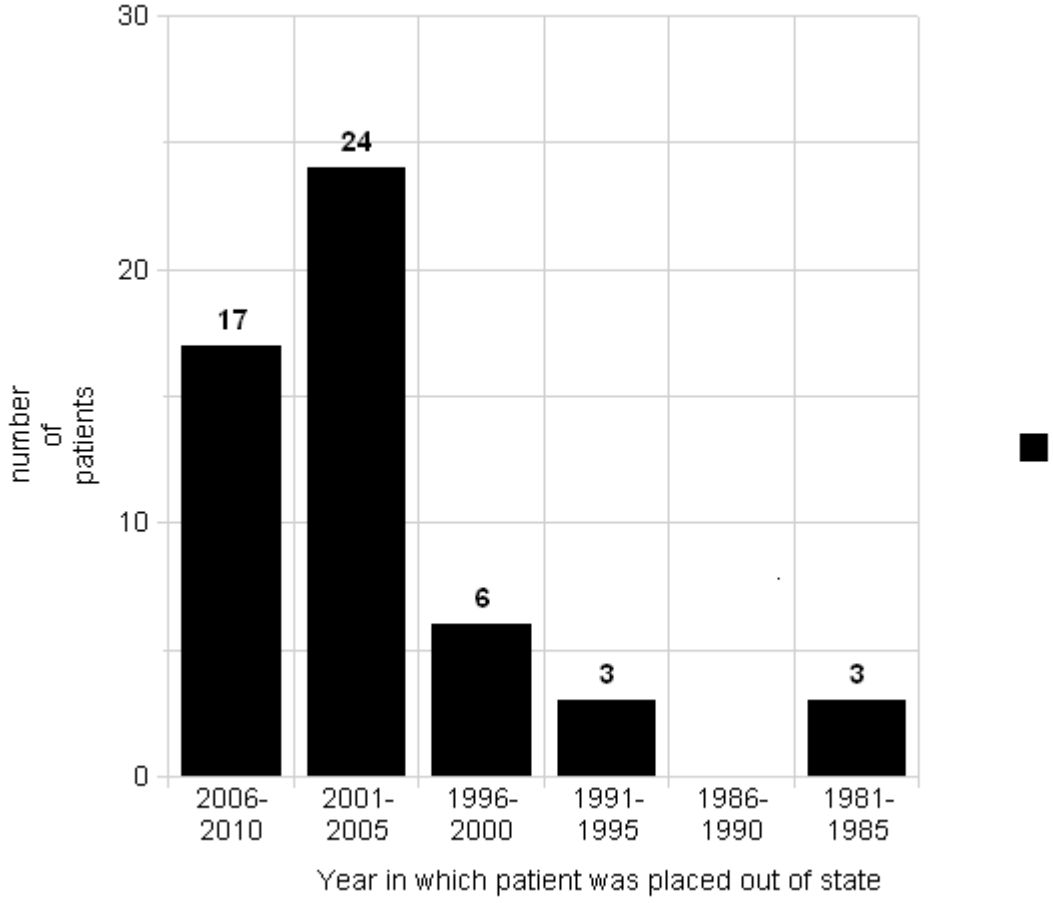
iv. Duration of current placements*



*N=53 due to missing data on duration of placement for two individuals

v. Cost of placements: annual and overall

The FOI document available to us detailed the cost of the placements of most of those people who remained out of state at the time of the current FOI request, i.e. November 2010. We do not for the purposes of the current report have information on the cost of placements for people who were previously out of state and have returned – with the exception of two recent returnees whose details were included on in the FOI document.

With that caveat, and the corollary that any figures we now present are an underestimate, we can report that the cumulative cost of placing the 55 individuals who were out of state in 2010 was over €30 million. The estimated annual cost of these placements is just under €5 million.[11]

[11] Annual cost of placement data was missing for one individual, from Dublin South West. Total for the remaining 54 individuals was €4.95 million, using January 2010 sterling-euro and dollar-euro exchange rates.

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Conclusions

1. Mental health services for people with intellectual disability have enjoyed minimal development since the publication of *A Vision for Change* in 2006.

2. Mental health of intellectual disability teams, 39 of which were recommended in *A Vision for Change*, have just not materialised, and thousands of Irish citizens with intellectual disability and comorbid mental illness are being denied the right to adequate mental health care.

3. 55 Irish citizens with an intellectual disability are placed in specialist services out of state, the vast majority in Northern Ireland. The fact that 75% of the placements are in Northern Ireland refutes any argument that the Republic of Ireland does not have the critical mass for such specialist service provision.

4. It is estimated that at least 137 more people with ID require specialist services that are not available. This is an unacceptable situation.

5. The export of Irish citizens comes at a considerable financial cost as well as human cost. The annual cost of placement for 20 individuals was reported as under €50,000, and for a further 20 individuals is between €50,000 and €100,000; the annual cost in 6 cases is €100-200,000, in 7 cases is €200-300,000 and in one case is more than €300,000. The huge variation in placement cost is curious and requires investigation and explanation by the HSE. It is estimated that an uncomplicated placement of an individual with MHID needs in Ireland costs €80,000 [equivalent to £67,600 approximately].

6. The annual cost of placing all 55 people who are currently in residential care out of state is €5 million.

The true cost for those 54 individuals for whom we had annual costings may have been higher as the reported cost of several placements was less than €5000, a sum so low as to raise doubts about the accuracy of those reported costs.

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Where do we go from here?

1. The provision of mental health and forensic mental health services for people with an intellectual disability, as set out in *A Vision for Change*, requires immediate prioritisation by the HSE as clearly to date it has not been afforded any discernible concern.

2. All Irish citizens with an intellectual disability should be able to avail of an appropriate specialist service at home.

3. A comprehensive and coherent national policy is required with respect to provision of specialist services for people with an intellectual disability and behavioural problems.

4. The College of Psychiatry of Ireland commits itself to cooperate with the Department of Health and Children and the HSE to develop appropriate specialist service provision for persons with an intellectual disability to optimise each individual's quality of life.

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Appendix 1: Location of placements in descending cost order[12]

Location of placement	Responsible HSE Area	Annual Cost	Year placement began
Rowan House Care Principles, Suffolk	South	£282,240	2004[13]
Armagh Care Services, Richhill, Co Armagh	South	£221,784	2001
Location not specified: UK	North East	£220,000	2007[14]
St Luke's Hospital, Essex	West	€196,820	2006
Location not specified: UK	North East	£195,534	2008
Location not specified: UK	North East	£192,013	2006
Location not specified: NI	North East	£188,968	2004
St Andrew's Healthcare, Northants	South	£184,756	2008[15]
Cambian Asperger's Service, Cambridge	South	£173,671	2007[16]
Location not specified: UK	North East	£158,002	1999
Northgate NHS Trust, Newcastle-on-Tyne	West	£155,222	2008
Location not specified: NI	North East	£113,423	2002
Location not specified: NI	North East	£106,179	1997
Consensus Gretton Homes, Northants	South	£104,144	2009
Location not specified: NI	North East	£102,852	1983
Location not specified: NI	North East	£77,369 [x7][17]	2004 (1); 2005 (2); 2006 (3); 2007 (1)
Location not specified: USA	North East	$78,000	1981
Location not specified: NI	North East	£66,295	2003
Praxis Care, Belfast	South	£61,064	1996
Toynton Linkage College, Lincolnshire	South	£61,055	1993[18]
Alderwasley Hall School, Derby	South	£55,190	2000
Stradreagh Hospital, Co Derry	West	£53,030	2008
Camphill, Glencraig, Co Down	Dublin Mid Leinster	£52,776 [x5][19]	2005
RNID, Harkness Gardens, Co Derry	Dublin Mid Leinster	£48,048	No date supplied
Camphill, Holywood, Co Down	Dublin Mid Leinster	£42,017	2005
Camphill, Holywood, Co Down	South	£40,298	2005

[12] Highlighted data refers to placements that have commenced since *A Vision for Change* was published.
[13] In UK since Oct 2004 & current placement since July 2010
[14] FOI document does not state year of commencement but cites "3 years" as duration of placement
[15] Placed in UK in Dec 2008 but moved to a different service in UK end of Sept 2010
[16] Placement ceased in March 2010 and has returned to Ireland; not included in figure of €5 million annual cost.
[17] 7 people placed in this location
[18] In UK since 1993, in current placement since Sept 2004
[19] 5 people placed at this location

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Appendix 1:
Location of placements in descending cost order - Cont'd from page 14

Location of placement	Responsible HSE Area	Annual Cost	Year placement began
Leeds Jewish Nursing Home	Dublin Mid Leinster	£40,000	2005
Location not specified: NI	North East	£37,715	2002
Location not specified: NI	North East	£34,146	2007
Location not specified: NI	North East	£32,978	1999
Killadeas Day Care, Co Fermanagh	West	€29,892[20]	2003
Kilbroney House, Rostrevor, Co Down	South	£29, 380	1985[21]
Location not specified: NI	North East	£27,525	2007
Camphill, Clanabogan, Co Tyrone	Dublin Mid Leinster	£27,185 [x4][22]	2005
Camphill, Mournegrange, Co Down	South	£24,617*	Not reported[23]
Location not specified: NI	North East	£14,872	1999
Camphill, Mournegrange, Co Down	Dublin Mid Leinster	£14,453	2005
Camphill, Mournegrange, Co Down	West	£13,431*	2008
Location not specified: NI	North East	£8,571	2001
Foyle H&SS, Co Derry	Dublin Mid Leinster	£5,602	2008
Camphill, Mournegrange, Co Down	South	£3,915*	1993

*Camphill Mournegrange, has several annual costs described. It has not been possible to confirm the accuracy of those costs or whether they all apply.

[20] Cost tendered in euro although all other NI places cited in pounds sterling, clarification waits as to whether this is an error.
[21] Year not given but "25 years" reported as duration of placement.
[22] 4 people placed
[23] FOI document states: "This client has been placed in N.Irl for years".

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Appendix 2: Financial Outlay* per HSE Area

HSE Area	Total Annual Cost	Average cost [range of cost pp]
Dublin Mid Leinster[24]	£517,138	£39,780 [£14,453** - £52,776]
HSE South	£1,303,169	£100,244 [£3,915** - £282,240]
Dublin North East*	£2,040,656	£85,027 [£8,571** - £220,000]
HSE West	£453,997	£75,666 [£5,602** - £196,820]

*Limitations in above information:
The travel cost for staff of HSE and families visits for all of those placed has not been factored into these figures.
**Clarification from the HSE as to the accuracy of very low annual charges reported in some instances has been sought, but response not received at time of going to press.
The person placed in the US has been omitted from these calculations.

[24] Data is incomplete as financial data in respect of all of those placed has not been received.

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