East Midlands User Led Organisations Project

September 2009
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Introduction

This report has been produced following a piece of work undertaken during 2009 to establish the levels of co-production between Local Authorities (LA’s) and User Led Organisations (ULOs). The report was commissioned and managed through the Personalisation Programme Board (PPB) in response to the Government’s agenda on personalisation.

In January 2005 the Government published *Improving the Life Chances of Disabled People*. A key recommendation in this report states that: “By 2010, each locality (defined as that area covered by a Council with social services responsibilities) should have a User-led Organisation modelled on existing CILs (Centres for Independent Living).”

As part of Putting People First one of the objectives is to provide; ‘Support for at least one local user led organisation and mainstream mechanisms to develop networks which ensure people using services and their families have a collective voice, influencing policy and provision.

The Local Authority Circular also gives clear guidance; ‘An enabling framework to ensure people can exercise choice and control with accessible advocacy, peer support and brokerage systems with strong links to user led organisations. Where ULOs do not exist, a strategy to foster, stimulate and develop user led organisations locally.’

The Department of Health (DH) has also made considerable investment in the development of ULOs across England in the last eighteen months and has provided resources for the individual development of organisation and also mentoring opportunities for new and/ or developing ULOs. In the East Midlands there are two ULOs that are developing under this scheme, Leicestershire Centre for Integrated Living and Derbyshire Centre for Inclusive Living.

As part of the ULO project the DH, in partnership with the Independent Living Movement, have developed design criteria (Appendix 5) that should assist all ULOs but in particular will measure those that are part of the project. In the same way they have produced a list of minimum services that will be expected to be delivered by a ULO (appendix 4).

The added value that is gained by having services that are provided by organisations that are developed and managed by people who have or are
using the service cannot be underestimated. Organisations such as these began to evolve in the 1970’s when disabled people realised that they needed the support of other disabled people in order to ensure that their issues were taken seriously. It has taken over 40 years for government to acknowledge the importance of these organisations and their commitment in Putting People First and their recent *Putting People First – working with user led organisations* outlines the benefits of working with ULOs and provides advice on how meaningful relationships can be formed.

**Aim of the Project**

To assist Local Authorities and the Personalisation Programme Board to achieve a high level of co-production and user and carer engagement in the development and roll-out of the Personalisation and Transformation Programmes set out in detail in the Department of Health Circular Transforming Social Care LAC (DH) 2008.

**Key Objectives**

- Establishing links with the National User Led Organisation Project and identifying any ULOs from other Regions which might be willing and interested in providing peer support to potential ULOs in the East Midlands Region
- Making contact with ULOs in the East Midlands Region which have been approved as Wave 2 ULO Project Sites.
- Identifying from all Local Authority Personalisation Leads their plans and budget provision for providing a comprehensive information, advice, advocacy and brokerage service for all client groups.
- Setting up a Regional ULO Support Group in the East Midlands for current and potential ULOs and CILs and establishing the links for this Group to the National ULO Project and programme meetings for the rest of 2009.
- Consulting with the Regional Citizen Leaders Forum to establish if service users and carers believe that a Local ULO can provide the support and training required by current and new Citizen Leaders. Contribute to planning for the Second Regional Personalisation Toolkit Day in the East Midlands which will be on Co-Production.
- Mapping throughout the East Midlands Region of all ULOs, CILs and all other organisations currently providing information, advice and advocacy on personal care and personal budgets to provide a comprehensive report for the Personalisation Programme Board on advocacy, brokerage, peer support, advice and information services available including self-funders.
• Interim and final reports to the PPB

Methodology

There were various approaches taken to address the objectives of this piece of work and flexibility was needed in order to gain information. Questionnaires (Appendix 1) were initially sent to all LAs in the region to previously identified lead contacts for the development of ULO’s in their LA area and a separate questionnaire (Appendix 2) sent to identified ULOs using information provided from a project recently undertaken by the National Centre for Independent Living mapping ULOs across the country. Contact was made with the two CILs that were being funded by the DH ULO project and with a lead from the DH itself for any help or information that may be available. Contact was also made with the DH ULO project wave 1 organisations to establish if any would be willing to offer support to organisations in the East Midlands.

Findings

1. Despite considerable investment into local authorities via the social care reform grant there is little evidence of investment of this money into the development of ULOs. Only two LA’s indicated any sort of investment and the combined amounts total at less than £15,000 from a significant total budget in the East Midlands Region. Northamptonshire had invested in a User Led Organisation to support their local Citizen Leaders initiative and Leicestershire has invested just under £5,000 although it is not clear from the information exactly what they used the money for. It must be noted however that information in a number of cases regarding funding arrangements by LA’s was incomplete or left blank. Rutland indicated that there was money available for 09/10 but did not say how much and what the investment might be for.

2. Most LAs showed no evidence of strategic plans to implement recommendation 4.3 of Improving the Life Chances of Disabled People, some were not working with any ULOs and others had no connection or awareness of any ULOs operating in their area. Northamptonshire had developed a specification for the development of a CIL which requires the successful organisation to be constitutionally 75% controlled by people who use the service and to be in place by March 2010. The specification has also followed the design criteria set out in the DH ULO project (appendix 5) and included eight of the twelve needs to independent living as developed by disabled people’s organisations as essential services. Derbyshire is working with its existing ULO which
meets the 21 design criteria and has plans in place for further development of more ULOs in the area. This ULO also is part of the Wave 2 DH ULO project and is developing further in relation to their agreement with the DH. Leicester City is following a similar approach and working with its existing ULO, also a wave 2 site, although has not indicated any extra investment to develop the ULO capacity in relation to supporting the Personalisation agenda. Lincolnshire, who currently has no ULOs in their area, are reviewing their advocacy services in order to help their thinking in relation to the development of ULOs in their area in relation to Information, Advocacy and Brokerage in connection to developing self directed support. Others were in the process of starting to think about developing plans or waiting for staff to be appointed to take this work forward.

3. Evidence shows that LA’s have mixed understandings of what a ULO is. The information that was taken from the research undertaken by NCIL was based on data provided by LA’s which in turn produced a list of ULO in each LA area. Many of the organisations listed were quite obviously not ULOs, some were groups run by local authorities and others were groups run by large charities that are also not user led. Whilst the groups may be made up of people who use services the decision making and governance was clearly with a higher body and many of the groups listed were usually used as advisory. When contacted some of these groups replied stating that they were not user led and not appropriate to this piece of work.

4. Two local authorities (Northamptonshire and Nottingham City) had measures embedded in their procurement and commissioning procedures to monitor and evaluate user control in the management and governance of organisations they were commissioning. Northamptonshire had identified that they were now moving towards clearer measures in terms of a percentage control. This was only in reference however, to the development of a CIL, and Nottinghamshire were indicating a similar approach in relation to their Brokerage service, in neither case was it clear if this approach was to be taken as a standardised form of measure. Derbyshire were developing processes and appeared to be including their local ULO in this. They were also measuring the effect of Co-production in relation to their Self Directed Support Programme Board and Lincolnshire and Derby City had measures for user involvement/participation but there was no evidence of user control i.e. the decision making body of an organisation has a constitutional majority vote by people who would benefit from the service.
5. There was confusion regarding user involvement and user control and LA’s need to be better at measuring true user control. With this lack of clarity, there is still a danger that people who use the service will be overruled in decision making by more empowered non-disabled people. It is no longer acceptable to assume that non disabled people have the ability to make decisions on behalf of disabled people in relation to what they want in their lives, in the same way it would not be acceptable for men to make decisions about what was best for women in terms of things they need specifically for them to function effectively.

6. There have been considerable difficulties in obtaining information from ULO’s themselves regarding their views on investment and commitment from LAs in relation to their organisational sustainability and development. Of the few that replied to the questionnaires they all felt overwhelmed and under funded regarding the LA and Government’s agenda. This was not related to their expertise and capabilities as organisations but in relation to their capacity. It is difficult to get a true picture of the feelings of ULOs as responses were so limited despite several attempts and different approaches to gain information. It is not clear why ULOs did not respond to attempts to establish what the issues were for them, however ULOs generally report under funding and capacity issues and as this piece of work was unlikely to be a priority for them it could explain the lack of response and interaction. It is fair to say that from the responses received that ULOs typically felt under funded and often taken for granted by their LA’s. They reported being involved in developments around the personalisation agenda but not necessarily in a co-produced way.

7. All LA’s that were working with ULOs acknowledged the need for ULOs to be supported more effectively and identified areas including, training, funding, social enterprise development, regional support systems, strategic and business planning and marketing. With the limited information received back from ULOs themselves these areas were also identified. ULOs were interested in sharing information and expertise but when attempts were made to try and bring organisations together this proved difficult even for an initial discussion. Leicester CIL reported having identified a large number of organisations in the area who had expressed an interest in some sort of regional co-operation between organisations but evidence had shown them that distance, capacity and cost had thwarted attempts in the past to realise this.
8. In general if LA’s had Service Level Agreements or other contractual arrangements with ULOs these were usually in relation to Direct Payment Support Services.

Most were still developing their thinking around brokerage although Northamptonshire had developed an Independent Support brokerage service which was due to go live at the time information was being gathered and had just awarded a contract to a local ULO to provided support for oversight for this service. They were also about to undertake a review of advocacy services and planned to include the provision of information and support planning in their CIL development.

Nottingham City was about to start a commissioned pilot brokerage service to gauge demand and service development, at the time of writing this was going through the tender process.

Derby City indicated that there were plans to develop the area of advice information, advocacy and brokerage further and there was some capacity within its existing ULO and there were plans to incorporate this into further developments.

Nottinghamshire has a service user reference group, and involved service users in procurement and has some service based work within their day services provision for involving people with Learning Difficulties specifically.

Derbyshire has an agreement in place with their local ULO to deliver support planning and brokerage and had committed to work with the third sector to undertake a mapping exercise to inform an action plan to further develop opportunities for increasing social capital.

Lincolnshire at the time were reviewing their advocacy services which they expect to inform development regarding support planning, brokerage, information and advice.

Rutland were in early discussion stages but had indicated some user involvement in their procurement process and increased use in Internet opportunities, however there was no additional information about what this was.

Leicestershire were developing an engagement strategy and working with commissioners and planners to develop the market and is involving Carers and Service Users in this.
Leicester City was developing a service user/public stakeholder group under the Authority’s personalisation programme to ensure that everyone gets the chance to be involved in participation. The ULO will have a significant role on this group. Although this does not give a clear indication how the LA intend to deliver on information, advice, support planning and brokerage.

9. Consultation with the East Midlands Citizen Leaders group established that most of the existing Citizen Leaders were not being supported either by their LA or by a local ULO. Where there was support for the Citizen Leaders at a local level by a ULO there was evidence that the Citizen Leaders had a much stronger and visual presence and were being involved effectively and strategically in the personalisation agenda and that the Academy was growing locally. Having said this however there was some resistance by LAs to this approach being taken regionally and further work needs to be undertaken with Citizen leaders to establish the most effective way of harnessing this resource and ensuring that they are supported effectively. Some LA’s have not established as yet whether they will follow the Citizen Leaders Model but are certainly adopting some of the underlying principles and philosophies that underpin the Citizen Leaders Academy.

Recommendations

1. Local authorities need to adopt the national model regarding the definition and service delivery of a User led Organisation modelled on a CIL as a minimum in line with Recommendation 4.3 by April 2010.
2. The controlling body (decision making) of the ULO in any authority should be made up of a minimum of 75% of people who are recipients of the service or a requirement to make a constitutional change within 6 months and should be part of the contractual arrangement.
3. Further work needs to be undertaken to build on the existing list of ULOs in the region (see appendix 3) and to ensure an up to date list of ULO’s, specifically providing support for disabled and older people, is readily available. Dedicated time needs to be allocated to the development and maintenance of this resource which could be provided by a local ULO, LA or national organisation e.g. National Centre for Independent Living. To be useful to LA’s and ULOs it is important that this work is undertaken immediately to
assist those that are developing their ULO provision. It may be useful to include services for carers in this work also. Once completed there will be a useful resource in the region that can be shared between other ULO’s in order to share experiences and tools if the wish but also for LA’s to seek expertise for their area where they feel it is lacking.

4. A ULO regional Time Bank should be developed whereby ULOs could share their skills and experience to assist with capacity building with the region. An electronic network should be explored with the opportunity for an annual event where ULO are able to get together for their own benefit but also to learn and take back to their own locality.

5. A series of events should be delivered in the region before April 2010 to provide LA’s with support and information about the best ways to engage with ULO’s, how to support organisations that are not currently ULOs but aspire to be, exchange ideas and good practice regarding working with and supporting ULO’s and to hear the experiences of ULOs in working with LA’s to improve and build on existing relationships.

6. A dedicated post is assigned to assist LAs in this area of development as soon as possible. LA’s need some dedicated support time in order to further develop resources in their area and to further understand what is needed by ULO’s in order for them to function most effectively and support LA’s in their tasks. This support needs to be delivered by a provider that has experience of the Independent Living Movement, CILs and is user led but also has project management and change management experience. A good working knowledge of the personalisation agenda would also be essential.

7. Local Authorities need to examine what additional resources they could include when offering contracts and developing tender documents in relation to services provided by ULOs. This does not necessarily mean cash but other support that could be offered in-kind from LA expertise. For example, help with developing marketing strategies, training, accommodation, legal help, strategic and business planning advice, particularly where there are no voluntary infrastructure organisations offering this type of support in the area. These could be offered by ways of workshops or direct individual support where appropriate

8. LA’s should actively encourage ULO’s or potential ULO’s to access and make use of the website to support their development and also to assist LA’s in their development of ULO’s by offering suggestions and examples of good practice. Good practice within LA’s is currently being shared via the SDS network and the East
midlands website. There is potential however for ULO’s to benefit from access to this information particularly in relation to the message board. Shared information and discussion regarding relevant issues would provide a wider discussion and debate and alternative viewpoint if ULOs were encouraged to take part.

9. Outcome measures need to be developed in co-produced ways that reflect the ‘added value’ elements that a ULO provides. LA’s need to understand the added value that they get from ULOs and how their philosophy and working practices means that they are in touch with the issues that are current for disabled and older people in their locality.

10. Clear action plans need to be put in place by all LAs to ensure that they are prepared to implement recommendation 4.3 of *Improving the Life Chances of Disabled People*.

11. Local Authorities should agree and implement a user participation and payment policy which states how they will undertake and support co-production.

12. The East Midlands Citizen Leaders Academy needs ongoing support and resources in the medium term to establish the best use of this regional expertise.

13. Where Citizen Leaders are available within a LA area LA’s should engage with the Citizen Leader(s) and explore ways in which their expertise can be maximised and how they can assist LA’s to develop services in a co-produced way. Where LA’s do not have a Citizen Leader they can apply the values and philosophies of the Citizen Leaders Academy in relation to how they involve people who use services. Embracing the principle that people who use services are experts and rewarding them as such is crucial. Whilst many LA’s are recognising the value of their users experience they have not yet gone that extra mile and put policy in place to ensure that this expertise is rewarded. In no other industry is an ‘experts’ knowledge expected for free apart from in the world of Social Care.

**Conclusion**

The importance of working with User Led Organisations has not yet been recognised fully within the region. This project has highlighted the difficulties of attempting regional work with ULOs when resources are limited and the recommendations have attempted to resolve some of this by providing alternative means by which organisations can communicate and learn from each other without the need for long distance travel and extended meetings.
Whilst some of the original outcomes have not been fully achieved due to, what is believed to be, lack of capacity of ULO’s to engage at this stage with issues that are currently not their priorities and have no direct and immediate benefit to them, what has been highlighted is a way forward to further explore these issues.

There are a number of well established ULOs in the region and some real opportunities for sharing good practice amongst ULOs and LA’s which will in turn provide a much more effective resource and ultimately better lifestyles for the disabled citizens in the East Midlands. By working with ULOs LA’s are likely to deliver person centred services in relation to their personalisation agenda. ULO’s can also help improve the local economy by providing information, advice and training in relation to employment for disabled people. ULO’s ability to engage with groups of people that LA’s often find very difficult mean that a more realistic picture of service needs are achieved which may result in more effective commissioning of services.

It is apparent that LA’s are beginning to understand this and are now beginning to develop their thinking around how to engage better with ULOs and it is hoped that some of the recommendations in this report will help this to happen more effectively and in a timely way.

ULO are a resource that LA’s need to recognise and value and understand the impact that can be achieved in disabled and older peoples lives when they have the support and connections with an organisation that works alongside them, not one that makes assumptions about their issues.
References

*Improving the Life Chances of Disabled People, 2005* Department of Health

Local Authority Circular 2008

Putting People First Concordat

Putting People First – Working together with User Led Organisations

User Led Organisations Project 2007

Wendy Gross has been responsible for delivering on the areas of work described in this report and for the completion and delivery of the reports themselves.

Wendy works as a consultant regarding issues relating to independent living her particular interests are in relation to personal/individual budgets, brokerage, direct payments and User Led Organisations. She is a disabled person and has been using services for nearly 30 years; she has been involved in the disability movement for the last 17 believing in the right of equality for all and the fundamental right for each individual to have choice and control over their own lives.

Her background is predominantly in the third sector, locally and nationally, particularly in Advocacy, Independent Living and Direct Payments and more recently, Personal/Individual Budgets, but has also had experience of working in Health, Social Care and Education environments.

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User Led Organisations Project

Local Authority Questionnaire

This questionnaire is designed to identify how local authorities are working with User led Organisations and what commitment has been made in terms of support for those organisations. It is important that a realistic picture is formed regarding current and future plans for working with ULO’s in the region in order to identify where the gaps are. Please give as much detail as possible (the boxes will expand to include as much information as you choose) and evidence of any plans, strategies or documents referred to.

It is important that questionnaires are returned to me by email by Friday 5th June at the very latest

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<td>Local Authority Area</td>
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1. How many ULO’s do you currently work with in your LA area?

2. How many of these ULO’s do you have service level agreements with?
3. What is your local spend on funding ULO’s?

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4. Do you have any particular successes and outcomes that could be shared regionally as examples of good practice in this area of work?

5. A regional plan is currently being developed to support the development and engagement of ULO’s in services commissioning, provision and evaluation in the region.
   a) Is there any support your LA would find useful?
   b) Is there any support you feel ULO’s in your area would find useful

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<td>7. Strategic Planning</td>
<td>8. Regional ULO website</td>
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6. What does your Local Authority strategic plan for personalisation include for working with ULO’s and do you have any specific plans for assisting local ULO’s to build capability and capacity?

7. How do you intend to meet the requirements of recommendation 4.3 of *Improving the life chances of disabled people* by 2010 “*each locality should have a user-led organisation modelled on existing Centres for Independent Living by 2010*”.

8. What other ways do you include ULO’s in your work around personalisation?

9. How do you currently measure whether an organisation is User Led and what requirement do you put in tender documents and SLA’s to measure user participation in organisations that you fund?
10. What plans do you have in place to deliver information, advocacy and brokerage to support disabled people to be engaged and involved in service commissioning, provision and evaluation?

11. Please include any additional information here that would like to be included.
User Led Organisations Project

User Led Organisations Questionnaire

This questionnaire is designed to identify how local authorities are working with User led Organisations, what commitment has been made in terms of support for those organisations and if there are any gaps. It is important that a realistic picture is formed regarding current and future plans for working with ULO’s in the region in order to identify where the gaps are. It would be really useful if you could give ten minutes of your time to fill in this short questionnaire that will give us more information to give a clearer picture of what is within the region.

Please give as much detail as possible and include any additional information that you think we may find useful.

It is important that questionnaires are returned to me by email/post by Friday 19th June at the very latest

Return to:
Wendy Gross
Ivydene Terrace
Broughton
NN14 1NJ

Or email
wgrosstraining@headweb.co.uk

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<th>Contact Name</th>
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<td>Name of Organisation</td>
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1. What are the main activities of your organisation?

2. Who are the main group of people that benefit from your work?
   - Carers
   - Disabled People
   - Older people
   - Other (please give details)

3. Do you receive any funding from your Local Authority?
   - Yes
   - No
   If yes could you indicate of the types of activity you are funded for?
     - Advocacy
     - Information
     - Peer support
     - Housing
     - Direct Payments
     - Transport
     - Benefits Advice
     - Employment support
     - Equipment
     - Other (please give details)

4. Can you tell us how many people who are beneficiaries of your service hold decision making positions on your management board as a minimum?
   - 0%
   - Min 25%
   - Min 51%
   - Min 75%
   - Min 100%
   Other (please give details)

Do you have a constitution or other formal agreement that states that this is your minimum?
   - Yes
   - No
6. A regional plan is currently being developed to support the development and engagement of ULO’s in services commissioning, provision and evaluation in the region. Is there any support your organisation would find useful?

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7. How much are you involved in your Local Authorities plans for the Transformation of Social Care?

- Don't know anything about it
- We have received some information
- We have been given lots of information
- We have been asked to be actively involved
- We are actively involved
- We are working in partnership with our Local Authority
- Other (please give details)
7. How much are you involved in your Local Authorities plans for Personalisation?
   - Don’t know anything about it
   - We have received some information
   - We have been given lots of information
   - We have been asked to be actively involved
   - We are actively involved
   - We are working in partnership with our Local Authority
   - Other (please give details)

8. Please include any additional information here that would like to be included.
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<tr>
<td>Ability Northamptonshire</td>
<td>Sandra Bell</td>
<td>Burlington House, East Wing 369 Wellingborough Rd, Northampton, NN1 4EU</td>
<td>01604 62408 8</td>
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<td>abilitynorthants.org.uk</td>
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<tr>
<td>Derbyshire Coalition for Independent Living</td>
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<td>01773 74024 6</td>
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<td>Disability Direct</td>
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<tr>
<td>Disabled Peoples Alliance Northamptonshire</td>
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<td>01933 66480 0</td>
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<td>0116 222 5005</td>
<td><a href="mailto:dee@lcil.org.uk">dee@lcil.org.uk</a></td>
<td>lcil.org.uk</td>
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<tr>
<td>Central England People First</td>
<td>Ian Davies</td>
<td>Eskdaill House, Eskdaill Street, Kettering, Northants, NN16 8RA</td>
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<td>Peoplefirst.org.uk</td>
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<tr>
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<td><a href="mailto:ronuss@btconnect.com">ronuss@btconnect.com</a></td>
<td>userssupportservice.co.uk</td>
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<td>Vista</td>
<td>Jenny Pearce</td>
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<td>0116 2498824</td>
<td><a href="mailto:Jenny.pearce@vistablind.org.uk">Jenny.pearce@vistablind.org.uk</a></td>
<td>Vistablind.org.uk</td>
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Improving Life Chances – *ULO Project*
ULO Minimum Services

- Information and Advice
- Advocacy and Peer Support
- Support in using direct payments and/or Individual Budgets
- Support to recruit and employ Personal Assistants
- User-led Organisations
- Assistance with self-assessment
- Disability Equality Training
- Support the implementation of the Disability Equality Duty * by public sector organisations in the locality (includes consumer audits)

*Note the Disability Equality Duty has come into force since 2006 and was not within the ULO services defined in improving Life Chances.*
Appendix 5

Improving Life Chances – *ULO Project*

21 Design Criteria

1) Works from a social model of disability

2) Promotes independent living

3) Promotes people’s human & other legal rights

4) Shaped & driven by the initiative & demand of the organisation’s constituency

5) Is peer support based

6) Covers all local disabled people, carers & other people who use support either directly or via establishing links with other local organisations & networks

7) Is non-discriminatory & recognises & works with diversity in terms of race, religion & belief, gender, sexual orientation, disability & age

8) Recognises that carers have their own needs

9) Engages the organisation’s constituents in decision-making processes at every level of their organisation

10) Provides support to enable people to exercise choice & control

11) Is a legally constituted organisation

12) Has a minimum of 75% of the voting members on the management board drawn from the organisation’s constituency

13) Is able to demonstrate that the organisation’s constituents are effectively supported to play a full & active role in key decision-making

14) Has a clear management structure
15) Has robust & rigorous systems for running a sustainable organisation

16) Is financially sustainable

17) Has paid employees

18) Identifies the diverse needs of the local population & contributes to meeting them

19) Is accountable to the organisation’s constituents & represents their views locally

20) Supports the participation of its constituents in designing, delivering & monitoring of the organisation’s services

21) Works with commissioners to improve commissioning & procurement