

Shared Lives

Building Relationships and
Community with People who
Have Intellectual Disabilities

Roy McConkey, John Dunne and Nick Blitz



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AUTHORS

Roy McConkey

Roy is Professor of Learning Disability at the University of Ulster; a post jointly funded by the Northern Ireland Health and Social Care Board. A psychologist by training and a native of Belfast, he has previously held posts at the University of Manchester, in Dublin and in Scotland. He has authored, co-authored and edited numerous books and research papers in learned journals. He has acted as a consultant to various international agencies and this work has taken him to some 20 countries in Africa, Asia and South America. He is a Fellow of the International Association for the Scientific Study of Intellectual Disability.

John Dunne

John is recently retired as Director of Psychology with the Brothers of Charity Services, Galway, Ireland. He trained as a clinical psychologist in Ireland and the USA, and is an Associate Fellow of the Psychological Society of Ireland. He has had a particular interest in the development of a relationship and community model of service and in the application of positive psychology to the lives of people with an intellectual disability. He is author or co-author of a number of publications, book chapters and articles.

Nick Blitz

Nick is Medical Adviser to the Camphill communities of Ireland; having lived and worked in life-sharing communities for much of his life. Previously, he worked as a research scientist at Imperial College, London and McGill University in Quebec, where he was awarded his PhD on a Commonwealth scholarship. Following a career change, he worked as GP and Medical Officer to the Camphill Schools in Aberdeen and as Medical Consultant to the Camphill Communities in Scotland, before taking up his current post in 1998. He is involved in disability research, and lectures on Camphill courses in disability in Ireland and the UK.

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FOREWORD

Shared Lives is a challenging guidebook for how we think about and organize ‘support services’ for people with intellectual disabilities. But it is far more than that. It is a groundbreaking exploration of the issues of absolute value, self-empowerment and potential contributions of people with intellectual disabilities, a population that has historically been denied all these things.

To understand why this is new territory, it’s important to remember how far the movement to promote and protect the civil rights of people with intellectual disabilities has come over the last 50 years. After all, it is only in recent years and even then in far too few places around the world, that people with intellectual disabilities have begun to emerge from society’s shadows. For years, the world has seen only their disability, their comparative limitations, their perceived weakness.

Such a narrow view has had severe consequences: stigmatization, isolation and often institutionalization that leaves over 200 million of the world’s citizens without even the most basic rights and devoid of self-worth and potential.

This focus only on what people with intellectual disabilities were *incapable of* was pervasive. Even service providers, researchers, supporters and others dedicated to the advancement of the rights and abilities of people with intellectual disabilities have had their work and mindset influenced by this perspective. As a result, even today supporters’ efforts often deal primarily with issues that address their disability and their limitations (as seen by people without intellectual disability).

Rarely was the focus on the inherent gifts, talents and abilities of this population. But slowly that has begun to change. As Thomas Merton, the social-activist Trappist monk and poet gently reminded us: “*The beginning of love is to let those we love be perfectly themselves, and not to twist them to fit our own image. Otherwise we love only the reflection of ourselves we find in them.*”

So too has it been for those who serve people with intellectual disability. As work to support them has evolved and advanced, supporters on all levels have found themselves recognizing the unique gifts of persons with intellectual disability. They have found themselves being changed by those they set out to “help” as they become part of an ever increasing community that recognizes that they are not working *for* people who had been beset by some trauma or hardship, but instead are working *with* people who dramatically enrich the quality of their lives and their relationships.

Shared Lives picks up where this recognition and dramatic shift take place, and it challenges supporters, service organizations and societies to incorporate it in ways that are focused and action oriented. The book promotes an appreciation of the gifts of people with intellectual disabilities, and works toward an understanding

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of what it is about this population that can bring about transformative change – not only in themselves, but in others.

Consider it essential reading for not only those of us committed to the respect, acceptance and inclusion of people with intellectual disabilities, but for anyone who works to promote the potential and self-determination of all of us!

SHARED LIVES: AN INTRODUCTION



The real voyage of discovery consists not in seeking new landscapes but in having new eyes.

Marcel Proust

This is a book about people sharing their lives together. Even more, it's about supporting one other as we go through life.

It is about people who down through the years have been called by various names – mentally handicapped, learning disabled, intellectually impaired. But to those who know them well, these labels don't much matter. They have discovered that each person has a unique personality. Unless we get to know the man or woman behind the label as individuals with feelings, talents and aspirations, it will be hard to provide them with the support they need. Nor will we gain from the positive benefits that they can bring to our lives. We need to reduce the divide between 'them' and 'us'.

The book is also about other people who are also given various labels – 'family', 'volunteers', 'staff' or 'professionals'. We all share a common ambition. We want to make life better for the people we are supporting. In many ways, what we do is not remarkable. Some would call it ordinary, even mundane. But what is exceptional, is our persistent willingness to challenge expectations. For example we are prepared to question beliefs about people's supposed incompetence. We try to find ways of supporting them to do things for themselves.

Equally people with intellectual disabilities can enrich the lives of their families, friends and supporters. Often this is overlooked, even ignored. Yet their positive

influences are vital in creating resilient relationships that are mutually rewarding. These are the building blocks for creating communities of support that can help to revitalise modern society.

Our aims for the book are simple. We want to present people with an intellectual disability in ways that both addresses their needs and highlights their gifts, in keeping with the thinking of positive psychology¹. We want supporters to appreciate and reflect on the relationships they have with those they support, since mutual relationships are a primary means of ensuring each other's happiness and enabling each other's development – social, emotional and spiritual. Supporters tend to focus on daily tasks and the role they are expected to fulfil, without realising sufficiently that their work will be all the more effective and rewarding if founded on personal relationships. Finally, we want to explore how people can find the sense of community that can be lacking in urban societies especially.

THE POWER OF STORIES

The book is based around stories from everyday life as they usually illustrate the power of relationships. Many a story is based around adventure, romance and mystery but often we can identify most easily with the stories of ordinary life; as seen in the popularity of television soap operas. Yet their stories rarely feature people with a disability. Why? Maybe it's because these people are perceived to be so different that they can't be part of our everyday lives. Instead they are confined to special settings. Fortunately we are living at a time when society is more aware of discrimination and people with a disability are asking for more than pity or sympathy. Much more can be done to include everyone in community life.

Our stories point to how relationships can come about. They are not prescriptions but rather illustrations of what has happened in people's lives. People change people. Stories can touch us emotionally and it's feelings that drive us to act. It is when support is driven by deep feelings that it changes lives and makes a real difference to the whole person.

WHAT'S IN A NAME?

We had one problem in putting the book together. How do we refer to the people whose stories we tell? People in need of support are not all the same; just as people who are supporters are very different from one another. We decided to use the term '**supporters**' for people who are in a helping role outside of the family.

Supporters are often staff paid to work in a variety of services. They may support people in some form of accommodation or in the person's own home. Or they might work in schools, colleges and day centres or in some form of community-located activity such as employment and leisure schemes. They could be employed to work with only one person or they may support groups of people. In some organisations these roles are fulfilled by volunteers.

But supporters also include people in the community who may volunteer to support people in particular ways; such as friends and acquaintances, leaders in sports and social clubs, co-workers in businesses and so on.

Although the term supporters can include family members – parents, brothers and sisters –in this instance the word ‘family’ is enough to express the supportive relationships that they nearly always offer to their kin. A major theme of the book is the need to build communities of supporters from these three groupings – paid supporters, community supporters and family.

It was harder to find words for people who need or receive support. Scores of names have been used down through the years and dozens are in daily use in society. The problem with many of these names is that they devalue the persons labelled by them. Who wants to be called ‘mental’, ‘slow’ or even ‘special’; or known as a ‘client’ or ‘service-user’? In the end we opted for the phrase ‘people we support’. More often we shorten it to the word ‘people’ as a reminder that they are people first. We have more in common with one another than that which separates us. But the full phrase is needed at times to avoid confusion. Although all of us require the support of others, some people need more *life-long* support even in their adult years. This is the group we mainly focus on.

We realise too that grouping people under a common label runs the risk of creating stereotypes when the reality is that people vary a great deal. Our stories are examples of what has happened for certain people in certain places at certain times. You have to take from them the lessons you feel are applicable to you and the people you work alongside.

We are not implying that every story has a happy ending. Supporting people is not easy or straightforward. But appreciating the good times can see us through the challenging and testing periods.

LISTENING WITH UNDERSTANDING

Perhaps the greatest change that has occurred in our thinking about people in need of support in the 21st Century, is a realisation that their voices and views have to be heard and taken seriously². In years gone by, parents and professionals made all the decisions for them with scant consideration as to what they wanted. Such was their vulnerability and powerlessness that they went along with whatever was offered to them. Indeed this can still happen today. But this creates dependency and helplessness that accentuates their disabilities.

Supporting people to live more fulfilled lives means listening to their hopes and fears, understanding their capabilities and needs for support, and helping them to realise their ambitions and cope with the inevitable disappointments. This is no different from what everybody expects from a supportive relationship. But the people we support do not find it easy to speak up for themselves. That’s why we must go to extra lengths to ensure we listen to them and to mould our support to their needs and aspirations. We believe that the simple act of listening has the power to transform the relationship between supporters and the people they support³.

WHAT IS MEANT BY SUPPORT?

The term support is frequently used in modern services. But do we really provide the support that people want and need?

We view support as having four parts as the Figure shows. These are not separate. Rather they are like the colours of a rainbow. These merge into one another and together they produce what we call ‘support’. Various chapters of the book are devoted to each strand.



Supporters have to appreciate the personal qualities of the people they support; seeing them as valued citizens who can enrich the lives of their family, their community and their supporters. This entails changing mind-sets to a positive view of people, coupled with greater emphasis on the emotional aspects of the support we provide for them. Equally, the focus has to be on the individual needs of those we support. We must respond to them as persons and not to their labels.

This means getting to know them very well through watching and listening. Chapters 1 and 2 focus on these themes.

In Chapter 3 we describe the features of a supportive relationship and what distinguishes it from other types of relationships. Then in Chapter 4 we examine people’s need for mutual relationships and how this can be fulfilled. The supporter’s role in helping people to nurture friendships with others is addressed in Chapter 5.

In Chapters 6 and 7 we look at how people and supporters can come together with others in various social networks or communities. These provide a sense of togetherness and belonging while widening opportunities for people to live more active and fulfilled lives through leisure, education and employment.

Chapter 8 examines the building of alliances and the creation of partnership working across different support agencies, organisations and families. There are many obstacles to doing this but for us a starting point is for all agencies to be open to the new opportunities and choices within their localities. This is especially so when it comes to balancing risks with opportunities as we discuss in Chapter 9.

Finally Chapter 10 summarises how all these themes contribute to a sense of personal fulfilment.

THE ESSENCE OF SUPPORT

When these four strands come together, a radically different form of support service emerges. The bedrock is the relationship between two people; the person in need of support and his or her supporter. It is built around individuals – their talents and aspirations – and thrives on people’s creativity. It means building supports from the bottom-up. This simple truism echoes throughout these pages. Our primary theme is the power for change that is available in the working and personal lives of individual supporters. The practical steps they can take may seem small on their own, but when added together can greatly enhance the lives of the people we support. A fair number of supporters intuitively support people in these ways without realising the significance of what they do. By naming and describing their contribution, we want to affirm them while also giving other supporters an opportunity to learn from their example.

Given the infinite variety of human nature, we cannot present you with ready-made courses of actions to follow. And in any case, there is often no ‘right way’ of achieving the outcomes that you desire. Rather supporters have to make the best decisions based on what they know and the circumstances that they are faced with. As we will discover, certain decisions can create dilemmas that are not easily resolved, for example how to balance potential risks with valued opportunities. Supporters need to become adept at analysing and reflecting on the decisions they are called on to make. The final chapter addresses these issues.

RE-FOCUSSING SERVICES

It is increasingly evident that existing service systems can inhibit rather than encourage innovative practices by supporters. Modern health and social service organisations can easily become pre-occupied with paper-work, policies and procedures, health and safety issues and keeping within budgets, so much so that people’s feelings, needs and relationships are devalued. Administrative efficiency and accountability has its place but our hope is to redress the imbalance we perceive that is taking hold in ‘professionalised’ support services. Hence a secondary theme of the book is the new ways of thinking and working that are required to nurture supportive relationships in services and in society.

In essence then, our focus is on people and more especially on recognising and developing their talents. The history of disability services is rooted in managing and treating people’s deficits. Fortunately there are various professionals such as nurses, therapists and social workers who can focus on these particular issues. Their jobs and the techniques they employ are important and have their own literature. This book provides a rather different emphasis.

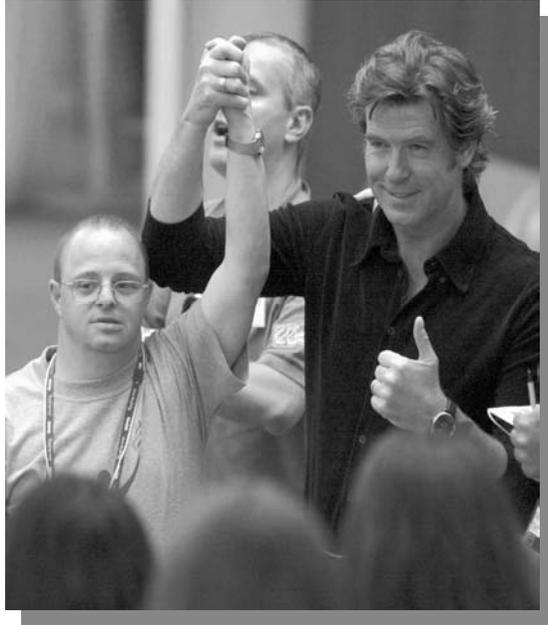
There is a danger that a focus on remediating people’s deficits colours all the supports the person receives. A better starting point is the person – full stop! We may well go on to define their special needs as a step in responding to them but this has to be done within the context of helping them to meet their ordinary needs – those that are common to all of us.

SUPPORTING SUPPORTERS

Supporters experience many pressures in their work and often they are expected to cope on their own. Without support they can become dispirited and disillusioned. Many supporters tell us that what keeps them going is the people they work with and we tend to agree. But that may not be enough. Much of what we say in the book applies equally to the relationships that supporters have with one another. Staff may need to be open to support from families of the people they support or from their allies in the community as well as providing these groups with the support they need.

We know that supporting other people is not always easy. Some people can be difficult to get to know, to like and to work alongside. It can be hard for supporters to pull together. We have no easy solutions to offer. But we believe in the human gains that come even from the times of struggle. It makes life challenging, exciting, frustrating, rewarding, exhausting, hilarious, demanding, tedious, fun and worthwhile. Unless we play our part and make the effort, then no relationships will form. We can't wait for others to make the first move. In nurturing relationships, all our lives will be changed for the better.

THE POWER OF POSITIVE EXPERIENCES



*Actor Pierce Brosnan and medal winner Karl Suppan from Austria
at the World Games of Special Olympics, Dublin.*

There will always be the thrill and fascination of watching the elite perform wonders of the physical. But Special Olympics, in a way, uses sport to capture wonders of the human spirit.

The Sunday Independent 29.06.03

Some years back, something extraordinary happened in Ireland, when thousands of athletes came from all around the world to take part in the World Games of the Special Olympics. At once they won the admiration, the respect, and indeed the hearts, of the whole country. The media struggled to capture the experience as it unfolded day by day. The most hardened journalists became like putty in the hands of the special Olympians, and wrote moving and deeply reflective pieces about their experience of the games.

Few events have gripped the public imagination so vividly as this enriching experience shared by the entire nation in an extraordinary outpouring of courage, joy, skills and compassion.

Athletes who are categorized by a society as abnormal because they have learning disabilities, demonstrated again and again that they have far greater abilities than some who see themselves as smarter or more able-bodied.

It was an object lesson in humility for us all, a marvellous example of volunteerism by the citizens of host towns and the many professionals and organizers who gave so unstintingly of their time and expertise throughout the past week and more.

Editorial, The Irish Examiner, 30.06.03

Two aspects of the games were highlighted in particular:

- The impact that the athletes had on communities all around the country, releasing a ‘latent goodness’ which led thousands to volunteer to open their homes and join in celebrating the event; and,
- The renewed awareness of ‘the potentiality of every human being’ that came through ‘glimpses of inspiring humanity.’ The athletes were seen as having offered something of great value to the whole of society.

For two weeks the Irish newspapers were full of extraordinary stories that showed that human spirit at its best as seen not only in what the athletes achieved, but also in how they went about it.

THE QUALITIES OF THE ATHLETES

Three particular qualities of the athletes were noted in various reports. First, was their courage and determination:

And then eyes turned to lane one, where the competitor appears to be stuck at the start. As we later find out, Hazel Zumbado, a slight 15-year-old from Costa Rica is deaf and mute and – out of the pool – confined to a wheelchair. She has the use of her arms but her hands don’t work properly. So she can swim, but as we clearly see, only with great difficulty. Yet now, slowly but surely, she is moving forward. Rising to her effort, literally, the crowd above the pool is also getting noisy. They are shouting, screaming, urging her every inch of the way; and her progress is measured in inches, as enormous effort translates into tiny advances through the water.

Suddenly the cheering gives way to a rhythmic handclap as when a 5000 meters runner is chasing a world record. There are now four assistants around her in the water, encouraging, and ready to help if needed. But the swimmer is going to make it without their assistance and with everybody in the packed gallery on his or her feet, applauding, she touches the wall in 1 minute 59.23

seconds. 'It's great, isn't it?' says a woman, who has suddenly appeared alongside you. 'Yea, fantastic,' you mutter, looking down pretending to take notes while blinking your eyes repeatedly. 'And the response from the crowd is wonderful,' the woman adds. 'Irish people have really opened their hearts,' the woman is saying. True, you nod still not able to look up and struggling to shut the door on your heart before it embarrasses you any further.

Frank McNally, The Irish Times 26.6.03

Second, athletes' kindness to one another, at times even foregoing the competition to assist others in need:

Half way around the 10-kilometre road race in the Phoenix Park, 30-year-old Swiss rider, Yann Mercet, suddenly started to slow down. Beside him his rival, Andorran, Jordi Julia, had crashed out and without hesitating, Yann eased off the pedals. He freewheeled while he checked his friend was unhurt.

Only when Jordi had remounted, Yann began racing again. The pair headed towards the line in first and second place. Jordi took Gold while Yann a few yards behind the finish happily settled for the Silver Medal. Had he kept going, he would have undoubtedly have won the top prize.

As the Swiss coach congratulated Yann on his medal, the rider seemed entirely unconcerned that four years of hard training near his home in Neufchatel had ended in Silver, rather than the Gold he won at the last World Games in North Carolina. He shrugged as he told me about the race. Of course he would stop for his friend.

Stephen Dodd, The Sunday Independent, 29.06.03

Third, awe at the effort they displayed when competing.

Gary Durkin (14) from Castlebar was an early participant in the Bean Bag lift. He sat in his wheelchair and gazed at the blue and yellow bags. If the silent urging of the audience could have moved them, they would have soared over Ballsbridge. 'I think he needs a little bit of encouragement,' said the MC, Nicola O'Loone. As the audience cheered, Gary stretched out a hand. Then he pulled it back. The hand went out again and the yellow bag was in the air and into the basket. Had he just climbed Mount Everest and abseiled back down in time for tea, Gary wouldn't have received more applause.

Alison Healy, The Irish Times 26.6.2003

THE HEART OF THE GAMES

Press commentators and the volunteers they interviewed tried to define what it was about the Games that affected them so deeply. Central to the experience was the spontaneity, the courage, the openness and the friendliness of the athletes. Possibly the most frequently used word in the media reports was 'heart.' Not just the great heart shown by the athletes, but everybody's heart.

He learned, as all who shared the tennis feeling learned, that, while feet and hands are important in tennis, in the game of life it's the head and heart that count – especially the heart. There were no losers last week. Love all.

Declan McCormack, The Sunday Independent 29.06.03

It caused people to reflect on what often seems absent in modern society. The taxi driver who spent the week shuttling volunteers and families to and fro summed it up:

You know what all this makes you feel like,' he says, 'Like you're not alone, 'cos that's kind of how you feel in this country these days. It's nice. Hope it lasts. I think it will. Maybe we found what we lost. I dunno.

Key to the success of the Games was that they were organised so as to give people personal contact with individual athletes. This happened particularly through the host programme, where people had one or two athletes to stay in their homes the week before the games. Having been deeply touched by their guests, many hosts followed them to Dublin to support them at the Games, and to share once more in the great feeling of togetherness they had known the previous week in their local community. One woman helped host the Irish Golf Team and then found herself arranging a totally unplanned week at the Games golf competition, though never previously interested in the game. "*Oh I had to come. I just couldn't bear it when they left us.*" she explained. "*It was like I was left with a big hole inside.*"

THE ELEMENTS OF SUCCESS

The impact of participants did not happen by chance. The organisers of the World Games deployed five key tactics that all supporters need to heed.

Promote positive images of people

The Games promoted the talents and personalities of the athletes in a wonderful way. People were given opportunities to prove themselves and had their successes applauded. This not only enhanced their confidence and self-esteem, but also changed other people's perceptions of them. This happened both at the Games and in the local communities where the athletes went to stay.

The media played a major role in promoting positive images⁴. Pictures from the World Games were beamed around the world. It is striking to contrast this coverage with the more usual media images of the people with disabilities. More typically these focus on stories of pity and distress, presenting situations where families are under intolerable pressure due to the lack of adequate supports, or where people are being treated badly in some dehumanising service setting. While such exposés are valuable in generating pressure for change, they also create very negative stereotypes of the people needing support. They do not present 'the triumph of the human spirit' that was repeatedly seen in the Games.

Create positive associations

The Games drew on a wide range of celebrities. Some like Nelson Mandela of South Africa and President Mary McAleese of Ireland spoke at the opening ceremony. Many others – well-known film stars, pop stars and professional athletes – presented medals for the various events. This produced many images of formerly devalued people in the clearly delighted company of those who are most highly valued in this age of celebrity.

Use ordinary settings

The Games took place in the wide range of setting used by everybody for major sporting fixtures, and on the whole, athletes took part in the same sorts of competition. They stayed in ordinary homes or in hotels and guesthouses, rather than in disability centres.

Perhaps this was part of the reason for the success of the volunteer programme. It was easier and more comfortable to offer support in ordinary settings rather than being asked to go into rather alien service settings dominated by professionals. Likewise, the people we support have to be seen in the ordinary settings - in shops, bars and buses; in schools, colleges and businesses; and in socially valued settings such as television programmes, theatres and concerts, if we are to encourage the general public to be more engaged with them.

Have a good time

Fun and celebration were major features of the Games, most of it generated by the spontaneity of the athletes and their obvious love of having a good time! This proved irresistible to everybody else. It also meant that people further lost any sense of stigma as they met and mixed with others in a most enjoyable way. Much more can be done in ordinary life to create occasions of celebration and fun that bring all sorts of people together and create bonds between them.

Expect achievement

The World Games presumed that athletes would succeed not fail. The very act of taking part was an achievement for many. Likewise, the expectation of achievement in everyday life should encourage supporters to have people do more for themselves, be it learning to wash their hands or to use a dish-washer. But just as in the Games, participation in community life for some may require hard work and self-discipline so that people do not let themselves down. This coaching role is a key one for supporters.

The positive mindsets created by the organisers of the Games did not happen by accident; nor were they some sort of contrived strategies. They followed naturally from their belief in the athletes that was based on the experience of many years.

The Irish Games confirmed once more how well founded were these beliefs in changing hearts and minds.

THERE WAS A PRICE

By the end of the World Games, people were both exhilarated and exhausted. A great deal of hard work had gone into the Games, not only in Dublin but all around the world, as athletes and their coaches trained and competed in local and national competitions for months and years. It took a great commitment to sustain that effort over such a long period of time.

And there were the hidden and not so hidden times of crisis at the Games – rows among athletes and organisers; despair and exhaustion when hoped-for success did not happen; supporters at the end of their patience; people making unrealistic demands; people feeling unappreciated – and all the other human difficulties that can arise at a pressured time.

But everyone walking out of the stadium after the closing ceremony would have said it was all worthwhile despite the pain. What was achieved repaid the effort a thousand fold. The Games were a wonderful event, but not in a facile or pretty way. It was too real, too human, for that. The athletes stole the show.

WHAT THE ATHLETES OFFER IS WHO THEY ARE

Throughout all the ceremony and competition, the athletes performed simply as themselves. As one writer noted:

We like the predictable; the organized social dance where we know what to expect and what is expected of us. All this goes out the window when we are dealing with people with an intellectual disability. They haven't learned hypocrisy and prevarication, double speak and phoney. What you see is what you get. If they like you, you'll know it and if you're boring, well you'll know that too. Initially, that's a bit scary but it grows on you – you might even want to continue living this way, ask the volunteers.

Marianne O'Malley, *The Irish Times* 26.06.03

This experience of deep and accessible humanity made Irish people feel instantly at home with the athletes, despite the barriers of culture or language. People were allowed to glimpse something of their own deepest identity – the part of themselves that is made for relationships with others – and beyond that, by being brought to a place of shared humanity by the athletes and by experiencing a sense of community with them. For a time, this replaced the loneliness that arises from living in a society that values achievement and possessions more than relationship and community.

Wolf Wolfensberger⁵ summed up this thought well in a short but powerful article in 1988, where he listed the positive characteristics of those labelled as 'mentally retarded,' and placed first "*their growth of beautiful 'heart qualities'*" and argued that their resources are more concentrated on relationships. Far from being disabled

in terms of their capacity for relationships; he saw this as a particular strength for many.

In the professional literature on people with intellectual disabilities, little reference is made to their positive qualities. On the contrary, most of what is in the research journals only highlights the shadow side of those we support, so much so that it distorts our images of their full humanity. For example, we undertook a survey of all articles published in six intellectual disability journals between 1996 and 2000. This showed that out of a total of 2,789 articles, only 21 focussed on anything positive. That is less than 1%, compared to the 99+% that focussed on negative features.

The people we support certainly can have significant problems and challenges to address, and researching these topics can lead to new forms of intervention. In that sense, the negative focus of professional endeavours can have positive outcomes. But overall, the relentless emphasis on the negative in what is written about the people we support has unwittingly contributed to diminishing them rather than celebrating who they are and what they can offer. It is past time to take a fresh look and to find a new, more balanced vision.

AN EXCEPTIONAL EVENT?

Some might say that those Summer Games were a heightened, short-term experience that swept the country along in a tidal wave of emotion. Indeed the Games slogan was '*Share the feeling.*' Did those weeks give an unrepresentative picture? We suspect not because the same feelings are reported by family members and by service supporters who live and work with people every day. But often these remain private experiences that are not celebrated or even acknowledged. The rest of this chapter explores these experiences in more detail but this leaves unanswered the question – why do we fail to see the contribution that certain people bring to all our lives?

It is an important question, because if the experience of the World Games and those wonderful news reports were to be taken seriously in an ongoing way, the public perceptions of people would be rebalanced. They would be seen as

- People of talents rather than deficits;
- People who can achieve rather than being destined to failure;
- People who are responsible rather than dangerous;
- People who are attractive rather than strange; and,
- People who have a great deal to offer to others rather than just needing to be looked after.

As we argue throughout this book, all these changes in how people are seen, have to come as much from the heart as from the head.

THE POSITIVE EXPERIENCE OF SUPPORTERS

The feelings evoked by the World Games are also experienced by families and supporters. They know how the daily shared experiences with the people they support enhances their own lives. Yet this is rarely acknowledged or promoted. More negative images tend to dominate. Even today it is not uncommon for the parent of a child with a disability to be regarded with pity, while service supporters may be seen as ‘wonderful people’ because of the kind of work they have chosen to do. The reality of people’s experiences is far richer and more complex than that. As well as, and sometimes even because of, the undoubted difficulties they can face day-to-day, both families and supporters have a great deal of positive things to report about those they support and the beneficial impact this has on them.

THE FAMILY EXPERIENCE

For parents, the birth of a child with a disability can be a most painful time of disappointment, anxiety and grief. Not unusually in the early months and years, parents meet a series of professionals all asking about their child’s problems, with few taking time to enquire about the good times or the positive contribution their child has brought to their lives. Some professionals may add to parents’ fear and turmoil by projecting their own unconscious negative images regarding disability.

The emotional upset of parents is seldom resolved once and for all. It often recurs at various points throughout the child’s life, particularly at the milestones that may highlight their child’s limitations relative to other children. Feelings of guilt or depression may persist; marital strain and separation can happen. Parents’ sense of loneliness and helplessness is not helped by having to fight to get the support services that they feel their son or daughter requires. Yet despite all these and other pressures, many if not most parents continue to adapt to the new family member.

I was told, I cried, but I realised that we are in this together and I was determined to make the best of it. Then I fell in love with the child....

Parents learn to trust their own hearts and to think anew about the child, in ways very different from the unconscious negative images they may have previously held about what it means to have a disability. A desire to love and protect follows naturally from the sense that this child is “ours.” Not surprisingly, the family then starts to experience positives associated with having the child.

Up to recently, researchers used a stress-and-coping model when looking at parents and families of children with a disability. Now the realisation has dawned that these families “*are not just coping, they are thriving and positively benefiting from having a member with a disability – they are better people because of the experience.*”⁶

A content analysis of 60 books written by parents of children with various disabilities found that in addition to recounting significant demands and emotional stress, the majority of authors also felt that their lives had increased enrichment and meaning as a result of their experience with their children⁷. A review of fathers’

published accounts likewise reported strong positive feelings and personal growth, as well as stressful experiences and negative feelings⁸. The following key themes have emerged from these studies⁹.

The gains for families

Emotional gains: Parents and siblings talk about the emotions they have felt and of how deeply the person has touched their lives, including:

- Sharing love with the person;
- Pleasure and satisfaction in providing care for the person
- The person is a source of joy and happiness to them.

Personal Growth: Families speak of the growth they have experienced as a consequence of both the positive aspects the child has brought, and also the struggles of parenting the child. For example:

- A sense of accomplishment in having done one’s best for the child
- The child provides a challenge or opportunity to learn and develop
- Having the child has strengthened the family and/or marriage
- Having the child has led to the development of new skills and abilities, or new career opportunities, and
- A feeling of having become a better person - more compassionate, less selfish, more tolerant.

New priorities: A re-ordering of parents’ priorities for the better, comes from having the to support another person. This meant:

- A new or increased sense of purpose in life;
- A changed perspective on life, e.g. it clarified what is important in life, and made them more aware of the future;
- Learning to make the most of each day, living life at a slower pace;
- Increased personal strength or confidence;
- Increased spirituality and drawing strength from their faith.

Connected with others: Parent’s may develop a sense of belonging to a wider community. For example:

- Having an expanded social and community network through meeting other families in similar situation to theirs.
- Getting to know people working in services and voluntary groups who are supporting their family member

No doubt these four broad types of gains entail many struggles. Without minimising the challenges and heartaches, parents balance them by taking pleasure in the person’s development and achievements. It starts from birth as they find out

who this little person is and experience the love that flows between them. They begin to see the child as a source of satisfaction, as an object of love and a call to them as parents to change, adapt and grow. This then becomes a major strength in coping with the challenges and sadness that can also arise from time to time.

Such outcomes occur for adoptive parents as well as birth parents. A longitudinal study of families who adopted a child with a developmental disability found that the families demonstrated positive outcomes early in the process and that these effects were maintained over 10 years after the adoption took place¹⁰.

The transformation of what many see as a tragedy into a positive experience happens not only despite, but also through, the care demands the child may make. Mothers who reported higher levels of care needs in their child also identified more personal growth and maturity for themselves¹¹. Dealing successfully with challenge, enhances the feelings of efficacy that contribute to personal growth of the supporter.

More fundamentally, this growth arises from the feelings of humanity and love that the child's gifts and vulnerability engenders, as well as from the struggles to meet the needs and from the times of sadness, anger, and loss that may arise.

The experience of siblings

Brothers and sisters too are often supporters in various ways. Their experience may be no less rich and complex than that of their parents, but they may only realise that years later, as Jeanne's story illustrates. She speaks of both the price and the gains that were hers from having a twin brother with autism.

My life was always about Paul. I was very fond of him because I was really close to him. On the other hand it was very complex because I realized that Paul was a real rival.... I had to know exactly how life was going for him, because however it was going for him, was going to affect my life.

She and Paul shared a common world in a way that Jeanne took for granted when young. She did not see him in terms such as 'autistic' and was quite confused when that diagnosis was made.

Paul was like a bit of me. I was always more aware of him than my other siblings when I was a child, and I think he was more aware of me. When I was very small my mother couldn't give out to me at all in front of Paul. He would have a tantrum! She could give out to anyone else in the house but she could not give out to me. She forgot we had a little twin thing going. It was just like being able to speak another language, and I can de-code the non-verbal pretty well. I experienced myself like an opposite in that twin universe. Paul is non-verbal and I'm verbal. It's an intimate relationship. It does not depend on speech or even contact in many ways.

Jeanne's whole life was affected for good and for ill by Paul's autism. She felt guilty because she was bright and Paul wasn't. As a teenager she felt bad because she could have a boyfriend and he couldn't have a girlfriend. Everything good she

experienced had the dimension that Paul couldn't have this, and that was very difficult. But as well as the sad or painful realities, Jeanne feels she also gained from being Paul's twin.

On the positive side it made me very sharp at reading human situations and relationships and situating myself. But it also made me hypersensitive to the world around me. In a way I was like a hare checking everything to make sure it was safe.

A lot of the things I've become are compensations arising from trying to reach Paul in social terms. Basically I'm a very timid person: I was a very timid child and very shy and anything I did like that cost me and to this day it does. I think that I learned from Paul something about reaching way beyond myself because I had to do that to reach him. I've become a friendly, open person in a way, but that wasn't where I started. You could say I have developed that strength because of Paul. And so I suppose I have certain abilities at that level that I gained from a lifetime of reaching Paul, because I did reach him and I still reach him.

Like Jeanne, many siblings have positive things to say about their personal gains from having a family member with a disability, but usually with a price. At times it is demanding and painful, but even then, research suggests¹², there can also be real gains from having experienced a shared life.

THE EXPERIENCE OF SERVICE SUPPORTERS

Service supporters too have a great deal of positives to recount¹³. They make it clear that the richness in their experience does not come from being paid, but comes rather from the humanity of those they support. One group of service supporters generated the list of characteristics they found among the people they supported (see box).

Of course they were not implying that everyone displays these qualities all of the time! Rather it's a reminder of people's qualities that we can easily overlook. Hence it is worth learning more about what these service supporters said about their experiences: their own words are very telling.

Positive perceptions of supporters

- Their openness to others, with a non-judgemental acceptance.
- A sense of presence, living in the 'Now'.
- A calming influence through their slower pace of life.
- Naturalness, spontaneity and enthusiasm.
- Builders of relationships and community: generating loyalty and love.
- Acceptance and resilience.
- Trusting and helpful.
- A willingness to forgive.

Openness and acceptance

Anna ran personal development programmes in an adult training centre, and she recalled a recent visit to another centre where she had never been before:

As I was there early, I went into the canteen. There was one man sitting on his own and I just knew that I could go and sit beside him, that he wanted me to sit with him. He did not give me any particular sign, but there was openness in his body language and energy. There is openness in most people we support: they are not as defended as other people, not as caught with “Who is she now, and what is she going to think of me and what I have to say; and how do I make an impression?”

There is great acceptance. You are going to be taken first of all as who you are yourself, not as your role. The encounter is from person to person. The boxes that we put one another in are not there with them. They bring you somewhere deeper in yourself, a place of greater humanity and vulnerability. It’s just this whole thing about not feeling threatened, so I’m allowed to be who I am. I have nothing to prove. Is that because of their disability? I do not think so. It’s ‘nothing to prove’ because of their openness and acceptance.

A sense of presence and a calming influence

Anna was also very interested in the sense of presence she found in people, and how this linked for her to important values in her own life.

They have a presence.... The Buddhists spend years meditating to try and come into the present moment, but our people have it. Now maybe they have it because of a disability, but maybe they’re enlightened Buddhists under a tenth lifetime! The Buddhists go on about you’re either looking into the future and trying to plan things, or you’re stuck in the past and hung up on things, whereas all there is in reality is right now. That is where many of our people are.

Supporters are also struck by the calming effect of people’s slower pace of life:

It’s calming, I think because it brings me into the simplicity of now. There is no agenda, nothing to prove, and nothing to argue about. When I sit with them when they are doing art, and they get so absorbed into it, especially the people with autism. On a busy day Sean can be very distressed. You do something calm with him, or when we go into town and sit having coffee, he completely calms down. It’s just the ritual of the buns and coffee and he’s in his own world, but sometimes he puts his hand here on me and says, “Thank you,” and will leave the hand there which is amazing for him. Now that just melts me completely. So there is something about the slowness, the pace, that’s extremely deep. It cuts right through all my defences. It goes right into the bone. The pace is slower, and everything slows down.

Naturalness, spontaneity and enthusiasm

Catherine, an arts worker, loved people's spontaneity, but never appreciated how powerful it was until she had the chance to observe those she supported acting on stage:

Watching actors going out there, not being nervous, loving the stage, no stuff going on – 'What will they think of me?' 'What if I go blank?' 'What if....' They just feel that people would be delighted that they were going on stage because they are so delighted themselves.

Builders of relationships and community

Kieran, a pastoral worker, has a commitment to those he supports that is far beyond any narrow professional definition of his role; such is the depth of satisfaction that people bring to his life. In searching for a way of describing what he meant, he remembered his cousin John Paul:

John Paul could have ended up in a centre had his mother showed interest years back. Instead he has been working on a farm in the local community - working at being part of the community and claiming his place in the community. Everybody knows John Paul.

When he wants to work he will, but production is not his agenda. His agenda is being John Paul. In order to be John Paul, he seeks to have a relationship with others. If he's not being productive in the conventional sense, he is productive in calling people to a place of humanity and friendship.

Acceptance and resilience

There is no doubt but that having an intellectual disability at times presents a major challenge and a considerable burden to those we support. The challenges are not only of understanding and learning, but may also include communication difficulties, physical disabilities, and/or social isolation. Overall there may be considerable limitations placed on one's possibilities and choices.

Faced with such restrictions, many people might be expected to become depressed. And while those we support can go through difficult times emotionally, in general they have a remarkably positive outlook on life, as described earlier. Walter is often struck by the resilience and acceptance of those in his Camphill community.

As a toddler Heather was a slow developer and developed serious epilepsy that responded poorly to all the different drugs. At 17 she had brain surgery for seizures. Unfortunately this was unsuccessful and left her with significant speech difficulties. Recently, however, a new anti-epileptic drug was tried which has finally controlled her seizures. Then, at 26, Heather developed severe rheumatoid arthritis, which has slowly improved with medication.

In spite of all these challenges Heather moved in her late teens from the family home to a life-sharing community and recently into independent supported living. She keeps her home immaculate, sees to her own breakfast and supper, and does her own shopping. She works part-time at the cafe in the local hospital and helps with the cleaning in the community. Her main activity is weaving and she is very accomplished. Her health has not deterred Heather's determination to make the best of her life. She inspires those working with her to carry on with life despite their own relatively minor pains and aches.

A willingness to forgive

Jim has worked in services for many years, sometimes in very challenging settings. His commitment has always been obvious, but he is not a man given to easy sentiment. Yet when asked what touched him particularly in his work, his answer was immediate:

I am often struck by the generosity of the people I work with in forgiving me or other staff when we get things wrong, or when we have moments of being impatient or even unpleasant. I am not saying that forgiveness always happens regardless, because of course people hold grudges at times as everybody does. But I do see when the person likes you, how quickly they can move on from being upset with you. I am sometimes very moved by that, and grateful too.

Because of course you don't like yourself if you have been short or a little mean with somebody. It can be really healing when the person nonetheless reaches out to you. It is like as if who you are in that person's eyes is greater than whatever faults you may have, and that you are accepted regardless. Our training textbooks or our service policies do not talk about that, but for me it is one of the most beautiful and hopeful things about my work.

New Perspectives

These assets and gifts of people in need of support are not often acknowledged, even though they are the daily experience of many service supporters. Perhaps they have been consigned to silence because of the dominance of service models that are geared more towards problems and pathologies and the provision of care, than models that emphasise people's gifts and creating opportunities for them. Perhaps the deeper human gifts have had little scope of expression in the prevalent professional mind-sets of paid supporters who are trained to identify and deal with people's problems. We are not trained to celebrate people's capacities. Whatever the reason, it is past time that service supporters should begin to share such experiences with the wider community.

THERE IS THE SHADOW SIDE TOO

To highlight family and service supporters' experience of so much that is positive and life enhancing is not to suggest that those they support are seen as somehow perfect in their humanity. Such an idea would imply an offensive 'holy innocents' image that sees them as less than fully human and results in a denial of both their needs and their rights. No less than everybody else, the people we support may sometimes be happy, sad, kind, selfish, open or closed, depending on what is happening within and around them at a particular time, and on how they have been treated in life to date.

As a result, supporting a person can both give deep satisfaction and be very demanding. But in good times and bad, there is always a shared humanity, because those we support are more people of the heart than of the head and generally do not hide either the richness or the rawness of their feelings or needs. Responding either to people's openness and affection or to their fears, angers, or hurts, can only take place through the supporter's willingness to be present and respectful in a way that affirms and gives life. In doing so, his or her own humanity also is challenged and enriched.

Besides, all of us have our shadow side too, as does society as a whole. But we often have far less healthy ways of dealing with it than has the person who is open and direct in what he or she feels. Instead, sociologists tell us, we may attempt to deny our own darkness by projecting it onto those that are perceived as in some way 'different.'¹⁴ They are asked to carry the darkness of society, as well as their own shadow.¹⁵

In particular there can be prejudice against those who force us to recognise our own neediness and fears. Their obvious disabilities can be an unwelcome reminder of how potentially vulnerable everybody is to sickness or disability. We are never as secure or as in charge as we might like to pretend, and ultimately it all ends in death anyway.

When a society does not wish to face such realities, people like those we support can become the focus of prejudice, causing them to be isolated and ill-treated, even to the point of death. This happened to hundreds of thousands of people with a disability in the Second World War concentration camps¹⁶. It happens today where life-saving medical treatments are routinely withheld from children with a disability, including those with Down syndrome¹⁷. It is seen where even those who would normally oppose abortion, find it acceptable where it is likely that the baby would have a disability and is presumed to face a 'very poor quality of life.'

If we are to secure the dignity and place in society of those we support, then supporters have no choice. We must help to draw them from the shadows and declare their gifts and value. In the past, we have all too often failed in this respect. However there are encouraging signs that services and society are starting to get it right. People are seen in neighbourhoods and on television: they are no longer shut away. People are being helped to do things for themselves, and encouraged to be more independent. But above all, people are starting to speak up for themselves.

WHOSE LIFE IS IT ANYWAY?



Living ‘a good life’ means that one is able to determine the course of one’s own life and have the opportunity to create an existence based on one’s own dreams, visions, wishes and needs.

Holm, Holst, Balch Olsen, and Perlt, 1996

For generations, well-intentioned services have presumed they knew what was best for the people in their care, and they acted without any consultation or consideration of their preferences. Those they aimed to help often found it easier to comply than to complain. Their own voice was stifled or ignored. Others made decisions for them.

The presumption was that people labelled as having an intellectual disability, were so different that they did not need to have the same rights and entitlements as others in society as they would be unable to exercise them. This discrimination still exists. Prejudicial attitudes live on and will only die out when repeatedly challenged.

The best people to make that challenge are those most affected by a denial of their rights. They know what is important in their lives. What matters to them tells us who they are, and how they must live in order to find personal fulfilment. After all it is their life – isn’t it? They want supports that enable them to create ways of

life in which they can flourish, including participation in the larger society that is their heritage.

The same messages echo when people are given a voice such as they have in recent reports coming from England, Scotland, Ireland and Croatia¹⁸. They want:

- To be respected for who they are.
- To be self-reliant and to do things for themselves.
- To have the same choices in their lives as their non-disabled peers.
- To be in control of their lives and determine for themselves what is best for them.

Appreciating and responding to these core aspirations is the hallmark of a good supporter. Let's see what this means in practice, starting with a reminder of the past and a journey that began many decades ago.

THE STRUGGLE FOR RIGHTS

Over the past half century there have been major shifts in how people are treated when they are considered to be intellectually disabled. Today people are living in a relatively benign era, at least in more affluent countries of the world.

- People no longer live in remote institutions; most have been relocated from hospitals and nearly all children grow up in families.
- In most of Europe, their rights to education and to 'an ordinary life' are enshrined in legislation and increasing numbers are joining the workforce and taking part in community activities.
- Official Government policies emphasise social inclusion, choice and advocacy. 'Person-centred services' are the new buzzwords.
- Services seek to promote human development across the lifespan, and much has been achieved by way of new styles of services and creating more productive lifestyles for the people they support.

Yet for very many people there remains a great gap between their day-to-day experience and the well-meaning rhetoric of state policy or the efforts of service providers. Although most people may now experience physical inclusion within their community, they often remain *socially isolated*, despite everybody knowing that our well-being depends on sharing a sense of community with others. It is the quality of our relationships that generates a satisfying quality of life. Often we are so pre-occupied with the provision of high quality *care* in services that too little energy goes into supporting people to become known and valued in their local communities, and providing them with opportunities to live a fulfilling life¹⁹.

In part this stems from societal expectations of people in need of support. These still stress their need for care and protection over the valued contribution they can bring to society. Many years ago Wolf Wolfensberger²⁰ identified seven well-defined images of people labelled as 'mentally retarded'. These were: a sick person

whose life is defined by clinical treatment; a subhuman organism without human rights; a menace to be segregated or even destroyed; an object of pity; a burden of charity; a holy innocent who is less than fully human; and a developing person. All but the last of these are views that have been imposed upon those we support by society's prejudices and fears.

These negative images persist. Whether at the level of policy or in the delivery of services, 'service users' continue to be seen almost exclusively in terms of what they need to be *given* in order to progress, and almost never in terms of what they also can *offer*. Many people find the term and the concept of 'user' offensive, suggesting as it does that they only use services but don't contribute to them. Most are trapped as objects of service delivery. To be seen as agents, instead of objects, means recognising their right to determine their own lives and accepting what they have to offer to others. But rather than being valued, many people are still made to feel ashamed of who they are, and that they should be grateful for whatever supports they might receive, however meagre. Notions of charity predominate over entitlements or rights.

The great challenge, then, facing them and their supporters is how people are not only known and accepted in their communities, but also loved and valued for the contribution that they can make to society becoming a better place for everyone²¹. We can be sure too, that if people are not actively valued, they will most certainly be devalued.

Finally, the 'does he take sugar?' culture also persists, in which others decide on their behalf, usually justified on the grounds that 'we know better'. People are not asked for their opinion, and even if they were, their responses may not be taken seriously.

In sum, people with an intellectual disability have experienced oppression in much the same ways as other marginalised groups, such as ethnic minorities. In extreme instances this has resulted in their institutionalisation in mental hospitals, forced sterilisation and even death in concentration camps. Today the oppression can be more subtle but nonetheless real whether it be from individuals, organisations, communities or Governments. Such experiences make people feel inferior and unequal which further perpetuates their submission to the oppressive forces that can be at work in our society.

THE IMPORTANCE OF SELF-ADVOCACY

But these negative attitudes of the past are no longer passively accepted. With support from advocates, increasing numbers of people are fighting for their basic rights with courage and dignity as they slowly overcome their feelings of inferiority and inadequacy.

In this struggle for rights, people with an intellectual disability are walking the road already taken by other formerly devalued groups²². For them, their journey begins at the margins of society, until a new awareness and assertiveness regarding the injustice of their position leads them to the heart of society as they struggle for their legal and social rights. They define together who they are and develop a pride

regarding the worth of their own views and values. This usually occurs through self-advocacy groups, where people develop the confidence and skills to speak up for what they want or do not want in their lives. The support of peers at self-advocacy meetings not only gives great encouragement but also creates a collective voice that is far stronger than that of any individual on his or her own. Their final objective is freedom to lead the life that fulfils people as they see it, and to make their contribution to the wider community.

Barbara Goode, the first lady with a self-acknowledged intellectual disability to address the U.N. General Assembly, put it this way²³.

Our voice may be a new one to many of you but you should better get used to hearing it.

Many of us still have to learn how to speak up. Many of you still have to learn how to listen to us and how to understand us.

We demand that you give us the right to make choices and decisions regarding our own lives.

We are tired of people telling us what to do, what they want. Instead let us all work together as a team!

The advocacy journey internationally has to be repeated anew in each locality. This means people being facilitated to come together to share common aspirations and concerns. They need support in developing the confidence to communicate their aspirations for change and to challenge injustices. They must be brought into dialogues with the people who hold the purse-strings and decide what supports will be provided. They need to critically review the progress that is made – if any – and not be afraid to speak out.

There is little doubt that advocacy at a national and regional level has primarily driven policy change and helped to create the new styles of support services that exist today. It can be equally powerful for individuals – or can it?

SPEAKING UP CAN MAKE A DIFFERENCE

Joseph had been sent to a reformatory school at the age of three and in his teens moved to an institution for adults. His life changed for the better in his early thirties, when he moved to live and work in the community. Then his life ‘went through a bad patch’ and he started drinking a lot. He was returned to the institution, twenty years after he left it.

I was not a happy man. I did not know how long it would be for. Living out in the community is good, and living in here is not good. Here there is nothing for me to do, stuck watching television. I’d like to be out in the community. They tell me they have no place for me. I think myself they don’t want me to go. They want me to be stuck in here all my life. I am happy (going to my job every day) because I am out of the place I don’t like - the institution. I am still stuck living here, ten years later. Nothing happens. Inside is not a community: it is a sad place.

Joseph made a short film about his life which was shown at a national self-advocacy conference in Ireland. He gave a stirring speech after the showing of the film in which life seemed to be looking up for him:

They (the services) are understanding what I want for myself. I hope I will be back in the community soon, have my freedom, and be able to do what I want to do. Living in the institution is not right. Everyone should have hope for the future, and life would be better.

At the following year's conference, Joseph gave a one-word update on what had changed for him during the intervening year: "*Nothing.*" There was a stir of anger in the hall and strong condemnations of Joseph's service, which were repeated at other meetings and conferences in the months that followed. Service managers were greatly embarrassed, and while privately they talked of the 'good reasons' why it had not been possible to find Joseph a home in the community, they also said that they were determined that this would change by the following conference. They had been forced to take notice of Joseph's wishes.

Joseph's experience is not an isolated example. Similar stories are often recounted when reviews are held of an individual's person-centred plans. The promises made in response to the aspirations that the person identified some 12 months back, fail to materialise and life for them goes on unchanged and unchallenged. Why does this happen, when we won't put up with such inaction in our own lives?

THE ISSUE OF POWER

Joseph's story and that of thousands like him, is but one example of the powerless people in services feel about having control of their own lives. He had complained for years about his unhappiness in the institution. His service had made sympathetic noises but had done nothing. Joseph himself was not in a strong enough position to demand action. It was only when he advocated for himself publicly and got the support of hundreds of others that the power balance began to shift in his direction. Thanks to what he learnt in his self-advocacy group, Joseph at least had the ability and confidence to speak out. Others, in situations as bad or worse, may have no power at all.

The power people have to make things happen, depends on three things:

- Their personal resources compared to others including their competence, communication, money and friendships.
- The degree to which they are dependent on others for assistance, and,
- Whether alternative arrangements or relationships are available to them that reduces their dependency and offers real choices.

Put this way, we can see immediately that the people we support often have little power over their lives.

For a start, their resources are comparatively limited, not only materially but also when it comes to speaking and acting for themselves. They may lack the skill and understanding to argue their case.

Also they depend on others in so many ways, sometimes totally so. They may be fearful of offending them by taking actions that their supporters may not approve of.

For those living in specialist services, they may find themselves without any real alternatives when their current life situation is unhappy. It is often difficult if not impossible for them to change their service provider. Indeed they may not be able to change support staff whom they dislike and have little opportunity to get the person of their choice instead. They have to put up with what is provided for them – no matter what they want.

On the other hand, supporters have much greater power compared to the person they support. Whether they are family, community or paid supporters, they can control resources and circumstances that are important to the person. They need not depend in any significant way on him or her, and they generally have both work and social alternatives, should they so wish.

But above all of these, there is another factor that emphasises the power of supporters. They are expected by society to ‘take charge’ of those who are dependent. If anything untoward were to happen, the blame would fall on the supporter as they are seen as having the power to prevent the person from harming themselves or others.

Of course, having greater power than someone else is not necessarily a bad thing. It depends on how the power is used. It can be exercised for the good of persons, by enabling and supporting them in every way possible through increasing their resources, reducing their dependency and finding alternative ways of increasing their own power.

Equally power can be mis-used as when it is used to dominate, to enforce control and compliance, thereby increasing dependencies and poor self-esteem. Supporters may not even be aware that they are doing this, so used are they to taking control.

That is why putting in place the laws and systems that support people’s rights and give them power over their own lives, has become the key issue in our time for those we support. Only when they are empowered to gain a sense of control over their own lives, will their identity become a confident one, irrespective of any disability they have.

GROWING INTO A CONFIDENT IDENTITY

The emergence of a confident identity can be seen in a new generation of young people who have grown up as part of their society rather than apart from it – the so-called ‘integration generation’. They take pride in their achievements – living in their own home, having a paid job, going to College – the list is growing by the year throughout Europe and the world. Each new addition provides another role model for future generations and forces us to stretch our boundaries of what we think is possible.

Nor do the new generation try to hide their disabilities as a former generation was inclined to do when they were relocated from institutions²⁴. Their main preoccupation was to avoid getting identified as a person with an intellectual disability. For this reason they avoided association with other labelled persons, resulting in a great deal of social isolation. This is still a reality for many living in segregated services²⁵.

Once people start to be part of mainstream society and are growing in confidence, they also want to form social groups, have meeting places and share accommodation with friends who share their identity. Like other formerly marginalised groups, they choose to spend their time with others who have similar perspectives and aspirations to theirs. They are unconcerned that doing so would stigmatise them. Instead, they have a confidence in pursuing their own vision of who they are and what is important to them. This development has been seen in noted in Denmark²⁶ for example.

We see a movement away from formal integration 'outside' in ordinary society or the ordinary school, towards a more fragmented integration that seeks to retain the opportunities for the disabled to meet each other through the establishment of co-operative housing, meeting places, centres, cafes, and festivals.

Today people proudly come together with others in campaigning or self-advocacy groups, thereby demonstrating the sense of freedom and empowerment that is characteristic of those who had achieved their basic rights²⁷. Their representatives may work alongside government officials in planning service provision, they meet with politicians to lobby for more resources, and they argue their case face-to-face with Ministers. Some groups have grown into organisations that provide a range of services for the members, deliver training courses for service staff and undertake their own research and evaluation projects; all done with support if required but through collective leadership. What a difference a generation can make!



Compass Advocacy Network is a user led and managed group for adults who have learning difficulties in County Antrim, Northern Ireland. They provide information and training and assist members to set up self advocacy groups in their own areas. They also provide volunteers to help members to organise and run their groups. The volunteers support members in learning new skills to empower them to carry out their roles in the groups.

Independent advocacy representation for members is also available through volunteers. Members can request an independent advocate to assist them at meetings, reviews and service planning events. They can choose the person they wish to act as advocate and may change the arrangement if the partnership does not work out.

They have set-up a recycling co-operative and sell goods in a local shop as well as on E-Bay.

They have a drama group that visits schools to make students more aware of what it means to have a learning disability.

An annual conference is organised that brings together advocates from across Ireland.

CREATING A BETTER LIFE

What makes life personally satisfying to us cannot be defined by others, whether family, services or society. Quality of life is not something that is presented to us but rather it is something we actively create for ourselves if given the chance to do so.

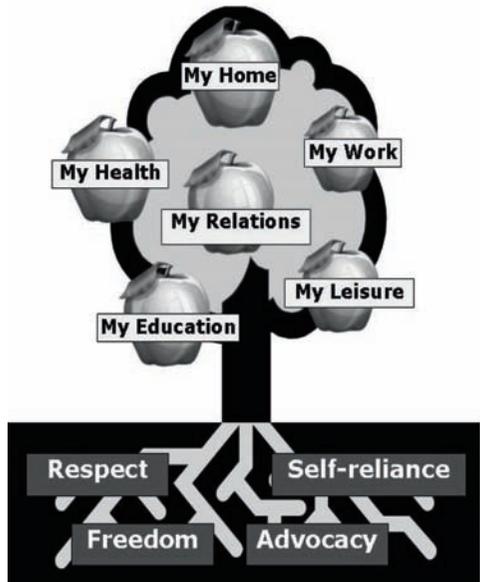
Because of their restricted experience, poor self-esteem and low expectations, it may take time for some individuals we support to realise what they want from life, and what they have to offer, but many do achieve this. As their confidence grows, then what is personally important to them becomes clear, regardless of what others may think. This means giving them the space and the opportunities to express their desires and ambitions.

In recent years various studies have collected the views of people with intellectual disabilities in different countries²⁸. This has been done through people meeting in groups, or in interviews or by completing questionnaires. A remarkable consensus emerges from the findings as to the priorities people hold for their lives. Admittedly, these are the views of more able people who can speak up for themselves but it is just as likely that they apply to people with more severe or profound disability who may not be able to express themselves as clearly.

We might use the apple tree of life as a means of illustrating the fruits they value. But these fruits are only possible if there are healthy roots that enable the tree to thrive. Hence we also need to identify what it is that helps people to flourish.

The fruits of life

My relationships: People placed great store on their relationships with family and friends, and with their support staff. They spoke of the loneliness they experience and being socially isolated. Having a boyfriend or girlfriend was mentioned as well as the opportunity to marry.



“Friends help you to get your rights – they help if things go bad.”

“People are not encouraged to be in relationships by families or staff”

“We need more opportunities to start small and before going to the boyfriend-girlfriend stage”.

My home: They spoke about having a place of their own; of living in the community rather than in special centres or homes; of choosing the people they lived with; of being in a safe and pleasant neighbourhood convenient to facilities, and of playing their part in household tasks.

“People want a choice of independent living options.”

“I would like to share with my girlfriend maybe sometime in the future.”

“I want more independence and privacy but I need staff to help me with the cooking.”

My Health: They recognised the importance of keeping fit and leading healthy lives. They wanted equal access to health services and for doctors to tell them about the treatments they were given. They knew the pain associated with the death of loved ones.

“Doctors don’t listen, they just look away and talk to someone else like the staff.”

“I can’t read the information on tablets – there should be pictures or symbols”.

“I lost my mother last year – I think of her every day.”

My Work: Opportunities to undertake productive work were frequently mentioned, preferably in paid employment. They felt the attitudes of employers needed to change. The rules around social security allowances prevented people for getting paid work.

“Getting jobs is hard outside of the workshop.”

“I go to lots of job interviews and don’t get any of them. Employers don’t want to employ disabled people.”

“We’re not getting enough pay for the work we do.”

My Education: They wanted opportunities to learn and to be trained in skills that would help them to get a job and more generally to do things such as handling money and travelling independently.

“I missed out on secondary school – there was no bus to take me.”

“I want to get into a training course that leads to real work.”

“We need to know more our entitlements and speaking up for ourselves.”

My Leisure: They wanted to know what was going on in their local community and to be supported to join in the activities that interested them on a regular basis. They spent too much time in the home watching television.

“I want to mix with other people in the community.”

“How about more discos and clubs that we can meet our friends safely.”

“I like to visit my relatives at weekends”.

The roots of life

Throughout these findings there are some deeper themes; the roots that are needed for the person to flourish and produce the fruits that people cherish for themselves.

Respect: They wanted to be treated as adults who can be trusted with responsibilities. The hurtful attitudes of others and the bullying they had experienced proved to them that prejudice still existed in their community.

“Treat me as me!”

“People should consult me about what I want to do or I think should happen.”

“We’re called names when walking passed teenage gangs or groups outside of pubs in town and cities”.

Self-reliance: People wanted the chance to do things for themselves – being independent was how they put it. Commonly given examples were managing their money; going out with friends and having privacy.

“If I didn’t have needs I wouldn’t be in a group home but I can still do things for myself.”

“I have to hand over half my money and I manage the rest but I could manage all of it.”

“I wish I could learn to drive.”

Freedom: People wanted to break out from the control they experienced in their lives. This meant having choices – so they could make their own decisions – and having control over the things that are important to them, such as how they spend their money and their relationships with others.

“It’s our own lives, it’s our decisions!”

“Having a relationship must be a person’s choice.”

“I have no choice which staff come to my house; I get on better with some than others”.

Advocacy: They wanted their rights to be recognised and to be supported in obtaining their rights. People felt they should be consulted rather than told what to

do. Their confidentiality should be respected and private matters should not be discussed with other people.

“We need to let the public know that we’re no longer to be treated badly.”

“People need to stop putting themselves down”.

“It’s OK to make a commotion if you’re being treated unfairly”

As you will no doubt have noted from reading these lists, people’s aspirations for their lives are little different to those we hold for ourselves, which is yet further evidence of our shared humanity. But what is very different are the many obstacles they experience in trying to fulfil these aspirations. In part these derive from the impairments that they may have been born with, which affect their capacity to learn and develop. But more crucial are the barriers they encounter within a society that denies them the opportunities and supports required to experience a good quality of life. The remainder of the book describes the supports people require in order to surmount their impairments and reduce the barriers they encounter.

OUTCOMES OF SUPPORT

The fruits and roots of the apple tree of life serve another important purpose. They provide the yardstick against which the support we offer people can be judged. Put simply, have we improved the quality of their life?

Today there is greater appreciation that supports have to be judged in terms of the outcomes they produce for the people supported²⁹. The core questions are ones like these: have we helped people to live where they want to live; to be productively occupied, to have friends and to be treated with respect? Outcome-based evaluations are a stringent test of the investment we make in supporting people. Some would argue this is too demanding because of the other factors outside of the support service that can affect these outcomes. This is true but in response we would contend that is not just the attainment of the outcomes that are important but rather it is the focus for learning that they offer about what helps and hinders their accomplishment. These insights should energise the service to improve the supports it offers to people. And should this not happen, outcomes do keep the focus on the person being supported.

By contrast, service providers have been judged mainly on the ‘inputs’ they have delivered to people – the number of support hours a person receives; the availability of special therapy, the new facilities they have opened and so on. More recently the focus has shifted towards *how* the support was provided and regulations were enacted by governments that defined the quality of the care offered in state-funded residential homes and day centres. The link between the quality of care and people’s quality of life was presumed rather than examined³⁰.

Re-appraising deficits

One further point is worth noting in what people say about their lives. Although they acknowledge their limitations, these do not dominate their thinking in the same way that health and social service staff tend to talk about their needs. They are more inclined to focus on people's deficits and differences rather than their talents and aspirations. They focus on poor health, challenging behaviours, attention deficits, mental health problems ...and so on. Much time and effort is spent on assessing and treating people's problems. Granted it is right and proper that people should get the specialist support needed to address their difficulties, but this emphasis cannot dominate the way people are supported, for two reasons.

- Their problems are likely to be exacerbated by the poor quality of life they experience at present³¹. Hence enriching their daily lives must be an integral part of any treatment approach and is certainly necessary for bringing about sustained improvements.
- Effective treatments for many health issues are built on boosting people's self-esteem, self-control and self-confidence while helping them to acquire more positive behaviours to replace the negative ones that hold them back³². Focussing only on the latter is not sufficient.

Person-centred

The summary we have presented of people's aspirations provides an overview of what they generally think will enable them to live more fulfilled lives. But it is crucial that we focus on individuals and assist them to define what is particularly important for their life, now and in the future. Admittedly it is not always easy for people to speak up for themselves or to make known their hopes, fears, desires, concerns, dreams and limitations. Yet our own personal advocacy helps to test out the realities of who we are and the opportunities that life can offer us. Crucially it also enables us to garner the support of others in fulfilling our aspirations. Thus the greatest support we can offer to people is with their own advocacy. In Chapter 3 we will explore more fully the means for doing this through the personal relationship between a person and his or her supporter.