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Time to Move on from Congregated Settings A Strategy for Community Inclusion

Report of the Working Group on
Congregated Settings
Health Service Executive
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Feidhmeannacht na Seirbhíse Sláinte
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CHAIRPERSON'S FOREWORD

I am pleased to present the Report of the Working Group on Congregated Settings, which is the outcome and culmination of a very significant piece of data capture, research and analysis. The Report was initiated by the Primary, Community and Community Care Directorate in 2007 to develop a national plan and associated change programme for moving people from congregated settings to the community in line with Government policy.

From the mid 1800s onwards there was a view that the best way of providing support to people with disabilities was to care for them in residential institutions, separate from local communities. Over time, there has been a major shift in that thinking. As a society, the supports we now provide for people with disabilities are driven by the values of equality, the right of individuals to be part of their community, to plan for their own lives and make their own choices, and to get the personal supports they need for their independence. These expectations for people with disabilities are underpinned by our legislation and policy, as well as by international conventions, and our knowledge of evidence-based best practice.

There has been a strong move by the state over many years to ensure that people with disabilities have choices and options based on these values; most recently, the Multi-Annual Investment Plan (MAIP) provided additional funding for a 5-year period (2005 – 2009). 307 new respite places and 61 enhanced respite places were funded, recognising the clear evidence that providing respite is a key element in supporting families to remain in their communities and avoid admissions to residential settings. New residential places were also provided under MAIP; 804 new residential places and 406 enhanced residential places were provided.

Service providers have also been taking initiatives to enable people to move from congregated settings. The survey conducted for the Working Group confirmed that 46 centres surveyed for our Report have enabled clients to move into the community from congregated settings, with 619 clients moved into the community in the period 1999 – 2008.

In spite of these initiatives by the state and providers, a group of people remain in congregated settings separate from communities and without access to the options, choices, dignity and independence that most people take for granted in their lives. Admissions to congregated settings in the period 1999 to 2008 (693) exceeded the number moving out. In 2008, 45 clients were admitted to Congregated Settings.

The aim and commitment of the Working Group has been to make a compelling case to change this reality for the 4,000 people in the 72 centres covered by our Report. Our proposals aim to ensure that there will be no further admissions and no further need for congregated settings. I believe that we have made that case, and that our

proposals are both feasible and imperative. The vast majority of those whose circumstances are addressed in our Report have spent more than 15 years in a congregated setting. Many are older people. The Working Group believes that the time to act on their behalf is now.

The way forward

The Working Group is proposing a new model of support in the community. The model envisages that people living in congregated settings will move to dispersed forms of housing in ordinary communities, provided mainly by housing authorities. They will have the same entitlement to mainstream community health and social services as any other citizen, such as GP services, home help and public health nursing services, and access to primary care teams. They will also have access to specialised services and hospital services based on an individual assessment. People will get the supports they need to help them to live independently and to be part of their local community. A core value underpinning our proposal is that people should make their own life choices, neither the HSE nor Service Providers own a client but have a responsibility to maximise their independence.

The challenge

The model proposed by the Working Group is simple in approach but will significantly challenge the system to deliver; it will present a challenge to many stakeholders, including staff, families, the HSE, service providers, the Department of Environment, Heritage and Local Government, and a range of government departments and agencies.

I know from experience that staff working in congregated settings are dedicated and motivated to provide the best possible services to clients in very difficult environments. Many staff may feel that the proposed model will not meet the needs of their clients. The proposals will test the capacity of service providers to deliver the new model. They will need guidance and advice as part of the change management process. A significant investment will be needed for a change management programme to assist service providers and staff to meet the demands of the new model.

Families will initially have concerns about their family member moving to the community, so engaging with families and demonstrating success is an integral part of change management. The proposed model will test also the capacity of Primary Care Teams to respond effectively to community needs and it will demand an acceleration of the roll out of Primary Care Teams.

Clearly, the delivery of housing in the community for homes for 4,000 over a seven-year period will be a significant challenge to the housing authorities especially in recessionary times. A multi-agency approach among key government departments

and agencies will be needed to deliver the transition and the new model successfully. However, the framework for this multi-agency approach is well established through the national Disability Strategy and its component parts.

Funding the transfer to the community

The Working Group recognises the significant investment in existing congregated settings. In 2008, €1.6 billion was spent on Disability Services.¹ This figure represents 29% of the Primary and Continuing Community Care Budget in 2008 and increased from €1.218 billion in 2006. The data collection from the 72 sites covered by the Working Group's Report confirmed a spend of approximately €417 million on congregated settings, which equated to 34% of the total Disability Budget for approximately 13% of the population of people with disabilities and an average cost per person of €106, 000 per annum. The DOHC Value for Money and Policy Review will provide a further level of analysis of the costs associated with people in congregated settings. This information will enhance the data in the report to support implementation of the report recommendations.

The new model of community support envisages that people moving from congregated settings will use Primary Care and Specialist Supports in the Community, as well as complementary Nursing and Social Supports; when we factor in this change in funding methodology, and also retain the current level of resources now invested in congregated settings, I am satisfied that the total national allocation for congregated settings will meet the future costs of the new model of community-based support when all clients are living in the community.

However, we have also recognised some important national and local considerations than must be factored in to the funding the transitioning process:

- Current levels of funding per person in congregated settings vary significantly; we found that among the 72 centres reviewed for our report, the top ten "per capita costs" ranged from €152,000 per capita up to €232,000 per capita per annum and the lowest ten centres range from €37,000 to €66,000 per capita per annum. We have not attempted to correlate dependency levels with unit costs. Some service providers may be able to facilitate the move to the community, within existing resources whilst other providers will need additional funding either recurring or for a period of time. It may also be necessary to re-deploy funding from one site to another site.
- The international research demonstrates that even in the case of well-resourced services, bridging/transitioning funding may be needed to maintain parallel systems for a period of time.

¹ HSE Resource Distribution Review, 2008.

- As I noted earlier, service providers have been using existing resources and some element of the Multi-Annual Investment Funding to facilitate people to move out of congregated settings. However, disability budgets have been reduced by a minimum of 5% in the period 2008-2010, and there is now less flexibility within budgets, to fund further movement to the community within existing resources.
- Many current service providers have indicated their willingness to make available to the state, their current assets, when the facility is closed. Revenue from the sale of such assets would go towards capital infrastructural deficits in the move to the community.

Taking account of all these factors, the Working Group makes proposals for the transitioning process that involve retention of current resourcing levels, flexible use of those resources alongside mainstream services, and provision for transitioning funding through a Congregated Settings Fund.

Accelerating the transition

The Working Group proposes that in 2010 there should be 5 – 7 Accelerated Learning Sites (also referred to as demonstration sites), which will demonstrate effective, efficient and most sustainable ways of delivering the new model of service. The sites should include people with significant challenging behaviour in both rural and urban settings and in both HSE and Voluntary Settings.

Acknowledgements and Thanks

The term “Working Group” truly reflects the commitment and time given by each member of the group. I was very fortunate to chair a group who were strongly committed to enhancing the quality of life for clients in congregated settings. The knowledge and experience of the membership and their work on key aspects of the report was invaluable in reaching conclusions and recommendations of the Report. Accordingly, I would like to record my sincere gratitude to each member of the Working Group.

I was also fortunate to have a Project Manager whose experience in disability matters is well respected both in Ireland and internationally. His network both nationally and internationally gave us easy access to research findings and key players involved in the closure of congregated settings. He personally visited in excess of 30 of the 72 sites and he also conducted site visits to England, Wales and Sweden. He dedicated long days and nights to achieve the goal and I wish to record my sincere thanks to him.

I also wish to record my gratitude to the National Disability Authority (NDA) who were very supportive to us in providing meeting facilities, undertaking analysis of data and access to research. I particularly wish to thank Ms. Eithne Fitzgerald who worked tirelessly to ensure milestones were met.

For the many service providers who want to get on with the task of enabling people to make the transition to community, I applaud your enthusiasm and wish you every success. For those who are not fully convinced, I hope the work of the Accelerated Learning Sites and your own experience of how people benefit will confirm that the our proposed model is a sustainable entity.

Our focus should be on delivering what is achievable rather than dwelling on challenges. I hope those living in congregated settings today can look forward soon to a new way of life and an exciting future within a welcoming local community.

Pat Dolan
Chairperson

THE PROPOSED NEW MODEL OF ACCOMMODATION AND SUPPORT IN THE COMMUNITY – AN OUTLINE²

All housing arrangements for people moving from congregated settings should be in ordinary neighbourhoods (*dispersed housing*) in the community, with individualised supports (*supported living*) designed to meet their individual needs and wishes.

Dispersed housing

Dispersed housing means apartments and houses of the same types and sizes as the majority of the population live in, scattered throughout residential neighbourhoods among the rest of the population. All those moving from congregated settings should be provided with dispersed housing in the community, where they may:

- Choose to live on their own
- Share with others who do not have a disability
- Share their home with other people with a disability (to a maximum of four people with a disability)
- Opt for long-term placement with a family.

Supported living

Supported living means providing the range and type of individualised supports to enable each person to live in the home of their choice and be included in their community. Forms of individualised supports include:

In-home support

In-home supports are those forms of support that enable the person to live independently and safely in their own home. As well as support provided by paid staff, *Smart Technology* (technologies used to support people to remain independent in their own homes) should form part of the new model of in-home support.

Inclusion support

Inclusion supports are those supports aimed at facilitating each individual to develop active linkages and relationships with services and people in their own locality and local community.

² See Chapter 8 for the detailed account of the proposed new model of support.

Community-based Primary Care and Specialist Supports

HSE Primary Care teams should be the first point of access for all medical and social care including public health nursing, home help services, meals on wheels, social work, psychological interventions, with a clear pathway to secondary specialist disability-specific teams when required.

Work/Further Education

A range of employment options, with appropriate supports, should be available. These services should be independent of in-home supports and should offer opportunities for meaningful work.

Person- centered planning

Each individual should develop their own person-centered plan tailored to their individual needs, wishes and choices.

Advocacy

Each individual may need the help of an advocate when making or updating his or her person-centered plan.



EXECUTIVE SUMMARY

The context

Over 4,000 people with disabilities in Ireland live in the congregated settings, which were the subject of this report – a residential setting where they live with ten or more people. Notwithstanding the commitment and initiative of dedicated staff and management, the picture that emerged in the course of the work done for this report is one of a group of people who live isolated lives apart from any community and from families; many experience institutional living conditions where they lack basic privacy and dignity. Most have multiple disabilities and complex needs.

The background

Over a period of 100 years from the 1850s onwards, special residential centres for children and adults with intellectual disabilities were set up in Ireland, mainly by religious orders. From the 1950s, the development of community-based services began to emerge, spearheaded by Parents and Friends Groups.

From the 1980s onwards, the thrust of policy and practice has been moving steadily towards community inclusion for people with disabilities. The emergence of self-advocacy groups of people with disabilities, with a strong focus on equality, citizenship and rights was a key factor in this advance.

Public policy in Ireland over the past 20 years has favoured the development of community-based services; *Needs and Abilities*,³ the policy for people with intellectual disabilities, published in 1990, made detailed recommendations for discontinuing residential provision that is not domestic in scale. It proposed a range of community-based alternatives, including forms of adult foster care, and supports for families to enable them to maintain their family member in a home situation. In 1996, the Review Group on Health and Personal Social Services for People with Physical and Sensory Disabilities, *“Towards an Independent Future”*⁴ also signalled a move away from large institutions, towards small living units and mainstream housing provision. At that time too, the Report of the Commission on the Status of People with Disabilities *“A Strategy for Equality”* (1996),⁵ laid the foundation for the National Disability Strategy.⁶ The Strategy gives effect to the Government’s

³ Department of Health. ‘Needs and Abilities’: A Policy for the Intellectually Disabled. Report of the Review Group on Mental Handicap Services. Stationery Office, 1990.

⁴ Department of Health. ‘Towards and Independent Future.’ The Review Group on Health and Personal Social Services for People with Physical and Sensory Disabilities. Stationery Office 1996.

⁵ ‘A Strategy for Equality’. Report of the Commission on the Status of People with Disabilities (1996)

⁶ National Disability Strategy (2004) http://www.dohc.ie/publications/nds_strategy.html.

mainstreaming policy, which includes the mainstreaming of housing provision for people with disabilities.

In response to public policy and investment, the numbers in the congregated settings have been declining, and most centres have made arrangements to enable residents to move to the community. However, admissions have continued, and over the period 1999-2008, were marginally higher than numbers leaving the congregated settings.

The Working Group on congregated settings

In spite of the advances made in moving people from institutional to community-based settings, 4,000 adults with disabilities continue to reside and live out their lives in large congregated settings. Accommodating people in these settings clearly runs counter to the state policy of inclusion and full citizenship.

In 2007, the HSE set up the *Working Group on Congregated Settings* to develop a national plan and change programme for transferring this group of people to the community. The Working Group had the following terms of reference and objectives:

- To identify the number of congregated settings and the numbers of people currently living in these settings
- To develop a comprehensive profile of the client group in each setting, in terms of numbers, age, nature of disability and support needs
- To identify the costs of the current service provision
- To estimate the range of services required in order to provide alternative living arrangements
- To develop a framework based on best international practice and up-to-date research to guide the transfer of identified individuals from congregated settings to a community based setting
- To develop a national plan and change programme for transferring people to the community
- To indicate the likely capital and revenue costs of implementing the programme, with particular reference to an assessment of resources, including capital that can be re-deployed/re-allocated
- To detail a communication strategy to disseminate the framework for the project and the proposed implementation plan.

The Working Group defined congregated settings as settings where ten or more people with disabilities were living.

The vision and principles guiding the Working Group

The Working Group had a clear vision for the people living in congregated settings. That vision requires that this group of people will be actively and effectively supported to live full, inclusive lives at the heart of family, community and society. They should be able to exercise meaningful choice, equal to that of other citizens, when choosing where and with whom they will live.

The philosophy of the Working Group is that neither funders nor providers 'own' people with disabilities nor should they exercise control over their lives on the basis that they are service users. People with disabilities have the right to direct their own life course.

The work programme

The Working Group undertook a detailed work programme to enable it to make evidence-based proposals. An in-depth survey gathered information about the people currently living in congregated settings, their service provision and their lives, and the resources currently being invested in the provision of that service. The survey was complemented and given depth through a series of visits to congregated setting by the Project Manager for the Working Group.

A review of international research on the costs, benefits and outcomes of de-institutionalisation and community living was carried out. The experience of other countries that have undertaken de-institutionalisation programmes was gathered through study visits to Sweden, England and Wales and through dialogue with experts with knowledge of de-institutionalisation experience in Norway and the United States. The challenges, successes and obstacles experienced in these countries helped the Working Group to frame its proposals.

The people and the places

The survey conducted by the Working Group showed that agencies are providing accommodation in congregated settings across 20 counties. The settings range from those with one unit to a setting with 34 units. 26 settings provide one unit, with the number of places in each unit ranging from 10 to 52 places. The average number of places in single unit settings is 19. The largest congregated setting has 34 units, with places for 340 people.

Just over 4,000 people live in these congregated settings, with slightly more men (52%) than women. The vast majority are people with intellectual disabilities. 3,800 residents have primarily an intellectual disability and 300 have primarily a physical or sensory disability. A high proportion of residents have severe or profound intellectual disabilities, considerable levels of challenging behaviour and high levels

of multiple disabilities. Many people have significant physical disabilities and an intellectual disability. Residents are mainly middle-aged. About half those with intellectual disabilities are in the age range 40 to 60 years. Visits to 30 settings confirmed a picture of similar populations in the congregated settings and point to a substantial population of people with high levels of dependency, who are ageing and, in some cases, have dementia.

The research findings

Research studies examined by the Working Group showed conclusively that community-based services are superior to institutions as places for people with disabilities to spend their lives. Key findings were that:

- Community living offers the prospect of an improved lifestyle and quality of life over institutional care for people with intellectual disabilities
- This applies to old and new institutions, whatever they are called
- Community living is no more expensive than institutional care once the comparison is made on the basis of comparable needs and comparable quality of care
- Successful community living requires close attention to the way services are set up and run, especially the quality of staff support.

The research underlined that moving from congregated to community-based models of accommodation and support is not just a case of replacing one set of buildings with another. Successful community-based support services must be in place – carefully planned around the needs and wishes of individual people and then continually monitored.

The international experience

International experience was examined through visits to Sweden, Wales and England and through dialogue with experts knowledgeable about the Norwegian and the US experience. The examination confirmed that the direction of policy in these countries is towards dispersed accommodation in the community and supported living. Innovative options, including use of technology to minimise reliance on staff are widening people's choices and enabling people with complex needs to be independent. There is a clear move away from clustered accommodation towards facilitating people to live in their local community with people of their own choosing.

The account of the Norwegian experience drew attention to the risk that the movement to the community can be undermined by absence of rights legislation, diversion of funding to other needy groups, undue initial focus on housing alone, loss of qualified professionals, and poor oversight and auditing of services.

The US experience confirmed that everyone can live in the community, and that people with the most severe disabilities make the most gains. It emphasised the importance of building the capacity of local communities rather than on a narrow focus on closing institutions. The US experience also underlines the need for careful planning, and for putting individualised supports in place at the time of closure and beyond.

The compelling case for action

Based on the outcomes of the work programme, and the deliberations of the members, the Working Group took the view that the case for taking action now to address the situation of people living in congregated settings is powerful and unassailable. The ethical case to move people from isolation to community, and in some cases, from lives lived without dignity, is beyond debate.

Congregated provision is in breach of Ireland's obligations under UN Conventions. The provision contradicts the policy of mainstreaming underpinning the Government's National Disability Strategy. We now know what needs to be done to change people's lives and why their lives must change. This knowledge brings with it an obligation to act. The benefits for people with disabilities and the wider social benefits from including people with disabilities in their own community justify the radical programme of change envisaged by the Working Group.

The recommendations

The Working Group's recommendations are wide-ranging. Policy initiatives to support the transitioning programme are recommended; a new model of inclusive, community-based support for people moving from congregated settings is proposed; Proposals are made for ways of implementing and funding the transitioning programme. The elements of a change strategy to support the transitioning process are also identified. The recommendations are as follows:

National policy and support frameworks for the transitioning programme (Chapter 7)

RECOMMENDATION 1 (7.2)

Department of Health and Children vision and policy statement

The Department of Health and Children should issue a vision and policy statement on the closure of congregated settings and transition of residents to community settings. The policy should mandate that:

- All those living in congregated settings will move to community settings
- No new congregated settings will be developed and there will be no new admissions to congregated settings
- The move to community will be completed within seven years and minimum annual targets set for each year in order to reach that goal.

RECOMMENDATION 2 (7.3)

National Housing Strategy for People with Disabilities

The Working Group's proposals should be reflected in the National Housing Strategy being prepared by the Department of Environment, Heritage and Local Government. The strategy should describe the eligibility of people with disabilities for publicly funded housing supports.

The Strategy should reflect the research evidence that dispersed housing in the community provides a better quality of life for people with disabilities than cluster-style housing.

RECOMMENDATION 3 (7.4)

National oversight

A named senior official of the HSE should be charged with driving and implementing the transitioning programme, assisted and guided by a National Implementation Group. The Department of the Environment, Heritage and Local Government should be represented on the National Implementation Group.

Progress on implementation should be reported every six months to the HSE Board, to the Department of Health and Children, and also reported to the National Disability Strategy Stakeholder Monitoring Group. The housing letting practice in Local Authorities should be monitored as part of national implementation.

RECOMMENDATION 4 (7.5)

A manpower strategy

A manpower strategy to support the programme of transition to community settings should be devised by the National Implementation Group in partnership with key stakeholder groups. The strategy should address staffing requirements and skill mix needs for community inclusion, skill development and professional development requirements, and the human resource aspects of the transition programme.

RECOMMENDATION 5 (7.6)

National Protocols to support community inclusion

A Working Group should be set up to co-ordinate the development of a range of protocols to ensure a co-ordinated approach to community inclusion for people with disabilities. These protocols should be developed across key government departments and agencies, in partnership with the National Implementation Group; they should be prepared within the framework of the National Disability Strategy and have regard to the Sectoral Plans prepared under that Strategy.

RECOMMENDATION 6 (7.8)

Change management programme

A change management programme to support the transitioning programme should be developed and resourced. The change management plan should be executed by HSE and overseen by the National Implementation Group.

Moving from congregated settings: A new model of support in the community (Chapter 8).

RECOMMENDATION 7 (8.1)

A new model of community-based support

The provision of accommodation for people moving from congregated settings to their local community must be broader than a plan for accommodation; accommodation arrangements for housing must be part of a new model of support that integrates housing with supported living arrangements.

The new model of support should be based on the principles of person-centeredness; it should enable people with disabilities to live in dispersed housing, with supports tailored to their individual need.

RECOMMENDATION 8 (8.3)

Dispersed housing in the community

All those moving from congregated settings should be provided with dispersed housing in the community, where they may:

- Choose to live on their own

- Share with others who do not have a disability
- Share their home with other people with a disability
- Live with their own family or opt for long-term placement with another family.

Purpose-built community housing funded by the HSE should be provided for any children under-18 years old moving from congregated settings.

RECOMMENDATION 9 (8.3)

Maximum of four residents who choose to share accommodation

Where home-sharing with other people with a disability is the housing option chosen by the individual, the Working Group recommends that the home-sharing arrangement should be confined to no more than four residents in total and that those sharing accommodation have, as far as possible, chosen to live with the other three people.

RECOMMENDATION 10 (8.4)

Supported living arrangements

Supported living arrangements should enable the person to choose to:

- Decide on, control and manage their own supports
- Contract with a third party to help with the management of their individualised support package
- Choose to combine resources with others to pay for shared supports as well as having some personalised supports.

RECOMMENDATION 11 (8.5)

Supports for range of needs

People with disabilities living in dispersed accommodation in community settings will need a range of support programmes to help them to plan for their lives, and take up valued social roles. Essential programmes will include:

- Person-centred planning
- Advocacy
- Support for community inclusion
- In-home support
- Community-based primary care and specialist supports
- Work/further education support.

RECOMMENDATION 12 (8.5)

Strengthening access to community health services

Action is required by HSE to strengthen the capacity of community health services to deliver supports to people with disabilities.

RECOMMENDATION 13 (8.6)

Distinct statutory responsibilities for aspects of provision

The housing authorities and HSE should have distinct responsibilities for the needs of people with disabilities living in the community.

The HSE should provide for the health and personal social needs of residents moving to the community while responsibility for housing rests with the Department of Environment, Heritage and Local Government and local authorities.

RECOMMENDATION 14 (8.6)

Separation of delivery of in-home supports from inclusion supports

Governance, management and delivery of in-home supports should be separate from provision of inclusion supports, to ensure that the person with a disability has maximum choice of support providers and maximum independence.

RECOMMENDATION 15 (8.6)

Coordination of support provision

The individualised supports for people with disabilities should be delivered through a co-ordinating local structure based on defined HSE catchment areas, within which the full range of supports is available.

RECOMMENDATION 16 (8.7)

Funding mechanisms for personal supports

A study of the feasibility of introducing tendering for services should be undertaken by HSE, to examine its potential in an Irish context.

Support services should be funded by way of service level agreements between HSE and providers. Individuals should get their own personal service level agreement

which outlines who is responsible for delivering each aspect of their support provision.

The scope for introducing forms of individualised budgets giving people as much control as possible over their choice of supports should be examined by HSE.

The scope for individual or family governed supports should be explored and developed. Such arrangements should be provided for in service level agreement processes, tendering processes and other administrative/funding arrangements.

Funding Community-based Support and Housing: Options and Costings (Chapter 9).

RECOMMENDATION 17 (9.1)

Retain all funding currently being spent on congregated services

Funding currently in the system for meeting the needs of people in congregated settings should be retained and redeployed to support community inclusion; any savings arising from the move should be used for new community based services.

The scope for involving the personnel currently working in congregated settings in delivering community support provision, and how that resource might transfer, should be explored in partnership with stakeholders through the proposed manpower strategy.

RECOMMENDATION 18 (9.6)

The accommodation needs of people moving from congregated settings should be met through a combination of purchased housing, new-build housing, leased housing or rented housing.

The appropriate mix of options would be facilitated via individual housing authorities, overseen by the Department of Environment, Heritage and Local Government. It could include housing provided by a housing association, standard local authority housing, housing rented on a long-term arrangement from a private landlord, or a family home.

RECOMMENDATION 19 (9.7)

Meeting capital costs of new housing stock

There will be instances where purpose built new housing in the community to meet particular individual needs will need to be built, or purchased and made accessible.

Where agencies providing congregated settings may be disposed to sell land to help to fund new accommodation, and need short/medium term financing to enable accommodation to be built or purchased for residents before property and land can be sold, this short-term funding should be provided by the state by way of loan.

RECOMMENDATION 20 (9.7)

Eligibility for Rent Supplement/Rental Accommodation Scheme

All those making the transition from congregated settings should be assessed for eligibility for Rent Supplement or Rental Accommodation Scheme. This subject needs detailed consideration by the Department of Social Protection, Department of Environment, Heritage and Local Government, and the Department of Health and Children.

RECOMMENDATION 21 (9.8)

Local planning for social rented housing for people moving from congregated settings

A local re-housing plan should be prepared and jointly co-ordinated by local authorities and HSE, in collaboration with service providers. The plan should be based on best practice in including people with disabilities in local communities and should facilitate dispersed housing with personal supports.

All residents in congregated settings should be assessed by housing authorities to establish their eligibility and need for social housing support. Service Providers should ensure that their clients are assessed for housing by the relevant local authority.

RECOMMENDATION 22 (9.9)

Allocation priorities

Housing authorities should give consideration to reserving a certain proportion of dwellings for people with disabilities. A suite of letting criteria specific to housing for people with disabilities should be developed and reflected in a national protocol.

Funding, Resourcing, and Managing the Transition to the Community (Chapter 10)

RECOMMENDATION 23 (10.2)

Phasing the transitioning programme

A seven-year timeframe for the overall national closure programme for congregated settings should be set. Within that timeframe, specific annual targets should be set at national and local level to guide the phasing and prioritising process, in consultation with the HSE.

RECOMMENDATION 24 (10.3)

Local oversight

An implementation team should be set up at Integrated Service Area level within HSE and a named person given responsibility for supporting the transfer of people into the community; this person should be responsible for ensuring that local public and voluntary services are prepared to respond to the development of a comprehensive community support infrastructure.

RECOMMENDATION 25 (10.3)

Agencies transitioning strategy and plan

All agencies currently operating congregated settings should be required to submit their transitioning strategy to HSE, with detailed operational plans, timeframes and deadlines, based on the review recommendations. Agency proposals should be part of annual discussions with HSE in respect of service agreements.

RECOMMENDATION 26 (10.3)

Accelerated Learning Sites

A number of ***Accelerated Learning Sites*** should be funded to provide ambitious and accelerated implementation of the policy and robust examples of evidence-based transitions to models of community living.

The choice of sites will allow the learning to be evaluated across:

- Statutory and non-statutory services
- Different levels of need, including those with severe and profound disabilities or significant levels of challenging behaviour

- Different geographic regions
- Different levels of current funding per client.

RECOMMENDATION 27 (10.4)

Congregated Settings Fund

A range of new funding streams should be brought together in a Congregated Settings Fund. The Fund should be available to:

- Uplift the core funding linked to individuals in settings currently surviving on a very low funding base relative to individuals in other congregate settings
- Provide interim “bridging” funding to congregated settings at particular points in their transition cycle
- Support ambitious and accelerated implementation
- Provide emergency funding in settings where remedial actions are needed
- Make provision for adaptations and assistive technology.

RECOMMENDATION 28 (10.4)

National Evaluation Framework

A comprehensive evaluation framework for the transitioning project should be agreed at national level to ensure a standardised approach to evaluation across all Accelerated Learning Projects and other settings involved in transitioning to the community, and an agreed minimum data set. The evaluation framework should be agreed prior to start of any project. It should be informed by similar work conducted internationally. In order to ensure the integrity of the evaluation in each site, an independent agent should undertake this evaluation across all participating sites.

RECOMMENDATION 29 (10.5)

Creating readiness

Resources should be made available as part of the change management planning to support people with disabilities, families, and staff to transfer to the community and to develop community readiness.

RECOMMENDATION 30 (10.6)

Providing access to advocacy

A dedicated and appropriately resourced advocacy provision should be provided over the period of the transfer programme for those moving from congregated settings.

RECOMMENDATION 31 (10.7)

Review of residential settings outside remit of the Working Group

The HSE should initiate a review of large residential settings for people with disabilities which were outside the scope of the Working Group, for example, people inappropriately placed in Nursing Homes. The aim of the review should be to ensure that residents in these settings can access community-based support and inclusion, in line with the Working Group's proposals for residents of congregated settings.

A number of people with disabilities are still living in mental health settings, and their accommodation and support needs fall within the remit of *Vision for Change* proposals. The Working Group recommends that this group should be given top priority in the *Vision for Change* implementation process and be moved to appropriate community settings in line with the recommendations in this Report.

CHAPTER 1

INTRODUCTION

1.1 THE WORKING GROUP ON CONGREGATED SETTINGS

In 2007, the HSE set up the *Working Group on Congregated Settings*. The purpose of the Working Group was to develop proposals and a plan to deliver community based, person-centred responses for people living in congregated settings. The Working Group had the following terms of reference and key objectives:

- To identify the number of congregated settings and the numbers of people currently living in these settings
- To develop a comprehensive profile of the client group in each setting, in terms of numbers, age, nature of disability and support needs
- To identify the costs of the current service provision
- To estimate the range of services required in order to provide alternative living arrangements
- To develop a framework based on best international practice and up-to-date research to guide the transfer of identified individuals from congregated settings to a community-based setting
- To develop a national plan and change programme for transferring people to the community
- To indicate the likely capital and revenue costs of implementing the programme, with particular reference to an assessment of resources including capital that can be re-deployed/re-allocated
- To detail a communication strategy to disseminate the framework for the project and the proposed implementation plan.

1.2 THE MEMBERSHIP OF THE WORKING GROUP

The membership of the Working Group was made up of representatives of key stakeholders including voluntary and statutory service providers, representatives and advocates for people with disabilities, the National Disability Authority and the Department of Health and Children. The project was led by Pat Dolan, HSE, and managed by Christy Lynch, CEO of the Kare Association, Kildare, who was seconded to manage the project on a full time-basis. The members were:

- Pat Dolan, Local Health Manager, Sligo/Leitrim and West Cavan and Lead LHM Disabilities, HSE West (Chair and Project Leader)
- Christy Lynch, Chief Executive Officer, Kare, Co Kildare (Congregated Settings Project Manager)

- Brendan Broderick, CEO, Moore Abbey, Co.Kildare
- Mark Blake Knox, Board Member, Not for Profit Business Association and CEO Cheshire Ireland
- Deirdre Carroll, CEO, Inclusion Ireland
- Brian Dowling, Assistant Principal Officer, Disabilities, Department of Health and Children
- Eithne Fitzgerald, Head of Policy and Public Affairs, National Disability Authority
- Paudie Galvin, Acting Director of Services, Southside Intellectual Disability Services, HSE Dublin Mid-Leinster
- Mary McArdle, Regional Director of Nursing HSE North East*
- Brother Laurence Kearns OH, Provincial, St John of God Hospitaller Services
- Suzanne Moloney, Area Manager, Disability Services, HSE South**
- Martin Naughton, Disability Federation of Ireland
- Winifred O' Hanrahan, National Director of Services, Brothers of Charity
- Jean Wright, Self Advocate with intellectual disabilities

*Member of Working Group until March 2009

** Replaced by Patrick Nelligan, Assistant Manager Intellectual Disability Services, HSE South, from November 2009.

1.3 THE SCOPE OF THE PROJECT

The project was concerned with all individuals with intellectual, physical or sensory disabilities living in larger congregated settings. Larger congregated settings were defined for the purpose of the project as living arrangements where **ten or more people** share a single living unit or where the living arrangements are campus-based.

Using this definition and working closely with the Health Research Board, which manages the national databases for disability services, the Working Group was provided with a list of agencies whose residents would come within the scope of the project.⁷ Residential services that were not on the national databases, such as residential services for people with autism were not included in the project. Intentional communities⁸ were not included.

People living in units de-designated under either the Mental Treatment Act 1945 or the Mental Health Act 2001 were included in the scope of the project. The term 'de-designated unit' usually refers to accommodation on the grounds of psychiatric

⁷ See Appendix 1 for list of agencies that came within the Working Group's remit.

⁸ 'An intentional community' is a planned residential community designed to promote a much higher degree of social interaction than other communities. The members of an intentional community typically hold a common social, cultural, political or spiritual vision. They also share responsibility and resources. Intentional communities include co-housing, residential land trusts, communes, eco-villages and housing co-operatives.' (www.wikipedia.org). In the Irish context, intentional communities include Camphill Community and L'Arche Community.

hospitals. The de-designated units are dedicated intellectual disability services with a separate management structure to the psychiatric services on the same campus. The clients living in de-designated units are included on the National Disability Database.

People living in mental health service settings that are not de-designated were not included, as their needs are due to be addressed as part of the implementation of the national policy on mental health services set out in the *Vision for Change*.⁹ People with disabilities living in nursing homes were also outside the Working Group's remit.

1.4 THE VISION FOR THE FUTURE

The Working Group set down a clear vision for the kind of life that people living in congregated settings should be able to aspire to in the future. The philosophy underpinning the vision is that neither funders nor providers 'own' people with disabilities nor should they exercise control over their lives on the basis that they are service users. People with disabilities have the right to direct their own life course.

The following vision statement served as a guide and focus for the work:

All individuals currently residing in congregated settings will have the opportunity/right to move to a home of their choice in the community. They will be provided with the individualised supports required to ensure an enhanced quality of life through maximum community participation.

In delivering this vision the process must ensure each individual's right to:

- *Choose, receive and direct the services and supports they need*
- *Participate in family and community*
- *Be independent and make individual choices*
- *Have the opportunity to maximise their full potential*
- *Receive outcome based services and supports*
- *Be treated with respect and dignity*
- *Be assured of their health and safety*

1.5 THE PRINCIPLES AND ASSUMPTIONS GUIDING THE WORK

Within the framework of the vision statement, the Working Group developed assumptions and principles to guide their approach. The Working Group agreed that:

⁹ Department of Health and Children. *Vision for Change: Report of the Expert Group on Mental Health Policy*. Stationery Office, 2006.

- All people with disabilities can live with adequate support, in an ordinary home, in a range of typical neighbourhood settings
- Proposals would be guided by the principles enshrined in the UN Convention on the Rights of People with Disabilities
- The focus would be on planning for community-based, person-centred responses for people currently living in congregated settings
- The plan would focus positively on achieving the vision rather than only on de-institutionalisation
- Evidence-based best practice in the field would underpin all proposed developments
- The rights and quality of life of citizens with disabilities is primary and the plan's time frame and funding will be based on this
- The plan would be open to new, creative and innovative responses to meeting individual needs
- Maximum participation of all stakeholders in the development of the plan would be encouraged through a comprehensive consultation process
- Particular attention would be given to ensure the views of service users are included
- The knowledge, expertise and commitment of staff that currently exists within services would be respected.
- The plan would be realistic about the time frame required to effect such a change and cost associated with same;
- The plan would take account of the complexity of the issue of cost, including any transitional costs should they arise
- The plan would advise on the system infrastructure required to manage this change.
- The use of current resources will be maximised
- The agencies are committed to implement the agreed framework.

1.6 THE WORK PROGRAMME

The key elements of the work programme undertaken by the Working Group were as follows:

- Learning about the current situation: collecting information about the people currently in congregated settings, and their lives
- Learning from research: reviewing the literature on the transfer of people from congregated to community settings and identifying key findings
- Learning from international experience.

Learning about the current situation: visits and survey (Chapter 3)

The Working Group wanted a clear understanding of the group of people living in larger congregated settings and a comprehensive profile of their situation so that a realistic and appropriate plan could be brought to Government. The mechanisms used were (i) visits to larger facilities by the Project Manager and (ii) a survey of all congregated settings that fell within the scope of the project.

Visits to 30 congregated settings enabled the Project Manager to meet with management, staff and residents and see at first hand the nature of the facilities and services available to residents. The visits also provided an opportunity to learn about the work and the planning that has been done by organisations that are moving people out of congregated settings to the community.

Data collection was undertaken by means of a survey of residential centres, which complemented the qualitative information gathered through visits by the Project Manager. The nationwide data collection commenced in early August 2008, giving agencies a five-week period to return completed questionnaires. Financial data collected related to audited accounts for 2005/2006. All centres contacted responded to the survey.

Learning from research

A review of the research literature on living arrangements for people with disabilities was undertaken to guide the preparation of proposals. The literature review looked at evidence from studies about the impact of institutional living compared to community living on important aspects of people's lives, including choice-making and self determination, community involvement, social networks, friendships and relationships. It also looked at the relative impact of different forms of living arrangements, and, in particular, the differential impact of campus or cluster-style housing compared to dispersed community living.

The learning from international experience

The transfer of people with disabilities from congregated settings to community living has been addressed in many jurisdictions over a period of many years. It was important to learn from these experiences, and to learn from things that did not go well, as well as successes.

The main mechanism for gathering the learning from international practice was a series of study visits to agencies in Wales, London and Sweden and a Round Table with experts in the field,¹⁰ hosted by the National Disability Authority (NDA). The

¹⁰ NDA Round Table on "Deinstitutionalisation: Moving the Agenda Forward." December 2007.

agencies visited were selected based on recommendations arising from ongoing research being conducted by the NDA; the services visited had significant experience in providing high quality community-based services as an alternative to congregated settings. In addition to site visits, the Project Manager made contact with experts in the United States, Canada and the UK, with a view to gathering more information about the experiences there.

Eliciting the views of stakeholders

The Working Group was committed to consulting stakeholders, and to paying particular attention to hearing the voice of service users. The membership of the Working Group was constructed to be broadly reflective of key stakeholders. In particular, to ensure that the service user perspective would influence the ongoing work of the group and its proposals, Jean Wright, self-advocate with intellectual disabilities and Martin Naughton, Disability Federation of Ireland, were co-opted to the Working Group at an early point. The visits by the Project Manager to a wide cross-section of congregated settings provided an opportunity to hear the views and experiences of staff and management in those centres.

1.7 THE REPORT

Part One of the Report (Chapters 1-6) sets out the case for urgent action to enable the 4,000 people living in the congregated settings covered by the Working Group's Report to move to live in local communities.

In Chapter 2 of the Report, the policy and legislative background to provision of residential services in Ireland is outlined. Chapter 3 gives an account of the population of people in the 72 congregated settings covered by the Report, and important aspects of their lives, based on the programme of visits and a detailed survey conducted by the Working Group.

Chapter 4 summarises a review of research literature on living arrangements for people with disabilities. The literature review looked at evidence from studies about the impact of institutional living compared to community living on important aspects of people's lives and pointed to the compelling evidence that dispersed housing in the community delivers a better quality of life for people with disabilities than clustered housing.

Chapter 5 gives an overview of the learning gathered by the Working Group from a number of jurisdictions about the experience of transferring people with disabilities from congregated settings to community living. Key features of the approaches adopted in these countries are described, as well as factors that supported or impeded successful transitioning.

Chapter 6 draws together the compelling case for taking action now to enable people in congregated settings to make the transition to a new life as part of a local community. This chapter outlines the Irish and international policy and legislative imperatives for change, as well as the ethical and economic arguments. While the challenges are recognised, the case is made that the long-term benefits for people with disabilities and for society outweigh the challenges and justify the radical programme of change being proposed.

'We Moved On': Stories of Successful Transitions to Life in the Community describes the life experience of people with disabilities who have made successful transition from life in a congregated setting to living in their local community.

Part Two (Chapters 7-11) of the Report outlines the strategy for action to enable everyone currently living in a congregated setting to move to the community within a seven-year time frame.

Chapter 7 sets out an overarching national framework for the transitioning process. It proposes essential policy developments, a national housing strategy for people with disabilities, and arrangements for national oversight of progress towards implementation of Report recommendations. It makes recommendations for a manpower strategy, interdepartmental protocols, and a national change management programme to assist the implementation process.

Chapter 8 proposes a radical new model of provision based on principles of person-centeredness. The model envisages that all housing for people moving from congregated settings should be in ordinary neighbourhoods (dispersed housing) in the community, provided mostly by housing authorities; each person should have access to a range of individualised supports to enable them to live in the home of their choice and be included in the community. The differing responsibilities of health service providers and housing authorities in the new model are outlined.

Chapter 9 describes a funding strategy for community-based support and housing. The costs of ongoing support provision in the new model are examined, and the costs of supplying the housing needs of those leaving congregated settings through a mix of housing options that include purchased housing, new-build housing, leased or rented housing.

Chapter 10 focuses on the arrangements for enabling the 4,000 people in congregated settings covered by the Report to make the move to the community. It makes detailed proposals covering the phasing, management and funding of the transitioning programme. The importance of a national evaluation framework to monitor progress is addressed. Supports to help current residents and families to make the step to community living having spent many years in congregated settings are proposed.

Chapter 11 provides a summary of the Report's recommendations.

PART ONE

THE CASE FOR ACTION

CHAPTER 2

THE EVOLUTION OF RESIDENTIAL SERVICES FOR PEOPLE WITH DISABILITIES

2.1 THE EARLY DEVELOPMENT OF CONGREGATED PROVISION

Residential institutions for people with disabilities have a long history in Ireland.¹¹ In the 18th century, workhouses, poorhouses and asylums accommodated people who were sick or destitute and people with mental health problems.

By the end of the 19th century, there were 22 large residential institutions in Ireland, each with a catchment area of one or two counties, where staff and residents lived, and where there was no interaction with the world outside the institution. During the 1850s, a focus on the special needs of people with intellectual disabilities developed. As a result of lobbying by prominent citizens, the first institution for people with intellectual disabilities, the Stewart Institution, opened in 1869, with four teachers and a programme of instruction.

More than 50 years passed before a second special residential institution was opened. In the late 1920s, the Daughters of Charity agreed to turn an existing home for children into a home and school for children with learning disabilities. Over the following 30 years, several religious orders opened special centres around the country. The development of special centres marked the start of a process of specialisation, and this approach was strongly embedded in the 1960s, with the development of a range of new professions specialising in therapies and services for people with learning disabilities.

2.2 DEVELOPMENTS IN THE 1950s AND 1960s

The 1950s saw the development of Parents and Friends Groups, a movement that grew strongly in the 1960s, with the setting up of local groups in counties around Ireland and the development of services and facilities in communities.

The Commission on Mental Handicap (1965)¹² recognised that care in the community was generally superior to and 'more therapeutic' than institutional care. The 1970 Health Act and the development of community care services in the country's health boards underpinned the emerging community-based approach to service provision.

¹¹ McCormack, B.(2004) 'Trends in the Development of Irish Disability Services' in Lives and Times: Practice, Policy and People with Disabilities. P.N.Walsh and H. Gash (eds). Rathdown Press.

¹² Department of Health. Commission on Mental Handicap. Stationery Office, 1965.

2.3 DEVELOPMENTS SINCE THE 1980s

The Green Paper *'Towards a Full Life'* (1984) recognised the slow growth in provision of residential services for people with physical disabilities. It noted that the majority of people with physical disabilities who could not live at home were maintained in county homes, psychiatric hospitals and orthopaedic hospitals, geriatric hospitals and centres for people with intellectual disabilities.¹³ The review of accommodation carried out at that time found that few of the centres reviewed, apart from Cheshire Homes, were equipped to meet the needs of people with physical disabilities:

*'Accommodation tends to be in open wards and dormitories offering little privacy to residents who are likely to spend much of their lives there...Even for the younger and more mobile residents, there are few opportunities to leave the confines of the home and this serves to heighten boredom and frustration...Residents have little if any say in the day to day operation of what for many is the only homes they will ever know.'*¹⁴

Since 1990 in particular, the movement towards community inclusion for people with disabilities has had a strong impetus, drawing especially on American influence, and the emergence of the disability rights movement in Ireland and internationally. The advent of Centres for Independent Living in the early 1990s and the beginning of availability of personal supports spearheaded the movement by people with physical disabilities to take control over their lives and choices, including their choice of accommodation.

The redirection of policy towards community-based living arrangements was clearly evident in the 1990s. In 1990, The Report of the Review Group on Mental Handicap Services, *'Needs and Abilities'* made comprehensive recommendations on the need to move from large congregated settings to domestic scale accommodation and access to community-based health services. It recommended that families should be supported to enable adults with intellectual disabilities to live at home; where a person must leave home, the substitute home should have all the characteristics of a good family home, other family care schemes such as adult foster care should be initiated. The Report proposed that large numbers of highly dependent intellectually disabled people should not be placed in one location. Small group homes should be provided where a small number of adults are supported to share a home, and also that existing residential centres that were not domestic in scale should be discontinued as soon as possible, and replaced with appropriate provision.¹⁵

In 1996, *'Towards an Independent Future'*, the Report of the Review Group on Health and Personal Social Services for People with Physical and Sensory Disabilities,

¹³ Department of Health. *'Towards a Full Life'*: Green Paper on Services for Disabled People, 1984, p94.

¹⁴ *'Towards a Full Life'*, p106.

¹⁵ *Needs and Abilities Report*, Chapter 9.

made recommendations about residential provision. As the extract below shows, this Review Body signalled a move away from large institutions, towards small living units and use of mainstream housing provision:

‘Developments of new homes and independent living should be located in urban areas or easily accessible to retail and leisure facilities.’

‘Each health board, in consultation with the co-coordinating committee, should examine the viability of establishing in its area small independent domestic dwellings with support ...Health Boards and voluntary bodies providing services to people with disabilities should liaise closely with Social Housing organisations and local authorities to ensure that an adequate number of accessible houses is available to people with disabilities who wish to pursue this option.’¹⁶

The Commission on the Status of People with Disabilities (1996) proposed that, as part of a mainstreaming agenda, the Department of the Environment should formulate a national policy on housing for people with disabilities. The Commission proposed that people living in residential centres should be provided with income supports in a way that promotes autonomy and choice, and that payments be clearly defined as between accommodation, personal assistance and care elements. The proposals also included provision for advocacy, quality standards and monitoring of standards.

The most recent policy initiative in relation to people living in institutions was the decision by the Department of Health and Children in 2002 to adopt a programme to transfer people with intellectual disabilities or autism from psychiatric hospitals and other inappropriate settings. The aim of that programme was to provide more appropriate care settings and an enhanced level of services for:

- People with an intellectual disability and those with autism accommodated in psychiatric hospitals;
- Those accommodated in de-designated units which were formerly designated as psychiatric services;
- Others who moved some years previously from psychiatric hospitals to alternative accommodation now unsuitable for their needs.

In response to public policy and investment, the numbers in the congregated settings have been declining. The survey of congregated settings conducted for the Working Group (Chapter 3) shows that 619 people had been transferred out from the settings covered by this Report between 1999 and 2008, and that 46 of the 72 centres had made arrangements for service users to transfer to the community. However, reported admissions to congregate settings in the same period at a total of 692 had exceeded the reported numbers transferred to the community over that period.

¹⁶ Department of Health. (1996) Towards an Independent Future, Summary of the Review Group Report on Health and Personal Social Services for People with Physical and Sensory Disabilities p8

CHAPTER 3

THE PEOPLE AND THE PLACES

3.1 GATHERING INFORMATION ON THE PRESENT SITUATION

In order to provide a detailed profile of the lives of people living in congregated settings and the services they receive, the Working Group arranged for the Project Manager to visit 30 residential centres that were part of the Working Group's remit. The information gathered by the Project Manager was complemented with a survey of residential centres. Through these two work projects, a comprehensive picture of the situation of people living in congregated settings as at Autumn 2008 emerged.

The survey methodology

A questionnaire was developed drawing loosely on the Living Environment Schedule developed by Emerson and colleagues.¹⁷ A number of members of the Working Group piloted the survey in their own services.

The questionnaire was in two parts - a centre questionnaire, addressed to the manager of each centre, and a unit questionnaire, filled in by the manager of individual units on a campus.¹⁸ The assessments as to the degree of support needs and capacities of residents were made by the unit managers.

Following consistency checks on the data, all centres were contacted by the Project Manager in June 2009 to clarify the data on numbers and expenditure. Individual queries on the data were also followed up. As a result, amended figures were submitted by a number of centres in the light of the discrepancies uncovered and clarifications given.¹⁹

The survey questionnaires are contained in Appendix 2.

¹⁷ Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., Jarbrink, K, Knapp, M., Netten, A., Walsh, P.N., (2001). Quality and Costs of Supported Living Residences and Group Homes in the United Kingdom. *American Journal of Mental Retardation*, 106,5, 401-415.)

¹⁸ 72 centres submitted centre questionnaires. These covered 4,005 long-stay residents, but in a small number of cases other residents such as those receiving respite care were included in certain answers. Unit questionnaires were available for 69 centres (The non-participating centres had 63 residents in total). The unit questionnaires cover 4,034 residents, again with a small number of short-stay residents covered. (The non-participating centres had 63 residents in total)

There are minor inconsistencies in the data supplied in response to different questions, where, for example, people receiving respite care were included along with long stay residents. The Working Group did not consider such small discrepancies to invalidate the broad picture provided here.

¹⁹ In April 2011, three centers which had included non-residential services in their original returns submitted corrected data which has been incorporated into this report and its analysis.

3.2 THE CONGREGATED SETTINGS

The survey shows that agencies are providing services in 72 congregated settings across 20 counties. The size of settings ranges from those that have one unit to a setting with 34 units. 29 settings provide one unit, with the number of places in these single units ranging from 8 to 52 places. The average number of places in the single unit settings is 18. The largest setting has 34 units, with places for 340 people.

3.3. THE PEOPLE LIVING IN CONGREGATED SETTINGS

Just over 4,000 people are living in the congregated settings in the project, with slightly more men (51%) than women. The vast majority are people with intellectual disabilities. Some 3,800 residents have primarily an intellectual disability and about 300 have primarily a physical or sensory disability.

Table 1: Numbers living in congregated settings, by primary disability

Residents whose primary disability is:	Nos.	%
Intellectual disability	3,802	93
Physical or sensory disability	297	7
Total	4,099	100.0

The National Intellectual Disability Database (NIDD) profiles the population with intellectual disability as a whole. Comparing this data with the Congregated Settings survey shows that people with intellectual disabilities living in congregated settings are typically older and have higher levels of impairment than people with intellectual disabilities generally.

Over half of those with intellectual disabilities living in congregated settings have a severe or profound level of disability compared to about one in five of those registered on the database (Table 2).

Table 2: Profile of residents with intellectual disabilities in congregated settings and NIDD by severity of disability

	Mild	Moderate	Severe	Profound
Congregated settings survey	9%	34%	44%	13%
NIDD 2008	36%	43%	17%	4%

Note: excludes those whose level of disability is unknown

People living in congregated settings account for just under half of all people with intellectual disabilities living in a residential care service (Table 2). A quarter of people with mild intellectual disabilities in residential services live in a congregated setting.

Table 3: Comparison of residents with intellectual disabilities in congregated settings and all residential services (NIDD 2008)

Degree of disability	Mild	Moderate, severe and profound	Total (including unknown degree of disability)
Congregated settings survey	337	3,448	3,913
NIDD 2008	1,315	6,772	8,262
- <i>community group homes</i>	897	2,976	3,894
- <i>residential centres</i>	230	2,771	3,015
- <i>other residential places</i>	239	1,109	1,381
Congregated as % of all residential provision	26%	51%	47%

Source: Table 3.2 NIDD 2008; Congregated settings survey

3.4 The age profile of residents

People living in congregated settings are mainly middle-aged. About half of residents are in the age range 40 to 60 years, with a further 20% aged over 60. About 100 residents were aged less than 19 years.

As people with disabilities get older, they are more likely to live in residential care, including larger centres. Direct comparisons with the NIDD are not possible because different age cut-off points are used, however it appears that a high proportion of over-55s live in a congregated setting.²⁰

3.5 ENTRY TO RESIDENTIAL CARE

Almost three quarters of people in congregated settings have been living there for over fifteen years. There is a continuing small number of admissions to these centres, with 45 admissions in the preceding year (2007), and 317 in the preceding five years (2003–2007) (Table 4). Close to half of residents moved into a congregate setting from the family home, while one in six had moved from residential schools or childcare centres.

²⁰The Congregated Settings Survey used age brackets of 50-60, 60 to 70, whereas the NIDD uses 55 and over. The over-60s in congregated settings are equivalent to a quarter of all those with ID aged 55 or over. The over-50s in congregated settings are equivalent to 55% of all those with ID aged 55 or over. Taking the midpoint, that suggests that about 40% of people with ID aged 55 or over may be living in a congregated setting.

Table 4: Length of time residents in centre have received residential services from Provider Organisation (current and previous)

	Number of Residents	
Less than one year	45	1%
one to five years	272	7%
five to ten years	375	10%
ten to fifteen years	338	9%
Over fifteen years	2,850	73%
Total	3,880	100%

46 centres of the 72 reported they had transferred service users to transfer into the community, but a significant minority of centres had not done so. A total of 619 residents were reported to have moved into the community in the previous ten years (1999-2008). However, reported admissions to congregate settings in the preceding ten years at a total of 692, had exceeded the reported numbers transferred to the community over that period.

3.6 THE LEVELS OF DISABILITY OF RESIDENTS

Among residents with intellectual disabilities, a majority (57%) have a severe or profound level of disability; about one in ten (9%) have a mild disability and a third (34%) have a moderate level of disability (Table 5).

Table 5: Numbers of residents of congregated settings with Intellectual Disability by age and level of ability

Age	Mild	Moderate	Severe	Profound	Unknown	Total	%
Under 19	2	11	40	32	0	85	2%
20-29 years	25	95	176	59	8	363	9%
30-39 years	37	175	359	111	31	713	18%
40-49 years	55	314	497	164	53	1083	28%
50-59 years	83	324	358	104	23	892	23%
60-69 years	68	232	153	29	10	492	13%
70-79 years	43	106	58	9	3	219	6%
80-89 years	23	22	17	0	0	62	2%
90+ years	1	3	0	0	0	4	0%
Total	337	1,282	1,658	508	128	3,913	100%
% excluding unknown	9%	34%	44%	13%	-	100%	

Multiple disability levels

The picture that emerged from visits to the residential centres is one of a high proportion of people with severe and profound intellectual disabilities, considerable levels of challenging behaviour and high levels of multiple disabilities. The population of clients was similar in all the settings visited. Many people with intellectual disabilities have significant physical disabilities as well as their

intellectual disability. There is a substantial population of people who are ageing and, in some cases, have dementia, and this brings with it increased levels of dependency. The level of dependency is significant. This poses particular challenges for staff and for facilities required to meet people’s needs.

The profile of clients observed in visits to residential centres is confirmed by the survey, which shows that most residents have multiple conditions. The data suggests that over 80% of residents whose primary disability was intellectual and over 70% of residents whose primary disability was physical or sensory had another condition. The prevalence of multiple disabilities and the degree of severity has implications for the supports required in whatever setting people are living (Table 6, Table 7).

Table 6: Number of residents whose primary disability is intellectual by age and type of additional conditions

Age	Intellectual Disability (no additional conditions)	Intellectual Disability & mental health difficulties	Intellectual Disability & physical/sensory disability	Intellectual Disability & medically fragile	Intellectual Disability & Challenging Behaviour	Intellectual Disability & Autism Spectrum Disorder
Under 19	7	2	34	26	3	18
20-29 years	46	47	95	57	123	51
30-39 years	120	110	225	121	243	108
40-49 years	217	200	297	163	367	101
50-59 years	206	184	270	184	198	43
60-69 years	92	122	118	90	103	12
70-79 years	39	68	47	64	45	3
80-89 years	5	11	17	17	7	0
90+ years	1	2	1	1	0	0
Total	733	746	1104	723	1089	336

Note: The disability categories are not necessarily mutually exclusive

Table 7: Number of residents with physical or sensory disability by age and type of additional conditions

Age	Physical or Sensory disability (no additional conditions)	Physical or Sensory disability & mental health difficulties	Physical or Sensory disability & intellectual disabilities	Physical or Sensory disability & neurological conditions	Physical or Sensory disability & addiction problems
Under 19	0	11	18	5	0
20-29 years	5	8	42	18	0
30-39 years	19	10	77	23	0
40-49 years	22	15	100	48	4
50-59 years	22	20	64	32	3
60-69 years	15	11	43	17	1
70-79 years	3	11	23	2	0
80-89 years	0	2	4	0	0
90+ years	0	0	0	0	0
Total	86	88	371	145	8

Note: This table may include some people already tallied in Table 6. The disability categories are not mutually exclusive.

3.7 LEVELS OF SUPPORT NEEDS

Many of the residential services have, over the years, developed some community-based, as well as campus-based, provisions. Younger residential service users are more likely to live in the community-based services whereas older service users are more likely to live in campus settings. In some cases, individuals who were “more able” were moved to a more community-based service. Therefore many people were left behind are those whose needs are more complex in a variety of ways.

The data from the unit questionnaires showed a high degree of support needs among residents in relation to activities of everyday living. Staff assessments were that over 70% would need help with dressing themselves, about a third needed help with eating and almost 90% needed help to wash. 40% are unable to walk independently. Only 35% can speak in sentences. Staff considered about half the residents to exhibit challenging behaviour (Table 8).

The level of dependency among residents will necessitate careful planning to support their involvement in local communities. However, the Project Manager’s report on visits indicated that these support needs are not different from those of large numbers of people with intellectual disability currently being accommodated and supported in community-based accommodation.

Table 8: How many residents in this unit....

	Nos.	Does	Does not
Feed themselves independently	2,671	68%	32%
walk independently	2,344	60%	40%
are continent	2,125	55%	45%
dress independently	1,123	29%	71%
wash independently	503	14%	86%
restricted mobility	1,033	29%	71%
uses a wheelchair with support	842	25%	75%
uses a wheelchair independently	208	7%	93%
speak in sentences	1,389	37%	63%
sign or speak words or phrases	1,110	30%	70%
exhibit challenging behaviour	2,069	54%	46%
take psychotropic medication	2,168	57%	43%

Note: The percentages were calculated as a proportion of residents in those units which supplied data for individual topics in the table. For individual sub-questions, the numbers of residents on which the above table is based ranges between 3,078 and 3,957 covering between 76% and 98%. of residents in the sample.

3.8 PREMISES AND LIVING CONDITIONS

The site visits to residential centres by the Project Manager identified significant variation from agency to agency in the quality of physical facilities. Managers and frontline staff described the struggle to provide basic provisions for bathing, toileting, and dental hygiene.

The survey also gathered detailed information on the nature of physical facilities and levels of access to personal privacy. The survey found that there are significant issues around lack of privacy and dignity, as demonstrated in the data on shared bedrooms and bathroom facilities, people being changed in communal areas and situations where people have no personal belongings or where their personal belongings are communal property.

20 older people with severe disability with one accessible shower and 2 wash basins. People wait their turn to be washed and have their teeth cleaned.

Project Manager's observations

A ward with 10 beds side by side with minimal space between, and no curtain dividing them

Project Manager's observations

A Unit for 15 severely disabled people, two have significant medical problems which result in their being peg fed. All others need high levels of support in all the essential activities of daily living. The number of staff on duty at any given time is 3. There are significant periods in the day where only 2 people are on duty to cover the basics i.e. getting people up, dressed, washed and fed. Service users either do not have a day programme or if they do it is a very limited session, maybe once or twice per week. Some people get no day provision at all.

Project Manager's observations

Bedroom and bathroom facilities

According to the survey, just over half of residents had a single bedroom. A quarter of residents were living with 4 or more to a bedroom, while one in 10 were living with 12 or more people to a bedroom (Table 9). Half of all units with shared rooms had 2-4 feet between adjacent beds, while 10% of units with shared rooms had less than two feet between adjacent beds.

Just 7% of residents had an en-suite bathroom. The average number of residents per WC in each unit is 2.5, and per bath/shower room 3.7. About 90% of WCs and bathrooms are accessible – an important consideration when such a high proportion of people have mobility difficulties.

Arrangement for changing residents who are incontinent is an important consideration. Unit managers reported that in nearly a third of units, residents

requiring to be changed were changed in a communal sleeping or day area rather than in a private area.

Table 9: Shared bedrooms

No. of bedrooms occupied by:	Number of rooms	No. of persons	% of persons
1 person only	2,276	2,276	52%
2 persons	433	866	20%
3 persons	63	189	4%
4 persons	56	224	5%
5 persons	30	150	3%
6 persons	12	72	2%
7 persons	4	28	1%
8 persons	4	32	1%
9 persons	2	18	0%
10 persons	3	30	1%
11 persons	3	33	1%
12 or more persons	37	444	10%

Personal items

The survey indicates that virtually all residents have their own clothes, with clothes storage in most cases available in the bedroom. Staff reported that personal belongings become communal property in about 15% of units.

3.9 ACTIVITIES AND INCLUSION

The lack of day service was consistently evident in the course of the project manager's visits, with staff in the units/wards trying to provide everything for the service user. The picture observed by the Project Manager is confirmed by the survey. For a significant minority of residents there are no activities or very limited day activities. 11% had no structured day programme, with a further 18% having a limited day programme in the ward or sleeping/living area.

The picture of daily life that emerges from the survey is of people whose lives are largely confined to the centres where they live, few of whom take part independently in mainstream community activities outside the centre.

Person-centred planning

According to the survey, in about a third of units residents had limited access to person-centred planning or no person-centred planning

Table 10: Person centred-planning (PCP)

	%
no PCP planned or implemented	9%
limited, ad hoc, person-centred planning, implementation and review	23%
Structured planning and implementation of PCPs, some gaps	43%
Structured planning, implementation and review of PCPs with little or no gaps	25%

Daily activities and routines

Over a quarter of residents have either no day programme or a limited day programme in their wards. Just under a quarter are involved in employment or attend a workshop. 16% are involved in off-campus activities. Staff report that about one in five residents undertake activities independently, and about half do so jointly with staff. About two thirds of residents take part in daily physical recreation such as a walk or sport. Routines typically appear to be characterised by early-bed-times with the median time for the first people in a unit going to bed at 9 pm, and the last at 10.30 pm.

Table 11: Structured day programmes

How many residents in this unit have a structured day programme...	No. of residents	%
off-campus employment or workshop	263	7%
off –campus other day programme	336	9%
on-campus employment or workshop	609	16%
on-campus other programme	1,582	40%
limited day programme in ward or sleeping/living accommodation area	688	18%
no structured day programme	444	11%
Total	3,922	100%

The importance of a staff input which actively supports independence has been emphasised by leading researchers.²¹ Table 12 shows that staff/resident interactions are still often characterised by passive roles for residents.

²¹ Jones, E., Perry, J., Lowe, K., Felce, D., Toogood, S., Dunstan, F., Allen., D., Pagler, J. (1999). "Opportunity and the promotion of activity among adults with severe intellectual disability living in community residences: the impact of training staff in active support **Journal of intellectual disability research**" 43-3, 164.

Table 12: How staff and residents engage in daily activity together

Which best describes involvement of staff and residents together in daily activity?	% of units
Staff supervise passive recreation	6%
Staff perform activities alongside residents	24%
Staff and residents jointly undertake activities	51%
residents undertake activities, under staff supervision	19%

Links to local community

Almost 70% of residents had engaged in at least one community activity in the previous month as a group, however only 15% were involved in mainstream community activity on their own.

Table 13: Mainstream community activities

(e.g. going shopping, to café or pub, match, cinema or similar activities in community venue)	No. of residents	%
Total number of residents engaging in 1 or more group community activities last month	2,738	69%
Total number of residents who engaged in 1 or more community activities on own last month	608	15%

Location

Lack of participation in the local community is compounded by the physical isolation of a number of the centres. A number of these centres are fairly isolated from mainstream community facilities. 27% of centres are located 1-3 miles from the nearest town centre facilities, 14% are located 3 to 5 miles, and 3% over 5 miles from the nearest town centre facilities. Two centres are also located a considerable distance, over half a mile from the main road.

3.10 FAMILY CONTACT

A significant minority of residents had no or minimal contact with family or friends in the previous year. About one in three had no such contact in the preceding six months, including about one in ten who had had no such contact in the preceding year (Table 14).

Table 14: Family contact

	No. of residents	%
How many residents typically have had family contact (phone call, visit etc.,) over the previous...		
Month	2,420	60%
Six months	1,330	33%
Year	1,001	25%
No contact in previous year	452	11%

Note: Due to the wording of the question, the responses were not mutually exclusive and totals add up to more than 100%.

3.11 STAFFING

General staffing levels

I do not believe it is possible to respond to the needs of these clients, to respect their rights and to treat them with the dignity they deserve on the current staffing levels. The evidence to date suggests that there will need to be significant refocusing of the use of resources currently in the system in order to improve the quality of life of the clients. When HIQA start their inspections and see some of the situations I have observed they are likely to comment about people's human rights and the need for people to be treated with dignity & respect.

It is important to emphasise that the issues raised [in relation to service users' quality of life] are not due to lack of commitment by the staff or by the providers of these services. Staff are aware that thinking has moved on and there is a lot of discussion about person centredness, rights, quality of life etc. Many people expressed their frustration at wanting to be able to respond to their clients in this way but not having the staff to do so.

These problems reflect the reality that it is impossible to provide high quality services without adequate staffing.

Project Manager's observations

Staffing levels, ratios and skill mix

People with complex needs may require considerable staff input, whatever the setting in which they live.

The survey indicates that the total number of staff employed across all centres for which this data was available²² was 5,368 – a ratio of 1.65 staff members per resident. (Table 15). On average there was one staff member on duty during the day for every 2.3 residents, and one staff member for every 5.9 residents at night

²² Data on centre staffing was available for 69 centres with 3,261 residents, accounting for 81% of residents in the survey.

Nursing staff (39%) and care staff (35%) accounted for the majority, with 3% being medical or therapy staff. The service is highly professionalised, with a ratio of approximately one nurse for every 1.6 residents.

Table 15: Staff for residential centre/campus (whole time equivalent)

	Number of WTE staff	%
care staff	1,886	35%
social care worker	223	4%
qualified nursing staff	2,102	39%
Medical staff (doctors, psychiatrists etc.)	45	1%
Therapy staff (e.g. O.T., physiotherapist, psychologist)	87	2%
housekeeping and catering	612	11%
management and administration	414	8%
Total	5,368	100%

3.12 COSTS

Centres were asked to provide details of their costs in 2005 and 2006, broken down as between pay and non-pay, HSE-funded, privately-funded and other.²³ Cost funded other than through the HSE totalled €4.1m, or less than 1%.

Dividing the 2006 expenditure data by the 2008 data on resident numbers gives an approximation of costs per head. On average, HSE-funded spending in 2006 came to €106,000, of which 83% represented pay.

However, there was a very wide dispersion of cost around this average. A quarter of all centres had a per-capita HSE cost of under €77,000; 50% lay between €78,000 and €130,000, while a quarter of centres spent more than €130,000 a head. Total HSE spend in 2006 for the 70 centres for which data are available (covering 3,929 or 98% of total residents) totalled €417m.

The average cost to the HSE per head of staff for these centres, was €54,000 per annum per whole time equivalent, including medical, clinical, direct care and management staff.²⁴

²³ Two centres were unable to provide any separate cost data because of integration in larger budgets. Two large centres did not apportion costs for their congregated settings for 2005. On average, where there was comparable information for 2005 and 2006, HSE-funded expenditure was 2.7 % higher in 2006.

²⁴ Calculated by taking HSE pay expenditure for 2006 divided by total centre whole-time equivalent staffing in 2008. Data on both costs and staff numbers were available for 66 of the 72 centers, accounting for 3,261 or 81% of residents covered by the survey.

Table 16. Cost range per capita: ten highest cost and lowest cost settings (HSE cost)

Top ten HSE cost 2006	Lowest ten HSE cost 2006
€ per capita	€ per capita
231,575	65,861
192,748	62,353
190,261	60,721
187,737	55,227
168,146	50,457
163,318	49,972
161,171	46,084
160,797	45,525
157,697	41,273
152,477	37,394

Some centres (covering about one in six residents) reported other sources of expenditure, for example FÁS. On aggregate this added just 1% to overall national expenditure on congregated settings. Non-HSE funding accounted for an average extra €7,000 per capita in the centres concerned, and about 6.5% of their budgets.

Multi-Annual Investment Programme funding

Up to 25 centres received funding over the period 2005 to 2007, totalling €15.7m. (€8.9m. capital and €6.8m. revenue over the three years) under the Multi-Annual Investment Programme for disability.

3.13 SUMMARY

The survey, together with the Programme Manager's visits depicts a population of whom over half (57%) have a severe or profound intellectual disability. Most people have been in the congregated setting for at least 15 years, and have minimal contact with family or friends.

There are high levels of multiple disability and dependency. For many, there were significant issues in relation to lack of privacy and dignity, and limited daily activity. The model of service is strongly medicalised, with almost 40% of staff made up of qualified nurses.

While costs vary from centre to centre, the average payment per person by the HSE is €106,000 per annum, of which 83% is made up of staffing costs.

CHAPTER 4

THE LEARNING FROM RESEARCH

4.1 WHAT THE RESEARCH TELLS US

The Working Group examined international research findings about the benefits and costs of deinstitutionalisation and community living, in order to provide a solid evidence-base for its work. As part of its review of the international literature, the Working Group drew in particular on

- a recent large-scale international review of research on the cost-effectiveness of community living²⁵
- a National Disability Authority review of the literature on quality of life for people with intellectual disabilities²⁶
- a paper by disability experts from the UK's Tizard Centre to the NDA's 2009 conference, which surveyed the research findings over a lengthy period²⁷
- a National Disability Authority review of the literature on clustered versus dispersed models of community housing²⁸.

4.2 THE OUTCOMES OF DE-INSTITUTIONALISATION

There is an extensive international research literature, which has examined the quality of life for people with disabilities comparing institutional and community options.

The literature takes account of two factors that affect judgements about the impact of living arrangements and life outcomes for persons with intellectual disabilities. Firstly difference in outcomes is strongly associated with the personal characteristics of the individual with intellectual disabilities, and in particular with their level of

²⁵ Mansell, J., Knapp, M., Beadle-Brown, J. and Beecham, J. (2007) **Deinstitutionalisation and community living – outcomes and costs: report of a European Study**

²⁶ Walsh, P.N., Emerson, E., Lobb, C., Bradley, V., and Mosely, C., (2007) Supported Accommodation Services for people with Intellectual Disabilities: a review of models and instruments used to measure quality of life in different settings. NDA

²⁷ Mansell J. and Beadle-Brown, J. (2009b). Cost Effectiveness of Community Living for People with Intellectual Disabilities: an international perspective (conference paper). www.nda.ie

²⁸ Mansell J and Beadle-Brown, J (2009a) Dispersed or clustered housing for disabled adults: a systematic review. NDA

intellectual disability or adaptive behaviour.²⁹ Secondly, people with more severe intellectual disabilities tend to live in larger or more institutional style settings.³⁰

From one study to another, there has been variation in the composition of the study population, the kind of community provision, and the degree to which those services follow a person-centred model, which are factors which can affect the results of individual studies. Notwithstanding this point, there is a consistency in findings spanning over thirty years of such research that points predominantly towards a better quality of life for people in community settings compared to living in institutional care.

Mansell and Beadle-Brown's paper (2009b) surveyed a series of successive reviews of this extensive literature:

"The large number of relevant studies (*i.e. comparing outcomes in institutions and in community living*) have been summarised in a series of reviews which illustrate typical findings. Kim, Larson and Lakin (2001) reviewed 29 comparative and longitudinal American studies between 1980 and 1999. In terms of adaptive behaviour, 19 studies showed significant improvements and two studies showed significant decline. In terms of challenging behaviour, five studies found significant improvements while two studies found a significant worsening in behaviour. Of the remaining studies where change was not significant, eight reported a trend towards improvement while six reported a trend towards decline.

Emerson and Hatton (1994) reviewed 71 papers published between 1980 and 1993, which examined the effect of moving from institutional to community services in the UK and Ireland. In five of six areas (competence and personal growth, observed challenging behaviour, community participation, engagement in meaningful activity and contact from staff), the majority of studies reported positive effects; only in one area (reported challenging behaviour) did the majority of studies report no change. Young *et al* (1998), reviewing 13 Australian studies of deinstitutionalisation published between 1985 and 1995, showed a similar pattern. In six of the nine areas studied (adaptive behaviour, client satisfaction, community participation, contact with family/friends, interactions with staff and parent satisfaction), the majority of studies report positive effects and in the remaining three (problem behaviour, community acceptance and health/mortality) the majority report no change.³¹

²⁹ Walsh et al. (2007) op. cit.

³⁰ Stancliffe, R., Emerson, E., and Lakin, C., (2004) Residential Supports in E. Emerson et al., **The International Handbook of Applied Research in Intellectual Disabilities**. New York & Chichester: Wiley

³¹ Kim, S., Larson, S. A. and Lakin, K. C. (2001) Behavioural outcomes of deinstitutionalisation for people with intellectual disability: a review of US studies conducted between 1980 and 1999. **Journal of Intellectual & Developmental Disability**, 26(1), 35-50;

Emerson, E. and Hatton, C. (1994) **Moving Out: Relocation from Hospital to Community**. London: Her Majesty's Stationery Office;

Young, L., Sigafoos, J., Suttie, J., Ashman, A. and Grevell, P. (1998) Deinstitutionalisation of persons with intellectual disabilities: A review of Australian studies. **Journal of Intellectual & Developmental Disability**, 23(2), 155-170;

Kozma, Mansell and Beadle-Brown (2009) reviewed 67 papers published between 1997 and 2007. In seven out of ten areas (community presence and participation, social networks and friendships, family contact, self-determination and choice, quality of life, adaptive behaviour, user and family views and satisfaction) the majority of studies showed that community living was superior to institutional care. In three areas (challenging behaviour, psychotropic medication and health, risks and mortality) research reported mixed or worse results.

Thus the general finding is that community-based service models achieve better results for the people they serve than institutions."

Summary findings

The NDA's 2007 study which reviewed literature published from 1995 to 2005³² has a useful table which summarises the findings across 98 different studies. The report reviewed 49 deinstitutionalisation studies (those whose primary aim is to evaluate the impact of process of deinstitutionalisation on the quality of life of people with intellectual disabilities, and 49 "post-deinstitutionalisation studies", which compared quality of life outcomes across different types of community based residences, or identified factors associated with variations in the quality of life within community-based residences. The table below summarises the findings:

The ticked boxes mark where there is evidence of a better outcome in a particular setting. This summary shows that with the exception of some aspects of physical health, in no other domain does the evidence show a better quality of life in institutional care.

Kozma, A., Mansell, J. and Beadle-Brown, J. (2009) Outcomes in different residential settings for people with intellectual disability: a systematic review. **American Journal on Intellectual and Developmental Disabilities**, 114(3), 193-222

³² Walsh et al (2007) Supported Accommodation Services for people with Intellectual Disabilities: a review of models and instruments used to measure quality of life in different settings. NDA

Table 4.1 - Summary of evidence on quality of life - institution v. community

	Institution	On transfer to community housing	Smaller v. larger community settings
Personal skills	Little evidence	√	√
Material well-being		Little evidence	No evidence
Choice and self-determination		√.	√
Other independence		√	
Social networks and friendships		√	inconsistent
Community-based activities		√	√
Employment		Little evidence	
Emotional well-being/mental health	√	No systematic link	Inconsistent
Physical health		inconsistent	√
Personal life satisfaction		√	

Based on Table 1.3, Walsh et al (2007) Supported Accommodation Services for People with Intellectual Disabilities. NDA

4.3 FINDINGS ON INDIVIDUAL ASPECTS OF QUALITY OF LIFE

The evidence on individual aspects of quality of life, using the framework outlined in Table 4.1, is summarised below. Of the domains listed in Table 4.1, 'material well-being' and 'employment' are excluded in the review below as, to date, there is little available evidence how residential setting impacts on these specific domains.

Health

It should be noted that while the health studies cited in the NDA literature review showed some negative health outcomes, a US literature review which looked at health status, health care use and outcomes for people with intellectual disabilities concluded that the overall health of residents was similar or improved when they moved from institutions to community settings.³³ Other studies have pointed to less

³³ Hayden, Kim and de Paepe (2005) Health status, utilisation patters and outcomes for persons with intellectual disabilities: a review of the literature. **Mental Retardation** 36 345-349

healthy lifestyles in community settings.³⁴ One study found deinstitutionalisation has been associated in some studies with unintended weight gain and loss.³⁵

Mortality

The evidence of an association between increased mortality and deinstitutionalisation is inconsistent.³⁶ Some earlier studies showed institutions either have higher or similar mortality rates after controlling for severity of disability.³⁷ Two large-scale studies from California reported deinstitutionalisation was associated with increased mortality.³⁸ Subsequent studies have not replicated those findings.³⁹ A 2009 study has shown the quality and diversity of the residential environment, and the extent of community integration lowers mortality risk among people with intellectual disability, after controlling for personal characteristics, and points out that such social and environmental characteristics had not been factored into the California studies.⁴⁰ Other research suggests that higher mortality was not

³⁴ Rimmer, Braddock and Marks (1995) "Health characteristics and behaviours of adults with intellectual disabilities residing in three living arrangements" **Research in developmental disabilities** 16, 489-499

³⁵ Bryan, Allan and Russell (2000) "The move from a long stay learning disabilities hospital to community homes: a comparison of clients' nutritional status" **Journal of human nutrition and dietetics** 13(4) 265-270

³⁶ Hsieh K, Heller T and Freels S (2009) "Residential characteristics, social factors and mortality among adults with intellectual disabilities: Transitions out of nursing homes" **Journal of Intellectual and Developmental Disabilities** 47 (6) 447-465. On p.448-449 this article reviews the findings of the literature on mortality and transitions to community care and shows an absence of consistent findings.

³⁷ E.g. Miller and Eyman (1978) Hospital and community mortality rates among the retarded **Journal of mental deficiency research** 22 137-145; Eyman, Grossman, Tarjan and Miller (1987) Life expectancy and mental retardation: a longitudinal study in a state residential facility. Washington DC: American Association on Mental Deficiency. At the time these studies were done, the profile of the institutionalised population could have been somewhat different to that in later studies

³⁸ Strauss and Kastner (1996) "Comparative mortality of people with mental retardation in institutions and in the community" (n=18,362) **American Journal on Mental Retardation** 101(1) pp 26-40 Shavelle and Strauss (1999) "Mortality of persons with developmental disabilities after transfer into community care: a 1996 update" (n=1,878); Strauss, Shavelle and Baumeister (1998) "Mortality in persons with developmental disabilities after transfer into community care (n=1,878) **American Journal on Mental Retardation** 102(6) pp 569-581. The 1998 and 1999 articles refer to the same dataset.

³⁹ For example Conroy and Adler (1998) "Mortality among Pennhurst class members - a brief report (n=1,154) **Mental Retardation** 36 (5) pp. 13-26; O'Brien and Zaharia (1998) "Recent mortality patterns in California" (n=7,923) **Mental Retardation** 36(5) pp.372-379; Lerrnan, Apgar and Jordan (2003) "Deinstitutionalisation and mortality: findings of a controlled research design in New Jersey" (n=300) **Mental Retardation** 41(4) pp 225-236

⁴⁰ Hsieh K, Heller T and Freels S (2009) "Residential characteristics, social factors and mortality among adults with intellectual disabilities: Transitions out of nursing homes" **Journal of Intellectual and Developmental Disabilities** 47 (6) 447-465.

related to relocation but to the presence of specific risk variables for the people moving out.⁴¹

Community involvement⁴²

Studies examining this aspect of deinstitutionalisation looked at people's involvement in community-based activities and their use of community facilities. Key findings can be summed up as follows:

- There is a need to acknowledge that rates of community participation are limited no matter where one is living and that this is especially the case for those with more severe disabilities
- Factors such as the adaptive behaviour skill levels of individuals and individual social competence impact on how well the individual with intellectual disability accesses his/her local community
- Community participation is associated with the quality of supports provided by organisations delivering services
- Increased community participation happens in community-based residences when compared with campus/cluster-style housing and more traditional style residential settings (nursing homes or centres for people with intellectual disabilities)
- Smaller-scale community residences provide more opportunities for community involvement than larger settings.
- Supported living and semi-independent living produce more community involvement than traditional group homes.

⁴¹ Lerrnan, Apgar and Jordan (2003) op. cit.; Read (2004) Mortality of people with learning disabilities following relocation from long-stay hospital to social care. **Journal of Intellectual Disabilities** 8(3) 666-676

⁴² Ager, A., Myers, F.K., Kerr, P., Myles, S. & Green, A. (2001). Moving home: Social integration for adults with intellectual disabilities resettling into community provision. **Journal Of Applied Research In Intellectual Disabilities**, 14 (4), 392-400;

Felce, D., Lowe, K., Beecham, J. & Hallam, A. (2000). Exploring the costs and quality of services for adults with severe intellectual disabilities and the most severe challenging behaviours in Wales: a multivariate regression analysis. **Journal Of Intellectual And Developmental Disability**, 25 (4), 307-326;

Conroy, J., Spreat, S. & Yuskas, A. (2003). The Hissom closure outcomes study: a report on six years of movement to supported living. **Mental Retardation**, 41 (4), 263-275;

Baker, P.A. (2007). Individual and service factors affecting deinstitutionalization and community use of people with intellectual disabilities. **Journal Of Applied Research In Intellectual Disabilities**, 20 (2), 105-109

Social networks, friendships and relationships⁴³

Friendships and relationships are an important aspect of all of our lives. Research, as cited below, shows that positive relations with others, that is, seeking to develop and maintain warm and trusting interpersonal relationships, is conducive to emotional wellbeing.

Key research findings about the impact of deinstitutionalisation on social networks, friendships and relationships are as follows:

- The deinstitutionalisation process is associated with larger social networks and increased number of relationships
- Some literature reports no differences in social networks, friendships and relationships between community houses and campus/cluster housing, nursing homes or residential centres for people with intellectual disabilities
- Other research indicates that people with intellectual disabilities in community-based homes experienced greater contact with members of their social networks as opposed to in campus/cluster-based housing, that people living in smaller settings experienced more social contact and that people in supported living had more interaction with people in their social network than people living in traditional group homes
- Family contact was unrelated to the size and type of living arrangements in some studies but was reported to have an impact in others; for example, in some studies people in small community settings had more family contact than residents in institutions and people moving from institutions to community settings had increased contact with their families

⁴³ Ager, A., Myers, F.K., Kerr, P., Myles, S. & Green, A. (2001). Moving home: Social integration for adults with intellectual disabilities resettling into community provision. **Journal Of Applied Research In Intellectual Disabilities**, 14 (4), 392-400;

Conroy, J., Spreat, S. & Yuskas, A. (2003). The Hissom closure outcomes study: a report on six years of movement to supported living. **Mental Retardation**, 41 (4), 263-275;

Walsh et al. (2007) op.cit

Donnelly et al., (1996) "one and two-year outcomes for people with learning disabilities discharged to the community **British Journal of Psychiatry** 168(5) 598-606;

Emerson, E. (2004). Cluster housing and freedom of choice: a response to Cummins and Lau's and Bigby's commentaries. **Journal Of Intellectual And Developmental Disability**, 29 (3), 187-197;

Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissiglou, S., Hallam, A., Knapp, M., Jarbrink, K., Walsh, P.N. & Netten, A. (2000). Quality and costs of community-based residential supports, village communities, and residential campuses in the United Kingdom. **American Journal on Mental Retardation**, 105 (2), 81;

Emerson, E., Gregory, N., Robertson, J., Kessissiglou, S. & Hatton, C. (2001). Factors associated with expressed satisfaction among people with intellectual disability receiving residential supports. **Journal of Intellectual Disability Research**, 45 (4), 279-291.

Self-determination and choice⁴⁴

The literature looking at the impact of deinstitutionalisation and community living on choice making and the ability to determine one's life is consistent in its results. The research indicates that:

- Increased choice and self-determination are associated with community-based and smaller settings
- While deinstitutionalisation and community living increased choice-making, the range of choices available tended to be limited; for example, few people with intellectual disabilities get to choose where and with whom they live
- The smaller and more personalised the living arrangement, the greater the opportunities for choice and self-determination but small size of accommodation is a necessary but not a sufficient condition to achieve this outcome
- Active support where staff are trained to provide facilitative assistance to residents, as opposed to completing tasks on their behalf, is an important predictor of quality of life for residents⁴⁵
- A more homelike setting also impacted positively on levels of choice-making.

Skills development⁴⁶

The research shows that deinstitutionalisation has impacted positively on the development of new skills and increased adaptive behaviour but in limited ways; the

⁴⁴ Ager et al., (2001) op. cit.; Robertson, J., Emerson, E., Hatton, C., Gregory, N., Kessissiglou, S. & Hallam, A. (2001). Environmental opportunities and supports for exercising self-determination in community-based residential settings. **Research in Developmental Disabilities**, 22 (6), 487-502; Stancliffe, R. and Abery, B. (1997). Longitudinal study of deinstitutionalisation and the exercise of choice. **Mental Retardation**, 35 (3), 159-169;

Robertson et al. (2001) op. cit.; Perry, J. & Felce, D. (2005). Factors associated with outcome in community group homes. **American Journal on Mental Retardation**, 110 (2), 121-135

⁴⁵ Felce D, Jones E and Lowe K (2000) Active support: Planning daily activities and support for people with severe mental retardation. In DS Holburn & P Vietze (eds) *Person-centred planning: research, practice and future directions*. Baltimore: Paul H Brookes; Jones, Perry, Lowe, Felce, Toogood, Dunstan, Allen, and Pagler(1999) Opportunity and the promotion of activity among adults with severe intellectual disability living in community residences: the impact of training staff in active support **Journal of Intellectual Disability Research** 43(3) 164

⁴⁶ Beadle-Brown, J. & Forrester-Jones, R. (2003). Social impairment in the care in the community cohort: the effect of deinstitutionalization and changes over time in the community. **Research in Developmental Disabilities**, 24 (1), 33-43;

Lerman, p., Apgar, D. & Jordan, T. (2005). Longitudinal changes in adaptive behaviours of movers and stayers: findings from a controlled research design. **Mental Retardation**, 43 (1), 25-42;

Walsh et al. (2007) op. cit.; Young, L. & Ashman, A. (2004). Deinstitutionalization for older adults with severe mental retardation; results from Australia. **American Journal on Mental Retardation**, 109 (5), 397-412.

increase in skills and adaptive behaviour is most evident after a move but may not be sustained over time. A review of US literature on deinstitutionalisation covering 1980 to 1999 found statistically significant increases in overall adaptive behaviour scores associated with deinstitutionalisation, and reported that an earlier review of the US literature spanning 1976 to 1988 had found consistently that positive adaptive behaviour changes were associated with people moving from institutions to community homes.⁴⁷ One study reports a greater increase in new skills post-deinstitutionalisation by residents with severe/profound disabilities than by those with mild/moderate levels of intellectual disability.

Behaviour that challenges⁴⁸

Most other studies that looked at levels of challenging behaviour report no significant changes in challenging behaviour after a move to the community. Some studies found significant improvements⁴⁹ while a small number found deterioration in certain behaviours such as passivity or disruptive behaviour.⁵⁰ The data suggests, however, that behaviour that challenges is managed differently in the different settings. Findings from specific studies noted that:

- institutions tend to use more restrictive practices
- community-based services were more likely to use sedation

⁴⁷ Kim, Larson and Lakin. (2001) Behavioural outcomes of deinstitutionalisation for people with intellectual disabilities - a review of US studies 1980-1999. *Journal of Intellectual and Developmental Disability* vol 26(1) 35-50

⁴⁸ Stancliffe, R.J., Hayden, M.F., Larson, S.A. & Lakin, C. (2002). Longitudinal Study on the adaptive and challenging behaviours of deinstitutionalized adults with mental retardation. ***American Journal on Mental Retardation***, 107 (4), 302-320;

Young & Ashman, 2004 op.cit.; Saloviita, T. (2002). Challenging behaviour, and staff responses to it, in residential environments for people with intellectual disability in Finland. ***Journal of Intellectual and Developmental Disability***, 27 (1), 21-30;

Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissiglou, S. & Hallam, A. (2000). Treatment and management of challenging behaviours in residential settings. ***Journal Of Applied Research In Intellectual Disabilities***, 13 (4), 197-215;

Hundert, Walton-Allen, Vasdev, Cope, and Summers (2003) A comparison of staff-resident interactions with adults with developmental disabilities moving from institutions to community living. ***Journal of Developmental Disabilities*** 10(2), 93

McGillivray, J. & McCabe, M.P. (2005). The relationship between residence and the pharmacological management of challenging behaviour in individuals with intellectual disability. ***Journal of Developmental and Physical Disabilities***, 17 (4), 311-325.

⁴⁹ Golding, Emerson and Thornton (2005) An evaluation of specialised community-based residential supports for people with challenging behaviour. ***Journal of intellectual Disabilities*** 9(2) 145; Young and Ashman (2004) Deinstitutionalisation in Australia Part 2 - Results from a long-term study. ***The British Journal of Developmental Disabilities*** 50(1) 29-45; Young (2006) Community and cluster centre residential services for adults with intellectual disability: long-term results from an Australian matched sample. ***Journal of Intellectual Disability Research*** 50(6) 419-431

⁵⁰ Nottestad and Linaker (1999) Psychiatric health needs before and after complete deinstitutionalisation of people with intellectual disability. ***Journal of Intellectual Disability Research*** 43(6) 523-530; Nottestad and Linaker (2002) Predictors for attacks on people after deinstitutionalisation ***Journal of Intellectual Disability Research*** 46(6) 493-502

- In whatever settings, problem behaviour is associated with lack of staff attention, and staff tend to respond more to challenging behaviour than to appropriate behaviour
- Psychotropic medication use to manage behaviour that challenges was similar in institutional and community settings.

Personal and family satisfaction⁵¹

Service-user satisfaction is an important element of service provision. Studies report that service users and their families are very satisfied with community-based accommodation and an increased satisfaction on deinstitutionalisation; while some service-users might state that there are certain aspects of the institution that they will miss (people and some activities) they did not wish to return.

Other findings were that while family members tended to be wary of the move away from institutional settings at first, the majority were happy with the move once it had happened.

Quality of life⁵²

The literature includes a small number of studies that have assessed overall quality of life as opposed to focusing on a particular domain or set of domains. A consistent finding is that overall quality of life improved after a move to the community.

4.4 FACTORS AFFECTING OUTCOME FOR RESIDENTS IN COMMUNITY SETTINGS

If a community facility replicates the practices of a large centre, this will limit the gains in quality of life which could be achieved in a smaller centre. The research literature shows that resident support needs and staff care practices are important determinants of the quality of life within community settings. Mansell and Beadle-Brown state:⁵³

Demonstration projects have shown that it is possible to greatly increase the level of outcomes achieved for people with the most severe disabilities (Mansell, 1994;

⁵¹ Gregory et al. (2001) "Factors associated with expressed satisfaction among people with intellectual disability receiving residential supports" **Journal of Intellectual Disability research** 45 (Pt5) 279-291; McConkey, R., Walsh-Gallagher, D. & Sinclair, M. (2005). Social inclusion of people with intellectual disabilities: the impact of place of residence. **Irish Journal of Psychological Medicine**, 22 (1), 10-14; Walsh et al. (2001) Quality and outcomes of residential settings provided for Irish adults with intellectual disability. Dublin: Centre for study of intellectual disabilities, UCD

⁵² Ager et al, (2001) op.cit.; Young & Ashman, 2004 op.cit.; McConkey et al. (2005) op. cit.

⁵³ Mansell and Beadle-Brown (2009) "Cost effectiveness of community living for people with intellectual disabilities - an international perspective" Paper to NDA conference 6 October 2009

1995) to a level higher than achieved in any institutional setting. It also reflects characteristics of the design of the services themselves (Felce and Perry, 2007). Most importantly, it reflects differences in staff performance. Previous research has suggested that the way staff provide support to the people they serve is a key determinant of outcome. This result has been found in comparative studies of houses versus other settings (Felce, 1996, 1998; Felce, de Kock and Repp, 1986; Felce *et al.*, 1991; Mansell, 1994, 1995), in experimental studies within houses (Bradshaw *et al.*, 2004; Jones *et al.*, 2001; Jones *et al.*, 1999; Mansell *et al.*, 2002) and in regression studies (Felce *et al.*, 2000; Hatton *et al.*, 1996; Mansell *et al.*, 2003). In general, it appears that, once the material and social deprivation found in institutions is addressed by their replacement by small-scale services in the community, the main predictors of at least some important outcomes are resident need for support (i.e. their adaptive behaviour) and the care practices of staff (particularly the extent to which they provide facilitative assistance or 'active support' (Brown, Toogood and Brown, 1987; Felce, Jones and Lowe, 2000; Mansell *et al.*, 2005; Mansell *et al.*, 1987). Thus the implication is that the shift from institutional care to living in the community is a necessary but not a sufficient condition for better outcomes for all residents. In addition to the change of accommodation, it is necessary to change the kind of staff support provided.⁵⁴

⁵⁴ Mansell, J. (1994) Specialized group homes for persons with severe or profound mental retardation and serious problem behaviour in England. *Research in Developmental Disabilities*, 15, 371-388; Mansell, J. (1995) Staffing and staff performance in services for people with severe or profound learning disability and serious challenging behaviour. *Journal of Intellectual Disability Research*, 39, 3-14; Felce, D. and Perry, J. (2007) Living with support in the community: Factors associated with quality-of-life outcome. In S. L. Odom, R. H. Horner, M. E. Snell, & J. Blacher (Eds.), *Handbook of Developmental Disabilities*. New York: Guilford Press;

Felce, D. (1996) Quality of support for ordinary living. In J. Mansell & K. Ericsson (Eds.), *Deinstitutionalization and Community Living: Intellectual Disability Services in Britain, Scandinavia and the USA* (pp. 117-133). London: Chapman and Hall;

Felce, D. (1998) The determinants of staff and resident activity in residential services for people with severe intellectual disability: Moving beyond size, building design, location and number of staff. *Journal of Intellectual and Developmental Disability*, 23, 103-119;

Felce, D., de Kock, U. and Repp, A. C. (1986) An eco-behavioural comparison of small community-based houses and traditional large hospitals for severely and profoundly mentally handicapped adults. *Applied Research in Mental Retardation*, 7, 393-408;

Felce, D., Repp, A. C., Thomas, M., Ager, A. and Blunden, R. (1991) The relationship of staff: client ratios, interactions and residential placement. *Research in Developmental Disabilities*, 12, 315-331;

Bradshaw, J., McGill, P., Stretton, R., Kelly-Pike, A., Moore, J., Macdonald, S., Eastop, Z. and Marks, B. (2004) Implementation and evaluation of active support. *Journal of Applied Research in Intellectual Disabilities*, 17(3), 139-148;

Jones, E., Felce, D., Lowe, K., Bowley, C., Pagler, J., Gallagher, B. and Roper, A. (2001) Evaluation of the Dissemination of Active Support Training in Staffed Community Residences. *American Journal on Mental Retardation*, 106(4), 344-358;

Jones, E., Perry, J., Lowe, K., Felce, D., Toogood, S., Dunstan, F., Allen, D. and Pagler, J. (1999) Opportunity and the promotion of activity among adults with severe intellectual disability living in community residences: the impact of training staff in active support. *Journal of Intellectual Disability Research*, 43(3), 164-178;

4.5 DISPERSED HOUSING VERSUS CAMPUS/CLUSTER STYLE HOUSING

Dispersed housing may be defined as apartments and houses of the same types and sizes as the majority of the population live in, scattered throughout residential neighbourhoods among the rest of the population. Campus or cluster style housing is the term applied to provision of a complex of houses on a specialised campus, or homes for people with disabilities which are clustered in a specific housing estate or street.

While the policy of de-institutionalisation has been broadly adopted in most jurisdictions, there is still some debate about the appropriate forms of living arrangements to be provided outside large institutions. This debate centres on the case for developing housing for people with intellectual disabilities in campus-style/cluster settings. Campus housing may seem like a practical response (e.g. building a campus on existing institutional land). Clustering residential homes together may be seen as practical in service delivery terms. Another argument advanced in favour of campus/cluster style housing argues that people with intellectual disabilities are more likely to develop of friendships and relationships, within the community of their peers with intellectual disabilities. However, the evidence shows that better quality outcomes are delivered in dispersed as against clustered housing.

Mansell, J., Elliott, T., Beadle-Brown, J., Ashman, B. and Macdonald, S. (2002) Engagement in meaningful activity and 'active support' of people with intellectual disabilities in residential care. *Research in Developmental Disabilities*, 23(5), 342-352;

Felce, D., Lowe, K., Beecham, J. and Hallam, A. (2000) Exploring the relationships between costs and quality of services for adults with severe intellectual disabilities and the most severe challenging behaviours in Wales: A multivariate regression analysis. *Journal of Intellectual & Developmental Disability*, 25(4), 307;

Hatton, C., Emerson, E., Robertson, J., Henderson, D. and Cooper, J. (1996) Factors associated with staff support and resident lifestyle in services for people with multiple disabilities: a path analytic approach. *Journal of Intellectual Disability Research*, 40(5), 466-477;

Mansell, J., Beadle-Brown, J., Macdonald, S. and Ashman, B. (2003) Resident involvement in activity in small community homes for people with learning disabilities. *Journal of Applied Research in Intellectual Disabilities*, 16(1), 63-74;

Brown, H., Toogood, A. and Brown, V. (1987) *Participation in Everyday Activities*. Brighton: Pavilion;

Felce, D., Jones, E. and Lowe, K. (2000) Active Support: Planning Daily Activities and Support for People with Severe Mental Retardation. In S. Holburn & P. Vietze (Eds.), *Person-centered planning: research, practice, and future directions*. Baltimore: Paul H Brookes;

Mansell, J., Beadle-Brown, J., Ashman, B. and Ockendon, J. (2005) *Person-centred active support: a multi-media training resource for staff to enable participation, inclusion and choice for people with learning disabilities*. Brighton: Pavilion;

Mansell, J., Felce, D., Jenkins, J., de Kock, U. and Toogood, A. (1987) Enabling individual participation, Developing staffed housing for people with mental handicaps (pp. 197-231). Tunbridge Wells: Costello.

The recent review for the National Disability Authority of clustered housing compared with dispersed housing in the community⁵⁵ showed that dispersed housing was superior to cluster housing on the majority of quality indicators studied. The studies examined in this review identified disadvantages to clustered housing, which included increased size of living unit; living in a home that was also used for short-term (respite) care; less home-like settings and furnishings; lower staffing ratios; poorer internal procedures for individualised planning, activity planning, allocating staff support to residents and the training and supervision of staff; greater depersonalisation, rigidity of routines, block treatment and social distance between support staff and residents; greater use of anti-psychotic and anti-depressant medication; decreased contact with social workers; less choice; smaller social networks, including having *fewer* people with intellectual disabilities and “inclusive” relationships in the person’s social network; greater rates of people leading sedentary lives; having fewer hours per week of scheduled activity; participating in fewer and a smaller range of leisure and social activities.⁵⁶

The only exception to this was found for one particular type of clustered setting, village communities [intentional communities] which were identified as having some benefits over dispersed housing models.⁵⁷ Village communities however typically serve a less disabled population and depend on a supply of people willing to live communally with disabled residents. They are therefore an important element of the spectrum of service provision but they are only ever likely to occupy a niche in the market for care. They are a marginal form of services, accounting for about 2% of residential provision in England. They are unlikely to be a feasible option across the board for people with intellectual disabilities.⁵⁸

4.6 COSTS OF COMMUNITY LIVING

A key factor in examining the literature and evidence on costs in different settings is the problem of making like-for-like comparisons. Different kinds of residential services can vary significantly in terms of the support needs of the populations they serve, the quality of the service delivered, the service model used, staffing level and skill mix, and the funding model. Institutions which come from the hospital tradition

⁵⁵ Mansell J and Beadle-Brown J (2009a) Dispersed or clustered housing for disabled adults: a systematic review. NDA

⁵⁶ See Emerson (2004)

⁵⁷ See Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., Knapp, M., Jarbrink, K., Walsh, P. N. and Netten, A. (2000b) Quality and costs of community-based residential supports, village communities, and residential campuses in the United Kingdom. *American Journal on Mental Retardation*, 105(2), 81-102. People in village communities (n=86 in this aspect of the study did better on measures of person-centred planning; rigidity of routines; activity planning; staff training/supervision; medical checks; less crime risk; more hours of recreational/community activities compared to dispersed housing. On most other measures there was no statistically-significant difference relative to dispersed housing.

⁵⁸ Mansell J and Beadle-Brown J (2009a) Dispersed or clustered housing for disabled adults: a systematic review. NDA

tend to have a different staff mix to small-scale community residences. Models of host-family placement, supported independent living and staffed group homes can differ from one another in terms of cost profile.

The evidence in the US is that community options are significantly cheaper than large residential centres.⁵⁹ Stancliffe and colleagues cite 12 separate research studies which show community care as cheaper, citing cost figures from three specific studies where the community option was 5% to 27% less expensive.⁶⁰ This reflects lower wage costs in the community sector compared to state-run institutional services; residential centres which are operating below their original designed capacity, and the costs of meeting increasingly strict regulatory requirements for institutional care.⁶¹ As deinstitutionalisation has proceeded, disproportionately more of the less dependent residents move out, raising the unit costs for those who have remained in the institution.⁶² Lakin and Stancliffe argue that

“(Evidence that) per-person costs rise as institutions are downsized, means that steadily-paced total institutional closure is the best approach for service recipients and taxpayers alike. The common practice of downsizing (i.e. size reductions but not closure) at a leisurely pace not only deprives "residual" service recipients access to more effective opportunities and better quality of life, but also subjects taxpayers to prolonged periods of paying inordinately high costs for inferior outcomes”⁶³

US data on residential services for people with intellectual disabilities is published on an annual basis by the University of Minnesota. This shows that the per-capita support costs in the more medically-oriented facilities known as ICFMRs⁶⁴ are significantly lower for small-scale services. In 2008 average annual per resident expenditures were \$146,066 in state-operated facilities with 1-6 residents, \$171,360 in facilities with 7-15 residents, and \$188,318 in facilities with 16 or more residents. Among US community services, the model of service, standards and wage rates are more important influences on cost than size of setting.⁶⁵ The cost per capita of

⁵⁹ Lakin and Stancliffe (2005) "Expenditures and outcomes" Ch. 14 in Lakin and Stancliffe (eds) **Costs and outcomes in community services for people with intellectual disabilities**. Baltimore: Brooke; Spreat, Conroy and Fullerton (2005) A cost-benefit analysis of community and institutional placements for persons with mental retardation in Oklahoma. **Research in Developmental Disabilities**. 26(1) 17-31.

⁶⁰ Stancliffe, Lakin, Shea, Prouty and Coucouvanic (2005) "The economics of deinstitutionalisation" (p.295) in Stancliffe and Lakin (eds) **Costs and outcomes of community services for people with intellectual disabilities** Baltimore: Brookes

⁶¹ Lakin and Stancliffe (2005) op.cit. p.323

⁶² Stancliffe, Lakin, Prouty, Shea and Coucouvanis (2005) op.cit.

⁶³ Lakin and Stancliffe (2005) op. cit. p.322

⁶⁴ Intermediate care facilities for people with mental retardation are 24-hour a day full service care facilities for people with intellectual disabilities, and must provide active treatment. The residents generally have additional forms of disability. About three quarters of the residents live in facilities have 16 or more beds..

⁶⁵ Lakin and Stancliffe (2005) op.cit. p.323

Home and Community Based Supports (which covers a range of community-based options from residential group homes, supported independent housing, residential supports for people living in the family home, and fostering) in 2008 was \$42,486.⁶⁶

Costs findings in the US can differ from those in Europe reflecting differences in how care in the community is organised and funded.

- Medicaid funding for Home and Community Based Supports is based on the premise that it will be cheaper than the alternative of ICFMRs while catering for a similar population.⁶⁷
- In the US, staff costs in state-run institutions are on average higher than in community-based options
- A number of states operate a standard Rate Book which set out what will be paid for different elements of service, and registered providers can offer their services at the standard rate.

The major EU study on deinstitutionalisation, costs and outcomes reviewed studies on costs in Italy, Germany and the UK, with the majority of available research relating to the UK.⁶⁸ The research reviewed comprises evaluations of deinstitutionalisation projects undertaken for residents with mental health difficulties and for residents with intellectual disabilities. Overall, the EU study concluded that there is no evidence that community-based models of care are inherently more expensive than institutions, once the comparison is made on the basis of comparable needs of residents and equivalent costs of care. The study concluded that typically people who have lower levels of disability/support needs would cost the same or less in a community setting than in an institution. People with higher support needs living in a low-cost institution (which may be poorly staffed and of low quality) are likely to cost more in a community setting than in their current placement - however if the comparison is made with an adequately-funded institution, the costs would not be greater. In other words, it is the investment in adequate quality rather than the switch to a community setting that would drive any costs. The study concluded that the costs of supporting someone with high support needs in the community would be similar to the cost of funding the individual in an adequately-funded institution. Overall, the higher quality of service to be obtained in a community setting makes this the more cost-effective option, the study concluded. This study also found there can be transition costs where the old and the new services are run in parallel over a transition period where there is partial closure.

Larger facilities have greater options to disperse the responsibility for supporting those with greater needs across the staff complement. As such costs per resident are

⁶⁶ Lakin, Larson, Salmi and Scott (2009) Residential Services for people with Developmental Disabilities: Status and Trends through 2008. University of Minnesota. <http://rtc.umn.edu/risp08>

⁶⁷ The funding basis for community-based service is termed a "waiver", as the obligation to provide care in an ICFMR residential centre is waived if satisfactory alternative services in the community can be provided at less cost

⁶⁸ Mansell, J., Knapp, M., Beadle-Brown, J. and Beecham, J. (2007) **Deinstitutionalisation and community living – outcomes and costs: report of a European Study**

lower for each additional resident.⁶⁹ Research examining the relationship between level of need of residents with intellectual disabilities and costs has consistently reported greater costs for those with higher dependency needs, in particular those with challenging behaviour, whatever the care setting. Mansell et al, the authors of the EU study conclude however that although there are wide variations in costs associated with persons with varying levels of intellectual disability, much of the between individual variation in cost remains unexplained.

Individual studies provide a varying picture on differences in costs as between community and institutional settings, again with the caveat of the importance of making like-for-like comparisons. US studies as noted show community options as cheaper while some UK studies have found lower costs have been found for “traditional” services when compared with community residences.⁷⁰ An extensive study examining the quality and costs of different types of residential provision for people with intellectual disabilities was undertaken in the UK and Ireland by Professor Eric Emerson and colleagues in the late 1990s. Comparisons of NHS residential centres, village communities (intentional communities) and dispersed community housing revealed that, after adjusting for residents’ level of ability, village communities were the least expensive option but provided marginally lower quality supports when compared with dispersed housing.⁷¹ It is important to note that these intentional communities provide for those with greater levels of ability and typically rely on the support of volunteers - therefore it’s not a like for like comparison

The US study by Rhoades and Altman (2001) reported lower costs in small settings⁷² as opposed to UK studies by Emerson et al (2000)⁷³ and Felce et al. (2003)⁷⁴ who found the costs to be lower in larger settings. Walsh et al. (2007) note a “robust and consistent” (p.49) relationship between the personal characteristics (levels of intellectual disability and adaptive behaviour) of service-users and service costs. The literature would support the proposition that the costs of supporting people with more significant disabilities and complex needs are usually expensive whichever living arrangement is provided. This cost can be justified as community-based options are more likely to deliver improved quality of life.

⁶⁹ Knapp (2005) Perry, Romeo, Robertson et al. (2007) Outcomes and costs of community living: semi-independent living and fully-staffed group homes. **American Journal on Mental Retardation**

⁷⁰ Felce, D., Lowe, K, Beecham, J. & Hallam, A. (2001). Exploring the relationships between costs and quality of services for adults with severe intellectual disabilities and the most severe challenging behaviours in Wales; a multivariate regression analysis. **Journal of Intellectual and Developmental Disability**, 26 (1),109

⁷¹ Emerson, Robertson, Gregory, Hatton, Kessissoglou, Hallam, Knapp, Jarbrink, Walsh and Netten (2000) Quality and costs of community-based residential supports, village communities and residential campuses in the UK. **American Journal on Mental Retardation** vol 105(2) 81-102

⁷² Rhoades and Altman (2001) Personal Characteristics and Contextual Factors Associated With Residential Expenditures for Individuals With Mental Retardation. **Mental Retardation** 39(2) 114-129

⁷³ op.cit. see footnote 40

⁷⁴ Felce D, Jones E, Lowe K, Perry. Rational resourcing and productivity: relationships among staff input, resident characteristics, and group home quality. **American Journal on Mental Retardation** 108(3) pp.161-172

Overall, there is no evidence that community-based models of care are inherently more costly than institutions, once the comparison is made on the basis of comparable needs of residents and comparable quality of care. Community-based systems of independent and supported living, when properly set up and managed, should deliver better outcomes than institutions.

4.7 OVERALL CONCLUSIONS

The evaluation of community-based models of care for people with intellectual disabilities, compared with the institutions they replace, generally shows a relatively clear picture. Over and over again, studies have shown that community-based services are superior to institutions. Key findings are that:

- Community living offers the prospect of an improved lifestyle and quality of life over institutional care for people with intellectual disabilities.
- This applies to old and new institutions, whatever they are called.
- Community living is no more expensive than institutional care once the comparison is made on the basis of comparable needs and comparable quality of care.
- Successful community living requires close attention to the way services are set up and run, especially to the quality of staff support.
- Dispersed housing in the community delivers a better quality of life than clustered housing for people with disabilities.

Shifting from institutional to community-based models of care is not simply a case of replacing one set of buildings with another. Successful community-based services need to be carefully planned around the needs and wishes of individual people and then continually monitored and adjusted as people's needs and wishes change. Much evaluative research and comment emphasises the risks that community-based services do not provide sufficiently skilled help for people with complex needs such as profound intellectual and multiple disabilities, challenging behaviour or mental health problems.

CHAPTER 5

THE INTERNATIONAL EXPERIENCE OF IMPLEMENTING THE TRANSITION TO COMMUNITY

5.1 GATHERING INFORMATION ON INTERNATIONAL EXPERIENCE

Approaches to deinstitutionalisation in Wales, England and Sweden are outlined here based on information gathering during site visits, which included meetings with service providers and international experts in the field of service provision for people with intellectual disabilities. Dialogue with experts familiar with the deinstitutionalisation programmes in Norway and America is also documented. These insights have served to confirm the direction being taken by the Working Group and to inform the thinking about effective implementation strategies.

5.2 THE WELSH EXPERIENCE

The *All Wales Strategy*, launched by the Welsh Office⁷⁵ in 1983, was at the forefront of innovative community-based service provision for people with disabilities in the UK. The Strategy was preceded by a Working Party Report,⁷⁶ which set out a blueprint for the services required.

A major element of the *All Wales Strategy* was the restructuring of responsibility for service provision. Formerly within the remit of the health services, responsibility for health and social support was transferred to the local authorities by means of their social services function. Each local authority was required to submit plans detailing their proposals for new community-based services. These plans were scrutinised by the Welsh Office to determine whether they complied with the All Wales Strategy principles.

The restructuring of responsibility for service provision provided a framework for replacing large hospital settings with smaller dispersed community-based services. The Strategy recommended that once community-based residential options were available in a given location, no new admissions to existing hospital sites should be made. The proposed community-based accommodation was specified as:

⁷⁵ The Welsh Office was the pre-devolution predecessor of the Welsh Assembly Government.

⁷⁶ Welsh Office (1982) Report of the All Wales Working Party on Services for Mentally Handicapped People. Cardiff: Welsh Office

“The accommodation itself should be in ordinary houses and made available from local (public or private) housing stock. This means that new purpose-built hostels, hospitals or units should not form part of the pattern.”

The *All-Wales Strategy* recommended that community-based provision should provide for no more than four residents in one setting.

A halfway review of the first 10-year period of the strategy (i.e., after 5 years) revealed that while considerable progress was made in some areas of service provision, the numbers of people with intellectual disabilities in large hospital settings had reduced more slowly than was desired. Much of the available funding was used in new residential services for people living in the family home and for day services, rather than for moving those in institutionalised settings to community living. This situation contrasted with the pace of progress in England, where despite a lack of dedicated funding, the deinstitutionalisation process occurred with greater speed than in Wales. The success of deinstitutionalisation in England was largely due to the fact that moving those in institutionalised settings into community living preceded any attempts to address waiting lists for residential services for those living in the family home.

The second half of the first ten-year period of the *All Wales Strategy* placed renewed emphasis on the resettlement of persons from congregate settings. Subsequently, targets for the closure of the remaining old hospitals have been set but not yet attained. By 2008, two congregate settings with small residual populations remained.

Key features of the Welsh approach

Residential options

A variety of residential options are available to people with disabilities in Wales including Registered Care Homes, Supported Living and Sessional Supports/Domiciliary Care.

Supported living was the residential option preferred by service providers in Wales for all those with disabilities, irrespective of level of need. Supported living properties are typically owned by housing associations (social housing charities) who provide both the property and housing management services (such as furniture, gardening, heating, lighting, etc) under an assured tenancy. Through contractual agreements with funding bodies, the property is specifically identified as a residential property for supported living.

Tenancy arrangements

Supported living can be provided in singular or shared dwellings. Where dwellings are shared, the maximum number of tenants is usually four. Tenants may also be

offered supported living in community-based self-contained flat developments. These developments contain between four and seven self-contained flats, each with its own front door. A communal area is available for tenants and usually comprises a living or dining space.

The tenancy status of supported living residents ensures their security of tenure. Tenants cannot be moved to other premises unless they are in breach of generic tenancy agreements such as failure to pay rent or causing nuisance to neighbours. Tenants have exclusive occupation of the premises, which means that the tenant can refuse access to the property.

Social care arrangements

Provision of social care is separate from the provision of housing and housing supports. Typically, three contractual arrangements are undertaken to provide these supports: a contract between the housing provider and the tenant to ensure payment of rent; a contract between the local authority and a care provider to provide care support; and a contract between the local authority and a support provider to provide housing-related supports. Depending on the level of need of tenants, supports from domiciliary care agency staff may range from 24 hour on-site support to drop-in floating support.

Novel methods to promote independence, such as the use of technology, are emerging within the supported living model. Smart home technology is being employed to enable tenants to live in their own property with minimal staff levels, and has been applied in the homes of persons of varying levels of ability, including those considered to have complex needs.

Funding of social care

Supported living costs are met from a variety of sources. For example, rent and housing related services charges are funded from housing benefit. The local authority funds social care. Housing-related support is funded by the *Supporting People Grant Scheme* (grants awarded to provide housing related supports to vulnerable members of society including people with disabilities). More recently, self-directed support options enable the person with a disability to commission his/her own social care supports. Two mechanisms are currently available for commissioning self-directed support: *direct payments* and *individual budgets*. Direct payments are cash payments made directly to people with disabilities in lieu of services usually provided or arranged by social care services. Direct payments are typically used to support the individual to engage in community activities and cannot currently be used to purchase permanent residential care, local authority provision or health care.

In contrast to direct payments, individual budgets are not a payment mechanism per se. Individual budgets are the amount of money calculated as being needed to meet an individual's overall needs, drawing on all available funding streams. The individual is therefore in receipt of funding from an array of schemes. Individuals

may avail of some funding using direct payments while availing of others, for example day care services, via traditional funding routes. To date, individual budgets have been pioneered more extensively in England than in Wales, where direct payments are the preferred option.

Staff Salaries

An overriding issue commented on by service providers in Wales was the disparity in salaries between UK and Irish support staff. Details of gross annual salaries for a range of support workers were supplied by one service provider and identified the following gross annual salaries for Support Workers (£13,319), Service Managers (£21,835) and Area Managers (£31,077). These salaries can be contrasted with Irish Social Care Workers (ranging €34,357 - €45,939) and Social Care Managers (ranging €55,598 – €63,885). Notwithstanding the currency differences, Irish support staff report higher salaries than their UK counterparts. Service providers in Wales (and UK) are free to determine salary levels, unlike Ireland, where, in the main, salaries are determined with reference to scales set by the Department of Health and Children.

Tendering

Recently, the commissioning landscape has altered dramatically in Wales, with the introduction of new tendering arrangements. Service providers interviewed believe that the tendering process has resulted in considerable variation in the levels of support proposed by competing organisations; there may be an incentive for organisations to specify lower levels of support based solely on cost decisions but likely to compromise the quality of service provision. To ensure minimum levels of quality, service providers interviewed on this site visit stated that local authorities should revert to explicitly stating in their tender documentation the levels of support required in order to meet residents' needs.

The overall picture of service provision in Wales is one which values independent community-based living options for people with disabilities. Health and social care are independently accessed and it was noticeable that none of the agencies met during the site visit employed nursing staff. Medical services are accessed generically through the NHS system if, and when, required. Tenancy arrangements and the application of smart technology combine to achieve greater levels of independence for people with disabilities residing in the community.

5.3 KEY FEATURES OF THE APPROACH IN ENGLAND

Models of support in England are similar to those in Wales including registered care homes (with and without nursing care), and domiciliary care supports including supported living. The *Commission for Social Care Inspection (CSCI)*, established in 2004, is the regulatory body for registered care homes and domiciliary care agencies in England. National minimum standards are applied to these services during site

inspections, after which reports are available for public viewing on the CSCI website (www.csci.org.uk).

As in Wales, NHS provides health care to residents as and when required. Multidisciplinary teams with specific expertise are available on request to meet with residents. As in Wales, nursing professionals were not employed by service providers interviewed during this site visit.

Service providers interviewed during the site visit described their experiences of providing supports to institutional providers who were transferring residents to community living. Following a successful tendering bid to undertake the transfer, project managers are placed on site in the hospital setting and direct the deinstitutionalisation process. Extensive consultation is undertaken with the residents, hospital staff, residents' families and other interested parties to determine which community-based option is most appropriate for each resident. These service providers have now amassed considerable expertise in undertaking resettlement projects and are identified as 'preferred' service providers for these tenders. Service providers commented that particular skill is required in re-training hospital staff to work in community-based services. This transfer of staff is termed 'transfer undertaking protected employment' (tupe) and ensures that the new community-based service provider honours the terms and conditions of employment of former hospital-based staff. With appropriate training, and particular emphasis on an ethos of supporting independence, former hospital staff have adjusted well to community-based settings. As was reported in Wales, both service providers visited in England identified supported living as the optimal choice for residents.

The tendering process outlined above in relation to Wales is also a feature of the English commissioning system. The experience of tendering in England, however, seemed more favourable than that experienced in Wales. In England, tendering is conducted approximately every three to five years. Unlike the experience in Wales, where service providers compete to provide services at low cost, service providers in England commented that their tendering process is forcing service providers to compete on the basis of quality. Those who provide quality services gain 'preferred' tender status and are more successful in being awarded tenders than those who provide poor quality services. As the staff 'transfer' to the new service provider, the number of organisations providing supports in England is thus likely to decrease in the future. As such, it is expected that a smaller number of better quality service providers will operate.

The site visit to England reinforced much of the findings from Wales. Community-based independent living is the service of choice. Supported living options, direct payments and self-directed service provision are likely to dominate the future landscape of service provision in the UK.

5.4 THE SWEDISH EXPERIENCE

Sweden has a long history of local planning for deinstitutionalisation. Legislation in 1955 transferred responsibility for people with intellectual disability to local councils. By 1970 all councils had built new institutions and residential homes or done extensive work to upgrade existing facilities. The smallest centre for adults housed 100 persons and the largest 500 persons at this time.

From 1980 the numbers in large residential institutions started to decrease, due to the development of day activities. Group homes were also forming and having a day activity place was a prerequisite to moving to such homes. Initially people with mild intellectual disability moved to group homes. By 1985 it was considered that those with moderate intellectual disability could have a good life in group homes and parents began seeking this approach. By the 1990s group homes were providing care to most of those with multiple disabilities.

New legislation made it illegal to care for children in institutions and in the case of adults it was agreed that in the long run they should not be cared in institutions either.

From that point residential centres for adults were not allowed to take on new residents unless they had tested the suitability of a group home for that individual and it was found that they would not benefit. Over a five-year period those with more moderate intellectual disability were moved into group homes.

In 1997 the Government found that there were still too many residential homes. Parliament decided that special wards in hospitals should be closed and that the remaining 40 residential centres should be closed by 2000. By then a lot of expertise in group homes had developed. No extra funding was provided to support the closures and the new approach.

Institutional services were completely eliminated in 2000. At the same time it was found that there was a need for 3-4 back up residences for short-term care arrangements. There are currently about 70 people throughout Sweden who mainly for reasons of age were not transferred to group homes and it was decided to continue to support the existing residential care arrangements for the duration of their lifetime.

Group Homes/grouped individual apartments

Group homes have generally involved a small number of apartments in a building, not necessarily grouped together, with a vacant apartment available for support workers. There were requirements in relation to the size of each apartment and the accessibility needs of persons with disabilities living in such homes were built into building design requirements.

About 20,000 people have full individual apartments (own kitchen), which is the individual's private home. It is illegal to place such apartments together so that they give a feel of an institution. In other cases, the individual apartments may be linked ("group accommodation") and the adjacent staff apartment provides a communal meal space, and possibly a shared bathroom for the group of supported apartments.⁷⁷

In the 1980s grouped individual apartments operated on the basis of 4 apartments in each group. However by 1990 it was decided to allow up to 5 apartments and this was followed by a Court decision leading to regulations allowing for a maximum number of six if so wished by an individual and their parents. Today 40%-50% of grouped individual apartments have 5 apartments and 50% have 4 apartments. No grouped settings have more than ten apartments.⁷⁸ The moves to grouped settings has led to further developments where some individuals did not feel the need to live in such arrangements and have moved out to more independent living arrangements but generally remain close by.

While there are waiting lists in some counties for grouped living arrangements, typically a place would become available within twelve months, and it is open to individuals to take a court case if there is undue delay.

Today 57% of adults with intellectual disability live in grouped apartment settings, 23% live independently and 20% live with their parents. The total number of adults concerned is 36,400.

5.5 THE US EXPERIENCE

In the US, there are now eleven states⁷⁹ which have no residential institutions for people with intellectual disabilities. 48% of those receiving residential services in the US in 2008 were living in homes with three or fewer residents.⁸⁰ In the US in 2008, in addition to the 588,000 people with intellectual disabilities living in the family home, about 116,000 people with intellectual disabilities were living in their own homes, 38,000 were living with host families, and about 271,000 living in group homes or other shared arrangements with other people with disabilities.⁸¹

⁷⁷ See Hayward R (2008) **Deinstitutionalisation and community living - outcomes and costs - Country report - Sweden** Tizard centre, University of Kent p. 536-7. For comparison, Sweden has about 8.35m. people, and is about twice the population of Ireland, so the equivalent of about 10,000 people with intellectual disabilities, in an Irish context, live in individual apartments receiving a support service.

⁷⁸ Hayward, op.cit. p. 526

⁷⁹ Alaska, District of Columbia, Hawaii, Maine, New Hampshire, New Mexico, Rhode Island, Vermont, West Virginia, Michigan and Oregon. See Lakin, Larson, Sami and Scott (2009) Residential services for people with developmental disabilities - status and trends through 2008. University of Minnesota. Available <http://rtc.umn.edu/risp08>, p. iii

⁸⁰ Lakin, Larson, Sami and Scott (2009) Residential services for people with developmental disabilities - status and trends through 2008. University of Minnesota. Available <http://rtc.umn.edu/risp08> p.vii

⁸¹ Lakin et al (2009) op cit p. iii

Since 1977, the number of residents in institutions had fallen from approximately 150,000, to 36,000 in 2006. An extensive closure programme has seen the number of large state facilities for people with intellectual disabilities fall dramatically. In 1977, 84% of people with intellectual disabilities receiving residential services were in centres of 16 or more people. By 2008, that had fallen to 13%. Three quarters of people with intellectual disabilities receiving residential services in 2008 lived in places with six or fewer residents, and almost half in settings with less than three residents.

There have been significant increases in spending on individual and family support in recent years, and a levelling off in spending on institutional settings.

From the late 1960s, residential facilities for people with intellectual disabilities, termed ICFMRs⁸², funded by Medicaid, were introduced, offering an alternative to intensive nursing placements. In 1981, legislation was introduced to allow states to fund home and community-based services from Medicaid as an alternative to ICFMRs, provided that was cheaper. This facilitated a major expansion of community-based services, and a reduction in the numbers in ICFMRs. For example, between 1992 and 2008 the numbers receiving community supports grew seven-fold, while the numbers in ICFMRs fell by a third.⁸³

The Americans with Disabilities Act (1990) provided a legal right to live in the most integrated setting, and courts have used these provisions to make rulings that larger residential centres should close.⁸⁴ The Protection and Advocacy Service has also taken some lawsuits for closure of institutions.

Key lessons learned from the US experience about the transitioning process included the following:⁸⁵

- Every person with a disability can live in the community – there are no exceptions
- People with the most severe disabilities make the most gains
- Begin process with people with severe and profound disabilities rather than leaving them until last.

⁸² Intermediate care facility for mental retardation.

⁸³ Lakin et al (2009) p. 85-86

⁸⁴ For example, on 1 March 2010, a court ruling in New York ordered closure of large residential centers for people with mental illness, citing these provisions. See www.nytimes.com/2010/03/02/nyregion/02mental.html

⁸⁵ "The American Experience". Paper presented by Dr. Nancy Thaler, Executive Director of the US National Association of State Directors of Developmental Disability Services, at NDA Round Table on Deinstitutionalisation, 6th December 2007

- Group homes are not the only model - there are other successful models in the US such as host family placement, and people living in their own individual homes.
- Person-centred approaches are essential
- Focus on building community capacity rather than on closing institutions
- Consider new options: shared living; support to families in their homes; helping people find a matched person to live with; individual budgets
- Create supervision and quality assurance procedures for these innovations
- Plan strategically to expand community services and anticipate challenges. Shared living co-ordinators or support workers can support a number of individuals living in the community
- Communicate and build trust, keep promises
- Maximise opportunities for development of individualised supports at the time of closure and afterwards
- Develop a working relationship with the local community
- Consider the roles of institutional staff both during and after closure.

5.6 THE NORWEGIAN EXPERIENCE⁸⁶

A 1969 review found that 109 institutions were providing for 5,500 people in Norway, and there were no provisions for families choosing to keep their child with a disability at home. A committee appointed in 1982 in response to growing concerns about standards of care recommended that all institutions be closed. This resulted in a total reform of services implemented from January 1st 1991.

A nationwide registration of people with intellectual disabilities (1988-1991) found that 5,100 people were living in institutions and 4,000 adults were living at home.

The vision guiding the reform programme was one of no more segregated services. People with intellectual disabilities should access mainstream services and mainstream services must change to accommodate all Norwegian citizens, whether or not they have a disability.

The target was that all institutions should be closed by 1995; responsibility for service provision would transfer from central government to local communities; all disabled adults would be integrated into mainstream services and provided with their own homes in their local communities and all children would attend mainstream pre-schools and schools.

⁸⁶ Based on 'Deinstitutionalisation in Norway: Lessons to Learn. Paper given by Ms Kathryn Stiles, KARE, Co. Kildare, at NDA Round Table on Deinstitutionalisation, December 2007.

The goal in relation to housing was that adults with intellectual disabilities should own or rent their own home; the houses should be in their local communities and of the same standard and form as any typical home in that community. Support services should be linked to the individual, not the accommodation; staff do not sleep or have offices in the person's home.

The reform programme envisaged that people with disabilities would access leisure, transport, health services on the same basis as all other citizens, with appropriate support services.

After ten years, there was a general improvement in the standard of living of people with learning disabilities and opportunities for a 'normal' life. Many people now live in their own homes; services are provided in the local community. After 16 years, research findings show that 55% of people with learning disability live in their own accommodation; 15% are adults living with their families and 30% are children living with their families.

Of those living in their own accommodation, 16% own their own home, 5% rent privately and 79% rent from the social services. Of those renting from the social services, 43% live with others, 29% live in homes that are clustered and 28% live on their own. The trend is to build bigger houses for larger groups, to build houses close to houses for other minority groups, and to cluster houses for people with intellectual disability. Support staff are linked to houses not individuals, with the result that 30 to 40 part time staff can be linked to one house.

One researcher (Ivar Brevik) has concluded that Norway has now developed a new form of care which he calls 'collective care' and which he argues is a form of 'segregated integration.' People's homes are integrated because they are in local communities, but segregated because they are built specifically for people with intellectual disabilities, they tend to look different from other houses, and generally have more than one person with a disability living in the house.

Factors seen as linked to the limited success of the reform programme was absence of rights legislation, diversion of funding to other 'needy' groups, lack of competence in delivery of community services, loss of qualified professionals, initial focus on housing, and poor oversight and auditing of services. She advises that in order to avoid these pitfalls it is necessary to ensure rights by appointing personal coordinators to support people to plan for their lives, and develop legislative support for those life plans; staff skills must be strengthened, and systems set up to ensure transparency and accountability of services with regular evaluations and audits. A holistic focus on all life arenas from day one, for each individual, is essential.

5.7 REPORT OF THE AD HOC EXPERT GROUP ON THE TRANSITION FROM INSTITUTIONAL TO COMMUNITY-BASED CARE

An EU-convened Expert Group has recommended that Member States undertake action plans and strategies for the development of services in the community and the closure of long-stay institutions.⁸⁷ The Expert Group has drawn together the experience of Member States where reform of institutional settings has been carried out. This Report states:

*"Costly improvements in the physical conditions of existing institutions, which are often proposed as a response to findings of substandard care, are also problematic because they fail to change the institutional culture and make it more difficult to close those institutions in the long term"*⁸⁸

The Report points to several key challenges of the deinstitutionalisation process have been identified:

*"These include the replication of institutional culture in community-based services, and the long-term persistence of parallel services (failure to close the institutions. Conversely there is a risk of failure to create appropriate community-based services due to unrealistic targets and timetables which exceed the capacity for their development"*⁸⁹)

⁸⁷ Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care. European Commission Directorate-General for Employment, Social Affairs and Equal Opportunities, September 2009 p. 20

⁸⁸ Ibid, p1

⁸⁹ Ibid.

CHAPTER 6

THE COMPELLING CASE FOR ACTION

6.1 WHY CHANGE MUST HAPPEN

The Working Group believes that there is a compelling case for urgent action to transfer the people living in congregated settings to new forms of community living and community participation. The most pressing argument is an ethical one – the need to radically improve the quality of life of people living in congregated settings and to offer them options and choices that respect their individual wishes, needs and dignity. As the survey conducted for this report shows, many have spent most of their lives in congregated settings, often isolated from any community. The time for a better life for them is now.

As demonstrated clearly in Chapters 4 and 5 of this report, the case for improving the day-to-day reality of the lives of people in congregated settings is strongly established in research and international best practice. The case is reinforced by Irish legislation and policy, EU and international policy, all of which set the direction for evidence-based change.

6.2 THE ETHICAL CASE FOR ACTION

The Working Group has gathered information about the people living in congregated settings, the staff who serve them, and has documented many facets of their lives and circumstances. The survey data and visits to individual centres has shown that many of those living in congregated settings experience poor quality of life, with little or no purposeful activity, lack of privacy and basic dignity. The best efforts of dedicated staff cannot compensate for isolation from community, lack of individualised supports, poor quality environments, or a deeply embedded culture of dependence.

In many ways, the people in congregated settings have been ‘left behind’ as additional resources were directed to waiting lists and new provisions, as was raised with the Project Manager during site visits:

Several agencies made the comment that the clients in large congregated settings have been forgotten over the years and the bulk of the resources have gone to waiting lists, in many cases to people on the waiting lists for the agency providing their service.

The result of this has been that limited resources have been available to address the needs of people who are already in the service. It seems that a

significant gap has emerged between the quality of residential services that have been developed in more recent years, and the quality that is being provided in the larger settings.

Project Manager's Report

The changing needs of people living in congregated settings creates an additional imperative for change; as this group ages, their level of support needs increase; congregated settings are not resourced to respond to those needs.

From an ethical perspective, the case for taking action now to address the situation of this group of people is powerful and unassailable.

6.3 IRISH LEGISLATION AND POLICY

The National Disability Strategy, (NDS), which was launched in 2004, embodies the commitment of Government to ensure full and equal participation of people with disabilities in all aspects of life in Ireland. The fundamental premise of the National Disability Strategy is that people with disabilities should take their place in the mainstream of communities, not separated from them, that public services must be accessible and must provide integrated services to people with disabilities and others. One of the 'pillars' of the NDS is the requirement on key Government Departments to produce Sectoral Plans setting out how they will make provision to ensure that people with disabilities can access their services.

6.4 INTERNATIONAL COVENANTS

The International Covenant on Economic, Social and Cultural Rights (ICESCR)

The International Covenant on Economic, Social and Cultural Rights is a multilateral treaty adopted by the United Nations General Assembly in December 16, 1966, and in force from January 3, 1976. It commits its parties to work toward the granting of economic, social and cultural rights, including labour rights and rights to health, education, and an adequate standard of living.

Rights provided for under the Convention include the right to:

- work, under "just and favourable conditions with the right to form and join trade unions (Articles 6, 7, and 8);
- social security, including social insurance (Article 9);
- family life, including paid parental leave and the protection of children (Article 10);
- an adequate standard of living, including adequate food, clothing and housing, and the "continuous improvement of living conditions" (Article 11);

- health, specifically “the highest attainable standard of physical and mental health” (Article 12);
- education, including free universal primary education, generally available secondary education, and equally accessible higher education. This should be directed to “the full development of the human personality and the sense of its dignity and enable all persons to participate effectively in society (Articles 13 and 14);
- participation in cultural life (Article 15).

The Convention was ratified by Ireland in 1989. The first national report by the Irish Government to the UN Committee on economic, social and cultural rights in respect of action to implement the provisions of the Convention was given in 1999.

The UN Convention on the Rights of Persons with Disabilities

Ireland has signed the UN Convention on the Rights of Persons with Disabilities and is working towards its ratification. In signing the UN Convention, Ireland is committed to maintain a policy direction in line with the Convention.

The text of Article 19 of the Convention, reproduced below, sets out clearly that people with disabilities should be supported to live in the community rather than in institutional settings or segregated from the mainstream of the community.

Article 19

Living independently and being included in the community

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- (b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Council of Europe Action Plan 2006-2015

Action line 3.8 of the Council of Europe Action Plan on Disability 2006-2015 on community living focuses on enabling people with disabilities to live as independently as possible, empowering them to make choices about how and where they live. The Action Plan proposes several specific actions by member states including:

- A co-ordinated approach in the provision of community-based quality support services to enable people with disabilities to live in their communities and enhance their quality of life
- Housing policies that enable people to live in suitable housing in the community
- Support for formal and informal help, making it possible for people to, live at home
- Tailored support provision, including advocacy, to reduce risk of social inclusion Support fro making informed choices with the assistance where appropriate, of a skilled advocacy service.

6.5 EVIDENCE FROM INTERNATIONAL RESEARCH

The research evidence examined by the Working Group (Chapter 4) clearly shows that life in the community is better for people with disabilities across most domains. People in small-scale community-based provision or supported living arrangements have a better objective quality of life than people in large, congregate settings. Particularly, they have more choice-making opportunities; have larger social networks and more friends; access more mainstream facilities and participate more in community life; have more chances to acquire new skills and develop or maintain existing skills; and are more satisfied with their living arrangements. These results are found in studies from a number of jurisdictions with different welfare state models and welfare arrangements. This shows that the model of community living for adults with intellectual disabilities is not bound to certain countries and it can successfully be implemented in different situations. Outcomes are related to personal characteristics and to service quality. This underlines the need to deliver a different model of service, not simply to transfer institutional models to a community setting.

6.6 THE INTERNATIONAL EXPERIENCE

The international experience shows that other jurisdictions have successfully addressed the need to enable people to move from congregated settings. They have learned how to do this well, and have found that community living can be provided for everyone. We can learn from both their successes and their challenges as we move forward with an Irish programme of change.

6.7 VALUE FOR MONEY

The Government has set up a *Value for Money and Policy Review* which is examining whether current resources being invested in disability services can deliver better service quality and outcomes for people with disabilities and their families. The work of this Review coincides in a timely way with the Review.

In 2008, the HSE invested approximately €1.6 billion in services and facilities for people with disabilities. The data collection from the 72 sites covered by the Working Group's Report confirmed a spend of approximately €417 million per annum on congregated settings. This is a significant expenditure. The question for the Working Group was whether the state is getting best value in terms of good outcomes from that investment for residents of congregated settings. Based on its analysis, the Working Group is confident that better quality of life and better outcomes could be secured for this investment by enabling and supporting residents to move to live in their local community, with appropriate supports.

A significant investment would be needed to bring a number of congregated settings in line with HIQA standards⁹⁰ for residential services for people with disabilities. However, rather than continuing to invest in a model which is not in line with best practice, the thrust of policy now must be to move progressively towards community-based residential services for people with disabilities.

6.8 SUMMARISING THE CASE FOR ACTION

All of the evidence gathered by the Working Group underlines the case for immediate action on enabling people living in congregated settings to move to the community. Neither the model of congregated provision nor the reality is in line with our obligations under UN Conventions. The provision is in tension with the direction and thrust of Irish disability and equality legislation and with the policy provisions of the National Disability Strategy. Most pressingly, we now know what needs to be done to change people's lives and why their lives must change. Given the data that has been gathered in the survey undertaken by the Working Group, Ireland arguably has more data on this population than any other state. This knowledge brings with it an ethical obligation to take action.

It is clear that the programme of action required to enable over 4,000 people to move to community settings will pose significant challenges. The new model of support being proposed by the Working Group will represent a major cultural change and challenge to many staff, residents and families. However, the long-term benefits for people with disabilities and the wider social benefits from including people with disabilities in their own community justify the radical programme of change envisaged by the Working Group.

⁹⁰ National Quality Standards: Residential Services for People with Disabilities. Health Information Quality Authority. www.hiqa.ie

‘WE MOVED ON’

**Stories of Successful Transitions to Life
in the Local Community**

JIMMY'S STORY

Jimmy is a 31-year old man who has Down's syndrome. He has a hearing difficulty and epilepsy. He lived for 16 years in a congregated setting catering for 28 men and women. He moved to a group home in 2000 to live with 4 other young men of similar ability and support needs. One staff member was required at all times to support the 5 men, with a 'sleep over' in place at night.

Once Jimmy settled into his new home, he learned to travel independently to work and to use all community facilities and services. He enjoyed his freedom and independence and indicated in 2007 that he didn't want to live in a staffed home any longer. He chose to move with another young man to a tenancy arrangement in a house in the locality. Soon his other two friends decided to join him. All four get the individual support they need in their new arrangement.

This move brought challenges for Jimmy and for his family. His family adjusted slowly to the fact that they no longer controlled Jimmy's money, that he operated a post office account independently, and that he made decisions around budgeting. They worry about his vulnerability with his money. Jimmy is learning the importance of making the right decisions about money – to plan, not to borrow, and to pay for all his needs.

Jimmy is adjusting to living as an equal member of a small group of people sharing tenancy. He is learning the importance of respecting other people's space, others' property. He continues to adjust to his role and responsibilities in the community and is learning to manage the consequences of his occasional untoward behaviour. His newfound skills have helped him to get work opportunities.

Jimmy has learned to manage his health and his medication, and responds positively to technologies in his home to help manage his epilepsy. His relationship with his family, from their point of view, has changed dramatically. He is no longer dependent on them, he prefers to spend his weekends with his friends and participating in local activities, his visits home are shorter and he prefers to act independently of family.

Jimmy's family found it hard to adjust to his newfound independence and his need to be his own person. Staff met opposition to new ideas and new ways of supporting Jimmy to meet his goals and outcomes. A lot of time was spent supporting and reassuring them, through regular meetings, and constantly showing them the benefits to Jimmy of living in the community, learning new skills, meeting new people and getting involved in the locality he lives in.

Jimmy is living a fulfilled life and is constantly building his independence. He enjoys living with others, and at this time has no ambition to live alone; however he is quite independent of the group when he wishes to be. His support needs are intense when he meets a new challenge, but on the whole he is very capable of going about his daily life with little support.

MICHELLE'S STORY

Michelle is a 25-year old woman with a great sense of humour who enjoys interacting with people with whom she has a relationship. She has a great love of music and dances with great rhythm at every opportunity. Michelle communicates without words. She has been diagnosed on the Autistic spectrum.

Michelle lived for a number of years with four young men in a residential unit which catered for the needs of people who present with challenging behaviour. During this time

Michelle attended a local day centre. However her behaviour prevented her from fitting into the routine and there were many times when Michelle missed the opportunity to attend. In many ways she seemed happier not to attend, choosing instead to spend her time in her room listening to her music. Her preference was to eat alone rather than join her peers. Michelle would respond with challenging behaviour to any attempt to integrate her into the group. Michelle had difficulty with staff changes and with any lack of continuity in her life. She was clearly unhappy to be part of this group, and given the varied needs of the group, staff had little time or opportunity to individualise her programme.

In October 2005, an opportunity arose for Michelle to move with three other women to a new house in the community. As this move was unplanned and sudden due to the need for renovations at the residential centre, there was anxiety at the lack of time for transition planning for individuals, staff and families. The transition was particularly challenging for Michelle as she did not know the staff or the individuals with whom she was living. After about six months, Michelle began to build her trust and relationship with the team. As staff began to get to know Michelle and her family, they used their deepened knowledge to work out what Michelle's personal outcomes were in life, what her priorities were, how she wanted to spend her days, who and what was important to her. They learned what upset Michelle and responded in ways that helped her to manage her anxieties better. Her key worker has helped her to strengthen her relationships with her family and has reintroduced her to the community where she grew up in. Her home environment provides her with the privacy, safety, security and consistency essential to her quality of life. She no longer fears or opts out of using her community and can adjust to the demands for her of attending functions, participating in leisure pursuits, and visiting her family.

The commitment of the leadership and team to the provision of a person-led approach, and a consistent and flexible staff team and relief panel were key to Michelle's success; The staff's commitment to positive behaviour support and to the development of Michelle's natural support network also made a major contribution to a good a good outcome for Michelle.

PETER'S STORY

I was born in Dublin in 1947. I lived at home until I was 38. In 1985 I was given a residential placement. This was hard because it was not my choice to leave home. There were good times and bad times and I wanted to leave. The days were long and weekends longer.

I lived in a bungalow with nine other people. I shared a bedroom with 3 other men. The only privacy I had was a curtain around my bed. I lived here until 1994.

In 1991 I took part in a project that allowed me to be listened to, to work and to make new friends. This was my chance to do something worthwhile. I started working in a pub twice a week counting the money from vending machines. It felt good getting out, meeting people and having money. It felt good and people thought of me differently. I worked in the pub for a number of years and made some good work friends. I decided to retire about 6 years ago.

Since then I go to a community day service where I get help to go out and about. I love going out for a breakfast roll and buying the papers. I often go up to the library and spend some time reading. I like my own company. I get to meet a lot of people in my day service and I enjoy the banter and craic. I love football and have gone with my friends to football matches.

In 1994, I moved to a community house. This was what I wanted but I was anxious at first. I have my own room with my own things, my own TV, music and stuff. Living in the community means I can get help to go to the local shops, post office and to go to the church and light a candle. I like getting my daily mirror newspaper and putting a bet on in the local bookies. They all know me in there. I am well known in my neighbourhood and stop and chat to my neighbours. I also meet up with my old neighbours when I'm out and about.

I use a wheelchair so getting out was difficult but the house has an accessible car, which means I can go out with one staff and do things I want to do. I like music and went to see Sonny Knowles, which was a great night out. I get to have weekend breaks away and holidays. I got to go away 8 times last year!

Contact with my family is important to me. Connections with family are better since being in the community. It's nice when family visit because I have my own privacy as a result of having my own room. I go on my own to see my sister every couple of months.

STAFF COMMENTS

Peter lived in residential for nine years. He had no privacy as he was sharing a house with nine people. Peter communicates using a communication board called a Bliss

Board; this board has over 200 symbols on it. He uses a wheelchair, which he can't propel himself. Peter is completely reliant on the support of staff to help him communicate his needs and participate in activities. A lot of the time his frustrations in residential services resulted in behaviour that challenged and he was on medication to manage his moods.

Peter wanted to move to the community but was anxious about the change. However when he moved to a community house, he became calmer and settled in over time. He now lives in a very homely environment with his own privacy, and shares the house with three ladies. His home is in the heart of the community, which means he is able to get to local amenities. He has been part of the local community for nearly 14 years now.

Peter's contact with his family has improved since he is calmer and much happier and this allowed him to build his relationships with family as well as making new friends.

FAMILY COMMENTS

Peter is close to the family and was very upset by the separation of moving into residential services. The lack of privacy was a problem. He shared a room with three other men. When we came to visit it was in a communal area, which Peter disliked. He was very frustrated when we visited and would become upset when we went to leave.

When he moved to the community the biggest improvement was the homely environment. Peter moved to what he was use to. He has his own room with his own things. Peter settled immediately and he became much calmer. His medication decreased. He would say that he was charmed to get the place. He has much more going on in his life and great opportunities to get out and about. Peter for the first time feels he is involved.

NUALA'S STORY

My name is Nuala and I am delighted to tell you how my life has changed for the better. Since July of this year I have moved full time into my own apartment and it's great.

I would like to tell you a bit about myself. I'm 43 years old. I was born in 1965 and I lived with my parents, one brother and two sisters in a small village. When I was 14 years of age my mother brought me into a residential service to live.

I was there for twelve years and shared with nine other girls and in three different chalets. It was ok living there. We had certain times to go to bed, after the 9pm news and we were called at 7.30 in the morning. Sometimes when I was tired I'd sneak back to bed but the night nurse would be back in calling us. We couldn't choose our own food we had to take what we got or there wouldn't be anything else there as it was cooked in the big kitchen and brought to the chalets. We couldn't choose our own clothes, staff bought them for us.

From 1991 I lived in 4 different community houses. It was nice just living with four people I got on kinda ok with them. I moved to different houses because I was always complaining and not getting on with the people I lived with. I kept looking to find someplace I could be happy. I made life very difficult for those I lived with. I was not as bad as I was before. I could control myself a bit better probably because I was older and more mature. Also I had a staff that really listened to me and did her best to help me. People did try and help me we used to have meetings at the house and the workshop but I hated them because people were talking about me and not really listening to me.

Things started to change in 2007. We still had meetings but now I could choose who I wanted at them. I could also choose what we were to talk about and in the last few months I have started to chair my own meetings and I decide what goes on the agenda. These are called circle meetings.

My dream was to have my own place and I got it. I got my own apartment in July 07. It was the best thing that has happened to me. My dream has come true. That year I used to go there for a few hours every day. I had support to prepare my own meals and to do shopping and anything else I wanted. I knew I didn't want to share with anyone and I didn't want staff telling me what to do. I also didn't want to have to ask to go out.

I make my own choices now like buying clothes, food, furniture, cushions and ornaments to make the place look nice. I love to light candles to make people feel welcome. I can invite people who I want when I want. I like living on my own and having my own private space.

I have support up to 10pm at night and for a few hours Saturday & Sunday. There is an emergency response installed so if anything happens they are alerted. If I need them I just press the button on my wrist and they will talk to me. I feel safe living there and I always make sure that everything is turned off and the doors are locked.

I had a job a good few years ago but it didn't last because of my moods. I now have a cleaning job four days a week for four hours a day. The money is great. I do voluntary work in a day care centre one morning a week. I like this as my mother was in a nursing home for a few years and I used to visit her and this is why I wanted to work with old people. So I keep myself busy.

I have my own bank account and A.T.M. card so I can take out money when I want. I pay my own bills. I need to put money aside each week for these. I found that hard in the beginning and sometimes now as I love buying cd's and dvd's and I don't always have enough money for everything. One thing I got was a locker I can lock. This is for my own personal stuff that the house parents used to have locked in their room and I would have to ask them for it. Things like my passport, bank books, post office book & medication.

I'm organising a house warming party for my friends. I get to go to concert or to the pub when I want.

I don't have people telling me what to do. We meet every so often to plan and organise what I want and need to do. I like this because I'm listened to. I am more respected. I feel people trust me more and as a result I have more confidence.

I go to the gym with my friend one day a week and I go on my own on Saturday and if I want to go any other day I can. I invite my friends over sometimes or I go and visit them. I go to art classes on a Thursday night and I meet new people there. I have my own mobile phone so I can contact people. I can go and browse around the shops when I want.

My life has changed big time. I have control over my life. I have found my feet. I am very happy now. The monster is gone I can control myself. My dream has come through.

Thank you for reading my story.

KATE'S STORY

Kate is a much-loved severely autistic daughter. Kate regressed into autism when she was between two and three years old. She became hyperactive and emotionally disturbed, displaying severe anti-social behaviour; banging her head off walls, windows and glass panels in doors (we claimed so much for broken windows under our house insurance that they refused to cover them thereafter).

When she was ten, the professionals told us that we as parents, were in danger of collapse and the siblings were at risk. Only one service provider would consider taking her at the time. The next 17 years generated feelings of gratitude in no small part because of the safety levels that were in place in an enclosed campus and we as a family settled into a comfort zone that was predictable and secure knowing that our Kate was being cared for by concerned, compassionate, committed staff in a safe environment.

Over the years our abilities to envisage new possibilities have been repressed by dependency and isolation. The aspirations we had for our daughter in the early years were blunted. About four years ago, with four other services users, Kate began to attend a day service for people with Autism. Almost immediately her behaviour modified, she became more biddable, her self-injurious behaviour declined and she smiled more often. She had consistent staff looking after her and she was doing interesting things in a community setting. For the first time we experienced staff stating publicly that it was a joy to work with Kate. Before, there were case conferences about her negative behaviour - Kate was always a problem. However, she still lived in a locked ward with four others that displayed challenging behaviour.

Two years ago we applied to have Kate moved nearer home. It was the best initiative we ever took on her behalf because she was placed in a house in the community and cared for by innovative, enthusiastic staff imbued with a new vision of a "person-centred" autonomous life for Kate.

During the last year Kate has learned to go shopping (without grabbing sweets), to wait in queues for service, to prepare food without sampling it, to do house work and to enjoy social outings and interactions in the community.

She has benefited from funfairs, horse riding, race meetings, meeting friend's in their homes, travelling on trains, on the Luas and on the ferry to Wales. She had dined out on numerous occasions in "posh" hotels and goes to swimming, gym activities and discos. She has become a member of the residents' association and is known and acknowledged by her neighbours.

Two staff were always on duty initially but staff decided themselves that one staff on duty was sufficient with two when special events were happening. The highlight of her social calendar was her 30th Birthday Party where the extended family members

and friends described her as “loving”, “radiant” “fabulous looking” “happy” “calm” and enjoying herself.

The staff started tackling her fears by teaching her life skills. To enable her get rid of her fear of hospitals they took her to the local hospital where they initially sat in the coffee dock and watched medical staff walk by. She has advanced from sitting in the car outside a doctor’s surgery to going in to the waiting room to meet him. She lets the dentist see her teeth when the dentist comes out to the car and has graduated to allowing a curved mirror to be placed in her mouth. Staff took her to a beauty therapist to get her used to touching and being worked on intimately and she recently allowed a chiropodist to treat a corn on her toe. Small steps for others, giant steps for Kate.

Kate’s self-injurious behaviour has gone completely. She is more affectionate, will interact more on request and her understanding has greatly improved. I would not have believed the improvement possible except I witnessed it firsthand.

Kate’s story is a good news story where certain events and good people concurred to enable to her to leave institutional care, get proper funding, live in the community, be supported by extraordinary staff, have avenues of proper living opened up for her and experience unimagined opportunities. Everyone in institutional care deserves the same chance.

Pat's Story

Pat is forty-year old man who lived in a group home for over 20 years. He also attends a day centre. His mother died some years ago and she had been the main support and decision-maker for Pat. He had been indicating for a while that he didn't want to live in the group home and had been effectively communicating this through challenging behaviour. When staff reflected on the incidents Pat was involved in, it was apparent that his unhappiness with his living situation was a key factor in his behaviour.

When establishing a planning circle with Pat [a group who work with Pat to plan his supports] it was important to work out a process for engaging his family. His brother had come forward as the main decision-maker but he lived in England. His sister lived locally and she agreed to become involved as she and pat were close and he often spent weekends with her. The team agreed to keep the brother informed by sending information as needed. The team then struggled with trying to work out what Pat wanted. They began to develop a vision for what Pat's ideal situation would look like. Pat preferred space, he liked to be away from people with disability and he needed to have strong community connections.

About this time, a family contacted the organisation about the possibility of setting up a Home Share arrangement [living with a family]. The social work team linked them up with Pat's planning circle. Once the initial introductions were made, Pat had a few visits to the house. As things were progressing well, on one visit the family suggested Pat might like to stay a night to see if he liked it. Pat picked his room, packed his bag, moved out, and again, despite efforts to plan a gradual move, didn't come back.

He managed the adjustment really well. It was only some way into the arrangement that Pat did get cross one day. The Home Share family were amazed to see this side of him, as he is usually someone with a very sunny disposition. On exploring things further, his support staff discovered that he was missing contact he had previously made with a person who volunteered with him. The team were able to re-establish this contact and he now spends a day with that person every second weekend.

Pat's own family also are happy with the arrangements. Initially they were worried that these changes may mean that the organisation was backing away from supporting Pat. However, they are re-assured that these changes are what Pat would like for himself and that he still has support from the organisation as needed. His family are in contact with the Home Share family and these relationships are working well. Pat went to England recently with his Home Share family and they were all able to meet up with his brother in England. He enjoys coming in to the centre but makes his own way there independently. He does activities he chooses in the centre, including a recent successful art project. The support circle keep in regular contact with his Home Share family as a backup and as a sounding board. Overall, things are going much better for part and things are also better for those in the group home who now have more space and opportunities.

PART TWO

PROPOSALS FOR ACTION: THE STRATEGY FOR COMMUNITY INCLUSION

CHAPTER 7

NATIONAL POLICY AND SUPPORT FRAMEWORK FOR THE TRANSITIONING PROGRAMME

7.1 NATIONAL POLICY AND SUPPORT FRAMEWORK

The strategy for implementing the Working Group's proposals will require policy support, and changes to service delivery systems; it will involve national action and local action. A national policy and support framework will be essential in order to progress, manage and monitor the implementation of the transitioning programme.

The elements of the national policy and support framework should include:

- Department of Health and Children vision and policy statement on the closure of congregated settings and transition of residents to community settings
- Department of Environment, Heritage and Local Government policy on housing provision for people with disabilities
- National oversight and governance arrangements for the transition programme
- A manpower strategy
- Multi-agency protocols
- National standards for community-based living
- A change management programme.

7.2. DEPARTMENT OF HEALTH AND CHILDREN VISION AND POLICY STATEMENT TO SUPPORT THE TRANSITION

Within the framework of the National Disability Strategy, the Department of Health and Children should adopt a clear policy for the closure of congregated settings and should incorporate the vision and planning for the transfer of residents to community settings in its revised Sectoral Plan.

The policy should apply to all those living in congregated settings, no matter how severe or complex their disability. The policy should provide that no new congregated settings should be developed and no admissions should take place to congregated settings. The Department should underpin the policy of closing congregated residential provision by setting closure targets within a seven-year timeframe.

RECOMMENDATION 1

Department of Health and Children vision and policy statement

The Department of Health and Children should issue a vision and policy statement on the closure of congregated settings and transition of residents to community settings. The policy should mandate that:

- All those living in congregated settings will move to community settings
- No new congregated settings will be developed and no admissions will take place to congregated settings
- The move to community will be completed within seven years and minimum annual targets set for each year in order to reach that goal.

7.3. DEPARTMENT OF ENVIRONMENT, HERITAGE AND LOCAL GOVERNMENT HOUSING STRATEGY

The Department of Environment, Heritage and Local Government is the body with overall policy responsibility for housing; the National Disability Strategy spells out Government intent that services for people with disabilities will be mainstreamed, and this intent is reflected in the Department's Sectoral Plan.⁹¹ The Department's Housing Strategy for People with Disabilities is due to be completed in 2010 and will set the strategic direction for housing policy in the short to medium term.

The Strategy should incorporate the Working Group's proposals. It should reflect the findings of the international research review conducted for this report, which indicated clearly that dispersed housing in the community delivers a better quality of life for people with disabilities than clustered housing.

⁹¹ Department of Environment, Heritage and Local Government. Sectoral Plan 2006. www.environ.ie/Local Government/Local Government Administration/Sectoral Plan.

RECOMMENDATION 2

National Housing Strategy for People with Disabilities

The Working Group's proposals should be reflected in the National Housing Strategy being prepared by the Department of Environment, Heritage and Local Government. The strategy should describe the eligibility of people with disabilities for publicly funded housing supports.

The Strategy should reflect the research evidence that dispersed housing in the community provides a better quality of life for people with disabilities than cluster-style housing.

7.4 NATIONAL OVERSIGHT

The closure and transition programme is likely to be a key policy implementation issue for the foreseeable future. A national oversight and governance system is essential in order to ensure progress in line with targets and to check that the right thing is being done in the right way.

Implementation will involve a significant change management programme and a comprehensive, ongoing communications process to communicate the transitioning plans, and to manage the expectations of both the public and the political system. The HSE, along with other service providers, will need to engage, through partnership processes, with staff representative groups on the issues associated with the proposed model of provision for people leaving congregated settings, including changes in skill mix, rostering arrangements and potential changes in providers. The transitioning programme will require workforce and financial planning processes at national level, and may involve the transfer of resources between services.

Within the framework of the National Disability Strategy, a National Implementation Group, including representation from the Department of Environment, Heritage and Local Government, should oversee the implementation of the Working Group's proposals. A senior official should be given responsibility for driving the implementation process.

The HSE, as part of its executive responsibility, and working through the National Implementation Group, should monitor and report on progress on implementation on a six monthly basis the HSE Board, to the Department of Health and Children, and also reported to the National Disability Strategy Stakeholder Monitoring Group.

RECOMMENDATION 3

National oversight

A named senior official of the HSE should be charged with driving and implementing the transitioning programme, assisted and guided by a National Implementation Group. The Department of the Environment, Heritage and Local Government should be represented on the National Implementation Group.

Progress on implementation should be reported every six months to the HSE Board, to the Department of Health and Children, and also reported to the National Disability Strategy Stakeholder Monitoring Group. The housing letting practice in local authorities should be monitored as part of national implementation.

7.5 A MANPOWER STRATEGY

I have not met any service user in any of the large settings who I feel could not be served in a community setting provided the right supports were put in place. Sometimes, people who have never been involved in supporting service users with complex needs in a small setting within a community find it difficult to envisage such a scenario. Due to the current staffing levels and the need to ensure that basic health & safety issues are addressed, some of the current provision tends to be very traditional in its approach. Investing in staff and up-skilling staff will be necessary to ensure that when people move out of larger settings into community based settings the culture of the congregated setting does not transfer to the new model of service.

Project Manager's observations

The proposed new model of support for people in the community (Chapter 8) will require a different skill mix, different skills and ethos; it will challenge many current practices. Staff roles in a community setting will be defined differently, with a greater emphasis on promoting independence and facilitating inclusion.

Staff with the skills, knowledge and approaches needed to support people in community-based living will be essential to successful transitioning; many of those making the transition will have family members who will also be a hugely important source of support; in the individualised approach proposed by the Working Group, the key to success is providing each person with access to people competent to help them to make the transition and to support them in the longer term. In the absence of this, research suggests that the move to community may not achieve the good outcomes that are possible.

Staff currently working in congregated settings should be given every opportunity to train and acquire the skills for job opportunities in supporting people in new

community living arrangements, within the framework of a commitment to high quality service. Comprehensive training and re-training will be needed for management staff as well as for support staff, in order to develop and embed the new culture of inclusion and community participation. Partnership and collaboration arrangements with existing community-based agencies should be drawn on as a source of support for the training programme.

Agencies who are involved in the transitioning process will be required, as part of their preparation, to develop a human resource plan. However, it will be essential that agencies have the support of a national level manpower strategy which 'clears the way' for their planning.

A manpower strategy to support the programme of transition to community settings should be devised by the National Implementation Group in partnership with key stakeholder groups, to address all of these requirements. The strategy should deal with staffing requirements for community inclusion, skill development and professional development requirements, and the human resource management aspects of the transition programme.

RECOMMENDATION 4

A manpower strategy

A manpower strategy to support the programme of transition to community settings should be devised by the National Implementation Group in partnership with key stakeholder groups. The strategy should address staffing requirements and skill mix needs for community inclusion, skill development and professional development requirements, and the human resource aspects of the transition programme.

7.6 NATIONAL PROTOCOLS TO SUPPORT COMMUNITY INCLUSION

A multi-agency approach involving many stakeholders will be needed to deliver community inclusion. National protocols will be needed to guarantee this multi-agency approach. These protocols should promote independent living and social inclusion, and clearly identify the bodies responsible for standards and supports.

Protocols will be required on matters such as tenancy arrangements, payment of rent supplements, inpatient charges, payment of 'living expenses' and other areas of individual eligibility for financial support.

Protocols are already being developed between key Departments as part of the National Disability Strategy. Similar protocols will need to extend to bodies such as further and continuing education providers, transport providers, existing and new providers of disability services; the protocols should be reflected in service level agreements.

A Working Group should be set up to co-ordinate the development of these arrangements as a matter of urgency, in partnership with the National Implementation Group overseeing the transitioning programme and within the overall framework of the National Disability Strategy.

RECOMMENDATION 5

National Protocols to support community inclusion

A Working Group should be set up to co-ordinate the development of a range of protocols to ensure a co-ordinated approach to community inclusion for people with disabilities. These protocols should be developed across key government departments and agencies, in partnership with the National Implementation Group; they should be prepared within the framework of the National Disability Strategy and have regard to the Sectoral Plans prepared under that Strategy.

7.7 NATIONAL STANDARDS FOR COMMUNITY-BASED LIVING

Standards against which community-based accommodation and supports for inclusion can be inspected, monitored, and funded are essential.

The HIQA standards for residential services⁹² are framed around quality of life, safety, rights, anti-discrimination, person-centeredness, community integration, responsiveness of service. At a minimum, community-based accommodation for people with disabilities must meet the HIQA standards; these standards will also apply to those who continue to live in congregated settings pending transfer to the community. However, standards now need to be developed that are based on the objectives of community inclusion and full citizenship for every person with a disability.

7.8 A CHANGE MANAGEMENT PROGRAMME

The proposals for enabling 4,000 residents of congregated settings to transfer to community settings over a period of time will involve a complex array of providers, funders, policy makers, people with disabilities and families. An overall change management plan will be needed to support this transition. That plan should provide for:

⁹² National Quality Standards: Residential Services for People with Disabilities. Health Information Quality Authority. www.hiqa.ie

- Communicating the vision for the programme and developing a shared ownership of that vision among staff, families and people with disabilities
- Building collaboration and teamwork among service providers at local level and with communities
- Ensuring that stakeholders have opportunities to shape the planning and delivery of the transitioning project
- Providing clear leadership at national, regional, local and agency level
- Putting in place formal mechanisms for action learning, so that knowledge and learning is shared from the start among all those with a stake in the project, including agencies who are not yet involved in the early phases
- Training and development programme for staff and management
- Support and preparation programmes for service users and families, and family and individual leadership training
- Ensuring access for residents to suitably prepared advocates
- Designing mechanisms for ongoing monitoring and evaluation.

The change management plan should be executed by the HSE and overseen by the National Implementation Group.

RECOMMENDATION 6

Change management

A change management programme to support the transitioning programme should be developed and resourced. The change management plan should be executed by HSE and overseen by the National Implementation Group.

CHAPTER 8

MOVING FROM CONGREGATED SETTINGS: A NEW MODEL OF SUPPORT IN THE COMMUNITY

8.1 TOWARDS A NEW MODEL OF SUPPORT

All those now living in congregated settings should have the opportunity and right to move to a home of their choice in the community. However, while a person's home offers safety, warmth and a good environment to live in, it cannot be and should not be the person's complete world. Our lives and family lives are not solely determined by our home. Independence and inclusion in our own community is a measure of a fully engaged life for people with disability, as it is for everybody.

For this reason, the planned provision for people living in congregated settings must be broader than a plan for accommodation; arrangements for housing must be part of a wider person-centred support plan full community participation and inclusion.

While the focus of these proposals is on the needs of people currently living in the congregated settings covered by this report, the model being proposed has wider application over the long term for all individuals with disabilities who need the supports outlined in this model in order to participate fully in their community.

Delivering this model of support will require strong partnership between the HSE and housing authorities, and among disability service providers and mainstream service providers. HSE and the housing authorities should have shared and distinct responsibilities. The delivery of individualised supported living arrangements should be co-ordinated and funded at local level through the HSE. Housing authorities should be responsible for provision of accommodation.

The proposed new model should be based on person-centred principles and have the following key components:

- Access to dispersed housing in local communities (8.3)
- Access to supported living in dispersed housing through a comprehensive range of individualised supports (8.4, 8.5).
- Distinct statutory responsibility for elements of support provision (8.6)
- Separation of responsibility for delivery of in-home supports from delivery of inclusion supports (8.6)
- Local coordination of HSE-funded support provision (8.6).

RECOMMENDATION 7

A new model of community-based support

The provision of accommodation for people moving from congregated settings to their local community must be broader than a plan for accommodation; accommodation arrangements for housing must be part of a new model of support that integrates housing with supported living arrangements.

The new model of support should be based on the principles of person-centeredness; it should enable people with disabilities to live in dispersed housing, with supports tailored to their individual need.

8.2 PERSON-CENTRED PRINCIPLES GUIDING THE NEW SUPPORT MODEL

The principles of independence, inclusion and choice are the cornerstones of the movement from campus/institutional settings to the community. The person-centred approach should inform the development of supports for those transferring from congregate to inclusive community settings. The core elements of person-centred practice include:

An over-riding commitment to self-determination: The person's aspirations, goals, and needs will direct the support arrangements to be put in place. People will be supported to lead a life on *their own terms* i.e. exercising choice equal to that of other citizens.

An intentional and sustained focus on inclusion: A commitment to inclusion involves fostering a high level of engagement with the local community and wider society and support for building social roles and relationships. Both generic services and disability service providers should gravitate towards inclusion. The aim is to help citizens with disability to become enmeshed in their local community, with the help of a network of local community contacts, supporters and friends.

Supporting people to live a fulfilled life: Citizens with disabilities should have access to meaningful employment and valued roles. The segmentation of people's lives into residential and "day services" is not compatible with person centeredness. Citizens with disability should be supported to explore their own interests and choices rather than being confined to a set range of centre-based activities.

Individualised arrangements: The person-centered approach requires service providers to design and support individual arrangements *one person at a time*, recognising that group activities struggle not to revert to group-based patterns of activity that may not take account of individual needs and wishes.

Mobilising and sustaining “natural” and “freely given” supports: The person-centred approach involves enabling people with disabilities to get support from family, neighbourhood and community sources as well as paid support. To do this well, service providers must scan what is available *outside* of the specialist service and seek out and mobilise a strong personal network of friends, supports and advocates.

8.3 DISPERSED HOUSING IN THE COMMUNITY

All housing arrangements for people moving from congregated settings should be in dispersed housing in ordinary neighbourhoods in the community, with supports designed to meet their individual needs and wishes.

*Dispersed housing*⁹³ may be defined as apartments and houses of the same types and sizes as the majority of the population live in, scattered throughout residential neighbourhoods among the rest of the population.

In choosing their dispersed living arrangements, people may opt for one of a wide range of possibilities:

- Some people may choose to live on their own
- Some may opt to share with others who do not have a disability
- Some may choose to share their home with other people with a disability
- Some people may opt to live with their own family or opt for long-term placement with another family.

Where home-sharing with other people with a disability is the housing option chosen by the individual, as part of their person-centred plan, the Working Group recommends that the home-sharing arrangement should be confined to no more than four people in total and that as far as possible each should have chosen to live with the other three people.

Purpose-built community housing funded by the HSE should be provided for any children under-18 years old moving from congregated settings.

⁹³ Mansell, J. and Beadle-Brown, J. Dispersed or clustered housing for adults with intellectual disabilities: a systematic review. Dublin: National Disability Authority pp10-11.2009

RECOMMENDATION 8

Dispersed housing in the community

All those moving from congregated settings should be provided with dispersed housing in the community, where they may:

- Choose to live on their own
- Share with others who do not have a disability
- Share their home with other people with a disability
- Live with their own family or opt for long-term placement with another family.

Purpose-built community housing funded by the HSE should be provided for any children under-18 years old moving from congregated settings.

RECOMMENDATION 9

Maximum of four residents who choose to share accommodation

Where home-sharing with other people with a disability is the housing option chosen by the individual, the Working Group recommends that the home-sharing arrangement should be confined to no more than four residents in total and that those sharing accommodation should have, as far as possible, chosen to live with the other three people.

8.4 ACCESS TO INDIVIDUALISED SUPPORTED LIVING ARRANGEMENTS

Differentiated forms and levels of support will include the following options:

1. Some people will choose to decide on, control and manage their own supports;
2. Some people will need a third party to help with the management of their individualised support package;
3. Some people who choose to share their home with other people with a disability may combine resources with them to pay for shared supports as well as having some personalised supports;
4. Some people may opt for long-term placement with a family that provides part of their support (shared living arrangements).

Shared Living

Shared Living is an option where the person with a disability chooses to live with a family, couple or individuals who provide them with support. An example of a model of *Shared Living* is that operated in Vermont, USA:

“Shared Living Providers are considered professional caregivers who enter into a contractual relationship with a Provider Agency. It is a relationship based on a combination of shared values, clear boundaries, open and frequent communication and ultimate respect for the person they support. Shared Living Providers are required to provide 24 hour care, participate as a member of the individualized support team, and when necessary be the employer of contracted respite and/or day support workers. In turn, Agencies conduct thorough screenings ensuring appropriate matching of clients and providers. Extensive pre-service trainings are mandated and on-going in-service trainings are offered periodically throughout the year. Program Managers offer frequent and consistent monitoring and assistance to both the client and Shared Living Provider. Additionally a 24-hour on-call crisis response team is available with a range of supports including the option of emergency respite. All providers receive an annual allocation of respite to be used at their discretion.”⁹⁴

RECOMMENDATION 10

Supported living arrangements

Supported living arrangements should enable the person to choose to:

- Decide on, control and manage their own supports;
- Contract with a third party to help with the management of their individualised support package;
- Choose to combine resources with others to pay for shared supports as well as having some personalised supports;
- Opt to for support from a family with whom they live.

8.5 ACCESS TO A COMPREHENSIVE RANGE OF SUPPORTS

People with disabilities living in dispersed accommodation in community settings will need a range of support programmes to help them to plan for their lives, and take up valued social roles. Essential programmes will include:

⁹⁴ Zura, M., (2009). Community Living for all Vermonters; there's no place like home. Proceedings from National Disability Authority 2009 Annual Conference "Promoting Independent and Community Living for People with Intellectual Disabilities", Croke Park, Dublin, 6th October 2009.

- Person-centred planning
- Advocacy
- Support for community inclusion
- In-home supports
- Community-based Primary Care and Specialist Supports
- Work/Further Education support.

Arrangements for the provision of these kinds of support should incorporate the proposals contained in *New Directions: Personal Support Services for Adults with Disabilities*.⁹⁵ That Report makes detailed proposals for the provision of supports for adults with disabilities.

Person centred planning

Each individual should develop their own person-centered plan tailored to their individual needs, wishes and choices. The plan describes how the person wants to live their life and what supports are needed to make that possible. The person may need the help of an advocate when making or updating their plan.

Advocacy

Access to independent advocacy will be a cornerstone of the transition to the community. It will provide people with the means to make choices based on an awareness of possibilities rather than choice based on limited life experience, which is the reality for many citizens with disability. The involvement of the independent advocate also ensures that the appropriate checks and balances characteristic of good governance are safely embedded within the delivery model.

Independent advocacy includes but is not confined to professional independent advocacy services. Individuals with a personal relationship with and commitment to an individual service user will be a positive source of advocacy support for individuals. Informal, personal advocates may need preparation and development in their role as advocates.

Inclusion supports

The main means of meeting the individual's support and lifestyle requirements will be the person's immediate network of supporters, which may include paid staff, as well as friends, community contacts and volunteers.

⁹⁵ *New Directions: Personal Support Services for Adults with Disabilities*. Report of the National Working Group for the Review of HSE Funded Adult Day Services. Publication pending.

In-home supports

In-home supports are those forms of support that enable the person to live independently and safely in their own home. As well as support provided by paid staff, *Smart Technology* (technology to enable people to live independently) should form part of the new model of in-home support, to facilitate independence and community inclusion must be harnessed as part of the new model of support. Funding should be allocated to the development of *Smart Technology* for people with disabilities.

Community-based Primary Care and Specialist Supports

HSE Primary Care teams should be the first point of access for all medical and social care for people with disabilities including public health nursing, home help services, meals on wheels, social work, psychological interventions, with a clear pathway to secondary specialist disability-specific teams where they are in place.

Individual health action plans should be developed in conjunction with the primary care teams with input and guidance from specialist practitioners and teams.

The specialist team should be an adjunct to the primary care team. Included in this speciality would be the development of care of the elderly specialist teams who would advise services that care for older people with a disability on best practices.

Delivery of timely and needs-led routine health supports along with the back-up of specialist supports to people with disabilities in their own community will require increased capacity in these services by HSE. Work needs to be done by HSE to strengthen this capacity.

Work/further education

A range of employment options, with appropriate supports, should be available. Supported employment job coaches should be available in each catchment area. These services should be independent of in-home supports and should offer opportunities for meaningful work.

RECOMMENDATION 11

Supports for range of needs

People with disabilities living in dispersed accommodation in community settings will need a range of support programmes to help them to plan for their lives, and take up valued social roles.

Essential programmes will include:

- Person-centred planning
- Advocacy
- Support for community inclusion
- In-home supports
- Community-based primary care and specialist supports
- Work/further education Support

RECOMMENDATION 12

Strengthening access to community health services

Action is required by HSE to strengthen the capacity of community health services to deliver supports to people with disabilities.

8.6 MANAGING THE DELIVERY OF DISPERSED HOUSING AND SUPPORTED LIVING

The management of the delivery of the new model of dispersed housing and supported living should have these key features:

- Distinct statutory responsibility for aspects of support provision
- Separation of responsibility for delivery of in-home supports from inclusion supports
- Local coordination of HSE-funded support provision

Distinct statutory responsibility for aspects of provision

The housing authorities and HSE should have distinct responsibility for the needs of people with disabilities living in the community. HSE or service providers on its behalf should provide for the health and personal social needs of residents moving to the community. Housing authorities should supply the housing needs of people with disabilities.

RECOMMENDATION 13

Distinct statutory responsibility for provision

The housing authorities and HSE should have distinct responsibilities for the needs of people with disabilities living in the community.

The HSE should provide for the health and personal social needs of residents moving to the community while responsibility for housing rests with the Department of Environment, Heritage and Local Government and local authorities.

Separation of responsibility for delivery of in-home supports and inclusion supports

The infrastructure being proposed for managing the delivery of supports envisages a separation of the functions and of the management/ governance structures of those providing within-the-home supports and those supporting the person to engage with, build relationships and valued roles within, the local community.

By separating the delivery and governance of residential supports from inclusion supports, the person with a disability has scope for greater choice and independence; a decision to change their provider of inclusion supports need not be dependent on or impact on their accommodation arrangements; similarly a decision to move to a new home or living arrangements need not involve the inclusion service provider.

RECOMMENDATION 14

Separation of delivery of in-home supports from inclusion supports

Governance, management and delivery of residential supports should be separate from provision of inclusion supports, to ensure that the person with a disability has maximum choice of support providers and maximum independence.

Local coordination of HSE-funded support provision

The individualised supports for people with disabilities should be delivered through a co-ordinating local HSE structure based on defined catchment areas, within which the full range of supports are available.

Catchment areas should be coterminous with the primary care team catchment area and reflect the local referral pathway to services. The HSE general manager should engage with all agencies in an area to develop this coordinated service.

RECOMMENDATION 15

Coordination of support provision

The individualised supports for people with disabilities should be delivered through a co-ordinating local structure based on defined HSE catchment areas, within which the full range of supports are available.

8.7 FUNDING MECHANISMS FOR PERSONAL SUPPORTS

A number of new approaches to the funding of support provision should be examined, aimed at maximising the effectiveness of the use of available resources and maximising the level of choice and control that the person with a disability can exercise over their own programme of supports.

HSE Tendering

The scope for introducing tendering arrangements for purchase of support services should be examined by HSE. A detailed analysis of a tendering system should be undertaken, to see if there is a better way of allocating funding that takes account of the Irish context

Service level agreements

Supports for the people moving from congregated settings should be funded by means of the service level agreement with HSE. Individuals should get their own personal service level agreement which outlines who is responsible for delivering each aspect of their support provision.

New forms of individualised budgets

Systems of individualised budgets can give the person with a disability a greater measure of control over their life choices. Use of such systems, including systems of Direct Payment, where money is given directly to the person with a disability instead of a service provider should be explored in order to wider option for citizens with a disability to select the services they require.

While international experience indicates that only a minority takes up direct-funding options, the introduction of this option could introduce a new dynamic which has a potential to motivate service providers to become more proactive and responsive.

The scope for individual or family governed supports should also be explored and developed. Such arrangements should be provided for in service level agreement processes, tendering processes and other administrative/funding arrangements.

Service standards

To support the service level agreement process, and for tendering processes to work, service standards linked to the objective of community inclusion and full citizenship will be essential (see also 7.7).

RECOMMENDATION 16

Funding mechanisms for personal supports

A study of the feasibility of introducing tendering for services should be undertaken by HSE, to examine its potential in an Irish context.

Support services should be funded by way of service level agreements between HSE and providers. Individuals should get their personal service level agreement which outlines who is responsible for delivering each aspect of their support provision.

The scope for introducing forms of individualised budgets giving people as much control as possible over their choice of supports should also be examined by HSE. The scope for individual or family governed supports should be explored and developed. Such arrangements should be provided for in service level agreement processes, tendering processes and other administrative/funding arrangements.

CHAPTER 9

FUNDING COMMUNITY-BASED SUPPORT AND HOUSING: OPTIONS AND COSTINGS

9.1 THE FUNDING STRATEGY

The funding strategy for community-based living should have these elements:

- Reconfiguration of use of existing HSE funding based on the proposed new model of community living and individualised support
- Retention of all funding currently linked to congregated settings
- Funding for essential transitioning costs (chapter 11).
- Funding of housing by the Department of Environment, Heritage and Local Government.

9.2 RECONFIGURING EXISTING FUNDING

Significant funding is already allocated to the congregate provision. In 2008, €1.6 billion was spent on Disability Services.⁹⁶ This figure represents 29% of the Primary and Continuing Community Care Budget in 2008 and increased from €1.218 billion in 2006. The data collection from the 72 sites covered by the Working Group's report confirmed a spend of approximately € €417 million on congregated settings, which equated to 34% of the total Disability budget for approximately 13% of the population of people with disabilities and an average cost per person of €106,000 per annum.

Many service providers have over the past two decades, on their own initiative, enabled significant numbers of people from congregate settings to move to the community without additional funding. The survey conducted for the Working Group confirmed that of the 72 centres reviewed for the report, 619 clients have moved from 46 centres into the community from Congregated Settings in the period 1999 – 2008.

The Working Group recognises that the people now living in congregated settings have complex needs. In whatever setting they live, they will need significant supports to make sure that their needs are met. Average costs typically used to estimate funding requirements may not be appropriate for those individuals who are currently living in the larger settings. However, the costs being incurred are based on the existing service model in these settings, and are not directly comparable to the community-based approach being proposed by the Working Group. The new

⁹⁶ HSE Resource Distribution Review, 2008.

approach envisages accommodation costs and clinical supports being funded from separate mainstream funding streams. The model involves use of primary care and specialist supports in the community, as well as complementary nursing and social Supports.

With these considerations in mind, the Working Group is satisfied that the current level of resources being invested in congregated settings would be sufficient to implement the policy objectives of this Report, assuming that flexible and efficient application and reconfiguration of the resource is optimised. The sample costings for community-based supported living models provided below (9.4) confirm the view that current funding levels should enable the overall transitioning programme to be done on a cost neutral basis.

There are some important caveats. Firstly, disability budgets have been reduced by a minimum of 5% in the period 2008-2010, and accordingly there is less flexibility within budgets, to fund further movement to the Community.

Secondly, despite the significant monetary investment in existing congregated settings, international research indicates bridging finance/transitional funding may be required, while the new model and old model are open concurrently. Transitional funding is dealt with more fully in Chapter 10 (see 10.4).

It must also be noted that the top ten “per capita costs” in the 72 current congregated settings range from €152,000 per capita up to €232,000 per capita per annum and the lowest ten centres range from €37,000 to €66,000 per capita per annum. [Dependency levels have not been correlated with unit costs.]. Given these significant variations in current per capita funding in congregated settings, it may be necessary to re-deploy funding among sites.

9.3 RETENTION OF ALL FUNDING CURRENTLY LINKED TO CONGREGATED SETTINGS

The key to meeting the costs of the new community-based individualised support model will be to access funding and resourcing currently linked to the person now residing within the congregate care setting. Current funding should stay in the system and be redeployed; any savings arising from the move should be used for new community-based services.

Deployment of current staffing in congregated settings

Staff currently working in congregated settings constitute a very significant part of the available resource provision for residents. The new support model being proposed by the Working Group envisages a different skill-mix and different use of staffing resources. Skilled staff should have roles that make best use of those skills in the new support model. In particular, highly skilled professionals should not be deployed in meeting basic care needs.

The manpower strategy (7.4) should actively pursue the scope for involving the staff currently working in congregated settings in community support provision, and should propose how that resource might transfer to community support.

The development of primary care teams should take account of the existence of specialist personnel within residential services and other disability services; positive partnership arrangements will need to be agreed with staff in voluntary organisations and protocols agreed in relation to their participation in HSE primary care structures.

RECOMMENDATION 17

Retain all funding currently being spent on congregated services

Funding currently in the system for meeting the needs of people in congregated settings should be retained and redeployed to support community inclusion; any savings arising from the move should be used for new community based services.

The scope for involving the personnel currently working in congregated settings in delivering community support provision, and how that resource might transfer, should be explored in partnership with stakeholders through the proposed manpower strategy.

9.4 THE COST OF INDIVIDUALISED COMMUNITY-BASED SUPPORTS

The Working Group envisages that the personal support needs of people moving from congregated settings to the community will continue to be met by the HSE, based on the new model of support outlined in Chapter 9.

The indicative costs of these support services shown below are based on costs in a number of settings currently delivering a service that approximates closely to the proposed new model of support provision. There are many examples of this type of service in Ireland. While these may not adhere fully to the requirements of the new model, they are sufficiently close, in the view of the Working Group, to provide a good indication of the costs likely to be incurred. The examples chosen for indicative costing purposes include services being provided to people with a range of services for people with physical disabilities and services for people with intellectual disabilities.

INDICATIVE COSTS OF INDIVIDUALISED SUPPORT SERVICES

The following are examples of a range of costs for individualised supports in three agencies. It must be noted that these costs are not directly comparable and may be based on differing approaches to costing of the elements of the service provided.

EXAMPLE 1: Community setting for people with intellectual disability

Low Support	Cost per person in community house	€55,616
	Cost per person in Supported Living	€13,713

Four people live in a Community House and access their local community actively with one staff on sleepover duty. This team of staff also gives support to six other service users that are in Supported Living arrangements.

Medium Support – cost per person **€67,352**

Five people live in a Community House; two staff are on duty every evening to facilitate one-to-one support with people accessing their local community.

High Support – cost per person **€151,000**

Three service users live in a four-bedroom community house, due to physical needs of one service user. Two staff are on duty at all times due to challenging behaviour.

EXAMPLE: 2 Community setting for people with intellectual disability

Four service users share a four-bedroom community house; the cost of one sleepover, day service and managerial costs are included. Clinical support costs are not included.

Cost per person per annum: **€50,000-€55,000.**

EXAMPLE 3: Community setting for people with physical disability

Individualised support is provided for 8 people where each lives in their own home which is rented or owned. Clinical support costs not included.

Cost per person per annum: €19, 873.

9.5 FUNDING FOR HOME-SHARING AND LONG-TERM PLACEMENT IN FAMILIES (SHARED LIVING)

Shared Living is an option where families, couples or individuals provide support to an individual with a disability in their own home (see also 8.4). The funding for this provision would be supplied by HSE.

Costings from similar shared living schemes in Vermont, USA, suggest that the cost of shared living support arrangements represent a small fraction of the cost of support provision in an institutional setting.⁹⁷

9.6 SUPPLYING AND FUNDING COMMUNITY-BASED HOUSING/ACCOMMODATION

The Working Group proposes that people moving from congregated settings should live in dispersed housing in local communities provided in the main by local authorities.

A mix of housing options

The accommodation needs of people moving from congregated settings should be met through a combination of purchased housing, new-build housing, leased housing or rented housing.

The appropriate mix of options would be facilitated via individual housing authorities, overseen by the Department of Environment, Heritage and Local Government. It could include housing provided by a housing association, standard local authority housing, housing rented on a long-term arrangement from a private landlord, or a family home.

⁹⁷ The average annual per person cost in fiscal year 2008 in Vermont was \$35,494, compared to the annual per person cost, adjusted for inflation, in named institution of \$283,470. Marie Zura, op.cit.

RECOMMENDATION 18

Mix of housing options

The accommodation needs of people moving from congregated settings should be met through a combination of purchased housing, new-build housing, leased housing or rented housing.

The appropriate mix of options would be facilitated via individual housing authorities, overseen by the Department of Environment, Heritage and Local Government. It could include housing provided by a housing association, standard local authority housing, housing rented on a long-term arrangement from a private landlord, or a family home.

9.7 INDICATIVE COSTING OF HOUSING OPTIONS

To quantify in broad terms the cost of provision of housing in the community, a number of alternative scenarios are presented. These are for the purpose of calculating a range of costings and are not presented as optimum policy options. The costings shown are sensitive to actual house prices in different areas and for individual house types, in what is an unstable housing market. For the rental option, the costs are sensitive to future movements in rents.

There are approximately 4,000 people living in congregated settings. The availability of a range of suitably located housing units should not constitute a problem, given the overhang of housing supply in the current Irish market.⁹⁸ The key issue is funding to ensure that individuals can access appropriate housing.

Four scenarios are costed below⁹⁹

1. The **capital cost of rehousing** (purchase option) is costed based on two alternative assumptions:

- a) 1,000 new homes required with everyone accommodated in 4-person group homes

⁹⁸ While estimates differ, the numbers of vacant homes is very large. Minister Finneran has estimated 100,000 to 140,000 vacant homes. A September 2009 Construction Industry outlook report by DKM estimated a housing surplus of some 136,000 units (<http://www.cisireland.com/NewsItem.aspx?NewsId=205>). The National Institute for Regional and Spatial Analysis based in NUI Maynooth has estimated about 300,000 vacant homes

⁹⁹ Costings used in this section are indicative. They do not include certain leasing costs such as start-up and technical costs, or re-instatement costs to housing authorities at the end of the lease.

- b) 2,000 new homes required to provide a range of housing sizes and options, e.g. fostering, individual units, smaller shared units. For costing purposes a mix of 800 1-bed units, 800 2-bed units and 400 4-bed units is assumed.

2. **The current cost of rehousing** (rental option) and assuming a tenant contribution as per differential rent or Rental Accommodation Scheme, is costed based on the same assumptions.

	1. Capital cost/purchase option	2.Net annual rent cost/rental option
Assumption	€m.	€m.
1,000 new homes	354	9
2,000 new homes	442	15

Capital cost of re-housing: purchase/build options

The capital cost of rehousing 4,000 people over a six-year period, if all the replacement housing is bought or built, would be approximately €60m. a year (assumption 1 – group housing option) or €75m. a year (assumption 2 – mix of house sizes).

Where new housing stock needs to be built/bought, sources of funding may be secured from direct government funding, selling of lands around the large congregated settings, public/private partnerships or joint investment plans between DOE, local authorities, HSE and service providers.

Certain agencies providing congregated settings may be in a position to consider selling land to help to fund new accommodation, and have indicated a willingness to explore this possibility. However, in the interim, there some bridging funding may be required, to fund the purchase of the new accommodation before the vacated centre could be sold.

Current cost of re-housing: social housing options

The main options for social rented housing are:

- local authority housing (built, bought, or made available by a developer as part of the social housing commitment under Part 5 of the 2000 Planning and Development Act)
- housing owned or leased by the voluntary housing sector
- long-term leasing (up to 20 years)
- private rented housing (RAS scheme or supplementary welfare allowance).

Local authority housing

There are long waiting lists for local authority housing, and it is likely that specific arrangements would need to be engaged in with the relevant local authority about prioritising individuals transferring from congregated settings and when such transfers would take place as suitable housing becomes available.

Numbers (2008):

- Current housing stock: 118,000
- Vacancies arising: 4,300
- New build: 4,900
- Bought: 800.

Voluntary housing

Currently, there are about 22,000 housing units managed by voluntary housing bodies. These include general-purpose housing associations (such as Respond and Clúid), housing associations associated with disability service providers and other disability-specific housing.

There are capital subsidies available, and with a greater focus on leasing for mainstream housing, capital funds are likely to be focused more on special needs housing. Capital subsidies have been used to fund village-type clusters as well as individual units.

Purchase or leasing via voluntary housing associations

Purchase or leasing via voluntary housing associations offers a potentially wide choice of locations.

Leasing

It is Government policy to consider long-term leasing as an alternative to buying or building housing, however there has been limited interest to date from landlords in this option.

Private rented housing

Private rented housing offers a good choice of locations and does not lock-in the provision of housing to a specific location. Long-term security of tenure may however be an issue.

If people are rehoused in leased accommodation in vacant properties, it would be essential to ensure that vulnerable people are not isolated in "ghost estates" but there are natural community supports in their neighbourhood. The issue of what happens at the end of a lease period would also need to be resolved.

Under the *Rent Supplement Scheme*, designed to deal with short-term housing need, individuals pay the first €24 a week in rent from their welfare payment, and the balance (subject to a rent ceiling) is paid by the state. Where there is a long-term housing need, the person can be transferred to the *Rental Accommodation Scheme*

run by local authorities. Under this scheme the local authority rents for a medium-term period on commercial terms from a private landlord, and sublets on a differential rent basis to the tenant.

All those making the transition from congregated settings should be assessed for eligibility for Rent Supplement or Rental Accommodation Scheme. This subject needs detailed consideration by the Department of Social Protection, Department of Environment, Heritage and Local Government, and the Department of Health and Children.

RECOMMENDATION 19

Meeting capital costs of new housing stock

Some purpose built new housing in the community to meet particular individual needs will need to be built, or purchased and made accessible.

Where agencies providing congregated settings may be disposed to sell land to help to fund new accommodation, and need short/medium term financing to enable accommodation to be built or purchased for residents before property and land can be sold, this short-term funding should be provided by the state by way of loan.

RECOMMENDATION 20

Eligibility for Rent Supplement/Rental Accommodation Scheme

All those making the transition from congregated settings should be assessed for eligibility for Rent Supplement or Rental Accommodation Scheme. This subject needs detailed consideration by the Department of Social Protection, Department of Environment, Heritage and Local Government, and the Department of Health and Children.

9.8 Local planning for social rented housing for people moving from congregated settings

In order to make best use of the available social rented housing for people moving from congregated settings, a local plan will be needed, jointly co-ordinated by local authorities and HSE, in collaboration with service providers.

The plan should take full account of the ethos of inclusion and person-centeredness which underpins the Working Group's proposals. In particular, the plan should take account of the following considerations:

- A small number of local authority estates experience extreme social problems. Care should be taken to ensure that people being rehoused into local authority accommodation from congregated settings move into a stable community capable of offering natural community supports.
- Vulnerable people should not be isolated in "ghost estates" where there may be no natural community supports in their neighbourhood.
- Care should be taken to avoid practices of 'over-loading' districts and neighbourhoods with three, four and more houses in fairly close proximity, thus creating a close equivalent to a cluster/campus arrangement.

RECOMMENDATION 21

Local planning for social rented housing for people moving from congregated settings

A local re-housing plan should be prepared and jointly co-ordinated by local authorities and HSE, in collaboration with service providers. The plan should be based on best practice in including people with disabilities in local communities and should facilitate dispersed housing with personal supports.

All residents in congregated settings should be assessed by housing authorities to establish their eligibility and need for social housing support. Service Providers should ensure that their clients are assessed for housing by the relevant local authority.

9.9 ALLOCATION POLICIES

Elected members of local authorities draw up the housing allocation policy (formerly the letting priorities scheme). This can apply to allocations of social housing projects or leased accommodation as well as to local authority tenancies. Following the enactment of the Housing (Miscellaneous Provisions) Act 2009, Regulations to introduce a new needs assessment process are being prepared. Housing authorities should give consideration to reserving a certain proportion of dwellings for people with disabilities.

The Circular on assessment of long-term need for social housing (issued in conjunction with new guidelines on Rent Supplement SWA circular 10/09, July 2009) set out criteria for assessing current accommodation:

- unfit
- materially unsuitable
- overcrowded
- inappropriate e.g. because of serious medical or social problems

- documentary evidence is required where someone can no longer live in their existing accommodation despite adequate space for their needs. A letter from a social worker would count as evidence.

These criteria will not address the needs of people with disabilities. A suite of letting criteria specific to housing for people with disabilities should be developed and reflected in a national protocol. These criteria should provide for tailored housing solutions for individuals and cross-council letting agreements, for example, to facilitate a person with a disability to live close to family members.

RECOMMENDATION 22

Allocation priorities

Housing authorities should give consideration to reserving a certain proportion of dwellings for people with disabilities. A suite of letting criteria specific to housing for people with disabilities should be developed and reflected in a national protocol.

9.10 CONCLUSIONS

It is the view of the Working Group that the cost of HSE-funded supports for people with disabilities moving from congregated settings to live in the community can be met within the 'envelope' of funding currently available to that group of people. This view is based on the findings of the survey (Chapter 3) in relation to per capita expenditure on current provision, together with the range of indicative costs of community-based provision as demonstrated in the examples set out earlier in this chapter.

In the case of housing provision, a mix of new builds and social rented housing is likely to be needed. If the entire requirement were met through new builds, the capital cost over a six-year period would be approximately €60m. a year (assumption 1 – group housing option) or €75m. a year (assumption 2 – mix of house sizes).

The accommodation needs of people moving from congregated settings should be met through a combination of building/purchasing new housing stock, rented accommodation and leasing of purpose-built accommodation. The appropriate 'mix' of options should be facilitated through the Housing Strategy of the Department of Environment, Heritage and Local Government.

CHAPTER 10

FUNDING, RESOURCING AND MANAGING THE TRANSITION TO THE COMMUNITY

10.1 THE KEY PROPOSALS

The key proposals for funding, resourcing and managing the transitioning of the people in congregated settings to the community deal with the following:

- Phasing the transitioning programme
- Managing the transitioning programme
- Resourcing the transitioning programme
- Preparing people for transition
- National evaluation framework
- Review of residential settings not addressed by the Working Group.

10.2 PHASING THE TRANSITIONING PROGRAMME

Over the period of the transitioning programme, every person now living in a congregated setting should be provided with a home in the community. There should be no new admissions to existing congregated settings and no capital funding allocated to build new congregated settings.

An active transfer programme will be needed to secure closure of all congregated settings. Ending admissions will be a necessary but not a sufficient step to bring about closure. On the basis of the current admission rate, ending admissions would result in about 500 fewer people living in congregated settings over a ten-year period. As fewer than 7% of residents are aged over 70, the rate of natural decrease is likely to be small.

It is estimated that, allowing for natural decrease and a bar on admissions, a programme of transition to community for about 750 people a year would be needed to achieve closure over a five-year period; a programme of transferring about 500 people a year would be required to achieve closure over 7 years, and about 300 people must transfer each year to achieve closure over a ten-year period.

The Working Group proposes that the move to community for all residents of congregated settings should take place within a seven-year timeframe. Specific annual targets should be set at national and local level to must guide the phasing and prioritising process.

RECOMMENDATION 23

Phasing the transitioning programme

A seven-year timeframe for the overall national closure programme for congregated settings should be set. Within that timeframe, specific annual targets should be set at national and local level to guide the phasing and prioritising process, in consultation with the HSE.

10.3 MANAGING THE TRANSITIONING PROGRAMME

The Working Group proposes that the National Implementation Group should ensure that co-ordinated and appropriately paced plans are in place to implement the closure policy (7.4). Within the overall national implementation framework, responsibility for implementing the closure policy objectives should rest with the HSE.

At local level, the responsibility for formulating local time-framed action plans is best placed at Integrated Service Area level of the HSE, and be managed by those who have local responsibility for resource allocation and commissioning. Each Integrated Service Area (ISA) should be responsible for ensuring that local planning and delivery systems to implement the national policy objectives are in place.

A local implementation team should be set up in each HSE Integrated Service Area level and a named person given responsibility for supporting the transfer of people into the community; this person would be responsible for ensuring that local public and voluntary services are prepared to respond to the development of a comprehensive community support infrastructure.

Local plans should be monitored by the National Implementation Group to enable this group to have oversight of the progress towards achieving the strategic goals of the transitioning process.

RECOMMENDATION 24

Local oversight

An implementation team should be set up at Integrated Service Area level within HSE and a named person given responsibility for supporting the transfer of people into the community; this person should be responsible for ensuring that local public and voluntary services are prepared to respond to the development of a comprehensive community support infrastructure.

Provider proposals

All agencies currently operating congregated settings should be required to submit their transitioning strategy and plans to HSE, with detailed timeframes and deadlines. Agency proposals should form part of annual discussions with HSE in respect of Service Arrangements.

RECOMMENDATION 25

Agencies' transitioning strategy and plan

All agencies operating congregated settings should be required to submit their transitioning strategy to HSE, with detailed operational plans, timeframes and deadlines, based on the review recommendations. Agency proposals should be part of annual discussions with HSE in respect of service agreements.

Accelerated Learning Site funding

In order to speed the transitioning process, a number of **Accelerated Learning Sites** should be funded to provide ambitious and accelerated implementation of the policy and robust examples of evidence-based transitions to models of community living.

Accelerated learning site funding should be proposal-led. Criteria should be applied to (a) the range and distribution of sites and (b) the capacities required from individual providers. The choice of sites will allow the learning to be evaluated across:

- Statutory and non-statutory services
- Different levels of need, including those with severe and profound disabilities or significant levels of challenging behaviour
- Different geographic regions
- Different levels of current funding per client.

Funding criteria

All funding proposals (provider plans generally and Accelerated Learning Site proposals) should demonstrate the intention to address the following criteria:

Practice values

- Enhancement of privacy and dignity
- A strong emphasis on promoting self-determination
- Intentional strategies for developing and mobilising personal networks of support (i.e. "freely given" non-paid support)
- Explicit strategies for promoting inclusion and creating community readiness
- Evidence of the involvement of independent advocacy

- Inclusion of persons with high support and complex needs
- Explicit integration with generic health and personal welfare services, e.g. primary care teams, community welfare supports, and specialist multidisciplinary teams.

Organisational effectiveness

- A strong cost-effectiveness rationale
- Optimising the efficiency and value-adding impact of new skill mix configurations
- Well developed quality assurance safeguards
- An openness to independent evaluation
- Readiness for Immediate implementation.

RECOMMENDATION 26

A number of ***Accelerated Learning Sites*** should be funded to provide ambitious and accelerated implementation of the policy and robust examples of evidence-based transitions to models of community living.

The choice of sites will allow the learning to be evaluated across:

- Statutory and non-statutory services
- Different levels of need, including those with severe and profound disabilities or significant levels of challenging behaviour
- Different geographic regions
- Different levels of current funding per client.

10.4 RESOURCING ESSENTIAL TRANSITIONING COSTS: A CONGREGATED SETTINGS FUND

As the survey conducted for this Report showed (3.12), some congregated settings are surviving on much lower funding levels than others and will need a funding uplift to move in the recommended direction.

Even in the case of better-resourced services *at certain points in the transition cycle* (where resources have yet to be transferred and reconfigured within the new delivery model), international experience confirms that there will be a need for 'bridging' funding to maintain parallel systems for a period of time. Indicative funding linked to an individual may constitute keystone funding within the agency, removal of which may have ramifications for the sustainability of arrangements on which others are dependent.

Interim emergency improvements

The survey identified situations which are intolerable in the immediate term, arrangements which violate fundamental standards of privacy and dignity. Immediate measures are needed to remedy such situations without mitigating the urgency of simultaneously moving to develop alternative arrangements.

There is a compelling need to identify immediate *emergency funding* to support such temporary measures. The local implementation teams charged with delivering the commitment to transfer persons from congregate settings should make judgements about what requires immediate remedy and what is justifiable on an interim basis. The HIQA standards introduce an authoritative source of guidance in this context.

Costs of adaptations and Assistive Technology

Some provision should be made for adaptations to existing housing units in the community and installation of smart technology aimed at maximising scope for independence.

Congregated Settings Fund

The Working Group took the view that a *Congregated Settings Fund* should be established, with funds from government, and from sources such as philanthropic funding and Dormant Accounts funding, for a transition period.

The main uses of this Fund would be:

- To uplift the core funding linked to individuals in settings currently surviving on a very low funding base relative to individuals in other congregate settings;
- To provide interim “bridging” funding to congregated settings at particular points in their transition cycle
- To support *ambitious and accelerated implementation* of the policy vision within a number of advanced learning sites - sites which are demonstrating practice innovations and developments that could guide and inform implementation of the policy objectives across the broad provider spectrum
- To provide emergency funding to settings where urgent remediation is needed.
- To make some provision for adaptations and assistive technology.

All applications to secure funding from the Congregated Settings Fund should be proposal-led. Proposals should indicate the use to be made of the funding to advance the transitioning policy objectives.

RECOMMENDATION 27

Congregated Settings Fund

A range of new funding streams should be brought together in a Congregated Settings Fund. The Fund should be available to:

- Uplift the core funding linked to individuals in settings currently surviving on a very low funding base relative to individuals in other congregate settings
- Provide interim “bridging” funding to congregated settings at particular points in their transition cycle
- Support ambitious and accelerated implementation
- Provide emergency funding in settings where remedial actions are needed
- Make provision for adaptations and assistive technology.

10.5 NATIONAL EVALUATION FRAMEWORK

A key element of national and local oversight will be information gathered through comprehensive evaluation of the Accelerated Learning projects and other settings involved in the transitioning process. Without evaluative data, the experiences of the move from congregated to community-based settings will not be available to guide the wider transitioning programme.

The evaluation framework should be agreed at national level to ensure a standardised approach across all projects. A consistent approach to evaluation across all sites is needed, given the small number of residents participating at each site. Combining data from various sites with small populations provides appropriate power for statistical analysis of the findings – an important ethical consideration when gathering sensitive data from vulnerable populations.

The evaluation framework should be agreed prior to the setting up of advanced learning projects. The design should be informed by similar work conducted internationally. In order to ensure the integrity of the evaluation, an independent agent should undertake the evaluation task across all participating sites.

RECOMMENDATION 28

National Evaluation Framework

A comprehensive evaluation framework for the transitioning project should be agreed at national level to ensure a standardised approach to evaluation across all accelerated learning projects and other settings involved in transitioning to the community, and an agreed minimum data set. The evaluation framework should be agreed prior to start of any project. It should be informed by similar work conducted internationally. In order to ensure the integrity of the evaluation in each site, an independent agent should undertake this evaluation across all participating sites.

10.6 PREPARING PEOPLE FOR TRANSITION

Many people with disabilities have spent several years in congregated settings. They may have had limited opportunities for personal development. They will need support to move to community settings, and, once there, to develop their capacities for friendship and relationships, and for acquiring valued social roles.

People who have never had the chance to make choices will need experience in choice-making; they will need information they can understand. They may have become used to routines and care practices that will change radically. They will need help to deal with that change. The impact of change must be managed through careful person-centred planning.

For family members, the prospect of their relative living in the community can lead to concerns about having to take up a carer role again; their sense that their family member was secure and safe may feel threatened.

Resources will be needed to help people and families involved to make the transition; training and professional development for staff working with them shape the success of the transition and embed the new model of community-based support is

Individualised, community-based support needs practical involvement with several stakeholders in the local community. The transitioning plan prepared by each provider should say how this work will be done. A local programme to promote understanding of the transitioning policy rationale and objectives will be essential.

Providing advocacy to support individual decision-making

Each individual will make life-changing decisions and choices – possibly for the first time in their lives. In addition to support for choice-making and for successful inclusion, people will need advocacy to help them to articulate and follow through on their wishes.

Advocacy groups and specialist service providers deliver advocacy supports to people with disabilities; however, this provision is not uniformly available. Individuals with a personal relationship with and commitment to an individual service user will be a positive source of advocacy support for individuals. Informal, personal advocates may need preparation and development in their role as advocates.

Under the provisions of the *Citizens Information Act 2007*, responsibility for the advocacy services rests with the Citizens Information Board. During 2007 a number of advocacy projects were established in residential centres. Six such projects now exist, with the advocate employed by an external body in order to ensure independence from the service provider. A further strand of the CIB plan is the development of the Personal Advocacy Service (PAS). However, the roll-out of this service is currently on hold, due to the current financial climate.

A dedicated and resourced advocacy programme should be provided for those moving from congregated settings over the period of the transfer programme.

RECOMMENDATION 29

Creating readiness

Resources should be made available as part of the change management planning to support people with disabilities, families, and staff to transfer to the community and to develop community readiness.

RECOMMENDATION 30

Providing access to advocacy

A dedicated and appropriately resourced advocacy programme should be provided over the period of the transfer programme for those moving from congregated settings.

10.7 Review of residential settings not addressed by the Working Group

As noted in the Introduction, a number of large residential settings for people with disabilities were outside the scope of the Working Group's remit, and will not be addressed as part of the implementation of *Vision for Change: The Report of the Expert Group on Mental Health Policy*. These include nursing homes, residential centres for people with Autism, and Intentional Communities.

The Working Group recommends that these residential settings should be reviewed by the HSE. The review should identify actions needed to ensure that residents can access the same levels of community-based support and inclusion being proposed for residents of congregated settings.

In addition, a group of people with disabilities continue to live in large mental health settings; action to address their needs fall within the scope of the implementation of the *Vision for Change* strategy. The Working Group is of the view that a programme to offer this group community-based accommodation, support and inclusion, in line with the recommendations of this Report, should be given top priority in the implementation of the *Vision for Change* implementation process.

RECOMMENDATION 31

Review of residential settings outside remit of the Working Group

The HSE should initiate a review of large residential settings for people with disabilities which were outside the scope of the Working Group, for example, people inappropriately placed in Nursing Homes. The aim of the review should be to ensure that residents in these settings can access community-based support and inclusion, in line with the Working Group's proposals for residents of congregated settings.

A number of people with disabilities are still living in mental health settings, and their accommodation and support needs fall within the remit of *Vision for Change* proposals. The Working Group recommends that this group should be given top priority in the *Vision for Change* implementation process and be moved to appropriate community settings in line with the recommendations in this Report.

CHAPTER 11

SUMMARY OF RECOMMENDATIONS

National policy and support frameworks for the transitioning programme (Chapter 7)

RECOMMENDATION 1 (7.2)

Department of Health and Children vision and policy statement

The Department of Health and Children should issue a vision and policy statement on the closure of congregated settings and transition of residents to community settings. The policy should mandate that:

- All those living in congregated settings will move to community settings
- No new congregated settings will be developed and no admissions will take place to congregated settings
- The move to community will be completed within seven years and minimum annual targets set for each year in order to reach that goal.

RECOMMENDATION 2 (7.3)

National Housing Strategy for People with Disabilities

The Working Group's proposals should be reflected in the National Housing Strategy being prepared by the Department of Environment, Heritage and Local Government. The strategy should describe the eligibility of people with disabilities for publicly funded housing supports.

The Strategy should reflect the research evidence that dispersed housing in the community provides a better quality of life for people with disabilities than cluster-style housing.

RECOMMENDATION 3 (7.4)

National oversight

A named senior official of the HSE should be charged with driving and implementing the transitioning programme, assisted and guided by a National Implementation Group. The Department of the Environment, Heritage and Local Government should be represented on the National Implementation Group.

Progress on implementation should be reported every six months to the HSE Board, to the Department of Health and Children, and also reported to the National Disability Strategy Stakeholder Monitoring Group. The housing letting practice in Local Authorities should be monitored as part of national implementation.

RECOMMENDATION 4 (7.5)

A manpower strategy

A manpower strategy to support the programme of transition to community settings should be devised by the National Implementation Group in partnership with key stakeholder groups. The strategy should address staffing requirements and skill mix needs for community inclusion, skill development and professional development requirements, and the human resource aspects of the transition programme.

RECOMMENDATION 5 (7.6)

National Protocols to support community inclusion

A Working Group should be set up to co-ordinate the development of a range of protocols to ensure a co-ordinated approach to community inclusion for people with disabilities. These protocols should be developed across key government departments and agencies, in partnership with the National Implementation Group; they should be prepared within the framework of the National Disability Strategy and have regard to the Sectoral Plans prepared under that Strategy.

RECOMMENDATION 6 (7.8)

Change management programme

A change management programme to support the transitioning programme should be developed and resourced. The change management plan should be executed by HSE and overseen by the National Implementation Group.

Moving from congregated settings: A new model of support in the community (Chapter 8).

RECOMMENDATION 7 (8.1)

A new model of community-based support

The provision of accommodation for people moving from congregated settings to their local community must be broader than a plan for accommodation; accommodation arrangements for housing must be part of a new model of support that integrates housing with supported living arrangements.

The new model of support should be based on the principles of person-centeredness; it should enable people with disabilities to live in dispersed housing, with supports tailored to their individual need.

RECOMMENDATION 8 (8.3)

Dispersed housing in the community

All those moving from congregated settings should be provided with dispersed housing in the community, where they may:

- Choose to live on their own
- Share with others who do not have a disability
- Share their home with other people with a disability
- Live with their own family or opt for long-term placement with another family.

Purpose-built community housing funded by the HSE should be provided for any children under-18 years old moving from congregated settings.

RECOMMENDATION 9 (8.3)

Maximum of four residents who choose to share accommodation

Where home-sharing with other people with a disability is the housing option chosen by the individual, the Working Group recommends that the home-sharing arrangement should be confined to no more than four residents in total and that those sharing accommodation have, as far as possible, chosen to live with the other three people.

RECOMMENDATION 10 (8.4)

Supported living arrangements

Supported living arrangements should enable the person to choose to:

- Decide on, control and manage their own supports
- Contract with a third party to help with the management of their individualised support package
- Choose to combine resources with others to pay for shared supports as well as having some personalised supports.

RECOMMENDATION 11 (8.5)

Supports for range of needs

People with disabilities living in dispersed accommodation in community settings will need a range of support programmes to help them to plan for their lives, and take up valued social roles.

Essential programmes will include:

- Person-centred planning
- Advocacy
- Support for community inclusion
- In-home support
- Community-based primary care and specialist supports
- Work/further education support.

RECOMMENDATION 12 (8.5)

Strengthening access to community health services

Action is required by HSE to strengthen the capacity of community health services to deliver supports to people with disabilities.

RECOMMENDATION 13 (8.6)

Distinct statutory responsibility for aspects of provision

The housing authorities and HSE should have distinct responsibilities for the needs of people with disabilities living in the community.

The HSE should provide for the health and personal social needs of residents moving to the community while responsibility for housing rests with the Department of Environment, Heritage and Local Government and local authorities.

RECOMMENDATION 14 (8.6)

Separation of delivery of in-home supports from inclusion supports

Governance, management and delivery of in-home supports should be separate from provision of inclusion supports, to ensure that the person with a disability has maximum choice of support providers and maximum independence.

RECOMMENDATION 15 (8.6)

Coordination of support provision

The individualised supports for people with disabilities should be delivered through a co-ordinating local structure based on defined HSE catchment areas, within which the full range of supports is available.

RECOMMENDATION 16 (8.7)

Funding mechanisms for personal supports

A study of the feasibility of introducing tendering for services should be undertaken by HSE, to examine its potential in an Irish context.

Support services should be funded by way of service level agreements between HSE and providers. Individuals should get their own personal service level agreement which outlines who is responsible for delivering each aspect of their support provision.

The scope for introducing forms of the individualised budgets giving people as much control as possible over their choice of supports should be examined by HSE.

The scope for individual or family governed supports should be explored and developed. Such arrangements should be provided for in service level agreement processes, tendering processes and other administrative/funding arrangements.

Funding Community-based Support and Housing: Options and Costings (Chapter 9).

RECOMMENDATION 17 (9.1)

Retain all funding currently being spent on congregated services

Funding currently in the system for meeting the needs of people in congregated settings should be retained and redeployed to support community inclusion; any savings arising from the move should be used for new community based services.

The scope for involving the personnel currently working in congregated settings in delivering community support provision, and how that resource might transfer, should be explored in partnership with stakeholders through the proposed manpower strategy.

RECOMMENDATION 18 (9.6)

The accommodation needs of people moving from congregated settings should be met through a combination of purchased housing, new-build housing, leased housing or rented housing.

The appropriate mix of options would be facilitated via individual housing authorities, overseen by the Department of Environment, Heritage and Local Government. It could include housing provided by a housing association, standard local authority housing, housing rented on a long-term arrangement from a private landlord, or a family home.

RECOMMENDATION 19 (9.7)

Meeting capital costs of new housing stock

There will be instances where purpose built new housing in the community to meet particular individual needs will need to be built, or purchased and made accessible.

Where agencies providing congregated settings may be disposed to sell land to help to fund new accommodation, and need short/medium term financing to enable accommodation to be built or purchased for residents before property and land can be sold, this short-term funding should be provided by the state by way of loan.

RECOMMENDATION 20 (9.7)

Eligibility for Rent Supplement/Rental Accommodation Scheme

All those making the transition from congregated settings should be assessed for eligibility for Rent Supplement or Rental Accommodation Scheme. This subject needs detailed consideration by the Department of Social Protection, Department of Environment, Heritage and Local Government, and the Department of Health and Children.

RECOMMENDATION 21 (9.8)

Local planning for social rented housing for people moving from congregated settings

A local re-housing plan should be prepared and jointly co-ordinated by local authorities and HSE, in collaboration with service providers. The plan should be based on best practice in including people with disabilities in local communities and should facilitate dispersed housing with personal supports.

All residents in congregated settings should be assessed by housing authorities to establish their eligibility and need for social housing support. Service Providers should ensure that their clients are assessed for housing by the relevant local authority.

RECOMMENDATION 22 (9.9)

Allocation priorities

Housing authorities should give consideration to reserving a certain proportion of dwellings for people with disabilities. A suite of letting criteria specific to housing for people with disabilities should be developed and reflected in a national protocol.

Funding, Resourcing, and Managing the Transition to the Community (Chapter 10)

RECOMMENDATION 23 (10.2)

Phasing the transitioning programme

A seven-year timeframe for the overall national closure programme for congregated settings should be set. Within that timeframe, specific annual targets should be set at national and local level to guide the phasing and prioritising process, in consultation with the HSE.

RECOMMENDATION 24 (10.3)

Local oversight

An implementation team should be set up at Integrated Service Area level within HSE and a named person given responsibility for supporting the transfer of people into the community; this person should be responsible for ensuring that local public and voluntary services are prepared to respond to the development of a comprehensive community support infrastructure.

RECOMMENDATION 25 (10.3)

Agencies transitioning strategy and plan

All agencies currently operating congregated settings should be required to submit their transitioning strategy to HSE, with detailed operational plans, timeframes and deadlines, based on the review recommendations. Agency proposals should be part of annual discussions with HSE in respect of service agreements.

RECOMMENDATION 26 (10.3)

Accelerated Learning Sites

A number of **Accelerated Learning Sites** should be funded to provide ambitious and accelerated implementation of the policy and robust examples of evidence-based transitions to models of community living.

The choice of sites will allow the learning to be evaluated across:

- Statutory and non-statutory services
- Different levels of need, including those with severe and profound disabilities or significant levels of challenging behaviour

- Different geographic regions
- Different levels of current funding per client.

RECOMMENDATION 27 (10.4)

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- Support ambitious and accelerated implementation
- Provide emergency funding in settings where remedial actions are needed
- Make provision for adaptations and assistive technology

RECOMMENDATION 28 (10.4)

National Evaluation Framework

A comprehensive evaluation framework for the transitioning project should be agreed at national level to ensure a standardised approach to evaluation across all Accelerated Learning Projects and other settings involved in transitioning to the community, and an agreed minimum data set. The evaluation framework should be agreed prior to start of any project. It should be informed by similar work conducted internationally. In order to ensure the integrity of the evaluation in each site, an independent agent should undertake this evaluation across all participating sites.

RECOMMENDATION 29 (10.5)

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Resources should be made available as part of the change management planning to support people with disabilities, families, and staff to transfer to the community and to develop community readiness.

RECOMMENDATION 30 (10.6)

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RECOMMENDATION 31 (10.7)

Review of residential settings outside remit of the Working Group

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A number of people with disabilities are still living in mental health settings, and their accommodation and support needs fall within the remit of *Vision for Change* proposals. The Working Group recommends that this group should be given top priority in the *Vision for Change* implementation process and be moved to appropriate community settings in line with the recommendations in this Report.

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APPENDIX 1

CONGREGATED SETTINGS INVOLVED IN THE WORKING GROUP PROJECT

Name of Centre	County
1. St. Dympna's Sacred Heart Hostel	Carlow
2. St. Dympna's, St. Anns Ward	Carlow
3. St. Patrick's Cheshire	Carlow
4. COPE Foundation, Montenotte,	Cork
5. Grove House, Intellectual Disability Service, Gurrabraher	Cork
6. Lota Services, Glanmire,	Cork
7. St. Laurence Cheshire Home	Cork
8. St. Patrick's Upton Service	Cork
9. St. Raphaels, Youghal,	Cork
10. Donegal Cheshire Apartments	Donegal
11. James Connolly Memorial Hospital Carndonagh	Donegal
12. Inbhear Na Mara Residential Unit, Bundoran	Donegal
13. Sean O'Hare Unit, Stranorlar	Donegal
14. Barrett Cheshire House	Dublin
15. Cara Cheshire	Dublin
16. Cheeverstown House	Dublin
17. Good Counsel Centre, Ballyboden	Dublin
18. Hawthorns, Stilorgan	Dublin
19. Pea mount, Newcastle,	Dublin
20. Richmond Cheshire House	Dublin
21. Sisters of Charity, St. Margaret's Centre, Donnybrook,	Dublin
22. St. Michael's House The Glens, Ballymun	Dublin
23. St. John of God Islandbridge	Dublin
24. St. Josephs Centre, Clonsilla	Dublin
25. St. Joseph's Intellectual Disability Services, St. Ita's Hospital	Dublin
26. St. Louise's Centre, Glenmaroon	Dublin
27. St. Michael's House Baldoyle	Dublin
28. St. Paul's Hospital, Beaumont,	Dublin
29. St. Rosalie's, Partmarnock	Dublin
30. St. Teresa's Centre, Temple Hill	Dublin
31. St. Vincent's Centre, Navan Road	Dublin

32. Stewart's Hospital, Palmerstown	Dublin
33. The Children's Sunshine Home	Dublin
34. Galway Cheshire House	Galway
35. John Paul Centre	Galway
36. Kilcornan Centre, Clarenbridge	Galway
37. Oak Grove, c/o St. Brigids, Ballinasloe	Galway
38. Renmore House	Galway
39. The New Building, Ballinasloe	Galway
40. Glebe Lodge, Castleisland	Kerry
41. Kerry Cheshire	Kerry
42. St Mary of the Angels, Beaufort,	Kerry
43 Aisling House, Maynooth,	Kildare
44 Moore Abbey, Monasterevin	Kildare
45. St. Raphael's, Celbridge	Kildare
46. Caomhnu Kilkenny, Kilreene	Kilkenny
47. St. Patrick's Centre	Kilkenny
48. Alvernia House and Community Service	Laois
49. Brothers of Charity Services Bawnmore	Limerick
50. Rathfredagh Cheshire home	Limerick
51. St. Vincent's Centre, Lisnagry	Limerick
52. St. Mary's Drumcar	Louth
53. Aras Attracta, Swinford	Mayo
54. O'Dwyer Cheshire Home	Mayo
55. Clogher House Residential Centre	Monaghan
56. Abbeyview Residences	Sligo
57. Cloonamahon Centre, Collooney	Sligo
58. Cregg House, Rosses Point	Sligo
59. Damien House Intellectual Disability Services, Clonmel,	Tipperary
60. Cairdeas, Ferrybank	Waterford
61. Carriglea Cairde Services, Dungarven	Waterford
62. Waterford Cheshire Centre	Waterford
63. Lough Sheever Centre	Westmeath
64. St Mary's Delvin	Westmeath
65. St Peter's Centre	Westmeath
66. St John of God House, Enniscorthy,	Wexford
67. St. Senan's Hospital (Wexford Mental Health Service)	Wexford
68. Ardeen Cheshire Home	Wicklow
69. Carmona Services	Wicklow
70. Sunbeam Dunavon	Wicklow
71. Sunbeam Hall Lodge, Arklow	Wicklow
72. Sunbeam Valleyview Bungalows	Wicklow

APPENDIX 2

Survey of Congregated Settings 2008

(adapted from Living Environment Schedule)

Centre Questionnaire

For response by the Centre Management

Name of respondent:
Position of respondent:
Name of interviewer:
Date of interview:

1.	Name of Provider Organisation:
2.	Name of Centre:
3.	Address of Centre:
4.	County:
5.a	How many residential units does the Provider Organisation manage <i>on campus/residential centre?</i>
5.b	How many, if any, residential units does the Provider Organisation manage for 10 or more persons <i>off campus/residential centre?</i>

Interviewers should ensure a Unit Questionnaire is collected for:

- (1) all residential units on campus or*
- (2) any off-campus residential unit with ten or more residents*

6. Type of Centre (please tick applicable option(s) below)	
<i>ID residential centre</i>	
<i>ID & mental health residential centre</i>	
<i>Physical disability residential centre</i>	
<i>Sensory disability residential centre</i>	
<i>Physical & sensory residential centre</i>	
<i>Other (please specify)</i>	

NOTE THE ABOVE ARE NOT MUTUALLY EXCLUSIVE RESPONSES

7. Size of Centre	Number of Residents
<i>Number of long-term residential places</i>	
<i>Number of long-term places currently in use</i>	

8. Gender of long-term residents attending centre	Number of Residents
<i>Number of women</i>	
<i>Number of men</i>	

9. Length of time residents in centre have received residential services from Provider Organisation (include current & previous)	Number of Residents
<i>less than one year</i>	
<i>one to five years</i>	
<i>five to ten years</i>	
<i>ten to fifteen years</i>	
<i>over fifteen years</i>	

10.a Total number of residents in residential centre whose primary disability is Intellectual Disability	

If there are no residents whose primary disability is intellectual move to Question 11a

For Question 10b we appreciate that some individuals could be categorised in more than one section however we are asking you to make a judgment call and choose a category which you feel is most relevant from the perspective of providing them with staff support.

10.b Number of residents whose primary disability is intellectual by age & type of additional conditions						
Age	Intellectual Disability (no additional conditions)	Intellectual Disability & mental health difficulties	Intellectual Disability & physical/sensory disability	Intellectual Disability & medically fragile	Intellectual Disability & Challenging Behaviour	Intellectual Disability & Autism Spectrum Disorder
Under 19						
20-29						
30-39						
40-49						
50-59						
60-69						
70-79						
80-89						
90+ years						

10.c Numbers of residents with Intellectual Disability by age & level of ability					
Age	Mild	Moderate	Severe	Profound	Unknown
Under 19 years					
20-29 years					
30-39 years					
40-49 years					
50-59 years					
60-69 years					
70-79 years					
80-89 years					
90+ years					

11.a Total number of residents in residential centre whose primary disability is Physical & Sensory	297
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For Question 11b we appreciate that some individuals could be categorised in more than one section however we are asking you to make a judgment call and choose a category which you feel is most relevant from the perspective of providing them with staff support.

11.b Number of residents with Physical & Sensory disability by age & disability type					
Age	Physical & Sensory disability (no additional conditions)	Physical & Sensory disability & mental health difficulties	Physical & Sensory disability & intellectual disabilities	Physical & Sensory disability & neurological conditions	Physical & Sensory disability & addiction problems
Under 19 years					
20-29 years					
30-39 years					
40-49 years					
50-59 years					
60-69 years					
70-79 years					
80-89 years					
90+ years					

12. Number of residents who were referred from	Number of WTE staff
<i>mental health facility</i>	
<i>parental home</i>	
<i>community group home</i>	
<i>residential school</i>	
<i>child care facility</i>	
<i>don't know</i>	
<i>other (please specify)</i>	

13. Staff for residential centre/campus (whole time equivalent)	Number of WTE staff
<i>care staff</i>	
<i>social care worker</i>	
<i>qualified nursing staff</i>	
<i>medical staff (doctors, psychiatrists etc.)</i>	
<i>therapy staff (e.g. O.T., physiotherapist, psychologist)</i>	
<i>housekeeping and catering</i>	
<i>management and administration</i>	

Question 14 seeks information on the actual cost associated with this residential centre. To complete this question you will require pay and non pay costs for the years 2005 and 2006. In addition, you will be asked to separate out these costs according to whether they are funded from HSE, Private or Other sources.

14(a) What was the actual cost for all pay & non pay associated with this residential centre during	Pay Costs		
	Cost funded by HSE	Cost funded privately	Cost funded by 'other'
2005			
2006			

If you have categorised some costs as 'other' please specify the source of these costs:

14 (b) What was the actual cost for all pay & non pay associated with this residential centre during	Non-Pay Costs		
	Cost funded by HSE	Cost funded privately	Cost funded by 'other'
2005			
2006			

If you have categorised some costs as 'other' please specify the source of these costs:

15. As you are aware, additional funding was made available to Provider Organisations through the Multi Annual Investment Plan. Please specify how much of these funds you have received <i>specifically for existing residents in this centre</i> in 2005, 2006 and 2007		
	Capitol €	Revenue €
2005		
2006		
2007		

16. Distance between centre and road (please tick one option)	✓
0 – 50 metres (yards)	
50-100 metres (yards)	
100 -500 metres (yards)	
500 meters – 1 kilometre	
More than a kilometre/ ½ mile	

17. Distance between centre and nearest town centre facilities (please tick one option)	✓
<i>0 - ½ mile</i>	
<i>½ - 1 mile</i>	
<i>1 - 3 miles</i>	
<i>3 - 5 miles</i>	
<i>over 5 miles</i>	

18. Over the past ten years has your agency moved service users from this Centre into the community?

Yes

No

If yes, how many residents have moved in the previous ten years?

Can you identify factors that facilitated the move to the community?

Can you identify factors which were barriers to moving to the community?

What lessons have you learned that might be of benefit to others who may be undertaking a similar initiative?

19. If you have any comments on the current quality of service provided in this centre and/or specific actions you would like to see introduced to maintain/improve the quality of service please note these below. Some issues are prompted for your consideration:

Health & Safety

Building infrastructure/quality

Service deficiencies

Resident issues

Staffing issues

APPENDIX 3

DETAILS OF HOUSING COST CALCULATIONS (CHAPTER 9)

Nos. in congregated settings: 4,000

Nos. of housing units required, 2 scenarios:

Scenario 1:

At 4 persons per unit, 1,000 houses

Scenario 2:

800 x 1 bedroom units - 800 persons

800 x 2 bedroom units - 1,600 persons

400 x 4 bedroom units - 1,600 persons

Total - 2,000 housing units for 4,000 persons

(These are purely arbitrary, for costing purposes)

House price data

As it is difficult to get reliable house price data, and to distinguish by size of house, two separate sources were combined

- ESRI/TSB house price index Dec 2008 (last date this data produced) price for 3-bedroom house €267,731. Discounted by 11.1% house price fall Jan 2009- Sept 2009, rounded price €238,000
- 3-bedroom house price converted to 1,2, and 4-bedroom house price using weights derived from daft.ie House Price Report Q3 2009 for six areas - north, west and south Co. Dublin, Cork, Limerick and Galway cities (unweighted totals). These weights were 100 (1-bed), 130 (2-bed) 146 (3-bed) and 217 (4-bed). This yielded house price estimates of €163,000 (1-bed); €212,000 (2-bed); and €354,000 (4-bedroom)

The results are sensitive to volatile house prices and to the particular weights to calibrate the different house size.

Housing rent

The Daft.ie Rental Report, Q3 2009 was used to estimate the rental costs of 1-bed, 2-bed and 4-bed housing. As there are no weightings supplied, unweighted averages

from seven areas (north, west and south Co. Dublin, Cork, Limerick, and Galway cities and Ulster) were used to derive an estimated rent. The result was an estimated average monthly rent of:

1-bed	€670
2-bed	€828
4-bed	€1,160

It was assumed that each tenant would be paying rent under Rent Allowance Scheme according to the Dublin City differential rent scheme, i.e. 15% of remaining income after deducting €32 a week. That works out at €25.80 a week or €112 per month per tenant. It was also assumed that each tenant in a 2 or 4 bedroom house would pay this contribution.

This left the net monthly cost to the Exchequer of providing each type of house on a rental basis per month (ignoring any future rent reviews or changes in tenant income or contribution)

1-bed	€558
2-bed	€604
4-bed	€712

This works out at about €1.2m. per month or about €15m. per annum for the mixed housing scenario. For the uniform 4-person group homes, the annual cost works out at around €9m. per annum.