# SUPPORTING PEOPLE TO LIVE SELF-DIRECTED LIVES IN THE COMMUNITY

## LEARNING FROM 54 IRISH PROJECTS

GENIO In the Business of Smart Social Investment

## Contents

## Introduction

This paper outlines the key learning from 54 projects which have been supporting people with disabilities and mental health difficulties to move, usually from institutional settings, to live self-directed lives of their choosing in their local communities. The focus of this paper is on describing the implementation learning that has taken place; how this happens in practice; and the factors which lead to and support positive outcomes for the individuals.

These 54 projects are in counties throughout Ireland, in urban and rural settings and in a variety of service providers; HSE, Section 38 and Section 39 providers. A breakdown of the beneficiaries of 43[1] projects from 2010 to 2012 shows that all levels of need among beneficiaries is represented; mild (35%), moderate (40%) and severe (24%). A breakdown of this data is in Appendix 1.

The paper draws on a significant body of data collected from these projects during on-site visits (at least three for all the projects) which included meetings with the project leads, key staff and the people being supported as well as family members, advocates and other allies. Quantitative and qualitative data is collected on each site visit and this data informs this paper. In addition, information collected from learning events in which the projects participated, feedback from Genio-provided training, group meetings and one-to-one interviews with project personnel has also been considered. This data is supplemented with data obtained from an independent evaluation of 23 of these projects conducted by Prof Roy McConkey and colleagues[2] from the University of Ulster. The qualitative data from this study is substantial; interviews took place with 197 people supported, 112 relatives, 144 key-workers, and senior managers from 18 of the projects.

This collective experience has demonstrated that it is possible, not just to move people from institutions but, to support people to move in a way that produces better outcomes - a 'better life' - through the development of individualised or personalised supports. The McConkey evaluation concluded that *"personalised housing and support options are feasible to implement in Ireland across people with a variety of disabilities and mental health difficulties and with different levels of support need"* and that personalisation produced better outcomes than congregated settings at a significantly lower cost for many. This reflects the findings of other studies (European Commission 2009):

> *There is strong evidence in support of transition from institutional care to community-based alternatives (deinstitutionalisation). These can provide better results for users, their families and the staff while their costs are*

[1] A further 11 community living projects were supported in 2013. This figure relates to the years 2010 to 2012.

[2] McConkey, R. et al. (2013) *An Evaluation of Personalised Supports to Individuals with Disabilities and Mental Health Difficulties*, University of Ulster and Genio. Available at: http://www.genio.ie/files/Evaluation_Personalised_Supports_UU2013_0.pdf

*comparable to those of institutional care if the comparison is made on the basis of comparable needs of residents and comparable quality of care (p.6).*

The purpose of this paper is to summarise the key learning to date with a practical focus on implementation and practice and to identify the components for success. It does not purport to be a definitive guide on 'how to do deinstitutionalisation' but it does distil insights and pointers as well as identifying pitfalls and things to avoid based on the experience of 54 projects. As well as drawing on the findings of the McConkey study, limited reference is made to one other important source; *Common European Guidelines on the Transition from Institutional to Community Care*[3]. There is a body of evidence from other jurisdictions that could be usefully referenced to provide a context for a more detailed consideration of the components of success and this is planned in a follow-up report. In the interests of making the learning to date available in an accessible way and in a timely manner, this summary paper has been prepared. It is intended that this paper will be revised annually based on continued learning and developments in the current 54 projects and in new sites.

## Context

### Disability

Two key policy documents; *Time to Move on from Congregated Settings* (HSE 2011, known in shorthand as the 'Congregated Settings report') and the Policy Review and Value for Money of Disability service in Ireland (Department of Health 2012, known in shorthand as the 'VFM report') provide an overarching framework for the reform of disability services, which will inform how services are to be developed and delivered in the disability sector in general, over the coming years. Recognising that the implementation of these policies is a significant challenge, the HSE has given this priority in the Social Care Division Plan for 2014 and has formed a series of working groups examining specific issues under the direction of a steering group. Guidance for community transition plans has also been developed to inform and guide organisations that are supporting individuals to move[4].

The Congregated Settings report describes the 4,000 people with disabilities living in congregated settings in Ireland and proposes "*a new model of support in the community… with people living in institutions moving to dispersed forms of housing in ordinary communities, mainly provided by local authorities… [with access to] the supports they need to help them to live independently and to be part of their local community. They will have the same entitlement to mainstream community health*

[3] The European Expert Group on the Transition from Institutional to Community Based Care (2012) *Common European Guidelines on the Transition from Institutional to Community Care.* Available at: http://deinstitutionalisationguide.eu

[4] Health Service Executive (2011) *Time to Move On from Congregated Settings: A Strategy for Inclusion*. HSE Publications. Available at: http://www.hse.ie/eng/services/list/4/disability/congregatedsettings/commtransplans.pdf

*and social services as any other citizen…a core value underpinning this proposal is that people should make their own life choices*" (p. 4).

The VFM report proposes a very significant re-framing of disability services towards a model of individually-determined supports and implementation of a more effective method of assessing need, allocating resources and monitoring resource use. The policy is grounded in the vision:

> *To contribute to the realisation of a society where people with disabilities are supported, as far as possible, to participate to their full potential in economic and social life and have access to a range of quality personal social supports and services to enhance their quality of life and well-being.*

This vision will be supported by the twin goals of:

1. Full inclusion and self-determination through access to the individualised personal social supports and services needed to live a fully included life in the community; and

2. The creation of a cost-effective, responsive and accountable system, which will support the full inclusion and self-determination of people with disabilities.

### Mental health

Most mental health community residences (or hostels) were developed in response to the 1984 mental health policy *Planning for the Future*, which was focused largely on reducing the number of people in psychiatric hospitals in Ireland. Much of this deinstitutionalisation occurred through relocating inpatients to houses in the community which were mostly owned by mental health services and were fully staffed by nurses, care assistants and domestic staff employed by mental health services. The current mental health policy *Vision for Change*[5], recommended that the remaining mental hospitals in the country should close, and that in terms of housing for people with mental health difficulties, that *"Opportunities for independent housing should be provided by appropriate authorities with flexible tenancy agreements being drawn up in accordance with each service user's needs. Arrangements that best enable service users to move from high support to low support and independent accommodation need to be considered."*

The Housing Strategy for People with a Disability 2011-2016[6] (which includes people with mental health difficulties) and the accompanying Implementation Framework[7]

[5]Department of Health and Children (2006) *A Vision for Change. Report of the Expert Group on Mental Health Policy*. Dublin: The Stationery Office. Available at: http://www.dohc.ie/publications/pdf/vision_for_change.pdf?direct=1

[6]Department of Environment, Community and Government (2011*) The Housing Strategy for People with a Disability 2011-2016*. Dublin: The Stationery Office. Available at: http://www.environ.ie/en/DevelopmentHousing/Housing/PublicationsDocuments/

set out to "*facilitate access for people with disabilities, to the appropriate range of housing related support services, delivered in an integrated and sustainable manner, which promotes equality of opportunity, individual choice and independent living".* This is an important supporting strategy for the implementation of several of the recommendations in the disability and mental health policies described above.

### Individualised supports

Individualised supports are described in the VFM report and have been described operationally by Genio as follows:

- planned and delivered on the basis of a consideration of their wider needs and the potential contributions of the person, moving away from a focus on deficits;
- a response to one person rather than group-based;
- chosen by the person (or their family or advocate as appropriate);
- delivered in the community, fostering inclusion, and participation rather than in segregated, stigmatising settings;
- inclusive of family and community supports and mainstream services;
- reliant on paid professionals only when appropriate;
- cost-effective and represent good value for money.

These policies provide a clear commitment to the person with a disability or mental health difficulty as a citizen, with all that entails, as someone who makes their own choices and is supported to do this if necessary, who is not just located in, but actively participating in their community and who is supported to do this through individualised supports that are tailored to them and their abilities, wishes and needs.

These national policy commitments have profound implications for how disability services are delivered henceforth. It will not be sufficient to assign people into small groups and move them to houses that have been chosen for them. A different approach is required. One that is focused on listening to and finding out about the person and providing supports based on what is learned. This is not a 'one size fits all' approach and can be a challenge to implement as it is so different to how services are currently structured and to what has been provided up to now. The situation for mental health is somewhat different, with all the large mental health hospitals now closed, the focus is on some 3,000 people in smaller settings in the community, often referred to as 'mini-institutions'.

With the scale of change involved, and the number of people who we must spend time getting to know, a helpful analogy is of a journey for all involved, most

[7]Department of Environment, Community and Government (2012*) The Housing Strategy for People with a Disability 2011-2016: Implementation Framework*. Dublin: The Stationery Office. Available at: http://www.environ.ie/en/Publications/DevelopmentandHousing/Housing/FileDownLoad,30737,en.pdf

importantly the individuals and their families, but also staff and whole organisations. The road is not a smooth motorway from A to B, but a windy, bumpy lane, with different directions to be chosen and some dead ends. What is important is that it is always moving forward with purpose and with a worthwhile destination in sight - a good life for the person, that they have chosen and that is fulfilling for them. The destination is not the move; it is the life beyond the move.

## Supported self-directed living

Based on the policy documents described above and the learning from over 200 demonstration projects, Genio is developing a framework that can be used in a very practical way to support self-directed living (SSDL). SSDL describes core elements of thinking and practice relating to the arrangement of high quality 'person-centred' or 'individualised' supports that enable people with disabilities, mental health difficulties and dementia to maintain or develop full and meaningful lives in their communities[8].

These elements are set out within an SSDL Framework; a reference guide that provides empirically grounded recommendations for those who want to succeed in helping supported individuals to achieve good lives of their choosing and it covers many of the issues in this paper in more detail. This framework is currently in preparation and, when available, will be used by Genio to assist organisations who are supporting people to move in an individualised way.

## Learning from other jurisdictions

Deinstitutionalisation has been underway in other jurisdictions for many years, from the 1960s in the mental health sector and from about the 1980s in the disability sector. The thinking about deinstitutionalisation and the approaches to be used have developed quite radically since these early efforts. Ireland is well placed to learn from decades of experience and to use the most well-developed thinking and ways of working in order to achieve the best outcomes for the people being supported to move.

One of the strongest messages to come through from other jurisdictions who have undergone this process is that deinstitutionalisation is about much more than simply moving location. A position paper prepared by the International Association for the Scientific Study of Intellectual Disability (Mansell & Beadle-Brown, 2010) noted:

[8] http://www.genio.ie/what-we-mean-by-supported-self-directed-living

> It is important to note that 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. (*p*.109)

Efforts from the past, which focused on simply getting people out of the institution relied on a perhaps naive assumption that those who moved would somehow acquire the skills they needed to participate in their community, even though they may never have had the opportunity to develop those skills. Another key assumption was that staff, who had been trained to work in a particular way and in a particular environment, would easily switch to working in a very different way. While outcomes for some who moved from institutions were good, for others their life did not change substantially as they now lived in what were often termed 'mini-institutions', with the same staff and practices in place. Improvements to the physical environment were very welcome, but the hoped-for outcomes of integration and 'independent living'[9] did not materialise for most. Rather than write this process off as 'a failure', we need to recognise the reasons why these early efforts were not as successful as they could have been and address these reasons to achieve better outcomes.

The learning from other jurisdictions and Ireland has highlighted that the process is more complex that previously assumed and has pointed to the need for three **simultaneous** streams of activity;

1. identifying accommodation;

2. supporting the person not just to move but to fully integrate with and participate in their community; and

3. changing the way in which the organisation operates in order to move from supporting groups of people in a small number of buildings to supporting people living in their own homes.

The learning described in this paper is based on this overall approach to deinstitutionalisation i.e. these three activities happening simultaneously. This is a very challenging undertaking and is much more complex than simply identifying new accommodation for a number of people. It is, however, happening, albeit on a small scale to date, in many settings in Ireland.

[9] This does not mean 'living on your own', rather it refers to self-directed living with appropriate supports

## Components for success

From our work over the past four years in supporting 54 organisations in this process, the following characteristics have been identified which have been most strongly associated with good outcomes for the person and the organisation:

- **Multi-level leadership**
- **The person leads the process**
- **Involving families and allies**
- **Engaging and consulting with stakeholders**
- **Staff skills and training**
- **Readiness**
- **It's about more than housing**
- **Building strong and lasting relationships through linking with the community**
- **Start small and 'model' change**
- **Challenge of reconfiguration**
- **This takes time**
- **Focus on outcomes and monitor progress**

Each of these features are described in more detail below. These match very closely to the *Ten lessons on how to achieve community living* described in the *Common European Guidelines on the Transition from Institutional to Community Care*[10].

[10]European Expert Group on the Transition from Institutional to Community-based Care (2012*) Common European Guidelines on the Transition from Institutional to Community-based Care.* Available at: http://deinstitutionalisationguide.eu/

### Multi-level leadership

Leadership is consistently identified in the literature as a critical factor in any change process. However, this emphasis on leadership needs to be more deeply understood in terms of implementing change. While the presence of a charismatic and committed leader is very helpful, our learning indicates that multi-level leadership is at least as important. Multi-level leadership means there is 'a champion' at all levels of the organisation and in other key groups, who supports and drives the move to a new way of supporting those using the service. Multi-level leadership involves identifying, mentoring and supporting leaders and champions at all levels:

- CEO/senior management
- Board/regional and national managers
- Service managers (including finance, HR etc. as well as direct service managers)
- Front-line staff/key workers
- People supported
- Family members/carersOther staff groups

Ideally, this means buy-in among a majority of those at different levels in the organisation but, importantly, effective change can happen with a small number of committed individuals in place. Additional leadership supports in the form of project management and advisory groups can also be helpful. A model of multi-level leadership reinforces the fact that at every level in the organisation, people need to take responsibility for the activities within their remit and to model and support the change in their everyday work. In effect, it also implies a model of shared leadership across these multiple levels, including with people using services and families, which is also a powerful tool for change.

In practice this means that leaders need to be identified, mentored and supported throughout the organisation and among those using services and families. Skills and issues relevant to leadership from these stakeholders are described:

**At CEO/senior manager level:**

The main requirement is a strong and clearly communicated commitment to support people in the service to move, not just 'out of the institution' but, for the whole organisation to move to a system of individualised accommodation and support for each person. In order to do this successfully, the leaders need a good understanding of what 'individualised supports' really means. It is essential that this message and the plans to implement it are communicated continuously throughout the organisation and to the people using services and their families (see section on 'engaging and consulting with stakeholders' below for more detail). It can be useful in making the policy 'real' for staff and other stakeholders to identify a specific and compelling reason for supporting people to move. (One example of how this can happen is for a person to be identified whose needs are not being met with current

support arrangements or is a person who has continuously expressed the desire to live somewhere else. Developing individualised accommodation and support arrangements for this person or small group can be a helpful starting point).

A key requirement from CEOs/senior managers is the willingness to 'stick with it' through the inevitable challenges and to continually seek solutions and work through challenges and barriers as they arise. Linking with other organisations who might be further ahead can be very helpful as it can provide, not just peer support but also, practical solutions to similar issues that may have been successfully resolved elsewhere.

**At the organisational level:**

It is difficult for CEOs and senior HSE service managers to really drive change of this complexity without the commitment of the board of the organisation (for voluntary organisations), the regional and national managers for HSE organisations, and Executive Clinical Directors (ECDs) for mental health services. The publication of clear policy, endorsed at national level (described above) is very helpful as it describes in broad terms the type of services that are required into the future. However, moving from broad policy descriptions to changes in a specific organisation is a challenge and the board and senior managers need to commit to the change and to the challenging culture change and shift in mindsets that is required. Learning from others who are further ahead in the change can be a very practical way of providing reassurance and practical assistance. The Immersion event organised by the National Federation of Voluntary Bodies with Genio support and similar events organised by Genio and others have helped to inform all the stakeholders of the possibilities and to create a more conducive climate for change.

**At service manager level:**

An understanding of individualised accommodation and supports is required and the implications of this for how current service arrangements may need to change. Ability to support staff through a period of change and uncertainty is important. A strong message that came through from managers of staff who had been trained in new methods for supporting people is that staff can't then switch back and forth between the 'old' and the 'new' model and that this doesn't make the best use of their newly acquired skills. This may have implications for how staff are assigned within the organisation.

**At key worker level:**

A range of personal skills and competencies have been found to be particularly helpful; greater flexibility, confidence to try new things, creativity in finding solutions for problems that may present, willingness to find out about the people they support in a different way i.e. their abilities and strengths rather than an exclusive focus on

deficits. Some of the strongest leaders within organisations have emerged among key worker/community connector roles. However, they require the necessary support within the organisation to fully realise the full potential of their work. To support learning, key workers/support staff should be encouraged to participate in exchanges with other providers who have already embarked successfully on this journey within Ireland for guidance and peer support.

**People supported:**

Individuals who have been the first to move and/or are developing as 'natural leaders' and are willing to take on this role should be supported to gain specific skills so that they can act as a leader/champion for their peers. This could be through the provision of specific training, mentoring and additional support. There may already be individuals in the organisation who have received advocacy or similar training and who have experienced the new form of accommodation and support who would be willing to take on this role. It must be recognised that specific support should be provided for the person if they agree to take on this role. The value of the person as an informal leader through peer modelling should also be recognised and may not involve a 'leadership role' as such.

**Family members/carers:**

As with the people being supported, family members have often emerged as leaders through their experience of advocating on behalf of their family member and their experience of individualised support and accommodation for their family member. Family members can have a big impact when speaking with other family members who may be about to embark on this journey. Support should also be provided if families take this role on via training and information sharing.

**Leadership supports:**

Project management:

An identified person with project management skills has been found to be a key factor in supporting this change process. The role of this person is to keep the project on track, to oversee all the different inter-related parts and activities and to keep moving the process forward. This does not necessarily need to be a new post. It can be an existing staff member who already has project management skills or is given training in such skills. It can be a full or part-time post depending on the scale of the change but protected time is required to make this successful.

Advisory/steering groups:

Working with a well-chosen advisory or steering group has been found to be helpful for several projects which were successful in supporting people to move and to be more integrated into their community. It is important that bringing together a group such as this is done thoughtfully and that clear Terms of Reference are developed so

that the role and function of the group is clear. A supportive advisory group can help maintain momentum, can communicate the messages and progress more widely, and can bring their expertise and experience to bear on providing solutions to barriers and challenges that may be encountered. For example, developing partnerships with local county councils and businesses has also proved successful when supporting people on their journey to live a better life in a community of their choosing. However, there is also the potential for such a group to act in a way that slows progress, diverts activity in a non-productive or undesirable direction, and is generally unhelpful in implementing the task in hand, hence the need for care and thought before this is undertaken.

### The person leads the process

National policy speaks about "individually chosen supports", with the person being involved directly in making decisions about their lives and in the design of the supports and services they receive to help them achieve their goals. One of the ten lessons identified by the EU guidelines is to "*make the needs and preferences of people central to planning"*. Our experience across many projects and across different sectors is that this focus on exploring with the person what kind of life they want and then marshalling resources (within and outside the service) and putting the necessary supports in place has generally been effective in achieving good outcomes and is often cost-effective once it is established. While the description is very straightforward, this can take a considerable amount of time and dedicated effort to achieve.

Supporting self-determination and self-direction is a key task and means that practical measures need to intentionally be put in place so that the person can be self-directing and so that their autonomy is supported. For some individuals this means that the person is supported in making decisions and having their voice heard. Supported decision-making or co-production arrangements may need to be put in place. The involvement of family, circles of support and independent advocates should be considered if the person is unable to communicate their decisions, will and preferences. These arrangements will differ depending on the nature of the disability and may not apply to people with mental health difficulties.

Implementing 'the person leading the process' means that the person's wishes may conflict with the wishes of the family and/or they may conflict with what staff believe the person needs. It is important that the person's wishes and dreams are listened to and supported by an independent advocate if necessary. The family should be kept up-to-date of the person's wishes and plans, however the person receiving supports should remain the primary focus at all times. It is often beneficial for families struggling with this change to link with families who have already been on this journey for peer support. It is also very important to communicate with families on a regular basis and to be very open and honest. Families should be supported to

attend information sessions and training as this will assist families in understanding the benefits of supported self-directed living for their relative.

While needs assessment and planning tools can be helpful, they can impose a view of the person that is addressed in terms of deficits and can channel support in unfruitful directions. They usually assess the person in a setting where they may have been deskilled over many years or may not have had the opportunity to develop particular skills and interests. This does not mean that the person does not have the capacity to develop new skills and may not give an accurate picture of the supports the person needs. Our experience has shown that taking time to really listen to the person without recourse to assessments and tools can reveal hitherto unrecognised abilities and interests of the person.

The *Distinctive Identity Portrait Journal* has been developed by Genio to provide a new way of finding out about the person and a method for recording what is found out and it serves two purposes. First, it is intended to guide a creative and thorough process of 'discovery', finding out and exploring more about a person who may be otherwise relatively unknown. The journal provides structure to both the particular areas in need of exploration and the specific information that might be useful to the decision-making process around supports that may be needed. Second, the journal strives to provide an informal, creative way to document the learning gleaned through the process of discovery. It records information in order to capture the distinct details uncovered in the discovery process, through use of pictures, photographs and other materials. The *Distinctive Identity Portrait Journal* is not a planning tool or an assessment tool. It is simply a structure for the early work of getting to know a person in a new and different way. It is not, in and of itself, a solution or an end goal. Its usefulness is in the relationship among those using the journal, the creative process it encourages, the intentional and focused work of implementation, and the meaningful outcomes that can come out of the knowledge gleaned. Therefore, the hoped-for result is not a beautiful and exhaustive written report. Rather, the hoped-for result is a good life for the person willing to invest in the process.

**What to avoid:**

- Not providing appropriate support for the person so that their wishes can be established, which can lead to making assumptions about what the person wants or what the 'best interests' of the person might be;
- Having an over-reliance on standardised needs assessment or planning tools at the expense of finding out about the person's abilities and contributions; and
- Not allowing enough time for this part of the process.

## Involving families and allies

Families often have a central role in supporting their family member. As with all other aspects of planning, the contact with families should occur on a person-by person basis, shaped by the needs of the person and their current relationship with their family. Involving families needs to be done in a way that is timely, that acknowledges their concerns, that provides them with meaningful opportunities to be involved in developing a plan for their family member, that considers how they want to be involved in supporting their family member and that considers the wishes of the person.

**Timely:**

Contact with family should occur as early as possible in the planning process for their family member (i.e. not when a plan has been completed to move their family member).

**Addressing concerns:**

Experience from several projects has shown that time can be needed to build trust between the family and those providing services and that this time, with repeated meetings if necessary, should be facilitated. The service should actively seek out relatives' concerns and explicitly explain how they will be addressed. Investing this time and honestly addressing concerns, and acknowledging that 'we may not have all the answers' is crucial for building trust and for having their active support in a success of the move and in some cases, re-integrating the person back into the family circle. Opportunities to meet with relatives whose family member has already moved and to visit people in the new arrangements could offer much needed reassurance to those relatives whose concern primarily is the well-being of the person they love.

**Involvement in planning:**

Practical issues should be addressed, such as having planning meetings at times that suit the family member(s).

**Their role in supporting their family member:**

The family has a natural authority in caring for their family member. This may have been eroded if the person was moved to another setting when young but can be reinstated with support. Establish what the family is willing to do and what they are able to do. Remember to include the wider family (not just parents and siblings but extended family).

**The wishes of the person:**

As described in the section above, the person leads the process and their wishes should have pre-eminence while respectfully taking account of families' views. Mechanisms for resolving conflicting views should be available if this arises.

However, it is not always the case that the family is very involved with their family member. If a person has been living in a setting other than their home for some time, the family may have disengaged and may need to be supported to re-engage with their family member. It may also be the case that there are no surviving members of the family or that the family do not want to re-engage at this point. In these cases, circles of support or an independent advocate can be particularly helpful in engaging with others outside of services, who can support the person in moving to and linking with their community.

### Engaging and consulting with stakeholders

The necessity to engage and consult with stakeholders is essential in any change process of this magnitude. What is really important, however, is clarity around the purpose of the consultation and **how** this process is undertaken as it has the potential to either enable a genuine engagement that greatly facilitates a move, or to delay and complicate the process of supporting a person to move. Engagement should be future-focused on how different stakeholders are going to contribute to the new supports being developed.

As has already been described, engagement that is timely, respectful and that puts the person[11] in the lead role in making decisions and designing the supports they need is the most likely to lead to an effective move. The involvement of others such as families and staff is necessary, but the process around this i.e. the order, timing and phasing of engagement and consultation is important. The person should always be first in this process, followed by family and other allies. Staff who work with the person and others such as a circle of support should also be included as appropriate.

The purpose of engagement and consultation should be clear. If the purpose is to support the process of moving people to the community so they can be active participants, then the consultation should focus on gathering helpful views and support, not seek permission from any group regarding decisions to be made about a person's life and how their move takes place. For this reason, large-scale public meetings with stakeholders are often not helpful and it is not appropriate for unrelated others to influence the decisions to be made about specific individuals. If families are to be informed, the experience is that this is best done on a one-to-one basis and not in large groups. Consultation with the general community is not

[11] With an advocate, family member or other supporter if necessary

appropriate or helpful. Whatever decisions are made about consultation, meetings at the individual and family level must take place before wide-scale meetings.

### Staff skills and training

Three key issues have emerged around staff skills and training and these are echoed in the learning from other jurisdictions.

Firstly, the staff who currently work in residential settings have been trained to care for people and assist them in all the activities of daily living, not just personal care but taking part in activities etc. As a result individuals are very well cared for, but this approach can sometimes 'get in the way' of the person developing their own autonomy, taking part in mainstream activities, forming natural friendships and having a life similar to those of their peers. Staff need to be supported to gain new skills to develop a different understanding of supporting the person, rather than 'caring for' the person. Care and empathy are still needed, but they are channelled towards supporting the person to develop their own life. Training programmes which address this new understanding, as well as developing specific skills are necessary. In the McConkey study the views of staff were captured. They spoke of the need to be flexible, inventive and creative which was often in contrast to how they were expected to work in congregated settings:

> *My way of working has totally changed. In the residential settings you had all these rules and regulations. Now you have the freedom to make things happen.*

Secondly, opportunities should be taken as they arise to recruit staff with different perspectives and different skill sets into the service. The focus should be on identifying the specific skills and competencies that staff need to support people with disabilities to live a full life in their community on a one-to-one basis. Organisations that have begun to work in this way have realised that their recruitment processes need to change. For example, some organisations have included the person to be supported on an interview panel when their support workers were being recruited, and others have actively involved the person in drawing up the job description for their support workers. Greater flexibility may be required by staff and this presents a challenge for rostering and continuity of support. However, it has also been found to offer opportunities for staff who may be seeking flexibility in their working hours.

Finally, careful matching of support worker(s) with the person to be supported is a factor which has been strongly associated with successful moves. Shared interests and 'peer matching' can be very important. For example, matching a young man with a young male support worker can be key to accessing activities and interests for that person.

## Readiness

Traditionally there was a strong emphasis on 'getting the person ready for…' major changes such as moving home or getting a job. This often involved years of training and skills acquisition that didn't always lead to the desired outcomes. We also need to be aware that readiness is often defined by those involved in the care of the person but the person themselves is rarely involved in defining their readiness. This emphasis on 'readiness' is increasingly being challenged in the areas of employment and housing. For example, there is now a strong evidence base for a method called Individual Placement and Support[12] (IPS) in employment which focuses on getting the job or placement and then supporting the person in that job. Similarly in housing, the concept of readiness is being replaced by an emphasis on getting the housing and then providing the required support. Based on this work, the starting point should be that everyone is ready to move, with the emphasis on what supports need to be put in place to ensure this happens safely and in a way that is designed by the person. In practice there is a need to take into account a range of factors about the individual themselves and their wider circumstances, while putting the emphasis on moving the person (after the discovery work and informed planning has been done) and then putting the necessary supports in place so that they can learn new skills in situ, in the environment in which they will be practising them for the foreseeable future. This can mean frontloading support at the time of the move but the experience has been that this need often tapers off once the person settles in. In approaching safeguarding, rather than trying to imagine and allow for all the things that might go wrong, some services found it helpful to undertake to respond immediately to whatever issues might arise and to put plans in place for this type of response.

## It's about more than housing

Although it can become the predominant focus of 'the move', identifying housing or accommodation is only one of the three key tasks to be undertaken simultaneously. In order to realise the policy recommendations described in earlier in this paper, the person should make the decision on where they live and who they live with. They may need support to do this and this process may be impacted by real-world considerations such as the current shortage of housing but the 'test' of how other people who require housing are supported should apply and compromises may be required. In order to make the best decision about which accommodation might be the most appropriate, sourcing accommodation should not be the first task to be undertaken. Time should be built in for a process of really getting to know the person so that informed decisions can be made about accommodation options.

[12] Sainsbury Centre for Mental Health (2007) *Doing What Works: Individual Placement and Support in Employment, Briefing Paper 37.* Available at: http://www.centreformentalhealth.org.uk/pdfs/briefing37_doing_what_works.pdf

Learning from elsewhere also emphasises the need to understand why previous efforts at moving, or relocation didn't work. When placements failed, the reason given was often based on the assumption that 'this person can't live in the community'. However, if the reasons for a previous move not working are really examined they often reveal practical issues around the accommodation or other issues such as isolation and loneliness. This is the reason why the linking the person with their community is so centrally important and why at least as much effort needs to be expended on this as in 'finding a house'.

Once the person has identified the community in which they would like to live and community connecting has commenced, engage with local housing agencies, local county council and estate agents to identify a number of properties for the person to choose from. Linking with community based organisations with the appropriate skills and expertise will allow time for the support worker/community connector to continue to support the person in connecting with the community, developing relationships and coaching them in life skills to live independently.

### Building strong and lasting relationships through linking with the community

The process of supporting the person to move does not just involve sourcing accommodation, but also building links with the community in a very intentional and purposeful way for each person based on their abilities, contributions, wishes and needs. The building of links and relationships cannot be left to chance and time needs to be set aside for this element of the work.

Gaining a deep understanding of the person through a discovery process or using other person-centred planning tools in an in-depth way, leads to a need to engage more directly with the local community in order to address the needs and wishes identified by the person in the most effective way. This is one of the most crucial 'mind-shifts' that needs to take place in the process of supporting people to move to the community. If the needs and wishes of the person are always construed in a way that can be met only by people working within the service, there will never be enough staff or resources to meet the needs and wishes of each person individually. Even more importantly, using staff to do this creates a barrier for the person in achieving real integration and more natural participation in their community. If we think of how we make friends, it is usually through mutual interests i.e. meeting others who are interested in football, fishing, singing, going to mass or having a few pints. For many people with disabilities or mental health difficulties it is neither appropriate or necessary for paid staff to accompany a person on these activities. However, support staff do have a crucial role in identifying the 'who' and the 'what', in building the links, supporting both the person and those they are linking with, in creating conditions under which a new friendship can take root and grow and in ensuring appropriate and enabling safeguards are in place.

For example, when a supported person expresses a wish to gain a new skill (such as computer skills) or try something they have an interest in, the response of the support worker needs to be focused on “who is there in the local community who can help with this?”; “whose area of ‘expertise’ this is?”; “who might know people who can help?”; or “what group or organisation or service is there in the community that already does this?”. This way of working requires an investment of time and effort that needs to be taken into account when planning a move for a person. Experience from several projects has shown that a direct approach with a specific and time-limited request to a person in the community who may be in a position to help can be very fruitful. This intensive level of support usually begins to ‘taper off’ for many people as a more natural arrangement takes over. This initial support can be seen as an investment in a sustainable and appropriate support that can last for many years and offers opportunities for the person to meet other people in a more natural way.

**Practical things that help:**

Mapping of local community organisations, groups, services and resources that offer opportunities for recreation/leisure, sport, arts and culture etc. can be helpful. This is an exercise that may already have been done by a local community development group and a resource (e.g. website or leaflet) may already exist.

Recruiting staff with creativity in identifying different groups, who have many connections in their local community and who have strong social skills in approaching individuals, making friends, etc. may also be helpful.

A useful guiding principle in this process is “what is life like for this person’s peers?” or “how does everyone else make friends?” while all the time taking the lead from what the person wants for their life.

### Start small and ‘model’ change

One of the strongest learnings from our work to date has been the value of ‘starting small’. The challenge of acting on all three essential processes as described above is daunting. A very helpful way of addressing this is to begin the process with a very small number of people, about 1-5. This approach has many benefits. Firstly, there is a real live demonstration for the people being supported, the staff and the entire organisation that they can see in action and learn from. Those involved act as ‘peer models’ for the process and the change involved. For those who will be moving, seeing their peer (and friend often) preparing to move and then successfully move, gives them encouragement that this is possible. We often hear people say “If she can do it I can do it too”. Seeing this in action can also give families a sense of what is involved and how their family member can be supported to do the same. It is also helpful for staff to see the process in action and to hear from their peers what they tried, what did not work, and what the benefits and downsides are for staff. The McConkey report describes the experiences of staff who were directly involved in supporting people to move.

Rather than working out the number of people in the setting to move over the number of months/years available, start small and build incrementally as confidence and expertise builds. Finally, starting small is a helpful and manageable way to shed light on the organisational changes that may be required to support larger numbers of people, not just to move but, to be supported in their new homes. Many organisations have described the boost to morale and motivation in seeing a person make the move and really settle in well to their new home, trying new experiences and developing friendships in their community.

**Who should move first?:**

Our experience is that organisations rarely have to choose who will move first. There is often at least one person who is 'up for it' and has been requesting a move or a change in their living arrangements for some time.

In order to support the autonomy and self-direction of those who are being supported, ideally the organisation should not choose who should move. If no-one is self-identifying, the process of engagement and discovery described above should commence with a small number of people so that they can begin to make choices around moving. In the same vein, it is best to go first with those who really want to move and not to make choices based on the perceived support needs of the person, i.e. choosing the 'easy cases'.

**Planning while moving:**

Because this approach of starting with one or two people has been so successful in many organisations, we recommend that commencing the process within an organisation should not wait until a detailed plan to move everyone is completely finalised. It is very helpful to develop this plan **in tandem** with a small number of people moving as the learning and modelling from this process can inform the plan; and the organisation is also more ready to commence on the larger plan with the confidence and peer modelling from the initial movers.

### Challenge of reconfiguration

Supporting people as individuals to have lives of their own choosing, in different types of accommodation, is very different to the service currently provided by many disability and mental health services, which is based on supporting groups of people in designated accommodation. This means that these services need to be restructured and reconfigured to provide this different type of support. As one senior manager in the McConkey report described it:

> *In our experience, it (personalisation) is not something you can do for one person or a group of people in the midst of a bigger group, it has to be an ethos for everyone. People come away from conferences and say "that's all great but how can we do it without changing anything" – you have to change. This is all about change.*

In order to provide the supports for those who have moved, existing resources must be reconfigured so that the supports can move with the person. This may involve the closure of a small facility to free up staff or other ways of freeing up the necessary support staff. At the planning stage, this should be worked out so that the move can be sustained for the individuals.

### This takes time

To be done really well for each person, this process takes time. One of the challenges of planning and implementing a complex change process such as this is assigning timelines and targets so that there is tangible progress while ensuring there is respectful engagement with each person and that progress occurs for each person at their own pace. One way of resolving this tension is to consider the process at two levels; the individual and the organisation. This enables planning, target-setting and monitoring of progress to be clear and based on the different requirements of the individual and the organisation. Having this clarity also helps to address delays that may occur. For example, a delay may be due to a bureaucratic reason or an external factor, but may be attributed to the person i.e. ‘they are not ready to move’.

**For the organisation:**

Planning needs to build in flexibility and contingencies to allow for delays and to respond in ways that keep the process moving forward as much as possible. Once the work of moving a large number of people is underway (i.e. after the ‘starting small’ phase), working with a number of people at different pace allows for tasks to be staggered and for progress to be made overall, while moving at the pace of each person and not holding everyone to the pace of the slowest. Planning in blocks of activity may not be helpful (e.g. all individual planning to be complete by month N). Some may be finished earlier and some later and those who are ready should be moving on.

A balance is needed between positive and supportive pressure to keep things moving while being respectful of the person and their family and not being unrealistic. At the same time there is a need to guard against complacency and provide sufficient support to staff to ensure that delays are not due to a culture that is slow to change.

Allow staff appropriate time on a daily basis to spend getting to know the person and to discover what the person wants out of life. Once the discovery has been explored it is vitally important that staff are provided with the appropriate time and supports from other departments (HR, Finance etc.) to start the planning process along with the person.

**For the individual:**

It is essential to move at the pace of the person. This pace may be slower than expected and, in this case, it is important to keep a sense of progress and forward momentum even though the steps may be very small. It may be appropriate to examine why the pace is very slow i.e. are there unarticulated concerns or other issues to address? The pace can also be faster than expected and this can present a real challenge. There may be concerns that 'the person isn't ready' (see the section on 'readiness' above) or the service itself may not have the support arrangements in place. It should also be acknowledged openly with everyone at the outset (person, family, staff and management) that the process may move back a few steps, may stall for different reasons, or the person may change their mind and not want to move. This needs to be explored with the person to establish possible anxieties and the extent to which they are founded. However, also acknowledge that it is okay to leave a person for a while and move on to support the next person who is ready. Keep working at a less intensive level with the person who has changed their mind so that they can re-join the process at any time. Where the expected pace is different than that planned, service providers should really focus on those delays that relate to the organisation and move to resolve these delays immediately.

### Focus on outcomes and monitor progress

Providing feedback on progress and maintaining continuous forward momentum is greatly assisted by monitoring progress towards agreed outcomes. The first step in this is defining and agreeing on the outcomes to be measured. As outcomes in this process tend to be longer term (e.g. number of people settled into their new homes), it can be helpful to define the steps along the way and indicators for those so that progress can be described and captured in the same way. The table below provides an example of indicators that could be used to measure progress towards a long-term outcome. The indicators are, in themselves, important to capture as outputs and activities that are working towards this goal.

**Table 1. Example of indicators that could be used to monitor progress towards an outcome.**

| Outcome | Indicators of progress towards this outcome |
|---|---|
| **N persons settled in a home of their choosing, living with people they have chosen to live with (if relevant)** | N people who have begun discussing their move |
| | N people who are involved in discovery process |
| | N families who have been involved in discussions |
| | N people who are actively planning their move |
| | N people who have been supported to try new 'mainstream' activities |
| | N people who have been supported to view possible housing options |
| | N people who have a signed tenancy agreement |
| | N people who have met their neighbours |
| | N people who have moved. For people who have moved, average length of time in new home. |
| | N people who have been supported to get to know the facilities in their area (e.g. Post Office, shops, etc.) |

## Conclusion

This paper has distilled and described key learnings from a variety of projects that are actively working at supporting people to move to and live participating lives in their communities. It does not cover all the issues relevant to this work nor is it a 'definitive guide' on how to do this, but it does provide useful pointers and insights based on the implementation experience of others.

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## Appendix 1

**Table 2. Breakdown of community living beneficiaries by disability and mental health (2010-2012) – numbers and column percentages.**

| | Disability (Column %) | Mental health (Column %) | Total (Column %) |
|---|---|---|---|
| **Number of projects** | 27 | 16 | 43* |
| **Number of beneficiaries** | 277 | 222 | 499 |
| **Mild** | 86 (31%) | 88 (40%) | 174 (35%) |
| **Moderate** | 115 (41%) | 86 (39%) | 201 (40%) |
| **Severe** | 71 (26%) | 48 (21%) | 119 (24%) |
| **Missing** | 5 (2%) | 0 | 5 (1%) |

*A further 11 community living projects were supported in 2013. These figures relate to the years 2010 to 2012.



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