



## **The Value of User-led Groups Event A dialogue between user-led groups and funders**

**Tuesday 21 May 2019, 10am – 12.30pm**

### **Introductions to the day**

Lankelly Chase, NSUN, and Shaping Our Lives introduced the day by sharing some of the reasons why they felt it was important to hold such an event.

These included:

- Membership groups and networks reporting the increased number of user-led groups closing.
- Raising awareness of the crisis and the challenges user-led groups are facing.
- The need to work together to gather evidence on why this is happening and to find some solutions.
- The social impact these closures are having on people experiencing hardship.
- To understand what else might be emerging in this space and promote equality of voice

The day was facilitated in order to create a space for dialogue and sharing our views and experiences.

This report begins with the summary of the key discussion points under four key themes, and the appendix outlines the discussion points leading to these themes.

### **Summary of tabletop bucket lists**

**Key themes emerging from the discussions were:**

1. **Partnership working between user-led organisations and funders** - changing the power relationship, values and relationships, learning about each other.
2. **Capacity and resources** - funding approaches (including recognising the cost of inclusion of d/Deaf and disabled people), building capacity in user-led organisations.

3. **Standards** - raise awareness of the standards and principles of inclusive user involvement.
4. **Social change** - shared objectives, promoting leadership and challenging barriers.

**Actions and ideas from the tables have been organised under the four themes.** The table invites attendees to take ownership of their ideas and actions points and confirm their intention to be a lead / sub group member.

**1. Partnership working between user-led organisations and funders** - changing the power relationship, values and relationships, learning about each other.

**Ideas and suggested actions:**

- Regular joint forum/network meetings
- Joint communications, raising awareness
- Mentoring and secondment opportunities
- Dedicated support and funding for ULOs
- Discreet funding for development opportunities
- Development of strategic relationships between funders and ULOS
- Joint research and campaign network

**Next steps - Lead and sub-group members:**

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**2. Capacity and resources** - funding approaches (including recognising the cost of inclusion of d/Deaf and disabled people), building capacity in user-led organisations.

**Ideas and suggested actions:**

- Crowd funding (from established funders) for capacity support
- Ring-fenced assets for ULOs
- Raising awareness of access costs and setting principles (not a project cost but an essential overhead)
- How do we measure and evaluate outcomes of inclusive involvement and user-led work
- Address working with BAME ULOs and the most marginalised and under-represented groups
- Promoting large provider organisations commissioning user-led groups to deliver involvement of d/Deaf and Disabled People
- Work with non-user-led organisations to develop ethical policies and practice to encourage supportive working with ULOs
- Application processes and capacity building within user-led

<p>organisations</p> <ul style="list-style-type: none"> <li>• Re-defining risk</li> <li>• Fund legal support and challenges and mediation</li> <li>• Pooled resources between funders to provide access to support for ULOs to make applications</li> <li>• Support pooling of resources for technical help between ULOs, e.g. HR, fundraising, communications etc.</li> </ul>
<p><b>Next steps - Lead and sub-group members:</b></p> <ul style="list-style-type: none"> <li>•</li> </ul>
<p><b>3. Standards</b> - raise awareness of the standards and principles of inclusive user involvement.</p>
<p><b>Ideas and suggested actions:</b></p> <ul style="list-style-type: none"> <li>• Using user-led resources widely in funded work such as 4Pi model, Shaping Our Lives guides to inclusive involvement etc.</li> <li>• Promoting adherence to user-led standards to other funders and provider organisations</li> <li>• Co-produced national standards/charter</li> <li>• Joint approach to evaluating user involvement</li> <li>• Education and awareness building</li> <li>• Best practice examples</li> </ul>
<p><b>Next steps - Lead and sub-group members:</b></p> <ul style="list-style-type: none"> <li>•</li> </ul>
<p><b>4. Social change</b> - shared objectives, promoting leadership and challenging barriers.</p>
<p><b>Ideas and suggested actions:</b></p> <ul style="list-style-type: none"> <li>• Independent representation, mentoring and mediation by funders between user-led groups and other funders such as local government</li> <li>• Recognition, support and investment in user-led research</li> <li>• Building trust and respect of user-led perspectives</li> <li>• Developing leaders</li> <li>• Strategies for combatting power imbalances</li> <li>• Defining and supporting social change by user-led groups</li> <li>• Inclusion of user-led organisations as a recognised and critical sector (e.g. in NCVO Almanac)</li> </ul>
<p><b>Next steps - Lead and sub-group members:</b></p> <ul style="list-style-type: none"> <li>•</li> </ul>

## Appendix

The facilitators explained the purpose of the day as creating a space for dialogue and sharing our views and experiences.

The following aims to capture the overview of the first section of the morning

Ground rules for the session were discussed with an emphasis on creating a safe and open space, to be in a listening and building mode and assuming good intent.

The session started with people having discussions within their user-led groups' and funders' 'camps' about the current state - responding to the following questions:

1. What do you most care about?
2. What is challenging?
3. What support or understanding do you need from the other group?

### **Some initial points raised in the large group included:**

- There needs to be a network for ULOs like the funders' network
- People left without any care or support is putting more pressure on GPs, leading to more hardship, homelessness, loss of benefits or ending up in prison. It's a false economy!
- Less support in the community as user-led groups disappear
- Social and political issues and hostile attitudes are having an impact
- Groups are often cut off from each other and have limited capacity to participate
- Trusts and larger charities often working in conflict and competition with user-led groups; there continues to be a bias towards bigger non ULO organisations in the distribution of funding
- User-led groups compromised or punished (withdrawal of funding) if unfavorable reports are produced or they speak out against other organisations or bodies
- Groups are often cut off from each other and have limited capacity to participate
- ULOs have changed and saved people's lives

## **Feedback from the funders' camp**

### **1. What do you most care about?**

- Redressing the power imbalance
- Money being used most effectively
- Meeting need and positive social change
- Reaching marginalized / overlooked communities
- Involving people to help make the right decisions
- What has led to the decline of ULOs?
- Equality of voice – race equality organisations aren't led by white people so why are disability organisations led by non-disabled people

### **2. What is challenging?**

- Knowing that there are fewer opportunities and routes to funding for ULOS
- The amount of energy and strength needed to create system change around extreme disadvantage
- Feeling conflicted and guilty about the power funders hold
- Some funders having a paternalistic attitude
- Increasingly funders have their own funding agendas or strategies rather than being able to respond to the concerns of ULOs and service users
- The restrictions within some organisations and how decisions are made
- Equality of voice – Race equality orgs aren't led by white people so but disability organisations led by non-disabled people

### **3. What support or understanding do you need from the other group?**

- Changing the perception of limitless funds
- Understanding the limitations and the position of funders in awarding and declining funding
- Help from ULOs to reflect on whether funders include enough about the values of being user-led in assessment criteria – is it being valued and reflected enough? Is there equality of voice?
- Help from ULOs to decide what funders' priorities should be

## **Feedback from the user-led groups' camp**

### **1. What do you most care about?**

- Care about humanitarian issues – people on the ground – losing benefits, homeless etc.
- Fighting for our rights
- Appropriation of language, not authentic – peer support, recovery, user-led, co-production etc.
- People should be allowed to speak for themselves – e.g. when the views of people with learning difficulties are needed people go to non-user led organisations.
- Being as effective and impactful as possible – being unique and transformative

### **2. What is challenging?**

- Larger organisations competing with ULOs or being hostile towards them, there's a real power imbalance
- Having to tell people and organisations things they don't want to hear – often the results of our work aren't published
- Punitive approach to anyone who speaks out.
- Harder for ULOs to prove effectiveness and their worth – time constraints and capacity
- Harder for ULOs to gain visibility, for example, in the media and with policymakers
- The business side of things – don't always have the level skills and experience funders expect
- Cost of providing accessibility e.g. for D/deaf people
- Frustration at lack of community (ERT) representatives
- The conflicts of interest between being a provider and being a ULO.

### **3. What support or understanding do you need from the other group?**

- Funders really understanding what the unique role of ULOs is
- Funds being applied equally
- Feedback – knowing what funders learn from our reports and what they're going to do with the learning
- Joint learning across funders about some of the issues and how they can feed these back to government
- A shared understanding of how complicated and difficult things are for ULOs

- An understanding of discrimination from our perspective and the action needed to combat it.
- Recognition that rights have always had to be hard fought – ULOs are in best position to do that but need support and funding.
- Accessible application processes with support available if required
- More realistic timescales for funding applications and reporting requirements.
- Help from funders to connect ULOs across regions and across the country.
- Crowd funding system for funders to provide for everyday operation of ULOs.
- Encourage their larger funded charities to help ULOs with funding applications etc. This used to happen but not so much anymore.
- Exchange programmes

**Some further comments from the larger group:**

- Are funders trying to change (disadvantaged or tainted) people or the conditions that affect them? Turning people into normal people potentially takes them away from their community
- It feels like after making progress over the years we're now regressing
- ULOs are sometimes told they are not professional enough, the other times they're too professional – not representative of the let person
- Non-user-led organisations appropriating the language, space and approaches of ULOs – blurring the boundaries and understanding of the difference and not always demonstrating the best practice!