

Centres for Independent Living / Local user-led organisations:

A discussion paper by Jenny Morris

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Introduction

In January 2005, the government gave a commitment that:

By 2010, each locality (defined as that area covered by a Council with social services responsibilities) should have a user-led organisation, modelled on existing CILs (Centres for Independent Living).

Improving the Life Chances of Disabled People, 2005. p.91

This report looks at what needs to happen in order to fulfil this commitment. It was commissioned by the Valuing People Support Team.

How was the report written

A number of organisations were consulted on what needs to happen to fulfil the *Life Chances* commitment. They included:

National Centre for Independent Living
Shaping Our Lives
Breakthrough UK
Centre 404
People First
CHANGE
NEST (mental health service users in Essex)

Essex Coalition of Disabled People
Hammersmith and Fulham Action on Disability
Derbyshire Centre for Independent Living
Ealing Centre for Independent Living
Spinal Injuries Association.

An advisory group, made up of people with learning disabilities and family carers also helped with the writing of the report. They were:

Caroline Tomlinson, Alison Cowan, John and Lawraine Hails, Karen Flood, Nicola Barham, Richard Blake, Michael Ratcliffe. Centre 404 also facilitated a discussion with people with learning disabilities and family carers.

The expertise and experience of these organisations and individuals was invaluable in the writing of this report.

The report also draws on what is known about the activities and issues facing Centres for Independent Living and other user-led organisations, and sets this in the context of current government policy on voluntary and community organisations.

The report identifies some questions which may need to be addressed in the process of implementing the commitment in *Improving Life Chances*. In doing so, it also raises some questions about what needs to happen in order to develop the capacity of existing user-led organisations and encourage new user-led organisations. The views presented in the report are those of the author.

Background

Definitions

It is helpful to set out some definitions of words and phrases used in this report.

Independent living means having choice and control over whatever is required in order to go about your daily life.

Inclusive living means being fully included in society.

Service user means people who need support and / or equipment in order to go about their daily lives and who use services that are provided as part of the welfare state.

User-led organisations are those where the people who the organisation represents or provides a service to, have a majority on the Management Committee or Board, and where there is clear accountability to members and / or service users.

Centres for Independent / Inclusive Living are grassroots organisations run and controlled by disabled people. Their aims are that disabled people should have control over their lives and achieve full participation in society. They work towards these aims by representing disabled people's views locally and nationally, and by providing services which promote independent living.

The social model of disability says that the problem is not someone's impairment, illness, frailty or learning disability but instead, the problem is that they don't have the support, equipment or housing they need and they don't have choice and control over their daily lives. Although the social model of disability was initially developed by people with physical impairments, it is just as relevant to people with learning disabilities, older people, and people with mental health support needs.

The social model of disability and mental health service users

Essex Coalition of Disabled People believes that the social model of disability is as relevant to people with mental health support needs as it is to people with physical impairments. Their leaflet for people who use mental health services, says:

“Do you feel.....

- Categorised and controlled by the medical profession?
- You have a right to be treated with dignity and respect?
- That you are not the problem, society is?
- No one sees your strengths, only your weaknesses?
- Discriminated against and devalued?
- That your views are important and should be listened to?

Well, so do we!....If you see the link between the Disability Movement and the mental health system survivor / service user movement, then please contact us....” Leaflet issued by Essex Coalition of Disabled People.

What do CILs / user-led organisations do?

The current CILs and user-led organisations work towards independent living by:

1. Providing support to make choices and have control:

- support to help people to self-assess their needs
- support to use direct payments
- advocacy and support for self-advocacy
- peer support
- advice and information.

An example of providing support to make choices and have control: Peer support and a good information service

Derbyshire CIL employ disabled people as Community Development Workers. They aim to work with disabled people to give them “the knowledge and confidence to be able to live and work in the community as they choose....A very important aspect of community work relies on the knowledge and experience of disabled people who have already reached this point in their lives. By using their direct experience and knowledge, community work can be a powerful force”. The Community Development Workers go out to disabled people’s homes and assist with things like housing, benefits, training and education, employment, direct payments and support services. They have access to a comprehensive information database run by DCIL.

2. Providing services to meet people's needs, such as assistance in recruiting and employing personal assistants, an employment support project, a supported housing service, a peer support service.

Two examples of user-led organisations providing services to meet disabled people's needs

Hammersmith and Fulham Action on Disability (HAFAD) provides a range of services for young disabled people. These include holiday activities, work experience and volunteering, and enabling young disabled people to access mainstream youth provision.

One group formed a rap band, cut a CD and went on to perform live at festivals across London. Funding for HAFAD's Agenda for Youth comes from a variety of sources, including the National Youth Agency, and local neighbourhood, education and youth services.

The Spinal Injuries Association (SIA), a national organisation run by and for people with spinal injuries, provides a Peer Support Service, and a freephone Helpline (which also has an email and minority languages provision). These are funded by general fund-raising activities. The Department of Health funds the SIA to run self-management courses for people with spinal cord injuries.

3. By helping other organisations (in the statutory, voluntary and private sectors) to provide services which empower people:
 - by being consulted or involved in service development and provision
 - by campaigning for things like accessible transport and housing.

Consultation and involvement of service users

Centre 404 – a family carer-led organisation running services for people with learning disabilities and their families – is funded by the local authority to run a Parent Participation Project. The project has a database of parents of disabled children who are willing to be consulted, and runs monthly meetings for parents, providing information and training (including confidence building sessions).

Parents are involved in and consulted on service planning and delivery in a number of different ways, from setting up a sub-group of Islington's Parents' Forum to responding to plans for new children's services.

Newcastle Elders' Council was funded by Newcastle City Council to develop a strategy to improve the quality of life for older people.

There is widespread support for the role that user-led organisations have to play in the changes happening in social care:

“User-led organisations must have a crucial role in a new vision of independent living. They can play an essential role in transforming social care so that services are driven by the needs and wishes of those who use them to deliver real independent living. When resourced adequately, local user-led organisations have been found to be the most effective means of delivering a range of services including advocacy, self-advocacy, peer support, and supported decision-making. Services can be greatly improved by the people who use them having a leading role in delivering, monitoring and evaluating services. User-led organisations can play a key role in consultation processes because they have a knowledge base about issues around local service provision. They can also advise on practical issues on involving more marginalised groups in consultation”.

Inter-Agency Group of statutory and voluntary organisations: Response to Green Paper *Independence, Well-Being and Choice*.

www.nhsconfed.org/docs/iag_asc_greenpaper_fullresponse.doc

A vision for “user-led organisations modelled on existing Centres for Independent Living”

An advisory group of people with learning disabilities and family carers were consulted in the writing of this report. This was because CILs have not found it easy to include these two groups and it is important that user-led organisations are fully inclusive. These are some of the things that they said about their vision for an organisation which would fulfil the *Life Chances* commitment:

- A place with lots going on
- Part of the community – a sense of belonging
- A place where you can find out about other organisations and services
- A service that goes out to people and helps them through their journey to whatever they want to achieve
- A place where you can find out what is possible
- A place that influences change and learns from experience
- A place that gives others energy and support
- An organisation that stands up for people’s rights.

In many ways, the vision that the group had was of a vibrant local community centre, a place and organisation where a whole community comes together, not just people who need support in their daily lives. In order to achieve this, it would need to be linked into wider local and community networks.

Q.1

Should the Life Chances commitment be linked into other initiatives to promote local community organisations and community involvement? If so, how should this be done and by whom?

What would a “user-led organisation modelled on existing Centres for Independent / Inclusive Living” look like?

A number of organisations were consulted about how they thought the *Life Chances* commitment could be fulfilled. Most people thought it would not be possible for one organisation to cover all the activities required or to cover all the different groups of service users.

They thought that what is needed is a network of user-led organisations in each local area, connected together by common aims. This could take a number of different forms, depending on what was right for each local area. It could be a federation of organisations and / or an organisation in its own right. It could be a building and / or it could be a ‘virtual centre’, i.e. a website.

It probably needs to be more than an informal network of organisations in order to ensure that all the things that current CILs and user-led organisations do (listed in points 1-3 above) happen in each area. In lots of local areas, the foundations of a formal network already exist through the joint work done by organisations representing different service user groups.

Developing inclusive networks

Disability Connects is a network of disability related organisations in the London Borough of Ealing. “We aim to work together across the different impairment related boundaries to create change for disabled people of all types.

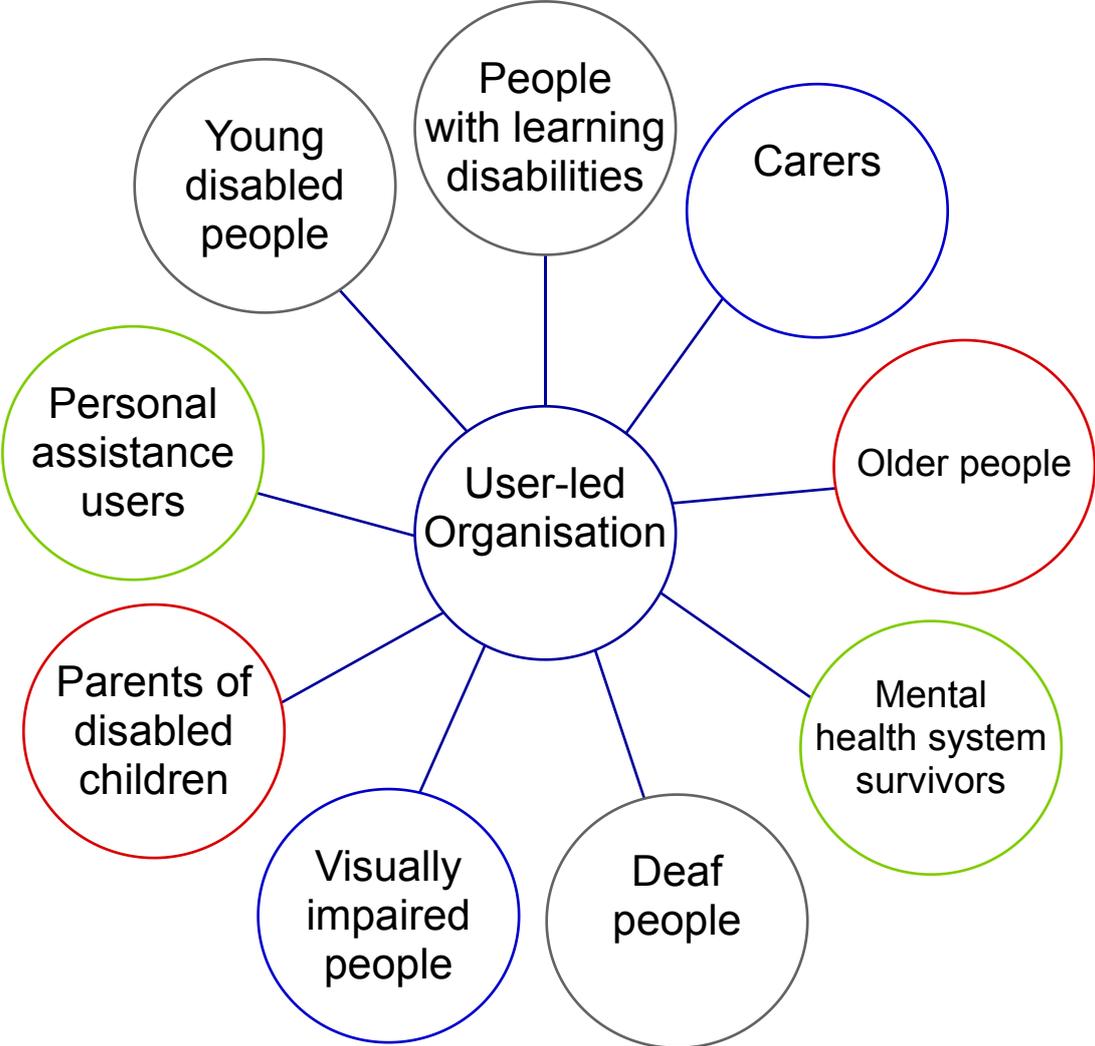
When we talk about disabled people we include: people of all ages, people with mental health issues, people with learning disabilities, people with conditions such as diabetes, blind people, physically disabled people and deaf people”. Organisations include: Ealing Centre for Independent Living, Ealing Crossroads, Alzheimers Concern Ealing and Ealing Mencap.

In some areas, CILs have been working with other local organisations to promote inclusive living amongst groups of people who have not traditionally been part of the disability movement. For example:

- Hampshire CIL has been working with Age Concern to increase the take-up of direct payments amongst older people
- Ealing CIL supported a group of 25 people with learning disabilities to pool their direct payments to pay the lecturer for a theatre course they had previously attended at a local college – because the college was withdrawing the course.
- West of England CIL has been running courses on direct payments in partnership with a provider of services to the South Asian community.

A network of user-led organisations could be both a network of organisations representing particular groups of people, *and* a network of user-led services.

A network of user-led organisations could look like this:



And a network of user-led services could look like this:



Q.2

Is a network of user-led organisations the best way of fulfilling the commitment in Improving Life Chances on user-led organisations modelled on existing CILs?

Barriers to creating user-led organisations modelled on existing CILs in every locality

There are some key barriers to the idea of a network of user-led organisations in every locality. Some of these barriers are about the way organisations currently work, some are about other factors which can make it difficult for user-led organisations to prosper and thrive.

The different groups of people who need support in their daily lives use different language to describe themselves and what they want

Different groups use different words: some older people who need support would not call themselves 'disabled people', some people who use mental health support services are not happy with the term 'independent living'. Some people don't like the word 'impairment'.

There are, however, lots of common ideas that all the different groups have. The three main ones are:

- The problem is society and lack of support, not the individual and their age, disability, impairment, state of mental health, etc.
- The most important thing is to have choice and control over the support needed
- 'Nothing about us without us' is a phrase used by all the different types of user-led organisations.

Amongst all the user-led organisations there is a common aim to move away from a charity model, to move away from ‘doing things to’ disabled and older people. Working on disability issues is not about ‘doing good’ but about getting human and civil rights.

The common goal is social inclusion and full human and civil rights so it may be that this is the kind of language that would be appropriate.

“I have no problem with the term ‘independent living’ but having heard the term ‘social inclusion’ I now prefer that as it describes more accurately what I’m about as an independent disabled person. The term independent living brings to mind isolation for me.
Patricia Chambers, Member of Shaping Our Lives”.

Q.3

Do we need a model ‘statement of values and aims’ which could be offered to local user-led organisations as a starting point for them agreeing common aims and values? If so, who should write this?

User-led direct payments support schemes have not always been very inclusive of people with learning disabilities, people with mental health support needs or older people

Research by Values into Action found that most disabled people’s organisations which ran direct payments support schemes have little involvement by people with learning disabilities.

The organisations said there were two main reasons for this:

- The disabled people's organisation lacked the expertise or experience of working with people with learning disabilities
- The needs of people with learning disabilities were very different to those of other members of the organisation.

However, those organisations that do include people with learning disabilities said that they do not need different advice and information but may need it presented in different ways.

Some CILs have done better than others at providing direct payments support services for people with learning disabilities. Those that have done well have adapted their service by, for example:

- Taking a broad definition of when someone has 'consented' to a direct payment, to allow for a whole range of methods of communication
- Using Circles of Support to enable someone to manage a direct payment
- Developing Independent Living Trusts to enable someone who 'lacks capacity' to be able to benefit from direct payments.

Southampton CIL has a peer-based support scheme to enable people with mental health support needs to use direct payments. It is successful because it addresses the particular issues relating to direct payments and mental health support needs (such as fluctuating needs, mental health crises). The support worker, a mental health service user herself, gives confidence to other mental health service users to help them use direct payments to meet their needs better than traditional services.

Q.4

What more needs to be done to encourage and empower user-led organisations to provide Direct Payments Support Services to people with learning disabilities, people with mental health support needs and older people?

Centres for Independent / Inclusive Living have not always been inclusive of people with learning disabilities

CILs consulted for this report recognised that their organisations have not always been fully inclusive of people with learning disabilities in the way they run their organisations. There are two main reasons for this:

- Historically people with physical impairments have been treated as being 'mentally handicapped' and have wanted to get away from the stigma and negative attitudes associated with having a learning disability.
- People can be afraid that they don't know how to behave or communicate with people with learning disabilities.

These are the some of the things that people with learning disabilities have found helpful when organisations include them as Committee members:

- Being clear that people with learning disabilities have a REAL voice on the committee.
- Having at least two people with learning disabilities on the Committee – never having just one.
- Agendas, minutes and all Committee papers put into Easy Read versions, and on tape if someone needs it.

- All Committee papers being sent out at least a week in advance.
- Having a supporter at the meeting if a person with learning disabilities wants this.
- All committee members agreeing that they will not use jargon.
- The chair of the committee taking responsibility for making sure everyone understands and has a chance to have their say.
- People with learning disabilities being able to stop the meeting if they need to have something repeated or explained.

People with learning disabilities are often helped by non-disabled people to run self-advocacy groups. Some disabled people who are used to running things for themselves think that non-disabled people have too much say in self-advocacy groups. This may sometimes be true but it may also be that there is sometimes a lack of understanding and knowledge about the role of support workers in self-advocacy organisations.

People with learning disabilities working for CHANGE recruited a Resource Worker. When a worker with learning disabilities needs some help to do a particular task, like reading a document or arranging a meeting, they then ask the Resource Worker for the help they need.

This means that the person with learning disabilities decides what help they need, asks for it, and directs their own support. They find this works better than employing support workers for each person with a learning disability because, in those circumstances, it's too easy for the support worker to take charge.

Historically, disabled people see no role for family members in their organisations. But family members have an important role in some organisations campaigning for the rights of people with learning disabilities. There are some really important allies in the learning disability field who have helped people with learning disabilities to access their human and civil rights. Sometimes family members also have an important role to play in enabling social inclusion for an individual child or adult.

Centre 404 is a family carer-led organisation but young people with learning disabilities are increasingly involved in the organisation. Young people are involved in running the organisation's leisure service and family members are not involved at all. Through this involvement, people with learning disabilities are also becoming involved in decision-making about how Centre 404 is run and in decisions about its future.

For example, members of the leisure service voted on the change of name for the organisation, and there is always one person with a learning disability on the three-person interviewing panels for all jobs at Centre 404.

The Chair of the Management Committee says: "The leisure service has developed into a real powerbase for people with learning disabilities in the organisation".

These are all issues which will need to be sorted out in order to create local networks of user-led organisations that can work together.

Q.5

What do CILs, self-advocacy groups of people with learning disabilities, and family carer-led organisations need to do in order to work better together? How can they be supported to do this?

Are carers service users?

Carers UK represents people who provide unpaid support to disabled people. They say carers are service users in their own right and need access to advice, information, advocacy and peer support just as disabled people do. But people with physical and / or sensory impairments have argued that they don't need 'care', and should not have to rely on the unpaid work of friends and family.

On the other hand, disabled people's and carers' organisations have some things in common. Carers UK is a carer-led organisation and supports many local carer-led groups. Many of the concerns of disabled people are the same as those of carers. Carers UK fights for carers to have more information about their rights to an assessment of their needs, to increase take-up of benefits, for the employment rights of carers, and for carers to be included in society.

Yet carers' interests can sometimes clash with other service users. In the mental health field in particular, there are sometimes conflicts about the sharing of information about people's needs and treatment. Although the term 'service user and carer involvement' is commonly used in the mental health field, carers often feel that their voices are less heard, while some service users challenge the right of family members to be consulted. This potential conflict within the mental health field may make itself felt within a network of user-led organisations and will need to be addressed.

In some localities, disability organisations have supported the closure of residential respite care facilities and day centres – in favour of resources being put into enabling people to access mainstream society – while carers have opposed such closures (as have some service users). Sometimes, these conflicts can be resolved by addressing the very real concerns that traditional services will not be replaced by better quality support.

Local networks of user-led organisations will need to have effective mechanisms for exploring potential conflicts of interest, and working towards shared understandings and goals.

Q.6

What action will be required, when building networks of local user-led organisations, to include local carers' groups and to address potential conflicts?

Commissioning and contracting

Services which have been developed by disabled people to help disabled people live independently – like personal assistance support schemes – are now increasingly being put out to competitive tender by local authorities. This often means that larger organisations bid for the work and offer lower unit costs, partly because they have the capacity to support more people and can therefore take advantage of economies of scale.

Peer support and self-assessment are often not fully valued within the new tendering processes. These have been important aspects of direct payments support schemes developed by disabled people, but they are not often part of the service specification, or if they are, are not given much priority. Arguably, these and other key roles, such as consultation, can only be done by user-led organisations.

User-led organisations often don't have much spare time or people to work on bidding for contracts, and can find it difficult to produce tenders within short timescales and to high standards. In contrast, some large voluntary sector and private organisations have a whole section of their organisation just working on tenders and contracts. This means user-led organisations are disadvantaged if they are competing with these larger organisations.

This is a particular issue for organisations led by or involving people with learning disabilities who may require more time and for documents to be available in accessible formats.

Q.7

What needs to be done to enable user-led organisations to compete on a level playing field for service contracts?

Policies concerning the voluntary and community sector

Initiatives to build the capacity of the voluntary and community sector have not, so far, identified the particular value and needs of user-led organisations. For example, the Compact – the initiative to improve the relationship between government and the voluntary sector – has not identified or addressed the particular role that user-led organisations have to play.

The work has addressed the particular roles and needs of black and minority ethnic voluntary and community organisations – for example by developing a Code of Good Practice. It would be useful if the Compact similarly addresses the roles and needs of user-led organisations.

Similarly, ChangeUp, the government programme to ensure that there is a strong infrastructure to support the voluntary and community sector by 2014, has not so far addressed the particular value or needs of user-led organisations. The different parts of the programme (the governance hub, Futurebuilders, etc) will also need to address the particular needs and potential of user-led organisations.

Q.8

What action needs to be taken to ensure that the work being done to strengthen the infrastructure of the voluntary and community sector also reaches, and addresses the needs of, user-led organisations?

Service users and their organisations experience barriers to being involved in decisions taken by public bodies

Representation of service user views to public bodies is a key role for user-led organisations. All the different groups of people consulted for this report said they experienced barriers to being consulted about, and involved in, decisions taken by public bodies. Whatever the group is, the barriers are the same. They include:

- Not enough time is given for proper consultation and involvement
- Meetings are too fast
- There is too much written material for people to read
- There is not enough time to find out what is happening
- There is an assumption that if a service user is invited onto a committee or group then that means they are involved: in fact, often they face too many barriers to being really involved
- There is a lack of respect for the experience of using services
- People are not paid for their time and expertise.

Q.9

What could be done to encourage good practice in involving service users? (see also Q.11 below)

Local user-led organisations do not always work well together and are sometimes in competition with each other for contracts and grants

In one local area, looked at for this report, there are four organisations who are potentially competing with each other for resources to support people with learning disabilities and their families. These are the local Carers' Association, an organisation founded by the parents of children with learning disabilities, a Speaking Up group of people with learning disabilities, and the local disability organisation.

They are all critical of each other's claim to be representative of people with learning disabilities and their families.

Q.10

Is it inevitable and / or acceptable that user-led organisations will sometimes be in competition with each other for service contracts? If so, what can be done to prevent this undermining networks of user-led organisations / CILs?

Opportunities

The commitment in *Improving Life Chances* offers a real opportunity to encourage and increase the role of user-led organisations in the development and delivery of services which enable people to have control over their lives and participate fully in society. There are also other things going on that could help with these aims, and that we need to make links with.

User involvement protocols

Improving Life Chances gave a commitment that:

- Government departments would model good practice in involving disabled people
- User involvement protocols would be developed by public bodies in consultation with disabled people.

The Office for Disability Issues has responsibility for supporting delivery of these recommendations. User involvement protocols will also be an important mechanism for fulfilling the requirement, under the Disability Equality Duty, for public bodies to involve disabled people.

Q.11

What contribution will the commitment that public bodies should develop user involvement protocols make to the goal of establishing user-led organisations in every locality, and how can action on these commitments be co-ordinated?

Support from Councils with social services responsibilities for user-led organisations to deliver direct payments support services

NCIL and the Association of Directors of Social Services have drawn up a protocol which says that “The National Centre for Independent Living (NCIL) and the Association of Directors of Social Services (ADSS) are committed to promoting independent living and the social model of disability” and that “in principle NCIL and ADSS believe that support services are often best provided by local user and care led organisations”. The protocol also urges local authorities, when setting up CILs and support services, to:

- Ensure that such organisations and services have appropriate expertise and capacity to deliver effective support. Wherever possible, commission these services from user and carer controlled organisations
- Consult users, carers and potential users about the nature of the support they require
- Include local representative organisations of users and carers in the consultation process
- Work with user led organisations to develop capacity: e.g. by facilitating “pump priming” or partnership working arrangements
- Ensure that local contracting procedures do not discriminate unfairly against small / new / user-led organisations
- Ensure that value for money considerations take account of the added value often contributed by local organisations representing potentially eligible service users
- Ensure that service specifications for contracts / service level agreements embody the ethos of independent living
- Consider using a restricted / selective tender list, to target organisations controlled by users
- Consider effective interim arrangements where a user-led support service does not yet exist: this could include seconding a member of staff on a short-term basis or contracting with a support scheme in a neighbouring authority

- Where no user led organisation exists provide seed funding to cultivate their development

(Association of Directors of Social Services / National Centre for Independent Living, June 2006)

Such support for user-led organisations will have an important role to play in fulfilling the *Life Chances* commitment.

Funding opportunities

Many funding organisations, especially the larger foundations, recognise the need to work closely with grass roots organisations to enable them to develop and take advantage of funding opportunities. *Fruitful Funding* by Julia Unwin, for example, looks at how funders and voluntary organisations can build relationships which benefit both.

Many successful user-led organisations have been able to grow because they received development funding in their early stages from their local authority or other statutory agency.

Development funding enables user-led organisations to create income generating services

Breakthrough UK was set up to provide training, employment and business opportunities to disabled people. Run by disabled people, it was initially provided with development funding by Manchester City Council, then became a company limited by guarantee and now has contracts in Manchester and Liverpool to provide employment, training and independent living opportunities for disabled people.

Q.12

What can be done, and by whom, to help small user-led organisations develop relationships with funders and with commissioners, which would enable small organisations to grow and survive in the new commissioning climate?

Link-Age and Link-Age Plus / Sure Start in Later Life pilots

Link-Age is the Department for Work and Pensions' strategy for building an integrated network of services for older people. Two of the component parts of the network are particularly relevant to the *Improving Life Chances* vision: easy access to advice and information; and ensuring that older people are involved in the process of planning and delivering community services.

Link-Age Plus / Sure Start in Later Life follows on from the Social Exclusion Unit's report on excluded older people. Eight areas are piloting the application of the Sure Start approach to early intervention and prevention. The DWP and the DH are committed to ensuring that advocacy services for older people are included in piloting of both Link-Age Plus and individual budgets.

Q.13

What links should be made with Link-Age and Link-Age Plus?

Individual budgets

The new system of individual budgets is about promoting self-determination. Information, advice, advocacy and peer mentoring services will be an important part of enabling people to self-assess their needs, apply for and use an individual budget. The new system needs organisations that understand the barriers to self-determination and are committed to helping people have control over their lives.

User-led organisations are the right organisations to do this and the pilot areas are working with CILs or similar organisations where they exist. However, if the implementation of individual budgets is to be done in an empowering way for all groups of people with support needs then user-led organisations representing all these groups need to be given a clear role. This is why there is a need for a network of user-led organisations working together in each area.

Q.14

Should some (or all) of the pilot areas for individual budgets be also looking at building networks of user-led organisations in their areas? What resources / assistance would they need to do this?

Disability Equality Duty

The Disability Equality Duty requires public authorities “to promote equality of opportunity between disabled persons and other persons”. The Code of Practice says that this includes encouraging the participation of disabled people in society, and disabled people must be involved in the way that public authorities fulfil the duty.

When the Home Office developed Compact - support for the voluntary and community sector - it fulfilled its Race Equality Duty by, for example, developing a specific code of practice for black and minority ethnic organisations. The key points for a framework of partnership between government and BME organisations include:

- Ensure BME organisations are an inherent part of consultation and policy processes through involvement from a large pool of individuals and organisations.
- Invest in the BME voluntary and community sector.
- Support the development of capacity and infrastructure within the BME sector at local, regional and national levels.

The Disability Equality Duty will encourage this kind of action in respect of disability organisations.

Current user involvement initiatives

There are some important user involvement initiatives happening which could help in developing local networks of user-led organisations. They include:

Involving people who don't usually get involved

There are a lot of things going on to try to involve groups of people who are not usually involved in user-led organisations. For example, Shaping Our Lives, a national user controlled, independent organisation, has received funding from the Department of Health to find out how to get more people involved, particularly: young people, people who communicate differently, people from black and minority ethnic communities, and people using residential services. They will produce guidelines and training materials.

Increasing involvement of people who use mental health services

Mind is working to increase service user involvement in statutory and voluntary sector services, at local, regional and national levels, and the National Institute for Mental Health in England (NIMHE) commissioned a report on service user involvement and is implementing its recommendations. One of these recommendations is:

A key focus for NIMHE should be enabling and supporting service users and carers to be involved in local groups. NIMHE needs to work with commissioners to support investment in the development of local mental health service user and carer groups.

If resources are put into local mental health service user and carer groups this will help to strengthen the network of user-led organisations. These developments in the mental health field need to make links with other user-led organisations.

Promoting user involvement to bring about change in local social care services

The Joseph Rowntree Foundation has funded a two year programme to develop “short-term, medium-term and long-term systemic solutions which can support older people, disabled people and a range of service users to have choice and control over their lives”. This is being led by Shaping Our Lives, the national network of people who use services. They are working with a number of local services and service users to identify ways of overcoming specific and general barriers to delivering choice and control to the person who needs support.

Q.15

What links need to be made with these and other user involvement initiatives?

What steps need to be taken to deliver the vision for a user-led organisation modelled on existing CILs in each local area?

In order to fulfil the commitment to establish “a user-led organisation, modelled on existing CILs” in every locality by the year 2010, action must be taken nationally, locally and by user-led organisations themselves.

Action at national level

The following things need to happen at a national level in order to create a strong network of user-led organisations in every local area.

1. National policies on the voluntary and community sector – including its increased role in the provision of public services – will need to take account of the particular value and needs of user-led organisations. (See Question 8 above)
2. A national organisation – such as the National Centre for Independent Living – to support and develop local networks.

Q.16

Is there a need for a national organisation to promote local networks of user-led organisations / CILs? Could NCIL take on this role? What further development and resources would NCIL need to do this?

3. A national system for registration and accreditation of:

- Disability equality trainers and consultants
- Service brokers
- Independent living advisors
- Advocates.

This national system is needed because the jobs of disability equality trainers, service brokers, independent living advisors and advocates are crucial to promoting independent living and disability equality. There is a need to ensure that those delivering these services are working to common aims and high standards.

Q.17

For some people, this suggestion is a controversial one because of the fear that a system for registration and accreditation will stifle innovation and flexibility. On the other hand, there is a need to find some way of ensuring both good quality services and a strong value base. What is the best way or ways of doing this?

4. Resources for Local Strategic Partnerships and local user-led organisations to develop networks in every locality. (See Question 19 below re the role of Local Strategic Partnerships) These are ‘pump-priming’ resources – in other words they are needed over a short period of time in order to build organisations which will in the medium to long-term be funded on the basis of the services they provide. This could be done by setting up a Development Fund, similar to the Direct Payments Development Fund.

Q.18

Is a Development Fund a good idea? How much money would be required and over how long a period? Who should fund it and who should do the development work?

Action at local level

Local Strategic Partnerships will need to map what user-led organisations there are in their local authority area. This would enable them to:

- Identify the gaps in user representation in their area
- Decide how to encourage new or existing organisations to better represent all groups of people who need support in their daily life.

Q.19

What action is required to encourage Local Strategic Partnerships to map user-led organisations in their area and take action to ensure there is a network of user-led organisations representing all groups of people who need support in their daily life?

Local user-led organisations will need to get together to decide how they can establish the kind of networks and user-led organisations that would suit their particular area.

Together Local Strategic Partnerships and local user-led organisations, will need to decide what level and type of development needs to happen, and who will do it. Where there are gaps in user representation within a local area, it is likely that resources will be needed to develop organisations to fill that gap.

In addition, Local Strategic Partnerships and local user-led organisations will need to look at whether some organisations need help to develop income-generating services; and at whether improvements need to be made to commissioning processes to ensure that user-led organisations are not disadvantaged.

Action amongst local user-led organisations

Local user-led organisations, if they are to operate effectively as a network, will need to start by addressing tensions which might exist between different groups, and build on common aims.

CILs will need to do better at including people with learning disabilities. This means including them in both running the organisation, and making sure that services (like direct payments support schemes) deliver what people with learning disabilities need.

Q.20

Should the National Centre for Independent Living – in partnership with organisations of people with learning disabilities - publish a good practice guide about how to be fully inclusive of people with learning disabilities? Is there a need for good practice guides for all the different service user groups? Or just one?

Conclusion

The commitment in *Improving Life Chances* provides an important opportunity to enable grassroots organisations to have a real say and to make their unique contribution to how services are run. However, there are lots of unanswered questions about how to get to having a user-led organisation modelled on existing CILs in every locality by 2010. This report has identified some of these questions in the hope that they will provide a starting point for making progress.

