

Next Steps

THE JOURNEY SO FAR

Sharing learning to
inform the movement to
individualised supports

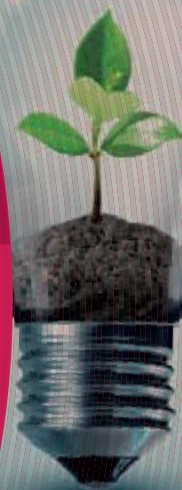




Table of Contents

Foreword & Introduction	4
1. Quantitative Results	
1.1 Demographic information	9
1.2 Case studies included in the report	10
1.3 People supported through the case studies	11
1.4 Results on overall numbers of people receiving individualised supports	12
1.5 Results from case studies involving the living arrangements of people supported	13
1.6 Results from case studies involving day supports	14
1.7 Outcomes for people living in the original settings after the participants in the case studies have moved out.	18
2. Reflection on Outcomes	
2.1 Reflection on initial outcomes for the person	19
2.2 Reflection on initial outcomes for families	20
2.3 Reflection on initial outcomes for staff	22
2.4 Reflection on initial outcomes for the organisation	23
2.5 Reflection on initial outcomes for the community	26
2.6 Systemic implementation: key learning points from the case studies to support the wider development of individualised supports	27
3. Learning from Life-stories	
3.1 Introduction	31
3.2 Bernie's story	32
3.3 Anne's story	34
3.4 Catherine's story	35
3.5 John's story	37
3.6 David's story	39
3.7 Adam's story	41
3.8 Emily's story	44
3.9 Transformation of Day Supports	45
3.10 The Step-In Network	47
3.11 Using Natural Community Supports	49
3.12 An Organisational Approach to Individualised Supports	52
4. Conclusion	54

Foreword



National Disability Policy has seldom, if ever, been as comprehensive or richer in potential as it is now. This policy context presents many extraordinary opportunities for people with Intellectual Disability to be supported to live a life of their choosing, but also presents significant challenges.

A major strategic objective for the National Federation of Voluntary Bodies is to provide leadership and practical support to member organisations in the implementation of policy.

In furtherance of this strategic objective the National Federation, with support from the Health Service Executive, initiated the Next Steps Project in 2012. The Project has as its primary objective the promotion of individualised supports for people with Intellectual Disability whom our member organisations support in their day to day lives.

Comprising some 23 Service Provider participants using a case study approach, the Next Steps Project is essentially a Community of Practice and Learning through which the participating organisations have the opportunity to share experiences and identify meaningful solutions to challenges which arise in the movement to individualised supports.

I am very pleased to present this report which is a very comprehensive outline of progress and outcomes to date including its many significant achievements, not least of which was the international recognition which it achieved by the Global Zero Project at its award ceremony at UN Headquarters in Vienna, Austria in February 2015. Welcome as this much deserved Award is, even more rewarding is the fact contained in the report that a minimum of 739 people with Intellectual Disability are receiving individualised supports provided by organisations participating in this project, some 236 of whom are directly represented in the results of this report.

This report provides a range of quantitative and qualitative information. **Section 1 provides the research on the numbers** of people who have participated to date and the ways in which their lives have been impacted in terms of where they live and the ways in which they spend time during the day. **Section 2 presents the detailed learning from the work** undertaken to date, including supports and barriers - gathered through a questionnaire reflection on the outcomes for people themselves, their families, staff and organisations. Section 2 also reflects on the implications for further, systemic implementation of individualised supports. **The stories of the real changes taking place in people's lives are presented in Section 3**, through the words of the individuals, their families, staff members and through photographs and links to additional information materials.

The findings of this report on outcomes to date have demonstrated that the provision of individualised support for self-directed living is viable and achievable in the Irish context. Individuals who wished to do so have moved from congregated settings, group homes and family homes to living in a wide range of community settings of their choice, including using mainstream housing supports such as Rent Supplement, (or the Housing Assistance Payment), and through privately rented accommodation. Others have remained in the original family home with individualised supports provided or have become tenants in homes provided by Approved Housing Bodies.

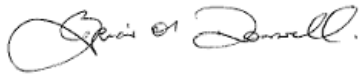
People have developed sustainable and valued roles in their communities and within their circles of family and friends - including through employment; active citizenship; through participation in

mainstream sporting, cultural, community and artistic organisations - and many have re-connected with families or taken on new responsibilities within their networks of their family and friends.

Significant challenges remain - and together with an overview of the implications from the learning of the work to date, these are set out in the conclusion of the report. Some of these challenges call for national responses to facilitate the progression to more systematic implementation of this kind of support. These include acknowledgement that compliance requirements can be in conflict with innovation - and there is therefore a need for flexibility within the system to allow a person to be supported individually in ways that facilitate them to achieve the goals that are most important to them in their lives; the success of capacity building and training in supporting individualised work and a consequent requirement that training should be continued and rolled out further; the need for a clear funding stream to support the housing needs of people moving into appropriate community settings; and the need for flexible budgeting and resource allocation models, which in turn sustainably take account of the potential for changing needs and the additional resource requirements that come as people reach older age.

I would like to commend and express my appreciation to all the Project Participants, the Project Steering Group led by John O’Dea and a special word of thanks to my colleagues Alison Harnett and Kathleen Greaney for their very determined and excellent management of the Journey So Far. I would also like to particularly thank all of the people who shared their personal stories with us in order to share learning through this project. The support of the HSE for the Project is also gratefully acknowledged.

We can all look forward to the next phase of the journey with much hope and excitement. I wish all associated with the Project continued success. As the conclusion of the report notes; the most important step in this work is the first step - getting started from wherever the person or the organisation is today - and working with others to share learning in the ‘next steps’ that are taken.



Brian O’Donnell

Chief Executive,

National Federation of Voluntary Bodies

Introduction

The National Federation of Voluntary Bodies Providing Services to People with Intellectual Disabilities, is the umbrella group for the Intellectual Disability service providers in the voluntary sector. With support from the HSE, the National Federation is undertaking the 'Next Steps' project in order to provide leadership and practical support to our members as they progress with the movement to individualised supports for the people who use our services. In doing this, the project is identifying supports and barriers in the change process. The objective of the project is to create shared learning that will assist National Federation members in embracing the change agenda envisaged in the new vision and policy landscape for services and supports to people with intellectual disabilities in Ireland.

The overall aim of these changes is to ensure that people with intellectual disabilities are supported to live a life of their choosing.

Through the project the National Federation has developed a community of practice and learning between our member organisations who are involved in the Next Steps project and key stakeholders including people supported by our members and family members, as well as close liaison with the relevant Government bodies and Departments. As the development of more innovative community-based supports continues, the information captured by this community of practice and learning is shared with the wider community.

The project began in May 2012, and one of the first actions taken was for the participating organisations to agree a shared vision for individualised supports against which to benchmark their work. The vision ^[1] (set out at the end of this introduction) was agreed by all participants and is at the centre of the initiatives the members are working towards. The group, through consultation, also agreed on 7 key themes that they felt would need to be addressed to move forward with individualised supports. These key themes, or building blocks are as follows:

- Being involved in decisions that affect my life
- Family leadership and engagement
- Staff and management development
- Community involvement and inclusion
- Reconfiguration of budgets
- Reconfiguration of service provision
- Gathering and sharing evidence of change in people's lives



Fig. 1 Key themes guiding work of Next Steps Project Participants

These themes have guided the focus of much of the work that individuals and the community of practice and learning have progressed during the course of the project to date.

The project has taken a case-study approach to progressing with real changes that support people in living a life of their choosing. Each of the participating organisations is reporting on their work with one person, or a number of people - on an individual, one person at a time basis, developing new types of supports in line with the agreed vision. Every two months the participants come together to share what they have learnt as they progress with this journey. The meetings use accessible agendas, minutes and communication styles to ensure that self-advocates who participate can be fully included. In defining the work that individual organisations are undertaking for the case study, each participant has outlined how the goals of their case study map on to the achievement of the aims of the following four policy documents:

- The Value for Money and Policy Review of Disability Services in Ireland [2]
- New Directions - Personal Support Services for Adults with Disabilities [3]
- The National Housing Strategy for People with a Disability 2011-2016 [4]
- The Time to Move On from Congregated Settings Report [5]



Fig 2. Goals of case studies are directly mapped onto the four key policy documents above

The project aims to ensure that through working together in new ways there is a multiplier effect and synergy in the learning gained. We are monitoring the initiatives undertaken and identifying supports and barriers in the change process, in order to share our learning in the change process with the wider National Federation membership and with all key stakeholders nationally.

The project has been working through this case study approach for just over two and a half years, from January 2012 to the present day. This report is an initial gathering of information on learning and outcomes from that work.

The information contained in this report comes from the following sources:

- Bimonthly reports submitted by each organisation over the course of the case study work;
- Data gathered through a 'Reflections on Outcomes' questionnaire containing qualitative and quantitative questions, developed by the National Federation and circulated to the Project Participants in August 2014, with an update questionnaire on living arrangements circulated in May 2015;
- Structured group discussion and consultation with members of the Next Steps Project at its meetings on 1 October 2014, 19 January 2015 and 22 April 2015; and
- Case studies presented at the Next Steps meetings from 2012-2014.

Vision of the Next Steps Project:

The vision statement set out below transcribes and directly maps on to the definitions of individualised supports from three key relevant sources agreed by the Project Participants: the Disability Policy Review (HSE 2011)^[6], the National Federation's Vision Statement (2009)^[7], and an international perspective from John O'Brien's Individualized Funding Think Tank (2009)^[8].

Individualised Supports for an Ordinary Life

Defining what we mean by 'individualised supports' for an ordinary life:

Individualised supports as defined in the Final Report of the Disability Policy Review (HSE, 2011)

Individualised supports are a personal social service which includes a range of assistance and interventions required to enable the individual to live a fully included life in the community. Individualised supports require the provision of a flexible range of supports and services that are tailored to the needs of the individual, and are primarily determined by the person. This provision enables people with disabilities to live as full citizens instead of having to fit into standardised models and structures.

Supports include assistance provided by others, whether in the form of personal care, communication or advocacy support, learning support, therapeutic interventions, aids and equipment, adaptations to the physical environment, and so on. Individualised supports are characterised as being primarily:

- determined by the person (in collaboration with their family/advocate as required and in consultation with an independent assessor) not the service provider or other 'experts';
- directed by the person (with their family/advocate as required);
- provided on a one-to-one basis to the person and not in group settings (unless that is the specific choice of the person and a 'natural' group activity, such as a team sport);
- flexible and responsive, adapting to the person's changing needs and wishes;
- encompassing a wide range of sources and types of support so that very specific needs and wishes can be met;
- not limited by what a single service provider can provide
- having a high degree of specificity. Provision that is expressed in terms of residential, day or respite does not capture the specific nature of an individual's support needs.

Being supported to live a life on one's own terms

Extract from National Federation Vision Statement]:

http://www.fedvol.ie/National_Federation_Publications/Default.757.html (2009)

Above all people have a deep rooted desire to belong, to be in relationship, to live within the intimacy and security of their family and friends, to be included in the greater life around them with all its attendant possibilities for hope and fulfilment and to do so, to the greatest extent possible, on their own terms. The implications of this simple truth will determine our actions on behalf of all citizens with Intellectual disabilities.

Individualized Supports Think Tank (John O'Brien, 2009)

We define individualized supports as an array of supports, services and resources that are person-centred, based on the unique interests and needs of the person, afford the person as much control over their supports as they desire, and are adaptable as the person's life changes. This means that supports are created around an individual's distinct vision for their life rather than created around a facility or funding stream.

1. Quantitative Results from the Questionnaire Survey (NFVB August 2012 & May 2014)

1.1 Demographic Information

Twenty four organisations are currently participating in the Next Steps Project. These organisations are listed below in Table 1.

No.	Organisation	Area/county covered in case studies
1	Ability West	Galway
2	Brothers of Charity Services, Clare	Clare
3	Brothers of Charity Services, Galway	Galway
4	Brothers of Charity Services, Limerick	Limerick
5	Brothers of Charity Services, Roscommon	Roscommon
6	Brothers of Charity Services, South East	Waterford, Kilkenny
7	Carriglea Cairde Services	Waterford
8	Cheeverstown House	Dublin
9	CoAction	West Cork
10	COPE Foundation	Cork
11	Daughters of Charity Disability Support Services	Dublin & Limerick
12	KARE	Kildare
13	Muiriosa	Midlands & Louth
14	Prosper Fingal	Dublin
15	RehabCare	Services provided nationally, case studies based in Castleblaney & Tullamore
16	SOS Kilkenny	Kilkenny
17	St. John of God Community Services	Dublin
18	St. Joseph's Foundation	Cork
19	St. Margaret's Centre	Dublin
20	St. Michael's House	Dublin
21	St. Patrick's Centre	Kilkenny
22	Sunbeam House Services	Wicklow
23	Walk	Dublin
24	Western Care Association	Mayo

Table 1 - Organisations participating in the Next Steps Project

The participating organisations between them support over 12,000 people with intellectual disabilities from across all 4 HSE regions¹, representing Section 38 and Section 39 service providers. Those participating provide a mix of residential, day and respite supports and have varied origins with religious organisations and 'parent & friend' organisations included.

¹ (4 HSE regions were in operation at the time of data collection, but have now been re-configured to reflect 9 Community Healthcare Organisations).

1.2 Case studies included in this initial report on outcomes

Reporting on the case studies began in January 2012 and continues to the present time. The organisations are at different stages in their involvement in the project, some having just begun case study work in recent months and others having documented the progress of case studies for over two years, depending on when the organisation began participating in the project. For the purposes of this progress report, data is included only from those organisations who have been involved for sufficient time to evaluate outcomes, as identified through responses to the questionnaire circulated in August 2014. Some organisations reported on more than one case study during the time period. In some cases, intended outcomes have been fully achieved, the person or people supported are now receiving a more individualised support, and the case study is therefore considered concluded for the time-being. (Of course, required supports remain in place and if the person's needs change, or a need for further work becomes apparent, then these case studies may once again become actively reported on within the community of learning.)

Table 2 lists the organisations who have case studies included in this report, as these case studies have reached a point where initial outcomes can be reported on. As discussed above, further work is already taking place but is not included in this report on outcomes.

Organisation
Brothers of Charity Services, Clare
Brothers of Charity Services, Galway
Brothers of Charity Services, Roscommon
Brothers of Charity Services, South East
Carriglea Cairde Services
Cheeverstown House
CoAction
Daughters of Charity Disability Support Services
KARE
Muiriosa
Prosper Fingal
RehabCare
SOS Kilkenny
St. Patrick's Centre, Kilkenny
St. John of God Community Services
Sunbeam House Services
Walk
Western Care Association

Table 2 Active and Concluded Case Studies included in the Progress Report

1.3 People supported through the reported case studies

A range of data were gathered on the demographics of the people that were supported in the included case studies, for the purposes of this progress report on initial outcomes. Twenty two case studies returned data in the 'Reflections on Outcomes' questionnaire which was circulated to the participating organisations during August 2014 (in some cases organisations had more than one case study included). Overall 236 individuals were included in this data. Thirteen case studies, in which 87 individuals were supported, focused on where the person lives, whilst 17 case studies, which included 223 individuals focused on day supports. Within those figures many organisations had case studies that supported people in both their day and living arrangements. In 18 case studies there were males supported and in 18 case studies there were females supported.

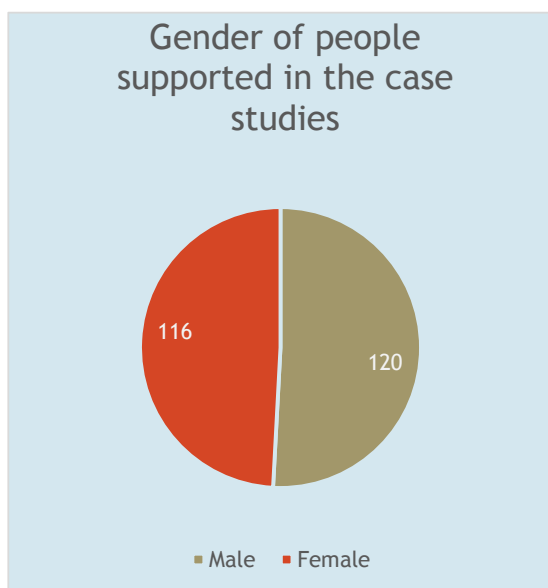


Figure 3. Gender of participants

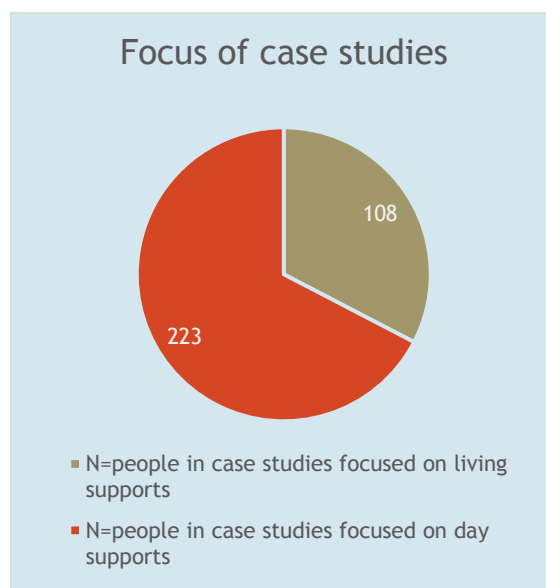


Figure 4. Focus of case studies

Figures 3 and 4 above indicate that the data returned represented an almost equal proportion of males and females, and a range of case studies that included day and living supports.

It is important to note that the case studies represent only a sample of the people being supported in individualised arrangements in each of the organisations. For instance in one organisation where approximately 45 people are receiving fully individualised supports, the focus of the case study for learning is on just one person rather than all 45, in order to provide in-depth longitudinal insights

into the process, shared on a bi-monthly basis with the community of practice and learning and providing detailed qualitative data.

It should also be noted that 90 people accessing **day supports** in a congregated setting were included in the study supported by one organisation, in which the focus of the case study was organisational change to move towards individualised supports. The groundwork for change across an entire organisation is being addressed in this case. The data relating to these 90 individuals have been excluded from some of the data sets below (this is noted in these cases) as to include this information which is focused on wider organisational change rather than individual change in the analysis would skew the results of the case studies that are based more typically on direct work with individuals.

1.4 Overall numbers of people receiving individualised supports

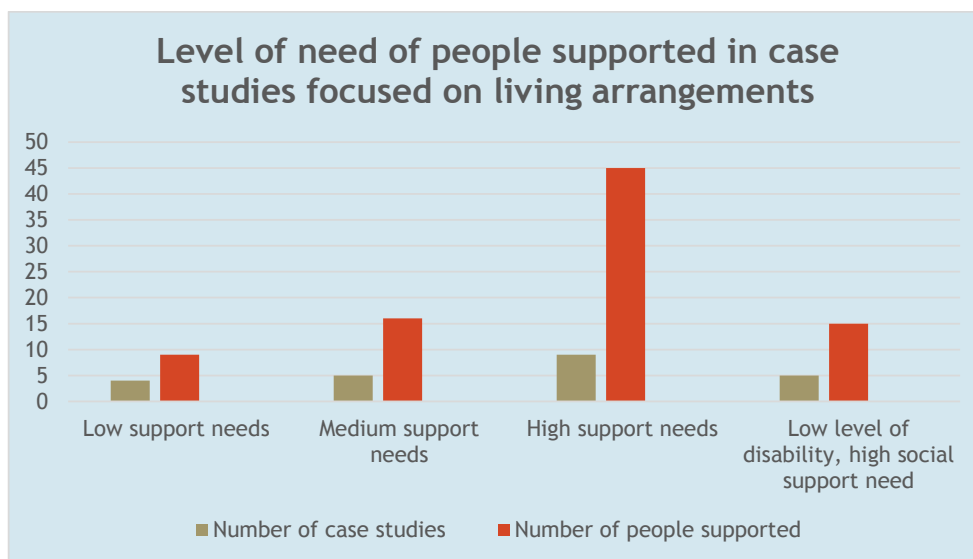
In the wider context, organisations are providing individualised supports in a range of ways. Some of this work (such as the case studies referenced in this report) is shared with the Next Steps Community of Practice and Learning; some is supported by training provided by Genio, including through grant-funded projects and capacity-building work such as the Enabling Excellence programme and other training programmes; and some of the work comes about as the result of organisation-specific initiatives. The progress report therefore asked the participating members of the Next Steps Project to detail the **overall numbers of people receiving individualised supports from the service providers in question, when all initiatives are taken into account.**

Fourteen organisations provided data on the overall number of people receiving individualised supports within their service provision as of August 2014. **The total number of people receiving individualised supports, as defined in the vision statement, reported by these fourteen organisations was 739.** Within the fourteen organisations who reported on this the minimum number of people per organisation receiving individualised supports was 5, the maximum was 200 and the average was 43. Again it is important to note that this figure represents a sample of the overall participating organisations in the project, as not all organisations provided data in response to this question.

The following sections of the report will provide information firstly from the case studies focused on the living situations of people supported, and then on the case study data relating to day supports.

1.5 Case studies involving the living arrangements of the people supported

The data returned from the 'Reflections on Outcomes' questionnaire (August 2014 & May 2015) demonstrates that people with a wide range of needs were supported in the case studies.



The greatest proportion of people supported in the case studies which focused on living arrangements, have high support needs. Individuals who have medium support needs were the next most frequently included, followed by those who have a very low level of disability but who may need significant social supports at different times in their lives, and finally those with low support needs as detailed above.

These results demonstrate that service providers are aiming to ensure that the movement to individualised supports is inclusive of people with all levels of need, and that the focus of learning outcomes through the case studies is often in working through the complexity of achieving these changes for people with significant support needs.

The 'Reflections on Outcomes' questionnaire asked the members of the project to detail where the people who were the focus of the case study were living at the beginning of the work. Moving to more independent living arrangements was (and is) a goal for many of the participants of the Next Steps Project, with the required supports in place. When the reporting on case studies began, the individuals supported were living in a range of settings - including congregated settings, group homes, the family home and some were in semi-independent housing attached to the service, as detailed in Table 3.

Table 3 - Where participants were living at the beginning of reporting on the case studies

Where people were living at the beginning of case study	No. of people	No. of Case Studies
Congregated Setting	25	6
Group Home	39	9
Family Home	13	5
Person in their own home (private rental)	1	1
Other	9*	2
Total	87	

* incl. 3 people began in semi-independent apartment in Housing Association attached to service

Table 4, on page 15, demonstrates a much wider variety of living arrangements in place following the work of the case studies, with many of these participants now accessing mainstream housing supports such as privately rented accommodation, Rent Supplement and social housing delivered by Approved Housing Bodies. The movement to mainstream housing options is underpinned by national policies including the National Housing Strategy for People with Disabilities 2011-2016^[4]; the Time to Move On from Congregated Settings Report (2011)^[5], and the Value for Money & Disability Policy Review (2012)^[2].

For some people, new accommodation in appropriate community settings has been secured, adapted and the person is awaiting the completion of the HIQA registration process before they can move in to their new home. One individual has bought their own home, whilst another has been provided with the individualised supports required to continue to live in their family home, after the death of their parents; thereby maintaining vital continuity and community links. For one person who is older a move has taken place to a retirement home. Sadly, the deaths have occurred of two of the individuals who were living in a congregated setting participating in the project.

However, there are also a significant number of people who are still awaiting movement to the settings of their choice. Section 2 of this report sets out the supports that have been identified to moving and the barriers that are impeding this movement for some people. The challenges that have been identified in the reflections discussed in Section 2 are key hurdles that impact on the ease or the possibility of movement to people's living arrangement of choice, and these issues have been raised by the National Federation of Voluntary Bodies with the relevant Government Departments and agencies.

In this way the information provided through the case studies has supported the development of detailed submissions and case study illustrations with regards to a range of issues that are centrally important to the movement to individualised supports (including submissions to the National Housing Strategy 2020, and to HIQA on a range of issues including its recent consultation on the criteria for Designated Centres).

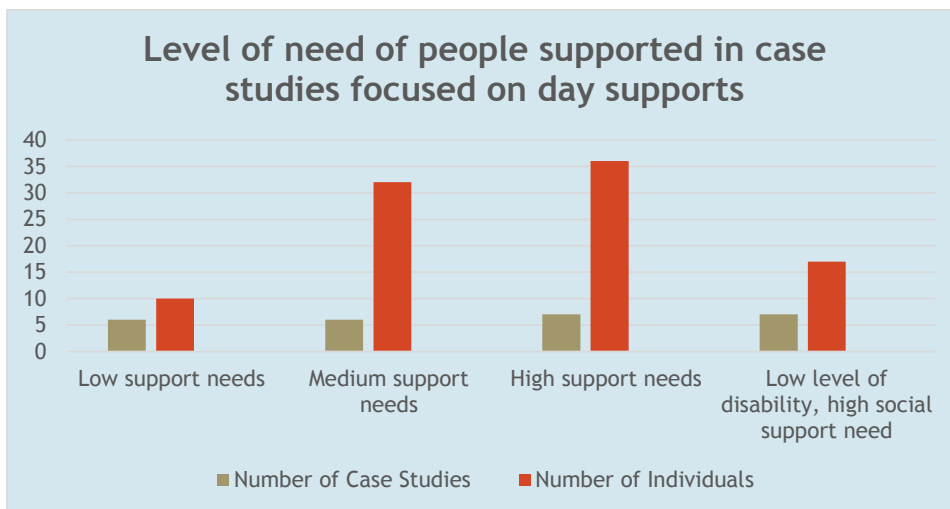
Table 4 - Where people are now living

Where people are now living	Number of people	Number of case studies
Private Rented	16	6
Bought own home	1	1
Receiving individualised support to remain in family home, parents deceased	1	1
Rent Supplement	9	3
Approved Housing Body	11	4
Service Provider Approved Housing Body	4	2
Group Home	7	3
Retirement Home	1	1
Still waiting to move from Congregated Setting	7	2
Still waiting to move from Group Home	15	4
Still waiting to move from Family Home	6	4
New home secured, ready to move, awaiting HIQA registration	9	2
Deceased	2	1
Total	89*	

** in the case of two people the figures were supplied for these individuals who joined after the beginning of the data collection, which is why there are 89 following the movement and 87 before.*

1.6 Case studies involving day supports

The data returned in the 'Reflections on Outcomes' questionnaire from case studies that focused on day supports also demonstrates that people with a wide range of support needs were included in the case studies.



(In this data the level of support needs for 90 individuals accessing services in one congregated setting was excluded.)

Fig 6. Level of need of people supported in case studies focused on day supports

Figure 6 shows that the highest number of people supported; as detailed through the sharing of 7 case studies, was 36 people who have high support needs. On the questionnaire one possible response included was an option for 'low level of disability, high social need for support'. This option was included because many of the participating organisations had highlighted that there are people who have the ability to live and spend their days very independently but who may also have particular vulnerabilities that require social support or where support may be intensively required for short periods of time as life circumstances dictate, and the person otherwise needs very little support. This was the case in 7 of the case studies reported and for 17 individuals. For some of the organisations participating, part of the learning for the case study was in gaining knowledge from these individuals about how they would best like to be supported (e.g. see page 43 of this report for further details).

Table 5 - Day supports accessed by people at the beginning of the case studies

Where individuals received supports at the beginning of the case studies	No. of people	No. of Case Studies
Congregated day service	63*	9
Smaller community day setting	34	6
Accesses the community or day supports from home	16	4
Other	3	2
Total	116	

**this figure does not include 90 individuals supported by one organisation looking at overall organisational change.*

The results in Table 5 show that the majority of the individuals supported in the case studies were receiving their support in congregated day service settings at the beginning of the work, followed by 34 people based in smaller community-based day service settings and 16 who accessed community settings and supports directly from home. For the two case studies that indicated ‘Other’ there were 2 people in one case study for whom the organisation held responsibility for providing supports but who had opted out of the existing day service, and in the second case study, there was one individual for whom it was indicated “*Mainstream settings. Accesses support only when needed*”.

Table 6, below, provides the results of the changes in the settings from which day supports are provided at this interim progress report stage, following the work to date in the case studies.

Table 6 - How supports are now provided

How supports are now provided	Number of people	Number of case studies
Via hubs in community-based settings	76	7
Via a hub in a congregated setting but accessing mainly community-based settings	12	4
Accessing mainstream settings only	8	4
No longer uses the supports of the service provider	2	2
Other	11	4
Total	109	

Significant changes took place for many participants in the case studies both in relation to the settings from which they now access community life and the roles in community played by individuals. These roles are explored further in Section 2 of this report and in the ‘Learning through Life-stories’ information that follows in Section 3.

Following on the outcomes of the case study work 76 people in the sample accessed for the report were using supports in community-based hubs. Others had moved to living life in mainstream community roles and activities only, with some even finding that they no longer required the support of the service provider.

In the case of 4 case studies that responded ‘other’, two individuals had begun to access community roles and living from home; six people were working within a ‘Supported Self Directed Living’ framework with the majority of options being accessed in the community but still accessing some options in a service provider context; two people had seen little change within the service setting but had now accessed paid employment; and in one case study in which people had already been accessing mainstream supports the option ‘other’ was ticked in to indicate that this was maintained. In one case study focused on the whole-life approach, an individual had moved into her own home and would now be able to access community supports via her home.

1.7 Outcomes for people living in the original settings after people involved in case studies had moved out

Participants in the study were invited to comment on outcomes for people living or spending time in the original settings from which people who were the focus of the work were moving.

For two of these people their day service has changed significantly to a more positive routine. A range of comments was provided in response to the impact that the work towards individualised support has had on those who were not yet the focus of the work but who shared living or daily environment with the focus individuals.

“Less stressful environment but still living with people that they do not wish to live with.”

“All people are now living with less people”

“Four of the five participants are still in traditional services. There is an individualised plan in place to support their move to Self-Directed Living. This plan is at varying stages of completion but all are being supported in the right direction”

“Numbers will decrease in group homes once the apartments are opened. This will have a very positive outcome for people remaining in the group homes.”

Further research is required to assess the impact for people who have not yet moved when programmes of change are taking place.

2. Reflections on outcomes

The 'Reflections on Outcomes' questionnaire that was circulated to the member organisations asked the participants to reflect on the outcomes of their work for a range of stakeholders: for the person themselves, families, staff members, and the community. They were also asked to comment on systemic learning for the wider organisation emerging from the work to date on the case studies.

As this was a questionnaire that aimed to collect a brief **overview of data from the staff members who are project participants and who directly attend the Next Steps community of learning, these are initial reflections only. Further research with each stakeholder group is required to directly gather the views and reflections of individuals supported, their families and the frontline staff involved in the case studies.** The initial reflections on outcomes, as described by the staff members who are project participants, is set out below:

2.1 For the person

A wide range of outcomes were reported for the people supported by the work that took place on the case studies. In the main, the outcomes reported were increased independence and ownership within the person's own life, enhanced connection with the individual's own family, and the development of meaningful roles in the community. A sample of the responses on outcomes for the person is outlined below:

- People who have moved into their own homes have seen a huge increase in self-confidence. They have willingly taken on all the responsibility that comes with this.
- A change from structured timetables to valued social roles. Not just present in the community but participating.
- People have increased relationships with their families.
- People are actively involved in getting the house ready, choosing paint and furnishings etc...
- Individuals take responsibility for decision-making with minimal support.
- *"Living in their own home. Using ordinary community resources, setting up bank accounts & paying bills for the first time."*
- Each has built on their skills and competencies.
- Increased independence and autonomy.
- As with most of us, people learn and develop by experiencing reality.
- One person who moved said, when asked if she would live in a group home again; *"No road back, sorry I didn't do it years ago."*
- A detailed comment shared in its entirety below provides further insight into the process for people supported by one of the participating organisations:

“With support, participants were able to move away from a centre-based programme where they had to do things at a specific time because they were part of a group, to participate in an individual community-based programme based on their needs, interests and hobbies and at a time that suited them. This individual community participation has led to them having socially valued roles and has also helped reduce the stigma they had about attending a centre for people with intellectual disabilities. All participants were supported to try different experiences and were therefore able to make more informed choices about what they really wanted to do and the supports they needed to be able to do it. The more confident and happy they became with their choices the less support they needed to continue. Two participants gained paid employment and require only minimal support from the service with this. One participant exited the service in May 2014 and went on to live independently in a place of his choosing. One participant still receives individualised support from external agencies to feel valued and find his socially valued role in the community.”

Challenges and learning points are also reported:

- Some have experienced difficulties in sourcing suitable accommodation.
- Issues developed between some people who initially chose to live together resulting in some moving out. This highlights the need for an evolving and flexible approach.
- *“Many are still spending a large amount of their time each week on activities (swimming, bowling, going out for lunch, etc.) rather than developing meaningful roles”*
- Change is taking too long for some.
- Change to be paced at a rate that people can cope with.
- The requirement to register houses with HIQA before moving in (due to the supports provided) is causing significant delays, lost opportunities for accommodation options and distress for the people moving.
- Having a clearly defined process and direction is vital for the work to make a difference in the person’s life. When the direction changes it can be very confusing for the person and someone needs to hold the vision and goals for the person in the case study. It is vital that the person involved is listened to and also challenged to experience new opportunities in order to be in a better position to make new choices.

2.2 For Families

At the initial stages of introducing the new direction of supports for their family member, the data gathered through the ‘*Reflection on Outcomes*’ survey report that families were very concerned and fearful about the move away from the “safe” group setting to the “unknown” of independent living, and a self-directed life. Many families were initially reluctant, and voiced their concerns. Organisations reported good outcomes when the family’s concerns were responded to by keeping the

family fully informed and actively engaged in the process. These ‘intentional conversations’ helped build up trust with the organisation. Many organisations highlighted the need for a strong partnership between support staff and the family for successful transitions to take place.

Comments received included:

- Families were reluctant at first when their family member started to live independently, however they are now very supportive.
- Initially a lot of fears about the move away from centre-based day services.
- Many expressed mixed emotions.
- Many have seen the difference in the development, growth and independence of their family members.
- Families now more involved in the running of the service.
- The challenge should not be underestimated - families struggled with moving their son or daughter from a safe, secure activity/training-based day centre to an unknown and vague community-based service. Family fears include the safety of their family member.
- *“Most of the families are now actively engaged with staff in seeking out opportunities for their son/daughter/sibling.”*
- Staff work much more closely with families and community organisations and indicated that the movement to individualised supports can be seen as an opportunity to engage further with families in a more inclusive setting.
- Families have a much more empowered and directive role in the supports their son/daughter/sibling receives.
- Family’s views of their family member’s roles have increased - they are now seeing the opportunity to having meaningful and valued roles in their local communities.

“Initially a lot of fears about the move away from centre based day services. They liked the security of a regular routine but have seen the difference in the development, growth and independence of their family members. Huge shift in expectations - they really see the benefits of living in the community for their family member. They can drop in any time they want. Family have helped with painting and decorating the house. However they are very concerned about renting as their family member has had to move three times.”

“No money would pay for what we have now” as Mum said herself. She appears much happier and calmer in herself. We know by the sounds that she makes. She comes to us twice a week for her dinner. She brings me shopping with her support staff one night a week and we also go to visit on a Wednesday night. We are delighted that she is home with us at long last. The support staff are like part of our family now and we chat to them all the time. You can see that she has built up a really good relationship with all the workers and they are very fond of her.” This is information from her Mum.

2.3 For staff

The 'Reflection on Outcomes' survey results report that staff members were challenged by the cultural shift from a protective, caring approach to one of enabling people to build independence. This caused uncertainty for some in relation to their new role, but overall as staff developed stronger relationships with the person supported and saw successes being achieved, confidence grew in the role change. A range of feedback from the survey is provided below:

- This new way of working was initially challenging for staff.
- Staff members are now expressing satisfaction with their changed work situation.
- Staff supporting individuals are very focused on empowering the individuals to make decisions and look at all options / supports available in the community rather than within our service.
- A staff member said that this change is *“totally positive, concerned to begin with but totally and utterly positive”*.
- *‘It’s a different way of working with the people we support.’*
- *‘Learning to problem solve and use your own initiative.’*
- Staff reported building relationships with family members.
- Staff advised to always ensure work is about maximising independence and building skills.
- *Excited and motivated by role change.*
- Staff indicated that they had developed stronger relationships with people supported.
- *“Increased job satisfaction seeing people develop, mature and achieve goals that give them socially valued roles in the community and not depend as much on service and support. It enabled staff to grow and develop as leaders as they strived to be innovative and cost-effective with ideas and resources to ensure the success of the project...”*
- One staff member said that; *“The person grew into who she is.....this was only facilitated by living in her own space and looking after herself.”*
- According to staff members this approach to working means that you must constantly take the time to stop and reflect upon your actions and ask *‘is this the best course of action to maximise the potential and the independence of the person I am supporting’*.

For some, concerns remain:

- Fear that *“what they signed up for has shifted to the point where they are no longer able to do their job.”*
- Uncertainty in relation to their new role
- *“It has been a struggle at times when the person has difficulties due to various reasons”*.
- For some, a lack of support if managers were not fully engaged in the change process
- To address concerns, *‘support for staff is essential, whether this is formal training or informal encouragement. It is essential that there is an obvious and visible support structure in place.’*

The staff who moved to support the first house in phase one are now expressing their satisfaction with their changed work situation.

Most of this team moved following putting in expressions of interest. A couple were employed through the normal recruitment process.

The staff who will move in phase two have now reconfigured and are currently working as a team with the people who will move in phase two. A number of meetings were held with the staff team to listen to a number of health and safety concerns that they wished to highlight regarding the environment in the new house. These matters have been addressed as a result of the staff team and management working together to come up with solutions.

“Staff have become very resilient and creative. They are working in a different way and are much more reliant on natural community supports.

They have developed an in-depth knowledge of the people they support and are continuously looking for new ways of connecting people within their community. Different way of working. Learning to problem solve and using own initiative.

Not as regimented and a lot less emphasis on rosters breaks etc.

Developed close working relationship with people living in the house and their families.”

2.4 For the organisation

In reflecting on outcomes to date for the organisations participating, it was highlighted that the organisations have actively worked to support the change process despite reductions in budget. Successes in case studies have led to increased confidence in progressing with developing further individualised supports. Many commented on the importance of *'building relationships'* with the person supported, family and organisation to ensure success. Training staff in this new approach was seen as essential to ensure that the change process is to be successful.

As a result of the success of the work that is ongoing organisations are now supporting individuals within their day services in different innovative ways. The qualitative results of the survey also highlight that it possible to support people who have complex needs to live independently.

Comments included:

- The move to individualised support has helped improve partnership with parents.
- We know from the case study now that it is possible to support an individual who has more complex needs to achieve positive outcomes.
- The organisation now supports individuals within the current day service and community houses in different innovative ways.
- The organisation has found that the determination of the people supported involved was one of the main factors in their success and this continues to drive change.
- The availability of good quality housing was a key factor in being able to progress the change, as was access to Rent Supplement and adaptation grants through the Local Authority.
- The work has led to a new strategic plan for the organisation.
- Work to date is evidence of turning policy into reality in line with New Directions and strategic plan of the organisation.
- ‘Enabling Excellence’ training (provided by Genio) has allowed time and space for the organisation to take an overview of their values and principles and ensure that these are now rooted in a theory to which practice can be applied.
- The importance of planning and the location of a community hub is a vital component for inclusion.
- The organisation has achieved a better presence in the local community and this has been achieved through building relationships with local voluntary groups and businesses.
- Planning is taking place for a practice development group with the organisation to continue the work and increase the use of this practice in the organisation.

These changes are not without challenge for organisations:

- Securing housing was and continues to be a key organisational challenge
- The need for HIQA registration in houses that are being planned in the community before the individual moves in is causing delay and distress. Additionally, *“the health and safety requirements to register with HIQA needs to be explored further for individuals and groups wishing to live in leased or social housing in the community”*
- There is a reduced security of tenure in rented accommodation.
- Providing the necessary level of flexibility required to provide individualised supports presents challenges
- Change is taking too long in some cases with a number of elements that are beyond our control - funding is an issue and there are significant risks involved.
- Part of the challenge is in accepting that it is not possible to provide both an individualised support service and a 9.00-4.00pm service.

- The new model of providing individualised supports presents challenges in terms of reconfiguring of staff rotas - particularly in relation to the labour court decision regarding sleep-overs.
- As support needs change or as people encounter difficulties in their new living situations or community roles, it becomes clear from the feedback that the process is not always linear and that there are challenges experienced for some along the way. A key learning point that was gained from this is best summed up by one participant *“Vital that we stay connected and vigilant to try and support the person wherever this journey takes them”*.
- For one case study that did not progress in the manner envisaged, the learning point that the organisation gained was *‘it probably would have made more progress if a project lead that did not have as much involvement in wider organisational issues was appointed.’* This feedback was echoed by others who highlighted that their role had expanded to include the ‘Person In Charge’ role under the HIQA Regulations, and that this duality of roles was impacting negatively on the ability to provide individualised support.
- Un-bundling of funding remains a barrier for those living in group homes, particularly in the absence of an agreed costing methodology or resource allocation model.
- ‘The funding of these changes is an issue’.
- *‘We are struggling to develop a robust recruitment process that embeds this philosophy in our systems’*.

“Any new model of service delivery will present challenges for an organisation. The main challenge has been how to provide the necessary level of flexibility required to provide individualised supports. The traditional day-service model of operating between 9.00am and 4.00pm does not offer sufficient flexibility to allow for individualisation of supports. Also the traditional approach of a group-led service does not allow for individualisation. Part of the challenge here is also around accepting that it is not possible to provide both an individualised support service and a 9.00-4.00pm service. When supports are targeted, individualised and person-centred they cannot also cover the hours of 9.00-4.00pm. However, the other side of this is that supports must be made available outside of the hours of a traditional day service model to include evenings and weekends as a person’s support needs dictate.”

From a funding perspective, the transition from the service location as the cost centre to the person as the cost centre continues to be a big challenge. We are looking at a number of ways to achieving this. These include building in a costing module into the organisation’s central information database, to looking at existing costing models and resource allocation tools in order to achieve this. The next phase of individualised support development will have to have a working model in place before the process of self-direction can progress.

2.5 For the community

Community as a whole have been very welcoming. Community participation by people supported is resulting in increasing awareness and acceptance of people with disabilities as contributing, active and valued citizens. Communities are becoming more aware of the positive contributions people can make, as employees, through volunteering and also in the economic benefit that their involvement brings to local businesses. Comments made included:

- Members of the community are beginning to get to know people.
- The community as a whole has been very welcoming and happy to help.
- Huge gains have been made for people through supportive terms of partnership with housing departments in the Local Authorities.
- People supported in the new model are housed close to where they live and often volunteer hours, they are seen as a valuable resource.

There have been learning points and challenges:

- We have also had to work hard at disproving the negative views that community members can sometimes (unconsciously) hold about people with intellectual disabilities.
- One of the challenges in locating the service in the community is a lack of community facilities in some areas or amenities that are expensive to access - making it necessary to seek options outside the local area.
- It is extremely important that the person accessing a particular community group, or class, or work/volunteering opportunity is genuinely interested in the area, are seen in a positive light, with a good first impression created. It is very important that the community group or business do not need to fear that *“a service provider will enrol a group of people into a class or course, effectively making what was a mainstream class into a specialised/segregated service. This should be avoided at all costs as it shuts down opportunities”*.

The roles that people play in the community are beginning to be seen not as tokenistic but ones that are valued in the same way as those of their peers.

“With over 20 people accessing the community individually in their own right as citizens in their own community, people are beginning to see people! With all their talents, abilities, personalities, stories and interests. Not only as those people from ‘that service’. This, as commented to me by one member of the public who uses our community service, has been life changing for him as he has learnt so much from the people around him.”

2.6 Systemic implementation: key learning points from the case studies to support the wider development of individualised supports

A central aim of the Next Steps Project is to gather and share learning to support the systemic implementation of individualised supports. The *'Reflections on Outcomes'* questionnaire asked participants for their recommendations to support this progression, in light of their learning in the case studies.

The comments made in response to this section of the questionnaire included:

- Teams must be enrolled in their own leadership. Expressions of interest give possibility for people to engage in the change process.
- Community Hubs need to be kept small to be most effective. Linking the hubs to existing community centres or resource centres is a good idea as you can share supports or facilities.
- On-going engagement with families is essential so that they can understand the benefits of this new model and support their family member to access it.
- Families who may have reservations benefit from seeing other individuals move on.
- The organisation has reflected on the planning tools used as part of the case study and have now revised and refocused the Individualised Planning Process, to become a more fluid, innovative and responsive process.
- It is a challenge to prepare staff to work in a very different environment, we need to develop and provide comprehensive, relevant training and ongoing support to staff.
- For our case study we linked the moving of people with complex needs from two different houses as they moved to their own apartments. This added complexity and instead this type of move should be done in stand-alone projects.
- Be aware that accessing property purchased from NAMA is a lengthy process - it can take a number of years.
- If I was doing this again I would include Independent Advocacy from the start.
- We are naturally concerned that we will always have the resources to support people as they age in particular, people left fully staffed 7-day group homes, a very safe, secure environment, and we want to ensure that we will not let them down in the future if they require more support - there needs to be flexibility to support evolving and changing needs.
- Vitally important to stay strongly connected to people and provide flexible supports and resources when required. Example: *"...people's lives change, as do all our lives, we must be responsive when things go wrong. Supporting people in their own home requires very different skills for staff, the emphasis must be on empowerment and maximising ability instead of helping people to do things.*

“Plans are now in place to close another congregated setting this year, which currently houses 17 people. The organisation is in the process of buying properties to assist the move. The case study provided invaluable information that is driving the process of helping people move toward independent living. From being involved in the project, the organisation feels the experience will ensure that the next move will happen at a faster pace because of the knowledge gathered through the case study”

- There is a need to address the challenge of transport for those living in remote areas who find it difficult to access mainstream services or employment.
- Some mainstream services believe that the person has received a service funded by the HSE and that they are therefore unwilling to provide access to participation in educational programmes in the community. There is a need for increased awareness-raising in the wider community.
- *“Yes I believe there is huge learning. It is possible to support any individual to live a life that is autonomous. The work does require careful planning and the support of the person’s family cannot be under estimated. As an organisation we have learnt from this case study, and there is a belief that this way of working is possible.”*
- This work takes time and if it is to be effective it cannot be rushed. Building the relationship between all parties (staff/community/family and the supported individual) is a process of negotiation and trust-building and if one part of this relationship isn’t working it has a knock-on effect on the other aspects.
- Effort and time must be spent working on good individual person-centred plans so as to draw out potential social roles, support requirements and conditions for success. There needs to be an emphasis placed on a move away from activities towards valued social roles.
- A strong ‘theory of practice’ is required to support and guide the work.
- Staff flexibility in working hours and working approach is important to the process.
- People with intellectual disabilities have so much potential and sometimes we as staff can hold them back.

“Look at the organisation support, it must be from top down, with buy-in from everyone.

Ideally a Management structure for individualised supports with a dedicated staffing that are provided with training on community life / Discovery process. Deploying the right staff with community skills is key to success. Ensure the vision is communicated.

Resources & finance need to be agreed before discovery work - Ring fence funding.”

- Ensure that initial candidates are representative of the needs of all those supported by the organisation.
- Have a selection criterion (in our case it was people who had “voted with their feet”)
- Engage with families, whether or not the families will play a significant role in the individualised support initiative
- Have an action plan for winning across staff.
- Try to avoid a “them and us” mentality (easier said than done)
- Anticipate training needs (both technical and operational)
- Identify champions.
- From the beginning, plan the expansion of the initiative.
- Plan the funding strategy and how will transition impact on this
- Plan community buy in.

Additional Comments

The ‘*Reflections on Outcomes*’ questionnaire provided a space for any additional comments. Comments made by the participants included the following:

- The organisation has observed that people who move out of residential group homes seem to change their attitude to day services and services in general very quickly. It has been our observation that people become more independent, more involved in their families and communities and no longer turn up at the day centre in the same institutional way. People spend a good deal of their time going about their daily living duties e.g. shopping, paying bills, ordering coal etc. It has become clear that the organisation needs to be able to provide flexible supports to people. It is our experience that people’s support requirements vary, we would be loathe to assign a specific amount of supports, ring fence this funding and assume that this meets the person’s needs. It has been our experience that there are times when people require minimal support, indeed may indicate that they no longer wish someone to call. It has become clear over time that it is vital that we stay vigilant and connected to people to anticipate problems and support someone in a timely fashion.
The reality of people living in their own homes and living their own lives has been an education and eye opener for staff. It has been our experience that people (staff and families) underestimate the abilities of people and frequently ‘over-support’ people. We are aware that our

project has focussed on people with low support needs, as opposed to supporting someone with high support needs to live in their own home as we are daunted by the cost of supporting such a person. This is a grave cause for concern in the organisation.

- The issue of Rent Supplement continues to be a major problem. The organisation is in receipt of support under the Rental Accommodation Scheme but almost insurmountable difficulties are encountered when people attempt to access rental assistance when they move into their own homes.
- Community-based hubs work very well and lead to better outcomes for the people they support. Families need a lot of input to see the benefits of the new model and to see it as a positive option for their family member. Assessing education / work options for people with higher support needs in community settings is challenging and more input is needed from other Government Departments to make this more accessible.
- The case study I have been reporting on was in relation to one person who lived in a congregated setting and moved to her own home. I have learnt so much from this case study in relation to the person being supported and also how the work has helped other people being supported in this way. Getting the groundwork right is very important and having the support of the person's family. Families have strong connections within their own communities and this creates natural supports for an individual.
- *'Proud and energised to be part of the project.'*
- *"The Next Steps project has been very beneficial to gather information and get advice. It has acted as a forum to share resources and organisations have been very open and generous with their information. This I believe has had a positive influence on the culture of organisations. In the past there has been a tendency for people to share their success stories without showing how they actually went about the project. This forum has provided us with step by step support. There are less obstacles because there is so much information available. It has also shown that individualisation is now expected to be the norm. These are not one off projects anymore."*

3. Learning from life stories



3.1 Introduction

The aim of the Next Steps project is to support organisations as they move towards providing more individualised supports for the people using their services. **Central to achieving this aim is the need to ensure that the experience and views of the person supported remain the focus throughout.** The Next Steps project has evolved into a community of learning and a community of practice, as the member organisations provide individualised supports through new models and learn from this experience. The life-blood of this community is learning through life stories and it is this learning that is at the heart of the case studies and the project itself.

Providing a forum for shared learning and ensuring that the voice of the person is heard are central to the process. The Next Steps project invites individuals whose experience is shared through the case studies to present at each of its meetings. There are six meetings of the project per year. Where possible, the person themselves presents their experience of the ways in which their life is changing. This usually involves discussing the differences in the person's life that have come about, positive or negative, and how supports have changed. For some people who wish to share but do not feel comfortable to share in a meeting forum, their experience is sometimes presented through video or other means. In addition, where possible family members share their experience of the changes, along with staff involved in the changes and management.

Two principles of the Next Steps project are the **honest sharing of information** and the creation of a **comfortable space for shared learning**. A culture has developed whereby learning is best fostered by sharing of what is working **and** the elements that are challenging, rather than focusing on successes alone. Similarly, there is an atmosphere of shared respect for the privilege that is afforded to the members by those who share the personal stories of their lives changing and every effort is made to ensure that the meetings are informal in tone and comfortable for those who wish to share. Many of those who have shared at the Next Steps meetings have chosen to go on to share their learning in the wider forum of the two national Next Steps conferences that have taken place to date, both of which were oversubscribed and between them allowed for over 440 people to benefit from the learning taking place within the project.

In this section of the report we have provided some information on a small selection of the life stories that were shared at the Next Steps meetings by people supported, their family members, the staff and managers. You can visit our website www.fedvol.ie, click on 'Innovation and Change' and select 'Next Steps Project' to find online links to extra information referenced in the stories below.



3.2 Bernie's Story - Moving from the family home into independent living

Bernie Byrne's story of moving into her own home, with support provided by KARE



Bernie Byrne (left) came to the Next Steps community of learning and shared her experience with us of moving to independent living and the changes that this has brought in her life.

Also sharing the learning with us were **Louise Mahon** (right), a manager from KARE (the organisation supporting Bernie); Bernie's mum **Maggie Byrne**, and Bernie's Life Coach, **Theresa Nolan** (below, right).



I always wanted to live independently. It's something I would have told staff over a number of years. My family never thought I could live independently.

I am independent now, happy, content and where I am living is my home now.

People often ask me 'would I like to move back home', or 'are you sorry you moved out'. My answer is **no!**

Bernie's mum **Maggie** shared her experience of Bernie moving into her own home.

Maggie explained that it was initially very hard to accept that Bernie would be able to live independently. This led to a lot of conflict with Theresa (pictured above with Bernie). Theresa stood firm on supporting Bernie's wish to move whilst also supporting the family to work through the concerns that they had about how safe this would be and how it would work. It was very emotional when Bernie moved out. Now that Bernie has been living independently Maggie says she has new liberty in her own life. She is happy that Bernie is happy and that she can relax in her own life knowing that. She said that Bernie's relationship with the whole family has changed. For instance, a family tradition of having dinners in one of the sibling's houses on Sundays now includes Bernie hosting the family her own home.



Maggie very generously agreed to allow us to film her presentation to the Next Steps group so that we could share this with other families. If you are reading this document online you can simply click the link below to see the film:

[Film presentation exploring family engagement with Maggie Byrne](#)



(L) Maggie (pictured in the middle) shares her story of how it felt from the family perspective when Bernie was moving out.

Theresa kept working with me and kept me informed. It's very important for staff to keep working with the family and keep trust.

Theresa worked with the family and talked and talked. We had many arguments but we got over all of that. Theresa supported Bernie all the way in what she really wanted to do.

Parents, please believe in your son or daughter's ability. Let them achieve their achievements and support them in what they want to do.

Theresa's story

From the perspective of the staff member supporting Bernie as a Life-coach, Theresa said that it did take a long time for the changes to take place. Initially there was shock and the family felt it couldn't happen but Theresa said as a staff person her 'No1 was Bernie and No2 was the family'. She provided ongoing support to the family whilst keeping the goals that Bernie had set for herself as the focus of her work.

"We got through it. It was a difficult time. You have to keep the individual as the focus and keep working with the family."

In spring 2015 Theresa informed the Next Steps group of the exciting decision that Bernie has come to, that she has decided she doesn't need to be linked with supports any more. KARE will provide support if Bernie ever feels that she needs it in the future, but this decision has demonstrated the extent to which a person's independence and empowerment can evolve when people's individual life choices drive the supports that they receive.



You can find out more about Bernie's story on the Next Steps webpage:

[A life of my own](#) - Bernie Byrne, Mag Byrne, Louise Mahon and Theresa Nolan, KARE

3.3 Anne's Story - Moving from a group home to independent living

Anne Looney, a Self-Advocate, shares her personal experience of making the move to independent living together with Aobheann Lindsay, from the Brothers of Charity Services in Clare.



Anne began to be supported by the Brothers of Charity services in Clare in 1985 at the age of 37 after her parents passed away. Since then she has lived in many group homes but has never enjoyed this way of living as Anne likes her privacy. Through her personal plan meetings it was identified she would like to live on her own with appropriate support.

Left, At a Next Steps meeting Aobheann Lindsay describes the supports provided by the Brothers of Charity Services Clare to Anne in the various stages of her move to her own home.

In 2009 an apartment was identified as suitable accommodation in Ennis. Unfortunately Anne was deemed ineligible for rent allowance at that time and had to give up renting in 2011 as the costs were too high without assistance. Regrettably while waiting to move to yet another group home Anne was diagnosed with cancer. This was a terrible shock but Anne coped incredibly well.

Banner Housing Association was approached as a means of moving forward with Anne's goal of having her own apartment, and Anne's name was put on the housing list. She was assessed by the Council as having a housing need.



In early 2012 apartments were acquired by Banner Housing Association and Anne was given the chance to move there. However, because they were bought from NAMA there were lengthy delays in getting acquisition. In early 2014, after two years of delays, NAMA completed the paperwork, but there was yet another barrier.



The apartments had to be registered with HIQA because Anne would be sharing support with people in other apartments. Anne was very frustrated with the lengthy delays as she had been waiting for 10 years to live in a place of her own choosing. All Anne wanted was a place she could call home. Finally after a further year of waiting the organisation were in a position to complete the registration with HIQA. Registration was received on the 10th of March, 2015. Anne was delighted and she began to prepare to move to the apartment.

Finally and with much celebration, after nearly 30 years of living in group homes, Anne moved in to her apartment on the May Bank holiday weekend, 2015. She moved on a Friday which is customary for good luck! We wish Anne the best

of luck in her future with her new home. [If you are reading online, you can click on this link to see a film that Anne has made about her personal experience.](#)



3.4 Catherine's Story - Moving from a congregated setting to living in her own home

Catherine lived in residential care for over 20 year's years, over 30 miles away from her loved ones. During this period of her life Catherine showed very high levels of personal distress and conventional rehabilitation proved unproductive.

Through reconfiguration of the resources that were at that time embedded within the institutional setting, Catherine, with the support and love of her family moved home to Clara in County Offaly to live near her parents, in April 2013.

Catherine now has a team of dedicated staff who work with her in an individualised way. They have been supported to really get to know Catherine and her needs. The change-over to living in her own home must have been difficult for Catherine but at the time she appeared to settle very quickly into her new environment. She has free access within her home and to her own van. Catherine's van is extremely important to her. She has more freedom in how her day goes and can give us cues as to what she would like to do. This is very subtle and requires a good knowledge of Catherine. The day is led by Catherine and not by the needs of the service being provided. Support staff work with the ethos of having the freedom of being present with Catherine and allowing that to dictate the day.



Catherine visits her family weekly, she drives down to the local football pitch, and she goes for long walks in her community.

What Catherine's story means to her family

As Catherine's mum once said *"Money would not buy what we have now"* This sums up what it means to her family in relation to her coming home to live in her own house and her own community, where the neighbours know her; she is Ber and Mary Carey's daughter, and sister to Noreen.

Catherine visits her parents twice a week for dinner, she brings her Mum shopping and has been known to collect Alex her nephew from hurling. *"The people supporting Catherine are like an extension of our own family as we know them so well"*. This was said by Catherine's parents on many occasions.

It was and is hard at times if Catherine is not having a good day, and this can be a worry for family.

Catherine has what we would call a life worth living within her own community. Her family did worry and wondered how Catherine would cope in her new surroundings, would she settle and sleep at night.

There are times when they still worry and we can sit down and discuss these worries and work together to ease the stress.

What Catherine's story means for the staff who support her

Catherine has a team of 8 people, with one person with Catherine at all times. No-one works with Catherine unless they have spent at least one month getting to know her. We do not put this stress on Catherine or her support person.

Personal support was recruited on the basis of their goodness of fit, personality attributes, motivation, commitment, and personal resourcefulness. This was a big ask and no one let Catherine down.

Catherine has taught us the importance of connecting on an emotional level with her and through this connection we can all work through the good and the not so good days.

Catherine's Mum once said '*You must keep digging until you find my beautiful Catherine*'. That is what we did and continue to do every day. The work is different than what we did in the past. We are not guided by what the service has to offer, we do not depend on the time something must happen at. We let Catherine guide us, if we feel Catherine needs to get out of the house, if she needs to go for a long walk, if she needs to sit in her van, then that is what we do.



We have many challenges and they continue to face us at different times, this can be daunting but we have made a commitment to Catherine and her family that we will work through the hard times and be more resilient coming out the other side.

Yes it does require a strong united team, who will come together every month to discuss and re-energize. Without this level of work we could not rejuvenate ourselves and keep the team uplifted.

This will always be how this team

will need to work to encourage and maintain sustainability.

The work truly begins when people move to their own home, then we start to truly see the individual blossom and become their true self. This can be a challenge for all parties including the person themselves. Living within your community means many things to us all, but being a true part of that community requires dedication and hard work from all involved.

Catherine is supported by Muiriosa through its Person Centred Wing, through which 48 people currently receive fully individualised supports and that number is increasing over time. The establishment of the Person Centred Wing benefitted from support from Genio.



[Coming Home - A film presentation of Catherine's Story, created by Genio](#)

3.5 John's Story - Moving from Living in a Congregated Setting to Living in the Community using mainstream housing supports

John Collins, his family and supporters describe the changes in life for a person with significant support needs moving out of a congregated setting



John Collins, who is supported by Brothers of Charity Services in the South East, came to the Next Steps community of learning to share his journey of moving from a congregated setting, together with his brother Colman Collins, John's keyworker Mary O' Donoghue, Team Leader for the de-congregation project Alan Blyth, and Lesley Ann Kavanagh, the organisation's representative on the Next Steps Project.

(L to R) Colman Collins, John Collins, Mary O'Donoghue and Alan Blyth

Planning for the move

The team shared with us the story of how resources were reconfigured support the move to a more individualised support for 8 people, from a congregated setting to two community houses, with people that they have chosen to live with. Having had many meetings with the team and family members, John's move was planned - from a house on campus at Belmont Park (a congregated setting) to an ordinary house in the community only a few miles from his family home. The staff supports that John would need in his new home were a significant element of the planning process and required reconfiguration of the existing resources in the congregated setting. For John, one element that was very clear from his communication and his circle of support was that he would love to have a pet dog of his own, having previously enjoyed time with dogs who had visited in Belmont Park.



Even though John doesn't use words to communicate, his love of animals is clearly communicated to the people who support him

A significant transition in John's life

John and three others moved to their new home in November 2012. The house is a rented accommodation. It was adapted to meet John's needs (including a wet room). John visited the house on several occasions before the move took place and the week before he moved in, he had his evening meal there. John's room was decorated with family pictures and lots of John's personal belongings. It is important to note that the transition was a very significant one for John and he appeared under

stress for the first few weeks after the move and lost weight. Staff and family were concerned for him but after an initial period of transition John settled in and began enjoying life in his new home.

What is different in John's life now?

It was agreed that it would be easier for John to get a dog if he didn't live in a busy congregated setting. John got a lovely dog with the help of his family. Her name is Molly. John's family believe this was a life-line for John as he got his dog just before his mother passed away. John now has a volunteer. The volunteer supports John to go to the cinema, town, park etc. She had a new baby recently so we have not seen her for a while. John joined the local library. He attends Mass in his parish and interacts well with people who knew him as a young boy.



John visits his friends from Belmont Park and seems to enjoy this. Skype was set up so that John could keep in contact with his siblings who all live in other parts of the country or abroad. During the summer the staff organised an afternoon tea/barbeque for the families, neighbours, and friends. It was really appreciated by John's family that we held it on their Mum's anniversary and all the siblings living in Ireland came on the day.

John's family share their thoughts about his move

John's sister, Christine lives in Sonoma, California in the US. Christine loves the fact that John lives in a house now rather than an institution. She said that she can talk to staff on a one to one basis, whereas it had previously felt like a big group of staff. Christine Skypes John on a regular basis and John's key worker Mary sends a monthly email to family to update them about what is happening in John's life.

In terms of learning points, however, John's family feel that the house is in an isolated location. They

"I love the fact that John lives in a house and not in the huge institution. I feel he's in a home, not just walls and furniture. He's looked after by staff who care about him and have his best interests at heart. We can talk to staff on a one to one basis, in Belmont it felt like a big group of staff. It's much more intimate now." John's sister, Christine

would have preferred if the house was in a village, near shops and John could interact more in the community. They also have stated that they would prefer a higher staffing level in the evenings. If John is unwell, there is more planning to be done with getting extra staff at short notice since he is not attending a day service. Christine says *"The house is lovely. I love John's bedroom, it's bright and roomy. The bathroom, sitting area, conservatory and garden are great."* Above all John's family have said that they feel John is supported by people who really love him and that is 'number 1' for them.



John with his family at his new home

What John's move has meant for staff

Staff reconfiguration to facilitate John's move began through an expression of interest process, which has led to significant buy-in from the people who put themselves forward. As staff members, a person's unique skills have the opportunity to come to the fore in a way that is less possible in the larger, centralised team. Staff members have a new sense of ownership in supporting John, and the others who moved, in accessing choice in how they live their lives. The individuals supporting John have enjoyed the opportunity to explore the community and be creative around possibilities to connect with the community. Listening to the family's concerns the staff have begun looking at other bungalows in the area that could be more suitable in terms of John's opportunities for community involvement and that would also be suitable for his support needs.

3.6 David's Story - Moving from Living in a Congregated Setting to Living in the Community using mainstream housing supports

David is supported by the Daughters of Charity in Dublin. At a Next Steps meeting he joined us to share his story, together with his mother, and the staff and manager supporting him. David had recently moved from a congregated setting into a rented apartment in the community. This brought about hugely positive changes in his life. Following the move, David also opened his first bank account, applied for his first passport, and took his first trip abroad to Disneyland in France, travelling by ferry.



David, Marie and Ciara presenting at the Next Steps Meeting

Ciara, who is residential manager with the Daughters of Charity, explained the process that the organisation went through to support David in making this move. A transition plan was worked through with David and his family, and an integral part of it was, the agreement he had with the Service that if it 'wasn't for him', he could move back and look at other options. However, after the preparation and planning was complete, David and his good friend of many years, moved out in March 2011. Staff linked very closely with Ciara, and, David adapted to his new living arrangements, 'as if he had always been there'.

Unfortunately one year later, the news came that NAMA had taken over the property and David was given 6 week's notice to move. In August 2012, David moved to a house, closer to his own family home, much to the delight of his mam and dad. This property proved to be far more suitable, with more links to his community facilitated through the location and accessibility of transport. Once again, David became part of the local community, shopping in the local centre, going to the cinema or bowling in the evenings, and dining in the local restaurants. David got to know his neighbours and readily accepted invitations to Summer Bar-B-Q's etc. His mam, dad and sisters were frequent visitors.

Throughout this time, David continued to attend a day service. He took part in an ASDAN programme to promote Independent Living 'Towards Independence' which sits below Fetac Level 1. In July 2014, David and his friends, moved to a fantastic new purpose built community hub, in the local area. However, once again, David was to receive bad news. The landlord was selling the house and we had 3 months to vacate. As it transpired, the house was later taken off the market, until recently. We were given a final date by which to vacate the house in summer 2015.

Staff are busy preparing for a new location for David. This will be his third move in four years, but like every other obstacle that he has overcome along the way, David has shown great strength of character, and an amazing ability to adapt to any situation.

Some key challenges

- Getting the Disability Allowance and mobility grant paid directly into David's new bank account (and a question about how that might interface with new long stay charges);
- Having to put up fire safety notices etc. and how this doesn't fit in with the concept of a person's home
- Questions about tenancy
- HIQA approval of any new accommodation before a person can move in to their new home, which is time consuming and can cause delays.

David's mother Marie talked about the huge changes that the move out has meant for David. Marie said *"He's happy, he's where he needs to be. I love when he's home. He loves to go back. It's the best thing that ever happened. He's so happy."* As a mother, Marie explained that there were anxieties that "no one could look after David like I can" but that the key element to the success of David's move was that she could always talk openly to the staff supporting David and that together they worked through any concerns or risks to ensure that the transition was safe. Quiet time is very important to David and Marie feels that he now gets this much more than he was able to in the congregated settings. She now feels that she can enjoy her retirement because she knows that David is looked after.

3.7 Adam's Story

An organisation shares the story of establishing a new support service and Adam shares his story of using these supports



Prosper Fingal established a new support service in 2012, as a direct response to the New Directions policy, and as a way of exploring how the vision outlined in this policy may be translated into real supports. The Howth service began working initially with seven individuals, and now supports eleven people. The service covers the Howth, Sutton and Baldoyle region and the main criteria for people transferring into the service from existing Prosper Fingal services was that they live within that catchment area. Prior to moving to the Howth service the people supported were travelling some distance out of their locality to access day services.

The Howth service was established with the aim of bringing people back into their own communities and supporting them in an individualised way. We chose a small premises, large enough to cater for meetings and to allow people to have a light lunch, but too small to be a drop-in or to allow for larger groups in a very central location in Howth village.

Prior to opening the service the staff carried out an extensive mapping of the local area, to establish the amenities and facilities that were present, and where there were deficits. During this time staff arranged meetings with local community representatives where we introduced ourselves and explained the type of integrated service we were planning to open. We also hosted a community information evening to assist in getting buy-in from the local community. We received very positive feedback.

The service offers individualised supports. We spend a great deal of time getting to know the people we support in many different locations and scenarios. We have found 'less is more' approach has worked well; we will directly support an individual to develop their skills and then step back to let them 'go it alone' while still providing indirect (by phone, through liaising with family supports and by support community-based mentors). We have found that we need to step back and let people take positive risks and make mistakes as this helps them to problem solve and thereby grow in their skills and confidence. Over time we have seen the confidence and skills of those we support grow and develop. A range of good outcomes have been seen including improvements in mental health to the point where supports are now being reduced, and people presenting themselves in a positive light, including for instance in the simple things such as having pride in the clothes that they choose to wear as well as in the way that they interact with people.



We asked Adam, one of the people we support and his mother, what the move to the Howth service has meant to him. Adam and his mother have given their permission for us to share his story.

Adam now has his own individualised schedule of activities that he does each week but before this could happen a large body of work was carried out to get to know him. Staff spent time looking at what things have succeeded for Adam in the past and what things have not worked out. We concentrated on his skills, likes, assets and interests. Staff also worked with Adam on his Personal Plan and on setting new goals. One of his goals is to move out of home and he has put his name on the social housing list. To prepare for this move he is working on his cooking and living skills. He is now responsible for a lot more in his home and is responsible for ironing his own work shirts.



Little by little Adam has built up a full and active individualised week. He works part-time in a local supermarket, he goes to the gym once a week with a friend, he enjoys golf and plays weekly and he also practices on a driving range. Adam volunteers on Sunday in his local church. He has a volunteer teacher who supports him 1:1 with his literacy and this support has seen his confidence grow. He is a big fan of Chelsea Football Club and has recently joined the Irish Chelsea Supporters Club and he is saving to go and watch Chelsea play in England. Adam is also a huge Elvis fan and has joined an Elvis fan club and plans to visit Graceland in the future.

In the centre I had to do cooking. I don't like that. I had no choice. Lots of people in the centre. Staff were very busy. My keyworker helps me with going out on my own now. I didn't do that in the centre.

Now I do lots of things outside, no staff. My keyworker helps at the start and then I get it on my own. It was easy to change to Howth service, it is near home. A little bit I miss my group of friends in the centre.

I make more choices for myself like going out with my friends. If I get fed-up doing something I can stop. I picked what I do for myself.

I would like an apartment near my Mum and Dad's house and near work. I would like to work more in my job. I want to go to Graceland. I am saving money now.

I am a man now you know, I have to do it for myself.

Adam's mum, Yvonne, also shared her experience. *"The main difference for our family since our Son's service changed is a very positive one. That difference being independence, both for him and for us. For us, the change occurred (more or less) at an age appropriate time in relation to his siblings and indeed his parents! Instead of 'mammy' organising his activities and his life there is a real sense that HE is steering his own life. HE tells us what he has arranged for his day and he has grown ever*

more confident as a result. For instance, he has become more proactive about arranging his Basketball travelling arrangements. Previously he would just presume that a family member would drop and collect him, whereas now he would only occasionally ask for a lift. Mostly now he will arrange with a teammate to go by train or if the weather looks bad he'll set up a lift shared by the two families. Importantly, it's HE does it for himself."

Initially Adam experienced some concerns when he picked up on some anxiety amongst his friends and a fear amongst parents that people moving to the new supports would 'fall between the cracks' and would lose out on services. He needed reassurance from his family that this was going to be a good change. Yvonne explains that she pointed out that his siblings' lives were changing too; one was starting out in college, another moved abroad. *"We all embraced the change with trust and we have seen our wonderful son grow enormously in confidence and independence."*

Adam's mother shares her experience

A lot of time and effort has been put into our son's Personal Plan, by both himself and his key worker(s). I believe that this has had a huge impact on him. He believes in it and I can see that it has given him a sense of purpose, a goal to work towards.

He knows that it's up to him to work towards his ultimate goal of Independent Living, in his own apartment or house just like his siblings is to happen. He takes pride in washing his own clothes, and has proved that men can do their own ironing (half the time!).

A lot of time and effort was put into identifying courses that he was interested in. One of those was a cookery course in Dublin city centre. Never in our wildest dreams could we have imagined that he would be able to take public transport on his own to Dublin, cross very busy streets and present himself on time for his class. But he was trained very carefully by his then key worker. She went with him several times and identified any potential dangers. She made him a book of photographs of the route with simple instructions which he kept with him. She did the return trip with him countless times until she was SURE that he could do it on his own. He got so much out of that course and told us about all the new friends he had made.

Another very positive thing about the new service is that from our viewpoint, our son gets more input rather than less as a result of the personal plan. All of his activities are relevant to his interests.

We hope that in time to come our son will certainly realise his ambition to live independently in his own apartment.

3.8 Emily's Story - Moving from a Group Home to living in rented accommodation

Emily Meagher talks about "Living my life, past, present and future"



Emily Meagher came to the Next Steps Community of Learning and spoke with us about the positive changes in her life since she has moved from a group home into renting a house with two friends. She said;

"I do not want to be treated like a child. I love cooking for myself. I had to wait for so long".

Emily's support worker **Marguerite Keohane**, from CoAction in West Cork, spoke about the differences in how she is supporting Emily and her friend that she shares with, since they moved into the rented house. She said that **Emily needs much less support and is living a more full life**. Emily has asked for help with managing finances, and Marguerite said that when she comes Emily has all her budgeting ready and she just needs to double check it. Whilst Emily and the others living in the house wanted overnight support at the beginning, this need has reduced and is currently provided on a needs basis by staff and a volunteer.



It was explained that for staff working with people to achieve individual supports there has been a learning process for everyone as that change is made. The difficulties in accessing rent supplement at the moment mean that the house is rented by Co-Action and sub-let to Emily and the other residents. Co-Action are **working on changing this so that the individuals rent in their own right**.

Emily came to present at the national Next Steps conference and provided great encouragement to others considering making a change in their lives, when she summed up by saying;

"If I can do this YOU can do it too!"

3.9 Transformation of day supports: An organisation's story of reconfiguration to support people in a new way

One of the key themes in the Next Steps Project is how we can **implement the New Directions policy on providing day supports in ways that respond to individuals rather than having group supports.**



Prosper Fingal here share the story of transforming one of their services in response to the wishes and needs of the people supported. Karen Tyrell, Mark Warrilow, Richard McCormack and Grainne O'Callaghan came to the Next Steps community of learning and presented their case study to tell us about how the supports are being delivered differently now.

Karen began by explaining that people who have low support needs had been **'voting with their feet' to show that the day service was not meeting their needs**, with low attendance and very little engagement. However, some people were then finding themselves in crisis situations. So the organisation started a process of asking people how they would like their supports provided differently and set out to reconfigure the service. Focus groups were held with people who were not happy with the supports or who were no longer attending and others talked about what they wanted on a one to one basis.



Above - Karen Tyrell describes the reconfiguration of supports provided by the organisation in response to people's preferences

As a result of the wide ranging consultation, a new support service was set up that is focused on **choice and flexibility**. There is a drop-in centre, with the focus on people moving out and doing things that they want to do themselves, but with the availability of the drop-in service for those who want to meet others also. Karen described how there was delicate balancing required with the drop-in centre to ensure that it was not becoming a barrier to people going out and accessing community roles and activities. Solving this required specific work with each individual to ensure that they got the supports needed to increase participation in community life.

Mark, Richard and Grainne shared with the community of learning their experiences of how the new support works for them. Mark told us that he is working in Starbucks for part of his week and that he is in control of the supports that he accesses. The supports that he initially had to begin working in Starbucks are no longer needed and sometimes there are nights out with the staff from his workplace - so that his workplace provides him with both employment and opportunities for socialising.

Mark said: I control what I do and when I do it.

I can come and go when I want to.



Richard told us about how he had disengaged with supports in the past but that he is now happy that he can come and go to the service as he pleases and access the types of support he wants. He had been doing a course in horticulture but was not happy with this and is now happier having changed direction.



Richard told us about how he volunteers for Tidy Towns and works in his family ice cream business “Storm in a Teacup”.

Grainne explained how the supports are working for her. She has a very full and active life and has been gaining confidence in travelling over recent years. She started by going with friends to a place very near to where she lives for one night but now travels for weekends to Waterford. It’s important to build up new skills gradually. Karen told us that Grainne has been a huge support to others, including helping people to learn photography.



Grainne said: “I keep my life this way. I love it this way. I run my own service. **I come and go as I please**, I work 3 days a week.

My timetable is very full, I am never idle!

Karen explained that increasingly some people may come in and out of needing supports at different times in their lives, and that this is a challenge for the HSE and our organisations to ensure flexibility so that people can access the supports that they individually need at particular times.

3.10 The Step-In Network



The **Step In Network** in Roscommon has shared their learning with the Next Steps project in a number of different ways, including at the Next Steps meetings and conferences, and through hosting study visits for other members of the Community of Learning. The Step In network shares with us through the involvement of the Brothers of Charity Services in Roscommon, but they operate as a network independent of the organisation, with their own Board of Management.

Information has been shared with us by **Emily Walsh**, the Network Coordinator, **Rachel Kelly**, and **Malachy McManus**; network members, **Paul Connolly**, a supported living volunteer for the network, and by staff members **Carolyn Gannon**, **Niamh McMonagle**, and **Benny Cunningham**; the Brothers of Charity representative on the project.

Emily explained to us how the network works. There are up to nine people who have disabilities living close by each other, with a supported living volunteer who provides 12 hours of support in terms of building the network, providing support and facilitating the members to provide support to each other. The role of the volunteer is to foster peer support within the network. The supported living volunteer usually has their accommodation paid for in return. The network members provide significant support to each other.

Supported living volunteer **Paul Connolly** explained that the supported living volunteer helps with areas that the network members ask about, such as practical issues with setting up bills, accessing mainstream supports and activities (e.g. a cookery class in mainstream setting rather than having a course run specifically in a day service), help with public transport etc. A key benefit of the supported living volunteer is that they know the locality and community that the network is in and can therefore provide links and information. Emily indicated that it is very important to be completely open and honest with families from the very start about what the network is and is not able to provide. The network has already seen hugely positive changes in people's lives. **Malachy McManus** made a presentation about his life, living independently in Athlone, with support from the Step In network.

Malachy talked about his work in a medical devices company, having a girlfriend and learning to drive. Initially when Malachy moved in he shared with university students but at the moment he lives on his own for part of the week and for the rest of the week another network member Mikey lives with him.



I work in a medical devices company.

I am also learning to drive.

I travelled to Austria as part of the European Journey to Belonging Project. It was a great new experience

Malachy McManus,
Self-advocate and Step In
Network Member

Malachy told us about how he participated in the *Journey to Belonging* European Project where people supported by organisations from the Next Steps Project came together with people from 5 European countries to talk about good practice in supporting people through transition points in their lives.

Malachy travelled to Austria, which was a very new experience for him. He made a presentation about his life to the partners from the other European countries and gained greatly in confidence from this opportunity.



Malachy is living independently with support from the Step In Network



Malachy is learning to drive. This is his Renault.

Emily said that it is a different way for staff to work with people too - it would be unthinkable to walk into someone's home unannounced.

The Step In Network and Brothers of Charity Services in Roscommon report every two months on the changes taking place, and a comment from one of the bi-monthly reports summarises the difference that is made in people's lives by having this type of support:

“The longer people live in their own homes as part of the network their level of confidence and independence increases. This is becoming increasingly evident over time. People are becoming increasingly in charge of their own life and confident and competent to use their skills in getting on with their own lives.”

The Step In Network shared with us the importance of welcoming families into the process, and working with volunteers or friends to enhance community linkage. It is also vitally important to work with staff members to build confidence and trust in the process that is being undertaken.

Some of the points made were as follows:

- Finding the right volunteer is extremely important. Trust must be established around how the 12 hours support are provided to the network
- Local businesses are interested in the network and asking lots of questions, which helps build people's understanding of individual's abilities.
- Athlone IT has been really helpful with the students providing good input.
- The natural supports have been there because people are building the network around where they are originally from.

The Keyring project in the UK (on which the Step In network is based) has provided important support to the group and has facilitated visits to the networks in the UK and provided mentoring support for the supported living volunteer each month.

The network has supported people moving from family homes and group homes to this model. They have found that it can be less complicated to facilitate people moving from the family home rather than group homes as there are different expectations built up when people live in group homes that can be difficult to overcome. Families are also finding that they risk losing their carer's allowance when the person moves to the network, even though the person may still be staying at home during weekends. This can be a barrier. One other difficulty can be finding properties to rent that fall under the Rent Supplement cap prescribed by the Local Authority. The network is independent of Brothers of Charity Roscommon, even though it is linked. Locally it is still seen as being linked and this can have two effects - on the positive side there is great goodwill locally for Brothers of Charity, but the network also wants to work on building its own identity. A second network is currently being developed in Roscommon town.



You can find out more about the Step In Network at their website: www.stepin.ie

3.11 Using Natural Community Supports in Provision of Day Services

An organisation shares the learning from transforming supports to develop community roles and connections for people with high support needs

The Daughters of Charity Disability Support Services provides Adult day Services to over 200 people attending St Vincent's Centre. The day service supports people with varying levels of ability across the life span.

The aim of Adult Day Services is to enable people with high support needs to be active participants in their local communities using the natural resources and amenities available. With the publication of the New Directions report more attention is now focused on having person-centred programmes that are tailor-made and responsive to individual needs and wishes and situated as close as possible to where people live.



Sharing a special moment, Lynn and Mary.

The Daughters became involved in the Next Steps project in 2012 and decided to focus attention on restructuring how Adult Day Services was provided, as this was closely aligned with one of the key pillars of the organisation's strategic plan from 2012-2016. This pillar was designed to look at reconfiguring day services for people with higher support needs.

The organisation had already embarked on the development of 4 small community based hubs located within the Dublin 7, 11 and 15 areas.

These hubs provided supports to 22 people who previously attending campus based day programmes. Each base location is part of a pre-existing community resource centre that is run by the local

community and facilities are shared with different groups from a wide variety of settings. This reduces overall costs and shares responsibility regarding maintenance, upkeep etc.



[Click on this link to see a video of how one of the hubs was created.](#) This was shown at the 2014 Next Steps Conference. If you are reading this as a printed book you can find the information online by going to www.fedvol.ie and searching for Publications.

In 2014 the Daughters of Charity Disability Support Service built a new day service hub in Dublin 15. There were a number of factors that influenced their decision to develop a purpose-built hub:

1. To ensure that people attending adult day services from within the Daughters of Charity's catchment area would attend a day service as close to their local community as possible
2. To provide an environment that was wheelchair accessible and able to cater for people with diverse needs and physical abilities. This enabled people to be part of the local community while retaining a base location to support individuals with complex needs.
3. As part of the Daughters of Charity's strategic plan to align developments of day services in line with national policy.

For some people the move from a campus based setting was challenging. Some families were concerned about the possible risks for their family member in the move. They worried about the tolerance and attitude of the local community and how integrated their family member would be. They had strong attachments to the campus based setting and believed it met the needs of the people who had a day service there. Other people were excited about the opportunities and the possibility of providing day services in a different way that would be more person centred and based around each person's wishes and preferences.

The Steps in the Transition

- Each person and their family were supported through a transition plan and were involved in all aspects of the decision-making process. A small number of families decided not to agree to the move as they believed it was not a good fit for their family member and this wish was respected.
- People moving off campus to the new hub began to spend time together and met once a week to have a cup of tea and talk about the future
- The multidisciplinary team helped each person develop a transition plan that explained things in a format that was easily understood and accessible. There were social stories created to map out the move and ensure everyone was involved.
- People went on visits to the new hub in small numbers and were given lots of time and space to explore and get used to the new environment.
- Support staff spent time mapping resources and activities in the local area so there were lots of opportunities to join different groups
- Familiar support staff moved with people to ensure that their transition plans and wishes for the future would be followed through on.
- The manager of the hub visited all the local shops, schools and community groups to introduce herself and tell people about the hub.
- A number of open days were held and everyone in the local area was invited to drop in.

Where we are now

- Valued roles in the community for each individual are being developed and fostered
- A few people are involved in story telling in the local preschool.
- Two people are helping put prices on items in the local shop.
- 1 person helps out in the local church.
- A few people have started a book club using a coffee shop in the Dríocht Theatre



(R) Learning the finer points of gardening, Shane and Tom a volunteer

What did we learn?

- Transition Planning is very important.
- Support staff need to be community focused and willing to take risks
- Get to know your local Residents Association, invite them in to meet you.
- Make links with all the local community groups
- Take small steps and celebrate all the achievements
- Supporting people to access community hubs for day services is not necessarily a cheaper model but it leads to better outcomes and an improved quality of life.

The feedback from individuals, families and staff has been very positive. Many of the connections regarding activities, grants or particular invitations arose because people were involved and visible within a local area. There have also been challenges regarding accessible amenities, and wheelchair accessible transport/ environments. However these challenges have motivated people to write to local authorities highlighting particular concerns and asking for changes to be made to provide for greater access and inclusion. Families who have experience of the community hubs are proving to be great agents for change as they can influence and allay fears of other families through sharing their own stories. We now have 45 people with high support needs using community hubs to access their day services.

Blanchardstown.

We are doing our bit with the local residents association to keep the place tidy and litter free. We have been allocated a piece of ground near the hub and 2 of the men with their support staff are keeping it litter free.

The local community centre have offered the use of their facilities to hold some sport activities

The hub is available to local groups who want to use it in the evening or at weekends.

The local National school invited people to their Nativity play last December.

7 local people are now volunteering in the hub in a range of different ways and are proving invaluable in making connections and networking



Choosing what to cook, Sarah

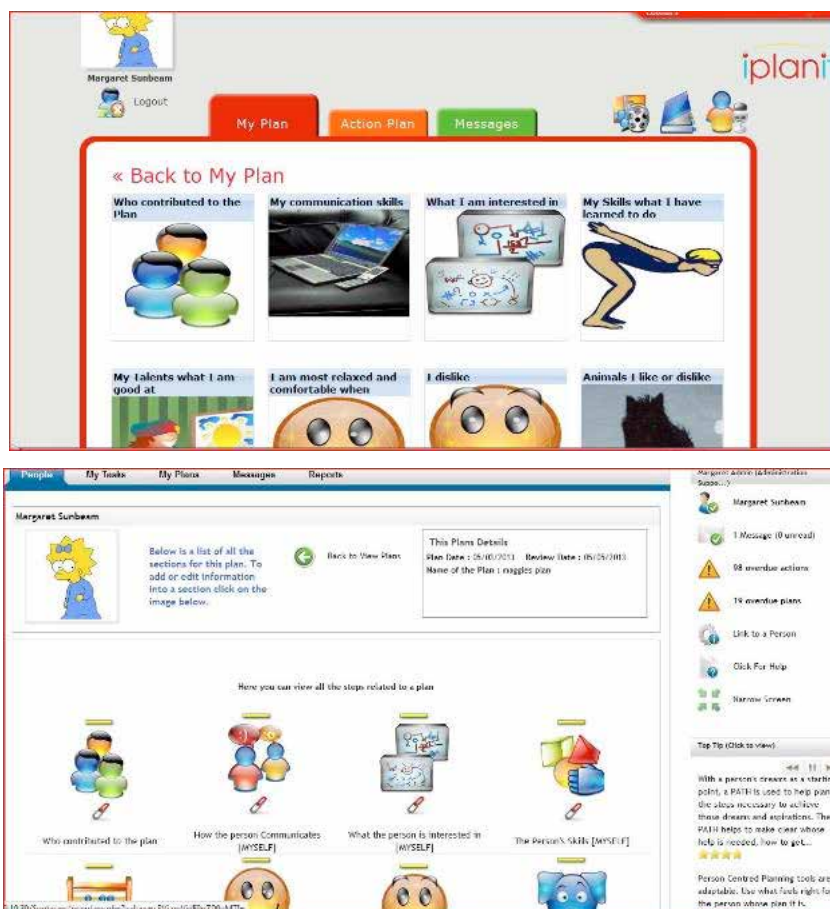
3.12 An Organisational Approach to planning Individual Supports



Sunbeam House Services have focused their case study learning on the work that they are doing to develop self-directed living.

One support to this work that they shared with us is the 'iPlanit' software system which they are using for personal centred planning. Sam O'Connor (a self-advocate) and staff from Sunbeam House Services (John Hannigan, Kevin Hoey, Margaret Randal, Paul Downes and Suzanne Bennett) shared their story with the Next Steps Community of Learning. Firstly they explained how the iPlanit system is helping them to achieve a more individualised approach to providing supports.

The iPlanit system is an online system for person centred planning that allows the individual, their family members and staff members from the organisation providing supports to share information on the person's individual plan online. The system has visual and audio inputs that make the information very accessible and the individual chooses what information that they would like to put into the plan. Below you can see two screenshots from the iPlanit tool.



Screenshots from the iPlanit tool

The iPlanit plan shows aspects of life that the person does **not** need support with as well as those that require support. This means that staff supporting the individual do not spend time on areas in which the person doesn't require or wish to have support.

The system allows the organisation to **ensure that the goals the person has identified in their plan are being worked on and progressed at all times**. It provides **accountability** from front line staff members to senior management with different views being available for the manager, the key worker, etc according to the appropriate information that they need. Areas of sensitivity can be managed so that only those who receive approval from the individual themselves have access to particular information.

Sam O'Connor explained what the iPlanit system means for him. He said "I can see and read and know what's happening. This gives me confidence. He also said that he has peace of mind because he knows who he can talk to. **"It's my decision but you can help me"**.

I have peace of mind because I know who I can talk to if I need it.

Using iPlanit I can see and read and know what's happening.

When you are supporting me to make big changes in my life **go at 10 miles an hour, not 100 miles an hour.**

Sam O'Connor, self advocate



Staff members said that the tool was helping them to make sure that planning was not just "An annual bureaucratic moment" because the system allows the plan to be updated on an ongoing basis, with the person's preferences being to the forefront.

The system incorporates **key performance indicators from the HIQA guidelines, New Directions and Personal Outcomes Measures**, as well as incorporating aspects of 35 quality systems. In Sunbeam House Services the pilot project has found that the tool opens up the plan for the circle of support. They have found some increased engagement with the individual plan from family members, for example with brothers and sisters who are away in Australia being able to log in and be involved.

The next phase of the development plan towards Self-Directed Living for Sunbeam House Services is to reorganise reporting lines within the organisation to facilitate a transition to Self-Directed Living (SDL). One example is that supported employment and home support services now report to the same senior manager as the SDL initiative. This places these individualised supports closer to SDL in order to assist the transition.

4. Conclusion

4.1 Introduction

This report has set out the outcomes to date from the work of the Next Steps Project. Through the quantitative data outlined in Section 1 it has provided information on the numbers of people that are involved in the work of the project, and the ways in which their lives have been impacted in terms of where people are living and spending their time during the day. Qualitative data in the 'Reflections on Outcomes' in Section 2 has provided rich data on the views of the staff participants of the project on the initial outcomes of the work for the people involved, their families, the staff, the organisations and the wider community. It has also reflected on the implications for systemic implementation from the learning gleaned through the case study work. Further research is required to gather the views of individuals supported, family members and people in community settings. The evidence of change in people's lives provides us with an opportunity for Learning through Life-stories, and these experiences have been generously shared with us by the people who have experienced changes in their lives, in Section 3 of this report.

The research contained in this report on initial outcomes has been gathered through self-reflection. The Next Steps Project would welcome the opportunity for independent evaluation of the work undertaken to provide further independent insights.

The remainder of this conclusion will set out the final reflections of the participants, will briefly highlight some work that is undertaken by the project in support of the case studies; will make a short comment on the costing of the work and will highlight an international award received by the project in February 2015.

4.2 Final reflections of the participants

The Next Steps member organisations came together on 1 October 2014 and on 22 April 2015 as a focus group, for a structured reflection on the challenges and barriers, supports and solutions that had been identified through the information presented above and to voice their concluding thoughts.

What we need to do next:

- We need to keep working on developing individualised supports and keep a focus on it.
- It is important that we are measuring outcomes to ensure that people's lives are getting better.
- Having the project based on real work with people supported is very useful.
- There needs to be a strategic plan in organisations for this to work, with a budget allocation.
- There needs to be a positive evaluation of risk (rather than being risk averse).
- It is important that people supported are listened to, to understand what they want.
- It's the right thing to do if it's right for the individual.
- We need more involvement of people supported.
- Families need to be involved.
- There is a need to have a platform for families to share their stories with other families to help ease their concerns.

- Providing individualised supports needs to become the norm, needs to become ‘what we do’.
- There is a need for well-researched evidence to guide further roll-out. Gather in depth information to provide concrete evidence of what works, along with solutions to barriers encountered.
- We need to upscale - with a strategy for moving forward. We should work with more people in an individualised way.
- It is important to have solid working examples of change to empower others to implement change in their organisations.
- Work on getting the message through mainstream sources such as television, newspapers etc. - broaden the message out beyond our services.
- More costing information is necessary.
- For Day Services, the right location for hubs is critical for people to become connected with their community. For older people and those with complex needs it is necessary to have a base - and to take account of the additional challenges involved.
- We need to take account of the results of the IDS-Tilda study on aging^[9]; in considering how the needs of older people can be met and how this interacts with individualised supports.
- Loneliness for people was identified as a problem within some of the case studies. There was a need for people to be supported in developing two-way friendships. In society in general people mainly live with others, but people with intellectual disabilities are often moving into places of their own and loneliness can become an issue.
- Travel to and from services is a critical concern for families, there is a need for training to develop independent skills - ‘street wise training’.
- Concerns were raised about how to take account of families’ work schedules with the development of individualised community-based supports.
- The participants find the Next Steps meetings very useful in terms of networking, bringing information back to the organisation, sharing information and experience to aid implementation of individualised supports, creating a transferable model.
- *“Next Steps keeps us on track and focussed on what we need to do”.*

Can this work for more people?

- *“This can work for 100% of people”.*
- *“Everyone should have the opportunity”.*
- Yes, but it must be one person at a time, and with involvement of families.
- Change needs to be slow and learn from successes and failures.
- We don’t know until we have a more concrete estimation of the costs, particularly the higher costs for people with high support needs and the need for transitional costs which must be identified and acknowledged
- It can only work when we understand and deal with the reality of families working and having to work - and therefore needing some form of hub facility so that they are enabled to still go to work.
- There is a need to focus on transition for school leavers

Building Blocks in the development of Individualised Supports

The introduction to this report set out the ‘building blocks’ identified at the outset by the Next Steps group as likely to be important in developing individualised supports.



Fig. 7 Building blocks set out at the beginning of the Next Steps Project

Having worked towards the goal of supporting people to live lives of their choosing for the past two and a half years, the group reflected on these building blocks as part of the preparation of this report.

Being involved in the decisions that affect my life

- Participants reflected that *“If this building block was not central to the work we are doing it would not be possible to see the evidence of changes we have witnessed.”*
- Legislation in relation to Legal Capacity and Decision making will support people in making their own decisions in future.
- It is a really important building block to make things happen. If people are not involved it is very hard to achieve a change for the person that makes sense for them.
- For people who require high levels of support - sometimes this building block is achieved with the backing of the person’s family, when they are not in a position to communicate fully their own wishes. Specific training in theories such as Social Role Valorization can be very helpful in this case.
- *“Where we have been most successful to self-directed living is where we have provided training around safeguarding - fear around safeguarding vulnerability will stymie the process if we don’t put that support in.”* Recognising the vulnerabilities that are there in an open way and then putting the necessary (and sometimes difficult decisions) around risk mitigation, puts us in a much better position to enable people. In our efforts to support people making decisions we have to address these issues.

Being involved in the decisions that affect my life

Family leadership & Engagement

- Family engagement is essential in this work of supporting people to live lives of their choosing.
- Not all families are the same and some want different things.
- Families supporting one another is of huge benefit.

Family Leadership and Engagement

- There has been a particular willingness to try something new when families are already at a point where they feel the service provision option is not the option they want - showing a different option is key to their involvement, showing the evidence to get to that place. It's a lengthy process and needs a lot of involvement.
- It is important that a balanced view is provided. Through examples in the media of people being attacked, fear has been heightened. We need to balance it with the positives and get the good stories out to the public.
- Some people have been disconnected from their families for a long time and the work is in re-connecting individuals with families.
- It is important to take note of the different stages and different approaches required when supporting the families of children, young adults, people at times of transition, and adults.
- There is a sensitive line between supporting the person to achieve their wishes and supporting the family, where these perspectives are different. The values of the person being first but the concerns of the family being understood and addressed are key.

Staff & Management Development

- Individualised work requires very active support to the frontline from management, with active listening. Every staff member is at a different stage and the work means different things to them. It can be a total role-change for staff - and this can be frightening, so management support is essential.
- It is important to listen to challenges and help to find solutions. A lot of challenges are not about funding - they are often about learning and creating an open culture for communicating difficulties.
- The reality of the requirements of HIQA compliance can be in conflict with innovation. This creates a very confusing environment for staff, which requires clear guidance from management.
- Encourage champions to come to the fore, seeing this change as an opportunity to do work they love doing. There must be leadership at all levels of the organisation in taking on this change.
- For individualised supports to work, it is important that the management goals are clear in supporting the work and that the vision statement of the organisation leads this.
- The vision statement of the organisation may need to be reviewed to ensure that the outcomes of individualised support can be achieved.

Staff and
Management
Development

Community Involvement & Inclusion

- People supported in the Next Steps Project have been getting involved in all areas of life - including sport, education, and employment.
- We need to be specific in reflecting on this building block - that what is required is building connections and having a contribution and a role. We must avoid focusing on activities that merely constitute 'community tourism'.
- Getting involved in the activities of a town is a great way to get to know people.
- It is important not to 'over subscribe' to particular community organisations or events.
- The group reflected on how much of our role is education - helping other organisations and people within our own internal organisations to understand people's valued roles.
- We have a lot of work to do in helping others to understand that people can participate as full citizens - this work should take place at all levels - individual, local, and national.

Community
Involvement
&
Engagement

Budget reconfiguration

Budget Reconfiguration

- Many of the case studies carried out their work in a context of significantly decreased budgets. However, sustainability without funding is the challenge, and reaching the systemic level will require some budgetary inputs.
- There is a need to take account of the numerical increase of people supported due to emergencies and significant changing needs in terms of older people when planning for this work.
- There is a need for cohesion of vision across the management team of an organisation to achieve the goal of providing individualised supports. The work of reconfiguring and unbundling funding requires the financial management and human resources management of the organisation to be fully on board with the vision to achieve this.
- The lack of a resource allocation model at a national level is a currently a barrier to increasing the number of people for whom individualised supports are provided.
- In some limited cases organisations have been able to access individualised budgets. The expansion of this availability should be promoted and consistency of access provided across the country.
- Using natural supports is key to achieving the necessary flexibility involved in this work.
- For some organisations, the deaths of people supported in the congregated setting have meant that high support vacancies have been re-filled by people previously living in the community who have had a significant increase in their support needs. A consistent approach in the implementation of national policy and in planning for the changing needs of the people we support is required.

Reconfiguration of Service Provision

Reconfiguration of Service Provision

- The group reflected that no organisation achieving the aims of the project could have made the changes without reconfiguring the way in which their service is provided.
- A huge attitudinal change has occurred. Staff members understand that their role has changed and will continue to change.
- The commitment of staff members to the work and the organisational commitment is essential to the goal of this transformation.
- People's understanding that *"I can support significant changes in the life of the people I am supporting as a staff member"* provides teams with empowerment and awareness of their contribution.

Evidence of change in people's lives

Evidence of Change in People's Lives

- Case studies have documented outcomes and show evidence of change in people's lives. People are directing their own lives and making their own choices. We need to get this evidence to wider audiences.
- We need to do further research in asking the individuals how they are getting on a little bit later, to see how to ensure sustainability of choice in people's lives
- The stories of individuals moving forward are the most effective way of helping people move in their own lives.
- The supports must be set up in such a way that they are capable of evolving as this work doesn't have a timeline. Providing individualised supports is not a 'once-off' - it's a process; life has ups and downs.

Having reflected on the building blocks that the group felt would be important before the process began, one additional building block that had not originally been explicitly included in the original list was noted for inclusion.

Valued roles in family and community.

Valued roles
in family and
community

It has become clear through the work of the participants, and through programmes such as the 'Enabling Excellence' and the 'Immersion' training programmes that were attended by some of group, that **having valued roles in your family and community are vital building blocks that support community inclusion**. The Next Steps group were of the view that this is so important to living a satisfying and connected life in the community that it merits its own place in the building blocks of this process.

The participants found that regardless of a persons' abilities or need for support the most satisfying and fundamental changes for people come when they develop roles that they know themselves make a valued contribution. Participants of all abilities gained confidence and enhanced community or family connections through the development of a range of valued roles - full or part time employment roles that are held by people are the bedrock of their engagement in the community and a central feature of the person's self-esteem and connection with others. Making a contribution in family or community life can transform relationships and build vital and sustainable connections.

The final observation made by the group in relation to the building blocks, was that in practice these themes are a set of relationships - they are strongly interrelated to each other with each interconnected and in support of the others rather than being a hierarchy.

A note on costings

The 'Reflections on Outcomes' questionnaire included a section that aimed to gather information on the costs associated with transitioning to more individualised supports, as described through the case study work. However, the results of this piece of data collection were not sufficiently comparable to allow any meaningful analysis. What was clear from the data gathered is that the research required to accurately measure the costs involved in providing individualised supports is a complex and detailed task that requires specific research and is beyond the current scope of this project. The Next Steps Project participants would warmly welcome the introduction of a national costing methodology and Resource Allocation Model.

Key barriers, challenges and supports required

Whilst the entirety of this report provides the detailed analysis of the supports and barriers that are identified by the work to date of the Next Steps project in seeking to move to the provision of individualised supports, there are a number of key challenges that the group has identified which require action at a national level in order to support the continued development of this work:

- Whilst the participating organisations welcome the introduction of the *National Standards for Residential Services for Children and Adults with Disabilities*, the group believes that there is a

need for reflection on the balance required to ensure that the burden of compliance does not adversely affect the movement to individualised supports. Participants have noted that the energy, commitment and time required for the innovative work that is necessary to transform services to deliver the vision of individualised supports, has been challenged by the sheer scale of the requirements for HIQA inspection and compliance. There have undoubtedly been positive learning points and improvements for people supported by the organisations as a result of the Registration and Inspection processes, however - in relation to moving to individualised supports the participants are of the view that there is re-balancing required to ensure that the flexibility and autonomy of the person which is at the centre of supporting people to live independent lives of their choosing is adequately catered for within the compliance process.

- There is an urgent need for a sustainable and ongoing source of funding to be identified which will provide access to mainstream housing options for people with disabilities in line with the National Housing Strategy for People with a Disability 2011-2016, and in particular for people transitioning from congregated settings. Currently there are difficulties being experienced by people with disabilities in relation to private rented accommodation; the Rent Supplement (soon to be Housing Assistance Payment); and due to the 2015 exclusion of people whose support needs mean that their home becomes a Designated Centre, from accessing the Capital Assistance Scheme. (If reading online you can [click here for further detail](#)) on difficulties experienced in a National Federation Submission to the Governments Housing Strategy 2020.
- The requirement for a new home to be Registered with HIQA before the person moves in (when their support needs indicate that the house will be a Designated Centre) has led to distress, frustration and missed opportunities. A more flexible approach to allow people to access the living options of their choice is required.
- A nationally available method of accessing individualised funding is required to support the movement to individualised supports; and a clear costing methodology and Resource Allocation Model is required to support the unbundling of existing funding as organisations undertake reconfiguration in support of achieving the vision of self-directed and individualised support.
- Funding streams that are put in place to provide individualised supports must take account of the need for flexibility as people's lives change, and as people age, in order to ensure the sustainability of the process and to ensure that people are adequately supported.
- There is a need to address the lack of availability of accessible locations within the community from which people with significant needs and mobility challenges can be supported to develop socially valued roles and community connectedness. This need requires acknowledgement that for some people with higher support needs the movement to individualised supports in both their living arrangements and their inclusion in community life has additional cost implications.
- Investment in training programmes such as the Enabling Excellence, Immersion and other Social Role Valorization training courses that have taken place have been a key support to the work undertaken. Further investment in such capacity building and training is strongly recommended.

Support for individualised approaches from the Next Steps Project

The Next Steps Project engages in a range of activities and roles designed to support the work of the member organisations in moving to individualised supports, e.g.:

- Gathering examples and information for submissions on key issues to Government Departments and bodies, to support the continued movement to individualised supports and to highlight successes and practical difficulties in this implementation. As an ongoing and current source of evidence in relation to the implementation of policy, data gathered from the Next Steps case studies have provided direct, on-the-ground and up-to-date information in submissions on topics such as the Housing Assistance Payment, HIQA Designated Centres, funding mechanisms and a detailed submission to the Government’s Housing Strategy 2020.
- A Policy Library Reference tool has been developed and will be launched on 29 September 2015 and made available on the National Federation website and will provide an overview of the key policies of relevance to people with disabilities and their families.
- The Next Steps Project has arranged for the dissemination of information about Assistive Technology and its potential uses in supporting people to maximise their independence in living in the community. The group has also arranged for visits to the Independent Living Ireland demonstration house in Athlone.
- Direct work is undertaken with organisations between meetings to support networking and visits with other relevant peers, support on development of specific initiatives and models, and the sharing of research.

The work of the Next Steps Project does not focus on creating pilot projects, but instead undertakes ongoing work that supports individuals in the lives of their choosing, whilst simultaneously forging new ways of working for the organisations involved.

Above all the Next Steps Project aims to create a community of learning which is open, friendly honest, and provides support to its participants in the movement to individualised supports that enable people with disabilities to live lives of their choosing.



There are undoubtedly challenges in achieving these goals, but many of the participants have commented that most important step is the first one; to **just begin and keep the vision and the person at the centre.**



In February 2015, The Next Steps Project was recognised as one of the 39 most “Innovative Practices 2015” globally, at the United Nations offices in Vienna. The project was highlighted at the 2015 Zero Project Conference, an international summit on independent living and political participation attended by more than 400 experts in the field from around the world, for its achievements in supporting people with intellectual disabilities to live lives of their choosing and sharing the learning from developing individualised supports as a community of practice.

[Further information on the Zero Project Award is available at this link.](#)



The participants of the Next Steps Project celebrate their Zero Project Award, May 2015

Appendix 1

Find out more - Next Steps Online Shared Learning Resources

As part of the National Federation's commitment to a shared learning approach, the life stories of individuals who have participated in the Next Steps Project have been shared at two national conferences to date; in 2013 and in 2014. Over 440 people attended these conferences in total. The presentations took a variety of formats, some with individual's stories presented by the person themselves, some by video, and with presentations by staff members, managers, family and community members. Links to a selection of these presentations is provided below:



Next Steps Dissemination Event 2013



The National Federation of Voluntary Bodies hosted an event on 31 January 2013 in Portlaoise to share the learning that emerged over the course of the previous year in the Next Steps Project, attended by Minister Kathleen Lynch. The aim of the event was to highlight the learning from case studies undertaken in 2012 as member organisations as they worked towards the provision of individualised supports for individuals supported by their organisations.

- [The Next Steps Project \(background, structure and themes of the project\)](#) - Alison Harnett, Next Steps Project Coordinator.
- [Managing risk to promote independent living - my journey](#) - Keynote presentation, Martin Doohar, Self Advocate and Next Steps Steering Committee member.
- [The Community Inclusion Project](#) - Liam Quinn, Day Services Manager - SOS Kilkenny.
- [Phase 1 of the In Control Project](#) - Louise Mahon, Project Leader & Christy Lynch, Chief Executive (KARE), Lisa McNabb, Self Advocate and Roisin McNabb, parent.
- [The community-based supported living project Step-In](#) - Benny Cunningham, Area Manager Brothers of Charity Services Roscommon, Niamh McMonagle, Locum StepIn Coordinator, Rachel Kelly, StepIn Project Member.
- [Living a Life - CoAction's Next Steps Project](#) Mary Seymour, Self Advocate and Next Steps Steering Committee member & Mary O'Donovan, Financial Controller, CoAction.
- [If I can do it, you can do it too!](#) Emily Meagher, Self Advocate
- [Reconfiguration of current service delivery to support people to move from a congregated setting](#) - John Collins, Self Advocate; Alan Blythe, Team Leader; Mary O'Donohoe, Team Member & LesleyAnn Kavanagh, Services Manager. Brothers of Charity Services South East
- [Changing within congregated settings to embrace the vision of individualised supports](#) - John Murphy, General Manager; Martina McCormack and Paul Power, Managers - St. Patrick's Kilkenny.
- [Development of new model of individualised day supports in line with New Directions policy](#) Pat Reen, Director of Services, Laura Creaner & Ashling O'Brien, Project Coordinators, Prosper Fingal.
- [Family Leadership & Engagement - Stepping Out and Moving In](#)(Part I) Ciara O'Keeffe, CNM2 - Daughters of Charity. [Part II](#) - Marie Lally, Parent and David Lally, Self Advocate.

Next Steps Dissemination Event 2014

- [My Day My Way](#) - Mary Reynolds, Daughters of Charity. [Film presentation](#) on a community hub developed by Daughters of Charity
- [Iplanit - A tool to guide self-directed supports](#) Ed Byrne and Kevin Hoey, Sunbeam House Services. [Text to accompany the Sunbeam presentation](#)
- [Coming Home - Catherine's Story - Catherine Carey & Lavinia Donoher, Muiriosa Foundation.](#) [Additional clarification re funding of Catherine's support.](#) [Film presentation of Catherine's story](#)
- [A life of my own](#) - Bernie Byrne, Mag Byrne, Louise Mahon and Theresa Nolan, KARE. [Film presentation exploring family engagement](#) in the movement to individualised supports.
- [Home from Home](#) - Ivan Deacon & Kevin Barnes, WALK.
- [Our Own Life](#) - Mary and William Seymour, [photos from Mary and William](#)
- [Are we there yet?](#) Mary O'Donovan, CoAction West Cork.
- [Listen Learn Lead - Moving on from Congregated Settings into Community Living](#) - Lesley-Ann Kavanagh and Liam Tobin, Brothers of Charity Services South East
- [Ideas and Actions sheet](#) from Next Steps Conference

If you would like to get in touch with any of the people involved in the case studies please contact Alison.harnett@fedvol.ie for further information.

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