



Centre for  
Independent  
Living CIC

## **How can ULOs meet the different needs of Carers and Disabled People?**



## Aim of document:

- How Can ULO's meet the different needs of Disabled People and Carers? A research based project to understand how ULO's can develop a bettering understanding of the needs of Disabled People and the needs of Carers; and from this decide if and how they should support these different groups of people. The toolkit proposes a number of methods that this can be achieved.

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### **Acknowledgement:**

We would like to thank SPIRIT (Southampton Platform for inclusive Research and Ideas Together) at University of Southampton for their support to update our toolkits.

<https://spiritdisabilityplatform.wordpress.com/>



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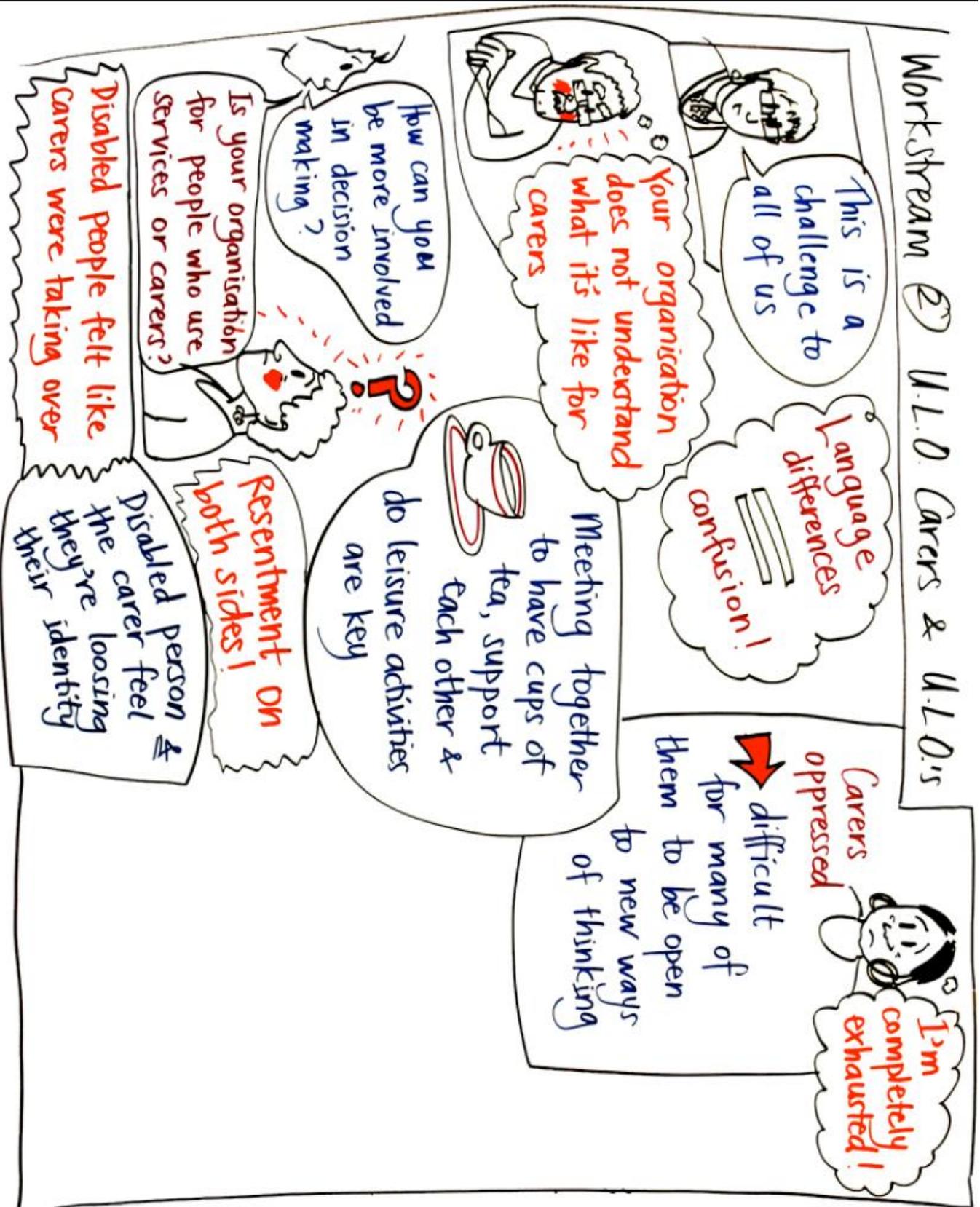
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### **Appendices:**

1. Copy of questionnaire we developed



# Graphic Executive Summary



# 1. Introduction:

## 1.1 Aim of project:

User Led Organisations are committed to supporting Disabled People to have choice and control in their lives and to be empowered to be active citizens within the community. However, the issue of supporting Carers in a Disabled People's Organisation is often a controversial subject.

The difficulty stems from the fact that the needs of Disabled People & the needs of Carers can be very different and lead to conflicts of interests. (see example box 1)

These difficulties have resulted in some ULOs (like SPECTRUM Centre for Independent Living) deciding not to directly peer support Carers and therefore remove any potential for conflicts of interest.

**Box 1: Example of potential for conflict:**  
A Carer might have a need for a 'respite' break and ask for the Disabled Person they care for to go into a care home for 2 weeks. However, the Disabled Person might not want to go into a care home because it would compromise their ability to work. In this scenario, whose needs get met? How would a support organisation deal with the unavoidable conflicts of interest? Let alone deal with the philosophical dilemmas of an organisation committed to promoting the rights of Disabled People?

However, the ULO Design Criteria suggests that ULOs should support both Carers and Disabled People. Local Authorities often issue tenders which require the bidding organisation to support both Carers and Disabled People.

The aim of this toolkit is to provide information and guidance to ULOs to help enable them to decide how to respond to these difficult dilemmas. There is no universal 'right' or 'wrong' solution and different ULOs are likely to decide on different solutions after they have weighed up the 'pros' and 'cons' and issues relevant to their organisation. This toolkit was developed as a result of research carried out with Carers, Disabled People and their organisations.

This toolkit was developed by SPECTRUM as part of our work for the Department of Health to support ULOs to build their sustainability. This Action and Learning project enabled SPECTRUM to investigate our issues and attitudes towards Carers in the development of this toolkit; and to help us decide how best to work with Carers in the future.



## 1.2 Methodology:

This toolkit was to be one of 7 different toolkits developed by SPECTRUM to help us improve our sustainability as a ULO whilst at the same time helping and guiding other ULOs to learn from our experiences. SPECTRUM's Project Manager for all 7 ULO toolkits defined what was expected as a result of this work (box 2), and allocated approximately 70 hours for the work to be completed in. The Project Manager then asked existing SPECTRUM staff to express an interest in doing a toolkit, the aim being to provide an opportunity for staff to do something different, and gain new skills and experiences in the process. SPECTRUM expected these new skills and experiences would improve its sustainability.

Berni Vincent, an experienced Support Worker, was selected to manage and produce the toolkit.

The following methodology was developed. This enabled us to develop a work plan for this project to ensure the project was completed successfully and on time:

### Actions/Methodology for work:

- Study and understand the task (see Box 2 [the task] and section 1.1 of this report [aims of project])
- Develop a proposal, based on the task, to develop a toolkit; detailing aims, objectives and outcomes (see appendix 1)
- Define what we mean by 'Disabled Person' and 'Carers' (see section 2.1)
- Draw up a checklist of key cultures and values (see section 2.2)
- Consider best consultation methods (see section 2.3)
- Design Questionnaire/ Focus Group Topics (see section 2.4)
- Identify relevant target groups, organisations and individuals to research (see section 2.5)
- Send out questionnaires / Attend focus workshops to hear views
- Analyse findings and statistics appropriately
- Use results to design toolkit
- Present findings (This toolkit), with SPECTRUM recommendations

### **Box 2: The task:**

Define a model of a Disabled People's organisation working successfully with user-led carers organisations, as a consortium partner (based on SCIL's evolving experiences); to ensure the different needs of Disabled People and Carers are identified and met.

- This will include an explanation of the common & different perspectives, needs and aspirations of Carers, Disabled People and other people.



## **2. Definitions Used**

In this section we have described the definitions and other decisions that we made to ensure this project had a clear understanding of what it was doing, why it was doing it, and how it should do it!

### **2.1 What do we mean by ‘Disabled People’ & ‘Carers’?**

When we say ‘Disabled People’ we refer to the Social Model of Disability. The Social Model is rooted in inclusion and equality principles; it looks beyond a person’s impairment and asserts that discriminatory barriers need to be removed to enable equal participation in society. Our definition of ‘Disabled People’ is therefore non-impairment specific and non-age specific; and includes Older People, people with physical, sensory and hidden impairments, people with learning difficulties, people with mental health difficulties, people surviving cancer and people with HIV/AIDS. Our definition is therefore much wider than that used in the Disability Discrimination Act.

When we say ‘Carers’, we mean someone who provides help and support to a partner, child, relative, friend or neighbour who could not manage without their help, in a generally unpaid capacity. This could be physical help, for example to overcome physical barriers that restrict access like a lift to the doctor. Or it could be practical help for example, with paying bills and rent. Or it could be emotional help for example with providing opportunities to meet friends if a person is lonely. These could be due to the challenges that disabled people face in trying to live independently and overcoming barriers..

### **2.2 Key cultures and values**

User Led Organisations (ULO’s) are based on equality and inclusion. They are membership organisations run and controlled by Disabled People and committed to campaigning for the full civil and human rights of Disabled People.

### **2.3 Deciding which consultation methods fit the research proposal**



After looking at the task, and taking account of the limited time available, it was decided that a questionnaire would be the best method to get feedback from Carers, Disabled People and relevant organisations. A small number of focus groups were also held to encourage more people to complete a questionnaire.

## 2.4 Designing the questionnaire/ focus group topics

The design of questionnaires is a skill and an important aspect of any research project. A badly constructed questionnaire can lead to biased or misleading results. For this project, we developed 8 questions which were designed to obtain views on the issues that we considered important aspects in the debate about how ULO's meet the needs of both Carers and Disabled People.

What follows is a list of the questions we decided to ask, and the reasons why we felt the question was important:

### Q.1 Is your organisation for Disabled People or for Carers?

*This was asked in order to establish which if replies were coming from the perspective of Carers, Disabled People or from Organisations. This would enable us to analyse the results to understand if these different groups had different views.*

### Q 2 Does your organisation actively involve service users in company decisions?

*This was asked in order to find out if organisations were run by their membership/users, and analyse is they had different views to non-ULO's*

### Q.3 Does your organisation actively pursue the involvement of service users from minority groups?

*This was asked to establish if inclusion was active and effective and whether or not they understood the potential for different cultural perspectives on the role of Carers.*

### Q.4 Does your organisation routinely evaluate the work of the organisation?

*This was asked to find out if organisations understood the purpose of being regularly assessed by those who used the service, and whether or not organisations had systems for understanding issues and concerns from the user base.*



Q.5 Would you say your policies and procedures encourage honesty and mutual respect?

*This was asked to in order that organisations recognised the principles of Equality and Inclusion and enabled users to raise issues that maybe uncomfortable or different to the views of the organisation.*

Q.6 From your perspective please describe the tensions that can be caused by the different needs of Disabled People and Carers?

*This was asked in understand what the issues are which cause friction between Disabled People and Carers, and where the difference in needs or wishes may lead to potential conflicts of interests. Support and service organisations will need to find ways of meeting resolving these issues if the needs of both Disabled People and Carers are to be met and in order that the philosophy of Choice and Control was maintained.*

Q.7 In your view what are values of your organisation?

*This question was asked to determine where the difference and similarity of values and principles between organisations.*

Q.8 How do you think Disabled people and Carers organisations can best work together in the future?

*This question was asked to identify common themes and opportunities for joint working.*

## **2.5 Identifying target groups, organisations and individuals to research**

We selected a sub-set of SPECTRUM members and a sub-set of local Carer-led organisations to send questionnaires to. In addition we sent questionnaires to a number of organisation in our local area who we know support Disabled People, Carers or both.



### 3. Toolkit

This section is provided in a checklist format which we hope will help enable ULOs to decide how they work with Disabled People and Carers organisations.

This checklist recognises that different ULOs will need to develop different solutions to suit their circumstances. This checklist asks searching questions to ensure ULOs properly consider the strengths, weaknesses, opportunities and threats (SWOT) in either working or not working with Carers.

However, this checklist is not intended to be definitive. You are encouraged to think of other considerations that are relevant to your ULO.

The checklist refers to definitions as developed in section 2 of this report, as well as the detailed findings in section 4 which resulted from the questionnaires and focus groups we used as the basis of our research.

Key Issues	Questions to ask
<p><b>Who the ULO is for.</b></p> <p><i>See definitions section 2.1</i></p> <p><i>See Detailed findings section 4.1</i></p>	<p>Does your Governing document restrict who your beneficiaries are? Will the interests of your beneficiaries be compromised?</p> <p>If your ULO is set up to represent the views or interests of a particular group of people, how do you know what they think in respect of working with Disabled People and Carers?</p> <p>What evidence or concerns or opportunities have you identified to enable an informed decision to be made?</p>



Key Issues	Questions to ask
<p><b>What the identity, aims, culture and values of the ULO are</b></p> <p><i>See definitions section 2.2</i></p> <p><i>See Detailed findings section 4.7</i></p>	<p>Does your ULO have an identity? (i.e. as an organisation run by Disabled People, fighting for rights and independence for Disabled People). Would your identity or the sense of belonging that members have be affected by working with Carers? If so, how best might this be mitigated?</p> <p>Examine your aims and objectives. Do they lend themselves to working with Carers or could your aims be compromised?</p> <p>What is your ULO's culture? Could your culture make it difficult to work with Carers?</p> <p>What values does your ULO hold? List them down. What positive and negative effect could working with Carers have to these values?</p>
<p><b>How service users are involved in ULO decisions</b></p> <p><i>See definitions section 2.3</i></p> <p><i>See Detailed findings section 4.2</i></p>	<p>Who runs your ULO? What do these people think about working with Carers? What information on the positives and negatives do they have to make an informed decision?</p> <p>What do your other stakeholders think? (i.e. staff, service users, volunteers, funders)</p> <p>If you have different opinions from different stakeholders, how can you resolve these? Is there a compromise? Or would a compromise cause difficulties for the ULO?</p>
<p><b>Involvement of minority groups</b></p> <p><i>See definitions section 2.3</i></p> <p><i>See Detailed findings section 4.3</i></p>	<p>Is the ULO's relationship with or without Carers a threat to the interests or culture of any of the minority groups you work with, or seek to work with?</p>



Key Issues	Questions to ask
<p><b>How you evaluate your work</b></p> <p><i>See definitions sections 2.4 &amp; 2.5</i></p> <p><i>See Detailed findings section 4.4</i></p>	<p>Do you have any evidence from your evaluations which are relevant to whether or not you should work with Carers?</p> <p>If not, have you considered consulting with your service users and other stakeholders on the issue?</p>
<p><b>Dealing with honesty &amp; mutual respect</b></p> <p><i>See definitions section 2.2</i></p> <p><i>See Detailed findings section 4.5</i></p>	<p>Honesty, openness, integrity and respect are obviously important factors to any organisation. If Disabled People and Carers have different needs and views, do you feel these compromise these factors?</p>
<p><b>Identifying tensions between needs of Disabled People and Carers</b></p> <p><i>See Detailed findings section 4.6</i></p>	<p>What work have you done to understand what difficulties or tensions can exist between the needs of Disabled People and Carers?</p> <p>Are there other ULOs similar to yours that may be able to discuss their experiences and their solutions?</p> <p>Are there Carers organisations you can talk to, to get their perspective?</p>
<p><b>Identifying any opportunities from Disabled People and Carers working together</b></p> <p><i>See definitions section 2.5</i></p> <p><i>See Detailed findings section 4.8</i></p>	<p>Have you identified positive reasons or opportunities that exist for working with Carers?</p> <p>List these opportunities – are there different ways of taking advantage of these opportunities? Might an alliance between different organisations help your ULO develop new opportunities that would not exist on your own?</p>



Key Issues	Questions to ask
<p><b>Identifying other relevant organisations which exist in your area</b></p> <p><i>See definitions section 2.5</i></p>	<p>All areas have different organisations and influential/powerful stakeholders that can make a big difference to the decision that you make. Do you know who these are? do you have friends or enemies? Should they influence your decision?</p> <p>Are there organisations in your area that already work with Carers or who are run by Carers? What do they think? Could a partnership between different organisations work better than your ULO trying to support Disabled People and Carers?</p>
<p><b>Identifying an model of meetings the needs of Disabled People and Carers, appropriate to your situation</b></p>	<p>There are many different ways of meeting the needs of Disabled People and Carers. Which is the best solution for your circumstances?</p> <p>The following are examples of solutions- Are any of these suitable for your ULO?</p> <p>One organisation supporting Disabled People and Carers equally – no issues of conflict of interest identified</p> <p>One organisation supporting Disabled People and Carers, but issues of conflict of interest have been identified, therefore you decide to have two teams, one supporting Disabled People and the other supporting Carers</p> <p>You identify a pre-existing organisation of Carers (or supporting Carers) and develop a partnership working agreement to enable your ULO to meet the needs of Disabled People and the other organisation to meet the needs of Carers. You have developed methods of referring between both organisations.</p> <p>There is no pre-existing organisation of Carers, but your ULO does not feel it appropriate to support Carers. However, you have identified a</p>



**Key Issues****Questions to ask**

small group of Carers who are keen to develop a Carer-led organisation. You agree to support this organisation to develop, and develop working arrangements to facilitate its development and funding.

You decide that it is inappropriate for your ULO to support Carers and decide simply to make it clear to stakeholders that your sole aim is to support Disabled People and represent their views.



## 4. Detailed Findings

This section provides information about what we found out from your questionnaires and focus groups. This has enabled SPECTRUM to feel better informed about the views of Disabled People, Carers and organisations concerning how we should work with Carers in future.

We refer to these findings in our toolkit in section 3. Your ULO may find this section a useful way of developing a better understanding of the issues associated with supporting Disabled People and Carers.

We received 30 responses from our questionnaires and focus groups. We received responses from 7 organisations, 11 from individual Carers and 12 from individual Disabled People.

These responses were analysed to develop a toolkit to help ULOs decide the best way of providing support for Disabled People and for Carers, taking into account the aims, values and culture of the ULO in question.

It is clear from our research that the values and culture of a ULO are critical factors in making these decisions, and that different ULO's may well make different decisions based on these factors.

### 4.1 Deciding who the ULO is for

	Organisations	Disabled People	Carers
ULO should be for Disabled People	1	6	1
ULO should be for Carers	3	1	4
ULO should be for both	3	5	5

Our research showed that organisations, Disabled People and Carers had a real mixture of opinions. This we feel reflects a confusion of the



identity and who the organisation should be for, and who should be involved in running a ULO.

What is clear though is that Disabled People generally did not see the need for Carer led ULOs and Carers generally did not see the need for Disabled Person led organisations. Feedback reflects a general lack of understanding of the needs of groups and individuals (i.e. Disabled People not understanding the needs and barriers of Carers)

A ULOs Identity and ownership may be compromised or unclear by trying to become one organisation which tries to support / represent all everyone.

ULO's which have values that include being run by the people they serve, may struggle to reconcile different camps in Disabled People and Carers.



## 4.2 Involvement of service users in ULO decisions?

	Organisations	Disabled People	Carers
Yes, service users are involved	7	10	7
No, service users are not involved		2	2
Don't know			1 (How?)

Our research shows that, in the main, organisations and their users feel that the organisation involves users in decision making. However, there is a sizeable minority of users who do not feel involved, indicating that ULOs should ensure all users are clear about what involvement they can have.

Organisations indicated a wide range of different ways for users to get involved, including:

- Work is overseen by the Board of Trustees, of whom the majority are carers and users
- Through AGMs
- Face to face meetings
- Questionnaires
- Open meetings
- Committee meetings
- Evaluation of services provided, in order to improve for the future.
- Consultation with members about what they want (i.e. members of clubs deciding about what they want to do)
- By consulting with users – and their families- to find out what support they need, what activities they would like to do
- Informal conversations influence our thinking



However, when we asked users, how they get involved, it was clear that Carers had a more basic understanding/desire to be involved in organisational decisions; whereas Disabled People demonstrated a more diverse range of involvement opportunities:

Carers	Disabled People
Attending a Caring with Confidence Course	Have meetings on a regular basis Committees, meetings, AGMs, peer groups
Discussions on where we might go beforehand	By inviting relevant speakers
Via attendance at our various meetings	To explain reality of our lives and the barriers and comparing this to rhetoric
Not enough	Invite people to talk about services available to Disabled People
	Writing and letting members know of issues needing a decision and requesting our views
	Concerns of how our wellbeing/ physically/emotionally/socially.
	Updates, newsletters
	Meetings locally and regional.
	Updates of policies.
	Opportunities to use telephone to link to disabled people
	Information in different formats
	Attending peer-support groups
	Using skills for volunteering



### 4.3 Does the organisation actively pursue involvement of service users from minority groups?

	Organisations	Disabled People	Carers
Yes	5	9	5
No	1	1	2
No response	1	2	4

Our findings show that whilst the majority of organisations, Disabled People and Carers feel minority groups are involved, there is a sizeable percentage who either do not feel minority groups are involved, or didn't answer the question (maybe suggesting lack of awareness of the issue)

We then asked organisations HOW they involved minority groups:

- Services should be provided in environments where people from black and minority ethnic communities can be confident of being understood and free from discrimination.
- By identifying the needs of local [minority] communities.
- Access to staff or advocates who speak their language, or to interpreters
- Active involved in groups run by/for minority communities, local and regional basis
- Several of our projects were funded to target areas of social deprivation and we have also done partner work with Forest Bus to include traveller families.
- Local voluntary sector umbrella organisations often work with minority groups in launching services and targeting excluded groups/individuals
- They recognise they are under represented on the project and have it on the agenda to plan how to raise awareness with BME groups
- We have recently developed Expert Patient Programme courses specifically to meet the needs of ethnic minority groups in some areas.



When we asked service users what their experience of how minority groups were involved/encouraged:

Carers	Disabled People
We have seen a variety of people from minority groups	Meetings. Asking questions
Transport and food organised if necessary	Asking advice
We are very inclusive and anyone can attend	We invite any group or representative to our group
	Several minority group events been undertaken

Feedback shows that while Carers and Disabled Peoples groups are making efforts to include people from minority groups, in practise there is little indication of how this works.

Organisations:

They are trying to engage with people from BME communities (and learning difficulties). Some organisations show evidence of meaningful engagement with BME groups e.g. working with travelling families.

Carers:

Welcome people from a variety of minority groups, but no indication of outreach or how this happens in practise.

Disabled People:

Feedback gave little evidence of people defining how to involve minority groups, or what the barriers were.



#### 4.4 Does your organisation routinely evaluate the work of the organisation?

	Organisations	Disabled People	Carers
Yes	7	10	7
No		1	2

All organisations evaluate their work, and most (but not all) service users agreed.

When we asked organisations HOW this was done:

- Yearly service evaluation of projects which is carried out from 3 perspectives the Service user, the partner agency and our staff's perspective. All the information is then collated into one document which is then published and widely distributed
- As well as quarterly management meetings, the trustees hold monthly sub-group meetings. There are also processes to ensure that we regularly monitor the quality of the services we provide with all our users, including staff and volunteers.
- We listen to our members and take on any concerns they have and encourage all of them to realise their own potential
- Most of our projects have steering groups and funders to report back to so work is constantly monitored and evaluated to enable us to improve the service we offer.
- Annual feedback questionnaire to young people team away day, team meetings.
- We have an ethos of encouraging self/team reflection and personal development, attendance at National conferences for best practice and guidance
- Expert Patients programme evaluates every course that is run.
- We operate a Quality framework called Stepping Stones to Success



When we asked service users what their experience of evaluation was:

<b>Carers</b>	<b>Disabled People</b>
Internal and external peer review. Feedback from service users	AGM. Regular meetings, annual updates
Via the committee	Keep in touch with members
Feedback from carers	Mission statement and terms of reference which are visited annually
Don't know	Hard work, regular communications

Organisations:

Some organisations demonstrate the monitoring of service through questionnaires.

Carers:

Confusion about what evaluation really is.

Disabled People:

Feedback demonstrates consistent communication. Generally Disabled People feel well informed and included.

## 4.5 Do your organisations policies and procedures encourage honesty and mutual respect?

	<b>Organisations</b>	<b>Disabled People</b>	<b>Carers</b>
Yes	6	10	12
No			



We asked organisations HOW they did this:

- The well being of service users and carers is always at the forefront of our policies and procedures with a person centred approach being adopted to implement them
- They are at the heart of the work that we do and are used in a practical way to focus on achieving our aims and objectives to drive the quality and improvement of the services we provide
- We all have a great banter between us and our motto is laughter is the best medicine
- As a council for voluntary service our mission is to support and promote sustainable development of the local voluntary and community sector. We work towards removing barriers to social inclusion by working with communities and individuals who may be socially disadvantaged, vulnerable and isolated
- Rights [of service users] discussed in groups
- We have a confidentiality policy, safeguarding policy, families also made aware of policies

Carers	Disabled People
We are encouraged to voice our opinions	By being practiced and by training
	Mutually respectful
	Talking to groups and taking their advice
	Encourage everyone to have their say
	Respecting everyone's view
	Discrimination on any grounds would be taken very seriously
	Members views requested



#### Organisations:

Limited evidence to indicate that honesty and mutual respect is shown.

#### Carers:

Some evidence to suggest honesty and respect is encouraged.

#### Disabled People:

Evidence to show clear understanding and practise around mutual respect.

### **4.6 Describe the tensions that can be caused by the different needs of Disabled People and Carers, from your perspective.**

Responses clearly showed that there are tensions. It is obvious from feedback that Carers need a lot of more support than they are offered to undertake their role, and that the lack of support often adds to tensions between the Carer and the Disabled Person being 'cared' for.

Research also identifies the value that both Carers and Disabled People attach to having their own identity, and that the Carer and Disabled Person should not be treated as the same. There is a need for identities to be kept apart.

#### Organisations:

- Parents with impairments feel bad about what their children do for them;
- Demand on both carer and user can affect health;
- Role reversal with young carer and parent.
- Anger/resentment at responsibility develops;
- Family carers often over protect the person they care for

#### Carers:

- Carers not understanding of all the needs;



- Disabled People who are parents feel bad about what their children do for them

#### Disabled People:

- Carers not respecting intellect of the Disabled Person
- Carers may try to take over
- No autonomy about [Disabled Person's] identity. Carers have the dominant role.

## **4.7 In your view what are the values of the organisation.**

#### Organisations:

- Helping others and improving quality of life;
- Working together and create a culture of hope, support and recovery;
- Offers real friendship and social activities
- Antidote to loneliness

#### Carers:

- Striving to create a community free from stigma and discrimination where diversity is recognised and respected;
- Caring about each others needs;
- Listening to each other;
- Give more respect and self esteem;
- Working together and create a culture of hope , support and recovery

#### Disabled People:

- Fostering independence;
- Offers real friendship and social activities;
- Antidote to loneliness;
- Important that people have a sense of belonging and self support
- Social activities and interaction very important (Peer Support).
- Feedback demonstrated some cultural tensions in terms of organisational identity.



## 4.8 How do you think Disabled People and Carers organisations can best work together in the future?

### Organisations:

- Talk to one and other
- Being clear on purpose of organisation and client groups
- Identifying barriers
- Avoiding duplication
- Sufficient funding
- Communication
- Hold meetings and training

### Carers:

- Have a laugh
- Exchange of knowledge
- Talk to one another
- Communication
- Hold meetings and training

### Disabled People:

- Hold meetings to share views
- Exchange of knowledge



## 5. Recommendations / Looking to the future

### 5.2 Recommendations (to SPECTRUM)

- SPECTRUM's current model of working in partnership with a Carers-led organisation to enable it to deal with potential conflicts of interest between Disabled People and Carers, evidently works and is considered a model of good practice. Both organisations would benefit from developing this working arrangement and considering widening the relationship to including with Carer-Led organisations (particularly young Carers groups in the future).
- In terms of project management, better care should be taken to allocate work in accordance with individuals experience, skills and abilities, to boost motivation.
- Consider timescales for extra work, and how this will fit with existing workloads.
- For small projects (this one totalled 70 hours expected work), I question the value of attending the overall project steering group in terms of time management, empowerment and good usage of time for those involved.

### 5.2 Personal Learning:

- As a long standing member of the Disability Movement the project interested me because I had a lot to offer.
- I put my name forward for the project in order to develop and increase my job role and revitalise a position in the organisation that had become mundane.
- Initially, I had hoped to work on Work stream 1 but was asked to undertake work stream 2 an area that I had neither experience nor prior interest in. I learned little from the experience other than reinforcement of Carers experiences.



- My ability to work as part of a team became apparent as this was not an area of work that interested me but I did not want to let my colleagues down. I do not feel that such dilemmas are uncommon in ULOs.
- This project proved to be worthwhile as results show the pressure ULO organisations are under to meet outcomes and conflicting needs with minimal funding and resources. This needs to be addressed.



# Appendix 1

This is a copy of the questionnaire we developed to better understand the issues around Disabled People and Carers

## Partnership working Questionnaire – ref W2

SPECTRUM is carrying out some research to determine how Carer led organisations can successfully work as partners with Disabled People led organisations.

To identify this we are asking relevant organisations to help us in this research by answering the following questions.

---

1. Is your organisation primarily for Disabled People or for Carers?

Disabled People  Carers

Both  (Please clarify in words)

---

2. Does your organisation actively involve service users in company decisions?

Yes  No

How?

---

3. Does your organisation actively pursue the involvement of service users from minority groups?

Yes  No

How?

---

4. Does your organisation routinely evaluate the work of the organisation?

Yes  No

How?

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5. Would you say your policies and procedures encourage honesty and mutual respect?

Yes  No

How?

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6. From your perspective, please describe the tensions that can be caused by the different needs of Disabled People and Carers:

7. In your view what are the values of your organisation.

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8. How do you think Disabled People's and Carer's organisations can best work together in the future?

Thank you.

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## CONTACT DETAILS



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