Whose Community Is It Anyway?

RETHINKING THE COMMISSIONING OF USER LED ORGANISATIONS AND CENTRES FOR INDEPENDENT LIVING

by **Simon Duffy**

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CONTENTS

About the author 2
Publishing Information. 2
Thanks to: 3

SUMMARY 6

INTRODUCTION. 9

THE DEVELOPMENT OF CILS 11

SELF HELP GROUPS. 15

COMMISSIONING 19

COMMUNITY. 23

MOVING FORWARD. 25

BUILDING ALLIANCES 28

CONCLUSION 30

Method 32
Bibliography. 32
Recent Publications 34

Summary

Centres for Independent Living (CILs) were developed by disabled people to support people to be full and active citizens. Today, after much work by disabled people, government policy has changed and there is now support at every level for the development of User led Organisation (ULOs) and the creation of CILs in every community.

- Unfortunately there is a grave danger that a well intentioned policy is now out of step with current reality. In particular:
- Current procurement practices can conflict with the provision of the best support to disabled people and can encourage the development of unduly professionalised services, rather than peer support.
- The development of self-directed support raises new questions about the scope, funding and function of Centres for Independent Living.

New forms of community organisation and social innovation have developed over the past 50 years and offer new possibilities.

Today there is a policy imperative to commission User Led Organisations to run Centres for Independent Living, but perhaps its time to think differently about this challenge. Perhaps the idea that government can commission community is incoherent. We need to develop a more respectful and balanced approach, one that recognises both the role of government and the independence and integrity of real community groups.

This paper outlines this challenge and describes some practical options for working differently. In particular it is important to:

- **Implement self-directed support correctly** - enable disabled people to choose how they get support, including management support
- **Use Community Sourcing strategies** - instead of old-style procurement
- **Involve self helps groups in the definition of policy on their own terms** - co-production
- **Create an alliance of self help groups**

Communities should not be owned, controlled or commissioned by government. Particularly today, when funding for vital supports is being cut and where the basic securities of the welfare system are being radically reduced, it is critical that community organisations can work together to independently define and defend our social systems.

It is perhaps time to ask: Whose community is it anyway?

INTRODUCTION

A key priority of government since Improving the Life Chances of Disabled People has been to ensure that there are disabled people's organisation's that are leading the way in every part of England (Cabinet Office, 2005). This makes good sense. There is significant evidence that local leadership from disabled people is critical to improving social care and delivering other public service reforms (what now goes by the rather unfortunate name of 'personalisation'). Often the primary focus of this strategy has been to create a 'Centre for Independent Living' or CIL.

However, while many would agree that this is an important goal, it is a goal that raises some important questions. To begin with there are worries about whether government can 'create' genuine community organisations, especially organisations of disabled people There is a danger that local government will end up funding organisations that may appear to have all the features of a CIL - but which, in reality, lack its essential spirit.

Second, government has also given itself many competing imperatives, in particular a commitment to tender for services, and to seek best value in open competition. The paradoxical result of these imperatives is that often CILs are now provided by organisations that don't seem to be either genuine community organisations or organisations led by disabled people. It is extraordinary to note that in some places profit-making organisations, like A4E, have been successful in winning tenders to provide CILs.

There is a further challenge also. There are several very effective CILs in existence, and these do provide powerful and positive models; but there is no reason to suppose that any one model is correct for each location and for all time. It would seem more reasonable to suppose that our ideas about CILs also need to evolve. In particular we need to be aware of the many different groups that exist or could exist - some of whom may not even use the concept of disability - and yet who can have a powerful and positive contribution to make.

In this report we want to explore how we might overcome these three problems:

- Stimulate and support genuine community development
- Rethink how government funds and supports CILs
- Explore how the model of the CIL might evolve in the future

This work is tentative. It is based on consultations with several dynamic community groups in Doncaster and builds on some of the observations and learning described in *Peer Power* (Duffy, 2012). It also draws heavily on the work of Howells and Yapp who provided important advice to the project (Howells and Yapp, 2013, Yapp and Howells, 2013).

Overall we found ourselves a little uncomfortable with some of the defining assumptions in this area; instead participants sketched a different vision of the kind of approach they would like to see developed in Doncaster. We hope that some of this may seem useful to people in other places too.

Community organisations need their own independence and integrity. While they may want to work with government to transform lives, communities and services, they should not be treated as 'services' - to be simply funded or controlled by government. Building respectful **relationships** between government and community is more important than money.

While community groups can and do provide services they can also do things that services rarely do - in particular they can enable self help and mutual support in ways that are not only more efficient, but which achieve some outcomes that public services can never match.

However, strengthening peer support is not an excuse for undermining the rights of disabled people and other disadvantaged groups, nor does it justify attacks on the welfare state. In fact activating local people to help each other, as citizens, may well be critical to sustaining and strengthening our social rights.

The role of government is critically important in the development of a decent welfare state, but so is the role of community. And the community does not belong to government; government belongs to and should be accountable to the community it is there to serve.

The Development of CILs

What follows is a very brief outline of the development of CILs and it cannot hope to do full justice to their value, variety or history. But unless we understand them in their historical context we are unlikely to understand what they can - at their best - contribute today.

The concept began in California in the 1960s and the first formal centre was established in Berkeley in 1971 (Shapiro, 1993). It was a hub for peer support, advocacy and a whole range of useful services, which enabled disabled people to lead independent lives. The system was also run and largely staffed by disabled people. It was an exciting innovation and critical in establishing that not only did disabled people have the right to independent living, but they could be at the centre of making that right a living reality.

In the UK these same ideas also started to become powerful in the 1970s and early CILs were established in Derbyshire and Hampshire in the 1980s (Glasby and Littlechild, 2009). Often disabled people were worked in close partnership with local government leaders to bring about radical change. There was no strong legislative framework, but enlightened leaders tried to bring about positive change in their particular area.

The role of CILs came into greater prominence after 1996 when the government finally made direct payments legal. Further, during the 'New Labour' era many leading disability activists worked closely with central government to produce an over-arching strategy on disability - *Improving the Life Chances of Disabled People* (Cabinet Office, 2005).

The role of the CIL was central to this strategy:

> ***One of the key ingredients for developing this new approach should be the direct involvement of disabled people, primarily through local Centres for Independent Living. The capacity within these organisations should be increased to enable them to play an effective part in supporting disabled people to achieve independent living. Centres for Independent Living are potentially well-placed to provide advice and information, advocacy support and practical assistance in managing individualised budgets.***
>
> Improving the Life Chances of Disabled People

Over time this idea has become central to government policy and is often repeated as a central goal and an essential part of a 'transformed social care system'. In fact the current policy has taken the original idea of independent living and extended it. Ideas like personal budgets and self-directed support have been applied to social care and to other services (including health and education), and this changes the context for the development of CILs (Cowen, 2010).

However in reality progress has been slow and patchy and a number of repeated problems are experienced:

1. Many CILs are not really run or controlled by disabled people. For example, some CILs are controlled by private organisations and non-disabled organisations. For example, currently the private organisation A4E works nationally and currently provides a CIL for 5 local authorities (see http://marketplace.mycareinbirmingham.org.uk/Service/Details/2862)
2. Many CILs are focused on people with physical disabilities but seem less accessible for people with other disabilities or for people who do not see themselves as 'disabled'. For example people with learning disabilities, older people or people with mental health problems do not always feel that the CIL is relevant to their needs (rightly or wrongly).
3. The typical funding model for CILs is largely based on the old direct payments model where (a) the citizen would be given a minimal payment, only enough for paying salaries and (b) management costs would be excluded from the direct payment and instead a 'free' service would be provided by the CIL. This deprives disabled people of the choice of how to get support and also leads to budgets for people taking direct payments to be artificially cut compared to people using other services.

All of this raises important questions about the best approach for supporting the development of CILs. It is even be possible to argue that as the idea of a CIL has become institutionalised within government policy, it has become increasingly defined from the top-down in ways that are not in the genuine interests of local people. See for example the Department of Health's *21 Criteria for a User Led Organisation* (Department of Health, 2007).

This is made clear by reflecting on the slow progress of public policy in this area. Ideas that were first developed in the 1970s are still not widespread and the practical implementation of those ideas is now influenced by many factors that were not imagined by the original innovators (see Figure 1).

At this point it may be useful to reflect on the local experience of people in Doncaster. For the kind of peer support that was always at the heart of the CIL vision does exist in many places in Doncaster, but not always within the formal structure of a CIL. This raises the question of how local people in Doncaster see the development of a CIL - not as a government priority - but as an important method for meeting their own local needs.

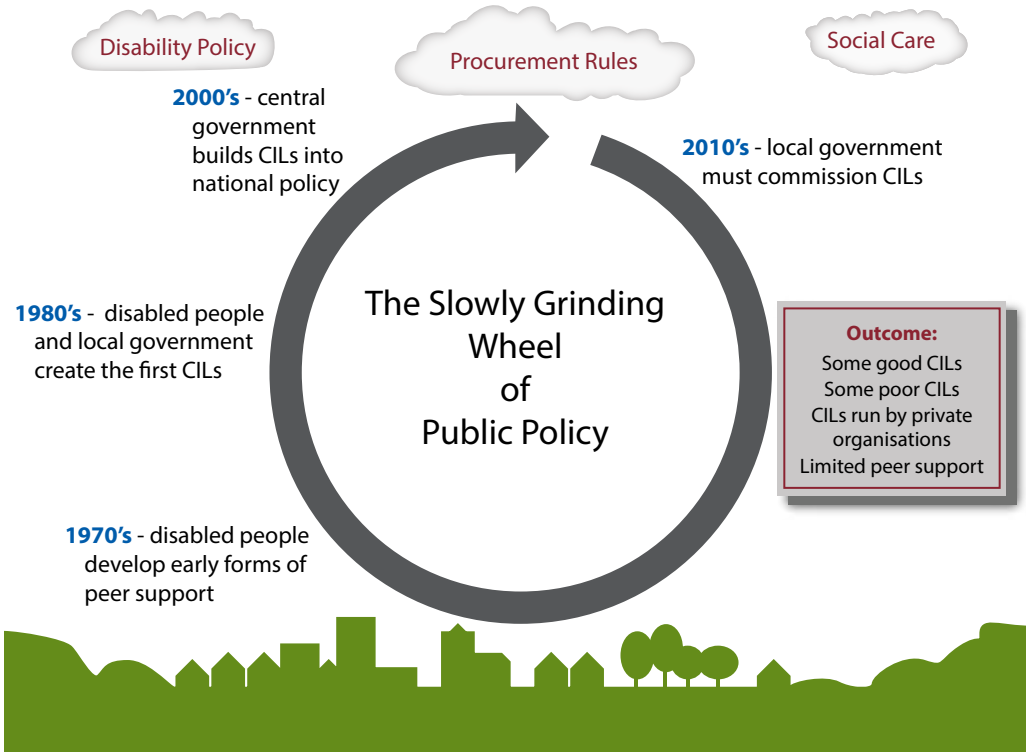

Figure 1 The Slowly Grinding Wheel of Public Policy

Department of Health's 21 Criteria for a User led Organisation

1. Works from a social model of disability perspective.
2. Promotes independent living.
3. Promotes people's human and other legal rights.
4. Shaped and driven by the initiative and demand of the organisation's constituency.
5. Is peer-support based.
6. Covers all local disabled people, carers and other people who use support either directly or via establishing links with other local organisations and networks.
7. Is non-discriminatory and recognises and works with diversity in terms of race, religion and belief, gender, sexual orientation, disability and age.
8. Recognises that carers have their own needs and requirements as carers.
9. Engages the organisation's constituents in decision making processes at every level of the organisation.
10. Provides support to enable people to exercise choice and control.
11. Is a legally constituted organisation.
12. Has a minimum of seventy five per cent of the voting members on the management board drawn from the constituency of the organisation.
13. Is able to demonstrate that the organisation's constituents are effectively supported to play and full and active role in key decision-making.
14. Has a clear management structure.
15. Has robust and rigorous systems for running a sustainable organisation (e.g. financial management / contingency planning).
16. Is financially sustainable as there will be no ongoing central government funding.
17. Has paid employees, many of which must reflect the organisation's constituency.
18. Identifies the diverse needs of the local population and contributes to meeting those needs.
19. Is accountable to the organisation's constituents and represent their views at a local level.
20. Supports the participation of its constituents in designing, delivering and monitoring the organisation's services.
21. Works with commissioners to improve commissioning and procurement.

Self Help Groups

Doncaster may or may not be unusual. However it was striking that we were able to find three dynamic organisations each of which was largely unfunded, self-sustaining and built around the gifts and passions of local people:

- Active Independence
- Personalisation Forum Group
- Doncaster 50 Plus

When we considered the strengths and attitudes of each group there was some important common ground:

- **Friendship** - the groups were social and friendly - which doesn't mean there is no conflict - but they value the different kinds of love and human experience that are found in coming together as equals. One person said that what they shared was 'loneliness' - that is people came together because they valued the relationships that this brought.
- **Expertise** - each group had real 'professional expertise' based on lived experience and their efforts to support each other through thick and thin. They also knew their own communities, their resources and their problems. If necessary they could do the formal things that life sometimes requires (like writing policies and procedures) but they liked to use ordinary language and to keep things simple, clear and flexible.
- **Independence** - each group was not obsessed with services or their relationship with services. The label 'service user' felt very peculiar. While there was no hostility to services, people did not define themselves by their use of services and sometimes services were either unhelpful or not available. People talked about having a life - not services. This sense of independence was very important to each group.
- **Entrepreneurship** - each group was outward looking and focused on bring about transformational change. The entrepreneurial practice is not about 'business' in some shallow sense - it is about making better use of what is available. What was important was to create better outcomes - how this was done was an open question. If this meant working with the private sector, drawing in new sources of funding or collaborating with public services then the group was ready and willing to explore what that would take.
- **Citizenship** - each group was focused on contributing as citizens to their local community. They were proud that they created local jobs, kept money in the local community and gave people a source of pride in themselves. They brought energy and focus to their work - but that work was defined by themselves.

None of these groups would pretend that they were somehow an alternative to public services or decent social rights. But they were also very aware that they could and should do many things that public services would never be able to do on their own. Nor were they happy with seeing themselves as 'users'. Whether or not people were using some

public services (and some people would like to - but were deemed ineligible) they did not define themselves as 'users'.

It is the perspective of the service system that turns people into users - because it only thinks about people in their engagement with services. But for people this is backwards. People are certainly people, hopefully citizens, but certainly not users. Services are just one part of life.

It is for this reason that I have chosen to abandon the language of 'user' and the term 'User Led Organisation' in this report. This not because of any hostility to the concept of a ULO, rather because it seems like, when you find an organisation that is living the spirit of a ULO then the people in it don't see themselves as 'users'. The whole notion of being a ULO seems to presume that people must justify and legitimise their actions by a code that is defined by services. This is to put the cart well in front of the horse.

Rather, the central quality of these groups seems to be the quality of peer support or self help: people, with something in common, working together to solve problems and make life better. So, I am going to use the term 'self help group' to describe these groups. Such self help groups are not 'just another service' that can be just compared to other 'service providers'.

Potentially these groups are dynamic partners who can work with local government and the NHS to:

- Critique current services from the citizens' perspective
- Challenge bad practice and define good practice
- Create new opportunities and solutions for local citizens

But they are not another service to be commissioned by local government for the community to use. Instead, they are a big part of the community that government and public services are there to serve.

What is fundamentally required is a transformation in the relationship between government and community - the relationship needs to become more respectful and trusting. in particular its important the government takes care to avoid:

- Dictating to communities what they need
- Tendering out services to providers from outside the community
- Using contracts to control and restrict local developments

It will be necessary to rethink the whole relationship between genuine community groups, like self help groups, and the commissioners who shape public services.

Active Independence:

We are a Peer Support group of Disabled people who, along with our PAs or carers, meet regularly to campaign for better and clearer access to personalisation & for easier systems for managing the finances. We began in 2003 as a Direct Payment Support Group. Between us we have years of experience of using personal budgets for our care and support needs, all of us employ our own PAs or carers. We know what its like to go on the roller coaster to achieve self-directed support. In 2011 we received funding which has helped us to launch as Active Independence, a 100% user-led organisation. We provide advocacy, information & guidance, tips and training on a range of aspects to do with accessing and managing a care and support package including assessments, recruitment of PAs or carers and how to be a good employer, all focusing on the model of person-centred care. We have 50 members and a committee of 6.

Doncaster 50 Plus:

Doncaster 50 Plus is an independent, self-governing, association of citizens who are over fifty years old. It is a constituted, democratic, body that is managed by older people for the benefit of older people. It is strictly non-political and non-sectarian.

The organisation was created to represent older people and to engage with the authorities and agencies that affect their lives so that it can work constructively for real and lasting improvements in the economic, social and environmental conditions of older people. For too long, older people have been told what is best for them instead of being asked what they want. Through Doncaster 50 Plus they have the opportunity to speak up for themselves and they should make sure that the opportunity is not lost.

There are more than 98,000 citizens over the age of fifty living in Doncaster, which is one third of the population and half of the voters. If only ten percent of them joined 50 Plus it would have a powerful voice that would be heard and listened to by all the authorities, organisations, politicians, and agencies that have an impact on their lives. Doncaster 50 Plus was established on 3rd June 2008 and has 1800 members.

The Personalisation Forum Group (PFG)

The Personalisation Forum Group is an award-winning group of 120 people who decided to stop being 'Service Users' and to create a new identity as members of their own DPULO (Disabled Persons User Led Organisation). The group is independent and provides practical peer support to each other, while also challenging the existing system to reform itself and to improve services for local people.

The group was started in August 2010 to help its members with mental health problems advocate for opportunity to use personal health budgets and direct payments. The group has gone on to develop a range of different community activities including: a food bank, peer therapy, football team, crochet club, art classes, creative writing, nights out, peer support, community gardening and much more.

Campaigning for reform and supporting mental wellness remain key activities of the group. A recent development includes taking on a Council employment service that had been cut. The group now employ an employment advisor to help the group and other community members with their CVs and offer assistance to find work. The group runs a Wellness Centre which is used by an average of 50 people a day (100 on the food bank day).

Commissioning

Increasingly government has placed more and more emphasis on the concept of commissioning and its centrality to the working of a successful welfare state. Despite the fact that there many questions to ask about the concept it is, as Jon Glasby puts it "the only game in town" (Glasby, 2012).

Well-intentioned public servants must therefore struggle to make the concept work in a complex environment where the constraints include:

- Uncertainties of purpose, value and need
- Changing political priorities, locally and nationally
- Reduced funding (e.g. 33% cut in social care by 2015)
- Bureaucratic procurement practices
- A high turnover of senior staff

The ideal of commissioning - as a highly rational and objective force, driving forward positive change in local communities - can seem untenable. At its heart is a contradiction. Real change and innovation is largely driven by shifting power and control towards citizens and into communities. Increased centralisation kills innovation and thereby reduces the capacity for genuine efficiency.

In particular, as Howells and Yapp explain, commissioning has been captured by a false understanding of the requirements of EU procurement law.

> *...the reluctance to commission locally in the past is based on accepted practice owing more to historic convention and a restrictive interpretation of EU procurement rules rather than what is practically possible. Fear of judicial review and the costs of defending such action have sat alongside such conventions and served to stifle the willingness of local authorities to commission locally and the ability of local organisations to bid for, and win, the right to deliver services in their area.*
>
> [Howells and Yapp, 2013]

Not only is the current interpretation of EU procurement laws incorrect it seems that the UK has an extreme tendency to organise local activities in ways that mean they are more likely to fall within the scope of European law.

In other words, in the UK, it seems we go out of our way to make things more bureaucratic and expensive than strictly necessary:

- We roll smaller contracts into larger contracts, putting them out of the reach of small groups or local organisations
- We focus only on price, but disregard the other factors that bring value to local communities, like the impact of the economy, environment and social capital

- Commodify services - focus only on those elements that can be purchased, ignoring all the outcomes achieved by volunteering or self help [As one group member put it "Do they know the value of overcoming loneliness?"]

Complex, large and long-term contracts for public services may sometimes be necessary, but they are certainly not the best place to start thinking about how to encourage and support the development of small, community-based organisations or self help groups.

Commissioning is locked into the service system that it funds. The goal becomes to continually commission the same kinds of services - just to change the banner that hangs over them.

In fact, worse than this, it turns out that the organisations who have been most successful at winning tenders are:

- Large national providers with dedicated bid or tender writing teams
- Organisations whose base, leadership and expertise exist outside the community
- Organisations who draw resources away from the local community

This is the very opposite of the kind of society we want to create. Our premise is that the current system has failed to take account of the rich range of skills, assets, energy and relationships that already exist in communities.

And there is an alternative approach. Instead of procuring services commissioners could invest resources, skills and energies into their communities (see figure 2):

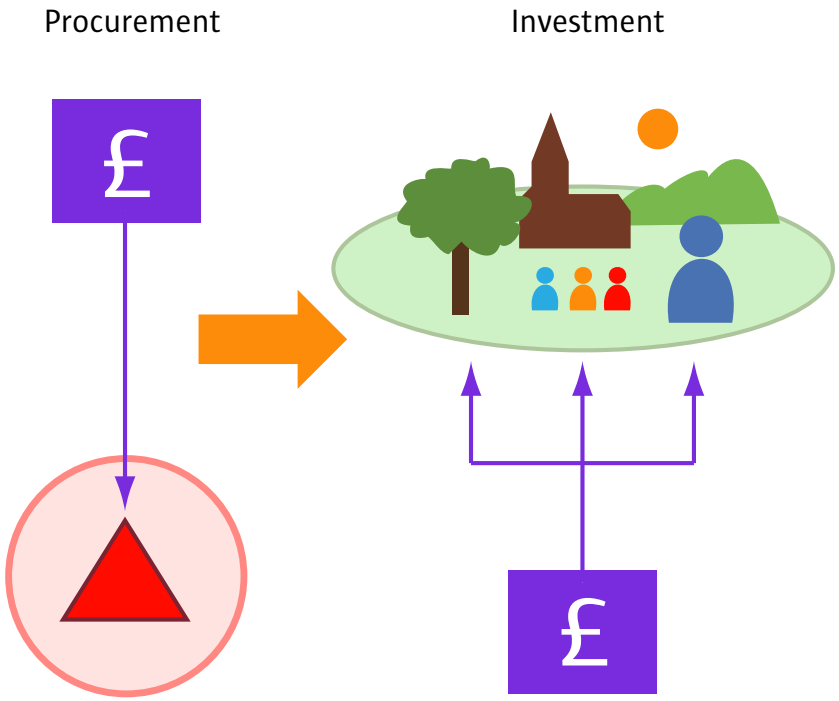

Figure 2 From Procurement to Investment

The challenge is then to rethink commissioning. To be more aware of the different options available for government as it manages its limited fiscal resources in order to make the best use of the community's capacities - in all their breadth and diversity. To ensure that - while staying within the law - government does not artificially close down options by bureaucratic thinking.

So, taking advice from commissioners and experts, the self help groups explored some of the different funding options available.

1. INVEST DIRECTLY IN CITIZENS

One of the most important strategies available is to directly fund citizens to bring about social change. In fact this is exactly what self-directed support should mean - but often it is not treated in this way. If government directly invests in individuals it can avoid undue complexity and get money directly to where problems can be solved. This is not just a matter of using personal budgets or personal health budgets, the same general approach can be used to give small grants for personal or community use.

2. USE GRANTS

Grants used to be a common form of funding for community groups and they are still legal and often very helpful. Small community groups can benefit from low cost grants that help get things moving, help pull in other forms of funding and which can be used flexibly. There does not need to be any expectation that these grants will be renewed, instead they can kick-start change.

3. CREATE A PILOT

Sometimes a new idea benefits from 'pilot status' - to recognise that it needs testing, developing and improving. Don't formalise it within a contract, rather explore how it is best developed. Piloting is a natural approach for working in partnership with community groups. Build into the pilot process the objective of sustainability and the avoidance of bureaucratic tendering.

4. COMMISSION THROUGH COMMUNITY

Community groups themselves can commission services in partnership with government. This may also offer up additional flexibilities and keep decision-making under the scrutiny of local communities. Communities can define both needs and solutions for themselves with officers providing guidance and support. Currently Barnsley is exploring this kind of local commissioning by making a different use of the ward structure for councillors.

5. KEEP CONTRACT VALUES LOW AND BELOW EU LIMITS

Certain processes need to be pursued when contracts are higher than the EU limit (currently 150,000 Euros). However community groups do not need contracts to be rolled into larger and larger sums or to be extend over time. Nor does the law require such an approach (Howells and Yapp, 2013). Instead smaller contracts are more likely to be won locally and to encourage local developments and positive economic multiplier effects to the benefit of the local economy (NEF, 2005). Smaller contracts, over shorter periods of time and with quick start dates will help grow local capacity and strengthen relationships of trust.

6. REDEFINE THE GOAL OF TENDERS

Even when tenders are published over the EU limit it's quite possible for the purpose of the tender to be defined in a way that promotes local purposes and increases the chance that local businesses, community organisations or self help groups will win them or will benefit from any out-sourcing. It is perfectly legitimate for government to prefer bidders who are more likely to improve the quality of the communities social, economic and environmental resources. Again, there is also no reason why local community groups cannot be involved in designing and reviewing these processes.

7. CREATE A JOINT VENTURE

Government is also able to create new organisations - joint ventures - in partnership with local community groups. There does not need to be a complete separation of the government and community - instead they can work in partnership.

8. FOCUS PUBLIC SERVICES ON COMMUNITY

Instead of seeking to endlessly privatise central public services they can be redesigned so that they can either be sold or provided free to local citizens. Many central legal and financial services would be very helpful to community groups. In the same way, open up public and government spaces for the use of community groups. In times of public spending cuts many physical spaces are empty - community groups can occupy and make good use of existing buildings - keeping them safe, well used and open to the whole community.

Community

Overall the critical question is how government thinks about community (and how the community thinks about government). Currently the tendency is for the community to simply be treated as (a) a tax payer and (b) a service user. This is a deeply flawed approach which converts all forms of social value into an economic exchange dominated by the state.

Communities are fundamental to our social well-being. They are not simply an aggregate of tax payers or consumers. Communities create:

- The institutions of civil society that give purpose to our lives: work, worship, play, leisure, art, music, friendship, love... and so much more. All the things that help life have meaning.
- The opportunity to join in, belong and connect to things and people that we value. All the things that help people find love.
- Trust, loyalty and good will within communities. All the things that ensure civility and reduce the need for force and punishment.
- Productivity and all the exchanges that create the economic value upon which taxes and public services depend.

Community depends upon good government, but community is not owned by government. Government exists to serve community. While community needs good public services it does not exist for the sake of public services. Public services exist to serve our membership of community - to support our active citizenship and to further our contribution to community life.

On this basis the prevalent pattern of commissioning - that seems to prefer larger contracts and outsourced provision and which lacks the means to support and sustain community - is toxic. We need a new vision for commissioning.

Our preference must be for:

- **Citizen control** - maximising independence, innovation and flexibility
- **The local and the small** - keeping money, skills and civic leadership close to home
- **Self help and peer support** - growing confidence and relationships, not dependence on systems
- **Trust and flexibility** - lower levels of contractual control and rigidity - higher levels of trust
- **Human relationships** - it is not bureaucracy and formality that strengthens community

Clearly this way of thinking has a relevance that goes far beyond the needs of disabled people and the importance of Centres for Independent Living. However it is also possible

that this different way of thinking is also a better way of thinking about the real purpose of independent living.

Disabled people want to be citizens - they do not want to be cut off from relationships or from community by services that do not value their strengths. It therefore makes more sense to build Centres for Independent Living in ways that reinforce community inclusion and community development. Treating a Centre for Independent Living as yet another public service to be commissioned by government (even if this is done according to all the right rules) seems out of harmony with the deeper purpose of independent living.

Outcomes and Research

Dr Lynne Friedli, an internationally respected researcher and expert on mental health, met with the group to explore the question of how best to find ways of measuring the impact of peer support and self help. She observed how current methodological frameworks were often blind to the value of peer support. As Dr Friedli puts it:

We think because we understand one, we also understand two, because one and one is two. But it is also necessary to understand 'and'.

However working with community groups to develop a better shared sense of what it is important to achieve and how it is being achieved (or frustrated) is possible and should be central to the task of commissioning. Improving the research methodology that should underpin commissioning would be a powerful method for opening up innovation and positive social change

Moving Forward

As ever, when working with dynamic local groups, there is often less interest in theoretical discussions and more interest in what is practical and can quickly bring real benefits. So, naturally, self help groups had some very specific ideas and goals that seem to offer some clear and attractive ways forward.

Here are 12 practical proposals for change:

1. REFORM THE SYSTEM OF SELF-DIRECTED SUPPORT

Doncaster needs to focus on helping people to use self-directed support instead of professionally led services. As one participant said: "back us - not the agencies." This requires important structural reform to local self-directed support systems:

- Include the management costs within people's budgets so that they can choose their own support and there's no perverse incentive not to self-manage. Don't distort the RAS to be biased towards agency services. People using direct payments are entitled to a budget to reflect their need - not a lower budget than someone using services.
- Let people choose their own sources of support for payroll, personnel financial support etc. Leave people free to buy management support from community groups or other local services. Terminate the use of in-house and contracted 'direct payment services' and let Active Independence, SYCIL and others all offer support.
- Ensure budgets are genuinely flexible to encourage pooling, innovation and community development across Doncaster.
- Personal assistants (PAs) should not be forced to work for less than agency staff.
- Let social workers use their judgement and experience to connect people to appropriate support from community organisations, self help groups and service providers (Duffy and Fulton, 2010).

2. DEVELOP INDEPENDENT SOCIAL WORK

Groups like Active Independence and PFG are capable of providing independent social work support to help people with assessments, plans and advocacy. PFG also aims to employ an independent qualified social worker to undertake independent assessments in the local community.

3. PROVIDE BETTER ALTERNATIVES TO HOSPITAL CARE

Provide an alternative to respite and crisis services for people in mental & social distress. PFG believes that it can reduce the use of hospital by offering alternative forms of support in times of crisis. This seems an ideal focus for some pilot work.

4. LET SELF HELP GROUPS COMMISSION ADVOCACY

Advocacy should be commissioned by local self help groups. They are in a much better position to judge quality and value for money than commissioners and they will ensure that services are accessible, local and effective.

5. FOCUS ON LOCAL NEIGHBOURHOODS

Ideas like Local Area Coordination could be developed to keep people part of their communities and out of services. Self help groups could be central to running Local Area Coordination systems (Broad, 2012).

6. COMMUNITY DEVELOPMENT

In some areas, or for some groups, there is no system of peer support and no self help. But the best people people to help facilitate this are people already involved in local groups. Instead of out-sourcing this work it may be best if groups provide mentors and facilitators to help develop other local groups.

In fact recent work by Rotherham Doncaster and South Humber NHS Foundation Trust (RDaSH) and the PFG has recently been features in the recent report Working *Together to Deliver the Mandate: Strengthening partnerships between the NHS and the voluntary sector*. (Addicott, 2013). The report describes how RDaSH and the PFG have been working together to provide informal support to people in the local community to build community resilience. The Trust has provided funding to help with the running costs of a Wellness Centre in Intake which is operated by PFG.

As Chris Hopson, Chief Executive of the Foundation Trust Network says:

> ***We have shown that real benefits for patients and the NHS come from combining and harnessing the expertise and knowledge of the public and voluntary sector providers. These partnerships are being formed up and down the country providing local designed services that respond to local communities' needs.***

7. PROMOTING INNOVATION

If Doncaster wants to promote efficiency, change and innovation it should develop 'Dragon's Den' opportunities to encourage people with new ideas. The Small Sparks system is a particularly powerful low cost innovation (Poll, 2013). Self help groups may contribute ideas, but they should certainly be included amongst the judges - they will be most likely to know what might work.

8. COMMUNITY QUALITY CHECKING

Groups like Active Independence can provide independent checks on the quality of services across Doncaster. It is people who are the best judges of good or poor services and there are well established national systems of quality checking to enable people to do this work well (Cornwall People First, 2013).

9. RESEARCH

It is local community groups that can help government identify needs, measure outcomes and efficiency. The whole process of defining what needs to change in our communities is best carried out in partnership with those communities (Gillespie, 2011). Moreover it is local people who can say best where money is wasted (e.g. drugs bill, crisis service etc.)

10. REFORM THE COMMISSIONING PROCESS

All groups felt that they could work with commissioners better to promote innovation and more community-focused solutions. In particular:

- The language of commissioning should reinforce the fact the money that is being spent is the 'people's money' not 'government money' and people - individually and collectively - should shape how it is spent.
- There should be more room for creative and respectful conversations - officers should not be ostracised by their organisations for talking to community groups. People and government should be on the 'same side'. Relationships should be respectful and positive, not faceless or hostile.
- All contracts and contract values should be in the public domain and citizens should be able to identify and scrutinise decisions made and suggest better alternatives.
- Tenders should not be defined or awarded until every effort has been to explore how to achieve the necessary outcomes through self help or other community efforts. Government should prioritise keeping money, skills and relationship - local.

11. REFORM SCRUTINY AND GOVERNANCE

There should be a radical review of governance structures. Doncaster 50 Plus felt strongly that older people could provide independent scrutiny of council activities - meaning older people would decide things for older people. The voices of people from the community should always be part of planning and decision-making.

12. FORM A DONCASTER COMMISSION FOR SOCIAL CARE

Self help groups could come together with professionals and others to run a collaborative commission to review and reform the social care system in Doncaster.

Doncaster's Innovation Fund

One of the outcomes of the work that led up to this report has been the development of an Innovation Fund which will be used to promote new developments in Doncaster. This model has already been successfully tested by the Personalisation Forum Group who used a small grant to successfully test the development of peer therapy. Andrew Goodall, of Doncaster Council, describes the new fund as follows:

Commissioners from Doncaster Council's Adults Commissioning team and NHS Doncaster Clinical Commissioning Group have developed an Innovation Fund. The Innovation Fund is a model of commissioning that will foster a culture of empowerment and the sharing of decision making with a range of stakeholders.

The Innovation Fund will provide funding options for Third Sector, User Led Organisations, self help groups, communities of interest and community groups to respond to commissioning priorities and test out new ideas. Creative and flexible service delivery and support in community settings will be encouraged and supported.

The Innovation Fund approach will support the development of partnership working and will have a focus on co-production, capacity building and social capital to support prevention, independence and wellbeing as well as piloting new projects that could have longer term effects. The Innovation fund process and its activities are a way of extending the 'offer' for Adults beyond, and as a complement to commissioning by the local authority and the NHS.

Building Alliances

As we explored the meaning of the terms ULO we found ourselves reflecting on an irony. Here were three local self help groups, entirely made up local people, worrying about whether their particular way of working measured up to the Department of Health's 21 Criteria for a User Led Organisation (Department of Health, 2007).

It began to feel as if local community groups had to get a badge from government in order to call themselves a 'User Led Organisation'.

The 'official criteria' certainly describes an interesting and worthy list of characteristics; and there are probably some organisations that meet all the criteria and offer a valuable resource to their local communities. But it is a peculiarly tight and constraining definition - as if every possible positive characteristic had been identified and then added to the list.

This kind of approach creates several problems:

- It puts government in charge of deciding who qualifies as a ULO
- It offers a narrow and bureaucratic definition of a ULO
- It excludes powerful and interesting organisations - e.g. the Personalisation Forum Group began by focusing on mental health - by the strict letter of the criteria it thereby fails to meet criteria described at point six (see page 14).

In fact the reference at point five to "peer-support based" organisations demonstrates a confusion in the whole concept. The category of peer is flexible and defined by each group - but it is limited. It implies 'someone like me' and some common bond around which people meet, help each other and perhaps organise something more ambitious. It cannot be fixed by the system above - it is defined by citizens themselves.

For these kinds of reasons the groups decided to put the 21 Criteria to one side. Their views was that the central challenge was not to define a 'badge' that would then be handed out by government to certain 'approved' organisations. The real value of their work comes from their real activity, experience and engagement with the community - not by ticking off boxes. It was not for the government to 'approve' but for citizens to 'decide' who was a real community group or a real self help group.

For these reasons the best approach for the organisations present was to form a wider alliance of self help groups in Doncaster. In this way, by working together and pooling the intelligences and connections of diverse groups (with their own specific focus) it seemed possible to provide their own legitimacy for their work.

The Doncaster Alliance is now in development and it will be interesting to see whether it can help people provide a better framework for balancing peer support with respect for the diversity of the whole community.

Statement by the DPULO Alliance Doncaster

This new Alliance will provide the opportunity for Disabled Peoples User Led Organisations to work collaboratively to influence and direct positive change to improve the lives of disabled people in Doncaster.

The Alliance has been formed as a result of frustrations that many of our local services have adopted the appropriate language and changed their public image to reflect corporate funding requirements but the reality is that their operations have not changed very much at all. The Alliance promotes true, grass root DPULO development and the right for disabled people to develop and deliver services through their own organisations.

The Alliance will work together to:

1. Promote equality, rights and social justice
2. Ensure the value of peer support is clearly understood and embedded in local services
3. Promote the unique value of DPULOs
4. Work collaboratively to meet real need in our community
5. Challenge discrimination, disadvantage and exclusion
6. Make better use of resources by sharing our skills and talents
7. Promote involvement and disability-led democratic action
8. Provide peer support and advocacy
9. Influence and shape local and national policy
10. Ensure that resources are transferred to DPULOs in order to build capacity and sustainability
11. Empower and resource disabled people to represent ourselves through our own organisations

Our values

Doncaster's DPULO Alliance believes in the social model of disability. This model was developed by disabled people to describe the discrimination they face from society. Instead of explaining limitations by pointing to medical conditions or impairments, the social model highlights that disabled people are disabled by any society that has not planned for their inclusion. Thus, action must be taken to remove these barriers so that disabled people can participate as equals in the full range of community, family, social, educational, political and economic life. In this way, disability shifts from being a private trouble and is identified as a public, social issue: a problem that has to do with the way society is organised rather than with individual deficit.

CONCLUSION

This report has been published at time of severe crisis for public services. Disabled people have demanded more control over their own support, and increasingly this demand is being recognised.

However we also find that funding for these very services is being cut like never before, and there is a continued drive to privatise services into organisations that suck money, skill and leadership out of local communities (Duffy, 2013). So, while the ideas of citizenship and community are being recognised with the left hand, they are also being undermined by the right hand. Instead of increased rights for citizens and stronger local communities we are seeing community and citizenship under attack.

Ideas like personalisation have now become corrupted and offer excuses for further attacks on the welfare state. These problems come into sharp focus when we consider the important challenge of how to commission Centres for Independent Living and User Led Organisations. Quickly we find that well-intentioned public policy comes into direct conflict with other priorities and principles. This report offers a radical new way of thinking about commissioning and the role of the community, and in particular, the role of disabled people in shaping their communities to be more welcoming and vibrant places.

There are three critical points:

1. The failure to implement self-directed support effectively puts at risk citizen control, self-management and ultimately the goal of establishing Centres for Independent Living. Currently the system is often fixed so that the setting of budgets disadvantages those who take more control. Instead of giving people management costs they are expected to use free services from a CIL commissioned on their behalf. This is not only inconsistent, it undermines the interests of disabled people. This is not to say there is no role for direct funding of CILs, but it is to say that stripping resources from those who choose to take more control is wrong.
2. Commissioning needs to be radically rethought. The need to sustain and develop vibrant local communities should be at the heart of our thinking. Instead a mechanical process of privatising services, often to organisations with no roots in our communities, ensures the worst of both worlds: poorer public services and poorer local communities. The idea of Community Sourcing as a key priority for local government may be critical for finding our way out of this mess.
3. Community is not a substitute for public services, but independent community groups are essential to both the quality and defence of public services. One of the grave dangers of commissioning voluntary sector or community organisations to provide services is that they just become another part of the public system and when rights and services are threatened they can no longer come to their defence.

We do not need puppet communities at a time like this. We need local leaders and organisations who are prepared to stand up for what is right, to defend and to rebuild the kind of fair and decent society most of us - disabled people especially - want to live in.

Method

This report was developed from two interactive workshops facilitated by Dr Simon Duffy of The Centre for Welfare Reform.

The organisations involved in the project included:

- Personalisation Forum Group
- Active Independence
- Doncaster 50 Plus
- SYCIL
- Doncaster MB Council

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