

**Shaping
Our Lives**

National User Network

S | P | R | U

Shaping Our Lives/Social Policy Research Unit

Social Care Outcomes Seminar

Issues for Professionals and Service Users

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1. FORWARD

This report is the fruit of a long collaboration between a service user controlled organisation and a university research unit. It is a sign that such collaborations *can* work and can offer a helpful way forward for policy and practice development – when trust and shared understandings develop.

The idea of a seminar which brought together service users with professionals and researchers to discuss the topic of outcomes has been some time in the making. The first funded piece of work undertaken by the project that was to become the user-controlled organisation, Shaping Our Lives, was concerned with developing a user perspective on outcomes, that is to say, what effect services and support actually had for service users. Because of common interests in outcomes, the Social Policy Research Unit was able to take the opportunity of part funding some of the group's early work. Together we recognise the essential place of user-led research and development not just in understanding social care outcomes, but also in taking forward new understandings into useful tools for development. At the same time we know there are differing perspectives, which may sometimes conflict. Our aim in planning such a seminar was to encourage a dialogue, conducted on an equal basis, with the aim of clarifying commonalities and differences, and identifying an agenda for future discussion and research.

It has taken some time to bring this idea to fruition, not just because of the need to find funding for the event, but also because of the competing pressures resulting from the need to sustain a self-financing research unit in the academic sector, and Shaping Our Lives' struggle to establish itself as a wider organisation with some infrastructure funding in the voluntary sector.

In 2002, Shaping Our Lives was awarded core funding from the Department of Health to act as a service user 'centre of excellence' to support service users and their organisations, at national and local levels, gain more effective user involvement in policy and provision and better quality services and support. Now as Shaping Our Lives National User Network, it is an independent and democratically constituted and user controlled organisation working across user groups.

The seminar has been conducted as part of a Department of Health funded programme of work on disability, and we are grateful for the Department's support. We look forward to further collaborations and hope this one will

encourage positive partnerships between other research and service user organisations.

Peter Beresford and Hazel Qureshi

2. INTRODUCTION

This report details a seminar jointly hosted by Shaping Our Lives and the Social Policy Research Unit (SPRU) as part of the *Outcomes for Disabled Service Users Project* currently underway at SPRU. The seminar sought to draw together key individuals from service user groups, such as Shaping Our Lives, researchers and professionals from local authority social services departments to address issues around outcomes. The intention of the session was to provide a forum at which professionals from social care and service users can exchange views on the outcomes of social care, with the aim of establishing common ground between different stakeholders concerning definition of 'outcomes' and to discuss possible areas of difference.

Shaping Our Lives, an organisation of service users, has been involved with SPRU for a number of years. A project with an explicit focus on 'user-defined outcomes' was established which had a remit to examine the perspective and views of service users (Shaping Our Lives, 1997, 1998). Shaping Our Lives' work has subsequently expanded to involve a development project with four local groups of service users (including disabled people, mental health service users/survivors, older people and people from black and minority ethnic communities who use services) to test out the ideas and themes highlighted by the first phase of the project. This project recently concluded and is shortly to be published as *From Outset to Outcome: Report of four development projects on user defined outcomes* (Shaping Our Lives, 2002). It was through meetings between Shaping Our Lives and SPRU that the agenda for this seminar evolved.

Outcomes for Disabled Service Users is the second SPRU project to focus specifically on the outcomes of social care for disabled people (in the context of this project 'disabled people' includes people with physical and sensory impairments of working age). The first project identified the desired outcomes of social care services for disabled people from the perspectives of a range of stakeholders – including disabled people, carers and local authority staff – and undertook development work with one local authority to establish a system for evaluating the outcomes for an equipment and adaptations service (for further information see Bamford *et al.*, 1999; Qureshi, 2001).

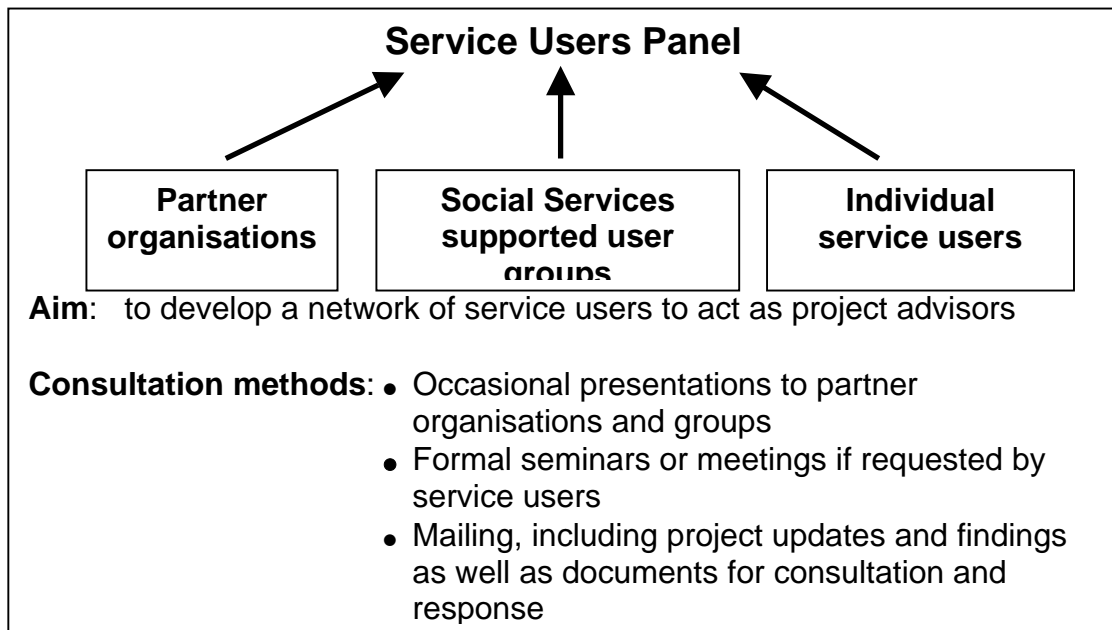
The current project seeks to build upon the basic framework of social care outcomes for disabled people by exploring opportunities for introducing an

outcomes framework into routine practice within the provision of social care services for disabled people. The project aims to develop the framework further by testing whether it is feasible and useful to incorporate an outcomes focus into assessment and review procedures with disabled service users (a summary of the project is in Appendix A).

Central to the project is engagement with service users, both individually and collectively via the service user and disabled people's movements. To this end a number of strategies are being employed: first developing SPRU's relationship with organisations of service users and disabled people – most notably Shaping our Lives – and secondly by establishing a service user's panel in the partner local authority. As a research institute SPRU has a long tradition of working collaboratively with service users and other groups involved in its research. SPRU is engaged in a wide range of social policy orientated research around two main areas, health and social care and poverty, living standards and social security and seeks to ensure that research participants' voices are clearly heard in its work. Furthermore SPRU recognises the importance and validity of user-led research.

User involvement and influence is also central to the project at a local level. Service users will be included in the development, trial and evaluation of the assessment, care planning and review tools being produced. All service users who have an outcomes assessment or review will be involved in the project. Service users are also involved in planning and project management. A representative of a local organisation of disabled people sits on the project advisory group alongside other experts from academia, local authority social services, disability organisations and our funders, the Department of Health.

A service users panel has been established. The aim of this panel is to develop a network of service users to act as project advisors over the life of the project. Three main mechanisms are being employed to recruit participants. Firstly, we are establishing links with partner organisations of and for disabled people and service users within the county, secondly we are working with existing user groups and panels currently supported by social services and thirdly, we are circulating information via social services and voluntary organisations with the aim of reaching services users not involved in other groups.



A variety of methods for consultation will be employed, including presentations by the research team, newsletters and direct requests for comment on particular aspects of the project. All information will be provided in accessible formats. A specific area of work with the service users panel will be the development of information and support about outcomes focused assessment for service users.

3. THE SEMINAR

The seminar involved 27 participants – 15 representatives of service user organisations, eight local authority social services staff and four academics (a full list of participants is available as appendix a). There were three presentations each followed by group discussions. The seminar concluded with a plenary session chaired by Peter Beresford of Shaping Our Lives.

The presentations

(Fuller versions of the presentations are available as appendices D-F).

Michael Turner presented Shaping Our Lives' work on user perspectives on outcomes of social care. He detailed the two projects Shaping Our Lives has completed since 1996 that initially sought to identify user perspectives on outcomes and the role users can play in work on outcomes. The second phase piloted methods of outcomes in practice with local groups of service users (including older people, and groups of service users from black and minority ethnic groups). The presentation ended with an outline of Shaping Our Lives current development of a National User Network, which have outcomes as a central focus.

Mick Ward of Leeds City Council's Modernisation Team outlined a number of initiatives underway in Leeds that are grounded in the social model of disability. The initiatives include ensuring that the skills and abilities of staff undertaking assessment are social model based and providing information for service users to make assessment and care planning processes more accessible. In addition a scheme to provide minor aids and adaptations without assessment and partnerships with local transport providers, media and estate agents was discussed.

Hazel Qureshi summarised her recent thinking on the potential of standardised outcomes in relation to defining rights to services and for measurement. Examples from recent practice in Northumberland and with mental health system users were used to illustrate important principles such as the linking of fairness and outcomes. Questions were raised about the role of service users in deciding standardised outcomes and where accountability for these outcomes should lie.

4. KEY THEMES

User defined outcomes

Context

That service users should be involved in the planning and delivery of services and that services should be needs rather than service-led is no longer subject to debate. The trend towards involving service users dates back to the early 1960s and can be traced through influential reports – Seebohm Report 1968, Griffiths Report 1988 – government documents – such as *Caring for People* 1989 - and legislation – Disabled Persons Act 1986, NHS & Community Care Act 1990. User consultation and involvement is 'no longer simply a good thing' (Beresford, 1992; Beresford *et al.*, 1997, 1998) it is required by legislation and demanded by service users and their organisations (Monach and Spriggs, 1994).

The development of outcomes focused social care has been broadly welcomed by user groups (cf. Nocon *et al.*, 1997; *Shaping Our Lives*, 1997, 1998, 2002) as it places the service user at the centre of defining the objectives of social care or local authority involvement in their lives. However, some concerns have been raised by user groups in respect of outcomes focused practice.

“Developing your own view of outcomes can be an empowering experience. I’ve seen some changes locally. Previously users weren’t sure whether they could work with a concept of outcomes, but then they realised they can do it. There is a link between user defined outcomes and empowerment.”

(Service user)

Firstly, adopting an outcomes focus can be as much of a mind shift for services users as it has been for statutory providers and their staff. Thinking beyond service-led provision can be a challenge and many service users will approach social services requesting a service they think they are likely to get rather than one that would support a particular outcome. Therefore, outcomes focused support and information is as necessary for service users as it is for social services professionals.

“We can’t pretend there isn’t a resource issue; that there isn’t a fairness issue”

(Local authority representative)

The need to address the right of black and minority ethnic people to be equally involved in the assessment process and in the definition of outcomes, both individually and collectively because of the particular discriminations and exclusions they face was also noted.

Secondly, it was felt important that service users should be regarded as ‘experts’ on their own lives, situations and aspirations.

“There’s an important notion of ‘holism’. Each person is treated as an individual, with their own outcomes – even if you have a service user developed framework.”

(Service user)

Service users should be equal partners or co-citizens (Rummery, 2002) in the assessment process and in the development of outcome objectives. Outcome objectives should not be allocated to particular service users or decided on their behalf.

“The service users I work with nearly all know what they need”

(Local authority representative)

Concerns were also raised about the use of a qualitative method of assessment in a context of ever increasing quantitative measurement. It was seen as vital that methods of measurement or evaluation should be developed alongside outcomes focused practice to allow the richness and creativity of the approach to be recorded.

“How can anyone measure my quality of life. Users can be the people measuring it. You must involve everyone from the start.”

(Service user)

There was considerable debate at the seminar about who should define the individual and collective outcomes of social care services. There was a clear

consensus that individual service users should be involved in defining their desired outcomes, however it was also felt important that organisations and groups of disabled people and other service users should be involved in defining desirable outcomes. It was also recognised that the wider population has a role in shaping the priorities of social care. It was noted that frontline staff have the closest relationship to service users and that their input was often useful. Fears were raised by some local authority staff that their professional voice/expertise might potentially be lost in an assessment procedure that privileges the service user, however as discussed below many welcomed a return to their more traditional role of advisor or supporter rather than gatekeeper.

Standardised outcomes

To have a minimum level of standards service users should expect was held to be very important by service users and professionals alike. However, there was much debate about who should set these minimum standards and how basic standards should relate to 'target' or 'desirable' standards.

"People need to know what's out there to ask for what they want."

(Service user)

It was recognised that in the context of limited or rationed services having a basic minimum that service users were entitled to allowed for greater clarity. Service users were keen for these basic standards to be enshrined as rights and as such non-negotiable. Professionals acknowledged that some basic standards should be viewed as rights but were aware of the tensions they face in reconciling service users' rights to services with limited resources.

"It's not always about resources. It can be about different ways of working like direct payments"

(Local authority representative)

A distinction between basic, target and desirable rights was felt to be useful in this context, not least because it might form a more equitable basis for distributing scarce resources i.e. all service users must enjoy basic standards before target or desirable standards are addressed.

“We need to start with the basics. Basic standards like being able to choose when you eat and drink.”

(Service user)

A criticism of standardised outcomes was that they can be culturally specific and thus exclusionary. Additionally a list of basic standardised outcomes might not allow for flexibility or reflect the particular priorities of individual service users, for example a service user might choose to pursue certain standards at the expense of others (for example a service user might prefer to rely on a carer for personal assistance as long as some provision is made for domestic cleaning) or might be in fundamental disagreement with a member of staff (for example a service user might choose to sleep on a mattress on the floor rather than use a variety of hoists).

“We need to look at things to do to help people push for better outcomes; the ability to break down barriers and access what you need. The additionality of racism, class and race are dual forces compounding powerlessness. Self-defined outcomes for black and minority ethnic people are likely to be better than externally defined criteria”

(Service user)

Furthermore some service users might reject certain basic standards (for example standards about levels of cleanliness or access to medical treatment). It was felt important to recognise that there will be both individual and common elements in outcomes measures as they relate to any particular person and this needs to be taken into account in any system of outcome definition and measurement.

“There is too much focus on professionals knowing better. I am not saying we shouldn't have people with expertise, but they should share it better (with service users).”

(Local authority representative)

Social model approach to service provision?

The social model is becoming something of a new orthodoxy within service provision. The majority of local authorities now claim to adopt a social model

approach to service provision, although there is often a gap between rhetoric and practice and between understandings of what the social model means (Barnes *et al.*, 2001; Barnes, 2002).

“It’s not how far along the road you’ve gone – it’s the direction you have decided to follow – not pretending we are there but we are on the route. The social model of disability offers a direction.”

(Service user)

The majority of seminar participants believed social model principles should underpin outcomes focused social care provision and while not ignoring recent critiques of the social model – that it fails to take sufficient account of the impact of impairment and that it has not fully taken on board the experience of groups such as disabled women and disabled people from minority ethnic communities – it was agreed that a focus on the barriers service users face rather than on their specific impairments or limitations was helpful.

“Look at the contrast in Hampshire with 500 people using direct payments and others using direct services. With the first, disabled people have more control, therefore outcomes are more likely to be met. The question is how to apply this to ordinary services.”

(Service user)

Some concern was expressed about the provision of minor aids and adaptations without assessment. The ability of most individual service users to identify the aids and adaptations required was acknowledged but concern was expressed about service users missing out on face to face contact with ‘expert’ social services staff who can advise and offer information about a much wider range of support services.

“It’s about making choices with the right information and support. I haven’t come across a service yet where I think that somebody can’t make a reasonable decision with the right information.”

(Local authority representative)

It was felt important to distinguish between the role of social services staff as advisors or supporters and the more rigid role of gatekeeper to resources. It was agreed that service users require good quality information and support to facilitate their choice and control over services.

“I’ve never quite understood what social workers do. There needs to be a shift from a gatekeeper role to them offering advice and support based on their expertise and empowering people by removing the barriers.”

(Service user)

Evidence

The move to social care practice being evidenced based raises questions about *what* constitutes evidence, *who* defines evidence and *how* evidence is collected and disseminated. It is important to recognise that evidence – particularly around outcomes – is highly subjective and influenced by a range of factors such as resource constraints or attempts to retain professional status and that there is much to be gained from less formally produced evidence.

Service users and particularly the disabled people’s movement have long been critical of research that has traditionally been ‘done on’ rather than involving disabled people. Involvement in such research can often be an oppressive experience for service users.

“The idea of outcomes as subjective is seen as a criticism. Is it going to be more difficult to push the idea of outcomes as subjective because it is not seen as scientific? Occupational therapy practice for example is often devalued as not evidence based. It is criticised for evidence being anecdotal.”

(Local authority representative)

A further frustration was expressed about automatic labelling of service user research and evidence as subjective while government or professionally produced evidence was held up as objective. It was felt this denigrates the rigour and high quality of much of the research produced by service users to second-class status and needs to be challenged. As disability research has illustrated, there is much to be gained from work that situates itself ‘on the side’ of service users.

“The trap that subjectivity is seen as about ‘wants’ as opposed to needs. If someone say it is personal to them, services get hung up about that. They use the subjectivity argument to dismiss views they devalue.”

(Local authority representative)

Many participants voiced the frustration of being involved in research and evaluation that did not appear to have any impact. Therefore, it was deemed very important that the link between evidence and practice should be clear and the necessary political will and resources to influence change should back up good quality research.

Voice

The voices of service users are beginning to emerge, in empirical research (cf. Campbell and Oliver, 1996; Morris, 1996; Begum, 1992) and in personal accounts (Hunt, 1966; Atkinson and Williams, 1990). Service users have developed oppositional voices to those who have customarily spoken ‘for’ them arguing that often in the past their voices have been silenced or ignored and their opinions have had little public impact. Governmental and statutory agencies have responded with initiatives such as ‘Consumers in NHS Research’ and by providing funding for organisations like Shaping Our Lives.

“Developing user defined outcomes must be seriously resourced. Resource the functioning of user controlled organisations to do this.”

(Service user)

This has been accompanied by more vocal dissent and opposition to traditional forms of service provision from within statutory services and the social care professions. Individual and collective groups of service users now have a clear mandate to represent the views and wishes of service users in order to influence and shape service provision.

“There is still an assumption some people have to be led and have to be told what is good for them.”

(Local authority representative)

However, representation brings with it new tensions. Some voices are louder than others, some individuals or groups of service users find it easier to make

their voice heard and to have their claims validated. Other groups, such as women, service users from minority ethnic communities and people with particular impairments such as communication impairment or learning difficulties, still have difficulty in making their voices heard.

There are often competing legitimate claims to resources and services made by different groups of service users. It is important to have equality between groups and space provided to ensure even the most marginalised and excluded voices are heard. There is a need for specific channels through which service users can be heard. It was felt that there is too much 'reinventing of the wheel' when it comes to user involvement; there is a surfeit of consultation that appears to have little impact and the focus now should be on good quality consultation that is clearly linked to change.

The importance of allowing staff (particularly front line staff) a voice was also raised. There needs to be a dialogue within statutory agencies that hears staff voices. Too often developments are felt to be top down with little reference to front line staff. It was seen as problematic that it is front line staff who have the closest relationship with service users yet have little voice of their own within larger organisational structures.

Summary of main points

1. User consultation and involvement is 'no longer simply a good thing', it is required by legislation and demanded by service users and their organisations;
2. Service users should be equal partners or co-citizens in the assessment process and in the development of outcome objectives;
3. A minimum level of standards service users should expect was held to be very important by service users and professionals alike;
4. The majority of seminar participants believed social model principles should underpin outcomes focused social care provision;
5. It was deemed very important that the link between evidence and practice should be clear and the necessary political will and resources to influence change should back up good quality research;
6. There are often competing legitimate claims to resources and services made by different groups of service users. It is important to have equality between groups and space provided to ensure even the most vulnerable are heard.

5. NEXT STEPS

It was clear from the group discussion and plenary session that participants were keen to take forward this dialogue between service users and professionals. It is important that awareness of outcomes-related issues is raised in both groups. This dialogue must also include the Department of Health and SCIE.

There is much existing experience and good practice of adopting an outcomes focus. This needs to be shared to ensure it has a greater impact on wider policy and political agendas as well as influencing the new social care organisations and structures. It must also be recognised that involving service users in defining outcomes and moving towards user-defined outcomes can be challenging for local authorities and their staff, therefore thought must be given to providing support and training to enable staff to work in different ways.

Clearly there is much still to discuss. Participants were committed to supporting more discussion about user involvement in outcome-focus practice and measurement. This wider discussion should include key related government and policy perspectives and provide an opportunity to share.

It was agreed that representatives of Shaping Our Lives and the Social Policy Research Unit should meet to discuss how the issues raised during this seminar might be taken forward and to feedback these discussions to disability and other service user networks.

For more information about Shaping Our Lives' outcomes projects please visit their website www.shapingourlives.org.uk. Details of the Social Policy Research Unit's outcomes programme are available on www.york.ac.uk/inst/spru.

References

Atkinson, D. and Williams, F (eds) (1990) *'Know me as I am': An anthology of prose, poetry and art by people with learning difficulties*, London: Hodder & Stoughton.

Bamford, C., Vernon, A., Nicholas, E. and Qureshi, H. (1999) *Outcomes of Social Care for Disabled People and their Carers*, Outcomes in Community Care Practice, Number Six, York: Social Policy Research Unit, University of York.

Barnes, C. (2002) 'Introduction: Disability, policy and politics', *Policy and Politics*, 30, 3, 311-18.

Barnes, C., Mercer, G. and Morgan, H. (2000) *Creating Independent Futures: An Evaluation of Services Led by Disabled People: Stage One Report*, Leeds: Disability Press.

Barnes, C., Morgan, H., and Mercer, G. (2001) *Creating Independent Futures: An Evaluation of Services Led by Disabled People: Stage Three Report*, Leeds: Disability Press.

Barnes, C., Mercer, G. and Morgan, H. (2002) *Creating Independent Futures: An Evaluation of Services Led by Disabled People: Conference Report and Preliminary Findings*, Leeds: Disability Press.

Begum, N. (1992) *Something to be Proud of. The Lives of Asian Disabled People and Carers in Waltham Forest*, London: Waltham Forest Race Relations Unit.

Beresford, P. (1992) 'No longer simply a good thing', *Community Care*, 26 March supplement, p.ii.

Beresford, P.M Croft, S., Evans, C., Harding, T. (1997) 'Quality in Personal Social Services: The developing role of user involvement in the UK', in Evers, A., Haverinen, R., Leichsenring, K. and Wistow, G. (eds), *Developing Quality in Personal Social Services: Concepts, cases and comments*, European Centre, Vienna, Aldershot: Ashgate, pp. 63-80.

Beresford, P., Balloch, S., Evans, C., Harding, T., Heidenshon, M. and Turner, M. (1998) 'Advocacy, Empowerment and the Development of User-Led Outcomes', in Craig, Y. (ed), *Advocacy, Counselling and Meditation in Casework*, Aldershot: Ashgate, pp. 226-36.

Campbell, J. and Oliver, M. (1996) *Disability Politics: Understanding Our Past, Changing Our Future*, London: Routledge.

Department of Health (1989) *Caring for People: Community Care in the Next Decade and Beyond*, Cm. 839, London: HMSO.

Griffiths Report (1988) *Community Care: Agenda for Action*, London: HMSO.

Hunt, P. (ed) (1966) *Stigma: The Experience of Disability*, London: The Guildford Press.

Lelliot, P., Beevor, A., Hogman, G., Hyslop, J., Lathlean, J. and Ward, M. (2001) 'Carer' and Users' Expectations of Services – User Version (CUES-U): A new instrument to measure the experiences of users of mental health services, *British Journal of Psychiatry*, 179, 67-72.

Modernisation Team (2001) *How to Survive an Assessment*, Leeds: Modernisation Team.

Modernisation Team (forthcoming) *Now! That's What I Call a Care Plan*, Leeds: Modernisation Team.

Monach, J. and Spriggs, L. (1994) 'The Consumer Role', in Malin, N. (ed), *Implementing Community Care*, Buckingham: Open University Press.

Morgan, H., Barnes, C. and Mercer, G. (2001) *Creating Independent Futures: An Evaluation of Services Led by Disabled People: Stage Two Report*, Leeds: Disability Press.

Morris, J. (ed) (1996) *Encounters with Strangers*, London: The Women's Press.

Nocon, A., Qureshi, H. and Thornton, P. (1997) *The perspectives of users' and carers' organisations*, Outcomes in Community Care Practice, Number Four, York: Social Policy Research Unit, University of York.

Northumberland County Council (undated) *Community Care Charter (Appendix 1: Our Community Care Outcome Standards)*
www.northumberland.gov.uk/drftp/527.htm

Qureshi, H. (ed) (2001) *Outcomes in Community Care Practice*, Outcomes in Community Care Practice, Number Seven, York: Social Policy Research Unit, University of York.

Rummery, K. (2002) *Disability, Citizenship and Community Care: A Case for Welfare Rights*, Aldershot: Ashgate Publishing.

Seebohm Report (1968) *Report of the Committee on Local Authority and Allied Personal Services*, London: HMSO.

Shaping Our Lives (1997) *Shaping our Lives: Interim Report*, London: National Institute for Social Work.

Shaping Our Lives (1998) *Shaping our Lives Project Report*, London: National Institute for Social Work.

Shaping our Lives (2002) *From Outset to Outcome: Report of four development projects on user defined outcomes*, London: National Institute for Social Work.

APPENDIX A: LIST OF PARTICIPANTS

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Phil Dearden, Acting Purchasing Manager, St Helens Social Services

Tracey Elder, Occupational Therapist, Derbyshire County Council

Dr Jennifer Harris, Senior Research Fellow, Social Policy Research Unit

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Peter Williams, Shaping Our Lives/TOPPS

APPENDIX C: OUTCOMES FOR DISABLED SERVICE USERS - PROJECT SUMMARY

This project builds directly on the first outcomes programme, in which social care outcomes were identified for disabled people of working age, (Bamford *et al.*, 1999). The first outcomes programme produced a basic framework of social care outcomes for disabled people. The research identified desired social care outcomes such as; maximising autonomy; having day-to-day personal needs met; access to social and economic participation; emotional well-being and maximising personal functioning (*ibid*). In this new piece of research and development work we intend to build upon these foundations by exploring opportunities for introducing the outcomes framework into routine practice within the provision of social care services to disabled people. The new project seeks to build upon the established framework by testing whether it is feasible and useful to incorporate an outcomes focus into assessment and review procedures with disabled service users.

Research timetable

| Phase | Activity | Timescale |
|---|---|------------------|
| 1. Initiation and planning | Establish LA partnership Appoint research staff Establish local implementation group User groups/professionals seminar Devise documentation and user information. Train staff; pilot documentation; evaluation; revision of documentation | 8 months |
| 2. Researched Trial Implementation | Research the trial implementation of outcome-focused tools for assessment and review in local context. Evaluation of acceptability to all stakeholders. Train staff in readiness for Phase 3. | 16 months |
| 3. Comparative Testing | Sampling for comparative test of the tools. Research the process of full-scale implementation of outcome-focused tools. Data analysis; interpretation; feedback to stakeholders | 12 months |
| Total | | 36 months |

Project Director: Dr Jennifer Harris
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 Social Policy Research Unit, University of York.

APPENDIX D: USER FOCUSED OUTCOMES

Michael Turner, Shaping Our Lives

Shaping Our Lives has been doing work on user perspectives on outcomes of social care for almost six years.

Our first project started in 1996 and looked at service user's views on the whole idea of looking at services in terms of their outcomes. It is an idea that is at the same time very obvious but also difficult to grasp. Service users and service providers alike have been focused on the process of service provision and how all that works.

During this first stage of the project we did about half a dozen focus group meetings with different types of service users – one of the things that sets Shaping Our Lives apart is that we work across all service user groups and that includes disabled people, people with learning difficulties, older people and survivors and users of mental health services. We are also in the process of looking at making links with young people who have been in or are in the care system, and in time we hope to look at users in drug and alcohol services as well, so it's a very broad approach that we've been developing.

At the end of that first phase of focus group meetings we had a list of findings on user perspectives on outcomes and indications of the value and importance of involving users in work on outcomes. From there we started to look at how we could make them work in practice and developed a project to pilot them by working with local service user groups over a longer period of time, which was funded by the Joseph Rowntree Foundation.

We ended up working with four local groups of service users. These were the Black User Group from the London Borough of Hammersmith and Fulham, the Ethnic Disabled Group Emerged from Manchester, Footprints and Walthamstow Mental Health Service Users Association, and the Age Concern Service Users Action Forum from Wakefield.

We particularly selected these groups because they represent service users who have been marginalised by service providers and in the service user and disability movements, so that we can begin this work from an inclusive position.

What we have found in working with the four groups is that our findings in the initial project were largely accurate. We also now have practical models of how local user groups can work on outcomes.

This is an important issue for us because in looking at outcomes and user involvement we can see that there is a real case for linking those two things together. With a focus on outcomes, user involvement can become a much more focused and well-defined process.

Another key finding of Shaping Our Lives' work has been that users want to approach outcomes on a subjective basis – looking at outcomes in terms of individual lives rather than through big systems of measurement and number crunching.

There is a recognition that you need a certain amount of number crunching to support that subjective work. One of the best arguments that I have heard on this was from a mental health service user/survivor who said that if services were working properly, the spending on drugs by the National Health Service would be going down rather than going up. That is a really good example of where there are measures that we could be using, but even here – where it is a measure that has been defined by service users – it also needs to be supported in a big way by subjective work by service users themselves looking at outcomes in their lives.

Another benefit is this approach is that it is not actually that expensive. The model that Shaping Our Lives is developing of involving service users could be implemented on a bigger scale but with a relatively small amount of money. In our work on outcomes – and in other work that Shaping Our Lives and other user-controlled projects have undertaken – we have found a high degree of consistency in the views of service users. So, you can learn a lot by working closely with a small number of people, and for less money than carrying out a big survey.

There seems to be a bit of snobbery about research at the moment, with professionals and academics saying that going out to talk to people with a tape recorder is not proper research and does not produce hard evidence. I think we are finding the opposite, that going out and talking to people is crucial to the research process.

With Shaping Our Lives' new funding to set up a National User Network there should be a real opportunity to develop a user-led approach to outcomes and involvement – and to research –at a local and national level in the next ten years.

Q: Where do you see this work going in the next three years?

A: Our first task is to develop a better picture of user involvement across the country. I don't think anyone has a clear picture of how many organisations there are out there, how they're supported, what they're doing, etc. There has been work carried out by the National Centre for Independent Living and the Centre for Disability Studies at the University of Leeds that has shown that a lot of local organisations are very vulnerable (Barnes *et al.*, 2000, 2001, 2002; Morgan *et al.*, 2001).

Our key aim has to be to look at how we address that and build up user involvement. The Government has made a clear commitment to service users being central to their quality strategy for social care. To achieve that we have to move away from user involvement being an optional extra which depends whether there is anything left in the budget at the end of the year.

APPENDIX E: ADOPTING A SOCIAL MODEL APPROACH

Mick Ward, Modernisation Team, Leeds City Council

A major role of the Modernisation Team is to support Leeds City Council and the local health service in implementing services based on a social model of disability and particularly on the removal of disabling barriers. There is a commitment in principle to do this and the Modernisation Team seeks to turn the theory into practice. A key issue, identified by disabled people in Leeds, was that of assessment.

Assessment

A key aim around assessment was to change staff skills and abilities to be social model based. This is done primarily through training; A Social Model of Assessment course has been devised that focuses on identifying the barriers disabled people face around independence, inclusion and equality and from that start to identify strategies to overcome them. The training course will be produced and delivered in partnership with Leeds Centre for Integrated Living and senior staff from Social Services. One aspect of the work of the modernisation team that is problematic from a social model perspective is that in Leeds, like in many local authorities, services are divided into impairment groups. However, because the social model is about barriers rather than individual's impairments, the work we are doing could be applied to different groups of disabled people.

How to survive an assessment

How to survive an assessment (Modernisation Team, 2001) was produced about 18 months ago and is a guide for disabled people in Leeds which aims to make the assessment process more accessible. It explains what an assessment is, how to get an assessment and then crucially talks about the strategies a service user can use in preparing for an assessment. It is sent to service users in advance of an assessment and initial findings suggest that service users who have received the booklet are thinking more carefully about how they run their assessment and this represents a significant shift.

Excerpts from *How to survive an assessment*

“Remember that you are not just being assessed for a particular service - it is your individual needs that are being assessed. It is only after that has been done that the process moves on to consider how your needs might be met. You should ensure you plan for both parts of the process.” (p.4)

“Remember; the problem is not you; it is the things around you causing difficulties or barriers in your life that are the problem. Find out about how the organisation that is assessing you carry out assessment. Ask them for information about the rules they have for deciding how they meet people’s needs. Get hold of the forms they use when they are doing an assessment, so you will know what questions you will be asked.” (p.4)

Now! That’s what I call a care plan

Now! That’s what I call a care plan - (working title) (Modernisation Team, 2002) is a guide for disabled people about controlling the care planning process because we have found that with assessments inappropriate services could still be delivered. The booklet tries to get service users to think about key questions like ‘what do I want to achieve in my life?’, ‘what do I want to change?’, ‘what are the barriers to me achieving that?’, ‘what’s getting in the way?’ and crucially ‘what might be the solutions?’ so that the care planning process is focused on service user’s answers to the questions. (This leaflet is still at draft stage and not official Leeds City Council policy.)

Excerpts from *Now! That's what I call a care plan*

***“Assistance is about increasing your independence, choice and control, so don't let the process of getting it make you feel guilty.”
(p.3)***

Examples from the checklist of the sorts of tasks assistance may be required include:

- ***Getting out of/into bed***
- ***Cooking/microwaving/ordering take away food***
- ***Feeding pets/walking dog/pet care***
- ***Setting the video for Coronation Street!***
- ***Taking your kids to nursery/school***
- ***Going to work***
- ***Religious needs***
- ***Hobbies (pp.4-6)***

“It is the job of the worker from social services to try and identify services to meet the needs that you have agreed. Make sure that you discuss all the possible options. ... Not all of these will be provided by social services, but your worker may be able to put you in touch with, or refer you to, organisations that can help. Leeds Social Services is committed to supporting disabled people in leading independent lives. However it can only work within its available resources and there are limits to the money the department has. However this should not stop you from putting down what you need. There is a section on the care plan for recording ‘unmet need’ and it is important for future service development that this is recorded.” (pp.7-8)

Providing services without assessment

Leeds has recognised that assessment itself can be a block and so the Council is testing the provision of minor aids and adaptations without assessment, for example grab rails, raised toilet seats, stair rails, door entry systems. The scheme involves the provision of minor aids and adaptations in Local Authority owned properties, private tenants and owner occupiers. The result so far (after six weeks) is a reduction in waiting lists for some aids and adaptations from a few months to a matter days and a saving of on average 40 occupational therapy visits a week. The next stage will be to roll out provision without assessment to other services.

Other projects

Working with First Bus to improve their range of accessible buses and to train bus drivers. Alongside supporting a 'travel training service' with METRO Training with the National Union of Journalists in Leeds and the production by disabled people of a leaflet detailing how to complain about media representation.

A project with Halifax Estate Agents to develop an 'Accessible Home' kitemark as well as providing better information for disabled people.

Q: Are you working on behalf of all disabled people and does that include people with learning difficulties? Because it's very important to cross the boundaries of service provision and share good practice with all staff who work with disabled people regardless of the type of impairment.

MW: I think you are right, the structures are very narrow and so while we adopt a social model approach which is inclusive it is difficult when services to disabled people are compartmentalised according to impairment. However, because a lot of the barriers disabled people face are common, the work we are doing although technically for people with physical and sensory impairments is relevant to other groups of disabled people. We have made good inroads into services for older people and disabled children but we probably have not done enough work around partnership with people with learning difficulties.

Q: I am an occupational therapist and while I applaud a system that stops people having to jump through hoops at assessment, I am worried that it could be taken too far and that service users, who would benefit from the

advice and expertise of a specialist like an OT, are missing out. Can you explain how far you would like to see provision without assessment extended?

MW: I think there is a distinction between expert assessment of, or with, a service user and service users making choices with the right information and support. We've not tested what the edge of that boundary is, but I think it's a long way yet. Social workers and OTs provide a useful service of expertise and information but we need to move away from their role as gatekeepers of services. Most non-disabled people use new equipment or take risks without assessment and disabled people should have that same right. I think people should have a choice about how much input a social services professional has but at the moment there is no real choice as the waiting list is five months long so it is about empowering disabled people and removing disabling barriers.

APPENDIX F: DO WE NEED STANDARDISED OUTCOMES?

Hazel Qureshi, Assistant Director, SPRU

Who, apart from the individual user, has the right to say what outcomes should be? I wish to argue that there are other groups with a legitimate right to have an opinion:

- *Users collectively* may say this person's expectations have been so depressed by their experiences of receiving services, and possibly their life experiences, that they do not expect what they *should have the right to expect*.
- *Professionals* may say this person does not realise the kinds of assistance that could possibly be provided: this person does not at this time have the knowledge of what *a good quality service should be capable of achieving*.
- *Citizens collectively (including service users)* may take a view that given the total resources available *it would not be fair* to meet this person's aspirations because to do so would take a disproportionate share of resources available to all.

I am going to talk about how you can potentially use outcome standards derived from more collective views, both in relation to defining *rights* to services, and for *measurement*.

I am going to do this by using two examples to illustrate what I mean. I just want to use the examples to draw out some principles which we might discuss. I cannot guarantee that either example is fully up to date or reflects current practice by any organisation. In particular I know the information about Northumberland's standards reflects the situation which obtained two years ago, when I copied the standards from their web site. I hold no brief for either example but I think they illustrate important principles.

The first example links fairness and outcomes, and relates to defining eligibility for services. It is a system developed by Northumberland Health and Social Services which they call *community care outcome-focused standards* (Northumberland County Council undated).

The second example comes from the arena of measurement (Lelliot *et al.*, 2001). It is a questionnaire designed to enable users of mental health services to assess outcomes for themselves, and compare their own outcomes with statements which reflect ideas about the outcomes, and the service quality, they ought to be able to experience.

First the eligibility system: The agencies have defined outcome standards relation to 21 areas of life. They have distinguished guaranteed, target and desirable outcomes. In information for users these are defined as follows:

Guaranteed:

- we guarantee assistance to meet this standard (if you want it)

Target:

- we aim to meet this standard and expect to be able to do so within our current resources

Desirable:

- we aspire to meet this but cannot devote resources to this until the target standards have been met for everyone

The areas of life for which standards are defined are:

| | | |
|---------------------|---------------|-----------------------|
| Personal hygiene | Breaks | Communication |
| Toileting | Relationships | Information |
| Self Care | Behaviour | Pain |
| Eating and drinking | Getting help | Thoughts and feelings |
| Getting about | Accommodation | Health and safety |
| Laundry | Cleaning | Money |
| Keeping warm | Occupation | Leisure and lifestyle |

Example: Target standards for communication

- Be able to make your needs and views known effectively to the people whose actions most affect your life
- Be able to read, watch TV or listen to the radio if you want to
- Be able to write, or record information in other ways, as necessary for correspondence or organising your life.

Examples of standards as described in the agencies' information for users

We **guarantee** to offer you any help within our responsibilities which you need to ensure that:

“your children’s welfare is not being significantly harmed, and your children are not taking inappropriate responsibility for your care”

“you have a safe way of getting in and out of your house”

“you can let other people into your home safely”

“you have any help you need to make your views known about key decisions”

If you are of working age we **may be** able to help you get a job, education or training, if not we **aim to** make sure you have a satisfying alternative way to occupy your time.

We will **probably not** be able to provide services to help you with your garden, or with decorating.

The important principles here are:

It gives some **rights** to assistance: if your life does not meet the guaranteed outcome standards you have a right to assistance.

The standards are public: open to debate, easy to understand.

It makes the link between individual outcomes and fairness: accepts that outcomes that are not achieved are desirable (rather than just ‘wants’), and that the reason they cannot be achieved is because of the importance of fair distribution of resources.

How to achieve the outcome is left open: to be decided with the user in their situation, hopefully thereby encouraging more imaginative responses.

Applies to all service users. The information describing the standards says “an approach based on equal standards for all should mean that it makes no difference what are the reasons for someone's problems. For instance, if someone would not eat adequately without care and support it should not be important whether this is because of dementia, depression, physical impairment, drinking problems or learning disability. The importance of meeting the standard should be the same (though the means of doing so will differ).”

Implications

- Local authorities/services should be encouraged to make clear statements about the outcome standards they aim to assist people to achieve.
- They should be accountable for them except in so far as the assistance required is outside their responsibilities.
- What role should users take in this process of making clear statements about outcomes? This I put forward as an area for us to discuss.

Outcome statements as a basis for measurement

My second example concerns the question: if you could get agreed outcome statements, could they be used to measure outcomes? I think yes, and the questionnaire (called CUES) developed by the Royal College of Psychiatrists in collaboration with NSF illustrates how this might work. In these examples, statements about how things ‘should’ be are followed by questions which invite the user to compare their own state with how things should be, and to indicate whether they are satisfied with how things are. They are then asked in an open-ended way to say what they would like to change.

For example a statement on “where you live” is:

“The place you live in should meet your individual needs. You shouldn't have to worry about having to move out, and it shouldn't be too out of the way. You should be able to come and go when you want, be alone when you want, and not be harassed by the people you live with, by staff or by neighbours.”

The questions following each statement take this form:

1. How does the place you live in compare with this description?

As good as this

Worse than this

Very much worse than this

2. Are you satisfied with the place you live in?

Yes

Unsure

No

3. What would you most like to change about where you live?

Open-ended space for response

Another statement about money is:

“You should have enough money to pay bills, stay out of debt and not miss meals. You should not have to feel isolated or cut off from society because of lack of money.”

As well as outcome statements there are statements about the quality of assistance received from services. For example:

“Many people find they need help with claiming benefits, filling in forms, and working out how to manage their money. You should get as much help as you need to do these things.”

Each statement is followed by three questions like the ones which related to “where you live”, but worded so as to apply to that statement.

The important principles here are:

- Statements are made about outcomes and service quality separately. This means we know the extent to which the user’s quality of life matches up with the agreed statements (from their perspective); how satisfied they are (their subjective view); what they would like to change.
- It does give some information to the user about what they have a right to expect

- We can get a user perspective on outcomes which does take account of other stakeholder views, as well as the user's own view.

Again, there are important questions in practice about how such statements are generated. In particular what role would service users wish to take in generating statements about what people "should" be able to expect?

These examples suggest it would be important to distinguish between statements which try to clearly reflect current entitlements, and those which reflect service users' ideas about what rights 'should' be. However both kinds of statement have their uses in evaluating outcomes actually achieved.