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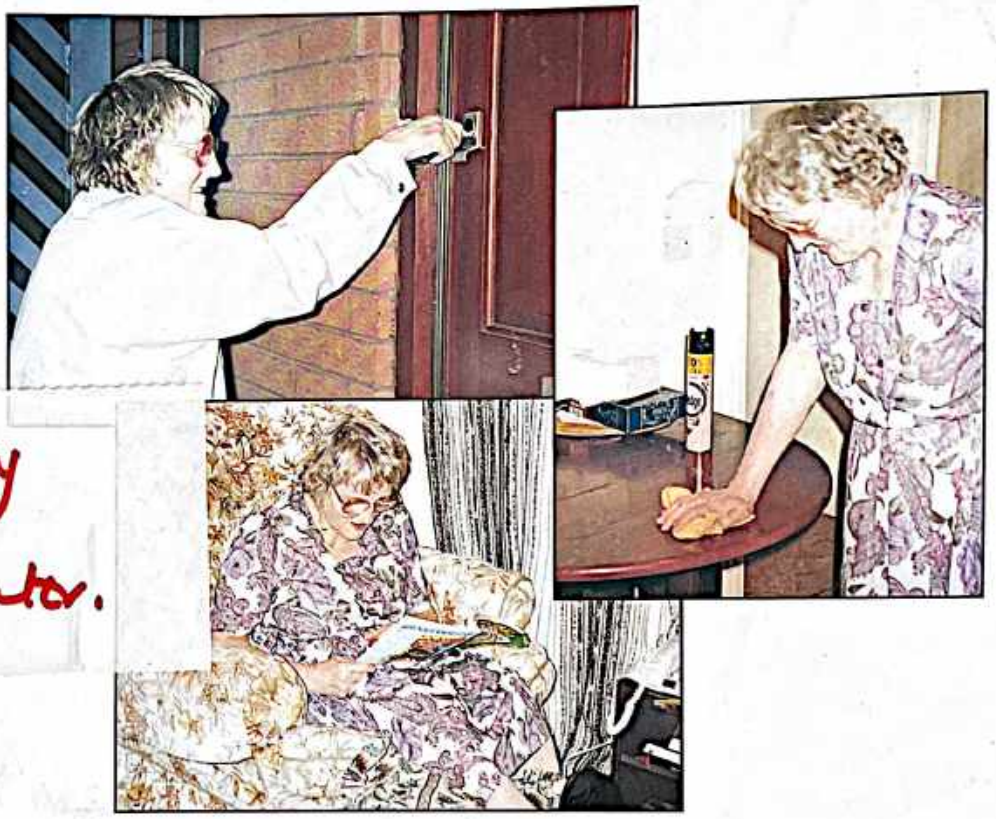
Supported Living

A new paradigm

Peter Kinsella



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ndt Supported Living Series

'A Home Of My Own'

Supported Living

A new paradigm

Peter Kinsella

Supported Living – a New Paradigm
Peter Kinsella

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"Group Homes – An ordinary life?"

This is not a new arcane wisdom. It is a common sense approach to help people with disabilities achieve ordinary lives. We need to illustrate how similar what we are doing is to what typical people do for themselves. We are simply taking "unconscious", learned activities, that everybody engages in, and making them into a "conscious" practice.

Smull & Harrison (1992)

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About the Supported Living Programme

The Supported Living Programme is a new project of the National Development Team, set up to promote opportunities for people with learning disabilities to live in real homes of their own. The Programme will promote alternatives to group homes which give people with learning disabilities real choice and control in their lives.

The mission of the Supported Living Programme is to work with people who use services, their carers, campaign organisations, and purchasers and providers of services to stimulate awareness about Supported Living and to facilitate and encourage the development of individualised Supported Living arrangements around Great Britain.

The Supported Living Programme (S.L.P) aims to:-

- Promote new patterns of support that extend our thinking about the present living and support arrangements for people with learning disabilities.
- Provide consultancy to interested parties in order to develop individualised Supported Living arrangements in a number of areas around Great Britain.
- Take a pro-active role in shaping and influencing local, regional and national policy.

- Work with people with learning disabilities and their families, raising expectations, promoting their voice and facilitating service agencies to listen to and respond to them.
- Promote new types of provider organisations committed to Supported Living.
- Promote and disseminate good practice in Supported Living by supporting people with learning disabilities to tell their own stories and by writing articles, monographs and position papers.
- Establish a national network of people actively involved in developing Supported Living and promote inter-agency working.
- Develop international links and promote exchange to facilitate learning around Supported Living.
- Stimulate learning and raise awareness through a range of publications, conferences and workshops.

Acknowledgements

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Special thanks to Ethel Boyd for the photographs on the front cover. Ethel recently moved into her own flat in a sheltered housing complex for older people, having lived in a group home for the last eight years.

The Commonwealth Fund gave me the opportunity through a Harkness Fellowship to spend considerable time with some excellent Supported Living agencies in the United States. Thanks are due to the many staff, service users and their families of: Options in Community Living; Developmental Services of Strafford County; Centennial Developmental Services; and Neighbourhood Connections; who gave so freely of their time for me to discover the meaning of their work. The following people had a profound influence on my thinking which is reflected throughout this monograph – Gail Jacob, Marilyn Wilson, Terry Dolan, Howard Manderville, Bill Jones, Marcie Brost, Don Anderson, Mark MacManus, Pat Murphy, Michael Smull and Dennis Harkins.

The major sponsor of the programme is the NDT. Co-sponsorship is provided, through the participation of their staff, by: North Mersey Community (NHS) Trust; Southwark Consortium; New Possibitities (NHS) Trust; Mersey Regional Health Authority; and Wandsworth Health Authority's Community Unit for People with Learning Disabilities.

Peter Kinsella

About the author

Peter Kinsella is an Associate Consultant of the NDT. He is also Development Manager for the Learning Disabilities Directorate of North Mersey Community (NHS) Trust. He recently held a Harkness Fellowship (the Commonwealth Fund of New York) studying community-based services for people with learning disabilities in the United States. Prior to this, he was the Area Manager for Mencap Homes Foundation in Merseyside.

Foreword

People with learning disabilities have, historically, long been seen as embodying opposite extremes. On the one hand, the isolated hospitals suggested a menace society needed to protect itself from or cure. On the other, charity drives sustained the image of the holy innocent, the eternal child who needed only pity. Many current services have tried to blend these opposites inside a confusing and unconvincing rhetoric. While we hear of "living and working in the community," we see people living in group hostels which are really little rehabilitation institutions, and spending their days in sheltered workshops where they are most effectively protected from earning money. We hear of "community participation," but often see this realised as specialised staff or volunteers rather than a social life built from mutuality and affection. This is not to dismiss the intentions of these efforts – the balance has been hard to achieve.

Not that we have achieved it. The idea of Supported Living moves us along as we struggle to transcend the out-dated images of pity and menace and realise a world of mutual respect. Increasingly, services conceptualise people with disabilities as "service users," as customers whose preferences need to be taken into account. Rather than using the medical model of classifying people and assigning them to treatment, services providers are more likely to ask, "what does this person need and (more importantly) want? How can we provide for those things?"

The danger is that we will have, once again, substituted rhetoric for reality. Just as a group home is not really a home unless the people living in it have chosen one another and actually run it, an individualised program of support is nothing new except in scale unless the person supported has created it and actually feels helped. The danger is that our tradition of "knowing better" and "wanting to help" overtake the person's own choices. Supported Living opens us to new ethical and personal dilemmas in choosing what kinds

of help we want to provide. As it stands now, the difference between the power of service users and service providers is so great that these conflicts and dilemmas can all too easily be dismissed or simply talked around.

For this reason – though the connection has not always been obvious – any service system that truly wants to support people requires the organisation of people who call themselves self advocates. Without this political cohesion, Supported Living will simply be another attempt by service providers to guess an another person's comfort. Absent any other guide, our best guesses are all we have, but with the emergence of an international "people first" movement, we not longer need to plan services in professional isolation. Good services that once relied on the parent movement and parent involvement have expanded the circle to include self-advocacy not only at the individual level, but at the collective level as well. We have a long way to go: self-advocacy is still often seen as something of a politically correct option, rather than a necessary element for decent services.

Peter Kinsella, who spent a year as a Harkness Fellow in the United States, has given us an introduction to how these ideas have taken root here. Now, with this monograph and his on-going work leading the NDT's Supported Living Programme, we Americans can look forward to seeing how this idea and attitude will adapt and thrive in Britain.

Herbert Lovett, PhD
Boston, Massachusetts
September, 1993

Shifting Paradigms

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In many respects, we live in exciting times. In society as a whole there has been a widespread move towards consumerism. And in the service world, we increasingly acknowledge that services are not necessarily giving people what they want. Service providers are learning to listen in new ways and are becoming acutely aware of the need to respond flexibly to the people who use services.

Although the last ten years have seen great changes, with the move from living in institutions to communities, non-disabled people are still not opting to live in the new community-based services that have been developed – surely the ultimate test of the quality of those services (Kinsella, 1993). Whilst it was easy to criticise the old institutional services, highlighting deficiencies in the recently developed community services has been more difficult. There has not been a consensus in the field, although every new approach and every new way of doing things has had its critics. This is hardly surprising, given the failure of yesterday's innovations to meet the expectations that so many people had.

In the service world, we increasingly acknowledge that services are not necessarily giving people what they want.

A central theme through this change has been a shift in the paradigm (or framework) underlying the design of the services (Bradley and Knoll, 1991). A paradigm in this instance is seen as a way of thinking in depth about the way services are designed and delivered. Such a paradigm shift is evident in the change from institutional services to community-based ones.

Val Bradley and James Knoll identify three paradigm shifts in recent times to illustrate these changes in our service systems. They identify an *institutionalisation and segregation (medical) model* which was prevalent until the 1970s. The emergence of a *deinstitutionalisation and developmental model* in the 1970s heralded a new era, with services viewing people with learning disabilities as people to be trained, socialised, habilitated and assessed through a continuum of educational, vocational and residential settings (Taylor,

1987). In the United States, in the 1980s, a shift to *community membership and functional supports* emerged with the realisation that deinstitutionalisation had resulted in little more than the transfer of institutional practices to smaller community locations. This last change is characterised by moving support to where people live and adapting support and the environment to each individual.

Julie Ann Racino (Racino *et al.*, 1993) and her colleagues at the Center for Human Policy in Syracuse, identify three frameworks which characterise the development of services in the United States and which mirror the changes illustrated by Bradley and Knoll: *rehabilitation; independent living and; support/empowerment* (see Table 1).

Table 1

Focus	Rehabilitation	Independent living	Support/empowerment
Definition of problem	Physical impairment, lack of vocational skill, psychological maladjustment, lack of motivation and cooperation	Dependence on professionals, relatives and others; inadequate support services; architectural barriers; economic barriers	Attitudinal, political, economic and administrative barriers to societal participation; inadequate supports within society
Locus of problem	In individual	In environment; in rehabilitation process	In society/environment; in rehabilitation process
Social role(s)	Patient-client	Consumer	Co-worker, community member, student, neighbour, so forth
Solution to problem	Professional intervention by physician, physical therapist, occupational therapist, vocational counsellor, and others	Peer counselling; advocacy; self-help; consumer control; removal of barriers and disincentives	Redesign of schools, homes, work places, health-care systems, transportation, and social environments to include everyone
Who is in control	Professional	Consumer	People in alliance with each other
Desired outcomes	Maximum activities of daily living (ADL), gainful employment, improved motivation, completed treatment	Self-direction, least restrictive environment, social and economic productivity	Pluralistic society inclusive of all people; quality lives as defined by people themselves; self-direction embedded in collaborative decision making and problem solving

From Racino, Walker, O'Connor and Taylor (1993). *Housing Support and Community*. Paul H. Brookes Publishing.

John O'Brien (1991c) illustrates two ways organisations and systems can develop, to explain the apparent emergence of these new paradigms since deinstitutionalisation took place. Systems may undertake a first order change, without altering the basic structure, assumptions and values of the system – people learn how to do the same things better. The second order change is one in which values, assumptions and structures change. People not only change how they do things – they change how they approach, respond to and evaluate situations and they learn how to do new things. It is not just about "finding a faster, easier way to dig the hole you are standing in" but "reconsidering where or whether to dig" (O'Brien, 1991). Kinsella (1993) argues that the move from hospitals in the U.K., whilst offering people home-like living environments, has created in many instances mini-institutions in the community. This is a good example of first order change.

Dana Meadows (1991) defines a paradigm as "not only an assumption about how things are; it is also a commitment to their being that way. There is an emotional investment in a paradigm because it defines one's world and oneself. A paradigm shapes language, thought, and perceptions – and systems. In social interactions, slogans, common sayings, the reigning paradigm ... is repeated and reinforced over and over many times a day".

Systems may undertake a first order change, without altering the basic structure, assumptions and values of the system – people learn how to do the same things better.

By this definition, it would be hard to assert that services have changed radically over the last ten years. In the United Kingdom, there are doubts that the paradigm shift of the 1980s, which led to the setting up of many group homes, improved the lives of people moving out of hospitals as much as was envisaged in our original vision of normalisation (Wolfensberger, 1972). Increasingly people are beginning to assert that we have done little more than create smaller institutions in the community (Sinson, 1993), and have fallen well short of our original aspirations (Ward & Kinsella, 1993), (Ward, 1988). Often we have merely relocated institutional practices. Support is still tied to buildings; people live with people that they do not necessarily get on with; and staff work to set shifts in houses – all of which we had in institutions. Maybe this is not such a new way of doing things after all.

Things are beginning to change, albeit slowly. There is

evidence that we are now on the verge of another paradigm shift – a very new way of doing things – a move towards community membership, support and empowerment. Many services in the U.K. recognise that locating people in houses in the community is not enough. The best services see people as community members and not clients. People with learning disabilities are asserting themselves more, through collective action, and the best examples of person centred planning are giving individuals a full say in the supports that they receive and the things that they do. Even the National Health Service and Community Care Act (1990) emphasises in-home, flexible supports as an alternative to admission to nursing and care homes. Whilst most of the examples of this sort of change are to be found in the U.S.A., there are now a few similar innovative developments in the U.K. We in the U.K. can learn a great deal from the paradigm shift in the U.S.A.

There appear to be four major paradigm shifts that are necessary for services to fully embrace providing person-centred community-based supports (Kinsella, 1992):

From:		To:
programs	→	flexible supports
facilities	→	community membership
management	→	leadership
mechanical change	→	spiritual change

This calls for a radically different ways of working, problem-solving, thinking and planning. These are changes which affect us in profound ways. They impinge on how we lead our own lives, they affect our perceptions, and strengthen and redirect our beliefs.

Ultimately this paradigm shift is about changing the change process itself. It is not simply about restructuring or reorganising services. It is about revising our values and our culture. It is reponsible for producing something very positive in ourselves, our organisations, our communities and in the lives of people with learning disabilities. This monograph expands upon these changes and illustrates the difference this new way of doing things is beginning to have on the lives of people with learning disabilities.

What is Supported Living

Supported Living is not just another model, nor is it another fad that will come and go. Supported Living is based on a set of beliefs and principles about people choosing where they live, who they live with (if anyone), which supports that they get and the lifestyle that they lead. It is not a prescription to cure all the ills of the service system: it is about people having control over their own lives.

The NDT (1993) has defined Supported Living as follows:

Separating housing and support

The agency that provides or coordinates supports is not the landlord, nor does it have any organisational connection to the property owner.

Focusing on one person at a time

A process of person-centred planning is used to find out what each individual person wants, and then to plan individually and assist them to secure the accommodation and supports that are right for them.

Individuals choose where they live, who they live with (if anyone), who supports them and how.

Full user choice and control

Individuals choose where they live, who they live with (if anyone), who supports them and how. Individuals hold their own tenancy or mortgage and are in control of their own money and household.

Rejecting no-one

There is an implicit assumption that everyone can live in the community. The fact that someone has complex needs does not mean they should be denied the opportunity to choose their own lifestyle. Attention is given to environmental adaptations and personally designed supports.

Focusing on relationships; making use of informal supports and community resources

The starting point is to build on a person's existing relationships and connections. Paid help is only used when natural and informal supports are not available. Paid supporters

work to develop a person's social network alongside their other activities.

According to John O'Brien (1993) Supported Living is achieved when "a person with a development disability who requires long term, publicly funded, organised assistance allies with an agency whose role is to arrange or provide whatever assistance is necessary for the person to live in a decent and secure home of the person's own". He explains that "Supported Living is a simple concept in danger of being complicated until its power to help people with developmental disabilities gets lost. Its simplicity is elegant" (O'Brien 1993).

One problem is that producing a definition immediately puts boundaries around Supported Living, implying that it is just another model in the continuum of residential services with the danger of it being seen as the end rather than a means to an end. Supported Living is not just another model, another option to offer people with learning disabilities, but a process to enable people with learning disabilities to be included in their communities and be fully and actively involved in them.

Gary Smith (Smith, 1990) identifies nine key principles that underlie Supported Living:

1 *People with disabilities should be supported in living arrangements which are typical of those in which persons without disabilities reside.*

2 *The services that a person receives should change as his or her needs change without the consumer having to move elsewhere.*

3 *A person with disabilities should exercise choice over where and with whom he or she lives.*

4 *People with disabilities should have control over their own living arrangements.*

5 *The aim of furnishing services and supports to a programme participant is to assist that individual to take command of his or her life while building critical and durable relationships with other individuals.*

6 *The services or supports furnished to an individual should be tailored to his or needs and preferences.*

7 *Services and supports are most effective when furnished where a person lives and within the context of his or day-to-day activities.*

8 *Supports must be extremely flexible, not restricted to particular types or categories of service.*

9 *People with developmental disabilities should not be excluded from Supported Living arrangements based on the nature and severity of their disabilities.*

The Minnesota Governor's Planning Council (1987) defined Supported Living as:

A move from short-term developmental planning to life-long functional planning.

A move from providing a service continuum with emphasis on special facilities and programmes to seeking a service array that adapts generic resources by providing the assistance and support as needed.

A move from fragmented grouping of separate and independent services (residential, day training, education) to recognition of the need for a holistic, independent and integrated service system.

A move from a system of offering models of service delivery to one where it is possible to create individualised support.

A move from a system of offering models of service delivery to one where it is possible to create individualised support.

A move from service payment based on facility budgets toward reimbursement based on vendor performance and individual needs.

Important common themes running through these definitions give an indication of what Supported Living is. However, because choice is an important aspect of Supported Living, every person's Supported Living arrangement is likely to be different in some way from the next. The essence of Supported Living is choosing where you live, who you live with and the supports that you receive (Ward & Kinsella, 1993). Supported Living raises issues of choice and control, social justice, human rights and the right of self-determination. The key underlying assumption is that everyone should have the right to these choices in the same way as the rest of the population.

In effect Supported Living is what most of the non-disabled population has – living arrangements in which we choose how we live.

For people with learning disabilities, Supported Living is about financial security: that is having enough money for a decent standard of living, having control over that money and deciding what to spend it on. It means having flexible and dynamic supports that are tailored to each person's situation and which change as their needs and expectations change. It is about having comprehensive supports (from paid and unpaid people) which are available when you want and need them. Supported Living means being accepted for who you are and what you are – it means understanding the person and their disability and what it means to them.

Supported Living is the natural seeking out and making use of the capacity and potential of communities and people's social networks. This includes accessing the range of ordinary housing stock available to the rest of the population. Supported Living is about the person with disabilities retaining power and control over their own lives and being in control of their own destiny. It is about leadership, with the leadership coming from people with disabilities.

Supported Living is about full inclusion and full participation in the communities in which people live. It is about mutual support and interdependence – giving and receiving. In Supported Living, the relationship between people with disabilities and their supports is one of reciprocity, based on personal relationships and commitment. Supported Living is about living with people and having people around you who love you and care about you. Above all else, it is not a model. It cannot be replicated on a large scale – each living arrangement is different from the next. Just as each of our lives and living arrangements is different, so it is with Supported Living.

It should become clear that Supported Living is a radically different way of doing things, embodying the paradigm shift which Michael Smull (1990) refers to as the paradigm of support. This involves changing the way that we think about people and services, changing the way our services are staffed and organised and changing the way in which we fund and regulate services.

Definitions like these are descripive rather than prescriptive. Some clarity about this new paradigm has emerged, but by its very nature, it is still hard to define Supported Living. Another way of understanding Supported Living is to be clear about what it is not. It is not (Smith, 1990):

- Simply offering services in "small residences".
- Synonymous with apartment programs.
- A model that rejects training as a valid component of service delivery.
- An "unsupervised" living arrangement.
- Another residential alternative.

Supported Living often gets confused with the issue of downsizing. Many people assume that Supported Living is about making group homes smaller but this arises from a fundamental misunderstanding. The problems with group homes go beyond the number of people living in them (Kinsella, 1993). Supported Living is not about size, nor about having an optimal number of people living together. It is about choosing who you live with – if that is with another three people, so be it.

Supported Living often gets confused with the issue of downsizing.

John O'Brien excludes the following from Supported Living (O'Brien, 1993):

- Another stop on the service continuum.
- An incentive or reward for good behaviour.
- A programme to fix people.
- Isolation and loneliness.
- Segregation by disability or income.
- Being assigned room-mates.
- Signing a lease on a place that staff control.
- Targeting a particular (dis)ability group.
- Forcing people to live the way we think is good for them.
- A set of uniform requirements and procedures.
- A fixed amount of assistance forever.
- Being grouped on the basis of disability.

- An excuse for letting bad things happen to people.
- Just getting an apartment to live in.
- A test to see if you can live with no problems and if not, you get sent back to group living.
- Compatible with services that congregate.
- Expecting that the amount of assistance necessary will always decrease.
- Another name for downsizing existing facilities into cheaper than group living smaller units or otherwise renaming existing services.
- Having permission to live in an agency.
- A way to avoid responsibility for careful decisions about threats to vulnerable people's lives.

The rhetoric and theory can only go so far. The next chapter describes the stories of some people who are described as having Supported Living services. It is only through our understanding of such people and their situations that a clear appreciation of what Supported Living is and what it means starts to emerge.

Stories

Jon

Jon is 28 years old and lives in Madison, Wisconsin. Jon lived at home with his parents until he was 25 years old. He was described by his medical records as having Downs Syndrome and mild mental retardation. Throughout his childhood he attended a mix of special school and mainstream school. In his early twenties, Jon and his parents started planning for his future and in particular his first move away from living with his parents.

So at the age of 25, Jon moved out from living with his mother and father. He had been referred to Options in Community Living, a local not-for-profit provider agency, and was assigned a Case Manager (Community Support Worker) called Ann. She helped him to find an apartment and room-mates to share the apartment with. Like most people with disabilities in the United States, Jon did not have much income, although he did work part-time in an office block. Therefore Jon needed to look for another person to share his apartment and spread the housing costs.

In his early twenties, Jon and his parents started planning for his future and in particular his first move away from living with his parents.

Jon found an old school friend, Mike, who was also looking for a place to move out to and they decided to live together. Both Jon and Mike needed support to assist them in living in their apartment. They opted to have a room-mate, Pete, who was licensed by the Dane County Department of Human Services and whom Options helped to recruit and match. Pete received a small monthly stipend and free rent for being Jon's and Mike's room-mate. He lived with them and received this money in return for his involvement. Importantly, he was not an employee of either Options or Dane County.

The three of them moved into an apartment close to a large shopping mall and on some of the main bus routes in Madison. Pete's role was to assist Jon and Mike with their shopping, daily planning, cooking, developing relationships with people in their community and supporting them in

making use of resources in their neighbourhood. A major part of Pete's role was just to "be there", helping Jon and Mike to solve problems, sort out any difficulties and meet their responsibilities as householders.

Ann had regular contact with Jon and Mike, and saw them usually at least three times a week. Her responsibilities were to assist them with their finances including financial planning, paying bills, writing cheques and ensuring that they had enough cash for the week. Options also had a contract from Dane County to provide Case Management services, and part of Ann's role was to coordinate the various supports that Jon and Mike received. Jon had the services of a job coach from another agency and Ann maintained links with her. She also helped Jon and Mike plan for the future and kept a general oversight of their situation. Although Pete was not an Option's employee, Ann "monitored" the situation, and provided informal support and direction to Pete.

Jon has an extremely full life. He is still an active member of the church that he went to throughout his childhood and he plays baseball regularly. He also enjoys cycling, fishing, bowling and hiking and backpacking, most of which he does regularly with his friends and Pete. Jon sees a lot of his family. He still regularly does many things with his parents, and spends time with his brothers and sisters when they are in town.

A year or so after moving into their apartment, Pete moved out. This was because that although Jon and Mike really got on with Pete, they realised that they did not need all of the support that he was providing, and that they could manage fine on their own without Pete being their room-mate. Pete moved out but then was contracted as a part-time "come-in" worker by Options to provide support for 15 hours each week. The emphasis of his role changed to helping Jon and Mike to get out and about more and to supporting them in their activities in making relationships. Although both of them, and Jon in particular, used a lot of local resources, these had never been used to maximum effect to build their social networks.

A year on, Jon and Mike's relationship had begun to deteriorate. They were not getting on at all. They certainly did not enjoy each other's company and did not like living with each

other. Both Ann and Pete could see this happening and supported Jon and Mike in trying to salvage their relationship but it became clear that they did not wish to continue living with each other. Jon decided that he would be the one to move and used this opportunity to move back into the neighbourhood he had grown up in. Ann helped him to find another place to live and another room-mate to provide some support and companionship to him (Jon had really missed this when Pete moved out). Consistent throughout all of this was Ann and Pete's involvement and support. Sometimes Jon was faced with difficult decisions, but Ann and Pete stood by him throughout.

Mark

Mark has been supported by Options for over 5 years. He has a muscle wasting disease which has severely limited his mobility and places great strain on his health. He rents a house in Madison which he shares with his room-mate, John, whom Options helped to recruit and match. John receives a small monthly stipend and free rent for being Mark's room-mate. He provides assistance to support Mark with getting out and about, preparing meals and problem solving. He describes this support as "just being there should anything crop up".

Their relationship is still at an early stage. They are both having to work hard at it to make it work and to get to know each other well.

John has lived with Mark for eight months now. Before John, Mark had had a quick succession of room-mates over the previous five years. Some stayed around for a few months, others stayed for just over a year. Many of them did not stay because they did not like the way Mark treated them. He occasionally got abusive towards them and would try to hit them. As a result Mark developed a reputation for being "challenging" to services.

Mark holds down two jobs with the City Council. He works in two different departments with responsibilities for general office duties and data entry into a computer. Some evenings, Mark and John play pool together at their local bar where Mark has begun to get to know quite a few people. Their relationship is still at an early stage. They are both having to work hard at it to make it work and to get to know each other well. There is a real commitment from John to Mark, which certainly bodes well for their developing relationship.

As Mark's room-mate, John is licensed and paid as a foster sponsor by Dane County. He is also employed by Access to Independent Living, a separate personal assistance agency, to provide services to Mark. This includes helping him to get up and get to bed, helping him to get to the toilet and other personal care needs. Although he is not actually employed by Options, John is supported and supervised by Jane, one of Options' Community Support Workers (or Case Managers).

Options continues to struggle to support Mark. They are trying to be better listeners, to help Mark fulfil his ambitions, to plan for the future and cope with his illness, and to help Mark connect into his community and build up a wider social network. Although John has now been with Mark for eight months and made a commitment to sticking with him, at some time it is likely that John is going to move on. Jane visits Mark a couple of times a week and assists him with his finances as well as supporting him in his relationship with John. She knows only too well that fulfilling Option's commitments to Mark means being there for him and supporting him even when he makes the "wrong" decision.

Helen

Helen is 41 years old and has been supported by Options for the last couple of years. Helen has been given many labels throughout her life including "mentally retarded", "psychotic", "mentally ill" and "difficult". She has had various brushes with the criminal justice system for offenses including battery, abusive telephone calls and breaking the terms of probation. She lives on her own in an apartment in Madison. At the time of writing, Helen is in the Dane County Jail House, having threatened to blow up the local T.V. station.

Helen is actively involved in her local church and has many friends and sources of support there. She is married but has been separated from her husband for all but a few weeks of her marriage. Options is helping Helen to do what is necessary to get a divorce. Although Helen does not have a paid job at the moment, she has had many jobs in the past and particularly enjoyed working at a local restaurant. Helen receives support from Todd, a Community Support Worker at Options. Todd is helping Helen to find a new apartment and has been closely involved with the probation officer in

getting Helen out of jail and negotiating new probation terms.

Supporting Helen means sticking with Helen come what may and accepting her for who she is. For Todd and other Options' staff, this means helping Helen to realise the consequences of some of her actions, and also standing by her and not passing judgement.

Names and circumstances have been changed in the above stories to preserve anonymity.

Jim

(reproduced with kind permission from Options in Community Living)

Jim is a big man with light brown curly hair and a wide smile that lights up a room when he's happy. To people who don't know Jim, he can be pretty scary when he's upset. He doesn't use many words. He's hard of hearing and uses a combination of gestures, sounds and signs to communicate. When he's angry he yells and waves his arms. Jim also has mild cerebral palsy which affects one side of his body. His favourite mode of transportation is a three-wheeled bicycle.

We moved Jim to another apartment and spent the next eight months struggling to figure out how to support him.

We met Jim about seven years ago when he lived in a group home. Before that he lived most of his life in institutions. He wanted to live in an apartment and was referred to Options for Services. He had a reputation for difficult behaviours and a bad temper when he got angry. The story was that when Jim moved from one facility to another (which was fairly often) he was usually transported in a sheriff's car.

We decided to set Jim up in an apartment with Tom, another man we support who is deaf. We thought they could both use sign to communicate with each other. They met and were agreeable to the plan. Jim moved in to Tom's apartment and it was a disaster from day one. They hated each other. They fought constantly. Obviously, this was not going to work. We moved Jim to another apartment and spent the next eight months struggling to figure out how to support him.

Jim was a mystery to us. It was clear he needed a lot of support and we were uncomfortable with the idea of his living alone. We considered a paid room-mate, but it seemed clear he couldn't tolerate anyone else living in his space. Jim

could not tell us in words what he needed but he made his unhappiness known. Jim kept all his possessions in boxes piled by the door. Staff would come over every day and unpack the boxes, put his clothes in the back in drawers, hang the pictures back on the wall and the next day everything was back in boxes piled by the door. During those months Jim was upset all the time. He would storm into the office raging and yelling and nobody could figure out what was wrong or how to help him feel better. All we knew was we weren't getting it right for Jim.

As we continued not to get it right, Jim's behaviours got more intense and more pointed. Instead of boxes piled by his door, we were finding his possessions in the skip behind his apartment – his t.v., his stereo dismantled and junked. Then he started attacking his apartment, destroying things and smearing faeces on the walls. Maybe Jim didn't have the words, but the message was loud and clear: "I'm unhappy, I don't like it here!" We spent a lot of time running interference between Jim and neighbours, pacifying the landlord, trying to calm Jim down, and agonising over what to do. There was a time where I thought, "This isn't going to work. He'll have to go back to the group home." But as much as I would periodically entertain the idea, I knew we had to keep trying. That we were being challenged to be more creative in our approach and to press harder to unlock the mystery of Jim's unhappiness.

We continued to struggle with different possibilities. We invited a behavioural consultant in to help us. During one brainstorming session we were talking about the paradox of Jim's need for lots of support and at the same time his need for lots of personal space and control. We then hit on the idea of a "paid neighbour" – someone who would live close by and who would provide day to day companionship and support, but who would also allow Jim the space he needed. The person would have regularly scheduled time with Jim that he could count on, but would also be flexible enough to respond to knocks on the door and phone calls when necessary. It seemed worth a try. Soon we hired Kathy to spend 15 hours a week with Jim and she moved in down the street from him. It was a match made in heaven. They loved each other and Jim seemed to change overnight into a buoyant, smiling, happy man. It was dramatic and moving to see.

Kathy's role was essentially to hang out with Jim and to offer the security of a relationship and a consistent presence in his life. She also acted as a bridge to the community and an interpreter of his behaviours to his neighbours and others who came into contact with Jim.

As Jim's sense of security increased, his endearing qualities quickly emerged. He is incredibly good natured, warm, friendly and generous. He inspires fierce loyalty in everyone who knows him. And he is known by many people in his east side neighbourhood. He is a familiar fixture in local restaurants and he is greeted by dozens of people as he tools around on his bike. He lives in a co-op apartment now and neighbours make a point of looking out for him and letting us know when there's something we need to do for him. He has three jobs – one in a bagel shop and another in a university fraternity house. His boss at the bagel shop was so crazy about Jim that when he opened a restaurant he asked Jim to work there too. There's a funny story about Jim and employment. When we met Jim he was at a sheltered workshop where he had been for years and years. They said he wasn't employable because of his behaviours. Yet without their knowledge, Jim had gone out and gotten an evening job at a local pizza parlour where he hangs out. So he was unemployable during the day and working in the community at night!

He has also been one of Option's teachers. He taught us about not giving up – to keep trying until we get it right, about seeing behaviour as communication, about the importance of being flexible.

Jim was also reconnected with his family in Milwaukee. When we met Jim, they wanted nothing to do with him. They were terrified of his anger and didn't know how to communicate with him. With Kathy's persistent encouragement, they invited Jim home for Christmas one year and the visit was a great success. Now he visits on holidays and talks to them on the phone frequently. His pride and joy are his twin nieces whose picture he proudly carries in his wallet.

Jim's presence brings joy to those who know him. His smile and gifts of fresh warm bagels can brighten our darkest days. He has also been one of Options' teachers. He taught us about not giving up – to keep trying until we get it right, about seeing behaviour as communication, about the importance of being flexible – that if something doesn't work, change it. He taught us the importance of shaping services around who people are, rather than making people fit into programmes and slots.

Now, seven years later, Jim doesn't need a paid neighbour anymore. Kathy and Jim continue their friendship and see each other almost every week. Jim gets along well with a few hours a week of support from his community support worker at Options, his friends, neighbours and co-workers. He still has ups and downs like all of us, but seems secure in knowing that when things go wrong there will be someone there to help out.

Gail Jacob (O'Brien & Lyle O'Brien, 1992)

Changing Roles

Supported Living is not just about a different way of doing things. It also calls for different roles and responsibilities, different types and levels of decision-making and a strong personal commitment to people and their rights. From the stories in the previous chapter, three important roles emerge for organisations like Options in Community Living. These examples are not a blueprint for Supported Living but they give a good indication of how existing roles need to change.

Community Support Worker (Case Manager)

In Options in Community Living, Community Support Workers act as case managers. Part of Options' contract with Dane County is to provide case management to the people it supports. "Case management" is one of those terms that means many thing to different people. Intagliata (1981) describes it as "a process or method for ensuring that consumers are provided with whatever services they need in a coordinated, effective and efficient manner". The Community Support Workers are the staff who help the person get involved in their community. They help them with their benefit claims and to get housing of their choice. They liaise with other service providers who may be supporting the person and coordinate this support. They help with budgeting and personal finance and important things like medical appointments. Community Support Workers also supervise any live-in or come-in staff.

A Community Support Worker, describes her work as being about the "tedious, messy and mundane things that really make a difference".

Whilst Community Support Workers are involved in providing some direct support, they have additional responsibilities which include providing oversight, thinking about the future and coordinating other important aspects of a person's life. Julie Nichols-Youens, a Community Support Worker, describes her work as being about the "tedious, messy and mundane things that really make a difference".

They do most of the groundwork with people, helping them to find a place to live and someone to live with, looking at the legal documents and sorting out the fine detail. When

people are settled, more often than not it is the Community Support Workers who support them in their developing relationships, assist them with their responsibilities as householders and are there if relationships break down.

Room-mates

Many of the people whom Options supports have room-mates ("live-in" workers). They are expected to do the things that would be expected of a person sharing accommodation in any other situation. "Room-mate" is defined in the Oxford English Dictionary as "one of two or more people occupying the same room". Yet this does not really capture the relationship or the role, which goes way beyond sharing accommodation. It is a relationship rooted in a deep personal commitment and desire to live with each other. Such is the intensity of the relationship, that many room-mates say that it is something that can be done only if you love the person.

A room-mate may be any combination of the following: a friend; a confidant; a source of support; someone to celebrate with; or someone to despair with. For others, it is a practical arrangement to help meet specific needs – perhaps assistance with personal care or meal preparation. Sometimes a room-mate will help a person get involved in their local community and they will participate in some activities together. Above all else, the person with disabilities has the right to "hire and fire" room-mates and be in control of the situation. Not liking the person (room-mate) who lives with you is good enough reason for them to be told to leave.

Roles and relationships in Supported Living vary massively from person to person. Some people have had ten room-mates in as many years. Others have had the same room-mate for five or six years. Some room-mates are college students (often mature students); others are people who are not receiving any fixed income (artists, musicians, poets, writers); others are unemployed; and some are in work. The sort of people who become room-mates varies considerably. Some are young; some are old; some associate with the injustice and discrimination that people with disabilities experience. When there is a good match, it is a joy to see. Whilst there is obviously skill at recruiting room-mates, the most important factor is that both people must want to live with each other.

A common arrangement is for room-mates to have at least one-weekend off in four and two nights off a week. But what does having time off from where you live actually mean? It is not like taking time off from a job – it is the room-mate's home as well. How would we take such time off in our own home? Just because it is the room-mate's designated night off, does not mean that they are going to stop living there. They are not going to go out for the evening just for the sake of it. It is one of those arrangements that requires flexibility and latitude on all sides. It is, after all, ordinary living and having formal time off does not necessarily fit neatly.

Sometimes room-mates are employed by the people whom the provider agency is supporting. In other situations the provider agency may employ them or room-mates may be registered as Adult Foster Sponsors, paid by the Department of Human Services (similar to a Social Services Department). Often they have a sub-lease from the person with disabilities. A futher option is for room-mates to be employed by another agency as personal care attendants for part of the time. This is an amazing array of complex arrangements for any organisation to manage and lead. There is not one Supported Living model.

Come-In Workers

Come-in workers are what we would call "peripatetic" workers. When people only need occasional support, come-in workers fill this role by doing much of what room-mates do. Come-in workers are also used to give room-mates a regular break and time to themselves. Quite often this happens over weekends, but again this varies from person to person.

This is an amazing array of complex arrangements for any organisation to manage and lead. There is not one Supported Living model.

Some come-in workers have very specific responsibilities. They are there to build a person's ties and connections into their communities and to support them in their new relationships. Others are there purely to provide personal care assistance or to do household chores in the same way as a home-help. Usually their work is targeted and specific to the activities and times that a person needs it. In all of this it is important to recognise that it is the disabled person's own home and that it is they who have the ultimate control and choice over their own lives. Supported Living is not achieved simply by transferring a group home support worker to a smaller setting – it goes way beyond that.

Challenges – the way ahead

To embrace Supported Living we need to make fundamental changes to the way we do things at every level. Supported Living is based on a set of principles, a way of doing things and a personal commitment to people and their basic rights, fired on by a sense of injustice. Supported Living is not about deciding which people will be able to live more independently – it is a question of getting it right for each and every person. This presents enormous challenges at every level of the system.

Support staff

The role of support staff in Supported Living is very different from the role of support staff in traditional services. They must have a clear understanding of support and what it means. They need to see themselves as connectors and facilitators – roles often discouraged in traditional services, which have emphasised physical care and housework. The process of support should be seen as one which enables people to take control over their own lives – it is both reactive and pro-active. Support must be non-judgmental. It is important to recognise that people will make mistakes and that these mistakes are often the learning opportunities to make better decisions next time.

Support staff need to be encouraged to develop personal relationships with the people they are supporting. They need to forget about the old disciplines of maintaining a "professional distance". This personal commitment is absolutely essential to Supported Living – the job cannot be done without it. It follows that some support staff will have to accept that the person whom they are supporting may not want them to provide their support and want them out of their house.

This commitment cannot be guaranteed by traditional training methods alone. Options in Community Living provides a good case study for the challenges facing people who

provide the support. Most of Options' staff have been on PASS workshops (Wolfensberger & Glenn, 1975). They recognise that this does not automatically give people the necessary commitment nor the skills, but find that such workshops offer staff a theoretical framework to understand their jobs, what they do and the experiences of people with learning disabilities.

Training may help to some degree, but it is not the only answer. Training must occur within the context of what is needed by the disabled person and recognise the primary roles of support staff: as facilitator, community connector, problem solver, champion of rights and fellow human being. Traditional classroom-based training is not enough. Options and many other Supported Living agencies rely heavily on modelling and mentoring as ways of learning about Supported Living and its meaning. Exposure to people who are supporting people sensitively is a very effective way of learning. A strong person-focused approach helps to promote the culture and ethos necessary for Supported Living although this is also dependent on the people who are doing the modelling doing a good job. Similar methods have been used to transfer learning between organisations, with Options and other Supported Living agencies receiving visits from people interested in developing Supported Living in their own service agencies.

Many Supported Living agencies rely heavily on modelling and mentoring as ways of learning about Supported Living and its meaning.

At the heart of Supported Living is a mix of people providing support in a wide variety of different roles. Ed Skarnulis encourages us to "support rather than supplant the family". The same approach needs to be adopted with informal community supports. Supported Living starts with finding out what natural community-based supports are available and making best use of them. Only then should paid supports be added in, and even then paid supports should focus on further developing the opportunities for more informal supports.

An emerging role for direct support staff is to make those connections into people's communities and learn new ways of relating to people that are not hierarchy based. Support staff need to find ways themselves of being supported by the community, for very quickly they will begin to feel isolated and unsupported. They need to look outward for support as well as looking inward to their organisations. This support

will only come from immersion and participation in the community. This is made easier by having local support staff who are already part of and connected to that community. Staff will need to become more autonomous. They will be in regular contact with community members and will need the necessary judgement to make decisions that are consistent with the organisation's mission and vision. Instead of referring to a practice manual for responses to particular situations, in Supported Living staff have to use their knowledge and judgement of the person and their expectations to inform their decisions. This has considerable consequences for how staff are selected. A necessary strategy is to employ local people and make knowledge and membership of the local community valid and necessary criteria for recruitment.

Support staff will need to take on the new role of coordinator for the many types of informal supports. Kinsella (1992) defined this coordination as "the assistance given to a person, and maybe their family, to help them come to a decision about how they want the service system to support them during their life in being fully connected to their community, and maximising all opportunities and choices that are available. It is a personal relationship based upon trust and empowerment and the belief that the service user is a unique and changing person who knows what they want but may need some assistance in communicating it; the process of service coordination involves ensuring that each person receives the supports that they need and want".

Many different types of support are possible. The following are some roles that have been identified in people's lives:

- Room-mate
- Friend
- Live-in worker - own home
  - carers home
- Visiting support worker - own home
  - carers home
- Personal care attendant
- Good neighbour/responsible tenant

- Partner
- Chauffeur/mobility person
- Family - birth
  - substitute
- Home help
- Volunteer
- Warden
- Counsellor
- Benevolent landlord/lodger
- Help-at-the-end-of-a-phone person
- Job trainer
- District nurse.

It should not be assumed where people are paid, that they must be employed (and thus controlled) by an agency. Supported Living is about people taking control over their own lives. One way of doing this is for people with disabilities to employ their own support staff – this redresses the balance of power immediately.

Supported Living is about people taking control over their own lives.

Regardless of the specifics of the support, the people involved in providing this support must develop new ways of truly listening to people with learning disabilities. This is achieved by seeing people with learning disabilities as the teachers and the leaders. Working from this angle puts the emphasis on the support staff finding ways to communicate: asking people what they want and responding accordingly. They need to find ways of listening that go beyond using their ears. Such listening only comes from long term commitment and the belief that people invariably do know what they themselves want.

The table below summarises the main changes in the roles and responsibilities in moving from traditional services to Supported Living arrangements.

Table 2

Traditional	Supported Living
Professional distance	Alliance with families and/or individuals
Service focus	"Informal supports"
Case management	Service coordination
Skill training	Bridge building
"Fitting into" programs	Creating individualised services
Agency commitment	Personal commitment
Clearly defined job roles	Flexible job roles
Agency accountability	Individual and/or family accountability
Bottom of hierarchy	Autonomy of worker
Deficit-based "fixing"	Supporting
Process	Outcomes

Reproduced from Walker, P & Racino J.A., "Being with People", in Racino J.A. *et al.* (1993) *Housing, Support and Community.* Baltimore: Paul H. Brookes.

Organisations

Supported Living raises a number of questions for service organisations:

- *Is there the accommodation out there?*
- *Will it cost any more?*
- *How can we monitor and regulate it?*
- *Do communities have the capacity?*
- *Do staff have the necessary skills to do this?*

Many agencies in the United States have addressed these issues (Taylor *et al.*, 1991) demonstrating that organisations can successfully embrace Supported Living and that it works for people. And we need to recognise that Supported Living is beginning to happen here in the U.K. albeit on a small scale. Developments are very recent and sometimes fragile, but in Liverpool, Southwark and Cumbria (to name but a few) there is growing evidence that Supported Living is taking off.

Costs

Some practical lesson stand out. From the evidence in the United States (Smith, 1990) it would appear that Supported Living does not cost any more than congregate methods of support. Many agencies (ALU in Maryland; Hope House Foundation in Virginia; Developmental Services in New Hampshire; Centennial Developmental Services in Colorado; and Community Integrated Care in Liverpool) have demonstrated that it is possible to convert from group homes to Supported Living without addittional funding. In an analysis of services across the United States (Smith, 1990) it was found that Supported Living was no more expensive, and in many cases was less expensive than congregate forms of care. Supported Living should not be seen as a cheap option but it is important to challenge with clear evidence the assumption that individualised supports are more expensive than group living arrangements with their assumed economies of scale.

Culture

Supported Living challenges the very essence of organisations – their structure, size, culture, values and systems. Gail Jacob, the Executive Director of Options in Community Living, describes Supported Living as having an element of liberation (O'Brien & Lyle O'Brien, 1992) and analyses the process as follows: "As time goes on, I am learning that liberation is something that goes far beyond the actual freeing of someone from an institution. That is perhaps the most dramatic act. But it is also just the beginning of a long and mysterious process. There is also an internal letting go that happens over time, sometimes after many years, in which there is an experience of personal healing and transformation which can seem miraculous ... the process is magical to me: a setting free of the human spirit, if you will. I think it has to with trust and feeling safe. It's about having space to try and fail, to have choices and control and it's about being treated with dignity and having continuity and security and being cared for. The liberation story is a humble one. It's about the everydayness of being with people over time ... I think what we can do for people is to help create that space for the flowering to happen. We can nurture that seed, feed it, give it space and hopefully in its own season it will blossom."

It's about having space to try and fail, to have choices and control and it's about being treated with dignity and having continuity and security and being cared for.

Size and structure

Giving people with learning disabilities this "space" calls for particular types of organisations. Racino (1993) in identifying some of the exemplary Supported Living agencies in the United States, illustrates that they are all small organisations, supporting between twenty and one hundred people. An organisation's size seems to play a pivotal part in its capacity to provide good Supported Living services. The NDT, through its fieldwork, has highlighted the tension between increasing the size of an organisation and improving the quality of its services. Each requires enormous energy and commitment which can distract attention from the other. Maintaining a small-scale organisation ensures that it is possible for the Chief Executive to know all of the people who use the service; that structures are kept flat and responsive; and that bureaucracy and administration are kept to a minimum (Bogdan, Taylor & Racino, 1993).

Values

Effective organisations have clear philosophies and values that are known throughout the organisation, and that shape everything that the organisation does. This culture is passed on to new workers in a variety of ways and is reinforced through training, support and supervision, and the very way everyone in the organisation talks, writes and acts. These statements of values are embedded in people's rights as human beings. Options in Community Living's (Johnson, 1985) mission statement is:

> *Options in Community Living believes that every person has the right to live in a home in the community as an active and accepted member. Its mission is to provide support and coordinate services to enable adults with developmental disabilities to live on their own in small, dispersed settings. The agency works with people to help them make their own choices and reach their own goals, with support available as often and as long as it is needed.*

Effective organisations make their mission statements come alive as part of everyday life. They are not meaningless phrases hanging up in an office but a set of beliefs which guide members of that organisation in all aspects of their work.

Listening

Effective organisations are taking the lead from people with disabilities. They have in common systems of person centred planning (O'Brien and Lovett, 1992), that put people with disabilities at the centre of the process and seek to find answers to the question, "What do you want?". This is done from the position of equal relationships, where the agency staff do not hold the power. There is a belief that each individual is unique, ever changing and with increasing expectations over time. Also there is a commitment to building upon a person's capacities and strengthening their community ties (Mount, Ducharme & Beeman, 1991). Effective organisations recognise people with learning disabilities as teachers, as people to learn from in their work.

Effective organisations are taking the lead from people with disabilities.

Taking the lead from people with disabilities requires learning to listen at many different levels and setting up the structures and systems within an organisation to support such listening. This means that instead of looking to the hierarchy (or practice manual) for the answers, there is a commitment to gaining a deeper understanding and knowledge of the person by spending significant time with them and the important people in their lives.

Effective organisations look for ways to enable people to have control in their own lives. They do this by ensuring that people either own or are the tenants of their own house and that they recruit and employ their own support staff if that is what they want. Organisations achieve this by being supportive rather than directive. They do this by providing the least intrusive supports

Leadership

Effective organisations have effective leadership. They see leadership not in terms of a person's place in the hierarchy but in terms of their personal capacity to bring about change for an individual, whatever their role and no matter who they. Max De Pree (1990) defines leadership as "liberating people to do what is required of them in the most effective and humane way possible". He explains that "leaders owe people space, space in the sense of freedom. Freedom in the sense of enabling our gifts to be exercised. We need to give each other the space to grow, to be ourselves, to exercise our diversity. We need to give each other space so that we may

both give and receive such beautiful things as ideas, openness, dignity, joy, healing and inclusion."

Supported Living embraces this sort of leadership. It calls for participation, trust and a belief in people. It calls for placing the authority for decision-making close to and with people with disabilities. Decisions cannot be made by remote bureaucracies but by people who are closest to the individual (Rucker, 1987). Maintaining direction is an important part of leadership and this is often vested in the agency Director. However this needs to be informed by personal knowledge of individuals who use the service. As John O'Brien says (1991) "the director needs more than the authority of position. The director needs the authority that comes from personal knowledge of people's situations and personal commitment to contributing to good solutions when difficult problems threaten to compromise the agency's direction and values". Effective organisations do not rely on the leadership of one person; they thrive through providing opportunities for all people in the organisation to exercise leadership.

Community alliances

Effective organisations promote community membership and participation. They encourage community alliances with their staff. They encourage commitment to and participation in other social justice issues. Some organisations give staff time to become actively involved in particular community activities such as residents' associations or playground campaigns. They see it is useful for staff to have opportunities for understanding the communities better and building connections for the people they are supporting. Organisations can also do this by supporting the local economy by using local shops, suppliers and meeting venues, rather than looking outside for these. Such a focus greatly increases opportunities for building communities.

Commitment

Effective organisations make a commitment to the people they are supporting. This is a commitment to stick with them come what may – in other words "zero rejection" (NDT, 1993). This commitment radically affects what an organisation does and how it does things. In making this commitment, an organisation is saying to the people who

use their service, "We are not going to give up on you. Whatever you do, we will carry on supporting you through good and bad times. We will not send you anywhere else because you do not fit". In making this commitment John O'Brien (1993) identifies obligations that an organisation has to the people who use its services:

- Treating you with respect and listening carefully to you so that we can keep getting to know you better.
- Working with you, and your family and friends, to establish the home life you desire and the assistance you need.
- Being flexible and creative with all the resources available to us to respond as your interests, preferences, and needs change.
- Learning from our mistakes.
- Following through on our commitments to you and not making promises to you that we can't keep.
- Minimising our intrusion in your life by periodically checking to make sure we are not doing unnecessary things in intrusive ways.
- Being on your side, in the sense that we will assist you to achieve the best resolution of the conflict possible in the circumstances.

The effective organisation is always asking, "What do you want next?".

These commitments ensure that an organisation constantly strives to get it right for a person and does not rest when things are working at a particular point in time. The effective organisation is always asking, "What do you want next?". Staff in effective organisations are encouraged to have a primary commitment to the person rather than to the agency. They are more concerned with doing good rather than looking good (Bogdan, Taylor and Racino, 1991).

Flexible

The effective organisation has a simple and lean structure that enables it to respond quickly and flexibly. It minimises hierarchy and operates through effective teamwork. Because one approach has worked with one person, it is not assumed that it would work with someone else. The effective organisation sees Supported Living not as a model but as a pattern of supports that will be different for each and every person.

This means that the organisation is a good coordinator seeking out comprehensive supports whilst not providing them all. The effective organisation makes full use of natural and informal supports and learns new ways of working with these supports that are outside their hierarchy and control. They work participatively by jointly problem solving, supporting not managing, and being unobtrusive in the lives of the people who are providing the informal supports. The effective organisation recognises that if someone is living with the person with a disability, then they probably know the person as well as anyone.

Reflection

Effective organisations provide time and opportunity for their staff to reflect upon their work and to regenerate themselves. Staff need opportunities to reflect on their practice over time in anticipation of new challenges (Flynn, 1989). Options in Community Living encourages their staff to write stories about their work to develop a greater understanding of what they are doing, why they are doing it and what it means to them. Kathy Lemke, from Options, writes the following about story telling (O'Brien and Lyle O'Brien, 1992),

> *"Whenever we tell a person's story, we take that respect and add validity to it. Stories are the way human beings recognise experiences, give names to feelings, celebrate perceptions of the world ... For persons with a disability, most often their experiences, feelings and perceptions are not related in stories either because they cannot tell their own story, or if they can, others are not listening. When we take on the role of their storyteller, and we do it with respect for them, we give validity to their experiences, their feelings and their perceptions of the world ... [Stories] spread the vision we want for people."*

Storytelling is just one means of developing a deeper understanding of and commitment to their work.

This monograph sets out some ideas to help the move towards Supported Living. Yet Supported Living is not a model that can be replicated. By its very nature, it presents a considerable challenge but this should not be used as an

excuse not to offer people better places to live. So many people say it cannot happen. So many people do not recognise inconsistencies between the lives of people with disabilities and the rest of the population. Supported Living gives people with learning disabilities the opportunity to have the same lifestyles, choices and experiences as the rest of us. We manage to achieve it for ourselves but quite often get it wrong when assisting a person with disabilities.

We know that it is not all going to happen tomorrow. As Bruce Anderson & Margaret Andrews explain (1990):

> *This is the not the work of a day, but it does happen one day at a time. We also know that for us, nothing happened until we stopped trying to decide IF it could happen, and started actively trying to make it happen. We can say from our own experience that 'the only thing standing in the way is the standing itself".*
>
> *To the people who say that this can only happen for people with 'mild' disabilities and can never happen for people with 'severe' disabilities: what we know is that our capacity to support any person ... has only been limited by our capacity to listen, learn and to teach. Every year, indeed every day, people are supported in living and working situations that most people would have thought impossible just a few years ago. It's time to stop putting limitations on who can and cannot be supported in being part of any community. It's time for communities to shout: 'COME HERE NOW. THERE WILL BE NO MORE WAITING. WE CAN FIGURE THIS OUT'.*

It's time to stop putting limitations on who can and cannot be supported in being part of any community.

Progress is being made in this country and there are many lessons for us to learn from the United States. But we need British stories to fill these pages. That is why the NDT is promoting Supported Living in the United Kingdom. Through this Programme, the NDT will be working intensively in six areas across Great Britain to promote these developments. We shall be using learning from a local level to shape services through regional and national workshops and conferences. There will be a series of publications (of which this is one) to highlight good practice and pull out key lessons and issues. This learning will be used by the NDT to influence policy with purchasers and providers of services throughout the

United Kingdom and with Government departments. A network of interested people will also be established, coordinated by the NDT, to provide mutual support, raise awareness and disseminate ideas. For more information about the Supported Living Programme, contact the NDT at the address at the end of this monograph.

There is the potential for many good things to happen. There are so many opportunities arising from the increased demands of people with learning disabilities themselves; the new Community Care legislation (NHS and Community Care Act, 1990); and the strong commitment of activists around the country. These opportunities have to be seized so that there are improvements in the lives and experiences of people with learning disabilities. From small beginnings, grow great things.

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Our mission is to take a lead in promoting valued opportunities for people with learning disabilities to develop, participate in and contribute to our communities.

Our aims are to:

- promote the will and capacity of ordinary citizens to include people with learning disabilities.
- promote and sustain comprehensive high quality services.
- promote better legislation and policy in Health, Social Care, Education, Employment, Housing and Transport.

We work with Local Authority Social Services and Education Departments, Health Authorities and NHS Trusts, and recently with TECs and Further Education Colleges. We also work on commissions from the voluntary and private sectors. Much of our work is across agencies. We offer individual and team evaluation as well as facilitation and both short and longer term consultancy. This field-work is at the heart of our business.

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