

Changing Our Worlds: examples of user-controlled research in action

October 2010

About this report

This report was commissioned by INVOLVE and written by Alison Faulkner.

The report has been written for a broad audience, but with the expectation that readers will have some understanding of research.

Information about INVOLVE

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For further information on INVOLVE please visit our website www.invo.org.uk

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Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.

Margaret Mead



Preface

This has been an enormously enjoyable and inspiring project to work on; the opportunity to meet such a diverse range of projects and people has been amazing. Almost all of them caused me to reflect on my own identity in relation to the identities of the people I met: issues of 'self' and 'other' recurred in different ways. The process has revived my interest in the politics of research production and the issues of power and empowerment. Whilst I hope that I have treated all of the seven projects fairly and equally, they inevitably raised different issues and feelings for me associated with the powerful themes they addressed.

With my own background in mental health research and as a service user/survivor, the first project I visited, Vision Sense, raised both familiar and unfamiliar issues. Following that visit, I began reading Paddy Ladd's (2003) 'Understanding Deaf Culture: In Search of Deafhood' and reflected on issues of community and culture inspired by learning about Deaf culture. With the Rainbow Ripples group, I felt the greatest sense of a shared identity and empathy. In reading the DITO (Disability, Information, Training, Opportunity) report I was deeply moved and shocked by the experiences of hate crime many disabled people experience in everyday life and wrote my next column for Mental Health Today (Faulkner, 2010) on this subject. In my meeting with Michael Shamash of DITO, we reflected on issues of 'self' and 'other' and some of the ways in which these attitudes may form in the society around us.

The Thyroid UK project and meetings took me into unfamiliar territory, which made it particularly important to listen well and to get it right when writing it up. Similarly, I have rarely worked with people with learning difficulties; Sarah, Claire and Philip whom I met at Connect in the North made me feel very welcome and shared very openly with me their hopes and experiences. The young people from Get the Life You Want (GLUW) and Have Your Say were truly inspiring and, once again, made me think about some new and unfamiliar issues; for example, the immense and additional loss for children and young people who are separated from their siblings in the care system.

Alison Faulker

July 2010

Acknowledgements

First of all, I would like to thank all of the people who agreed to take part in this project and shared their experiences, often with considerable passion and enthusiasm. Through them, thanks go to the many participants in each of the seven projects, people who I did not get to speak to but whose lives and experiences are represented here.

Particular thanks go to Vida Field for her help and support throughout the project: assisting with interviews, transcribing tapes, and commenting on drafts.

Thanks to Michael Turner, Mark Pettigrew and Patsy Staddon who each reviewed an earlier draft of the report and provided helpful insights and comments.

The Advisory Group of Mary Nettle, Rosemary Barber and Lucy Simons were a joy to work with and gave wise and supportive advice throughout. And I would like to thank INVOLVE, and in particular the Empowerment Working Group, for commissioning this piece of work.

Alison Faulkner

July 2010

Report summary

The aim of this project was to increase understanding and awareness of the role and value of user-controlled research through exploring in-depth seven examples of research where service users or disabled people controlled the research process (see the table on page 13 and the individual examples for more information about the projects).

User-controlled research

There are different ways of referring to and defining research conducted or controlled by service users, and some people use the terms ‘user-led’ and ‘user-controlled’ research interchangeably. Turner and Beresford, in their report ‘User-controlled research: its meaning and potential’ published by INVOLVE in 2005, suggest that control by service users is the key defining characteristic of user-controlled research, but that making change happen is commonly identified as its central purpose.

Researchers and service users and other key people were interviewed about their project. Questions covered: the origins of the research, the methods used, the nature and extent of user control over the research, and the dissemination and impact of the research findings.

1. The reasons for doing user-controlled research identified by these seven projects were:

- To make change happen
- To highlight the needs of marginalised groups
- Because ‘No-one else will do it’

All of the projects originated out of a commitment to changing or improving the lives of their community of service users, whether directly or indirectly, locally or nationally. Findings from the projects suggest that user-controlled research often arises from within groups of people frustrated by traditional research that overlooks or excludes them and/or services that do much the same thing. Frustrated by the failure of mainstream research to capture their needs or research the things they thought important, they found ways of doing so themselves.



Somebody needed to tell the story of our lives as LGB [lesbian, gay and bisexual] disabled people.

Rainbow Ripples



Through raising awareness of the experiences and needs arising out of their lived experience, groups like lesbian, gay and bisexual disabled people, young people in care, disabled people and Deaf people with mental health needs placed themselves on the map of human experience and were able to exert some influence on local and/or national service or policy development.

2. The projects demonstrated a range of different ways of doing user-controlled research. These included different:

- Research approaches
- Organisational bases
- Levels of control
- Sources of funding

Three projects employed or contracted service user researchers or disabled people to undertake the research; three adopted a ‘capacity-building’ approach in which service users were trained and supported to participate as researchers; and one undertook a clinical study coordinated by the group. A variety of methods included focused events in which people shared their experiences, and the more conventional use of questionnaires, interviews, and focus groups. Common to all of the projects was a shared identity between the researcher(s) and the research participants.

The extent of control by service users varied across the seven projects. Absolute control depended on service users having independent funding (and having control of that funding) as well as a user-controlled organisational base. Having control over the research was seen as vital by all of them. Many of the people interviewed spoke passionately about the significance of having control, both to themselves and to their organisation and their wider community of service users.



It just wouldn't have happened if we hadn't had that level of control.

Rainbow Ripples



3. The benefits of user-controlled research were identified as:

- Making change happen
- Access and trust
- Improved research quality
- Empowerment
- Credibility

Amongst these seven case studies are some powerful examples of user-controlled research making a difference. As stated earlier, all of the projects were committed to making change for the benefit of their community of service users. What is perhaps surprising is the degree to which they achieved this, given their scale and the size of their budgets.

A shared identity between the researcher and participants meant that trust could be established, particularly when conducting face-to-face interviews and focus groups, leading to improved access to participants and to open and honest accounts about the issue under investigation.



It's people who know asking people who know.

Connect Works



The value of a shared identity was also demonstrated when it came to designing the research, deciding upon the questions and analysing and interpreting the findings. The 'insider knowledge' ensured that the research would address the right questions, and be interpreted by people with an understanding of the nature of that lived experience.

For some projects, the increased accessibility that this shared identity brought with it was central to the success of the research. For example: a Deaf researcher who could communicate with Deaf participants using British Sign Language, young people in care talking to other young people in care, and the value of people with learning difficulties seeing a person with learning difficulties facilitating and leading a group.

Empowerment has been identified as a key principle of user-controlled research. These projects help us to understand empowerment and how user-controlled research can bring about empowerment for the service users involved. It was most often mentioned in connection with the two projects that involved supporting service users without previous research experience: the young people's projects and Connect Works. The young people talked of the opportunity the research had given for them to learn new skills and gain confidence. Empowerment reached out beyond the research and into people's lives.



People take us more seriously. That's what empowerment is. Empowerment: you know you can do it.

Young Researcher Network



4. The challenges of user-controlled research encountered by these projects included:

- Resources
- Discrimination
- Dilemmas surrounding identity and power
- Distress

In nearly all of the projects, individuals and organisations had contributed additional resources over and above the funding they had received. Some contributed their time and skills for free because of their commitment to the research. Others subsidised the available funds, whether in terms of actual money or staff time or both, in order to ensure their success.

Many of these projects represented people facing multiple discrimination. For at least two researchers, this became a very real part of the research process; one experienced abuse as he left one of the interviews and one researcher received abusive emails in response to publicity about the research.

Having control over the research did not necessarily mean that issues of control and power were predetermined or unproblematic. Sharing key aspects of personal identity or experience with research participants could give rise to some dilemmas on the part of the researchers. It could lead to people asking more of the researcher than they could perhaps offer, or to some discomfort on the part of the researcher about their role and the power they had adopted in relation to their interviewees. In addition, this shared identity could at times lead to distress on the part of researchers who shared difficult experiences.

All of these challenges highlight the importance of building in good supervision and support for service user researchers and ensuring that lone workers in particular have adequate opportunities for de-briefing and supervision.

5. The impact of user-controlled research demonstrated by these projects can be seen in relation to their:

- Impact on service users
- Impact on the research
- Impact on services
- Impact on policy

Nearly all of these projects had achieved what they set out to do, in making change happen. Some directed their findings towards people in decision-making positions within local services with the aim of making changes through policy and service development.

Service user/researchers involved in these projects talked passionately about gaining new skills, gaining in confidence and feeling empowered. Some had gone on to develop their skills further or to do more research. Many of the projects resulted in tangible outputs which aimed to extend their impact to their wider community of service users. Examples of these include: training packs, information packs and dedicated website, a training programme, DVDs and an improved pathway through mental health services.

Several projects were able to make use of their relationships with powerful allies to impact upon change. The Vision Sense project worked closely with a Deaf commissioner, who was able to understand the issues and politics surrounding the culture of Deaf people; Thyroid UK had a medical ally to assist them with their research as well as a wealth of expertise amongst their members; the National Youth Agency's Young Researcher Network acted as an ally in enabling the successful dissemination of the two YRN projects.

Some of the projects also achieved an impact on national policy, whether by virtue of their efforts at disseminating the findings, or through support from their funding body. Recommendations from the Rainbow Ripples report entered the Commission for Social Care Inspection inspection guidelines. Connect Works, through dissemination via the Skills for Care website may have had an impact on personalisation policy in relation to people with learning difficulties. The young people's projects were enabled to disseminate their findings at a national level through support from the National Youth Agency's Young Researcher Network, including taking part in a House of Lords' debate.

Introduction and background

This is the report of a project commissioned by INVOLVE with the aim of increasing understanding and awareness of user-controlled research. Through exploring a small number of projects in detail, the aim was to reach a better understanding of the role and value of user-controlled research. This study was designed to complement a previous mapping exercise, also commissioned by INVOLVE, which identified 45 examples of user-controlled research across the health and social care spectrum. These projects formed the pool from which these seven projects were selected for more detailed exploration. Further details including published reports and links to the project websites can be found on the INVOLVE research project database on the INVOLVE website (www.invo.org.uk).

There are different ways of referring to and defining research conducted or controlled by service users, as outlined in Michael Turner and Peter Beresford's report: 'User-controlled Research: its meaning and potential' published by INVOLVE in 2005. Some people use the terms 'user-led' and 'user-controlled' research interchangeably. However, others see a clear distinction between the two, where 'user-led' research is only partially controlled or directed by service users and/or is supported by a non-user-controlled organisation. Turner and Beresford suggest that control by service users is the key defining characteristic of user-controlled research, but that making change is commonly identified as its central purpose.

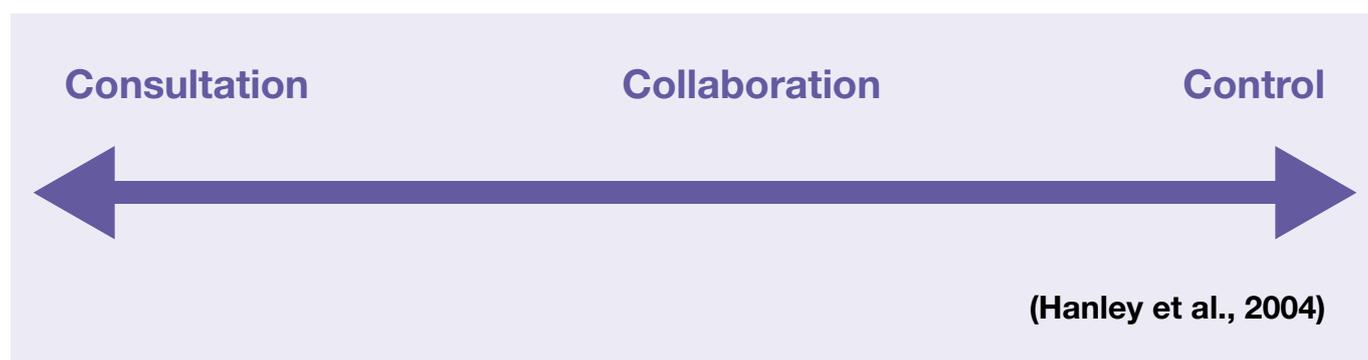
They further identify the aims in terms of:

- Empowerment – both through the process and the purpose of the research
- Being part of broader social and political change
- More equal relations of research production
- Being based on social models of understanding and interpretation.

The value of finding out more about user-controlled research lies partly in its ability to tell us more about one end of the proposed continuum of involvement (see below).

Most public involvement in research is concerned with the large and varied area in the middle of this continuum, with the research itself largely controlled by professional academic researchers. There are many examples of good practice in collaborative research (see, for example, Langston et al., 2005; Faulkner et al., 2008) and growing evidence of its impact (Staley, 2009). However, for many people coming from a service user perspective this approach is seen to 'embody inequalities of power which work to the disadvantage of service users' (Turner and Beresford, 2005; p. iv).

This report, then, turns our gaze towards the different situations in which service users (patients, members of the public) have seen the need to do their (our) own research rather than becoming involved in research directed by others. The focus here is on the value it has to those undertaking it and the difference it makes to the research, the research impact and the research experience when the agenda is clearly held and directed by service users.



User-controlled research has its origins in service users' dissatisfaction with traditional research (see Turner and Beresford, 2005), but also often in people's frustration with the services that fail to listen to them, as this report will demonstrate. There are a number of research traditions that have influenced or hold features in common with 'user-controlled' research. Perhaps the main one of these is emancipatory disability research which aims to empower or liberate service users through the research process. Research can emancipate disabled people/service users through challenging traditional research methods, adopting an inclusive and participatory approach to research, and through describing people's individual or collective experience in their own terms.

Survivor research (research by mental health service users/survivors) shares a common pathway with emancipatory research, in that it is controlled by mental health service users and has the aim of empowerment at its heart (Beresford and Wallcraft, 1997; Faulkner, 2004). Feminist research also began by taking a 'standpoint' approach, aiming to overturn the traditional roles of the researcher and the researched through sharing identity and understandings with the research participants. Key to these approaches is a transparency about the identity, perspective and approach undertaken by the researcher. This is followed through in user-controlled research in the range of ways in which service users undertake and control research that amplifies certain aspects of their own lives and experience.

One of the disappointments for this study was that no projects from black and minority ethnic (BME) communities were identified at the mapping stage; the author communicated with Jayasree Kalathil (a Black survivor researcher involved in the mapping project) about this issue. Kalathil suggested that these are concepts and modes of working that have developed within a survivor movement in which BME service users had very little role to play.



Even today there are very few BME user researchers around, very little money to train/sustain BME user researchers. Very little opportunities for BME user researchers to find work, especially in "general" projects that are not in some way ghettoised...I just feel there might be other definitions of how people see 'control'.

Kalathil, personal communication



The issue of control is discussed in later in the report (see the section on the role and value of user-controlled research) and allows that there were different levels and interpretations of control across these seven projects. Nevertheless, we must remain mindful of the fact that few Black or minority ethnic communities are directly represented in these projects. The one exception to this is the Shaping Our Lives project, Relationship Matters; their project steering group consisted of 12 members, six of whom were from Black and minority ethnic communities. Across the five groups involved in the project, participants included Black and minority ethnic service users and Welsh speakers, amongst a diverse range of service users and disabled people.

The aim of this study, then, was to explore a sample of between six and eight examples of user-controlled research, with a view to examine in detail the role and value of user-controlled research.

Methods

1. Selection of the seven projects

Forty-five projects had been identified in the initial mapping project. As projects had defined themselves as user-controlled research, it was necessary to assess their suitability for inclusion for the case studies. For example, some projects may have a high level of user involvement but were not actually controlled by service users. Therefore, a structured process was followed to select projects; this was carried out by members of the Project Advisory Group and Karen Postle, then a member of the INVOLVE Coordinating Centre.

Each project was reviewed by two people, using the information submitted to the mapping project. The reviews were carried out independently and then collated. With the information available, each project was checked against four criteria:

1. The projects are/were **user-controlled** – a definition derived from the Turner and Beresford report (2005) was used: Research that is actively controlled, directed and managed by service users and their service user organisations. Service users decide on the issues and questions to be looked at, as well as the way the research is designed, planned and written up. Service users will run the research advisory or steering group and may also decide to carry out the research.
2. The projects are/were **research** – a broad definition of research was used and all projects that set out to answer defined questions and followed a systematic process to collect and analyse information were included. If projects appeared to be service development work or consultations they were excluded.

3. The topic was relevant to health, public health and social care research.
4. The project was ongoing or completed within the past two years.

Where there was agreement between the two reviewers that all four criteria were met, the projects were added to the list for possible selection for the case studies. This led to a short-list of 19 projects.

The short-listed projects were organised into seven themes: learning difficulties; mental health; young people; general health; disabled people; lesbian, gay, bisexual and transgendered people; and general user involvement. Across these themes the projects were then listed in rank order to achieve greatest diversity across the range of other factors including funding source, aspects of user-control and any distinctive features of the projects. The project at the top of the ranked list for each theme was approached successfully.

The final list of projects included is set out in the table on page 13.

	Project title	Date of completion	Organisation	Theme
1	Deaf People’s Mental Health Pathways	2008	Vision Sense	Mental health
2	Comparison of urine and blood tests for thyroid function	Ongoing	Thyroid UK	General health
3	Connect Works (what people with learning difficulties want from personal assistants)	2008/9	Connect in the North	Learning difficulties
4	Disability Hate Crime	2007	DITO (Disability Information Training Opportunity)	Disability
5	The Rainbow Ripples report: (needs and hopes of Lesbian, Gay and Bisexual disabled people in Leeds)	2006	Rainbow Ripples	Lesbian, Gay and Bisexual
6	1. Get the life you want (GLUW) – Making the Lives of Young People in Care Better 2. Have Your Say – How Looked After Children are involved in the Review Process	2008/9	Supported by the National Youth Agency Young Researcher Network	Young people
7	Relationship Matters	2008/9	Shaping Our Lives	General user involvement

In practice, the project identity themes overlapped, with disability being a theme to (arguably) five of the projects.

For example 5 the completion date of the project was reported as 2008 in the information submitted to the initial mapping project. Once contact had been made with the user researchers and the actual completion date confirmed we felt committed to include the project in this report.

2. Questions

The second stage was to formulate a topic guide or set of questions to be asked about each project. A preliminary list of questions was amended following discussion with the advisory group and with each project as interviews progressed. A copy of the final list is attached in Appendix A. A secondary list was prepared for the commissioner approached for the Vision Sense project. Interviews did not necessarily follow this list rigidly however; they were regarded as semi-structured conversations and often diverged to discuss interesting tangential issues.

3. Interviewing and data collection

Site visits and group or individual interviews were undertaken with six of the projects; telephone interviews alone took place with project 7. Supplementary interviews or emails were undertaken where key informants were unable to be present at a site visit. For example, the project undertaken by Vision Sense was commissioned by the PCT so a telephone interview was set up with the relevant commissioner. Most of the interviews were recorded and transcribed for subsequent analysis and accurate quotation.

It was not possible to contact all of the people involved in the production of all of these projects. Some people did not respond to approaches made; others were no longer involved with or employed by the original organisation and proved impossible to find. There is always the possibility that those people who did not respond may have held different views about the projects than those who did respond.

4. Other sources of information

Copies of reports were another important source of information. Where possible, all of the project reports have been referenced for access by the readers of this report. Another important source of information was the internet. In some cases, it was possible to trace where a research project had been referenced on the web for use by third parties (e.g. the Department of Health in the case of the Rainbow Ripples report; the London Borough of Tower Hamlets for DITO's (Disability Information Training Opportunity) Disability Hate Crime research, and so on).

5. Feedback to projects

The first draft of each written example was sent back to the project participants to check for accuracy; amendments were made accordingly. They have also had the opportunity to review and comment on the full report prior to publication.

6. Structure of the Report

The seven examples are presented separately in the following sections. The presentation of the examples varies a little in line with the individuality of the projects; hence not all of the sub-headings used are consistent. Quotations have only been attributed to the speaker where a number of people with different roles were interviewed (e.g. researcher, commissioner, disabled person).

After the seven examples, a commentary on the themes and issues arising from the examples is presented in the section The role and value of user-controlled research.

The final part of the report summarises the main conclusions from this project.

Example 1:

Deaf people's mental health pathways – Vision Sense

Summary

This project explored Deaf people's experiences of mental health services with a view to improving their pathways through services for the future. It was carried out by Vision Sense, an independent, user-led, not-for-profit organisation, based in the North East of England (www.visionsense.co.uk), for the North East Commissioning Team for Mental Health and Learning Disabilities which is hosted by County Durham NHS PCT. The report was delivered in 2008. Technically it was a service evaluation; it did not require approval from a research ethics committee.

In this report, the term 'Deaf' is used for those who are born Deaf, mainly communicate through sign language and see themselves as part of a Deaf cultural community and 'deaf' for people who have acquired deafness and mainly use oral means of communication. The term D/deaf includes both communities.

Interviews were carried out with Susie Balderston of Vision Sense, researcher Verity Joyce, and Matthew James, commissioner.

Origins of the Project

The project was initiated by the Commissioners, partly as a result of the Department of Health report 'Towards Equity and Access' on mental health and deafness (Department of Health, 2005) and partly in the wake of two serious incidents involving Deaf people with mental health needs. The commissioner was asked to improve the mental health pathways for Deaf people in the North East; to move away from a pathway based on one specialist mental health nurse for all Deaf people with mental health needs in the region, and to improve outcomes for people whose main care was provided out of area. The Towards Equity and Access report meant that money was available to commission services that would improve the mental health pathways of D/deaf people in the region. The Commissioner was himself Deaf, so he had an understanding of Deaf culture and the importance of a user-led approach to the work.

The Project

The Commissioners designed the brief for the work and commissioned Vision Sense to carry it out. Vision Sense employed two Deaf researchers to find out from service users and carers their views and experiences of mental health services being used by Deaf people. The project steering group included representatives from the local NHS Trusts, the commissioners, local authority, Vision Sense, Northumbria University, and the Deaf researchers.

The project entailed a literature review, interviews with Deaf mental health service users and recommendations for the design of a mental health pathway. Interviews were undertaken with eight people who self-selected to be involved in the project, and two discussion groups reached 12 more. Participants were identified through a snowballing method aided by the Deaf researcher's contact. The researchers took written notes of the interviews; ideally they would have been video-recorded but the time and costs for this including culturally competent translation and transcription would have been prohibitive. Nevertheless, being Deaf herself, the researcher was able translate their words back into the way in which they communicated with her initially, remembering and using their expressions and mannerisms.

Control

Service user control of this project was not absolute, in that it originated with the commissioner and needed to meet the brief given. In his opinion, it was essential for the project to take place in what he considered to be a 'neutral' organisation and to be user-led, in order that it would fulfil the requirements of the commissioning cycle.



Commissioning now is about putting the patient at the centre. If you don't do that, then what you try to do in making a difference won't be widely accepted.

Matthew James



The research element was controlled by service users in the form of Vision Sense and the Deaf researchers. It was undertaken within Vision Sense's ethos of 'a strong commitment to the clarity and integrity of the user-led process and outcomes of equality and human rights in its purpose to create evidence, learning and improvement for all our futures.' Vision Sense uses an In Control grid, based on Arnstein's ladder of participation (Arnstein, 1969), to help them decide on taking on projects; if they do not have sufficient control, they will not take it on. This project was unusual for them in having such a direct link to implementation.

Things that helped the project

- A relationship of mutual respect and understanding between Vision Sense and the commissioners created the space for a user-controlled approach to the project.
- The commissioners' commitment to implementing the findings ensured that the project made a real difference to mental health services for D/deaf people.
- Competent Deaf researchers available to carry out the research ensured that the project could be grounded within the culture with integrity and full accessibility for Deaf mental health service users.

Things that made the project difficult

- A challenge for the Deaf researcher concerned the boundaries of her role and responsibilities. In the course of interviewing people who were vulnerable and often unaware of their rights, she found herself challenged ethically, both to provide information and, occasionally, to intervene to find help for someone who was at risk.
- Vision Sense described lengthy negotiations with the commissioners about content and language in the final report, which was resolved by agreeing to write two versions: one to inform commissioning decisions and a summary report for distribution to service users.
- Maintaining integrity: Vision Sense was concerned to keep the language of service users in the report and remain true to the concept of Deafhood and the social model of disability. They resisted using people's diagnoses and worked with the University to ensure that the training also reflected these values.
- Power and control: for the researcher, there was a growing awareness of her own power and influence and the development of her skills in contrast to the people she was interviewing. Coupled with this was an awareness of her relative lack of power in relation to the commissioners, mediated by Vision Sense. Maintaining that balance of power and the trust of the Deaf community was both a challenge and perhaps an integral part of being an 'insider researcher'.



I would love to be able to explain it on video because I want to empower them. The whole purpose of the research is to release them from their oppression.

Verity Joyce



Making a difference

The report was delivered to the commissioners and used to form the basis of service development. There is now a core specialist team in mental health for D/deaf people, training for mainstream staff (based at Northumbria University), and two Healthy Deaf Minds groups. Vision Sense argued for a second Healthy Deaf Minds group in order to cover another geographical region, and also to ensure that the training was based within an understanding of Deaf culture.

Advice for others

(from the Commissioner)

- Commissioners with a duty to fund user-led research or consultancy need to ensure they have adequate funding to do it.
- It helps to have an independent user-led organisation to undertake the work, to avoid the possibility of creating rivalry between different peer groups.

(from Vision Sense and the researchers)

- Extra time to take account of people's access requirements: e.g. three hours either side of every Steering Group meeting, a personal assistant to go through the papers for a meeting, to work out points people wish to make. With more money and time it could have been more user-controlled, more user friendly; more work could have been done on the translation of the questions into British Sign Language – there is a difference in grammar, facial expressions.



It showed that in this case Deaf mental health service users can tell commissioners how it can be and design the service themselves and see that service then be commissioned. This was a new experience for us and a fantastic opportunity to see service users driving developments.

Susie Balderston



Further information

Deaf People's Mental Health Pathways:
Commissioning Model Report

An Independent, User-Led Perspective
by Susie Balderston at Vision Sense,
May 2008

To obtain a copy of the report, telephone
0845 108 0553, fax **0191 428 3388** or
e-mail **access@visionsense.co.uk**

Example 2:

Comparison of urine and blood tests for thyroid function – Thyroid UK

Summary

This project was carried out by Thyroid UK, a small registered charity run by people with direct experience of thyroid and related problems with the aim of “Providing information and resources to promote effective diagnosis and appropriate treatment for people with thyroid disorders in the UK” (see www.thyroiduk.org.uk). The personal experience of some of their members (people with continuing problems despite blood test results that fall within the normal range) prompted this research. The aim is to examine and compare the accuracy of two different tests (blood and urine) in relation to people’s symptoms. It is a clinical trial, comparing the results of these tests from two groups of participants: a patient group (people who meet the set criteria for hypothyroidism) and a control group (people who meet the set criteria for absence of the disease).

Hypothyroidism is the term given to the symptoms caused by insufficient production of thyroid hormones by the thyroid gland which is in the throat. Symptoms that commonly occur include: tiredness, weight gain, constipation, aches, feeling cold, dry skin, lifeless hair, fluid retention, mental slowing, and depression (www.patient.co.uk accessed 3rd August 2010).

Interviews were carried out with the Chair, Lyn Mynott, the Trustees at the Thyroid UK AGM and with Jane Evans, the study co-coordinator.

Origins of the research

The research arose out of personal frustration and curiosity. Several of their members had experienced the symptoms of hypothyroidism for years before their blood tests showed an abnormal result and triggered the treatment that helped them; as one person said ‘you have lost part of your life’. They came to the conclusion that there was sufficient doubt about the blood test commonly used to diagnose and treat thyroid disorders (the TSH test) to warrant investigation. It is known that various factors can interfere with the accuracy of the blood test, but it remains the gold standard of thyroid testing in the UK. The urine test, which is used by some private practitioners and other European countries in place of the blood test, tests for the end products of thyroid activity and hence may provide a more accurate indication of its function. The team hope that their research will raise awareness of these issues and prompt more research, hopefully a larger study. It is still ongoing at the time of writing. Ultimately, their aim is to improve the treatment offered to people with hypothyroidism.



[Researchers] are not asking the right questions – are the tests as good as they should be?



The research

The team put the idea for the study into the Thyroid UK newsletter. A subcommittee was formed to coordinate the study. One member had worked as a research study coordinator and offered to help with the study. Dr John Lowe (a specialist in fibromyalgia and hypothyroidism based in the United States) will be advising on the research and doing the statistics. Another Board member will do the initial write-up of the study, and the subcommittee will have joint responsibility for finalising it with Dr Lowe's assistance. Thyroid UK obtained approval from the South London and Surrey Borders Research Ethics Committee based at St George's Hospital. The REC insisted that they use the General Health Questionnaire as well as the team's own screening questionnaire, as the latter had not been validated for this purpose. Since no previous questionnaires had been validated for this purpose, they had carefully selected items from other questionnaires. They felt the need to be '110% perfect' in order to achieve credibility.

The research process begins with the study coordinator carrying out an assessment to ensure the volunteers meet the strict criteria laid out in the protocol. This includes the questionnaire, heart rate and basal temperature, plus a short medical history. The questionnaire has a list of 13 symptoms, scored from 0 to 3; for the patient group, the score has to be over 26, for the control group it has to be 6 or under (questionnaire available from Thyroid UK).

Once these criteria are met and the person is allocated to one of the two groups, the study coordinator meets them at a private laboratory in London. The laboratory lets them have access to a room and carries out the tests at cost. At the time of writing, the team has achieved the 25 participants needed for the patient group, but have only recruited seven to the control group due to difficulties encountered with the body temperature criterion (see right).

Control of the research

This project is unusual in that it is a scientific trial under the control of people with direct experience of the condition. Within that context, the team has had control over the entire project with the possible exception of carrying out the laboratory tests themselves. They designed the project with the help of a medical advisor, have their own study coordinator and plan to write it up themselves, again with the assistance of the medical advisor.



We can do the research that we want, as against doing it the way others want it done.



Things that helped the research

- The main facilitator for the research has been the readiness of members and advisors to volunteer their help. The doctor in the United States has clearly been a valuable support and ally; coupled with the skills and abilities of members (a study coordinator, someone to write the first draft of the study, and journal editors) has made the study possible at low cost.
- The laboratory offering tests at cost has contributed to this.

Things that made the research difficult

- There were problems at the ethical approval stage. One doctor wanted to group people according to their blood test results, but Thyroid UK successfully argued that this would have been accepting the accuracy of the test results and therefore would undermine the purpose of the whole study.
- An anonymous person wrote to the ethics committee saying that they should not be allowed to do this research. However, the ethics committee simply forwarded the message to Thyroid UK and did not act on it.
- The main problem in getting the research completed has been a technical one. For people to be recruited to the control group they have to have a normal body temperature as body temperature relates to metabolism which relates to thyroid function. People who are hypothyroid generally have a low body temperature so in order to ensure controls are 'normal' they need to have a normal body temperature. Unfortunately, of 80 controls contacted to date, only seven have what is considered to be a normal temperature. This in itself is strange – and they may want to do some more research on body temperature later. The medical advisor thinks that a lower number of controls will be adequate for the purposes of statistical analysis.
- The project coordinator had to take a long time off when she was not well, which delayed things to some extent.

Making a difference

Thyroid UK plan to submit papers to journals to publish the results; Dr Lowe, their medical advisor, is editor of Thyroid Science and they have another editor amongst their members – of the Journal of Nutritional and Environmental Medicine. They plan to try the British Medical Journal or The Lancet.

They also plan to publicise the results through their newsletter and other organisations' newsletters, and will try sending their findings to other thyroid organisations such as the British Thyroid Foundation. Also, they are hoping to get involved with the James Lind Alliance, an organisation which facilitates the identification of research priorities shared by patients and clinicians, hence its strap line 'Tackling treatment uncertainties together' (see www.lindalliance.org). One of the potential challenges to publication in peer-reviewed journals and wider dissemination is that Thyroid UK is challenging the medical establishment through this research. The hope is that the research will be picked up and will lead to a larger study with more robust statistics.

As an organisation, Thyroid UK wants to do more research, and want to use research to change things:



We have to prove to them that the way they [NHS & the medical profession] are doing things is missing people and these people are ill and missing years of their lives.



Further information

Thyroid UK is a registered charity

www.thyroiduk.org.uk

Tel: **01255 820407**

Example 3:

Connect Works – Connect in the North

Summary

This project was carried out by Connect in the North (www.citn.org.uk), an organisation led by people with learning difficulties. Connect in the North works to improve services and opportunities for people with learning difficulties. The project used research as the basis for developing a training course to train people to become personal assistants for people with learning difficulties. The aim was to enable people with learning difficulties to be able to choose a personal assistant from a list of people who have already been chosen and trained by people with learning difficulties (The Connect Works Team).



I want to be able to choose who I want to look after me, rather than have others controlling me.

Claire Massa,
quoted in *Community Care*,
23 October 2008



For this case study, a group interview was carried out with Sarah Wheatley, who facilitated the project, and Claire Massa and Philip Hawley, people with learning difficulties who helped run the project. Some additional information has been taken from the Connect Works final report (see right).

Origins of the project

The original idea for the project came from a Connect in the North members meeting. Connect in the North believes that people with learning difficulties should have control over their lives. Training people to be personal assistants is one way of doing this. The personalisation agenda, which has become prominent in recent times, meant that the idea could be realised, as it helped them get the funding to carry it out. Personalisation means starting with the person as an individual with strengths, preferences and aspirations and putting them at the centre of the process of identifying their needs and making choices about how and when they are supported to live their lives (Social Care Institute for Excellence, 2010). Funding for the research part of the project came from Leeds City Council. Funding for the training came from Skills for Care: New types of worker money. The people involved were: Claire Massa, Jocelyn Richards, Philip Hawley, David Boyes, Bhupesh Limbachia, Alan Hicks, Manjinder Singh and Susan Hanley (who used to work at Connect in the North) with Sarah Wheatley supporting them.

The research

The team formed two groups: one to work on the research and one to work on the training. The group looked at their own lives as a starting point: they came up with a list of what they would want from a personal assistant and put it up on the wall for people to identify what is good and what is bad. In this way they designed the questions to ask of other people.

In the research, they spoke to 89 people, often in groups face to face, some through questionnaires. They would start a group with an icebreaker and then ask people the questions.

They would put up the answers on the wall and ask people to put stickers or ticks against the things that were important to them. The team would gather up the information at the end. Claire put the information on computer. They also sent out questionnaires to involve other members of the family, but this was not very successful.

The training

The research helped the team to design the training for personal assistants: what training do personal assistants need to make them understand what they have to do. It helped to decide what types of people should come on the training and what was in the training. One thing they found was that values (e.g. treating people with respect) were more important than experience. People also thought that being on time and record keeping were important features.

The team ran the Connect Works training twice. They selected people for the course, ran the training and evaluated the trainers on the basis of their coursework. They then evaluated the course and decided that it needed to be longer. Nine people from the training were chosen to be on a list of personal assistants. This is available to anyone with a learning difficulty who uses direct payments or has an individual budget. The plan for the future is to get the course accredited (see below).

Control of the research

Sarah's role was to facilitate the sessions, to give them a focus. She helped Susan and Claire to decide how to run the sessions. She also wrote up the ideas, writing it up in different ways for the group to decide which was best. They described the control of the project as 'equal but in different ways.' Claire or Susan would come up with the ideas and Sarah would fit it together. It was important to them that people with learning difficulties were in control of the project:



It made a big difference. I enjoyed doing every single bit of it.

Claire

I feel that people who are not disabled who organise these groups don't want to know what disabled people need. We would know what people want. Having disabled people doing this is a big thing. It's people who know asking people who know.

Philip

It's people asking the right questions. I also think it was powerful – people were seeing other people with learning difficulties in valued roles.

Sarah



People with learning disabilities selected people for the training course, trained people and evaluated both the trainees and the course itself, with Sarah's support.

Things that helped the research

The team listed many things that helped:

- Friendship was the main big thing – it had to be there to communicate with each other ‘I miss you all.’
- Working together; being patient, tolerant, understanding, thoughtful; having fun!
- No jargon
- Could slow down so people could keep up; we had breaks
- Being organised – the information was counted up and put on computer [Claire did this]

Things that made the research difficult

- There were differences of opinion amongst the group, but they reached agreement: ‘[we] would put opinions together to get your say into one.’
- Claire said she would get upset sometimes: ‘I would give a bit of my past to show what I meant by something, explaining something.’ They all agreed that there was a lot of support within the group which helped if someone got upset.
- Some participants did not turn up for the training course.

Making a difference

- One of the team, David, now works as an associate trainer, after volunteering for Connect Works. It is his first ever paid employment.
- People have employed personal assistants from the course.
- They have a list of trained personal assistants working in the community.
- People have really changed what they were doing and are happy.
- The 4 week course changed to a 10 week one: it is half a day a week for 10 weeks. It has been run twice
- It was a diverse group of people, which was good. Everyone felt able to share their views.

Future plans

Some barriers for the development of the project were identified in the project’s final report. Connect in the North found that there are barriers to trainers with learning difficulties running accredited training. This is because many organisations funding courses leading to qualifications require the trainers to have a qualification. It is difficult for people with learning difficulties to obtain a qualification in training, although Connect in the North is continuing to explore this. The Open College Network will accredit training led by people with learning difficulties but it is expensive for a small organisation.

Connect in the North are also exploring different ways of funding the training course for the future. These include:

- Contributions from people who have an individual budget
- Core funding from the local authority
- Learning and Skills Council in partnership with a local college.

Further information

Connect in the North

0113 270 3233 info@citn.org.uk

The project is reported on the Skills for Care New Types of Worker website and a copy of the report may be found there:

<http://www.newtypesofworker.co.uk/pages/projects/connect-works/useful-documents>

'Turning the Tables' Connect in the North helps people with learning disabilities train personal assistant. Louise Hunt, Community Care, 23 October 2008.

Example 4:

Disability hate crime – DITO

Summary

This study was carried out by DITO (Disability Information Training Opportunity), a small training, rights, employment and community resource run by disabled people based in Mile End in the London Borough of Tower Hamlets. It was funded by the London Borough of Tower Hamlets as part of the work of their Race and Hate Crime Inter-Agency Forum. The aim of the study was to determine the nature and extent of disability hate crime in the Borough. It was undertaken by Michael Shamash, at the time employed as a consultant on the project, and Stephen Lee Hodgkins, at the time Co-ordinator of DITO.

This case study is based on an interview with Michael Shamash and on a reading of the final report of the study. The case study was checked with Stephen Lee Hodgkins, the co-researcher on the project.

Origins of the research

The need for the study was identified as a result of the work of the Race and Hate Crime Inter-Agency Forum in Tower Hamlets, of which DITO was a member. It was felt that little was known about the nature or extent of disability hate crime, a feeling borne out by the study which found very little previous research on the subject. Disability hate crime has long been under-researched and under-reported. Despite the 1996 Hate Crime Statistics Act, under which the police have to report disability hate crime as a separate category, very few such crimes are reported, it is thought largely due to fears of reprisals. This background, together with what Shamash describes as the 'delicate social fabric' of Tower Hamlets, in which the incidence of hate crime is amongst the highest

in London, led to the Borough's interest in commissioning this research. In some ways, it was a case of synchronicity: disability hate crime became a priority through local and national publicity and hence created the conditions for the study to take place.

The research

The research consisted of four stages: a literature review, a small discussion group with disabled people to identify issues, a questionnaire distributed to disabled people, and interviews with key people in the Borough's network of criminal justice, social welfare and voluntary organisations to determine their activities in this area. The discussion group involved five participants, and the questionnaire reached 45 disabled people. The project was funded by the local authority to the tune of £5,000 and hence carried out 'on a shoestring.'

The research revealed high levels of unreported hate crime, much of it psychological (i.e. bullying, harassment, name calling) and much of it occurring on the streets in public places. Incidents were rarely reported, either due to fear of reprisals or because the victim did not think it worthwhile reporting something that would not be acted upon. Recommendations included the need for widespread publicity and profiling, education and training, the need for borough-wide coordination, the wider use of third party reporting sites and support for disabled people as victims of hate crime.

Control of the research

Control of the research was retained within DITO and the researchers did not feel that there was any interference from the local authority commissioners. The two researchers controlled the whole process and met up regularly to discuss who would be the key figures to talk to. They became part of the Race and Hate Crime Inter-Agency Forum, the hate crime co-coordinating body, on which sat representatives from housing, social services and health and youth and community groups, inter-faith forum and the police.

Shamash said it was important that the research was undertaken by disabled people:



It means that people who are likely to be on the receiving end of hate crime can take some ownership of acknowledging that process.

You're making sense of it through what you go through, it's not something that's 'out there'.



He saw it as operating at several levels: not only is it your lived experience but also your understanding of the nature of that lived experience, as well as enabling people to look at the wider implications for local policy.

He said that research has an important role to play within an organisation like DITO, in helping to describe and reflect upon the processes that define people's lives. Whilst it gives practical things like credibility and funding, he also saw it as formalising the organisation's understanding of people's lives, something they were already doing but on an informal basis. 'You're democratising the research process.'

Things that helped the research

- The timing was right; there had been some recent publicity about disability hate crime and the organisation Scope (disability charity for children and adults with cerebral palsy www.scope.org.uk) had published a report on the subject.
- As a research team, Shamash felt they were flexible; he felt it was important that they went into it with an open mind and a willingness to participate rather than creating resistances unnecessarily.
- Funding from the London Borough of Tower Hamlets; and DITO as an independent organisation led by disabled people able to undertake the research.

Things that made the research difficult

- There were few difficulties overall, although they would have liked the questionnaire to have reached more people. More forward planning might have helped to get a larger sample.
- More thought could have been given to disseminating the results of the study more widely, but they were used locally which was the original intention.

Making a difference

The report of the study is available from DITO (www.ditoh.org Tel 020 7364 6564). They won an award for a poster presentation of the project at the Nordic Nations Disability Research Conference 2007. The report was cited in a couple of academic articles (see, for example, Iganski, 2008).

Following on from this project, DITO carried out a publicity event and produced some materials, which may be found on this website: www.disablism.co.uk/. This is the website version of the 'Hate Crimes against Disabled People' information pack; it explains what hate crimes are and gives information about how to report them in Tower Hamlets. This also involved setting up DITO as a third party reporting site for disability hate crime. The project won a London Borough of Tower Hamlets Community Award.

Since the project, the London Borough of Tower Hamlets has developed its policies on hate crime including disability hate crime, and they refer to the study in the Hate Crime Manual on their website (www.towerhamlets.gov.uk/igsl/1101-1150/1133_hate_crime.aspx#Usefuldocuments).

Further information

DITO (Disability Information Training Opportunity) is a disabled persons training, rights, employment and community resource run by disabled people based in Mile End, East London.

www.ditoh.org Tel 020 7364 6564

Example 5:

The Rainbow Ripples report: The needs and hopes of lesbian, gay and bisexual disabled people in Leeds

Summary

This research was undertaken by a small group of lesbian, gay and bisexual (LGB) disabled people in Leeds called Rainbow Ripples, supported by the Leeds Involvement Project. The Leeds Involvement Project is a service user and carer organisation with the aim of enabling those who use community care services to take control over their own health and social care needs. They support a range of groups across Leeds to voice their views about services to local service providers. The research was funded by Comic Relief and undertaken by a disabled academic researcher based at the University of Hull. The research explored and documented the experiences of LGB disabled people in Leeds, their hopes and needs for services as well as the views of service providers. Follow-on funding was obtained from the Big Lottery with the aim of implementing some of the recommendations.

This case study is based on a group interview with four people: a former manager of Leeds Involvement Project, two members of the original Rainbow Ripples group which has now formally disbanded, and the woman employed as development worker for the implementation stage: Lucy Wilkinson, Doug Paulley, Dorothy Mallon and Quinn.

Origins of the research

Rainbow Ripples was originally set up to campaign for the rights of LGB disabled people in Leeds through the Leeds Involvement Project as a self-organised grassroots group. Rainbow Ripples originally employed a worker with the funding from Comic Relief, but after she left they decided to use the remaining money to fund a piece of research: 'Somebody needed to tell the story of our lives as LGB disabled people.'



We know what the issues are, we know how life is, but you have to have the paper to prove it before you can start influencing things.



The group decided to contract with someone to do the research on a traditional tender basis, partly in order to have more control over how the money was spent and partly in the hopes of gaining evidence for obtaining further funding. They put the research out to tender and appointed Ruth Butler at the University of Hull, a disabled lesbian academic researcher.

The research

The research entailed 20 interviews with LGB disabled people who live, work and/or spend leisure time in Leeds; 5 interviews with key service providers; and a questionnaire survey of 437 service providers in Leeds (of which 60 questionnaires were returned). The group and the Leeds Involvement Project had a commitment to the social model of disability; hence, the research was structured on the basis of the twelve demands of the independent living movement in order to reflect the experiences of disabled people in the disabled people's movement: 'Setting our own agenda, working in your own paradigm rather than somebody else's language even.'

The twelve demands of the independent living movement are: Education and Training; Transport; Technical Aids and Equipment; Housing; Personal Assistance; Employment; Advocacy (advice and support); Counselling; Health Care; Community and Social Life; Leisure; Safety, Harassment and Discrimination (Adapted from Southampton Centre for Independent Living, 2006).

The steering group met on a monthly basis for long discussions about the ethical issues, interviews and analysis. It was intense work, revealing some difficult ethical and political issues around disability, sexuality and identity. At the heart of the research were the conflicting attitudes facing people who embody these two different areas of life experience:

“

...the way disabled people are viewed as not having any sexuality as against LGB being all to do with sexual orientation and sex. And so for some people, LGB and disabled is seen as an adult safeguarding issue... the whole thing is seen as very sordid.

”

Control of the research

The group had overall control of the research, although it was contracted out to an academic researcher. From the outset, Rainbow Ripples made it clear that they were to have control over the research, and the researcher and the University agreed to these terms. That they had control was described as 'key' and 'integral' to the project. One of the members of the group described her previous experiences of research where, although it was intended to be user-led or user-controlled research, the local authority had ultimate control of the research and it felt as if service users were there 'to give them some cred.' The fact that it was a project led by LGB disabled people about LGB disabled people meant that:

“

...there was a degree of trust that you're not going to be painted in an adverse way or a way that's not honest, so you're more likely to answer the question in a more honest way because there's not the same degree of suspicion.

”

Also, it meant that they had control over the theoretical context within which the research was placed: it was framed within the social model of disability.

Things that helped the research

- The commitment of the group was clearly a major factor in enabling the project to happen. Despite some major challenges, the research reached completion and was well received.
- Funding from Comic Relief, support from the Leeds Involvement Project, funding from the local authority and from the Lottery enabled the project and its dissemination to run its course.

Things that made the research difficult

- There was a lack of engagement and support from public sector organisations.
- They had some difficulty getting sufficient participants for the research.
- The researcher received threatening homophobic emails, which had to be investigated formally.
- The research meant a lot of unpaid work for the group members: they felt that they had traded off paid involvement for independence because the latter was so vital to them.

Making a difference

The Rainbow Ripples report was launched and sent out to as many organisations as possible. They produced different formats, and placed a summary report, audio version, easy words and pictures version and a British Sign Language video on the website. In the first three months, around 400 reports were distributed or downloaded. It was taken up by the Commission for Social Care Inspection and the Healthcare Commission (now part of the Care Quality Commission: www.cqc.org.uk) and influenced inspection methods. It is also referenced in the Department of Health's (2007) 'Reducing health inequalities for lesbian, gay, bisexual and trans people – briefings for health and social care staff'; Briefing 13: Disabled lesbian, gay and bisexual (LGB) people.

Following the report's publication, the group applied for and received additional funding from the Lottery for an implementation phase. This started with an evaluation of the impact of the report, followed by development of a training pack and then three small projects based on three recommendations. The implementation phase did not get completed in full, due to a breakdown in relations with the 'parent' organisation following a change in management of that organisation. However, the report received national recognition and the group is justly proud of their achievements:

“

We did it as a small group of people; we put our hearts and souls into it.

”

Advice for others:

- Set up an independent organisation. ‘Just don’t ever think you can’t do what we’ve done but also don’t underestimate it.’



You can be user-controlled without having to train service users to do the interviewing, by contracting with a researcher as we did. It is important to know that there are different ways of doing user-controlled research.



Further information

Rainbow Ripples no longer meet as a group. However, the report is available in standard format, large print, easy read, audio and British Sign Language video on the website:

<http://www.rainbowripples.org.uk/>

Example 6:

Young Researcher Network projects: Get the Life You Want and Have Your Say

Summary

The two projects described here were both led by looked after young people and care leavers. Have Your Say in North Tyneside sought young people's views on the review system for children and young people in care with a view to making it more acceptable to young people. They had the support of the Local Participation Team in North Tyneside. Get the Life You Want (GLUW) in Bradford explored young people's experience of life in care to work out how they could get the life they want. They were supported by the Voice and Influence Team. Both groups were trained and supervised through the Young Researchers Network based at the National Youth Agency

www.nya.org.uk/youngresearchernetwork

Interviews (group and telephone) were carried out with Anthony Read and Elizabeth Goldsborough from the GLUW group, Jason Crawford and Daniel Crawford from Have Your Say, Norrina Rashid from Bradford Voice and Influence Team and Darren Sharpe from the National Youth Agency Young Researcher Network.

Origins of the research projects

These are two of 15 research projects led by young people funded by the National Youth Agency which supported and trained the young people to carry out the research. The Young Researchers Network was founded by the National Youth Agency to support these and other young researchers 'to undertake high quality research to influence and shape children's and youth support services.'

The Voice and Influence Team in Bradford do a lot of peer research with young people. They were trying to improve their contact with looked after young people so when they got the funding, they set up a group of young people in care and asked them what they wanted to research. The group had the freedom to choose any topic, and chose to look at young people in care and how their lives could be improved. They called their project 'Get the Life You Want' or GLUW.

Have Your Say, a group for young people in care in North Tyneside had found that every time they did a consultation with children and young people in care, the review system came up as an issue. They decided to do their research on how young people wanted it improved. They applied to the Young Researcher Network for funding, explaining what the project was, why they wanted to do it and what they needed. The Young Researcher Network then helped with the research proposal and training with interview techniques and other research skills.

The research

1. Get the Life You Want (GLUW) – Making the Lives of Young People in Care Better

The group of young people generated the questions they wanted to ask and narrowed them down in a session with the Young Researcher Network trainer. They used postal questionnaires, focus groups and interviews. The material was typed up and sorted into themes and discussed by the young people in a series of exercises which generated a list of recommendations. The group employed help for the typing and the statistical analysis. At the end of the process the group worked with a professional company to produce a DVD to distribute to young people in care.

2. How Looked after Children are involved in the Review Process (Have Your Say)

Have Your Say reviewed the local and national literature on the review process. From their own experience they generated the questions they wanted to ask and narrowed them down to three main questions: Who controls the review process? Are children and young people's views listened to? How can looked after children and young people contribute to the review process? They held an event to inform people of what they were going to do and an awareness training session for key staff so that they knew about the project.

They used one-to-one interviews and questionnaires with looked after young people and questionnaires given to young people as they left their review meetings. They also gained information from questionnaires for social workers and Independent Reviewing Officers. The information was analysed and recommendations for change generated by the group.

Control of the research

The Young Researcher Network was determined to fund only user-led projects so they carried out a careful support and vetting procedure at the start. They encouraged a discussion from the beginning about how the young people could use the support of the workers and which bits they would need most help with. Both groups were supported by workers as well as by the Young Researcher Network... 'but it was our idea and mainly run by us.'



They give you responsibility because sometimes you know more than other adults know because they haven't lived through it.



Both groups generated their own questions, analysed the responses and wrote up their findings, all with support. One group described doing the interviews themselves 'with the worker just sitting off to one side.' They were, and continue to be, involved in the dissemination of the findings and recommendations.

Things that helped the research

- The Young Researcher Network and the commitment of local support workers helped the research projects to happen.



Young Researcher Network helped us to get training, interview skills training, analysis training, training for proposal writing, questionnaire writing so we've got loads of new skills. We also did training on ethics and public speaking.



- The young people also found meeting regularly with their peer researchers from the other projects to be helpful in sustaining their interest and giving them the opportunity to meet new people 'You had someone else to update and ... someone to share things with.'

Things that made the research difficult

- The Have Your Say group did not get enough interviews at first, so they then did some interviews over the phone.
- The young people found that a lot of work was involved over an extended period of time...



I were at college at the time. I would get up at 7, finish college 4 or 5 ish and then work with Norrina 'til 8. It were a long day.



- The projects entailed additional resources in terms of both staff time and funding from the organisations that hosted and supported them. The small grants (of £3,000 per project) were intended only to add value to existing provision and services.

Making a difference

The Young Researcher Network trainer led a session on identifying the messages from the research, who they should be communicated to and how. The Have Your Say group in North Tyneside presented their findings to Social Services decision makers, heads of service, social workers and was commissioned to make a DVD to be given to all young people when they first go into foster care. The group has now become the local Children in Care Council and has to be consulted by the local authority. It is now starting to engage with younger children.

The GLUW group in Bradford had a big media launch and meetings with the Director of Children's Services and the Head of Social Care. They also took part in a young people's House of Lords debate to share their findings. Two of the seven recommendations have already led to changes and there is a willingness to pick up the other issues.

Both groups have presented at national conferences and the reports have been published through the Young Researcher Network. Both groups have featured in the Newsletter and the Journal of the Social Services Research Group.

Further information

Get the Life You Want: Making the lives of young people in care better by Elizabeth Goldsborough, Anthony Read, Haley Jones. http://www.bkyp.com/pdfs/gluw_report.pdf or contact Norrina Rashid norrina.rashid@bradford.gov.uk

How Looked After Children are involved in their Review Process by J Bradwell, D Crawford, J Crawford, L Dent, K Finlison, R Gibson, E Porter, 2008. Available on the National Youth Agency website (see below).

The Young Researcher Network has produced accessible materials for young researchers, the Young Person's Research Toolkit: <http://www.nya.org.uk/integrated-youth-support-services/young-researcher-network>

Further information available from: Dr Darren Sharpe, formerly of the National Youth Agency, now Sociologist in User Involvement in Research d.m.sharpe@hotmail.co.uk

Example 7:

Relationship Matters – Shaping Our Lives

Summary

This project was undertaken by Shaping Our Lives in collaboration with five other user-led organisations (ULOs). The aim was to explore the theme of networking: to facilitate, promote and increase active networking between service users and user-controlled organisations: ‘to build upon the premise that relationships matter.’ It was funded by the Equalities and Human Rights Commission for a one year period.

A telephone interview was conducted with Fran Branfield of Shaping Our Lives, and the report of the five events was used to supplement this information.

Origins of the research

Shaping Our Lives is an independent user-controlled organisation which started as a research and development project but became an independent organisation and national network in 2002. The idea for this project came out of Shaping Our Lives’ National User Group which meets quarterly. This is a diverse group of service users who are networked with local organisations of service users and who feed into much of Shaping Our Lives work. The group is diverse in terms of all equality issues and in terms of their experience of disabling barriers. They identified the need to explore how to improve networking across and between different user-controlled organisations and groups. Shaping Our Lives then applied for funding to the Equalities and Human Rights Commission during an open funding round held in the first year of that organisation’s formation.

The research

The project was undertaken in an innovative way, through the coordination of five regional events designed to collect evidence from service users about their lived experience. Interpreting research in its broadest sense, they saw themselves as ‘collecting knowledge from service users’ through these events. The first stage was to advertise through their network for five groups to organise the events. Each group was then supported to organise its own local event, although they were free to organise them independently. The five organisations were:

- CONTACT, a peer support service for disabled people based in Bradford;
- Disability Wales, the national association of disabled people’s organisations in Wales;
- Gateshead Action Panel, a disabled people’s organisation based in Gateshead;
- One Voice, a disability information service offering information and advice to people in the Lancaster & Morecambe area; and
- Independent Living Alternatives, a disabled people’s organisation based in London, established to promote the right of disabled people to live independently.

Each event involved the group inviting a diverse range of service users and organisations to attend and to discuss the issues, barriers and needs they face in relation to local networking. The focus was on networking across groups and people with different lived experiences. In total, 52 different user-controlled and disabled people’s organisations participated in the events with 82 people taking part.

Some of the groups organised their events without much support from Shaping Our Lives; others needed more support. Shaping Our Lives provided practical items such as guidelines for support workers, event ground rules, guidance for writing the report. Each group wrote up its own event and Shaping Our Lives wrote the final report based on the learning from all five events.



Often small organisations only have a small voice, even when they have a very important message to get across. Collaboration and ‘joined-up thinking’ between groups can amplify this voice and increase the possibility of change being effective.

Branfield et al., 2009



Control of the research

Control of the project started from the fact that the idea came from service users recognising the need for building on the value of networking and relationship. The project was led and coordinated by a service user-controlled organisation in collaboration with five other user-controlled/disabled people’s organisations. In this sense, the project was entirely controlled by service users, and in addition power/control was shared from the centre to the regional groups. The funders did not interfere with the project during its lifetime, but nor did they give any feedback afterwards.

Control by service users was vital to the project, and was thought to have resulted in empowering experiences for everyone who attended the events. All of them were accessible events with diverse groups of people attending, leading to new connections and relationships based on shared experiences of barriers and a shared desire to work together for positive change.



By sharing knowledge we build our capacity.

Branfield et al., 2009



Things that helped the research

- The enthusiasm of the local groups carried the project through. Most of them welcomed the opportunity it provided for them to network locally and make connections with new groups and new people.
- Practical support was provided by Shaping Our Lives to the five groups to enable the events to run smoothly.
- People were very tolerant of each other’s different needs and ways of being.

Things that made the research difficult

- It was surprisingly difficult to select the five groups as Shaping Our Lives had a good response to their advertisement at the start of the project.
- One or two of the groups needed a lot of support to enable them to undertake their event.
- This one-year project was seen as the start of something and it was difficult to see it come to an end without further funding or the capacity to follow it through as much as Shaping Our Lives would have liked. A greater emphasis is needed on funding to sustain successful projects; one of the challenges for small user-led and disabled people's organisations is the need to move on and find funding for new projects without being able to build on previous successes.

Making a difference

A full report, including all the reports of all five events, was completed and submitted to the funders. An accessible version was produced and placed on the website. All of the groups who attended the five events joined the Shaping Our Lives network SOLNET (<http://www.solnetwork.org.uk/>).

One of the disappointments for Shaping Our Lives was that they failed to obtain additional funding from the Equality and Human Rights Commission to take the work further; this meant that they were unable to find out to what extent the project had affected all of the local groups involved. However, they continue to work with one of the coordinating groups on joint projects and bids for new work.

Advice for others

- This is a valuable approach for gathering knowledge from service users: people feel that they own the project, can get fully involved and feel that they are making a difference. Shaping Our Lives feel that they have experience in running this kind of project now and are keen to use it again.
- Given the chance to do this project again, they would bring all five coordinating groups together at the start so that they could meet each other and learn from each other.
- Getting the groundwork in place before the start is important; planning for eventualities in advance is an important part of the project's success.

Further information

Shaping Our Lives website:

<http://www.shapingourlives.org.uk>

The report is available from

<http://www.shapingourlives.org.uk/ourpubs.html> or by emailing:

information@shapingourlives.org.uk

Tel: **0845 241 0383**

Text users please use TYPE TALK:

18001 0845 241 0383

Postal address: Shaping Our Lives,
BM Box 4845 London WC1N 3XX

The role and value of user-controlled research

The aim of this chapter is to look across the seven case studies and to draw out common themes as well as differences, in order to inform our greater understanding of the role and value of user-controlled research. Throughout this section, the projects are sometimes referred to by using short labels; these are given in the table below:

	Project title	Organisation	Project label
1	Deaf People's Mental Health Pathways	Vision Sense	Vision Sense
2	Comparison of urine and blood tests for thyroid function	Thyroid UK	Thyroid UK
3	Connect Works (what people with learning difficulties want from personal assistants)	Connect in the North	Connect Works
4	Disability Hate Crime	DITO (Disability Information Training Opportunity)	DITO
5	The Rainbow Ripples report: (needs and hopes of Lesbian, Gay and Bisexual disabled people in Leeds)	Rainbow Ripples	Rainbow Ripples
6	1. Get the Life You Want (GLUW) – Making the Lives of Young People in Care Better 2. Have Your Say – How Looked After Children are involved in the Review Process	Supported by the National Youth Agency Young Researcher Network	The Young Researcher Network projects
7	Relationship Matters	Shaping Our Lives	Relationship Matters

1. Reasons for doing user-controlled research

To make change happen

All of the projects were committed to changing or improving the lives of their community of service users, whether directly or indirectly, locally or nationally. As Turner and Beresford (2005) point out, the motivation to make change happen is central to the purpose of user-controlled research. The impact of the projects and the degree to which they succeeded in making change happen is explored further in sections 3 and 5 of this chapter.

To highlight the needs of marginalised groups

This study suggests that user-controlled research often arises from within groups of people frustrated by traditional research that overlooks or excludes them and/or services that do much the same thing. The seven projects powerfully demonstrate the needs and priorities of groups frequently ignored or overlooked by mainstream society, some of whom face multiple discrimination.



Somebody needed to tell the story of our lives as LGB [lesbian, gay and bisexual] disabled people.

Rainbow Ripples



Several of the projects arose out of the need of a group to describe an aspect or aspects of their lived experience; this is referred to by Turner and Beresford (2005) as one of the ways in which research can emancipate service users.

Through raising awareness of the experiences and needs arising out of their lived experience, groups like lesbian, gay and bisexual disabled people, young people in care, disabled people and Deaf people with mental health needs placed themselves on the map of human experience and were able to exert some influence on local and/or national service or policy development. Connect Works, in exploring the needs of people with learning difficulties in relation to their requirements of personal assistants, raised awareness of their needs and priorities within the context of national policy on personalisation.

No-one else will do it

Closely related to the above, several of the projects were responding to a specific need identified by the group: an issue that perhaps no-one else would know about or be interested in if they did not have the relevant lived experience. The Thyroid UK research is a good example of this, in that it was responding to the frustration of many of their members whose views about the inadequacy of the standard blood test for thyroid disorders have long been ignored by researchers and professionals in the UK. The young people's project 'Have Your Say', in exploring looked after children and young people's experience of the review process is another example of an issue identified out of direct experience. Relationship Matters, in exploring the value of networking across groups of people experiencing different disabling barriers, also addressed a theme unlikely to be a priority for non-service user-controlled organisations.

2. Ways of doing user-controlled research

Control

The extent of control varied across the seven projects and it became evident that the nature and level of control was not easy to deduce from information submitted to the initial mapping exercise alone. Absolute control depended on service users having independent funding (and having control of that funding) as well as a user-controlled organisational base. Two of the examples (The Young Researcher Network projects, Connect Works) originated from within non-user-controlled organisations and their control of the research was not absolute. The groups involved did not have control over the funding themselves but received training and support to give them the skills and knowledge to select their own topic and to undertake the research.



...it was our idea and mainly run by us.

Young Researcher Network

[it was] equal but in different ways.

Connect Works



In both cases, it was clear that the intention of the supporting staff was to enable the groups to have control over the research. Whilst these two projects may have had less control than the others, what they did achieve was to empower service users who had no previous research experience through the process of participation. It is hard to make a judgement on the basis of these seven projects, but this raises the possibility that some groups may benefit from a greater level of support even if it does mean a lesser degree of independence or control.

Although the extent of control varied across the seven projects, having control over the research was seen as vital by all of them. Many of the people interviewed spoke passionately about the significance of having control, both to themselves and to their organisation and their wider community of service users.

It was important to be able to do the type of research they wanted as well as researching the issues they wanted. For some, this was inextricably linked to their commitment to the social model of disability and the importance of carrying out research within the context of their chosen paradigm. One more experienced researcher referred to the essence of having control over the research as 'democratising the research process.' [DITO]



It just wouldn't have happened if we hadn't had that level of control.

Rainbow Ripples

Having disabled people doing this is a big thing.

Connect Works



The independence of certain projects was slightly compromised by their closeness to local commissioners; what some projects gained in influencing change through this relationship, they may have lost a little in independence. For example, there was some debate over the final report from Vision Sense because of the need for it to be framed in a way to communicate with the commissioners. Equally, Rainbow Ripples, in compromising none of their independence, may not have influenced local services as much as they might have wished. Similarly, Thyroid UK, in taking an entirely independent stance, may not have as many routes as they wish open to them when they come to disseminate their research findings. Again, it is hard to draw firm conclusions about the relationship between independence and influence from this small sample of projects.

Different approaches, different methods

Common to all of the projects was a shared identity between the researcher(s) and the research participants. This has already been highlighted as a common feature of emancipatory research (see Introduction and background), and tends to distinguish user-controlled from mainstream research. This shared identity is closely related to the core motivation of all of the projects to make change happen for others similarly affected by the issues under investigation.

Connect Works and the Young Researcher Network projects involved supporting the development of small groups of service users, whereby people without previous research experience were trained and supported to undertake the research themselves. This 'capacity building' approach is quite common throughout user-controlled, survivor research and collaborative research. It potentially creates the opportunity for the newly trained service user researchers to be empowered by taking part in the research process (e.g. through learning skills and knowledge, and gaining confidence).

DITO, Vision Sense, Rainbow Ripples each engaged individual researchers who shared key aspects of their identity with the service user participants. Rainbow Ripples contracted with an academic researcher to carry out the research on their behalf but selected a researcher who identified as a disabled lesbian and so shared identity with the research participants. The group controlled the research through setting the topics, identifying the questions and becoming fully involved in the analysis and report writing. The researcher brought technical research skills to the project: gaining ethics approval and employing content analysis of the data.

The methods used in the projects ranged from the more conventional use of questionnaires, interviews and focus groups through to more innovative and exploratory methods. For example, in Connect Works, people with learning difficulties facilitated focus groups and used unconventional but necessarily accessible methods of recording and analysing the data. The Shaping Our Lives project (Relationship Matters) took perhaps the most innovative approach to the research; through engaging people in five local events they explored people's experiences of the meaning of networking and relationships. This approach, taking the interpretation of research as 'gathering knowledge' from and with service users, is one they have found to be valuable and are keen to use again.

The Thyroid UK project stands alone in that it was a clinical study, the clinical aspect of which was undertaken in a laboratory on behalf of the organisation. The research was coordinated by a subcommittee of the Management Committee, with the study coordinator being a member of Thyroid UK with personal experience of thyroid disorder.

Organisational base

Five of the projects arose out of user-controlled organisations or groups which had different levels of funding and organisational security (although at the time of writing, Rainbow Ripples no longer meets as a group). They shared a strong ethos of promoting and encouraging the voice and the rights of service users or disabled people. Three of these organisations, Shaping Our Lives, Vision Sense and DITO, have a history of undertaking user-controlled research with a range of different service user or disabled people's groups.

The remaining two, the Young Researcher Network projects and Connect Works were different in that they were supported from within non-user-controlled organisations. However, both retained a strong ethos of supporting and enabling the groups to undertake their research with a significant amount of control and independence.

A common factor across at least five of the groups/organisations was a strong commitment to a social model of disability, which supports one of the potential aims of user-controlled research identified by Turner and Beresford (2005).

Sources of funding

Funding came from a variety of sources: local authority, NHS Primary Care Trust, Lottery, Comic Relief, charity fundraising donations, Skills for Care, the Equality and Human Rights Commission and the National Youth Agency. In some cases, very small amounts of funding were involved: for example, the DITO research received £5,000 and the Young Researcher Network projects £3,000 each (although these were supplemented by extensive support from their 'parent' organisations). It is significant that all of these funders share a remit to promote equality and diversity or to meet the needs of minority groups.

Whilst some of the projects identified a need and then obtained funding for the research (Connect Works, Thyroid UK, Rainbow Ripples, Relationship Matters), others (DITO, the Young Researcher Network projects and Vision Sense) took advantage of a funding opportunity arising out of local policy or service developments or, in the case of Young Researcher Network the funding round announced by the National Youth Agency. In relation to DITO and Vision Sense, local commissioners (the Primary Care Trust or local authority) had identified the needs of a particular group as requiring further exploration in order for service developments to reflect these needs. In each case, the commissioner chose a local independent and user-controlled organisation with whom they had an established relationship, to carry out the work.

3. The benefits

Access and Trust

For most of these highly marginalised groups, it was vital that the research should be carried out by someone who identified as a member of that group. A shared identity between the researcher and participants meant that trust could be established, particularly when conducting face-to-face interviews and focus groups, leading to improved access to participants and to open and honest accounts about the issue under investigation.

For some projects, the increased accessibility that this shared identity brought with it was central to the success of the research. The value of this was illustrated by, for example, a Deaf researcher who could communicate with Deaf participants using British Sign Language, young people in care talking to other young people in care, and the value of people with learning difficulties seeing a person with learning difficulties facilitating and leading a group. This essence of trust established through breaking down the barriers of power between the researcher and the researched was important to all of the projects. Establishing trust between the researcher and the researched is at the heart of user-controlled and emancipatory research.



...when you're interviewed by an academic or someone you don't know you don't have the same level of trust because you don't know what they're doing with that information.

Rainbow Ripples

It's people who know asking people who know.

Connect Works

If it had been someone else, they might not have wanted to talk to an adult. We know how to put things because we've been in care.

Young Researcher Network



Quality of the research

The value of a shared identity was also demonstrated when it came to designing the research, deciding upon the questions and analysing and interpreting the findings. The 'insider knowledge' ensured that the research would address the right questions, and be interpreted by people with an understanding of the nature of that lived experience. The importance of this was highlighted by Rainbow Ripples, DITO, Connect Works, and Vision Sense.



You're making sense of it through what you go through.

DITO

Adults may not see the same things as an issue, like going to a meeting wouldn't be an issue for an adult because they go to meetings on a day-to-day basis, they might overlook how hard it is going somewhere else but we understand that it would be a big issue. Young people know what to look for because they know what the problems are themselves.

Young Researcher Network



Empowerment



People take us more seriously. That's what empowerment is. Empowerment: you know you can do it.

Young Researcher Network



It is not always easy to articulate what empowerment is, although it is identified as a key principle of user-controlled research. These projects help us to understand empowerment and how user-controlled research can bring about the empowerment for the service users involved. It was most often mentioned in connection with the two projects that involved the support of service users without previous research experience: the Young Researcher Network projects and Connect Works. The young people talked of the opportunity the research had given for them to learn new skills and gain confidence:



...lots of training and loads of new skills and I've learnt how to talk to more people... when you know what you're talking about and know how to address people it gives you that confidence.

Young Researcher Network



“

I think it's empowered us.

Young Researcher Network

”

Perhaps more significantly, the young people and the people with learning difficulties came to recognise and develop their own expertise, not just through the research itself but also through its dissemination and implementation.

“

If you've lived through it you know more than going to university.

Young Researcher Network

”

The research and the Young Researcher Network gave the young people opportunities to speak at conferences and meet people at a range of events. Connect Works enabled some of the people with learning difficulties to carry out training themselves and to choose their own personal assistants. Empowerment, then, reached out beyond the research and into people's lives.

“

It wasn't just the research, it's opened lots of doors for us, we got involved in all sorts of other stuff...go to all sorts of places you wouldn't ever have gone to, like the House of Lords.

Young Researcher Network

I want to be able to choose who I want to look after me, rather than have others controlling me.

Connect in the North

”

Making change happen

Amongst these seven case studies are some excellent examples of user-controlled research making a difference. As stated earlier, all of the projects were committed to making change for the benefit of their community of service users. What is perhaps surprising is the degree to which they achieved this, given their scale and the size of their budgets.

The close relationship between Vision Sense and the commissioners in the Primary Care Trust, ensured that their service evaluation was able to influence the development of services for D/deaf people with mental health needs. From the start, they knew that there was funding available for implementing the findings, but this example also raises the importance for some projects of having powerful allies (which is also the case for Thyroid UK).

Both Rainbow Ripples and Connect Works obtained additional funding for implementing their findings (from the Lottery and Skills for Care, respectively); both included the development of training packages. DITO obtained additional funding for dissemination that included an information pack and accessible website on which to host it. In addition to this, several of the projects were able to inform national policy in some way (see section 5 in this chapter).

Credibility

Several of the projects talked of the importance of establishing credibility through carrying out the research, whether for their organisation or for their community – or both.

For small user-controlled organisations struggling to sustain themselves in a difficult financial and political climate, this was particularly important. Vision Sense had previously achieved credibility through obtaining a service level agreement with the Primary Care Trust on the advice of the commissioner. However, both the researcher and the Vision Sense lead felt the need to take further training in research skills subsequently, in order to improve their credibility to undertake similar projects in the future. DITO also valued the credibility gained through undertaking the research as well as the opportunity it gave for them to formalise the organisation's understanding of people's lives.

4. The challenges

Resources

It became evident that, in nearly all of the projects, individuals and organisations had contributed additional resources over and above the funding they had received. Some contributed their time and skills for free because of their commitment to the research (e.g. Thyroid UK, Rainbow Ripples). Similarly, other organisations subsidised the available funds, whether in terms of actual money or staff time or both, in order to ensure their success: e.g. the Young Researcher Network projects, Connect Works.

It has been pointed out elsewhere (Faulkner, 2004; Turner and Beresford, 2005) that adequate resources are needed to do this kind of research well. Some needed resources to increase and improve accessibility for service users with particular dis/abilities or use of language, both at the research and at the dissemination stages. Some needed additional resources in the form of training and ongoing support in order to be able to undertake and complete the projects successfully.

Shaping Our Lives was disappointed that they could not get the additional funding to secure and develop the newly-formed networks established by Relationship Matters. A lack of capacity in small user-controlled organisations can often mean moving on to the next project without being able to build on the successes of those already completed.

Discrimination

That many of these projects represented people facing multiple discrimination has already been mentioned (see section 1 in this chapter). For at least two researchers, this became a very real part of the research process. The Rainbow Ripples researcher received threatening emails in response to publicity about the research and the disabled researcher for DITO was verbally abused by a member of the public as he left one of the interviews. Similarly Thyroid UK, in addressing a minority issue in the field of thyroid disorders, was subject to a complaint made to the relevant Research Ethics Committee.

These experiences reflect the very issues that many of the projects are seeking to address, and powerfully emphasise the importance of planning in support for service user researchers, particularly lone workers. The importance of establishing good supervision and support from the start of a project is also indicated by the other challenges people faced during the course of these projects.

Identity and power

Having control over the research did not necessarily mean that issues of control and power were predetermined or unproblematic. Sharing key aspects of personal identity or experience with research participants could give rise to some dilemmas on the part of the researchers. Gaining people's trust through identification could lead to people asking more of the researcher than they could perhaps offer, or to some discomfort on the part of the researcher about their role and the power they had therefore adopted. For example, the Deaf researcher for Vision Sense struggled with issues of power and control. She felt ambivalent about the power she held as a result of her role in relation to the interviewees and at the same time felt relatively powerless in relation to the commissioners of the research.



This research has spurred me on because we need evidence for future funding for projects. I want to get my research skills up, report writing and things but I am aware that I'm growing in power. I've only realised it recently because of getting into emancipatory research. It's like I'm being paid, but you [interviewee] are the one who is still having to go through it.

Vision Sense



For the project to be truly emancipatory in relation to the participants, to engage them more fully in the project, would have needed more resources in terms of both time and money and, she felt it might have meant failing to obtain approval from the ethics committee.

Distress

A shared identity could also lead to emotional distress on occasions, where an individual's personal experiences were remembered or relived through interviewing others. This happened for one of the Connect Works researchers, but she said she felt well supported by the group with whom she was working.

5. The impact

The impact of the completed projects in this sample was disproportionate to their size and scale: in short, they 'punched above their weight.' This was largely due to a strong commitment to maintaining a focus on implementation from the beginning, and a proactive approach to making significant links and making use of networks. Connections with powerful allies were made or taken advantage of, some projects obtained further funding in order to ensure implementation and others were linked directly with local commissioners.

Impact on service users

There were many (predominantly positive) ways in which the research impacted upon the service users involved. As we have seen, some people talked passionately about gaining new skills, gaining in confidence and feeling empowered. Some had gone on to develop their skills further or to do more research (Vision Sense; the Young Researcher Network projects).

The impact of the research on the wider service user communities is rather more difficult to quantify, although some of the projects resulted in tangible outputs which had that aim in mind:

- Vision Sense produced an improved pathway through mental health services
- Connect Works resulted in a training programme for personal assistants led by people with learning difficulties
- DITO produced an information pack and dedicated website
- Rainbow Ripples resulted in a training pack and accessible formats for their findings
- Young Researcher Network projects produced DVDs for young people in care
- Shaping Our Lives developed the seeds of new service user networks around England and Wales as well as an accessible report.

Impact on the research

All of the projects mentioned the positive impact of service user control over the research in a number of ways, many of which have been mentioned already:

- increased access to research participants
- a relationship of trust between researcher and researched leading to a greater level of openness and honesty (less suspicion)
- improved accessibility for participants – and hence, inclusivity
- selecting topics and asking the right questions, based on ‘insider knowledge’
- more relevant analysis and interpretation of findings, based on a service user perspective
- dissemination that reaches the service users from whom the research originated (e.g. training by people with learning difficulties; accessible formats for findings to reach people with different disabilities).

Impact on services

Many of these projects had achieved what they set out to do, in making change happen. Some directed their findings towards people in decision-making positions within local services with the aim of making changes through policy and service development. Notable amongst these are the Young Researcher Network projects, DITO and Vision Sense.

Vision Sense stands out here in that it was closely connected with the commissioning cycle which had designated funds available to implement their findings. DITO was also connected with local commissioners; some of their recommendations were taken on board, they became a third party reporting site for disability hate crime. The Young Researcher Network projects also had an impact locally: Have Your Say made a DVD to be shown to children on entering foster care and they have become the local Children in Care Council. Two of the recommendations from the project Get the Life You Want project have been taken up by local services: two extra workers have been appointed to the fostering and adoption unit, in order to be able to do more family work, keeping in touch, sibling issues; and there are negotiations with the contracted provider about the location of tenancies to help avoid placing young people in difficult areas of the city.

Several projects were able to make use of their relationships with powerful allies to impact on change. The Vision Sense project worked closely with a Deaf commissioner, who was able to understand the issues and politics surrounding the culture of Deaf people; Thyroid UK had a medical ally to assist them with their research as well as a wealth of expertise amongst their members; the National Youth Agency’s Young Researcher Network acted as an ally in enabling the successful dissemination of the Young Researcher Network projects.

Impact on national policy

Some of the projects managed to have an impact on national policy, whether by virtue of their efforts at disseminating the findings, or through support from their funding body. Recommendations from the Rainbow Ripples report entered the Commission for Social Care Inspection inspection guidelines. Connect Works, through dissemination via the Skills for Care website may have had an impact on personalisation policy in relation to people with learning difficulties. The young people's projects were enabled to disseminate their findings at a national level through support from the National Youth Agency's Young Researcher Network, including taking part in a House of Lords' debate.

Conclusions

This section contains the key messages from this detailed exploration of seven user-controlled research projects.

1) These seven projects powerfully demonstrate what can be achieved by small organisations or groups of service users on sometimes very small budgets:

- most had found creative ways of ensuring that the findings reached the people that mattered, some through obtaining additional funding and some through their relationship with powerful allies.

2) The projects were motivated by the desire for positive change:

- to improve the lives of service users
- to improve services or influence policies that will affect the lives of service users.

3) These seven projects highlight the potential of user controlled research to raise awareness of the needs of groups and people often ignored or overlooked by mainstream society, creating opportunities to:

- describe and account for their lives, and to
- identify and explore specific needs not addressed by mainstream research.

4) The projects highlight the potential of user-controlled research to create the conditions for empowerment through:

- equalising the relationship between researcher and researched through a shared identity
- establishing trust with research participants
- enabling service users to participate in the research process with training and support
- leading to positive change.

5) The challenges they faced were common to many research projects involving service users:

- issues of identity and power, personal distress and inadequate resources
- however, a few of them also faced incidents of direct discrimination during the course of the research
- these challenges indicate the need for user-controlled research projects to establish support strategies to sustain them through difficult times.

6) The things that helped them to succeed included:

- passion and commitment
- funding
- good support and training
- support of powerful allies.

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- Turner M. and Beresford P. (2005b) **What User-controlled Research means, and what it can do**. (An easy read summary of a report about user-controlled research). www.invo.org.uk/publications

Appendix A: List of questions

Origins of the research project:

1. Where did the idea come from originally – or from whom?
2. How did it develop into a research project?
3. How did it get funded – and what was the influence of funders?

What makes this project ‘user-controlled’?

4. Who and how were service users controlling, leading and/or carrying out the research?
5. Is the project based within a user-controlled organisation or group?
6. Does it have support from non-service users?
7. What differentiates this research from research that involves service users: (do they have experience of both?)
 - a. If so, what are the differences and similarities,
 - b. ...advantages and disadvantages?

Process:

8. How was the research designed and planned – and by whom?
9. How was the project managed and run?
10. Was it influenced by any outside agencies – e.g. funders, etc. ?
11. Who carried out the research?
 - a. Methods
 - b. Training
 - c. Support
12. What approaches appeared to work for the project?
13. What have been the ‘facilitators’ for the project? What key features helped to make the research successful?
14. What have been the barriers – and how were they overcome?
15. Were there any ‘turning points’ or changes of direction? (why?)
16. Did any difficulties emerge along the way – and how were they overcome?

Impact of the project:

17. Whether the intended impact of the research was achieved and what actually happened, including explanations for these impacts.
18. What was the impact of the user-controlled research on those participating in the research?
19. Has taking a user-controlled approach added value to the research? (if so, how)
20. Did the research come up with ‘different’ outcomes or results as a result of being user-controlled (as against a collaborative or non-user run project)?
21. Have any publications emerged from the research? What – and can we have copies...?
22. What influence on practice has the research had – if any?

Learning from the experience:

23. Would you do anything differently if you were starting the project knowing what you know now?
24. What suggestions or recommendations would you make to others about to embark on something similar?

Appendix B:

Members of the Project Advisory Group

Rosemary Barber

Honorary Senior Research Fellow,
University of Sheffield and member of INVOLVE

Mary Nettle

Mental Health User Consultant
and member of INVOLVE

Lucy Simons

Public Involvement Advisor, INVOLVE

Further information

This report is supplemented by:

A summary report: Faulkner A. (2010)
Summary Changing our worlds: examples of user-controlled research in action,
INVOLVE, Eastleigh

An easy version of Example 3: Faulkner A.
and Connect in the North (2010) **Easy read version: Connect Works – Connect in the North,** INVOLVE, Eastleigh

We have also produced a series of short films available on DVD and our website. These include one film about user-controlled research and four short films presenting the examples of user-controlled research.

This publication is one in a series. Other titles available are:

Blackburn H., Hanley B. and Staley K. (2010) **Turning the pyramid upside down: examples of public involvement in social care research,** INVOLVE, Eastleigh

These and other useful INVOLVE publications are downloadable (free) from:

www.invo.org.uk

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Please see page 59 for a DVD which includes a 15 minute film about user-controlled research and short films about four of the examples described in this report.

Disclaimer: The views and opinions expressed in this publication are those of the authors and do not necessarily reflect those of INVOLVE or the National Institute for Health Research.



This report provides a clear guide to user-controlled research. The detailed examples address the practical considerations for user-controlled projects and will help others to steer clear of potential pitfalls and complete successful projects. They show the value and range of evidence that user-controlled projects can produce. And the key message coming from all the projects described is that improving health and social care services is the fundamental purpose of user-controlled research.

Michael Turner

Co-author of User-Controlled Research – it's meanings and potential
(now based at the Social Care Institute for Excellence)



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