



A report on the findings from those who have experienced or are currently experiencing severe and multiple disadvantage on what they would want and expect from a national organisation set up to represent them.

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## Summery

This report has been produced for the Lankelly Chase Foundation by David Ford in conjunction with Homeless Link. The report is based on research completed over a three month period to find out from those who have experienced or are currently experiencing severe and multiple disadvantage what they would want and expect and how this can be supported by a national organisation set up to represent them. The research also looked at the challenges that any new organisation might face in setting out to fulfil the requests from people who experience severe and multiple disadvantage.



Alone we can  
do so little;  
together we can  
do so much.

### Vision.

The vision of Expert Link is to become the main link between peer support groups, peer led organisations and individuals and becoming a national voice for those who are, or have been, marginalised by homelessness, substance and alcohol misuse, re-offending, mental illness. A report commissioned by Lankelly Chase and written by Heriot Watt University estimated that at least 586K are included in this cohort.

The original idea for expert Link came during the initial stages of the Lottery Funded Fulfilling Lives program when David was working with Expert Citizen Groups in both Bristol and Stoke and set up the first National Expert Citizen Group for BIG. The original idea was muted by David to Lankelly Chase at the first Residential of the Promoting Change Network. After a long break the idea was picked up and a proposal was drafted and presented to LCF.

The timing of the idea is ideal. Changes to the role of both the public and voluntary sector will continue at an unprecedented scale with reductions in funding from the public purse, increased innovation from the voluntary sector in response and the likely entrance of new, more activist based, movement into this space (we have already seen examples of this in London, Manchester and Nottingham).

A grant to further develop this idea was awarded by Lankelly Chase Foundation to develop a business case and strategy. We took three areas that they believed to be key for those with direct experience and based their work around these.

- Champion models of expert citizen involvement nationally and locally.
- Influence policy at all levels nationally and locally, as determined by the experience of the group.
- Influence and improve practice by providing simple and smart solutions to problems experienced by people using (or trying to use) services.

## **The Journey so far.**

With the funding from LCF we moved from a concept into a vehicle of exploration, reconnoitring the landscape.

This journey of exploration can be broken down into a number of parts;

1. Preparation.
2. Research and intelligence gathering.
3. David's observations and reflections.
4. Questions for Expert Link going forward.

### **Preparation.**

In order to engage people and provide credibility an online presence was set up describing the project and its links to both the Lankelly Chase Foundation. This consisted of a simple wordpress website, twitter account (now with over 2000 followers) and a face book page.

### **Research and intelligence gathering**

#### **Methodology**

The purpose of this part of the project was to seek the views and opinions that will inform future proposals rather than testing the efficiency of specific involvement models

Using this as a guiding principle a two phased approach was agreed. Survey one consisted of David approaching individuals and groups both in person and via social media to find out what it is that they would want.

A second survey consisted of an online survey filled out by groups and individuals. The purpose of the second survey was to understand the level of support for particular ideas from a wider group of people that can be reached through face to face interviews alone.

#### **Survey 1**



The first stage of the research was to establish what questions Expert Link should ask a wider audience about what they wanted or expected of Expert Link. This was achieved by developing a set of questions that was taken to groups and individuals with experience of SMD and presented to them for discussion

and feedback. The groups were, The Link with 4 attendees, Homeless Links Expert Advisory Panel with 9 attendees (4 of which were HL staff), The IF Group Bristol with 4 attendees, Stoke Expert Citizens with 7 attendees and 1 individual interview.

The questions were.

1. What would you want this umbrella organisation to do for you and other Peer Support Groups?
2. What would it look like?
3. Who should it include or not include?
4. What would it feel like or make you feel like?
5. What should be the key principles and values of this organisation?
6. Do you have any other ideas or comments?

During this process it became clear very quickly that the original concept of Expert Link had missed out one of the most important sets of people in its original planning, those who have been victims of abuse or had experienced trauma, such as ex-service personal who had seen active service, both of which are major contributing causes to SMD. The Expert Link web site and materials were changed to reflect this. *(Appendix 1. The findings were as follows.)*

## Survey 2

It was from the initial round of research that a second survey was developed. The aim of this survey was to test the initial findings by putting the survey out to a wider audience. The survey was compiled by David with the support of the Research Team at Homeless Link. The Coms Team then helped to develop and implement a strategy to promote the survey to its target audience via social media. The survey was also so promoted by David directly to those affected by SMD through contacts and also through Lankelly Chase at their Promoting Change Network residential event.

The three key questions and answers to them are as follows;

<b>Which of the following issues do you have experience of [please tick all that apply]</b>		
<b>Answer Options</b>	<b>Response Percent</b>	<b>Response Count</b>
homelessness	80.5%	70
alcohol or substance misuse	71.3%	62
offending	48.3%	42
mental health	75.9%	66

victim of abuse or domestic violence	44.8%	39
other [please specify below]	5.7%	5
Other (please specify)	16.1%	14
<b>answered question</b>		<b>87</b>
<b>skipped question</b>		<b>1</b>

Please note that other [please specify below] and Other [please specify] are a duplication. The responses that we received in those questions totalled 19, however on breaking them down there were only 14 respondents. 5 had no direct experience if SMD, 2 also had physical disabilities, 2 had also suffered trauma, 1 answered *Mental health*, 1 answered *All at once several times*, 1 answered *Victim of sexual violence*, 1 answered *LGBT needs and service use*. One response sadly, illustrates the complexity faced by many. She wrote



*“I’ve had my children taken from now and have been asking begging for help for years local authority and solicitors have not because of legalities and court orders due to my violent ex manipulating and abusing us through courts I’m now at my; lowest and being accused of being violent exposed to infection hep and HIV AND ANTISOCIAL WHILST LIVING MY HELL AND ALL I*

*EVER ASKED WAS FOR HELP”*

**Which of the following statements do you think best describes how Expert Link could make the difference to you? [Please tick up to four options]**

<b>Answer Options</b>	<b>Response Percent</b>	<b>Response Count</b>
An organisation that could share best practice and provide training for peer led groups	47.6%	40
An organisation that helps peer led groups share their experiences and set standards for how best to work together	52.4%	44
An organisation that helps peer groups to campaign and influence politicians and local decision makers	48.8%	41
An organisation that makes sure services are	70.2%	59

designed with people who have lived experience		
An organisation that raises public awareness of the issues people face and challenges the stigma and perception of people with support needs	65.5%	55
An organisation that helps people to access good services and encourages services to work together and provide support in a more joined up way	66.7%	56
<b><i>answered question</i></b>		<b>84</b>
<b><i>skipped question</i></b>		<b>4</b>

**We want Expert Link to reflect the people who are members. Which of the following statements best complete this sentence for you "For Expert Link to represent me it must...???" [please tick up to four answers]**

<b>Answer Options</b>	<b>Response Percent</b>	<b>Response Count</b>
Make sure everyone is listened to and treated equally	62.2%	51
Be open about what it does and why	42.7%	35
Be committed to helping me share my experience and views so that others can learn from them	40.2%	33
Focus on practical actions that can make a real difference to the support people get	56.1%	46
Never give up on people	48.8%	40
Look at all the problems people face together not just one at a time	43.9%	36
Accept me for who I am without judgement and respect my views	53.7%	44
<b><i>answered question</i></b>		<b>82</b>
<b><i>skipped question</i></b>		<b>6</b>



Those who responded to the survey represented a total group of 4773 people from across the country. The areas from which they came were, Liverpool, London, Cambridge, Southampton, Glastonbury, Birmingham, Canterbury, Nottingham, Salford, Hartlepool, Sheffield, Stoke-on-Trent, Newcastle, Sunderland, Middlesbrough, Little Hulton, Merseyside, Manchester, Birkenhead, Blackpool, Croydon, Isle Of Wight, Salford, Bristol, Wolverhampton, Peterborough, Edinburgh, Tameside, Great Yarmouth, Bury and *Homeless*.

The groups that responded included Two Saints, Salford Dadz, Addaction Blackpool, Noah Enterprise, Community Led, with a number remaining anonymous.

Some individual responses came from within organisations including, Tower Hamlets Council, Evolve Housing, IF Group, Winter Comfort, Connect Centre, Chapter One, Catching Lives, Opportunity Nottingham, Riverside, We Are Street Life, The Big Issue North, PHP, SHP, Groundswell, Bristol Reconnect, EHLF.

### **Promoting Change Network**

**Lankelly  
Chase**

The LCF Promoting Change Network residential formed a key part of the research. It gave David the platform to promote and discuss Expert Link, afforded the opportunity for him to forge and develop relationships with others and gave space and time for him to discuss issues and challenges that Expert Link may need to overcome in the future, including a number of discussions based on evidencing what Expert Link does and its achievements.

Crucially the PCN allowed the time and space for creative thinking in group settings and it was within one of these settings that David came up with the idea for a campaign and a call for action with the hashtag #thewealthwithin. The call would shift

the emphasis from the negative behaviour patterns and the labelling of people suffering from SMD onto the positive attributes and skills that people possess. One of the conclusions from the PCN was that #thewealthwithin would be developed with Expert Link taking the lead role. Taking the lead in the campaign would help to promote and raise the profile of Expert Link, helping it to reach a wider audience.

Following on from the residential David visited Opportunity Nottingham to attend the regular National Expert Citizens Group meeting, attended Voices of Experience annual conference in Stoke and had a meeting with the Chair of the Fulfilling Lives NECG and the CEO of Insight where support for Expert Link was positively discussed.

### **Advisory Panel**

David has set up an Advisory Panel made up from those with lived experience with the purpose of helping guide Expert Link through the planning and development stages as it grows. For Expert Link to grow and develop it is essential that it does not belong to and reflect the views of David but rather belongs to and reflects the views of all those who have suffered SMD. The Panel will act as a “critical friend”, ensuring that the views of those with lived experience have been fully listened to and that those views have had full consideration in the development of Expert Link’s strategy, also ensuring that Expert Link upholds the values set out by those it represents.

The Panel was made up of 6 people from around the country that represented a cross section of the SMD community at differing stages of their journeys. It also encompassed all of the challenges that the community faces.

At the panels first meeting they were presented with the findings of this report which they unanimously supported. They also whole heartedly supported the outline for taking Expert Link forward, which includes the #thewealthwithin campaign.

### **David’s Observations and Reflections**



During the process of completing the research there were a number of observations that David made that should be noted.

Once the opportunity to talk about Expert Link was afforded, the ideas and concept behind it were met with great enthusiasm and with a willingness to get involved. The keenest of the groups were those working in local areas only.

When making initial contact with groups through their hosts or providers, it appeared that sometimes they [hosts or providers] were overly protective when the group that they supported were or had been particularly vulnerable or had been subject to abuse.

It is important to try and understand the dynamics of peer led groups and organisations particularly where strong individuals have taken a lead role and find it difficult to see being part of a wider network.

We need to pay more attention to the fact that change, even when wanted or desired, can cause anxiety and fear for both service providers and users alike.

Whilst most organisations are supportive and willing to engage, they often lacked the resources to do so. Often the pressure and constraints around time made action very difficult.

The resources of those whom Expert Link aims to represent can be limiting. Direct access to technology and the skills and confidence to use them can be a challenge for some. Most also have skill sets that have been developed to seek reward for short term needs and where actions speak much louder than words.

### **Questions for Expert Link going forward**

When we reflect on the answers to both of the surveys and thinking about how to take Expert Link forward, there are a number of questions that arise. This is by no means an extensive list, however if we can answer these questions then we will be meeting the “asks” of those who took part in the surveys.

*How is Expert Link going to develop their brand and draw people to the organisation?*

*How is Expert Link going to develop a funding strategy to ensure that “It is sustainable and shows commitment”?*

*How do we support dialogue and learning between different peer lead groups, organisations and individuals?*

*How do we resource peer lead users groups and organisations to understand what they want and how to get it?*

*How do we support dialogue between those with lived experience and the commissioners, designers and deliverers of services?*

*How do we change public perceptions of severe and multiple disadvantages and reframe it so that it reflects the talents and skillsets of individuals?*

*How do we ensure that those who have or have had SMD are afforded the opportunity to recognise their own talents and skill sets?*

## Appendix 1

The findings from survey 1 where as follows:-

### What would you want this umbrella organisation to do for you and other Peer Support Groups?

Should be a lobbying organisation

Should ensure that Expert Citizens are engaged with the process

Should ensure that there is no commissioning without EC engagement

Should share information and modals of excellence

Should educate Health Trusts and Local Authorities [National Government] on reality

Should offer support up for groups and support for the supporters of groups

Promote the best of what there is out there

Members should adhere to a set of guidelines and rules

Membership to a guild of Peer Support Groups.

Should hold National Conference

Promote assets of people with lived experience

Focusing on needs of people

Code of practice for Peer Support Groups.

It should stop homelessness

It should get more help for victims of abuse

It should get more help for vulnerable people

It should help people with counselling and psychology

It should help services.

It would be useful to have a joint voice from all peer support groups that was able to talk to politicians and influence policy through their experiences

We would like it to play a role in helping people access good advice and services from one place

We would like the organisation to help join-up services in a more holistic approach. This would replace the disjointed way people access services at the moment.

It should share experience and best practice.

Groups should be able to learn from each other.

It should support groups with any challenges.

It should help train and upskill people so that they can manage/run/facilitate peer support groups.

It should lobby on behalf of the community

It should tackle stigma

It should deliver peer led training

It should have a kite mark that groups and organisations can become affiliated to that Authorities and providers recognise as a standard that they can trust.

#### What it would look like?

Should have formal structure and substance

Should be easy to access

Should have form.

Should have a board

Should be sustainable

Should have subgroups that specialize

Should not rely totally on social media

Answerable to something/body

#### Who should it include or not include?

Should be fully inclusive to all with "internal support needs" [ie not physical]

Should be fully inclusive.

It should work with everyone.

It should work with prisoners, domestic violence victims, care leavers and the military.

It should include people with depression.

It should be an inclusive group that doesn't give up on people.

It should be as inclusive as possible.

What should be the key principles and values of this organisation?

Respectful and non-judgemental

It should be sustainable and show commitment [demonstrating that complete recovery is possible]

Should be Empowering

Should never give up on people

Do no harm.

It should be inclusive

It should be holistic

It should be solution focused

It should be long term

Be informative

Be transparent

Be Inclusiveness,

Be Authentic

Be Transparent

Have Equality.

Any other comments?

When will it get going?