

Supported Living: The Changing Paradigm - from control to freedom

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Introduction

In the UK, USA and many parts of Europe, more and more people with learning disabilities are having more say in their lives. Inspired by the civil rights movement for disabled people, the growth of consumerism and individualisation in the broader market place and the demands for continually improving services, there is tremendous pressure for services to be more responsive to the aspirations and wishes of disabled people and their families.

In relation to a place to live for people with learning disabilities, these notions are captured by the idea of Supported Living and person centred approaches, in general. Supported Living starts off with a fundamental belief that every person has the right to lead their own life – determine how they live, with whom they live, who provides them with help and support and how they live their lives.

Changing models of service

The last century has seen very similar patterns of service development in many parts of the Western world. From the development and management of institutions for most of the century, through to the development of smaller community residential services in the '70s, '80s & '90s, culminating in the late '90s with a push to develop more individualised community services – what many people call person centred services.

In the UK, there has been growing dissatisfaction with the limitations of small group homes and larger residential homes. Initially, seen as the ideal alternative to institutions with notions of 'small family size groups', they have frequently turned out to be mini-institutions in their own right. Even those homes which have made very strong efforts to be person centred have found that living together in groups is difficult, requires considerable personal compromise, is sometimes financially more expensive and very difficult to move on from – not all a feature of the homes, per se, but often a feature of how such services are purchased.

Many of these homes have been built around the belief that who a person lives with should be determined by their disability. In the UK, we have homes for people with Downs Syndrome, homes for people with Autism, homes for people with multiple disabilities. Many of these small residential homes have been founded on the belief that people with similar levels of need should live together, and that when people learn new skills they should move on to more independent homes – in effect, they have to be 'ready' before they can move on.

Supported Living

This is completely different to how most people without disability labels lead their own lives. More often than not, we live with people whom we chose (on the basis of liking or loving them),

we choose the house or apartment we live in (often to be close to family, friends or work) and we move into our own homes before we are 'ready' – usually learning to cook, wash clothes, do house work as we go along – or if we are very lucky, living with someone who is good at doing these things and enjoys it as well!

This is, in fact, what we call Supported Living. Supported Living can be characterised in two ways.

At a personal level, it is defined by deciding:

- *How you live*
- *Who you live with (if anyone)*
- *Where you live*
- *Who supports you*
- *What you get help with*

At a service/systems level, Supported Living can be defined by:

➤ **Separating the provision of housing and support**

This is the important foundation for Supported Living. Through keeping housing and support separate, it gives the flexibility to change who provides the support without having to move house or moving house and having the support move with you.

➤ **Focusing on one person at a time**

You find out what is important to people by asking them and those who know and care about them. By using person centred planning, it prevents making disability-based assumptions.

➤ **Zero rejection**

All people, no matter what their label, how severe their disability can live in the community in their own homes. Thus Supported Living is for everyone - not just for people with low support needs. The challenge is to get the right support to people.

➤ **Full choice and control**

People with disabilities should be supported to choose who they live with (if anyone), how they live, where they live and who supports them. When people cannot make some of these choices, those who know, care about, and love the person should be instrumental in making informed guesses.

➤ **Building on relationships**

Every opportunity should be taken to develop community links, make use of informal and natural supports and reduce the reliance upon staff, wherever possible.

The key feature of Supported Living is that the whole ethos is Person Centred.

Some stories

Frank has Down syndrome, has diabetes and a label of 'challenging behaviour'. He has lived most of his life in institutions, and frequently been moved because he was 'too difficult'.

In 1996, he got the chance to move into his own home. His family were very dissatisfied with his services and campaigned for change. The local care managers at the time had started to use a different type of assessment and planning called Essential Lifestyle Planning. This planning looks at what is most important from the person's perspective and involves those who know, love and care about the person.

From this Frank, rented his own house, has a live in flatmate who provides companionship, and 20 hours of week from a visiting support worker. He gets support with looking after his house, managing his finances, in his job at a local factory and going out at night. Frank's life is totally different now: he has an active social life, he is not seen as having challenging behaviour and is supported by people whom he chose.

Paul and Ken lived in an institution all of their lives. They had labels of severe disability, challenging behaviour and needing 24 hour support. They now live in their own house, are supported during the day and evening (but not overnight) and again have very full lives.

Essential Lifestyle Planning was used again to determine what was most important to them and then their support was designed around this.

The key feature about Supported Living is that no two people's lives or services are the same.

In fact, no different to anyone else. In just the same way that who we live with and where we live is intensely personal to us, so it is with people with disabilities.

No matter how disabled people are, everyone should have the opportunity to be supported in their own home.

Key Factors for Successful Supported Living

1. Supported Living has to start with good person centred planning. In the UK, Essential Lifestyle Planning (Smull & Burke-Harrison, 1990) and Personal Futures Planning (Mount, 1989) have become two of the most common forms. At the heart of any good person centred planning process is an unwavering focus on the person, involvement of family and friends, aiming for community inclusion and identifying what is most important to the person, their skills and contributions. It is fundamentally different to traditional forms of planning which focus upon a person's deficits. Person Centred Planning respects people and builds capacity, recognising them as unique individuals. Supported Living is difficult to develop without person centred planning – it is this process which helps prevent assumptions being made about a person because of their label of disability.
2. Residential service providers have to change how they work. Organisations need to become accountable to the people whom they are supporting, be responsive to their

needs and wishes and seek to make disabled people more powerful and in control over their own lives. Factors which have often helped this have been:

- Providers staying small or larger organisations giving autonomy to local services and operating more like a federation of lots of small local services
 - Management systems that are built upon trust and are supportive of staff rather than punitive in approach
 - Training which improves workers knowledge, skills and attitude – and making this training available to people’s families as well.
 - Senior Managers who maintain contact with service users and build good relationships with them
 - Organisations which are flexible, creative and responsive - not driven by petty restrictive rules
 - Devolved financial management
 - Good links with and knowledge of local communities
 - Effective staff support processes
3. Funders of services (Commissioners) need to change the way that they work with people and their families to ensure good person centred services. As with Providers, they need to develop speedy, responsive and flexible systems that put people first.

This includes:

- Flexible and realistic funding arrangements - targeting resources where they are needed
 - Keeping the provision of housing and support separate
 - Care management processes that are built upon good person centred planning
 - Ability to creatively work around systems rules and other blockages
 - Determine quality through the real life experiences of people
 - Maximising all income
4. There needs to be a culture that supports innovation and acknowledgement about the need for change. Often this involves the painful acknowledgement that things are not as good as they can be. In many places, a willingness to try new things, a culture of partnership, and good joint training opportunities have all been important factors. The training needs to open people's minds as to what is possible, and create vivid images in people's minds. All too often, the biggest barrier is not funding, nor bureaucracy, but is the belief that the change cannot be made.

If there is anything to be learned from experiences in the UK and the USA, it is that everyone can (and should have the right) to lead their own lives.

People with learning disabilities have similar expectations to everyone else:

- Their own home
- A job
- Friends
- Feeling good about themselves

- Opportunities to pursue their own interests
- Feeling safe

It is not asking a lot to expect that our service system achieves this.

Individualised Funding

Where systems do not or cannot change, other opportunities are opening up. In the UK, Direct Payments are happening for more people with learning disabilities. In the USA, Self Determination is slowly becoming more common. Both of these take control away from administrators in services and place it in the hands of people and their families. People have access to their own funding and buy services direct. Some people will want this and others may not. However, the key theme is again looking to shift power away from services and place it in the hands of consumers. People vote with their feet and do not choose the existing congregate residential services which are available - like you and I, they want their own home.

Conclusion

Is this pie in the sky ideology? Certainly some people dismiss it as such. However, if that is the approach that we take, we do ourselves and disabled people an injustice. There is enough anecdotal and research evidence to show that Supported Living is effective, affordable and what many people want. The challenge is to take the lessons from across the world and apply them. Every country and its citizens has its own culture and it is important that things like Supported Living reflect and adapt to that. However, wherever you live, feeling good about yourself, being free from abuse and neglect, having economic independence, loving and being loved are important.

Throughout the UK, National and local policies are less and less leaving these outcomes as an optional extra, and increasingly requiring them as a basic expectation. Supported Living is here to stay.

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