

Lives Unlimited: An evaluation of recent peer support projects - and what next?

Summary of findings

- **Some individuals and families offered a cash budget felt that help was sometimes restricted due to procedural or time constraints**
- **Care managers were not always seen as having the necessary knowledge or experience to confidently facilitate ambitious support planning**
- **For some individuals and families it is important to be able to be able to set their own pace, and to have support from a variety of sources, if offers of choice and control are to be realistically and effectively acted upon**
- **Extra help with the crucial task of support planning can change, and improve, outcomes**
- **Peer support (ie the encouragement and practical assistance of experts by experience) is highly valued and demonstrably effective. But it needs to be provided on a more structured basis than is currently possible by Lives Unlimited**
- **Lives Unlimited is widely regarded as a beacon of experience and expertise**
- **There was universal support for Lives Unlimited maintaining, and if possible increasing, its influence and availability**

Background

Lives Unlimited was awarded an Awards for All grant in 2010 to establish circles that would support ten people to achieve the benefits that members of the group believe, based on first hand experience, circles can bring to the task of acquiring practical equal citizenship. This brief report seeks to evaluate the performance of the project, to comment on this performance, and to highlight any findings that have implications for the future role(s) of Lives Unlimited. The author of the report, a qualified social worker with 35 years experience of adult social services including 10 years working to promote self directed support, conducted the research on which the report is based through a series of semi-structured interviews with a variety of people who had been involved in some way with the project.

Summary of the project's performance

The group's resources of expertise, experience, time, guidance materials and local contacts were effectively coordinated in a well attended promotional event.

Feedback has confirmed this was experienced as well run, informative and thought provoking. Expressions of interest were promptly followed up, and members of the group made presentations on the purpose, practicalities and outcomes of circles to a number of local organisations and community groups active in advising or assisting people with support needs.

In spite of this successful launch and early promotion for the project, take up of the offer of help to establish circles was very limited, prompting the group to seek approval from Awards for All to move the focus of the funded work on to giving assistance to people with the crucial activity of support planning. Approval was given, and Lives Unlimited worked with other agencies to promote ambitious, action-oriented approaches to support planning, with a particular emphasis on the specific challenges faced by individuals and families around the transition from young peoples to adult services.

Feedback on the support planning activities was excellent. Once again, it brought members of the group into close working relationships with a number of professional services as well as with individuals and families. One senior service manager commented that the Lives Unlimited presentation put the potential of self directed support to change peoples lives into sharp focus, and established an evidence base to encourage more ambitious joint work between agencies and families in the future.

Every interview confirmed that Lives Unlimited is highly valued as a source of inspiration, information, advice and practical help.

Discussion

Whilst the primary purpose of the interviews conducted was to generate evaluative feedback on Lives Unlimited's delivery of a specific project (ie to help ten individuals or families establish circles), the brief included a wider exploration of experiences of self directed support procedures and processes to inform Lives Unlimited's consideration of its future activities. The findings from, and implications of, these wider discussions are discussed below under headings which represent the main themes identified by interviewees.

i) Awareness and knowledge

Respondents unanimously expressed a view that policies and procedures designed to encourage the successful take up of self directed support options are in their relative infancy, are often open to multiple interpretation, and can be experienced as confusing and daunting by both practitioners and individuals or families with acknowledged support needs. The point was frequently made by interviewees that policies and procedures are only a framework within which relationships of mutual trust and confidence have to be developed if outcomes are to be improved for all

citizens with an entitlement to support in pursuit of their rights to participation, choice and control.

There was general agreement that the language of self directed support seems to be unfamiliar and subject to frequent change, and that this in itself can be intimidating to individuals and families whose journeys are just beginning. There was support for a view that the offer of choice without sufficient preparation or help leads to some people feeling overwhelmed and disempowered.

Budget holding respondents expressed simple, subjective summaries of what self directed support means to them: “Choosing the support I need to live the life I want”; “Being in full control and being able to choose who helps me to do the things I want to do”; “An ordinary life”; “It’s about a whole life change, the big picture, not just about replacing like with like, but not assuming that all the services currently available are no longer required either – people need to be able to mix and match”; “A happy son – being able to choose how to get help, who from and at what pace means he is no longer stressed”.

Respondents from agencies stressed that changes in policy are only the start – philosophies and working practices have to change as well.

Many comments related to current perceived deficits: lack of knowledge, lack of confidence, lack of time to spend carefully considering options, lack of faith in the potential for dramatically changed futures. Importantly, every respondent recognised that this applied equally to both individuals or families and the professionals whose role it is to enable the exercise of choice and control. In the main, this was not expressed negatively: the hope was for mutual learning between citizens and professionals, with a shared willingness to learn by doing and to err on the side of ambition and calculated risk taking. There were some concerns expressed that a shift in the balance of control from professionals to citizens is experienced by some professionals as threatening, and that this can influence the nature of their relationships with individuals and families. Some people were very confident that their care manager was committed to a model of practice that embraced advocacy and championing the choices of their clients; others felt less confident that this was available to them.

Every interviewee highlighted the importance of informal information sharing, advice giving and encouragement between individuals and families as both a supplement and a complement to the help available from the statutory services. Every respondent viewed peer support as being at least very important, most saw it as absolutely essential. For some people, meeting members of Lives Unlimited made the difference between being preoccupied with compliance (with financial and employment responsibilities mainly) and being ambitious about changing lives for the better.

At the same time, the point was repeatedly made that not every individual or family will want to, or feel ready to, meet others and that the offer of contact and help needs to be maintained as an option to be exercised over time. This was suggested to be one reason why the short term project was undersubscribed.

Ambition was a word that was frequently referred to throughout the research. Real life, local examples of self directed support in action were clearly vital to giving some respondents the confidence to be ambitious, and the personal stories shared by members of Lives Unlimited were commented on as sources of inspiration.

ii) Process

Most people interviewed referred to the assertion of choice and control through the use of a cash budget as a journey, not an event. The availability and accessibility of information about rights and options were seen as factors affecting the first stage of their journey, and observations in section i) above apply. Two other crucial stages were discussed: the assessment of needs, and support planning.

Budget holders' expressed levels of confidence in the conduct of assessments of need, and the tools used, were mixed. The self assessment questionnaire was generally felt to be simplistic, failing to take account of complexity and the absolute need for flexibility. At its best, it was felt to be capable of producing an indicative budget that forms a basis for further discussion, and the detailed costing of alternative proposals, before a final budget is arrived at through a process of evidence based negotiation. This in turn demands a relationship with a care manager characterised by mutual trust, shared high expectations, and a willingness on the worker's part to respect the budget holder's own views and to act as an advocate within their own organisation when necessary. At its worst, the process was experienced as restricting and alienating, with individuals motivated to try to present information about themselves in ways that are perceived to be likely to get a 'better result' rather than necessarily accurately describing their circumstances.

Based on their own experience, some respondents felt that peer support during the needs assessment process would help to secure more positive outcomes. A perceived need for independent arbitration where agreement cannot be reached on what is a sufficient budget to meet identified outcomes was raised twice.

Support planning was universally regarded as a crucial activity in the achievement of genuine choice and control. Respondents frequently referred to help from family members, peers and resources in both electronic and printed formats as having been essential in achieving the best outcomes for them. Some expressed a view that the availability of the Lives Unlimited network had made the difference for them between a restrictive care plan and an enabling support plan. The support plan was referred to as the place where "people help you to think outside the box", with the best guides being experts by experience, sharing their examples of what works for them.

Without assisted, ambitious support planning there was felt (by budget holding respondents) to be a real risk that the only thing that changed was the name of the person managing the budget. One person talked about 'day centres being replaced by shopping centres', a reference to some evidence that staff employed to provide one to one support sometimes resort to the activity of aimlessly wandering around shopping centres in the absence of clear, action oriented and outcome focussed support plans. The range of wholly individual lifestyles and choices presented by Lives Unlimited was identified as a priceless counter to any experienced pressures to settle for 'second best'.

iii) Circles

Circles were specifically discussed as a means of empowering individuals and families to achieve their desired outcomes. With reference to the specific project under consideration, the low take up of the offer to help set up circles was regarded by most interviewees as evidence of the obvious, i.e. that there is no one size that fits all.

For some people, a circle has been the single most powerful influence on the success of their use of a cash budget to achieve the lifestyle changes they wanted. "A circle made the difference between staying sane and going under". They were described as being able to:

- maximise the cumulative creativity of family, friends and neighbours;
- provide a mechanism for the beneficial sharing of responsibilities;
- avoid the risk of a damaging isolation;
- help to balance roles and relationships within a family;
- establish an unstoppable momentum for change in an individual's life;
- sometimes be a vehicle for the recruitment of informed and motivated P As.

Obstacles to the use of circles were perceived to include:

- some peoples' sense that they are not ready yet, that they are still struggling to get to grips with the technical detail of being responsible for a budget;
- the fact that some people are reluctant to ask for help, and may fear rejection;
- a sense for some people that an organised circle is too formal – an existing social and familial network may already be functioning as a circle without needing to be formalised.

The general conclusion was that circles have the potential to be powerful tools for change, but they are not a cure all, they are not right for everyone and the time to enlist the help of a circle has to be carefully judged. The hope was expressed by all interviewees that Lives Unlimited would continue to champion circles as an effective tool to be available as a practical choice.

iv) A beacon of inspiration

Every interviewee expressed a very high regard for the inspirational examples of self directed support outcomes that members of Lives Unlimited have achieved, and now make available to give confidence to others through the website, networking, events and peer support. To celebrate success, to generate excitement and confidence, to inspire ambition, to share ideas and information, to infect people with a 'can do' belief in themselves were all seen as central to Lives Unlimited's continuing role in helping to shape the implementation of self directed support policies and procedures in York.

There was strong support for an ambition for the group to extend and stabilise its activities in a number of areas:

- Working with the council to improve the quality and delivery of information to new and potential budget holders, starting with a consistent, plain English definition of self directed support
- Increase the number of life stories and other resources on the website, and increase its visibility
- Utilising the experience and personal resources in the group, contribute to skills training for individuals, families and professionals
- Offer both task related and continuous peer support and peer mentoring alongside statutory roles and relationships
- Promote, and assist with the establishment of circles as a distinct support mechanism
- Develop specific training for PAs, utilising the insights gained by members of the group in pursuit of their own ambitions

At the same time there was recognition that the group is small, that individual members could be at risk of being over stretched, and that questions of capacity and resources have to be considered carefully. The group's ambitions need to be realistic and achievable.

To set expressed ambitions for the group into a national context, an extract from the Social Care Institute for Excellence's research briefing on co-production is reproduced below. In my view, this articulates a case for the inclusion of Lives Unlimited at the heart of local change, with a legitimate expectation of resource provision to enable it to play its full part.

The term 'co-production' is increasingly being applied to new types of public service delivery in the UK, including new approaches to adult social care. It refers to active input by the people who use services, as well as – or instead of – those who have traditionally provided them. So it contrasts with approaches that treat people as passive recipients of services designed and delivered by someone else. It emphasises that the people who use services have assets which can help to improve those services, rather than simply needs which must be met. These assets are not usually financial, but rather are the skills,

expertise and mutual support that service users can contribute to effective public services. In the words of Cummins and Miller, co-production is about how services ‘work with rather than do unto users’.

- ***Co-production emphasises that people are not passive recipients of services and have assets and expertise which can help improve services.***
- ***Co-production is a potentially transformative way of thinking about power, resources, partnerships, risks and outcomes, not an off-the-shelf model of service provision or a single magic solution.***
- ***To act as partners, both users and providers must be empowered. Co-production means involving citizens in collaborative relationships with more empowered frontline staff who are able and confident to share power and accept user expertise.***
- ***Staff should be trained in the benefits of co-production, supported in positive risk-taking and encouraged to identify new opportunities for collaboration with people who use services.***
- ***People should be encouraged to access co-productive initiatives, recognising and supporting diversity among the people who use services.***
- ***The creation of new structures, regulatory and commissioning practices and financial streams is necessary to embed co-production as a long-term rather than ad hoc solution.***
- ***Learning from existing international case studies of co-production while recognising the contribution of initiatives reflecting local needs is important.***

(Social Care Institute for Excellence, Research Briefing 31, ‘Co-production: an emerging evidence base for adult social care transformation’, March 2009.)

What next?

Lives Unlimited has demonstrated the currency of its members’ experiences of successfully utilising cash budgets to change lives for the better. It has knowledge, insights and skills which, when made available to others, can help to transform outcomes for individuals and families. It is very highly regarded both locally and nationally for its individual and collective achievements and expertise. However, its resources are largely limited to the availability of its members, whose lives are already busy and demanding. It will be important for the organisation to consider how best it can maintain or further develop its influence in the future, choosing either to restrict its roles to those that are sustainable within its current structure and resources, or to offer a wider range of help and support linked to plans to secure additional resources.

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