



Research on Self-Directed Lives:
Perspectives of People with Disabilities
and Families

Good Lives

by the
Research Group on Self-Directed Living

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Foreword

This report captures in a microcosm an ongoing struggle in Ireland and abroad to honour the value, distinctiveness and humanity of people with disabilities. The Research Group on Self-Directed Living has done this by starting with the unique journey in life that each person has undertaken and what has arisen out of the search for a good life in each instance. In this way, this report captures the value of starting with the uniqueness of each person and how the conditions of life that they have each faced have been engaged and addressed to the advantage of that person.

These are brief stories of intentional and thoughtful efforts to enable each person concerned, their family and allies to develop strategies that could serve to enrich each person's life prospects. While many challenges faced them it is impressive what has been accomplished by taking direction from the person and their needs and hopes in life and working towards a response to these that would be beneficial. What may be lost in this brief capturing of what has been achieved "one person at a time" is the value that can come from using an outlook and approach that does not start with a standardised model of service or support, but rather with the question of what can be done to enable a given person to obtain and enjoy the rich possibilities embedded in normal lives in the community.

This is not an accidental advantage stumbled upon in some random manner, but is instead a reflection of a growing area of practice and thinking that has borne similar fruit in the lives of countless people with disabilities in all manner of lives and lifestyles in the community. What this report illustrates in a small number of examples is that personalised lifestyles, largely directed by the people themselves are both feasible and desirable. In other words, what has been done in ten instances has revealed what can occur in thousands more if faithfulness is kept to keeping the person and their search for a good life that suits them at the centre of all decisions.

It also illustrates that while services and professionals may usefully be part of supporting the process, they must be extremely careful to not undo the authority and power of the person and their families by substituting it for their own. Hence, the "person centred" approach will be fatally undermined if it is not always accompanied by self-direction. These examples serve as proof that many others in Ireland would also benefit from such opportunities as this approach provides and it is imperative that they too get their turn at having a good life that suits them well. This will necessarily challenge the current system and its approach, but with so much promise to be had, there is no choice but to move ahead.

Michael J. Kendrick PhD

Independent International Consultant in Human Services and Community Work

Introduction

The wave of self-directed living is a worldwide phenomenon, one which has been felt in some places earlier and stronger than others, but clearly a global occurrence that is inexorable. Its growing influence has been felt by some in Ireland for some time now. This wave shifts perception away from seeing people with disabilities as passive objects in need of care, to equal subjects and citizens in charge of their own lives.

Self-directed living means people living good lives, ordinary lives, in ordinary places, as opposed to 'special' lives in separate, segregated places. They can be extraordinary lives as well. Self-directed living is also about providing people with the resources to take control. These resources include money, but also, perhaps even more importantly, the skills and abilities to articulate a vision, advocacy skills, communication skills, and, to a certain extent, public speaking skills. Within that process individuals will build confidence and ability to put across what it is that they are looking for.

The authors of this report represent a collective of individuals from Leap, the Centre for Disability Law and Policy (CDLP) NUI Galway, Sunbeam House Services, Áiseanna Tacaíochta (A.T.) and Fionnathan Productions. The group formed in 2014 and this is its first research project together. Through it, we hope to start a conversation among family members, people with disabilities, friends and supporters who are self-directing currently, or who are trying to move their disability supports to individualised supports or those who have a deep interest in this area but are not yet in a position to seek individualised supports due to lack of information or other reasons.

We began the Self-Directed Lives - Family Perspectives Project with a public presentation in Galway by Michael Kendrick PhD in March 2015 titled 'Enabling Good Lives For People In Difficult Times.' In this talk, Michael attempted to provide "a better appreciation of what can enable people to have good lives even in circumstances that may be adverse for them and their allies". He highlighted "the need for a concentration on employing our strengths and those of others creatively and using resources within our communities and networks that are largely overshadowed much of the time by an over reliance on money rather than people as a key resource in enabling good lives."

Following this presentation we hosted three Regional Workshops on Self-Directed Living during the month of April, in Galway, Mullingar and Dublin, inviting people with disabilities and families interested in learning more about self-directed living in Ireland.

Mostly, the three workshops were formatted identically, so that the same presenters attended each, following the same outlines in each place. The unique component in each workshop was the contributions and engagement of the participants, as those who came to each were invited to reflect and share in conversation about their own thoughts, feelings, and questions.

The presentations fell into two types.

The first type were actual stories of people with disabilities and families supporting a family member with disabilities in Ireland today, each in their own unique way, all seeking good lives. The family members who shared their stories focused on those parts of their family biography when choices were made and actions taken that caused things to start to go well. This report is not only a compilation of the stories shared from the podium, but added to those are stories of other families who attended the events, and graciously offered to share their approaches, successes and ongoing questions. The reason for this focus on what actually works in real stories was articulated by Rachel Cassen, a founding member of the research group: “We’ve been telling our war stories for years, and we’ve been getting nowhere. So we tried to move, very consciously, from the problem definition into a space of solution focus. What does success look like? What does a good life look like?”.

The second type of presentation at our three workshops focused on universal issues. These were given by individuals who, through a combination of research and experiences, are able to speak with authority about the history, international perspectives and theoretical framework of the movement toward self-directed living. Throughout the family stories below, you will find quotes concerning these universal issues, adding additional context. Links to video recordings to all presentations can be found in the appendix of this report.

We intend with this project to create a counter-narrative to the usual ‘deficit accounting’ way of describing the lives of people with disabilities and their families. The core purpose of the report is to show through individual stories how self-directed living can happen, at a variety of ages, from young children to school leavers and adults – and what other individuals and families who want to make this happen in their own lives can learn from these experiences. Each story contains key messages about how and why things started to work.

Traditionally in Ireland funding has been allocated to service providers who then offer a set menu of services to people and families. Increasingly people are seeking greater choice and control over how their funding is used. Many of the families in the stories presented in this report have managed to access some individualised funding for themselves or their family member. They have achieved that by getting a clear sense of what good support looks like for them and by working out what they want to do with that support. Then they have managed to convince the ‘powers that be’ to support them. The supports people have chosen have enabled them to go to college, move into a home of their own and direct for themselves the type of therapeutic, social or educational supports they require.

What follows is a series of contemporary stories of families and individuals in Ireland who have built their own surfboards and learned to surf. Although affected by disability, they have not let others’ definitions and expectations limit their approach to achieving good lives. The report also includes information on the key ingredients for building a successful system to support self-directed living in Ireland, as drawn from the ideas of participants in the three workshops described above. We also seek to place these stories and ideas for change in the context of current efforts to reform disability law and policy in Ireland and to provide practical guidance to people with disabilities and their families on how to set out on a journey of self-directed living.

Family Stories

Connie's Family Story



Brian is the father of a family of four living in Leitrim, with two daughters: Constance, age 10, who has Down Syndrome, and her sister Luchia, who is 9 years old. Connie attends mainstream school, and is doing well.

Their basic philosophy when it comes to meeting Connie's additional needs is "to do as much as we can for ourselves, and with other families in similar circumstances". They are involved with the local branch of Down Syndrome Ireland, and also on a national level, hoping to make a difference for their own family's lives, and particularly for Connie.

When she was younger, she received Speech and Language supports, but there was a lot of turnover in staff. Also, the quality of instruction and support varied: some were very good, some were "just OK". Brian and his wife recognise that speech development is quite important in the early years, and they were concerned that this lack of stability in services was impacting her well being.

Because the situation provided through government agencies was so far from ideal, they worked at community level, building a network of families with similar concerns, and are now self-funding professional speech and language services for a group of children and young adults.

As a individual family, they have been able to secure from the HSE support for After School Care. They sought this because they saw the need for Connie to have more interactions with peers than was available during the normal school day.

“What you see around people who are living self directed lives is a really impressive social landscape that needs to be acknowledged, including peer support, where families and people with disabilities themselves provide support and guidance and role modelling of the kind of life the individual wants to live.”

Dr Piers Gooding, Centre for Disability Law and Policy

Brian notes that one important element in their success in acquiring the right level and types of supports for Connie is that they have involved themselves in developing relationships and clear communication with HSE and school staff, “explaining to them the needs and why we felt it was necessary”. He feels that this is an early indication of what is possible when you make a case from something outside of what is established.

“Organisations like Down Syndrome Ireland (DSI) are great, but there is still so much that you have to do as a family unit.” He finds that the local DSI branch helps develop closer relationships between families who know and experience local issues, whereas the national organisation is slower and more “institutional”. Brian recognises its usefulness and importance for families, though, as it achieves good things over the longer term.

“It’s useful for families to work together in family based organizations, not just around the notion of support groups - that’s OK, that will take you some distance - but in terms of sharing really useful knowledge. Because we are the people who are living some of this stuff, we can support our family member to live a good life.”

Rachel Cassen, Leap

Brian’s experience is that there is a lot of support and focus to insure that children are well looked after in the early years. Now that she Connie is becoming older, opportunities lessen, and services seem to drop off. He attributes this to a decrease in “political weight” influencing policy decisions and the funding of programmes for older children, and is concerned that the will to adequately address the needs of individuals is even weaker when they reach adulthood.

The next step is to look at how they can support Connie to become more self-directed. “When the child is younger, the parents are taking cues from the child, but making many decisions about family life by looking at family interests in general, rather than specific interests of individual members. As they begin to assert their personality, parents have to take a different view, and to change how you deal with that. We’re evaluating how we’re interacting, and how we’ll need to interact with service and community to make sure she has a good life.”

Keith's Family Story



Catherine is the mother of a family living in Sligo with five children. Her son Keith has autism. His passage from childhood to adulthood has been very different from his siblings. There were no rites of passage, no major increase in the amount of choices, no open days or people looking to get him into their college. As a school leaver, his next place was unclear all through the summer. And when a place was provided, it was "not a great match". One of the fellow passengers on the bus each day alerted Catherine to some serious behaviour issues which were occurring, that may have resulted in a serious accident or incident. Something had to change.

The HSE provided eight hours of support, initially staffed by a person from a home help panel. Catherine had to make up for the time not staffed, so a decision was made that she would reduce her hours working outside the home and devise a community based program enabling Keith to have ordinary experiences and integrate in his local community.

One of the most rewarding activities was a small handmade card business developed by Catherine with Keith. This has raised in excess of €1,500 for charities, giving Keith recognition

and also meaningful work.

After reviewing what Keith needed, the family opted to become employers. The HSE offered monies in direct payment. This was an amazing opportunity for Keith to have control over how he was being supported and affording him choice in the way his service would be delivered.

He signed up for a Certificate in Contemporary Living course at St Angela's College in Sligo, in conjunction with the National Institute for Intellectual Disability. When he arrived at the college for his interview, he told his mother, "I do this myself." She waited in the hall for three quarters of an hour, while he was interviewed on his own, a milestone in Keith's growing independence.

After successful completion of that course, Keith went on to complete the Pathways to Possibilities programme. This course caused the family to ask the question 'What is the good life?'. Keith looks to his brothers as role models. They went away to college, live on their own, have jobs, and travel, so Keith has sought and achieved many of the same things for himself. His family came to recognise that a good life includes family, friends, education, and travel, as well as 'to be a valued member of one's community'.

Keith now owns his own car and house. The car was purchased for him by his family, and his supporters drive him where he wants or needs to go, but he is responsible for maintenance, NCT, and filling the tank with petrol.

He has moved to his own home, a house that formerly belonged to his grandmother. When he moved in, he designed the layout and purchased furniture. He has total control and autonomy when it comes to being a home owner.

Keith has travelled a lot, visiting twelve countries and many places around Ireland, travelling with family members and friends. He was delighted to visit his brothers in Australia and New Zealand, a surprising success, after Keith's earlier experiences with local transportation. He saves to fund his own holidays, and has big travel plans for the future.

One area of life that needs work is Keith's search for employment. Although he has had his own business, he wants a steady job where his strengths are recognised and he can get a regular income.

Catherine says that she and Keith's father have had to learn to stand back and respond to requests rather than directing Keith's life, to give him freedom to make his own choices. This is an approach that services that support him have embraced, though in some cases not so readily. Ultimately, though, they recognise Keith is much happier this way.

"There is a place for professionals in our lives. But that place is to do very specialised things to enable us to lead a good life. We've got to be very clear about what we want them to do, and be very persistent, bulldozer-like persistency, in asking specifically for what we want. That doesn't mean it's going to happen easily."

Willie Walsh, Clan Beo

Catherine says, “When we set out on this journey ten years ago, we met with some reluctance. It was very difficult at times. As we have continued to support Keith and allow him to direct his destiny, we have received encouragement and a willingness to embrace this model. Dreams take work, but they’re worth it.”

“What is a good life? The regular and reliable presence of family and friends, the chance to make a contribution, valued roles, being loved, and a home of your own. They are perhaps some of the foundational pieces of a good life.”

Rachel Cassen, Leap

Sophie's Family Story



Kate is the eldest sibling in a family of six from Athboy, Co Meath. There are two brothers and two sisters, all now adults, and her sister Sophie has an intellectual disability.

Kate says, "If you can imagine the ideal family for supporting their family member to direct their own life, our family is the opposite of ideal." Her father works many hours in Dublin, and rarely spends much time in Athboy. Kate and her two brothers attended boarding school, so the only few social connections the family has in Athboy are through her mother and Sophie.

Sophie attended a special school in Delvin 20 minutes away. Integration into the community has been an uphill struggle. At the age of 19 when Sophie left school, she was placed in a sheltered workshop, a day programme in Athboy, as this was the only option. She attended that programme until the age of 27. During that time, she "regressed dramatically", exhibiting depression, behaviour problems and an eating disorder, and Kate sees it as the worst period in their family's life.

Sophie has difficulty communicating. "She was telling us what was wrong, but we weren't able to interpret it." Sophie's only respite from her unhappy life was coming up to visit Kate in Dublin every second weekend. From this and visits to her brothers, she saw how her siblings were living: away from home, independent, with their own jobs. As she had none of this, she became frustrated for long periods.

Her mother, Helen, wrote consistently to the Muiríosa Foundation, asking for some significant change in the ways that Sophie's needs were being addressed. Consequently, when the Muiríosa Foundation started the Person Centred Wing, and Sophie fit the necessary profile, she was the first person put on the scheme.

“Funding was never given as block funding. It was we ourselves, as service providers, who were putting it into segregated group arrangements, building group homes, opening day centres, and putting people's money into it. ”

Mary Kealy, Former Chief Executive of Brothers of Charity

The co-ordinator for Sophie's planning was about the same age as Sophie, which was a great help toward Sophie forming a trusting connection with her. She worked for about 6 months, meeting everyone in the family, asking how each person could see themselves being a help to Sophie. And, over this time, the co-ordinator found out what Sophie wanted: her own home, and a job.

An apartment was found just five minutes' walk from the family home, in a nice area, and Sophie signed her own lease. To ease the transition, the plan was to have her sleep there a few nights a week, initially. However, on the first weekend, Sophie packed her belongings and left for the apartment, and did not come home for a visit for three months.

“People in general were absolutely miserable, they had very unhappy lives. they were basically being incarcerated in a large sheltered workshop, group homes, smaller day centres. And the complaints from people were 'I've no job.' 'I've no money.' 'I've no friends.' 'I miss my family.' 'I'm lonely.' 'I'm bullied.' 'I want to be paid.' and 'I want to get out of here.'”

Mary Kealy, Former Chief Executive of Brothers of Charity

The amount of skills she had to learn in a short time was incredible. Kate and the rest of the family realised that they had completely underestimated her abilities. She said, “Locking the door, using the phone, cooking, washing - we had always done these for her.”

Helen agrees with her. “Firstly what really amazed me is how much Sophie wanted this independence. This was a complete bolt out of the blue for all of us. Before Sophie left home I treated her like a child and pretty much told her what to do. Since that I have learned to treat Sophie as an equal. That brought about a big change in the way the rest of the family and the way other people treated her. I realise now I was just not showing her the respect everyone deserves.”

Helen goes on to say, “Incidentally it was frightening how speedily she learned to use an ATM machine. From that experience I have learned that it is so important to listen and try to

understand what her needs are.”

Funding was redirected for her from Muiríosa, and about ten hours of individual support per week was provided. Every day someone comes for a few hours. Helping Sophie to integrate into the community is the main job of the support staff. They are generally young women. Sophie has to like them if they are to be successful.

“We’ve got to start doing it. It’s not enough to wait for anybody else, for policy makers, for government, for state agencies, for service providers to do it. And they won’t do it unless we demand it, and show that it can be done.”

Dr Eilionóir Flynn, Centre for Disability Law and Policy

It would be easy for Sophie to stay at home and spend hours watching television, so finding the balance in support between letting her do as she wants and pushing her beyond her comfort zone, going to a concert, etc., is an important thing to get right. One of the challenges is that Sophie doesn’t have a lot of peers that are her friends. Had she gone to the mainstream schools, she would likely have a deeper social network. The lack of community connections is an ongoing problem.

Sophie has a job as a kitchen assistant in a crèche, and recently increased the amount of time she spends there from 2 days to 4 per week. Meaningful work is a massive part of her happiness and sense of self worth. She also volunteers at a lunch club for the elderly. Recently, she joined Macra na Feirme.

As well as being a daughter and sister, Sophie is an aunt, and a valued member of the family. Two years ago, she flew on her own to London to visit her brother. And this summer, she visited her other brother in France.

Harry's Family Story



Jo is a single parent and the mother of twins who are 15 years old, named Harrison & Haley. Harry has autism, and has attended five different schools. His placement in the first primary school he attended lasted for two years, when his parents were called in and told the school couldn't manage him.

The family went through the entire summer without a place in another school for Harry, until, at the last minute, a place was offered at a school 25 miles away. Although he was doing well there, the commute was taxing. When a new school with an autistic unit attached opened 5 or 6 miles from their home, the family decided that a school in the local community would be preferable.

There were major teething problems at the new school, however. The staff weren't trained properly to work with students like Harry and, after a year and a half, he was frequently out of control at school. Multiple pages of notes were sent home every day, and it was difficult to read so much negative feedback. Reading between the lines, it was clear that Harry was on the road to expulsion.

"It was very stressful, and we were all in very dark place," Jo recalls.

During that summer break, Harry said, "I can't go back there". His mum realised it too. She started to home school him then, and continued for two full years. During that time, she got to really know her son.

Eventually, they decided it was time to reenrol him in the standard school system. But, with a

record of having caused trouble at previous schools, it proved difficult to find one that would take him. Finally they found the Saplings School in Kilkenny, a school designed to cater to children with Autism and Complex Needs. Upon first meeting, the Principal said, "I really don't think this would work. He's much more advanced than the other children here." She took a moment to reflect, though, and said, "Every child deserves a school, to be mixing with other children. Maybe we should give it a try."

This proved to be an excellent placement for him. Although the complexity of challenges that most of the students had was greater than Harry's, that wasn't a problem. He went from being an 'underdog' to the 'top dog' in the space of a year.

Harry now attends the Good Counsel College in New Ross, a mainstream secondary school with 850 students. His mother credits the transition programme that the school designed for him as the key to successful integration into the school. The plan allowed him to attend only a half day per week for a few weeks, then one day per week, then two, etc., until he was attending the full week. "My son is a smiling happy boy now." The Principal at the school recently said to her, "Jo, there are 850 boys in this school. If I had to pick the happiest, it'd be your son."

"We have lost a lot of things from community that we need to build back in. We need to make sure that we as communities are there for each other, that we are welcoming, and that we all play our part as active citizens."

Dr Eilionóir Flynn, Centre for Disability Law and Policy

The other essential ingredient for success in supporting his integration into school life was healthy communication. Jo was impressed when Harry was brought into the discussions planning his school participation, and listened to when asked what he wanted. To make the transition a little less abrupt, the teacher who would be primarily working with him took photos of all the areas he would be attended.

Another important support for Harry and his family is Home Share. In this Genio funded programme,

families can volunteer (with very small financial benefit) to involve someone with a disability in their lives. It took about a year to set up the programme and to train the host families. Then families are linked up with each other according to the children's interests.

Harry was linked up with "an amazing guy, who we now consider a family friend". He takes him every second Saturday. In the morning they go to the Mart, with cattle sticks and wellies - all the farmers know him. Then they will spend part of the day engaged in household chores: cutting the grass, chopping logs, etc. Last week, all day was spent moving furniture. Harry feels a part of the family, and that's very important. "I don't want services that we don't have a personal relationship with."

Jo shares some of the important lessons she has learned thus far. Communication between Harry and all the people in his life is key. Having some kind of plan, visualising what you want

down the road is also very important. In dealing with service professionals, she recommends that one is firm and clear, but friendly. She has adopted the sandwich approach: start with complimentary feedback; then get straight into the meat of it, "what I'm looking for"; then finish off on a positive note.

"Working with professionals, we have to acknowledge their fear and their insecurities, and where they are coming from. If you go in with an attacking attitude, the barriers go up, you'll be labelled an aggressive parent, and very little will get done."

"Positive partnerships with services is useful. I think it is possible and certainly profitable to go into services with the aim of building relationships. You don't have to like everyone, you don't have to particularly get along with them, but to go in, and to be positive."

Rachel Cassen, Leap

Her own vision for the future began with her answering the question What do I want for my son? : "To have fun, and that he can make a contribution to the community."

Recently, Harry showed aptitude when helping a neighbour set up their lawn furniture. This experience led to a lawn mowing contract. Then Jo arranged a second contract with another neighbour, who asked, "Can he do windows?". This request caused Jo to think of a special gadget with water soap and squeegee all on one handle, which would likely allow Harry to get the job done well. She knows through experience that thinking of Harry's way of meeting the world as characterised by a 'learning difference' is more useful than putting labels on him. "Your own attitude will effect everything," she says.

She encourages others to always listen to the key stakeholder. When Harry's doing what he loves, everyone is happy. "I decided that I will get a good life for my son. He deserves it, and he can do it, but he needs support."

Maitiú's Family Story



Mick Quin and Roisin Moran are the parents of three children: Annie, age 31, Maitiú, age 24, and Josh, age 23.

Mick says, "When Maitiú was born, it was a big learning curve." They only found out that day that he had Down Syndrome. "There was lots of shock and awe at first, and then the calm of his presence." During the years before Maitiú went to school, his parents swapped over who was home to care for him.

Maitiú's early years were spent in Dublin. He went from mainstream school to a special needs school when his Special Needs Assistant support was pulled, and his parents decided to move him to a smaller classroom with more individual attention, and enrolled him in St Michael's Special School.

As a boy, Maitiú had speech therapy, when it was available, maybe twice or three times a year. "But every time we went nobody knew us. We had to do those things ourselves. If you want someone to be able to do anything well, it needs time and input."

When Maitiú was age 11 they moved to Westport, thinking it would be a better place to raise the family. St Anthony's Special School in Castlebar was very productive, although not always easy. Roisin says, "It was always hard to get him to go to school regularly. In the end, in despair, I asked his teacher to give him something practical to do that he enjoys, and to just forget about teaching literacy. She was adamant in her belief that Maitiú could learn to read. It took years from then, but it made a difference that she believed in his ability and stuck to her guns. Then one day, Maitiú sent me a text. I'll never forget that moment. I stood on the side of the road

and cried. Now he can send and read any text he needs to. It taught me never to give up on his desires but to search and search for a way to make them come true."

"Ordinary is the most precious thing in life. 'Special' doesn't do anyone any favours. In fact, it leads to a pretty bad life for people."

Mary Kealy, Former Chief Executive of Brothers of Charity

Maitiú has a good relationship with his siblings. Typical adult siblings - normal stuff. Mick figures there was some understandable jealousy from them toward their brother, because Maitiú got all the attention. "As a parent, you don't notice, because you're doing it 24 / 7 or more like 28 / 7."

Maitiú always loved film, acting out his favourite roles for himself and for family. He used to dress up with his brother for party shows in the kitchen. And he loved playing guitar, singing and dancing but only for himself. He was incredibly shy outside the home.

The Mayo Chapter of Down Syndrome Ireland started a drama group. They made him a huge hooded cloak. He led the group on stage and sat on a chair to the side for the whole show. Roisin says, "He neither sang nor danced, but that was the start of a new life. The director recognised both his desire and ability, and found a way to support his need at the same time, instead of seeing it as a barrier. Over six years with that group, Maitiú went on to sit without a cloak, to mouth words, to sing, eventually to dance, then to act and speak in lead role." Mick remembers that, during those years, it was the highlight of Maitiú's week.

At an event by Clan Beo, an organisation in Westport supporting people to lead meaningful and contributing lives within the community, they met a woman whose daughter with Down Syndrome was attending NUIG. The next day Maitiú had found a list of colleges using his laptop. Every night before he'd go to sleep he'd say "I want to go to college". His mother said they would find a way, but she hadn't a notion what could work for him.

Through a process of discovery, supported by Claire Murphy from Leap and Willie Walsh of Clan Beo, they found Blue Teapot, a performing theatre and arts group run by the Brothers of Charity in Galway. "We went to see their play, Sanctuary. That was it. Maitiú haunted us day and night. He applied for their performance course. He surmounted all his terrors to do the interview and audition, and was the first person outside Galway to get a place on their three year training course."

That meant they had to find accommodation in Galway. "He came to the various welfare offices and together we spoke on his behalf," says Roisin. He was given rent assistance in a two bed apartment. He signed the lease, and pays the rent. His parents have taken turns at being his flatmate, but the place is his responsibility. Every day for months, he'd get up in the morning and say "My apartment. My own apartment".

Mick and Roisin are separated at the moment. Maitiú lives in Galway with Mick for most of the week, and goes home to Westport to be with his mother most weekends. Mick knows that Maitiú is confused and saddened by his parent's separation.

And yet, their shared concern has helped them to iron things out. "Maitiú has been the catalyst,

the centre. All our hope and dreams, between us all, he's been at the centre of it."

"A lot of times, services deal with individuals. They deal with individuals just as individuals, as if they're not connected to other people. And there's none of us, who are living a good life, that are not connected to other people."

Willie Walsh, Clan Beo

He has only one year left with Blue Teapot so they are looking toward the next phase of Maitiú's life.

They have identified these principles to help guide them:

- to listen to Maitiú, and to seek out the desires behind the words he finds to express himself.
- to find ways to support him to use and develop his abilities
- to strive for excellence and not to give up when there are obstacles; all things come slowly.
- other families and family led organisations are a huge source of inspiration and support.
- services can help, especially when we know what we want from them and we are prepared to stick to our guns.

Owen's Story



Owen works as a Facilities Manager with Muscular Dystrophy Ireland. He suffered spinal injuries, at the age of 21, in a motorbike accident. "In one day I became disabled. I had no idea what disability involved. I was lying in a bed staring at the ceiling for one year thinking 'What will I do? Will I ever do anything meaningful in the rest of my life?'. It was pure shock and trauma. A lot of people were telling me I was still the same person. The only thing I could imagine was a cure."

Owen spent one year in hospital rehab, most of which was spent getting him accustomed to using a wheelchair. At the end of this time, he was faced with the question of where he would live. The professionals working with him advised residential care, because there would be a specially designed bed, bathroom and equipment, staff to get him up and put him to bed each day, everything he would need for the rest of his life.

He moved to a residential ward run by Cheshire Ireland, which he says was "not bad". He had his own room with "a bit of privacy", and was encouraged by staff to do things, and they were reasonably respectful of Owen's needs and wants. The level of care was fine, but he didn't much like the lack of choice in when to get up, or what food to eat. He decided after 3 or 4 years that, as others were moving out from the ward into their own homes, he would begin to look into it for himself.

His family were not supportive of the move, saying, "You'd be better off staying here. You're

well looked after. Maybe in a few years somebody will sort you out.” But he quickly realised that no one was going to do all that was required to live independently for him.

“Focusing on the technique of supporting people with disability won’t solve the problems. More money won’t solve the problems. But, creative solutions and a persistent idea of the good life, and the typical life, will really help.”

Dr Piers Gooding, Centre for Disability Law and Policy

The first hurdle was to get his budget transferred from the residential institute to a support service that could provide staff to assist him living in his own house. He was told that he would need to have a house before he would be given a personal assistance package. But the housing authority told him that he couldn’t have housing without first having a personal assistance package lined up.

Partly to develop his self advocacy skills, Owen attended college, studying Sociology and Politics.

He soon learned that his physical condition meant that he should be considered a ‘medical priority’ for community housing. The Housing Officer said that there was no accessible housing available in the community at that time, and that he would be contacted when something came up. Six months later Owen had heard nothing, and decided to search for himself. Friends advised him to drive around the community and look for what would be suitable.

He discovered that a housing association was building social housing nearby, and they were happy to provide a house to Owen. He worked with architect to build a simple small cottage with two bedrooms and a large living room, with large hallways and doors.

He had only 35 hours of personal assistance per week at the time, mainly to support his attendance in college. With that level of support, he was able to spend two nights per week at his house, and the rest of the time was still spent in the residential institution. When he was granted 120 hours of personal assistance, he moved out, but only after securing a signed agreement that he could move back if independent living arrangements proved unsuitable.

He then transferred his personal assistance package from Cheshire Ireland to the Irish Wheelchair Association, which allowed him to self-direct, hiring who he wanted, submitting pay sheets to the Irish Wheelchair Association, who handled payroll, insurance, etc.

Soon after, Owen met Martin Naughton, a leader in the Independent Living Movement, and became convinced that taking complete control of managing his budget was the way to go, through the *Áiseanna Tacaíochta (A.T.)* model of direct payments.

To do this he set up his own limited company, so that he could be his own provider of services. Rather than an intermediary giving Owen a certain number of hours of support, he gets his own budget directly from the HSE (brokered by A.T.) which allows a few more hours of support than had previous been available, as he now handles administrative tasks of payroll and PRSI himself. Running a limited company has many restrictions, such as the need to provide an audited

budget each year, and to send in assessment forms and PRSI payments each month. Owen says, "This model of direct payment is one model, it's workable. Better than service providers telling us what to do. People with disabilities doing it for ourselves".

"We're sick of waiting for something to happen. We're sick of hearing that we can't change the way people manage their supports until the policy changes, until the law changes, until we decide what resource allocation system Ireland is going to use, so we wanted to do something practical, and we wanted to do something now, and we know that there are people out there who are already doing it, who are managing to figure out a good life for themselves or for their family members without waiting for the law to change, or the policy to change, or everyone else to catch up."

Dr Eilionóir Flynn, Centre for Disability Law and Policy

Owen hopes to change models yet again - this time to self-directed payments through a grant arrangement with HSE, including grants for aids & appliances, so that he can choose his own chair, etc. rather than the current situation of limited choices for equipment provided by the HSE or service providers.

Now that Owen has lived in his own house for 13 years, he sees that working toward Independent Living was the key to getting out of the institution. "When I became disabled, I expected others to take care of me, and to make the right choices. I quickly realised that wouldn't happen."

Still, he has appreciation for many people working in services who helped him. "It's great to meet people who want to help you make it work, good people within service providers who say 'Why not? Let's do it.'"

All that Owen has ever fought for is the same level of choice and control in everyday life that most people take for granted.

Fionn's Family Story



Fionn was born to unmarried parents living 4,000 miles apart. Jonathan is American and Veronica is Irish. For most of the first 5 years of Fionn's life, they were a divided family, spending as many weeks together each year as was possible, on one side of the Atlantic or the other. It was only when Fionn became gravely ill that Jonathan gave up his career in the States and moved to Ireland. After major surgery, Fionn recovered, and his parents got married.

They were determined that Fionn should attend the local Steiner School in County Clare, which at the time was operating independently of the Department of Education. It was clear that Fionn would need a Special Needs Assistant to fully avail of the mainstream education they had chosen, but the Department officers were unwilling to provide the funding to a private school. In the High Court, they were granted the support they sought, based on Article 42 of the Irish Constitution. "Although we're not particularly disagreeable people, we've always been willing to fight for the right things for our son."

The highlight of Fionn's primary school was in Class Five, when he attended the All Ireland Steiner School Olympics. In an attempt to recreate the feel of the Ancient Greek Olympics, all the children wear togas for the games. Every one participates in all five events. Afterward, the award ceremony recognises the unique abilities of each, and the part that each plays in community. Fionn was reminded that he is essential member of his class, as are all the others.

Experiences like this gave him healthy self esteem, but also a strong sense of his responsibility to his peers and society.

But the academic challenges of mainstream secondary school didn't suit Fionn, and there was little support for creating an individualised curriculum for him, so he transferred to a special school for two years. At his new school the learning expectations were too low. And because some pupils had no learning difficulties, but 'behavioural issues', there were a number of bullying incidents. The final strike against the school was the commute of 90 minutes on a bus, in each direction.

When they learned that the local secondary school had a Leaving Cert applied programme, Fionn transferred for a second time, back to mainstream education. He loved being part of the local community, spending most break times whacking a sliotar around the yard with the other lads. He was happy in the early months, and he suddenly was greeting and being greeted by half the town wherever he went.

But school communities have written and unwritten rules, and Fionn was often in trouble for breaking them. You can jump on the back of an unsuspecting classmate, but only if there is a certain level of friendship. It's cool to curse with the lads on the yard, but not to bring saucy language into the classroom. Before Christmas, after a physical altercation with a Special Needs Assistant, Fionn received a permanent expulsion from the school.

Veronica and Jonathan knew that the decision was heavy-handed, and that the school's 'just following policy' stance was discriminatory against students who are slower to comprehend school culture, and so they appealed the decision. They won the appeal, and Fionn was allowed to rejoin his class, but the process took the entire school term.

So, during that time he was home schooled. Both his parents are trained teachers. His mother covered the core subjects, while his father created an alternative curriculum, exploring Fionn's many interests. Part of Jonathan's motivation in this partnership was to discover more about what Fionn might like to study or work at as a young adult after finishing secondary school. And once they saw how fun and rewarding it was to work as a father and son on things that interested Fionn, they never stopped.

One of those interests is nature. Fionn loves to explore wildlife, and is a member of numerous conservation groups, often going on outings, attending lectures or helping with projects. And he spends hours poring through nature books. Jonathan helped him to compile a slide show and practice a talk that he then gave at nearby primary schools. "Fionn was better at this even than I had hoped. I expected that his slight stutter might turn the children off, but they seemed to listen more attentively than they would have if I or another teacher were doing the talking. And Fionn loved it."

These first school visits had been informal arrangements with the schools, but Jonathan started to wonder how visiting 'experts' like Fionn gain legitimacy. He discovered the Heritage in Schools scheme, and contacted the Heritage Council. "I told them I knew an expert they should have on their panel, and that, because he was only 17, we would work together. I left out the part about Fionn having Down syndrome, because that had no bearing on the conversation at that point. They invited us for an interview, and Fionn became the country's youngest Heritage Expert." Since then, they have given presentations at schools all over the area.

Another interest of Fionn's is filmmaking. Fionn and Jonathan made a short film, interviewing people with Down syndrome around Clare. "The film was to show people with Down syndrome just as people: playing with a dog, baking scones, driving a car, going surfing."

The film got them an invite onto RTE's Saturday Night Show, where the host, Brendan O'Connor, asked Fionn how it feels to have Down syndrome, and Fionn's memorable answer was, "How does it feel to not have Down syndrome, Brendan?"

They started Fionnathan Productions, with other film projects emphasising the 'ability' side of people with disabilities, and interviewing celebrities, politicians, artists, etc., asking 'What do you love about your life?' Other interests of Fionn's that they have folded into their Social Enterprise include public music performances (Fionn plays traditional fiddle, and Jonathan guitar) and artistic collaborations with over a dozen visual artists.

"There are pockets of people doing really interesting things, who aren't prepared to live with what the system is offering them, and have gone off and done their own thing."

Dr Eilionóir Flynn, Centre for Disability Law and Policy

There wasn't much of a decision to be made when Fionn completed the Leaving Cert Applied course - he wouldn't be going to any of the traditional day service programmes that were on offer. The family agreed that he, with their help, should direct his life in a more typical direction: probably involving attending college or university, moving out of the house, maybe emigrating, making an income, making big mistakes, maybe getting married, or just enjoying a robust network of good friends he can relate to - normal, wonderful stuff.

Andrew's Family Story



Brega Kelly is the mother of a family living in Menlo, Galway, married to Ray. Her son Andrew is 17 and has autism. There are two other children in the family, his brother James 24, and sister Laura 22.

Andrew was the youngest. It was apparent initially that Andrew had a disability, although Brega noticed when he was a baby that, when pushing him in the buggy or driving in the car, if she changed direction, he would scream. Andrew did learn to talk when he was young, but then mostly stopped. "When he was four it just all went, and he then had limited speech."

At age four and a half, Brega and Ray brought Andrew for assessment, and were told that he did not have autism. A year later, he was diagnosed with autism and a mild learning difficulty. "That's how the first placement went wrong." The underestimation of his additional educational needs meant that he was placed in a mainstream school, within a special needs class. But it was soon clear that he needed more. "They couldn't cater for him, they didn't have the right staff. These children can't be held down at a desk - Andrew won't sit for two minutes. They need a different type of education, with more one-to-one attention."

They transferred Andrew to St Joseph's Special School, finding it to be a "fantastic school." Rather than expecting him to sit still to learn, they mix activity with numeracy, bringing education into the movement, and Andrew is much more at ease and learning well. He has

been at the school where he is now for seven or eight years, and has one year left.

Andrew is provided with services from Ability West, and he and his family are very happy with them. One weekend a month, he receives respite care, and things have gone smoothly. Brega is hoping to work with them so as to come up with a suitable service for when Andrew leaves secondary school.

Andrew needs a lot of down time. Brega is at home with him through the week when he is not at school, and she then works on weekends. She chose to not work full time, and is grateful to be in a position to make that choice, "because Andrew needs that."

"His siblings are a great support, but they won't always be around, as they have their own lives to live. They absolutely love their brother. Their friends really love him, too. Hopefully they'll always look after him." He loves his cousins, uncles, never forgets their names, even when he doesn't see them for a while.

"Try as we may as service providers, we can't love the people we provide services for. But your family loves you. They will do anything for you."

Mary Kealy, Former Chief Executive of Brothers of Charity

It seems that Andrew has influenced his sister's choice of career. Laura is in college in Waterford, in Health Studies. One module is for special needs exercise. She will go to Alaska this August for placement, working with special needs children, a highly competitive placement. "She probably wouldn't have gotten that, only that she talks so much about her brother."

They want to continue having Andrew live with them as long as they can, but it would be nice to have a day or two for Brega and her husband to do things knowing that Andrew is well looked after in a suitable environment. "The fact that I am at home means that I can manage things. But, everyone needs a break. Hopefully for the future we can have a good balance, a lifelong balance, for the whole family."

Brega feels that the other two children had to 'step back' to account for Andrew's circumstances. He doesn't like loud noises or crowds, so, whenever possible, they avoid them. When younger, the sound of the lawn mower or electric carving knife would drive him crazy. "Andrew needed so much attention. I'm always grateful that they could see we were under pressure, and didn't try to get in there as well and get a bit of the attention."

The family live in a nice locality, with 36 houses in the neighbourhood. All the neighbours know Andrew, and look out for him. "There isn't a neighbour that wouldn't know that Andrew shouldn't be alone. If we go for a walk, and he runs ahead, they come to the window to see that someone is with him."

Andrew enjoys going to Dunnes to buy a bottle of sparkling water. Many of the girls in the shop know him. He likes to say their names, and to go to their aisles to pay them. Sometimes they let him sit on their chair and swivel. There's a real sense of community spirit on these outings.

For a number of years, Brega has organised a charity walk, called 'Walk with Andrew'. Proceeds

from this event go to Ability West. This year, there were 400 people who came out and participated. "He's pretty famous," Brega says.

Andrew goes horse riding on Saturdays. He loves it. But Ray, his father, probably loves it even more. They meet other parents, get a chocolate bar, have time together.

Although it could all change, for the future Brega envisages "a hub for Andrew, with maybe four boys of similar needs, who would be supported in a house in the community. From there, they could go for walks, go swimming, etc. Also a family with whom Andrew could spend time, maybe one or two nights a week, to bring him more into an extended life. I'm very much open to suggestions what that will look like. He has a good future ahead, with supports from me. We will seek for him to have the best life that he can have."

"I think there is a misunderstanding about what closing down institutions means, that it means integrating people with disabilities into the normal community. But I think, actually, it involves transforming the community to recognise the true diversity of what human beings are. And being exposed to that really enhances people's sense of self."

Dr Piers Gooding, Centre for Disability Law and Policy

Daniel and Nathan's Family Story



Jacinta and her husband Joseph have two children, Daniel 12 and Nathan 21, and live in Dublin.

They recognised early on how difficult it would be for them to access services for Daniel, who is on the autistic spectrum, although that wasn't what they expected at first. "We just thought if your child needs something in this country, you'll just get what they need to have a good life. But the reality was very different." They were on a waiting list for one year before they could see a paediatrician, another waiting list for one year to see an occupational therapist, and a six month wait to see a speech and language therapist.

"I was very much trying to educate myself about his difficulties, so I could help him as best I could myself." Jacinta first took a Behaviour Management course offered by the Carers Association. What she learned in the course was helpful, as it provided her the skills to help Daniel when he had meltdowns. He is not very verbal, so she had to 'think like a detective' to work out the causes, all the while keeping her own composure.

She then did two other training programmes with the main goal of helping her sons; a Special Needs Assistant Training and a Childcare course. The Childcare course taught her the importance of play in developing social skills and education. "If you have children who can play by themselves or with their peers, you don't really have to look at that."

Jacinta is now doing a degree in Counselling, because she believes that her sons will need expert psychological help in the future. But she also recognises the importance of meeting her own needs. "To be a mother and to be the main care giver in the home, you tend to lose yourself. You need to mind you, to be able to give to everybody else. If you don't do that, that's when frustrations come on. You're not able to give your best for your family. Studying for a psychology degree really helps me. I absolutely love it."

A speech and language expert advised Jacinta that Daniel needs at least three half hour lessons in a week, on an ongoing basis. The reality of the situation was, the best service you could possibly get from the HSE was three blocks of six hours per year. "So I was armed with this knowledge of what he needed, but facing the reality of what he was going to get. We were five years into our mortgage. Any typical family wouldn't have much extra income to pay speech and language therapy."

She tried teaching him herself, but soon realised it wouldn't work. "I wasn't equipped to do that. First, I was his mother, and I should be able to enjoy him and have fun with him, but he was seeing me in this role of making him do speech and language drill work - that was really unfair."

When they were going through Daniel's assessment at age 4, a lot of the questions they were being asked to consider applied to his older brother Nathan. He had always had learning challenges and behaviour difficulties, and they now learned he had ADHD.

"I was going through a really tough time, getting to terms with both diagnoses coming in one year." The community public health nurse agreed to put in a home support package, which provided funding for help, but it proved to be of the wrong sort. "For the next year, people were coming into our home that weren't interested in working with our boys. A lot of the girls were early school leavers, and didn't know how to play. All they wanted to do was clean the house. I can clean myself. I really needed professionals."

Jacinta asked the disability manager to allow her to use the funding to hire specialists, but her request was refused. A year later, she asked again. This time, it was a temporary disability manager, covering the position while the permanent one was on leave. He agreed to use a company that provided home support to access a speech and language therapy trainee for Daniel, and a tutor to help Nathan prepare for and get through the Leaving Cert.

"Welcome to the non-compliant services users club. Be proud. There's plenty of us out there. I'd prefer to be with a messy bunch that don't all agree, than with a shower of nodding heads that do sweet Fanny Adams."

Willie Walsh, Clan Beo

For three years, the family had solid support. Then the speech and language trainee needed to take time off to complete her degree. Jacinta didn't want anyone new coming into her home. "I thought, the HSE is giving a pool of money to a company to provide services to my family, and probably losing 45% of this funding to the company. Why can't I use that instead of this company?"

The disability manager initially tried to dissuade her from accessing the funding herself, then put her in contact with Martin Naughton Áiseanna Tacaíochta. She told him their story. "Martin could appreciate that I am an expert in what my son needs. He made the arrangements with the HSE. I'm so glad A.T. does this for me, as it takes away a lot of pressure."

Jacinta is clear that directing services for Daniel is the best arrangement. "For now, we use it for speech and language as well as occupational therapy, because we think those will help him be more independent. Daniel's quality of life has really changed."

"The money that we were spending on extra services, and crippling ourselves financially, meant we couldn't go on holidays, we weren't able to do summer camps. This year, Daniel has been in a camp every week - in mainstream camps, with his peers. He doesn't get to do that naturally, because we live in a housing estate where it not safe for him to be outside, due to his communication difficulty. We don't have the freedom of most families, that he's just able to play outside the home for a long time."

"So we needed the financial means to be able to do that, and we have that now. I'm able to do my degree. I'm able to fulfil my needs, Daniel's money is for him, and it's used for his needs, but our little bit of extra income allows us the freedom to go to a movie, to a show, have a meal out, even go on a holiday like most families. We have that extra money now, where we didn't before."

"The practical, the how-to piece, is very important. Otherwise, it's all just aspirational, it's all just theory. What we can learn together is the how, the practical piece.' What have you done, and how did it work? And how can you advise me of some of the pitfalls and some of the strategies that you used?'"

Rachel Cassen, Leap

She is convinced that when families are put in control they will do the right thing. "A company is not emotionally attached. They are not going to do a 100% job, only 60%. I'm going to do 100% job because I'm looking at 20 years down the road. We need to invest now if we are going to have better outcomes. The state is starting to move now, realising that it's actually cheaper in the long run."

"Individual funding is freedom, is choice, is necessity. I would never accept anything else. This is their life, they'll just have to get used to it. That is the way of the future. Because we're not going back. We're not going to accept anything else."

Gabe's Family Story



Rachel is the mother of Gabe (22) and Francis (13). She moved to Dublin from London when Gabe was five days old and the family have made their home in Ireland.

Gabe is now living away from home and living the life that he wants for himself. It's not been easy for him but he's working hard to develop a good life. Gabe is his own man and decides himself how to live his life. He has learned that living an independent life and having good relationships with people is something that has to be worked at. Like many of his peers Gabe shares a passion for music. He is taking decisive steps to overcome his shyness and make connections with people who share his passions. He is producing and presenting a weekly radio show, attends the gym, shares an apartment with a non-disabled flatmate and is travelling to Vancouver this autumn to speak at a conference.

A few years ago things looked a lot less positive. As a young teenager Gabe moved with his family from Dublin to a small village in Co. Westmeath. He enrolled in a secondary school nearby. At this time Gabe and his family had a lot of service provider people in their life. There were a lot of appointments to attend, a lot of questions to be answered. Many of the simple questions were being asked over and over again. He was assigned some labels. It was difficult to understand what these labels really meant for Gabe. Medication was prescribed. His family constantly had to explain how to support Gabe to be included.

As they were new to the region it took some effort to make connections in the local community. As secondary school progressed Gabe was less and less happy. The school found it hard to understand that he was a student with additional support needs and not a person who was choosing to be 'challenging' or 'difficult'. There were some bullying incidents and Gabe was becoming more isolated.

By the middle of second year Gabe was spending a lot of time alone in his room. A few mates at school saw that things weren't going well and had the wisdom to open up to Gabe's parents.

The situation seemed like it was getting progressively worse. Everyone in the family felt the strain. Around this time his mother attended the Partners in Policymaking programme. The family realized that decisive leadership had to be shown by Gabe and the family.

They decided to take a two week 'holiday' from their commitments to attending service appointments. More importantly they decided to hold a planning meeting in their home and invite only people that Gabe chose.

Gabe's parents had no family connections in the area they moved to and realized that they would have to 'build' a community of support from 'scratch'. They also realized that they had a capacity for openness and hospitality that was valuable to the people they had contact with in the locality. Because they were starting from 'scratch' they had the opportunity to make their home open to people with whom they shared common interests and a common approach to living.

Gabe worked together with his mum on who to invite to the planning meeting and what to say in the invitation. They wanted to celebrate the gifts and strengths that the family and Gabe had to offer.

They also felt they needed to be open to the generosity of others in meeting the additional life challenges they were facing. Gabe had the chance to tell his story to the people he had invited. Apart from his immediate family Gabe felt comfortable inviting five friends that were in and around his age. He didn't feel that he wanted any staff from services or any school staff to attend this first meeting.

A person centred planning facilitator was invited to make sure that this story was recorded. Her job was also to make sure that no matter how difficult it was to hear, Gabe could openly talk about his experience of his life no matter how painful this was for people in his life. The planning meeting was a turning point for Gabe, his family and for the people who were invited. They heard clearly about the 'nightmare' that he was living. Gabe's family and friends understood better what this young man really wanted in his life. After the meeting Gabe and his family started to develop a plan to support him on his way to a better life. The plan included

mainly the natural supports that family and friends were able to offer and services played a minor role.

“Providing ways for the community to be in control and to develop informal supports and to tap into those natural supports is a really important element to the landscape of support.”

Dr Piers Gooding, Centre for Disability Law and Policy

It was decided that the initial two week ‘holiday’ from using services would continue indefinitely. Gabe and his family began to define for themselves what ‘good support’ looks like. It was provided from within the community in the shape of two men who had a similar passion for music and making things to Gabe. These two men worked very well with Gabe on things that mattered to him (whereas services seemed to be focused exclusively on what was important for him) and spent a lot of time focusing on music – both making music and attending musical events, and also introducing Gabe to new things such as hill walking and film making. Gabe no longer uses medication. Getting away from prescribed medication was a big challenge for Gabe and his family and was something that was identified very early on as important to him.

Over his time in secondary school Gabe and his mates learned from each other about the prize that is friendship. They were comfortable in each other’s homes. Sleepovers began to happen in a natural way and life became a little easier again. The family felt happier and more relaxed about inviting people into their home. As the different families grew closer they were able to share their own experiences of other types of difficulties they had had to face in their own families.

School was never easy academically or socially but Gabe did become popular among his peers. Over the 5 years up to his Leaving Certificate Gabriel and his family opened their home to a few more days like this first one, these get-togethers were more like parties with music and food becoming the reason to bring people together. The same mates were invited along with others who Gabe felt accepted him for who he was. It was never a very formal affair. It was never just about a person who might need support; it was always about friendship and hospitality.

A circle of support and person centred planning have been used by Gabe and his family to get to a place that is beyond what anybody dreamed at the first planning meeting in the family home.

“A Circle of Friends is a group of people who are intentionally invited to come together in friendship and support of a person who has a disability, for the purpose of protecting their friend’s interests into the future. It’s not people who are paid, but people who are invited in. Not with the expectation that they will have a responsibility for the person, but with the expectation that, if asked, they might be pleased to

take time out and agree to join the circle and develop the person ”

Willie Walsh, Clan Beo

People describe Gabe as ‘exuberant’, ‘friendly’ and ‘big-hearted’. Rachel talks of a powerful realisation around this time of becoming aware that she had spent years living her life in a quite embattled way - fighting for services for Gabe. Services, which when secured, often failed to deliver what they appeared to promise. She realised that her son was fast approaching adulthood, and what he needed more than anything was a life and a future which offered opportunity, hope, excitement, growth and possibility, and she began to focus on what a good life looked like for him, and on practising the art of asking.

Since completing his Leaving Certificate, Gabe and his family have been able to negotiate directly with funders to secure the type of individualised support that Gabriel needs to live his own life. The relationship the family have with service providers now is very positive and the family, with Gabe at the centre, set goals every few weeks to make sure life keeps getting better. The family believe that developing a compelling vision of a good life for Gabe and being able to bring people around that vision has been fundamental to their success. Gabe’s mates from school now live and study in different parts of the country and Facebook is more likely to be the place where they meet. They all have to face the challenges of finding new people who they can be friends with and ways of living that they can be comfortable in. For Gabe, the focus now is on developing socially valued roles where he can contribute his gifts and talents and build relationships with a range of people through showing up and taking part in ordinary community life.

Findings from Workshops

At each of the three Regional Workshops on Self-Directed Living, attendees were invited to express their ideas, and these were recorded.

The first question, 'What is A Good Life?' helped to orient us on a communal picture of what a 'good life' might contain. Some of the key elements of a 'good life' that participants identified were as follows:

being valued for your talents, friendship, belonging, community, security, home, freedom, independence, self worth, spirituality, paid employment, to be active, education, family, fun, money, variety, happiness, intimate relationship(s), getting married, contentment, travel, holidays, identifying and living your passions, inclusion, choice, privacy, equality, hobbies, achieving goals, sports, music, craic, health, entertainment, to be recognised, people you can trust, having your voice heard, appropriate assistance, choosing who you live with, developing your potential, socialising, keeping pets, public transport, making your own decisions, respect, having the right support, going to the gym, rights.

The second question looked for the key ingredients, the shared goals, that we need to be fighting for to create a national system for self-directed supports. Participants were asked about what they thought was really important in a system that supports a good life for every single person. Responses included the following ideas:

- individuals need to be supported in doing what any person their age is doing
- the system needs to offer portable funding, so supports move with the person
- the system needs to offer choices other than day services for young adults
- the system needs honesty
- the system needs integrity
- the system needs to be worthy of trust, and to work with people and families as equals
- individuals need support defining and articulating what they want
- the system needs flexibility (of funding)
- the system needs 'being of service' as its vision
- there needs to be a reduction in bureaucratic barriers through trusting people
- the application process needs to be uncomplicated
- the level of support should not be dictated through means-testing

- the system needs to allow and encourage creativity
- individuals need a roadmap to self-directing, and a bank of ideas from others who already have experience of self-directing
- individuals need information on how to set up a fiscal intermediary
- individuals need to believe that it will work
- the system needs to believe in families

Based on these responses, and aligning the contributions of workshop participants with other research in the field of self-directed living, the authors of this report suggest the following three criteria are essential pillars of a national system to support self-directed living in Ireland:

- A Responsive System Open to Change
- A Landscape of Social and Community Support
- Getting Resource Allocation Right

A Responsive System Open to Change

Groups like the Research Group on Self-Directed Living are advocating for the introduction of individualised funding in Ireland. However, we believe that in order for a system of individualised funding to be effective, the State and its infrastructure needs to understand all the ingredients participants at our workshops listed as important to make the process realistic. These include the need to make it accessible, flexible and effective for people, and to provide people with opportunities to develop their thinking about what a good life looks like for themselves or their family member and what their options are. Government and the state have to be willing to design a system that can respond to change. Even when we move into this new model, there is always the danger that the new system will be set in stone, and that suggestions about changing things as we go along might be ignored.

It is very important to make the system of individualised funding a dynamic process that is open to change, that acknowledges when things do not work well. The participants in our workshops do not want a system that puts people in different boxes, based on labels which define the levels of support that the State thinks they might need. They and we believe that it is far preferable to create a system of individualised funding that starts with the person and the wealth that they identify around them as opportunities for support and development.

A Landscape of Social and Community Support

We believe that the key to a successful introduction of a system of individualised funding includes a good landscape of support which allows the people and families to engage in social organising to make sure that rich natural resources are being shared among families and individuals, which then feed into policy and law. Those rich resources address the challenge of how to make the best of the opportunities that individualised funding brings. One way to facilitate this is to enable face to face meetings of people who are self-directing, coming together to discuss how they are using their funds to live the kind of lives they want. These meetings would become places where people can share their experiences: both people with

disabilities, directing their own supports; and family members, discussing how they could make use of their funding in innovative ways.

It makes sense to make widely available opportunities for sharing, information and support on how to access the opportunities provided by a new system of individualised funding to include independent planning and facilitation available to people and families through person and family led organisations.

Getting Resource Allocation Right

There are many places in the world where resource allocation models are applied, though all of them seem to have faults. Significant funding goes into the process of assessment and resource allocation, and these processes inevitably involve negotiating bureaucracy. Further, the assessment process tends to focus on people's deficits. This process is dehumanising and damaging, and cannot provide the answers to the question of how to help individuals have good lives.

In any new resource allocation system, the establishment of a fiscal intermediary is needed to manage funding. This intermediary would be accountable to funders, trusted by people and families and staffed by disabled people and family members, among others. Such a service could offer several options to families to manage their funding in several ways, depending on their circumstances and preferences.

Policy and the Move to Individualised Funding

The main developments in recent years that effect self-directed living are the Value for Money and Policy Review, the Time to Move On Report and New Directions. A synopsis of each follows.

The Value for Money and Policy Review of Disability Services in Ireland is an evaluation of the efficiency and effectiveness of the HSE-funded statutory and non-statutory disability services in Ireland. It was initiated by the Department of Health in June 2009 and was conducted under the auspices of the Government's Value for Money & Policy Review Initiative 2009-2011. It was published in 2012. The National Implementation Framework describes how the recommendations from the Value for Money (VFM) and Policy Review of the Disability Services Programme will be translated into concrete actions.

In 2007, the HSE agreed that a national plan was required to inform a programme to support people to live a life of their own choosing in the community. A Working Group on Congregated Settings was established. The working group's report: *A Time to Move on from Congregated Settings: A Strategy for Community Inclusion*, was published by the HSE in 2011.

The picture that emerged in the course of the work done for the report is one of a group of people who live isolated lives apart from any community and from families; many experience institutional living conditions where they lack basic privacy and dignity. Most have multiple disabilities and complex needs. The report's core recommendation is that people living in congregated settings should be moved to the community. The working group recommended a seven year timeframe for full implementation of the report's recommendations.

New Directions: Personal Support Services for People with Disabilities, published by the HSE in 2012, envisaged an approach to day services that would contrast with the current segregated nature of provision for people with disabilities underpinned by the principles of person centredness, community inclusion, active citizenship and quality service provision.

The review, established in August 2007, stated its purpose was 'to reconfigure and modernise HSE funded day services to embrace the principles of person-centeredness, access, accountability and quality.' The Report highlighted the requirement for a quality assurance system based on their findings that, despite some positive experiences, there were indications that service-users had little or no say in their choice of activities, engaged in the same activities or tasks repeatedly or spent significant amounts of time doing little or nothing. In 2014 the HSE, in collaboration with the NDA, published for public consultation *Draft Interim Standards for New Directions, Services and Support for Adults with Disabilities*. The standards, based on consultations with users of adult day services, arose from recommendations made in the *New Directions* report.

Practical Steps in Self-Directed Living - Starting Your Journey

Reflection by Rachel Cassen – Member of Self-Directed Living Research Group

Getting a Life, Not a Service

'How can we use what we have to create what we need?' is a question that we often ask ourselves and the families that we work with. It arises from a belief, a strongly held philosophy that much of what is good in life is not in the currency of money. It also comes from a recognition that we can lose years, decades even, in the struggle to obtain better services and more resources. But that ultimately our children's life is here and now. If we shift our focus, we can get busy creating with the tools that we have to build a good life, an ordinary life for the people we love and support.

More than ever, we believe that families need to be thinking about what really matters and what makes a difference in ensuring that we are living good lives and planning together to create meaningful lives with and for our children as they reach adulthood. Starting to think about creating a positive and hopeful vision for the future, a vision that is supported by others, is key to moving in the right direction. Planning for the future changes the present!

In our work with families much of what people say makes a good life is not provided by services. So, let's figure out

1. what we can do ourselves
2. what we need support with
3. what we can create in partnership with others.

If Not This, Then What?

Many families and support groups are clear on what they are against and what is not working – but less clear on what they are for and what is working. We suggest you start by developing a vision of a good life. Take time to discover what is important to your family member and what are their gifts and talents. Focus on their strengths, not their deficits. Get to know your child even better, and help them to recognise their assets and gifts - we all need support and encouragement to recognise, use and share these gifts with one another.

If your goal is community and an ordinary life, remember that communities aren't interested in our problems - only in what we can contribute. Take some time to plan together as a family about the essential elements of a good life for your family member. It may seem strange at first, but this visioning process is remarkably powerful in helping to set a positive direction. This

type of intentional behaviour is necessary to overcome some of the barriers which your family member may face and will help you to work out ways to get around typical setbacks.

Planning that we do together as families may take the form of an ongoing conversation and does not even need to be written down. This can help us discover where we want to get to, and to work together on ways to make that happen.

Bear in mind that children's (and adults') fundamental needs are for inclusion, participation, relationships, value and respect. Ask yourself how you can support that.

Where to Start

We know that an ordinary life, a typical life produces better outcomes for people than segregated pathways. Even so, people will try to direct you and your child to segregated options and you will need to be clear when this happens what your choices are.

This is not only important at crucial life stages like starting a new school or leaving school, but also when considering leisure and lifestyle options for your child, such as joining clubs and other groups. It is really helpful to connect with other families, and to work with people who are positive, have high hopes and are creative, and who have managed to create good lives for their own family member.

Work out what a good life is by creating a compelling vision of a good life that you can articulate to others. Thinking about what a good life looks like now and in one, two and five years' time will help you to get clearer on what you are working towards specifically.

Focus on belonging, relationships and valued roles. Many families have found this approach has a better track record than relying on services to figure it all out.

Be aware that relationships, friendships, lifestyle interests, work opportunities and living arrangements will not happen automatically. Begin to practice the 'art of asking' and of 'letting people in' to assist and guide you in supporting you and your family member.

Thinking About Roles – What We Can Do

All of us participate in society through our roles. It is through a focus on roles that we achieve many of the good things in life. Consider all the roles you occupy. Some were ascribed to you at birth – son or daughter, brother or sister. Others you acquired as you grew, taking up roles in school, the church, in sports groups and so on.

Because of culturally held low expectations, the lives of people with disabilities often do not follow these typical pathways. By working intentionally to create and sustain opportunities we can make sure our child is not left behind. Think about what valued roles your family member has in your family. Work on developing these roles first, as a strong foundation for taking up age appropriate valued roles in the wider community. At the same time, work on your child's image and competencies. Recognise that building and sustaining a good life for your family member is a lifelong project. Always try and select the most highly valued option for your child

as this maximises their chance of positive connections with their peers.

Think about what other people their age and gender do. If you are planning an eighteenth birthday party – ask yourself where do other young adults celebrate and in what way?

Positive Communications – Choosing to Place Your Focus On What Is Strong, Not What Is Wrong

The depiction of the process to obtain services as a battle is often heard from families. But what if waging this battle stops creativity and big thinking? What if we as families steadfastly refuse to draw the battle lines and chose to engage in a different way, by attempting to build positive connections with the people we come into contact with.

This is an intentional strategy, and yes it can be more challenging than 'giving out'. But it is also much more rewarding, often leading to feeling that people are with you, are on your side and are willing to support your ideas. Being friendly, well prepared, reasonable and willing to work in partnership can increase your chance of success, and bring allies and supporters around you.

Staying Connected

Is there a network (no matter how small) that you can draw on when things get tough? People in your corner are a blessing! What can you do to better advocate or speak up for your family member? What can you do that helps to grow connections between your family and the wider community?

If you are trying to increase the number of relationships in your family member's life working on positive introductions can help. Are you able to introduce your child in a positive way? Are you able to introduce them in a way which is likely to draw and invite people in?

Find a family based organisation that is interested in building the resilience, vision and goals of families who will support you to intentionally plan for the future. Self-directed living is about stepping into your own power and setting the direction of your own lives by taking back some control and ownership. It is essential to believe in the natural authority that you have as family.

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Special thanks are due to all those who attended the meetings, and to all the people with disabilities and family members who contributed their stories, both during the regional meetings themselves and in follow-up interviews. We hope to continue this work and seek to collaborate with others to advance self-directed living in Ireland. If you would like to get involved please contact one of the member organisations of the group, listed below, to find out more.

Leap

The Centre for Disability Law and Policy (CDLP), School of Law, NUI Galway

Sunbeam House Services

Áiseanna Tacaíochta (A.T.)

Fionnathan Productions

Resources and Further Reading

Video recordings of all presentations referenced in this report at the regional workshops are available on the Leap website: <http://www.leapireland.com/>

To learn more about practical ways to achieve a vision of self-directed living, we recommend the following sources:

Michael Kendrick runs Kendrick Consulting International, where “imagining better” gets very practical. He is based in the U.S. <http://www.kendrickconsulting.org/Pages/default.aspx>

To see an analysis of the steps involved to create a self-direction process framework that is realistic acceptable, moveable, effective, and flexible, see the work of Simon Duffy, Director of The Centre for Welfare Reform, a community of independent fellows based in the UK who are thinkers, innovators and leaders demonstrating a real commitment to equality and diversity. <http://www.centreforwelfarereform.org/who-we-are/>

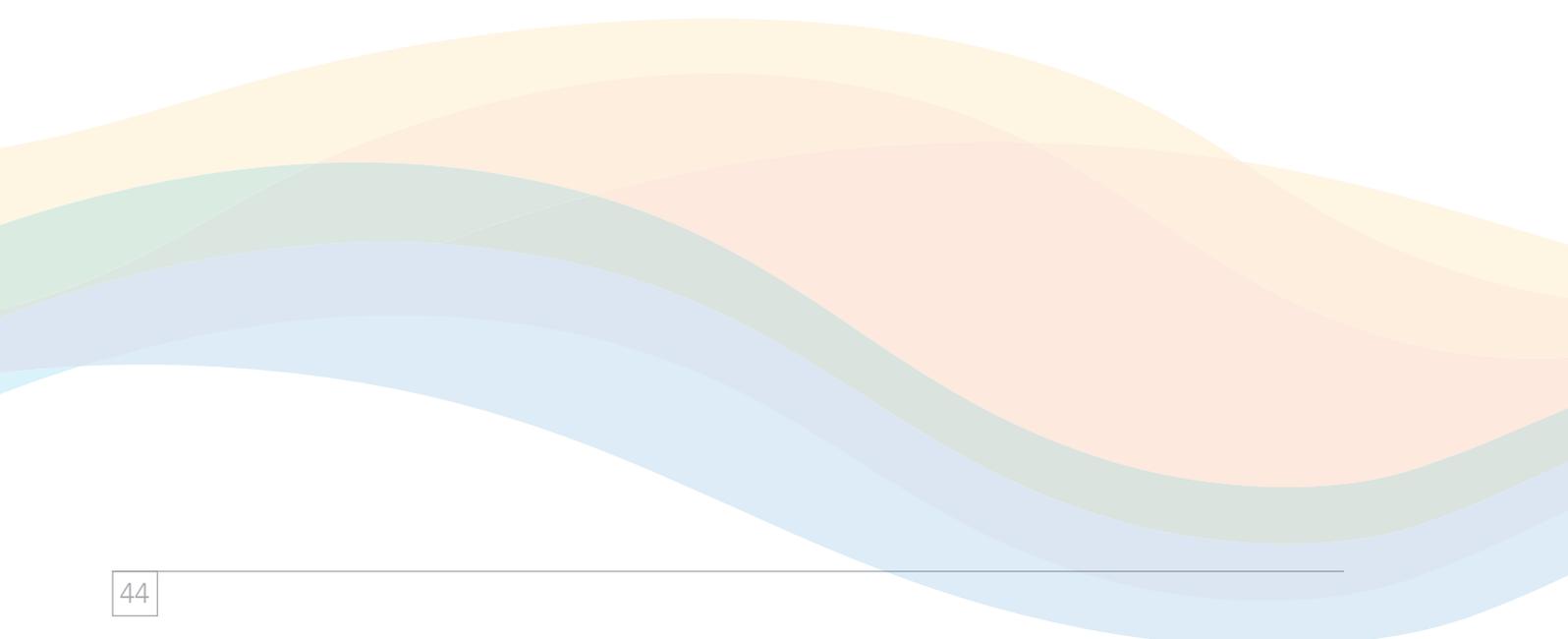
The Community Resource Unit Inc. (CRU) is leading work on the implementation of the National Disability Insurance Scheme in Queensland, Australia. Its mission is to engage a broad range of people in a movement for change so that people with disability will be welcomed and appreciated as they take their place in their communities. <http://cru.org.au/>

Manawanui is New Zealand’s pioneer and leading facilitator of Individualised Funding for people who want a no fuss way to manage their supports. <http://www.incharge.org.nz/>

Genio works to bring Government and philanthropic funders together to develop better ways to support disadvantaged people to live full lives in their communities. <http://genio.ie/>

Belonging Matters aims to inspire people with a disability, their families and allies to enable people with a disability to have opportunities and pathways typical of other citizens in the community - lives that are personally fulfilling, unique, socially inclusive and empowering. <http://www.belongingmatters.org/>

Imagine Better partners with disabled people and their families as they imagine, plan and go after the good things in life. We challenge and change how people, organisations and communities think about disability. <http://www.imaginebetter.co.nz/>





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