



Community Connecting

Discussion Paper

Title of paper:

Community Connecting

Status:

Discussion Paper

Date of last amendment:

22 December 2004

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1 Summary

This paper has been produced by In Control to stimulate discussion about community connecting. We are keen to ensure that the work we do through this programme does not get in the way of an individual's friendships and relationships, and indeed supports people to contribute to their community, make new friends, and develop networks of care and support in their own neighbourhoods.

The paper examines the barriers which prevent people from being included in their communities. It looks at some of the approaches which have been adopted to tackle exclusion. Some of these approaches have been adopted by people who specialize in working with disabled people, others come from the community development tradition. We have made a conscious effort to bring together diverse disciplines in the hope that In Control can make the best use of the learning on healthy communities, from whatever source. Finally we look at some of the strategies In Control can promote to support people with learning disabilities to be included.

2 Background

Most people with learning disabilities now live in the community but 'community care' has not led to significant changes in the size and composition of people's social networks. Very few people have reciprocal friendships and social interaction is largely restricted to interactions between service users and staff. At the same time it is evident that one of the key concerns of many people with learning disabilities is to achieve greater participation and wider social networks. Time and again, when people with learning disabilities are asked what they want, it is the chance to have an ordinary life with a job and friends, somewhere they choose to live. Yet the fact remains that disabled people are more isolated than other members of the community.¹

As well as having a desire to develop friendships, people with learning disabilities often have a concern to take up their role as active citizens. This could include voting and using community facilities eg. Leisure centres, libraries. It could also include being part of campaigns to clean up a local environment, keep an area safe, or support and include the more vulnerable members of the community.

At the launch of the Active Communities unit in November 2003, David Blunkett stated:

We want to do even more to help local people play their part in making their communities safer and more inclusive. The strength of our community life will be greatly enhanced if we can release the untapped energy of citizens and community groups.

In Control believes not only that people with learning disabilities are entitled to the opportunity to make friends and develop networks in their neighbourhoods, but also that they represent some of that untapped energy, and that communities are impoverished because people with learning disabilities are often denied the opportunity to make a contribution.

3 Barriers to building Community

We know that there are barriers which prevent people with learning disabilities from being included in their communities. Some of these barriers are outlined below:

- **Fear/hostility/prejudice in the community** - there is still discrimination against people with learning disabilities in the community.
- **Individual's lack of networks** - many people with learning disabilities have lived in institutions – they may have lost touch with their family, had few opportunities to make friends and little experience of what a friend is. Those who have lived at home may have been sheltered from the community. As a result they may have few skills in developing friendships as opposed to more formal caring relationships.
- **Staff ignorance on how to access community** - many staff do not live in the communities in which they work. If they do, they may be isolated themselves and have no idea of how to find out about what is going on or how to build productive relationships in the neighbourhood
- **Staff ignorance on how to support relationship building** - supporting individuals to meet others and develop friendships is a new role for some staff. They may have not have skills in this area.
- **Staff/carer fear of what might happen** - there are risks inherent in meeting strangers. The fear of what might happen can prevent supporters of an individual from supporting them to meet new people. Additionally, some staff can develop a very protective attitude towards the people they care for and resent others stepping into to support them or offer them different opportunities.
- **Institutional Barriers e.g. Police checks, registration, group living** - some organizations have had to change their structure in order to accommodate people with learning disabilities desire to be independent ordinary members of the community. Group living and group resourcing has been shown to get in the way of building friendships with people outwith the house. Registration means that houses often don't look like homes. Police checks bureaucratize opportunities to make ordinary friendships, nor are they always effective.

- **'They are other peoples' problem'** – for as long as most people can remember, people with learning disabilities have been cared for by the state. This has fostered a belief in many people, including families, that they are not capable of supporting people with learning disabilities or even talking to them. This attitude extends to mainstream services and community organizations. Community development workers and community leaders, who have skills, and experience, in connecting people, often believe that it is the job of specialist services to offer any kind of support to people with learning disabilities. ² In this way people with learning disabilities are denied the opportunity to take up their role as a citizen in a community.

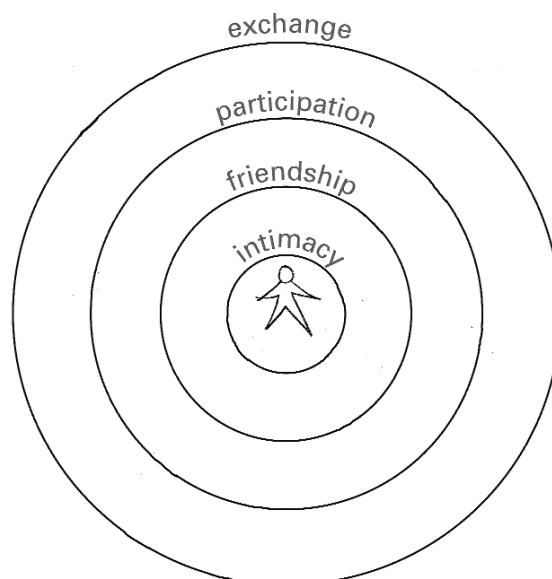
4 Approaches to Tackling Exclusion

Pioneers of the movement to promote more inclusive communities, in both the USA and Britain, have attempted to understand and break down these barriers.

4.1 *Judith Snow and the Inclusion Movement*

Judith Snow is one of these pioneers. She has developed a framework which maps relationships in four concentric circles (fig 1). The inner circle, the circle of intimacy, is where those with whom we are closest belong, our lover, husband or wife, our children, our dearest friends, those people who support us to define our identity. The second circle, the circle of friendship, includes good friends and less close family. The third circle, the circle of membership, includes those people who belong to something with us. They may be work colleagues, or fellow members of a choir or church congregation, they could be neighbours or fellow students. The fourth circle, the circle of exchange is for those with whom we have a paid relationship – the hairdresser, the woman in the newsagent, the doctor and so on.

Fig. 1



One of the main points Judith draws from this analysis of relationships is that we need to be in community to make friends. The people we meet at school or college or at work or through the church are the people who become our friends and our lovers. People move from the third circle into the second circle and first circle.

She is also very clear that people with disabilities bring gifts to community. As well as the obvious skills and talents they have, which have sometimes been overlooked, they bring the gift of themselves, their presence, their difference and the opportunity they offer others to interact with them and each other because of them. One of the very first Circles of Support formed around Judith. Judith benefited, in that it enabled her to move out of the institution in which she was then living. But those in the circle benefited too, not only from the relationship they had with her but also from the ways relationships developed with each other as they worked towards a common aim. ³

4.2 *John McKnight and Asset Based Community Development*

John McKnight has argued that services can, unintentionally, stand between a person with a disability and the community. He believes that support offered by services is support that in some cases would otherwise be offered by the community. The result being that ordinary community members begin to feel themselves unable to assist or even communicate with people with disabilities, believing that you need a special qualification to do so. Like Judith Snow, John McKnight believes that disabled people are not given the opportunity to show their assets to community as they are always being assessed in terms of what is wrong with them. It is these 'gifts' that form the basis of the essential currency of community exchange. He advocates the stepping aside of services in order to allow people with disabilities to contribute to community, and people in community to demonstrate their natural hospitality.

John McKnight takes a community development approach to connecting people with disabilities to their communities. His method is to research all the formal and informal clubs and associations, from mother and toddler groups to Rotary Clubs, in a particular area. He believes that these associations offer the route to community for those who are excluded. Within those associations are people who believe in their community, who wish to welcome people into it, and are well-connected themselves. These people he calls 'community guides'. And it is these people who can introduce those with disabilities into their community and find them opportunities to express their gifts.⁴

4.3 *The social model of disability*

The social model of disability defines the problem of exclusion as societal rather than individual.⁵ Disability activists, working with allies, in Britain and the USA

have focused on changing the structure of our society to enable disabled people to exercise their right to be included. The Disability Discrimination Act (2004) and the accessibility of cities like San Francisco are evidence of their success. But there are still many thousands of cinemas, restaurants, clubs, cafes and work-places from which disabled people are unable to access.

4.4 Community Development Tradition

One of the factors which makes Britain distinct from the USA is the existence of mainstream statutory services which are dedicated to promoting healthy communities. Although it has been argued that some services block people from accessing their communities, the reverse is also true. Good services, which really based on community development principles, can also be a great asset in working towards inclusion.

In Britain, there is a strong tradition of community development. The Scottish Community Development Centre has produced a model of community development which is based on research with practitioners in the field and has been widely accepted. (fig 2)

Fig. 2



A Healthy community has key characteristics:

- it is liveable i.e. a place or a social network within which people's needs are met, where they feel comfortable and have a sense of belonging
- it is sustainable ie. In social, environmental and economic terms it has a long term future
- it is equitable ie. it is founded on principles of fairness and justice and does not tolerate discrimination

As the model outlines, community development workers support individuals to make changes through: developing new skills (*personal empowerment*), working together (*community organization*) and participating in political structures (*participation and involvement*). Community development has a particular focus on supporting fair and just communities, working in areas of highest deprivation and concentrating on individuals who are traditionally most excluded like those from black and ethnic minorities or people with disabilities (*practicing positive action*). These working processes make up the four community empowerment dimensions.

The outcomes they seek from their work, and the reason why most community members would get involved, would be to make communities safer, more caring, wealthier, more creative and more democratic. These outcomes make up the five quality of community life dimensions.

Accepting this analysis means that community development workers need to become more aware of their responsibilities towards people with learning disabilities.

4.5 *Active Citizenship*

Political interest in participation and citizenship mean that there are now workers in the health services, leisure sector, voluntary organizations and Local Strategic Partnerships, as well as in community education, who are using community development skills and supporting individuals to make a contribution to their communities.

In practice, despite their emphasis on the most excluded individuals, most of these workers do not work with people with learning disabilities. They might think that other people like social workers do that. They might think that it takes specially qualified people to work with people with disabilities or they might not understand that people with disabilities have gifts to bring to community.

In Control encourages individuals, their families and their supporters to seek out community development services and practitioners in their areas and gain their support in accessing communities.

Promoting inclusive communities and enabling individuals to make an active contribution are supported by government policy.

The Government's vision for active communities is of strong, active and empowered communities - increasingly capable of doing things for themselves, defining the problems they face and then tackling them together. It is a vision in which everyone - no matter their age, race or social background - has a sense of belonging and a stake in society.⁶

The recent consultation paper on Building Civic Renewal (March 2004) emphasises the importance of including communities of interest, maintaining a principle of inclusion and employing generic community development workers to build capacity in communities.

The government Strategy for Neighbourhood Renewal is a scheme for putting more resources into the most deprived communities. Although, again this assesses needs rather than assets, it does mean that there are more resources in these areas, which could be made available to help people with learning disabilities access their community.

There are funds, like the Community Empowerment Fund and the Community Chest and Community Learning Chest, which are aimed at supporting local communities, including communities of interest, to influence local services.⁷

Some areas employ local people or 'community animateurs' to help promote and organise the participation of community members in activities that help to make positive changes to their community.⁸ These people could make very effective community guides.

In Control encourages people with learning disabilities to assert their rights as citizens in localities by using mainstream support and funding to access their community and influence services.

5 Response of In Control

At each stage of the programme In Control is encouraging individuals to tackle the barriers to exclusion using some of the approaches which have been highlighted.

i. Assessment

In Control is working with local authorities to help them identify a Resource Allocation System. Once this is in place an assessment will lead directly to an allocation of funding. Funding will be allocated on the basis of need (low/medium or high). People will then be able to plan with their budget in mind. The

assessment of need will be carried out by the care manager who will be interested in issues such as whether the individual needs 24 hour support, can cook for themselves or travel independently.

At this stage the individual's relationships and connections in the community are not up for consideration. An individual with high support needs who has lots of loved ones in his life will receive the same allocation of funding as an individual with high support needs who has no unpaid people in his life. Although, in some ways this might seem unjust, In Control does not want to penalize people on the basis of relationships, which cannot be relied upon to be permanent, nor to give care managers the responsibility of making judgements about how much a relationship is worth.

We would hope that new and creative ways of supporting people who are isolated will be found outwith the resource allocation system. One such way is the Small Sparks initiative. £10,000 has been made available to offer up to 40 small grants to people in In Control sites. The grants will enable people with learning disabilities to make a visible contribution to their community, through a small project or activity thus giving them a role as leaders within their communities and increasing their connections.

ii. Planning

People have the right to plan their own lives in their own way – with friends and family if they choose. Some people need support to make decisions in particular areas of their life. At this stage the individual will be thinking about who is close to him and who can help him plan. Using a process such as Judith Snow's relationship circles may be helpful.

It is important to be as thorough as possible when finding out about relationships. Sometimes people have lost touch with someone who they were close to, like an ex-staff member or a person they used to live with. Finding these people provides an opportunity for renewing friendships but may also lead to new insights into what is important to the person.

Family and friends have a crucial role to play but they may need support in taking up their role. They may never have been included in decision making before. They may also find it hard to see the individual as an adult or to separate their own needs from the person's needs. Paid staff often know a person well but in some cases they may be torn between a person's interests and the interests of the agency they work for and these dilemmas need to be discussed openly.

Ideally an individual would be able to rely on a circle of friends and family (sometimes called a circle of support) to help them make decisions.

Unfortunately, many people with learning disabilities are isolated, and for these people it is obvious that an important part of the support plan will involve building community. Having friends and connections in the neighbourhood will

improve their quality of life but also help to keep them safe. The balance between being independent but having adequate support from those close to you is often a difficult one for all of us to maintain.

The In Control guidance 'Supported Decision Making in Practice' gives a real example of an individual who made a Decision-Making Agreement outlining which decisions he wanted to make himself and which decisions he wanted his Mum to support him with. It is proposed that everyone who needs help making a decision has a Decision Making Agreement which allows them to be clear about which decisions they want to make for themselves and which decisions they need help with from family and friends. .

iii. Agreeing the Plan

At this stage the individual will be putting together the support plan and submitting it to the care manager. The Guide to Support Planning explains who might be involved in drawing up the support plan with individuals. It also gives guidance on understanding your community and joining in.

The Support Plan could be extended to give individuals the opportunity to identify their gifts and to think about how they can provide an opportunity for connection with others. It could include an initial attempt to map the community finding out:

- what local organizations exist
- where people go to hang out on a regular basis. (Ray Olsenburg calls these 'third places' – natural places where people go to chat and meet others. Normally these places are cafes, community centres or pubs, but they could be anywhere – even the local bank. It is in 'third places' that people are able to find out about what is going on in the community and meet others who are interested.)
- which individuals could be potential community guides

The care manager could review the support plan for evidence that the individual will be participating in community life as much as possible, and that particularly when people are very isolated, they are being supported to meet new people and make friends. The kinds of questions they might be asking are:

- Has the individual been supported to identify their gifts ?
- Has there been any initial attempt to map the community – is the individual using mainstream services whenever possible, e.g. swimming pools, college classes?
- Are they being properly supported to do so?
- When they are in ordinary places are they being supported to meet people eg by going along with someone who shares their interest and understands how they communicate, being appropriately introduced to people?

- Is there anyone in the community who can help them either paid, like a community education worker, or unpaid, like a well-connected member of the community – perhaps the landlord of the pub or the local vicar?
- If the support plan does not include opportunities for connection, what is the reason for it?

Living in community, as well as offering opportunities for love and connection, carries risk of abuse or attack. This is especially true for the more vulnerable members of society. It is also true that people living in institutions are also at risk of abuse and those people who have nobody in the lives who cares for them and looks out for them, are the most at risk.

The care manager needs to be looking for evidence both that risks are being taken ie, that the person is not being kept isolated for fear of what might happen, but also that those supporting the individual have thought about the risks and taken steps to minimize them. These steps should not be limited to police checks and might not even include them. The Guide to Support Planning outlines a seven step risk management framework. The Health and Safety Guide discusses risks in relation to developing identity and relationships particularly around sexuality.

iv. Individual Funding

Individual funding offers the individual control over their own money. This could be through a Direct Payment. But, if someone doesn't want to manage the money himself, he can still keep control with the support of a representative, or a Trust. An important option, which has not been used in England so far, is an Individual Service Fund. This is held by a provider (chosen by the person) and held in a restricted account. Funding is then used for a service designed exclusively for that person.

In our society, having control of your own money gives you both power and status within the community. It is another sign to the community that people with learning disabilities are citizens in their own right. It also enables them to contribute to the local economy by directly employing staff if they so choose.

Going to the bank on a regular basis also offers the possibility of connecting with bank staff, who might share common interests or who might be well connected themselves and interested in connecting others to the community - what John McKnight has termed 'community guides'.

There are other possibilities for banking money. They might be a local credit union which would offer the individual the chance to be part of a community venture as well as bank his money.

v. Organising Support & vi. Individual Support

At these stages in the In Control process the individual is setting up his own support arrangements or receiving support to do so. There is plenty of opportunity for supporting or building community connection. If she is already well connected it is likely that some support will be unpaid, coming from family, friends or workmates. There is flexibility in the funding for support and it may be that the individual will choose to use some funds to make this easier ie. Paying for a friend to accompany her to a football match or buying lunch for the friend who takes her shopping every work.

There will also be some paid support workers. Choosing the right support staff is crucial for many reasons, one of which is because they can act as important bridge into community. By being aware of the rights of disabled people, particularly in relation to the Disability Discrimination Act, they can also advocate on behalf of individual who is being unjustly excluded from community.

If he wants, the individual can employ people she already knows and trusts to support him, neighbours, friends, or extended family (although immediate family cannot be employed unless a good reason is provided). Alternatively she can recruit people who share common interests and are already well connected in the community. If necessary, she can pay a 'community guide' to introduce her to community.

At this point the individual should again be encouraged to find out what support she could get from mainstream services like community education, to help her access community.

If using a support provider the individual can choose one which is embedded in the local community. She can also specify what kind of staff she wants to support her. The job specification might include: a willingness to use your own connections and an ability to explore the community and connect with others. Alternatively, staff may need training in how to map a community and support people to make connections.

It may be that the individual will choose to use a support broker to help her organize her support. If she wants the broker to support her to make the best use of existing networks and to connect to her community this will need to be specified as part of the initial contract.

At these stages it is important to consider whether the individual wants to be supported to make a more formal contribution to her community. She might want to join a neighbourhood watch scheme; take part in a community campaign to clean up a park or join a community network which would give her a voice in service planning through the Local Strategic Partnership.

vii. Accountability

The Care Manager will still be responsible for reviewing individual arrangements. They will be looking to see deepening in an individual's relationships and a wider circle of friends and neighbours.

But there will also be arrangements which enable the individual to take charge of the review process, which will allow her, and her supporters to learn about what works and what doesn't. Sometimes community will not be a welcoming place and sometimes the individual will not like what she finds. Reviews will give people the opportunity to learn from setbacks and move on. They will also be a chance to celebrate success.

Individuals will also have the right to seek review by an independent panel which again provides an opportunity to involve well-connected members of the community.

6 Conclusion

Through self directed support, In Control is attempting to give people with disabilities the chance to design and buy support arrangements which suit both their lives at the moment and their dreams for the future. In this way it is hoped that those who have become trapped, will find their way out of 'serviceland'⁹ and that others will never find their way in. By removing the barrier of services, which, however hard they try, will always be institutional in some way, it is hoped that it will be much easier for people with disabilities to be part of their communities, and to contribute to them, quite naturally.

However even without institutional barriers, there are still the hurdles of fear, distrust and ignorance which mean that the process of community connecting often needs to be an intentional one, thought of and planned for at every stage.

1 Evans et al. 1994; de Kock et al. 1988; Jaholda et al. 1990; Cambridge et al. 1994; Rapley and Beyer 1996; Lowe and Paiva 1991; Allen 1989; Jaholda et al 1990; Simons 1997. cited in Chris Jones' unpublished MSc thesis

2 For a further exposition of the theory of how services damage communities cf. McKnight John: The Careless Society. Basic Books. USA. 1996

3 Snow J: What's Really Worth Doing and How to do it. Inclusion Press, Toronto.

4 For further information cf. www.northwestern.edu/ipr/research/rescommunity.html

5 For a further exposition of the social model of disability cf. Oliver M: The Politics of Disablement. Basingstoke, Macmillan Press. 1990

6 Quote taken from Home Office Active Communities website

7 For further information cf. www.homeoffice.gov.uk

8 For further information on Doncaster Health Action Zone's community animateurs cf. www.sccd.org.uk/reports/hazci.doc

9 A term originally coined by Pete Ritchie of Scottish Human Services Trust