Immersion Transformation Project:

An evaluation report

Roy McConkey

November, 2014

Acknowledgements

National Federation of Voluntary Bodies

The National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability (National Federation) is a national umbrella organisation for voluntary/non-statutory agencies that provide direct services to people with intellectual disability in Ireland. Their members provide services throughout the twenty-six counties in both urban and rural areas. In all, the National Federation comprises some 59 affiliated organisations who between them account for in excess of 85% of direct service provision for people with intellectual disability in the Republic of Ireland. Their members employ approximately 15,500 staff covering a wide range of professional disciplines providing services and supports to over 22,000 people with intellectual disability.

Genio

Founded in 2008, Genio is an independent, non-profit organisation based in Ireland. It is is driven by a vision of a society that benefits by valuing all of its citizens. Genio brings together Government and philanthropy to help develop and scale, cost-effective citizen-centred services so that everyone has the chance to live full lives in their communities. Genio is supported by the Atlantic Philanthropies in collaboration with the Department of Health and the Health Service Executive. Genio works in partnership with all stakeholders to re-configure resources to reform services, in order that they reflect national policy and international best practice. Established in March 2008, Genio Limited is an Irish registered Company and also a registered charity (CHY 19312).

Roy McConkey

Roy is Emeritus Professor of Developmental Disabilities at the University of Ulster, Northern Ireland. A psychologist by training and a native of Belfast, he has previously held posts in England, Scotland (with Brothers of Charity) and the Republic of Ireland (with St Michael's House). He is visiting professor at the University of Cape Town, South Africa, the University of Sydney and at Trinity College, Dublin. He has been involved in an evaluation of Genio supported personalisation projects and with a HRB funded research project led by Dr Christine Linehan at UCD examining moving from congregated to community living.

His latest book due to be published in 2015 is: '*Disability in a Global Age: A Human-Rights Based Approach'* co-edited with Edurne Garcia Iriarte and Robbie Gilligan from Trinity College, Dublin and to be published by Palgrave Macmillan.

Disclaimer

Contents

Executive Summary

In 2013, the National Federation of Voluntary Bodies launched the Immersion Programme with a grant from Genio Trust. Its aim was to support deep seated reform in how people with intellectual disabilities are supported to live lives of their choosing and which would lead to socially valued roles in the community. The programme had three main components.

(1) It started with a unique, five-day residential conference attended by nearly 300 participants from the change teams identified by 25 services across Ireland consisting of people receiving support, family carers, frontline staff, service managers, CEOs alongside HSE and community personnel.

(2) The Change Teams then undertook to identify and support three people who wished to be supported to live self-directed lives; maximising natural environment supports and facilitating their community belonging.

(3) A further feature of the Immersion programme was a twinning arrangement where organisations who have already made a commitment towards individualised supports, would twin with an organisation who was just beginning this process.

An evaluation of the programme was commissioned with three main aims. Firstly to celebrate the achievements; secondly to share the learning gained with respect to the actions that helped service transformation and the difficulties and barriers that had been encountered, and thirdly to identify the national issues that required to be addressed. Various sources of information were accessed during the evaluation: progress reports from participating services, questionnaire responses, interviews with change team leaders, focus groups with people supported, family carers and frontline staff, and a validation event held as a follow on to a General Assembly meeting of the National Federation.

This report contains a succinct account of the high level learning to emerge from the Immersion Programme and is aimed mainly at service personnel interested or involved in service reform. More detailed accounts of experiences gained are available in other reports that are available on request.

Six main achievements could be identified from the information gathered for the evaluation. (1) Participants were affirmed and motivated by the Immersion process; (2) partnerships were created across the main stake-holders; (3) new mind-sets were created about how people can be supported; (4) new types of support staff had been recruited; (5) people's lives had changed for the better and (6) community networks had grown. Many further examples were given of more specific achievements that arose in particular circumstances. Thus taken together there is much to celebrate in the relatively short time - 18 months - that the Immersion Project has been going. Moreover there now exists in Ireland a range of services who feel empowered to take forward the personalisation process and who can become a resource to others who have yet to embark on this journey.

Inevitable challenges remain in reforming services. Competing priorities limited the progress that the teams had hoped to make; the leadership tended to fall on committed individuals rather than being a team effort; smaller numbers of people had benefited from new arrangements with few personalised accommodation and support arrangements in place and the proposed twinning arrangements rarely happened. In retrospect none of these issues are too surprising and all provide helpful lessons in how improvements could be made to future initiatives aimed at reforming services.

A continuing concern is how the reform process can be instigated and advanced within services especially those who may be cautious or lethargic about embarking on it. The characteristics of those services that had reformed and those in the process of undertaking a service-wide reform are described but the most common approach adopted has been one of 'parallel reform' based initially on a small-scale model project. However a 'theory of change

model' is proposed to account for the complexities of service reform. This envisages changes in perceptions of disability and how people with an intellectual disability are viewed; changes on family perceptions and aspirations, major shifts in service cultures and the re-visioning of societal policies. This model and similar ones are needed to assist organisations to identify the key steps that are pertinent to their context and to devise an action plan for addressing them. As is very apparent to those services who have embarked on the process of personalisation, the difficult part is re-forming long established organisations.

Respondents in the evaluation identified further national issues which they felt require to be addressed as these had impacted on their attempts to introduce personalised arrangements. The Health Service Executive came in for particular mention in terms of difficulties encountered in accessing individualised payments; the pressure they placed on services to fit people into vacancies and the ongoing national restructuring has reduced the attention given to personalisation of disability services. Difficulties in accessing social housing were also seen as major obstacles both in terms of waiting list and issues around rent allowances. Concerns were raised by some agencies about the role of HIQA and how attention had been diverted in preparation for the inspection of services that had started in the past 12 months. A lack of community resources, in terms of natural supports and suitable facilities notably in more rural areas also limited to people's opportunities to lead more fulfilled lives. The identification of these and other societal issues that can impede service reform is an essential element in addressing them. Indeed it is the pressures coming from reforming organisations that will help bring about necessary changes in national policies and practices.

The final section of this report summarises respondents' views on the contribution that the National Federation could make to extend the personalisation of services. These actions equally apply to individual services but there are gains to be made from collective action as the experiences from the Immersion project have demonstrated. Five inter-related strands of work are noted: 1) ongoing training and support for member organisations and stake-holders, especially now that the Enabling Excellence Programme is drawing to a close; 2) the development of a media strategy around changing perceptions of disability and personalisation of services; 3) the promotion of advocacy among persons with intellectual disability especially as part of a national coalition with other marginalised groups; 4) the reshaping of parental expectations and the need for this to happen throughout the services provided to children and 5) continuing to represent the 'sector' in forging partnerships with other Government Departments beyond health and children's services; and with national agencies with whom it has shared interests.

1. It is recommended that this report, once it is agreed, is made available to the change teams in all the services which participated in the Immersion Programme. This circulation might be widened to the broader membership of the National Federation.

2. A second recommendation is that the Steering Group that led the Immersion Programme is recalled or possibly reconstituted and charged with collating responses to the Evaluation Report and proposing a future action plan around personalisation to the National Federation's Board of Directors and the General Assembly. This would take account of available resources and priorities but build on the ethos of Immersion and personalisation.

The National Federation has served Irish citizens with an intellectual disability well for many decades. Its members have spear-headed many initiatives that have transformed their lives for the better and that is wholly commendable. So too the Immersion Programme was another step along a road to better lives and it is commendable that the National Federation felt able to provide the leadership to make it happen. So you can look to the future with confidence that change is not a threat but rather an opportunity. I recommend that ethos to you.

Background to the Immersion Project

Services for people with intellectual disability have a long history in Ireland (Linehan et al., 2013). Provided mostly by voluntary organisations initially at little cost to the State, they encompass the full range of provision that is to be expected of an affluent European country in the early years of the 21st Century.

However the last decade has seen a period of unprecedented challenge and change to Irish health and social care provision. The main drivers in relation to intellectual disability services are summarised in Figure 1.

Personal outcomes

Intellectual disability services have not delivered the outcomes to which people aspire. Self-advocates in Ireland (Iriarte et al, 2014), as well as internationally, have pressed for greater opportunities in housing, employment, education and leisure. McCormack & Farrell (2011) undertook a review of the personal outcomes achieved for over 250 adult persons with intellectual disability across 22 service providers in Ireland and concluded that there was:

Figure 1

> *the need to develop more integrated services, to maintain people in their local communities rather than remove them into special settings and develop more reciprocal relationships with communities.(p. 300).*

The HSE report (2012) on New Directions in Day Services echoed the same change in direction as for residential provision.

> *The range of supports to which individuals will have access should equip them to:*
> - *make choices and plans to support personal goals;*
> - *have influence over the decisions which affect their lives;*
> - *achieve personal goals and aspirations; and*
> - *be active, independent members of their community and society. (p.16)*

UN Declaration Rights

Recent years have seen a radical shift internationally in thinking about disability and chronic ill-health. Medical models of 'care' have given way to new approaches that emphasise removing the social barriers to citizenship and equality of opportunity as embodied in the UN Convention on Rights of Persons with Disabilities (UNCRPD) (2006).

Article 1 summarises its purpose:

> *"to promote, protect and ensure the full and equal enjoyment of **all** human rights and fundamental freedoms by **all** persons with disabilities, and to promote respect for their inherent dignity".*

Furthermore Article 19 states:

> *Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.*

Inclusion International (2012) brought together the experience of self-advocates with intellectual disability and family members across 95 countries to review the international application of Article 19 of the Convention. They concluded:

In high income countries where service infrastructures have been developed they continue to be professionally driven, modelled after institutional care; segregated and isolating. Governments must introduce a reorganization of the service delivery system which requires a paradigm shift by all actors (disability and other service providers, public policy actors, families, employers, educators etc.) towards a system which is directed by the needs and aspirations of people with disabilities.(p.136)

Value-for-Money Review

In Ireland, there are signs that such changes are coming. The latest review of disability policy (Department of Health and Children, 2010) recognises that:

"there is a gap between the policy objectives and what is provided by many disability services. While current policy objectives emphasise 'full and independent lives' the available information shows that many disability services are not organised or provided in a way that supports this goal" (p.3).

This conclusion was further underlined in the Value for Money Review (Department of Health 2012).

The findings from the public consultation conducted as part of the VFM Review clearly show that people are now looking for more choice in disability services and control over how they access them. They are looking for flexible services that meet their individual needs and systems that vest more control with the service user and, where appropriate, their families. These features are not generally available in the existing system, particularly to people with intellectual disabilities. (p.xxi).

Moreover the review proposed that:

The HSE should drive migration towards a person‑centred model of services and supports through the Service Level Arrangement (SLA) process. Demonstration projects should be initiated by service providers as proof of concept and run in parallel with current services, and their suitability for wider application subsequently evaluated.(p. xviii).

Programme for Government

Politicians are now engaged with this agenda for change. The Coalition's Government Programme for National Recovery in Ireland (2011) pledged to ensure that the quality of life of people with disabilities is enhanced and that resources allocated reach the people who need them. Moreover they made this commitment:

We will move a proportion of public spending to a personal budget model so that people with disabilities or their families have the flexibility to make choices that suit their needs best. Personal budgets also introduce greater transparency and efficiency in funding service (p.54)

This promise builds on the funding shift that has taken place in various European countries as well as internationally. A review of the Australian experience with personalised funding reported largely positive outcomes (Fisher et al., 2010).

All respondents said that individual funding had improved their control, choice, independence and self‑determination in their lives. Using a standard measure of personal wellbeing, scores on all domains ... were similar or higher than the scores for the broader Australian population, except for personal health and future security. (p viii).

A similar review in England with over 1,000 users of personal budgets also noted gains but identified certain conditions for success (Hatton & Waters, 2011):

" The likelihood of people experiencing a positive impact from a personal budget is maximised by a personal budget support process that keeps people fully informed, puts people in control of the personal budget and how it is spent, supports people without undue constraint and

bureaucracy, and fully involves carers. Under these conditions, personal budgets can and do work well for everyone".(p.4)

There is also emerging evidence from Ireland around the costs of personalised services (McConkey et al., 2013).

In summary, there are significant pressures on Irish disability services to rethink their service philosophies and reform their mode of operations.

Immersion Transformation Programme

The National Federation of Voluntary Bodies on behalf of its members took on this challenge. A Steering Group[1] was formed and a proposed transformation programme designed. Maria Walls, then Director of Research & Policy Development, made a successful application to Genio Trust to core-fund the programme. In addition participating services would also make a contribution to the costs.

> *The aim of the Immersion Transformation Programme is to support deep seated reform in how people with intellectual disabilities are supported to live lives of their choosing, that lead to socially valued roles in the community.*

The Immersion Transformation Programme was intended to build on existing progressive service development momentum and the energy for change that was already evident in the sector. Such change was in line with Government and HSE policy, and the UNCRPD. Its objectives were to further develop the capacity of individuals, organisations, communities and government departments to enable the transformation of support services to achieve the life choices of people with intellectual disabilities.

The Immersion Programme had three phases:

    (1) Preparation for Immersion (The WHY);

    (2) Week-long Immersion Transformation Programme (The How) and;

    (3) Implementing change in local services and transforming services (The Doing).

Change Teams

The programme was intended to create an internal dialogue in organisations between the key stakeholders as one of the key change strategies. In preparation for Immersion, each organisation identified a Change Team comprised of two people supported by the organisation, two family members, two board members, two frontline staff, two senior staff members, the CEO along with selected community and HSE Departmental representatives. The benefit of this dialogue lay in the exploration of the potential for community engagement and on building of a shared vision for change. It is rare for this broad range of stakeholders to have the opportunity for such shared learning and development.

Intensive Event

The main focus of the project was a five-day, residential Immersion Transformation Programme in HOW to make such change a reality. The programme took place in the Malton Hotel, Killarney in late April 2013 and was led by international experts but grounded also in

---

[1] Bill Ebbitt HSE, Colette Kelleher Cope Foundation, Francis Coughlan SOS Kilkenny, Breda Crehan-Roche Ability West, Margaret Whitehead SOS Kilkenny, Adrian Noonan & Brian Hayes - Seasamh, Avril Webster Parent representative, Paul Doherty Genio, John O' Brien, Michael Kendrick, Kendrick Consulting Intl, Maria Walls, Caroline Looney, Mary Barrett & Kathleen Greaney, National Federation of Voluntary Bodies

the experiences of Irish organisations who had developed individualised supports. Nearly 300 people took part from 25 organisations (see Appendix 1). Further details of the programme and participants are available on request.

Each organisation also chose a Mentor on the transformation journey from the national and international presenters. This was to be part of the on-going transformation phase and involved setting key actions to be attained by three months, six months and 12 month reviews.

Supporting people into personalised arrangements

Each organisation was to identify and support three people who wish to be supported to live self-directed lives, maximising natural environment supports and facilitating their community belonging. In the main these were people who wanted a change in their support or were new entrants to the service. Often they self-selected themselves but services also identified persons whom they thought would benefit from a change. Some services successfully applied to Genio for grants to facilitate these new developments.

Twinning

The project was to be underpinned by a twinning arrangement where organisations who have already made a commitment towards individualised supports, would twin with an organisation who was just beginning this process. This relationship was viewed as a critical factor in the implementation phase. The aim was to share experiences between the agencies of the reform process and create a synergy in the management of change. It was also to create the opportunity for constructive critical dialogue between the agencies, to advance the reform actions and to assist each other in trouble shooting and addressing the challenges encountered.

Follow on

Participating services were asked to provide a six month written report describing the impact of the Immersion event and actions taken. A further written report was requested after a further 12 months. In addition, a one-day, follow-on seminar was held in September 2013 which was also open to new participants interested in finding out about service transformation. This provided an opportunity to show-case the experiences of Irish services and gave participants an opportunity for round-table discussions on the main issues they had encountered and possible ways of overcoming the challenges encountered.

Enabling Excellence

In response to service requests for further training and mentoring for their staff, Genio Trust in collaboration with the National Federation organised Enabling Excellence training led by Hope Leet Dittmeier. The aim was to enhance the capacity of service personnel to promote high quality supports so that individuals achieve Supported Self-Directed Living (SSDL). The training consisted of four modules each lasting three or four days (14 days in all) over a six month period. A key element of the training was to prepare one SSDL Leader in each organisation who would facilitate certain exercises and activities between modules in order to support learning in the practice setting. It was intended that these leaders would become 'in-house' resource people for services as training is rolled out to the wider organisation. In addition senior managers of organisations had to attend two of the training days and they were encouraged to join the SSDL Management Leadership Forum made up of senior managers from services which had participated in Immersion and another Genio training programme: *Endeavour for Excellence.*

Evaluating the Immersion Programme

The National Federation invited Roy McConkey in June 2014 to undertake an evaluation of the Programme. The aims of the evaluation were:

- **Celebrate achievements:** The evaluation would identify examples of good practice within Ireland around the personalisation of services. These lessons would serve as a model for others as well as evidencing the feasibility of transforming services.

- **Share the learning:** A major rationale for the evaluation would be to identify the learning gained with respect to the actions that helped service transformation and the difficulties and barriers that had been encountered. The evaluation report would provide a succinct summary of the high level learning gained by participating services that would be accessible and widely available to staff and family carers.

- **National Issues:** The evaluation would help to identify national issues relating to service transformation that may be difficult if not impossible to resolve at a local level. These issues could be taken forward by the NATIONAL FEDERATION in their ongoing dialogue with national agencies and Government.

Following Maria Walls resignation from the National Federation, Colette Kelleher (Cope Foundation) and Francis Coughlan (SOS Kilkenny) along with Mary Barrett (National Federation) agreed to act as the Steering Group for the Evaluation.

Figure 2 illustrates the sources of information that were available or were sought over the course of the evaluation.

Participants' reactions: Participants in the two major events (April 2013: September 2013) had completed evaluation questionnaires that identified what they had learnt from the event, how the learning impacted on them; what they found most challenging and how the National Federation could further support services.

Progress Reports: The leaders of the change teams were requested to submit a written progress report six months later (19 services responded) and again in March 2014: 12 months after the Immersion event (20 services responded). These reports gave information on the progress made in relation to the change teams, the development of individualised supports and twinning arrangements (see Appendix 2).

Figure 2

Change Leader Interviews: The change leaders of ten services agreed to take part in a telephone interview about their experiences on Immersion. Two others were approached but did not reply. The semi-structured interviews covered the following topics: the impact that the Immersion event had on them personally as well as the other people from the service that attended; the selection of people involved in the personalisation of their services; the factors that contributed to successful outcomes for the people; the barriers encountered and how they were or might be overcome; experiences of twinning with other services and how the future might unfold with respect to personalisation within their service. The interviews lasted around 30 - 40 minutes.

People's experiences: Two focus groups were held in Dublin and Kilkenny attended by over 40 participants mostly people receiving personalised supports (including those with profound

disabilities), family carers and frontline support staff. The intention was for people to share their experiences of the new arrangements; any difficulties they encountered and how they overcame them. We wanted to have the reactions of people who had most to gain from the project. Participants recounted their stories and discussed issues of common concern. In all, three hours of recordings were obtained.

General Assembly: Roy McConkey gave an oral presentation on the initial outcomes from the evaluation. He was assisted in this by change leaders in three of the participating services (Cumas New Ross; St Hilda's Service; and Gheel Autism Service) alongside reactions from representatives from HSE (Suzanne Moloney) and Genio (Fiona Keogh) plus John Hannigan, Sunbeam House & Chairperson National Federation, contributed on housing issues. Around 30 senior staff from a range of services attended the two hour event that followed on from a National Federation General Assembly Meeting that took place that morning in Monasterevin.

A great deal of detailed information arose from these various sources, some of which is documented in various reports that are available on request. However, the remainder of this report identifies the high level 'messages' to emerge, all of which could be found among the various types of responses received and across all the various respondents to the evaluation. Moreover, they can be further validated by the findings emerging from other evaluation and research projects currently underway (see McConkey et al., 2013: Linehan et al, 2014).

Achievements of Immersion

Figure 3 summaries the main achievements as perceived by the respondents in the evaluation.

Affirmation and Motivation: It was striking that most of the service participants in the Immersion Programme were already persuaded of the merits of personalisation but they felt that Immersion had further affirmed the 'rightness' of this new direction and were motivated to continue along this road. The feeling of solidarity that was engendered at the week-long event contributed greatly to this as they may have felt like lone pioneers lacking in expertise and only too aware of the risks they were taking.

Figure 3

Stake-holder partnerships: Immersion was unique in bringing together such a variety of participants to the same event – people who receive support with the frontline staff who provide support; service managers and CEOs with family carers; HSE and community personnel. This bold move more than paid dividends not least in giving everyone a shared vision of what personalisation should mean and how it can be brought about. The contributions from international figures in this area lifted people's horizons beyond the obvious realities they faced in service delivery and challenged them to critically review present policy and practices. Likewise the experiences of Irish colleagues demonstrated that change was possible. The costs incurred by services in funding attendances and releasing staff proved to be a valuable investment.

New mind-sets were created: Participants at the Immersion event spoke of a profound change occurring in their thinking; of 'light-bulbs going off in their heads'; a 'Eureka experience' and 'it all making sense'. Family carers too spoke of being more optimistic and feeling more in control. This change was as much of the heart as it was of the mind. This is no mean achievement with this cadre of self-selected participants: many of whose lives had already been immersed in intellectual disability. In practical terms the shift was from "doing things for people" to "listening to what people wanted to do". All seem agreed that the

personalisation process demanded new mind-sets at all levels within organisations but also beyond; extending into the HSE and Government thinking.

New support staff recruited: Following on from the above, a new type of support worker emerged as services moved towards personalisation. Often these persons had little or no prior involvement with intellectual disability services and did not come with the "baggage of how things are usually done". Rather they tended to be well connected in their communities and good at relating to people.   Other services looked to redeploy staff through seeking volunteers and those appointed tended to be more "adventurous, creative, questioning of established routines and advocates of change". Equally service managers had to adopt new supervision and mentoring arrangements in which supporters were trusted to do what was best for the person supported as often the contact was outside of service locations.

People's lives have changed: Many stories were given in interviews and at focus groups as to how people's lives were now different: such as a severely disabled woman and wheelchair user who travels by public transport to a local crèche where she reads stories to the children using her voice synthesiser. Or a reluctant day centre attender who now tutors classes in advocacy for new entrants to the service. People are living with people of their choosing and needing less support as they do more things for themselves. Family carers reporting feeling less stressed at having no longer to fight with services.   All these changes were attributed to the influence of Immersion and the stimulus for change engendered. In addition, some services had successfully obtained project funding from Genio to facilitate the transition.

Community networks have grown: Services were more outward looking and more connected into community resources. People and their supporters had linked with College courses, leisure facilities and employment opportunities. They were interacting with housing agencies, transport providers and social welfare staff. In general, they tended to avoid segregated activities by focusing more on local community facilities and opportunities. In part this was facilitated by the new support staff that had been recruited but also by the aspirations of the people they supported for whom ordinary life activities were a priority. Ironically many existing services in Ireland claim to be community-based but the Immersion Project has brought home how often they are apart *from* the local community rather than being *a part* of the community.

Conclusions: Many further examples were given of more specific achievements that arose in particular circumstances. These are summarised in Appendix 3 in terms of their impact of people supported, family carers and service staff as well as organisational impacts. Taken together there is much to celebrate in the relatively short time - 18 months - that the Immersion Project has been going. Moreover, there now exists in Ireland a range of services who feel empowered to take forward the personalisation process and who can become a resource to others who have yet to embark on this journey.

Continuing Challenges

Implementing reform was not without its challenges. As with any new venture, unalloyed success rarely happens and indeed there is as much learning to be gained from a lack of achievement as there is from accomplishments. Figure 4 summarises the continuing challenges raised by respondents during the evaluation. Once again this listing is not exhaustive but rather identifies those commonly expressed 18 months into the process. It also serves as a reminder of the ongoing work required to support

Continuing Challenges

Competing priorities
Committed individuals
Small numbers of people
Fewer new living options
Twinning rarely happened
Non-participating services

Figure 4

further personalisation of Irish services.

Competing Priorities: The ambitions and enthusiasm with which participants left the Killarney event met the cold light of reality in the months afterwards. For service personnel competing priorities placed a brake on the process and limited the progress they had hoped to make. Two in particular were mentioned. Services faced another round of financial cutbacks in 2013/2014 and this created financial uncertainty as to how new initiatives might be funded. Also the Health Information and Quality Authority (HIQA) were starting their inspection of services and this put additional pressures on services to ensure their buildings-based provision could pass scrutiny. These pressures may be particularly acute for new styles of services that are only beginning to emerge whereas with longer-established providers of personalised services, these constraints had a stronger counter force that might have mitigated their impact.

Committed Individuals: The concept of change teams that had worked very well during the Killarney event seemed to lose momentum in the succeeding months albeit to a lesser extent in some services than in others. The result was that the personalisation process fell on the shoulders of certain committed individuals and became less of a team effort especially when their role was not clear. For example, links with HSE personnel were not followed up due to personnel changes in that organisation. Also slow progress made it harder to retain the engagement of people supported and of family carers. The achievements noted above are a tribute to the individuals who continued to provide leadership to the process but the organisation risks losing this expertise should they leave their post.

Small numbers of people have benefitted: The goal had been for each participating service to identify three people for whom personalisation of support would be a goal. In general this target had not been met 18 months later and various reasons were given. The whole process of personalisation requires a great deal of time. First, it takes time to identify the needs and aspirations of the person by deep listening and building a trusted relationship. It cannot be rushed. Second, translating their dreams into reality is also a slow process which may require negotiations and resources that cannot be quickly obtained. For example, family carers spoke of the amount of time it took to get a personal budget from the HSE. The frustration felt by some respondents came from the recognition that many more people wanted and deserved personalised support but they were unable to deliver it.

Fewer new living options: The chief aspiration of Immersion was to bring about more personalised living arrangements for people with intellectual disability, especially those leaving family care or who were unsuitably placed in existing accommodation options. After 18 months, many fewer people than hoped had obtained their own place. The chief reason seemed to be difficulties in finding appropriate housing. Consequently, services had focussed more on accessing alternative day-time activities for selected persons. This seemed more manageable and addressed identified needs, especially for young people leaving school.

Twinning rarely happened: A major feature of the Immersion Project was to be the twinning of services so that they could mutually support and learn from one another. However this rarely happened and among the reasons given was the geographical distances involved, the lack of shared culture among the agencies, the potential for competition among neighbouring services and differing stages in the implementation of personalisation. In a few instances when twinning had worked it took the form of shared training events between similar services that were at similar points in the process even though they were not in the same locality. Perhaps this outcome is not too surprising given the newness of this initiative which logically makes sense but for which there were few precedents among members of the National Federation.

Non-participating services: The final challenge is one that did not come from the participants directly but rather it comes from an outside observer. In a sense the Immersion Project leaves untouched a sizeable if not major proportion of services for people with an

intellectual disability in Ireland. This is a reasonable stance initially as it would have been most ambitious to launch a single change programme that embraced all service providers assuming of course that they would be willing participants. Yet there seemed to be no coherent plan at the outset as to how non-participating services would benefit from the investment in Immersion. Arguably this remains the case and it is a point that the report will address later.

Conclusions: Immersion was an ambitious project that inevitably has its continuing challenges. In retrospect none are too surprising and all provide helpful lessons in how improvements could be made to future initiatives aimed at reforming services. Appendix 4 contains a summary of the strategies proposed by participants at the follow-on meeting of Immersion held in September 2013.

Producing Deep-seated Reform in Services

The main aim of Immersion was to produce deep-seated reform in services. Other informants spoke of needing to 're-invent services', or 'radically altering the Intellectual Disability sector' and of 'revolutionising service cultures'. Indeed many of the drivers identified at the start of this report would justify such dramatic changes. Yet existing health and social care structures and systems often seem impervious to change at worst or slow to change at best. Some have likened it to turning round an ocean-going liner. In this section of the report the insights on service reform gained from the evaluation are summarised and discussed.

Figure 5 attempts to summarise some of the insights that respondents provided in terms of bringing about organisational reform. Existing services could be divided into two groupings; those who have embarked on the reform process and, as noted above, the larger group of those who have yet to do so.

Figure 5

Within these broad groupings certain sub-groupings could be discerned. The relative number of these agencies is unknown so the diagram is perhaps more hopeful than realistic. Ongoing research by Linehan et al (2014) which contrasts services with differential progress in moving from congregated services should help to elucidate these issues further.

Perhaps the group that is most threatening to national change are those who might be labelled **'self-satisfied'** in that they claim they are already providing personalised services and hence there is no need for them to change. In this instance their words speak instead of their actions. Hopefully this is a small and diminishing group of service providers as the understanding and examples of personalisation become more evident across Ireland.

There are likely also to be some agencies for whom the term **lethargic** is more appropriate. They are not persuaded of "these new approaches" and remain content to continue doing what they have always done. Life and let live could be their philosophy.

Perhaps the largest groupings are those labelled as **cautious**. They are aware of the implications of the national debates and open to change but perhaps are unconvinced that there is any great demand among their service users for change. They are also wary of

changing the service structures and procedures that have stood them in good stead. They would welcome reassurances that the necessary reforms will be manageable and worth the effort involved in changing.

Admittedly these three descriptions may be speculative but echoes of them will have been heard at National Federation meetings as well as in other places including the HSE and Department of Health. For now though, the challenge is to promote the counter-narrative arising from organisations that have embarked on a programme of reform and change. The hope is that their experiences and examples will encourage the cautious, disturb the lethargic and challenge the delusional. The following schema is intended to assist service agencies to reflect on where they are in relation to personalisation and the strategies they are currently using as recounted by informants in this evaluation.

Reformed organisations: There are examples of some agencies that have undertaken major reforms of their service culture, structures, policies and procedures towards more personalised services. However, they would maintain that this is still an ongoing process as by definition, personalisation demands innovative responses as people's needs change and new challenges come along. This service grouping existed before Immersion and indeed were probably instrumental in encouraging the National Federation to undertake Immersion. Although these 'reformed' agencies were represented in the project it did not convert them so much as affirm their work to date and increased their enthusiasm and confidence. These agencies have strong leadership from the top and throughout the organisation. They have inculcated new management and staffing cultures alongside new staffing and support arrangements. A majority of their service-users will have more personalised supports and these are likely to be maintained despite cutbacks due to their cost effectiveness.

Reforming Organisations: Another sub-grouping are those who have committed to reforming their organisation and have instituted plans and procedures to bring about changes across the whole organisation, such as the re-organisation of responsibilities of senior managers and the provision of training for staff. Immersion certainly seems to have spurred them on and given them the tools and procedures for making change a reality. They have embarked on personalised provision for some service users and have plans to extend this as the change agenda rolls out.

Parallel Reform: Possibly the largest subgroup at this point in time are agencies who have set up a parallel reform project within their services as a means of identifying the means for making it work, gaining expertise in implementing it and unpacking the implications for their present practices. Indeed this is a strategy recommended by Genio Trust (Keogh, 2014). For example a small team may have been set up of a manager and support workers who will support a group of people identified as requiring new forms of support. Immersion seems to have encouraged these services to begin this process but they are conscious of the need for further support which Enabling Excellence has provided. However these agencies seem particularly susceptible to competing priorities such as was described earlier when it comes to making progress. The challenge will be rolling out the learning from the 'pilot' project across the whole agency. The risk is that they may slip back into the cautious category described above.

Deciding to Change
- Do we need to change?
- Have we the will to change?
- Is change for some or for all?
- Have we the personnel?
- Have we the resources?
- Have we a futures plan?
- Have we a shared vision?

As a summary, Figure 6 lists the key decisions that services may need to reflect on in deciding into which of the six categories they fit. The last two are especially important. Given the current emphasis by government on personalisation, what is the future plan for an agency if they decide NOT to be part of this shift?

Crucially though, greater clarity is required around the meaning of personalisation; both in concept and in reality. For example the description presented by the HSE in their Disability Policy Review may need expanding to emphasise the following[2].

- The supports will bring benefits to the person;

- They are quality supports;

- They address not just people's needs but also their aspirations, preferences, talents and abilities;

- Congregated models will need to be intentionally decreased to free up necessary resources;

- A mix of natural as well as formal supports is provided;

- Person-centred planning must be followed through with person-centred actions;

- Preference must be given to arrangements that increase the degree to which a person is assisted to obtain a greater degree of social inclusion.

Theory of change

A recurring theme throughout the evaluation was the paradox between the simple idea that underpins personalisation – namely building supports around the person according to their aspirations and needs – with the complexity of bringing it about in practice within established services. A common comment was the need for changed mind-sets. Figure 7 outlines a possible theory of change in this respect. The most basic involves perceptions of disability and a shift from focussing on people's deficits and dependency towards appraising their talents and promoting their self-reliance.
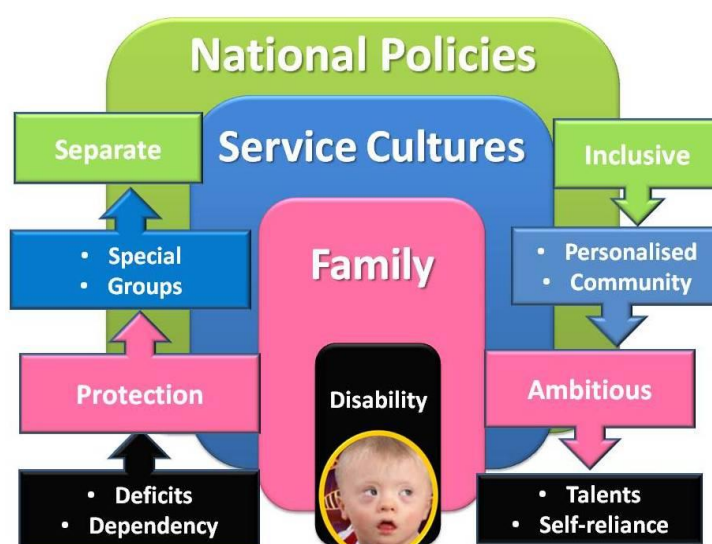
Figure 7

In this respect one staff grouping that was notable by its absence from the change teams involved with Immersion were clinicians such as psychologists, doctors and therapists as well as social workers. This may not have been intentional but it is suggestive of a shift from a medical model of disability with its focus on 'fixing' or remediating deficits.

Another major shift in mind-set is required from family carers as many informants noted and which other studies have reported (Keogh, 2014). They are often aware of their relative's vulnerability so a priority for them is that they should receive special care and protection and they have trusted services to deliver these outputs. However this has been at a price, in that they have not dared to hold the same ambitions for their disabled son or daughter as they have for their other children. Personalisation offers another approach that does have risks but promises a better life for the person and indeed the family carer.

---

[2] Commentary provided by Michael Kendrick in briefing paper for the Immersion Conference.

Service cultures also need to shift from a focus on special (usually segregated) provision designed for groups of people towards an individual model than is centred around natural communities and mainstream provision. As noted previously this requires a total re-appraisal of organisational structures and practices (McConkey and Keogh, 2014). In particular, Human Resource and Finance personnel should be actively involved in the change agenda. Board members also must understand and be supportive of the changes to the models of service they may have created in times past.

A final mind-set shift needs to occur in national policy-making. Traditionally disability is hived off into a separate stream of policy formulation and implementation whether it be in Government Departments, the HSE and other major statutory and semi-state agencies. The challenge is for disability to be included in national policies for all Irish citizens. This change will not come easily given the upwards pressures that come from the other levels in the system to maintain the status quo. However an inclusive policy approach will also assist in furthering the change agenda 'back down the line'.

Conclusions: A theory of change model – and not necessarily this one although it might provide a useful starting point – should assist organisations to identify the key steps that are pertinent to their context and to devise an action plan for addressing them. As is very apparent to those services who have embarked on the process of personalisation, the difficult part is changing the organisation.

National Issues

Respondents in the evaluation identified further national issues which they felt require to be addressed as these had impacted on their attempts to introduce personalised arrangements. At the National Federation General Assembly meeting Suzanne Moloney from the HSE was present and additional commentary on housing was provided by John Hannigan, Sunbeam House & Chairperson National Federation and on national policy by Fiona Keogh, Genio. However further work is required to try and resolve some of the issues that the evaluation has identified and no doubt there are others that could be added to the list.

National Issues

HSE	• Funding Individuals • Pressure on placements • Priorities within HSE
Housing	• Social Housing Lists • Rent Allowance • Access to capital
HIQA	• Traditional Provision • Flexibility • Personal Outcomes
Community	• Few natural supports • Lack of community resources • Further education and work

Figure 8

Health Services Executive (HSE)

A recurring theme in the evaluation was the ambiguous role of the HSE: on one hand their policies were very supportive of personalisation but actions on the ground often impeded its implementation. Three main themes dominated comments made about the HSE.

Individual payments: The difficulty in accessing individualised payments for people who had not been in receipt of a service previously, such as school–leavers. Although some respondents noted that this form of payment had been awarded it took a long time and a lot of persistence for it to happen but at least a precedent had been set.

Pressure on placements: The HSE continued to refer people to congregated settings or to day centres and seem reluctant to reallocate funds or to commit to other options. The cost-effectiveness of new styles of provision is still questioned when the evidence is there that it can lead to cost savings overall.

National Priorities on HSE: The ongoing re-organisation of the HSE has meant new staffing arrangements and changing in personnel; some of whom seem unaware of HSE policy with respect to disability services. Acute hospital provision and care of the elderly often receive greater priority than intellectual disability services.

The ongoing restructuring of the HSE presents additional challenges at this time but once complete, new opportunities could open up around shared working locally and nationally to address issues of common concern.

Housing

The Department of Environment, Community & Local Government came in for much criticism especially with respect to the views expressed in some local offices that "they do not deal with people who have intellectual disabilities; they are dealt with by health". Three particular issues were noted.

Social Housing Lists: People with intellectual disabilities may be on waiting lists for a long time as they do have the same priority for housing as other groups such as single parents. Moreover the accommodation offered to them maybe in unsuitable areas where they risk abuse and exploitation.

Rent Allowance: Two common comments were the inadequacy of the allowance in covering the costs of reasonable accommodation and that some private landlords were reluctant to accept tenants in receipt of rent allowance. These two issues severely restricted the housing options available to people with intellectual disabilities.

Access to capital to build housing units: Restrictions of how capital monies for social housing is assigned, precludes disability organisations from creating housing units that could be let to tenants whom they support. In other jurisdictions wider options are available to increase social housing provision.

Participants at the General Assembly recognised that the 'crisis' in social housing affected many other marginalised groups in Irish Society. Political action was long overdue and continual lobbying was needed. The laudable intentions behind the housing strategy for persons with disabilities are not being realised (Department of Environment, Community and Local Government, 2011).

The National Federation gathered issues being experienced by member organisations and the people they support with regards to housing in July 2014. A submission was made to the Government's Five year Social Housing Strategy, and the document was also circulated to the Value for Money & Policy Steering Group and the Housing Sub Group tasked with the implementation of the National Housing Strategy for People with a Disability 2011-2016. The housing submission can be accessed at the following link: http://www.fedvol.ie/_fileupload/Publications/NATIONAL FEDERATION%20Submission%20to%205%20Year%20Social%20Housing%20Strategy%20 July%202014.pdf

Health Information and Quality Authority (HIQA)

Participants welcomed the contribution of HIQA in ensuring that minimum standards were met in the delivery of services to persons with intellectual disability. However they had a number of concerns relating to future registrations and inspections.

Traditional provision: The standards against which services are judged by HIQA relate mainly to traditional models of services. The concern was that this might inhibit the development of alternative models of provision and divert resources to improving models of provision that do not provide value-for-money.

Flexibility: Related to the foregoing was a concern that it would be more difficult for services to make flexible responses in line with people's needs and aspiration given that the standards have to apply to all provision.

Personal outcomes: As has been argued elsewhere in relation to service standards, a more appropriate focus should be placed on the outcomes for persons in receipt of services which indeed is happening with the United Kingdom Regulators for example. Members of the National Federation had been to the fore in identifying personal outcomes as a primary indicator of service quality and fears were expressed that this emphasis would be lost.

While the National Federation is engaged in ongoing dialogue with HIQA, through the Providers of Residential Services for People with Disabilities Forum, in relation to these and other issues of concern to National Federation member organisations, the issues need to be constantly raised to ensure that they are successfully addressed (see National Federation submission to HIQA - Feedback to HIQA regarding Registration & Inspection of Residential Services for Children & Adults with Disabilities, October 2014). Some persons attending the General Assembly were of the view that HIQA inspections apply only to registered accommodation and that they were not relevant when it came to individualised provision in or from people's own homes. Nevertheless the energies involved in preparing for inspections and responding to the reports may detract from embarking on transforming services.

Community Resources

Finally some further challenging issues were raised that related to the communities in which services operated and the life histories of the people supported.

Few natural supports: For many people embarking on personalised supports their family networks provided the natural supports often needed to become more socially included. However some people have lost contact with their family or they have outlived their parents and siblings. It has proved difficult to recruit others to the role of natural supporters especially when people move into neighbourhoods that are new to them. In these situations there remains a heavy reliance on paid supporters and peers with intellectual disabilities.

Lack of community resources: In more rural settings especially, there was a dearth of community facilities for people to access and a lack of public transport to travel to the opportunities available in the nearest towns. One solution is for people to find accommodation in towns where they are within walking distance of facilities but this can prove difficult.

Further education and work: The opportunities for further education and to undertake vocational training courses is limited for school-leavers and even more so for older persons who missed out when they were younger. Again major towns and cities are advantaged by the educational provision that is available there. Employment opportunities have been created in Ireland through work experience, voluntary work and supported employment schemes. These need to be tied in with personalisation of services.

Community issues such as those noted here do not only affect people with intellectual disability but apply to other marginalised groups who cannot drive or afford a car that would enable them to extend their social networks beyond their immediate neighbourhood. In this respect services have common cause with other agencies promoting community development.

Future Contributions from the National Federation

The final section summarises respondents' views on the contribution that the National Federation could make to extend the personalisation of services. Of course these actions equally apply to individual services but there are gains to be made from collective action as the experiences from the Immersion project have demonstrated. It is unlikely that any one service would have had the impact that the Immersion Project has had. Figure 9 summarises five inter-related strands of work that the Federation could consider taking forward in the coming years.

Training and support: The National Federation is well established in this role and it is one that should be continued. The Enabling Excellence programme is coming to a conclusion; a valuable element of which has been the development of local service trainers. There would be value in the National Federation providing some form of ongoing support for them such as establishing a training network with a programme of refresher sessions.

There is the possibility that these trainers could perhaps adopt a collegiate approach to the training courses they provide: for example running courses that are open to all the services in their geographical area.

There would be value too in exploring how

Figure 9

these courses could be accredited and located with an established training agency in order to ensure the long-term viability of training opportunities that will be essential for the national roll-out of personalisation.

The National Federation might also consider developing further training targeted at specific personnel who seem to have been less of a priority thus far, such as Human Resource staff, Finance and clinical personnel.

Media Strategy

The National Federation is well placed to co-ordinate a media strategy that will inform the wider public but more especially family carers, about the 'good news' stories that are accumulating from recent experiences. In the main, the focus would be better placed on local newspapers and radio rather than the national media. This may help with the recruitment of natural supporters as well as educating the wider public, such as local politicians and community leaders, about the changed priorities in services.

Advocacy

The National Federation has a continuing role to play in advocating on the national issues identified above. However this advocacy needs to be set in the context of the stake-holder partnerships that were at the heart of Immersion and especially those with people with intellectual disabilities. Their advocacy is critical in ensuring that not only are personalised services provided to those who want them but also that they can challenge the quality of services they receive through their use of complaint procedures and whistle-blowing. Of course this advocacy needs to be promoted within local services also but there is extra value in having a national advocacy coalition.

Family Expectations

Reshaping parental expectations is a major undertaking and requires a coherent approach across service providers and an ongoing engagement with parent associations and advocacy groups. Arguably Inclusion Ireland has a key role to play in this as well as Syndrome/Condition specific groups such as Down Syndrome Ireland but the National Federation could assist their members in re-appraising the implications of the personalisation agenda within the services they provide to children and families.

Partnerships

Immersion was ground-shifting in the sense of the partnership working engendered, especially with mainstream, community agencies. These local alliances need to be replicated at a regional and national level. The National Federation is well placed to represent the 'sector' in forging partnerships with other Government Departments beyond health and children's services; and with national agencies with whom it has shared interests such as the Disability Federation of Ireland.

It would be unrealistic to expect the National Federation to respond to all these proposals given the limited resources at its disposal. However the detail of what they chose to do is not as important as the process used to decide on their future priorities. Just as Immersion aimed to produce a 'deep-seated reform in services', so too a similar re-formation or re-configuration may be needed into the future role and purpose of the National Federation. Hence the proposals outlined in this section are better viewed as a stimulus to debate among members and not a proposed programme of action. In due course, an action plan will emerge with defined outcomes possibly based on a logic model[3] that captures the revitalised purposes of National Federation.

The Next Steps

The end of the Immersion Project also marks a beginning: but of what? In the spirit of Immersion, the stake-holders need to be party to that decision.

1. Hence my first recommendation is that this report, once it is agreed, is made available to the change teams in all the services which participated in the Immersion Programme. This circulation might be widened to the broader membership of the National Federation.

2. My second recommendation is that the Steering Group that led the Immersion Programme is recalled or possibly reconstituted and charged with collating responses to the Evaluation Report and proposing a futures action plan around personalisation to the National Federation's Board of Directors and the General Assembly. This would take account of available resources and priorities but build on the ethos of Immersion and personalisation.

3. My third recommendation is in truth a recommendation. The National Federation has served well Irish citizens with intellectual disabilities for many decades. Its members have spear-headed many initiatives that have transformed their lives for the better and that is wholly commendable. So too the Immersion Programme was another step along a road to better lives and it is commendable that the National Federation felt able to provide the leadership to make it happen. So you can look to the future with confidence that change is not a threat but rather an opportunity. I recommend that ethos to you.

---

[3] Taylor-Powell, E., & Henert, E. (2008). *Developing a logic model: Teaching and training guide*. Available from: http://www.uwex.edu/ces/pdande/evaluation/pdf/lmguidecomplete.pdf.

References

Department of Environment, Community and Government (2011) *The Housing Strategy for People with a Disability 2011-2016*. Dublin: The Stationary Office.

Department of Health and Children, (2010) *Summary of Key Proposals from the Review of Disability Policy*. Dublin: Office of Disability and Mental Health.

Department of Health (2012) *Value for Money and Policy Review of Disability Services in Ireland*. Dublin, Department of Health.

Government of Ireland (2011) *Government National Recovery Plan 2011-2016*. Dublin.

Hatton, C. & Waters, J. (2011) *The National Personal Budget Survey.* In Control and Lancaster University.

Inclusion International (2012) *Inclusive Communities = Stronger Communities: Global report on Article 19: the right to live and be included in the community*. London: Inclusion International.

Iriarte, E.G., O'Brien, P., McConkey, R., Wolfe, M. & O'Doherty, S. (2014) Identifying the key concerns of Irish persons with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, doi:* 10.1111/jar.12099.

Keogh, F. (2014) *Supporting people to live self-directed lives in the community: learning from 54 Irish Projects.* Mullingar: Genio Trust.

Linehan, C., O'Doherty, S., Tatlow-Golden, M., Craig, S., Kerr, M., Lynch, C., McConkey, R., Staines, A., & Walls, M. (2013). *Mapping the National Disability Policy Landscape.* Dublin: School of Social Work and Social Policy, Trinity College Dublin.

Linehan, C., Craig, S., Kerr, M., Lynch, C., McConkey, R., O'Doherty, S., Staines, A., Tatlow-Golden, M. & Walls. M. (2014) *Responses to a Reconfiguration of Disability Support Services in Ireland.* Paper presented at IASSIDD European Congress, Vienna July 2014

McConkey, R., Bunting, B., Ferry, F., Garcia-Iriarte, E. & Stevens, R. (2013) *An Evaluation of Personalised Supports to Individuals with Disabilities and Mental Health Difficulties*. Mullingar, Genio Trust.

McConkey, R. & Keogh, F. (2014) Transforming organisations to deliver more personalised housing and accommodation supports in disability and mental health services. *Administration, 62(1), 91-118.*

HSE Working Group Report (2012) *New Directions: Review of HSE Day Services and Implementation Plan 2012 – 2016*. Dublin: HSE

Taylor-Powell, E., & Henert, E. (2008). *Developing a logic model: Teaching and training guide*. Available from: http://www.uwex.edu/ces/pdande/evaluation/pdf/lmguidecomplete.pdf

Appendix 1: Participating Services

1. Ability West
2. Brothers of Charity Services Roscommon
3. Brothers of Charity Services South East
4. Brothers of Charity Southern Services
5. Carriglea Cairdre
6. Cope Foundation
7. Cumas New Ross (formally Co Wexford Community Workshop)
8. Dara Residential Services
9. Daughters of Charity Disability Support Services
10. Gheel Autism Service
11. Leap
12. Kerry Parents & Friends Association
13. Malta Services Drogheda
14. Peamount
15. Prosper Fingal
16. RehabCare
17. SOS Kilkenny Ltd
18. St. Christopher's Service
19. St. Hilda's Services
20. St John of God Community Services
21. St Margaret's Centre
22. St. Patrick's Centre (Kilkenny)
23. Sunbeam House Services
24. WALK
25. Waterford Intellectual Disability Association

Appendix 2: Feedback Questionnaire

Immersion Monitoring & Evaluation March 2014

Dear Immersion member,

Continuing on as part of our requirements to meet Genio's evaluation and monitoring of the implementation of *Immersion – Towards a Good Life* there are a number of questions we need you to answer on behalf of your organisation. To this end we would appreciate if you could complete the short form below.

Organisation name:

Contact Person:

1. Please advise of the progress of your change teams work since September 2013 evaluation. *For example*

a) how many meetings have you had,

b) what actions have you undertaken,

c) what have been the key focus of discussions, and

d) what are the key learning points to date.

 2. Can you please confirm the names of the people that you are supporting into an individualised support as part of the Immersion Project *(please use their initials for reasons of confidentiality)*

2a) What progress have you made in arranging individualised support?

2b) Please give us a brief summary of any barriers/ difficulties you have encountered in arranging individualised support

3. Please advise details on the number and type of contacts that you have with your twinning partner and how the relationship is developing.

4. Please give us a brief summary of any barriers/ difficulties you have encountered in your twinning arrangements?

5. Would you be willing to take part in a telephone interview regarding the implementation of Immersion?   **Yes:**   **No:**

If yes please provide a contact phone number _____

Appendix 3: Perceived Impact of the Immersion Programme

The impacts deriving from the Immersion programme as reported in interviews and focus groups are summarised here in terms of the main stake-holders: the person with intellectual disability; family members; support staff and service impact. These are illustrative of specific instances at a moment in time and may not be common across all participants. They are listed in no particular order.

Impact on people supported.

➢ People are doing what *they* want to do.

➢ They are doing ordinary things like going for a pint, watching football matches.

➢ More mature, more confident, less shy; more outspoken, making own decisions.

➢ Out and about more – using public transport.

➢ They are chairing their planning meetings.

➢ Doing their own fund-raising.

➢ Organising days out for themselves and friends.

➢ Acting as a mentor/trainer to other service-users.

➢ With those who challenge- there are fewer tantrums and behavioural episodes.

➢ People with multiple disabilities and wheelchair users have personalised supports.

➢ Less need for support as time goes on.

➢ Living with people they have chosen.

➢ People are working in range of settings.

Impact on family carers

➢ They have a new-mind set about their relative –they see them as competent.

➢ They are fearful of their relatives being vulnerable and rejected – they did not ever expect to see them joining in community activities.

➢ They are more optimistic and open to more ideas.

➢ They feel more in control of the decision-making around their relative.

➢ Families feel less stressed as they are no longer fighting with services but maybe working harder to support their relative.

➢ The circle meetings have included family members which they have enjoyed.

➢ Start with families who are sympathetic and interested.

➢ Use parents to advocate and advise other parents.

Impact on support staff

➢ Looking at the person through new eyes.

➢ Establish close links with the family.

➢ Build trust with the family.

➢ Visiting the person at home means you learn more about them.

➢ Start where the person is at and go at the pace of the person.

➢ You don't need to fill every hour with activities.

➢ Be flexible and fluid – go with the flow set by the person.

➢ Go for quality in fulfilling person's interest.

➢ Persevere – things do not happen straight away.

➢ Prepare to join in with the person's choice of activities – be part of it!

➢ Attitudes change with other staff see success with people they know in their own services.

Impact on services

➢ We're getting to know the whole person rather than parts of a person.

➢ People have chosen their own support staff.

➢ We are more focussed on our local community.

➢ Moved to a community hub that is central and on bus routes so that people have access to local facilities such as leisure centres, college courses.

➢ People are on work experience and some have jobs.

➢ Using public transport more – including people in wheelchairs.

➢ Avoiding segregated activities such Special Olympics, Arch clubs.

➢ Utilise available funding to build supports around the person.

➢ No quick fix – there are many aspects to prepare for living independently with support.

➢ We hold regular reviews every four months to make sure was are getting it right.

➢ Management ask for regular progress reports.

➢ Staff within service have different levels of knowledge so we need to bring them all along including HR and finance.

➢ 'Fresh people have been recruited as support persons.

➢ Difficult to get individualised funding package from HSE but it has come through.

➢ Availability of transport in rural areas is a problem.

➢ Keeping the Board members of the service fully informed and involved.

Appendix 4: Proposed Strategies

Participants at a follow on event to Immersion held in September 2013, were asked to identify the strategies they had used to advance six core themes in the personalisation of services and how they have tried to overcome the barriers they had encountered.

Becoming more person-centred

➢ We should listen to the person and learn how to communicate with the person

➢ The person is our teacher….they can teach us so much.

➢ Getting to know the person in their own environment – understand the person

➢ Less emphasis on limitations and more on abilities.

➢ Careful planning – plan for success

➢ With our systems the person often has to adapt to the system rather than other way around.

➢ Less "staff centred" in our planning.   Facilitate the person to be in the centre – take small steps.

➢ Our attitudes need to change; get out of our comfort zone.

➢ Respect and good manners.

➢ Treat the person how you would like to be treated.

➢ Ensure people are making an informed choice.

➢ The person is the centre of any discussion.

➢ Information sharing

➢ Encourage Advocacy groups.

➢ Matching people with supporters of common interest

Family involvement

➢ Worked with one family at a time.

➢ Hold family information sessions – family forums.

➢ Hold celebrations for achievements.

➢ Leadership training for families.

➢ Service Providers could be more helpful in facilitating families for training e.g. manual handling. One to one may be more suited rather than a group training session.

➢ We should not assume that we know what families want. Families might come up with ideas.

➢ Don't be afraid to ask families for help - support should be shared with families.

➢ Families should be the drivers for change but older generations find it hard – work with younger families.

➢ A lot of the same family members come forward – we need to widen the group.

➢ Letters and information leaflets need to be more imaginative; less black and white text.

➢ Service User involvement with family carers.

➢ With the set ups, we have there is often great enthusiasm initially but it often fades.

➢ Noted that the traditional way can also work of meeting parents etc. if the person were listened to.

➢ Difficult for families. Sometimes difficult to come to terms with some decisions.

➢ Families involved only in fund raising.

➢ Family control of the pot of money.

Roles for support staff.

- ➢ Empathy with the person.
- ➢ Good observer, good communicator.
- ➢ Spends time getting to know the person
- ➢ Need to be flexible - support person to have a good life.
- ➢ Innovator - creative. Prepared to manage risks.
- ➢ Similar interests and hobbies to the person supported.
- ➢ Shared culture
- ➢ Building bridges into community and finding resources
- ➢ Direct and increased family contact.
- ➢ Explore networks of mutual friends
- ➢ Importance of circles of natural supports.
- ➢ Keep things on track
- ➢ Review the process and adjust if need.
- ➢ Know when to step back.
- ➢ Importance of training for support worker – this is vital.

Management issues.

- ➢ Management have to be flexible.
- ➢ Communication between management and the person plus their family and support staff needs to be a two way process.
- ➢ There is a good match between the person supported and the staff working with them.
- ➢ Put focus on managing risks not avoiding risks.
- ➢ Management to give time to do training.
- ➢ Reduce the amount of time spent on paperwork.
- ➢ Frequency of reports – weekly report might be enough
- ➢ Approach from staff to families – speaking in plain talking – good communication and must be tailored to suit the family.
- ➢ Change from a five day service to 7 or 8 hours individualised time so that people grow their network support
- ➢ Meetings are held in a person's house.
- ➢ Clarify issues around safe guarding and use of volunteers.

Funding

- ➢ People need to know where their money is coming from
- ➢ Some people are over funded and others underfunded. Some are piggy backing on others.
- ➢ Review how funds are managed - can they be managed differently? Debundle the costs.
- ➢ Different ways of sourcing finance – e.g. rent allowance
- ➢ What resources are available? Are there different connections to be made?
- ➢ What can other people bring in terms of resources e.g. friends, family, community supporters?
- ➢ Within the community there are things that don't cost anything; looking at what is available.

- It's not all about money, it's a collaborative process.
- More transparency to families around costs.
- Support people on how to manage their own money – new levels of responsibility – training needed
- Our business plans to HSE should demonstrate cost effectiveness.
- Buying hours for activities.
- Greater collaboration between agencies would save money.
- Focus on connectors in local communities rather than one-to-one formal support.
- Moving people back into their own community works.
- House mates can support one another.

Partnerships

- The most important partnership is with the person we are supporting (see above).
- Create personalised supports and identify partnerships to make this happen.
- Enhance partnership with families. More information shared with families.
- Start conversations. The lead organisation is committed to partnerships, willing to share knowledge.
- Open communication between services.
- The various day services in an area should be open up to each other- create forums – pool resources and communicate.
- Partner with local VEC local colleges,
- Partnerships with local amenities, shops, gym etc.
- Employment opportunities with local employers, cooperatives, Chamber of commerce
- Educational facilities. Special education schools with TY students. Experience more community activities during school and after school.
- Establish links with the new local councils and political representatives..
- Equality between all the partners.
- Join together for cost effective training.
- Reaching out to other providers and share experiences and resources.
- A directory of expertise within organisations to enhance shared learning. National Federation is a vehicle for this.