

User-Led Organisation Second Core Group Meeting Mint Lane, Lincoln 9th February 2011

Present

Nigel Webster	West Lindsey Disability Network
Susan Lipscombe	County Carers/LPCC
Jo Minchin	County Carers
Fay Cooper	LAPD

In Attendance

Sandy Marshall	National Centre for Independent Living
Emma Krasinska	Lincolnshire County Council
Charles Cooke	Lincolnshire CDA
Tara Kellie	Lincolnshire CDA

Apologies

Steve McGuinness	
Mike Martin	

SUMMARY OF ACTIONS FROM MEETING: 9th February 2011

General actions and decisions	Comments	Responsible Person	Relevant Dates
Carried forward from 19/1/11 Prepare Terms of Reference	Tara to adapt Cambridge model.	Tara	9 th March
Website	Tara to find out cost of registering shorter name for ULO site	Tara	9 th March
Skype	Jo to chat to Steve about remote meetings	Jo	9 th March
Training Grant Form	Tara to design training grant form members can apply to	Tara	9 th March
LCDA/ULO	LCDA to formalise relationship with ULO	Tara/Charles	9 th March
NCIL	Sandy to look into market place for offering training (TK also to send link for Vision Sense offering training)	Sandy	Before 31 st March
Constitution	Tara to make amendments as agreed and send out	Tara	9 th March
Members voting	Sandy to look at voting for disabled people who may lack capacity to vote as members in decisions on ULO	Sandy	Before 31 st March
Communication strategy	Sandy to have a start on –links to constitution and how members are contacted.	Sandy	Before 31 st March
Training bid to LCC	Tara to prepare bid after talking to Emma and Voiceability. Sandy to look at other neighbouring ULO's that could support with training etc.	Tara and Sandy	ASAP

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<p>Last meeting Matters arising</p>	<p>Minutes of 19th January approved.</p> <p>TOR – Not done yet as Tara was unavailable for it – Next meeting</p> <p>Accessibility – easy read, Helen Oliver has agreed to convert any documents in to easy read or photo symbols. Voice Ability will do this role for LULO</p> <p>The website – Mick has given access codes to upload the minutes and so on. Needs updating. Currently on LCC community website. Cost benefits. Website address is ridiculously long! Can we get a hosting address? Ian Flack? Laser red do hosting and mail for £9 a month. MAGICT do similar and are disability direct syndicate (Derby) their IT and Web development of up to 16 pages for up to £499. Tara to look into registering new address</p> <p>Critical friends ref group. Charles and sandy are here. Anne Mumby will try and come to the March Meeting.</p> <p>IT Involvement. Jo has not met up with Steve yet- Steve's mum has not been well.</p> <p>Skype looks useful. Business account will allow Conference calling. Jo to speak with Steve about it?</p> <p>Inclusive – one person's access is another person's barrier. Have to look at the next best way to overcome the problem. Have to balance that out. Always be aware of this.</p>	<p>All</p> <p>TK</p> <p>TK</p> <p>JM</p>

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	Emma, additional finding from LCC for training and development. Money has to be transferred before end of march, needs to go to CDA for the moment. Will be kept separate.	
Training and Development	<p>Need to give some way of funding training for members. Linkage are putting on an event with a workshop on IT and people with autism. Attendance fee. Jo would like to go. Suggestion that the ULO has a form of timebanking where by people can do things on behalf on the ULO and then attend training/ events they wish to in return. E.g County carers could contract the ULO for typing up their minutes, Jo would volunteer for that job. If later she would like to attend something relevant to the ULO her volunteer time banked, would be used for this. Pot of money for training should only be for ULO members and any training carried out must be of benefit to ULO as well as the person. ULO funds are for ULO development i.e Its not a pot of money for other groups to use. Maybe further down the line the ULO could act as a training hub and be a resource locator and possibly develop specific training and / or getting the funding to do it. The key thing is to ask if it furthers the interests of the ULO.</p> <p>Tara to put together training grant application form.</p>	TK
LCDA	<p>Need to formalise the relationship between LULO and the CDA.</p> <p>LCDA currently acts as executive instrument on behalf of the ULO, it will be directed by LULO. LCDA insurances will cover it, and enable the ULO to do what it wants to without over complicating responsibilities at this stage.</p>	CC/TK

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<p>NCIL</p>	<p>Sandy has a small contract from the National CIL to be here and support us.</p> <p>CIL is part of the reason we have direct payments now. Has made a big change in how disabled people are treated within society.</p> <p>Discussion around Lincolnshire services as personal budgets Sandy found in work at Derbyshire as direct payments manager that often the systems changed, the outcome for individuals didn't. In Derbs, there are lots of opportunities for managed bank accounts and so on, money management can be delegated if you want it to be.</p> <p>Tara wrote a report on the incentives and structures needed for people to take up personal budgets and so on, it was commissioned by the LCC, but the report has not been acted upon. Charles to chase this up with Pete Gittins</p> <p>Charles –asked if Sandy can identify the market for training from a ULO.</p> <p>Training for training's sake is something we have to be careful to avoid. We need to look at things that are going to achieve a revenue for the ULO. Vision Sense , are a social enterprise, massive training department. Tara to forward website. http://www.visionsense.co.uk/ Many different ways to access training, from tips to comprehensive service. Must have done a lot of market research to businesses and tailored model from the research – based in Sunderland.</p> <p>All businesses are cutting budgets at the moment, it's a hard one to crack. Nigel sold being disability aware to taxi drivers and it worked on being good for their business.</p>	<p>CC</p> <p>SM</p> <p>TK</p>

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<p>Involvement of other groups/ choice and control for people.</p>	<p>How do you reach all the small groups and represent them? How do you provide a united voice. You have to be responsive and in touch with them.</p> <p>It is all about finding the right language to get other groups involved.</p> <p>We could we be advisers on PB and brokerage? LA needs to personalise direct payment support first. There is a great need for this. WLDC refer people to Nigel to advise on benefits, Penderels are not operating as an independent charity and in effect working as a satellite of the county council. The system is still getting in the way. If giving financial advice, there are legal loopholes. Can get in to trouble need to be trained and qualified, also there are areas that you can not stray in to.</p> <p>The best way to support people is either through friends & family or through the small groups who provide peer support. To facilitate and train Family and Peers to do this would be a good way to go. It would be great for the ULO to have x amount of peer supporters within other service user groups to help other groups to be empowered.</p> <p>It would put clarity in to what personalisation was about. Need to support individuals right from the assessment stage to the point of budget decision. Basically we have no external service doing this, so it is entirely LA driven. It is a very top down structure.</p> <p>Once you know how much your budget is, you should have the choice about how it is managed. That control element is what is not happening. You should still be able to direct how or what services you get, but you don't need to manage the money to do so.</p> <p>Derbyshire kept some examples of innovative ways that people used their PB . We are poor about that in Lincs. This is something that the ULO could do.</p>	

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LCC Information	<p>Emma arrives: Clarify Partners in policy making. Is that just around people wanting to personally support themselves? PiPM is an depth course run by family carers and people with lived experience of disability. Give historical reasons for why things are and combine with cutting edge examples of how things could be in best practice and examples of it. Teach how to engage effectively with commissioners, and gives you a network of other people working in the same way.</p> <p>10 day course difficult for time commitment. We need a background of what is happening locally, how it is now and what alternatives there might be. What else could there be?</p> <p>Need a taster course to give people an idea. Practically Emma would be happy for us to design this. Have some funding in the transition grant before the end of march. Contract regulations are holding up masses of development at the moment, Emma would like to make available that sum of money to fit within our strategic aims.</p>	
Possible focuses for ULO action	<p>Charles – what's needed:</p> <ol style="list-style-type: none"> 1. A lot of people don't know what is going on, can be complex because of charging. ULO could organise a range of brief info sessions for potential champions / ambassadors / people who are already key in the community to engage them potentially leading to more detailed sessions. This would create a network of people a resource for people to start learning what their rights are and how to achieve them. 	

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	<p>2. PR and information on personalisation . We are not equipped to do that but we could trigger it if we make a proposal to the Coop for a national campaign? The group may raise awareness for us? Lincs co op for something more locally too? Fay – Lincs uni media and marketing publicity and promotion for free? Perhaps how we can market ourselves. People need to learn about what they need to make the best of this system.</p> <p>Does not need to be delivered before the end of march, need a well thought out proposal by then. In Derbyshire they put on 4 workshops in different areas of the county. Got about 100 different groups together. Do something similar with the potential to be peer mentors?</p>	
Constitution	<p>Group when through constitution following amendments to be made:</p> <p>Refer to individuals as disabled people, quite a fundamental piece of nomenclature. Society disables us, look at it in a social way. Disabled people mentioned first. Mental health act, quite clearly comes in as a disability. Don't use the word problem when referring to mental health. Add a glossary at the end of the constitution, it would help people interpret the document.</p> <p>A statement of the values could also be added as an appendix.</p> <p>Our aims:</p> <p>Point 2 would link in well in to the personalisation agenda.</p>	

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	<p>3 the environment needs to change, not disable people</p> <p>If we are working on a social model of disability, a person is disabled by society, it is the individual's experience that matters. These people will not accept me, they do not recognise my differences etc. This automatically includes older people too.</p> <p>5 not just increase, need fully inclusive lives. To ensure that disabled people, their families and carers, have the same opportunities (and responsibilities) as everyone else.</p> <p>6 this is not an aim, this is part of the business plan.</p> <p>New point, to maximise and choice and control for disabled people to live independent lives.</p> <p>This might be our mission statement.</p> <p>People can only make choices if they have the right information to make those choices (and process it!).</p> <p>What do we mean by independent living? We do need to define this. Without the services they need, people end up institutionalised in their own houses in the community, this is not independent living! People need to be accepted in their community. Sometimes this can only be achieved by being selective about your community.</p> <p>New point, -Non discriminatory and recognises and works with diversity in terms of race,</p>	

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	<p>religion, and belief, gender, sexual orientation, disability and age.</p> <p>Powers.</p> <p>Training is a means by which you achieve your aims...</p> <p>Members Meetings not AGM's as a heading</p> <p>You have to state that members can call a special meeting., and how. All members must be invited to an AGM, so there has to be notification at least 3 weeks before the AGM</p> <p>Core group is management board in effect.</p> <p>If 10% or 10 members (whichever is greater number) agree, they can also call a special AGM.</p> <p>Who is a voting member? Perhaps we need to define who the members are in the values. Disabled people need to make the decisions and steer the organisation. Carers are significant, and can be involved in debate, but they do not have the vote. Disabled people have to be in the majority. Sandy can go and do some research on this. Affiliate or associate membership for non voting members. How do you represent those without mental capacity? Advocacy? Total Voice? Don't bring organisations in as representative of constituencies, a representative can only represent an individual not many. Must find a way to represent those without capacity.</p> <p>Sandy will bring back other organisations constitutions on these matters.</p>	<p>SM</p>

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	<p>Core Group-don't need the words a quorum of, 1/3 is enough, 75% of the core group will be disabled people.</p> <p>Is it possible to achieve representativeness? No, great ideal but perhaps not practical.</p> <p>People can be part of core group without voting rights, need expertise. The core group can invite other members to be members of the core group. Ideally they would want to be voted on at the next general meeting.</p> <p>The core group can invite other members to join the core group. They are members, so they can vote. People can be invited to an individual meeting to provide advice, and that is separate to membership of the core group.</p> <p>The chair, secretary and treasurer -officers, can be shared by 2 people. Individual jobs can be too much for an individual. Marry up people who can communicate quickly with each other. Treasurer is a difficult post to fill. Constitutionally you have to have a chair, that can be a rotating position, appointed by the core group.</p> <p>It is the responsibility of the core group to keep accurate financial records and accurate minutes.</p> <p>If a member has done some agreed work, they can be paid back by agreement from the core group.</p> <p>What about grievances?</p> <p>Only at AGM called for the purpose. It has to have 2/3 of 10% or ten whichever is the</p>	

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	<p>greater.</p> <p>Residence? Non Lincs members may have been displaced because of lack of chances in the county. Not willing or true choice.</p> <p>We need to develop a communication strategy. Communication is important, but the how, is down to the strategy. Requesting how is up to members to provide on it's membership form.</p> <p>A decision to dissolve the company to be made by the members at an AGM called for the specific purpose.</p>	SM/TK
Training bid to LCC	<p>The business planning group decided to look at the training bid for LCC as this was more urgent than the business plan.</p> <p>What's Important:</p> <p>Inform and make people aware of their rights related to independent living.</p> <p>Independent living is about prevention, rehabilitation, as well as self direction. LCC didn't share much information about the pilot in East Lindsey.</p> <p>Need a course for discrete individuals to get their head around personalisation.</p> <p>How to access support? Who do you ring? No one seems to know. Shall we train people to be self directed support advisers. Often it is about empowering people to give the right answers to the questions asked.</p>	

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	<p>NB Voice Ability, must not duplicate what they are doing.</p> <p>What outcomes do we want?</p> <p>A group of confident skilled people who can offer advice and support to peers.</p> <p>It would be great if they were paid, but there probably won't ever be the money for that though.</p> <p>Rutland and Leicester ULO have been given £5000 just to find out what people actually know about personalisation. What is the agenda? People need to have a shared understanding of it. What does it mean for people living and working in Lincolnshire.</p> <p>Most people think it is just about money. It is much broader than that.</p> <p>Supporting people with assessments, supporting people with payments. £5,000 is effective for marketing. If you get 5 people out of 100 groups, that's a good return.</p> <p>So far the only people giving an overview of personalisation has been the LCC. Which has meant that we have only had their view. We have to have info sessions that independent of Lincolnshire.</p> <p>EMULO Network. Looking for funding bid. There are enough people from ULO networks to come over and help us with workshops.</p> <p>Perhaps ask other ULOs like DCIL about their experiences. Disability Direct. What can I</p>	

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	<p>do directory, about brokering services other than the traditional domiciliary care that most places provide.</p> <p>Start of with an information program. 10 till 1 not long enough, need a whole day.</p> <p>Lincs don't have a stakeholder engagement board.</p> <p>What is the Lincolnshire perspective? Give people time for networking. Full day is needed. Need to give people a wider understanding of what personalisation actually is.</p> <p>In control 7 steps. Look at website.</p> <p>5000 is enough for 5 workshops dotted around the county.</p> <p>Target audience – only disabled people? What is the make up of Lincolnshire. Lots of groups, but more people are not part of a group. Our aim is to ensure that this is primarily for disabled people. Priority to disabled people, any spare places to organisations and so forth.</p> <p>Each workshop for a whole day. 10.30 to 3.30. Prompt.</p> <p>Start using the grant for advertising. Invoice by the end of the month. Get someone to talk to us as the core group about personalisation. Where did it come from and what is out there? We need to be experienced and be able to answer questions about it.</p> <p>Sandy could try and find someone for us.</p>	<p>SM</p>

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	<p>We need to say to to LA that they are confusing everyone by changing policy and all of the different consultations. Call Cllr Graham Marsh to the meetings esp core group personalisation meeting.</p> <p>Core group training day with Cllr Marsh.</p> <p>People with Direct payments, doesn't mean they have been through the personalisation process... Acton Shapiro wrote a report on PB which could be useful to pick out what's needed.</p> <p>Sandy has some of the interviews, can probably support us to get the info from Acton Shapiro.</p> <p>Support planning from another ULO to show how people can be creative. This might be charged, but then that's money back in to a ULO. Support planning is key. By being creative with money, you can save a lot.</p> <p>Sheffield have put some support plans on their website.</p> <p>Tara to discuss again with Emma and Voiceability to ensure we don't duplicate with them and create the right sort of development.</p>	<p>TK</p>