

Service Users as Paid Researchers

Service Users as Paid Research Workers: Principles for Active Involvement and Good Practice Guidance

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Service users working in academic and other institutional settings can be a major asset to both the team and the research itself, with the potential to improve research relevance quality, and dissemination. However, without proper preparation and planning, there is great potential for the project to be derailed by tension existing between and among academics and service users. Hence, in order for this kind of service user involvement to achieve its full potential, some basic principles should be taken into account.

This chapter starts out with a discussion of the benefits that active involvement of service user research employees can bring to different aspects of a research project, as well as to others involved, including academic researchers and the service users. Common problems and challenges to such active involvement are also considered from the perspective of both. Subsequently, drawing on the literature as well as on personal experience, a number of key principles are recommended, essential for both senior researchers and service users to overcome the barriers to success and attain maximum benefit. The chapter concludes with a concise and practical step by step guide for senior researchers to achieve the active involvement of service user research workers.

INTRODUCTION

Research organisations, such as academic institutions, decide to pay service users as research workers for a variety of reasons. These include a general sense of obligation to people who have been disadvantaged, the value added to the project and/or to meet a grant application requirement. Regardless of the reason, the successful employment of service users requires researchers to dedicate the time and resources to support both services users and themselves. In this chapter, we will discuss the key principles of and considerations for hiring service users as paid researchers.

The paid service user research worker

For the purposes of this chapter, we are adopting the ‘service user’ definition of Branfield and Beresford (2002), which is people who ‘have or have had long-term experience of health and social care services or would qualify to receive such services’. Service users have in common the experience, voluntarily or involuntarily, of mental health treatment and mental health difficulties, and often the marginalization and discrimination that accompanies these experiences.

When we talk about paid service user research worker (SUR) in the chapter, we are referring to people hired, in part because they are service user, to actively participate in the research production process. The employment may only be for a particular research project or as regular staff to participate in ongoing projects, but would be over a significant time period. Thus, SURs are to be distinguished from service users hired for discrete non-analytical activities, such as data entry. SURs are also to be distinguished from academic and other experienced service user researchers, such as author Delman (Griffiths *et al.*, 2004) have an excellent discussion on this topic.) This chapter will thus focus on service user researchers who wish to have active involvement in a research project but who have little experience or education in research.

The researchers overseeing the hiring process we will refer to as ‘senior’ or ‘academic’ researchers.

Benefits of active service user involvement

In our view, the active involvement of service users in the research process will improve the relevance, quality, and impact, and thus the social value, of the research. In addition there are other powerful potential benefits for everyone involved, including stigma reduction, researcher education, and service user skill development.

Quality and relevance of research

Service users bring an experience and expertise (Deegan, 1993) that can enrich all aspects of the research process (Beinecke and Delman, 2008). Through their interactions with service users, researchers can develop a better understanding of the daily lives and hopes of service users, leading to more relevant study questions and outcomes measures.

Many service users have been ‘study subjects,’ and are aware of the kinds of research methods most acceptable to service users (Beinecke and Delman, 2008). Service user input here can result in survey questions that more understandable and consent forms with more user friendly language (Beinecke and Delman, 2008). In addition, SURs can be leaders in deciding how to most effectively and sensitively recruit service users, including people who are homeless and other groups difficult to reach. In this way, their presence can effectively lead to the completion of the research project in a timely and effective manner.

In addition, Clark *et al.* (1999) and others have found that study participants feel more free to talk openly to service user interviewers, leading to more honest and in depth data.

Dissemination, translation to policy and practice

Research results are often disseminated in lengthy documents with an overabundance of research jargon, limiting their policy impact. SURs can help motivate senior researchers to focus more on dissemination for policy impact (O’Donnell and Entwistle, 2004).

Studies have demonstrated that research findings are much more likely to have a policy impact if written up as brief summaries and without jargon and/or if delivered orally (World Health Organisation, 2004). Service users who have participated in research design, data collection and analysis, are in an excellent position to explain the research findings in a clear and thoughtful way (Israel *et al.*, 2003). And when SURs present research results orally while citing their personal experiences, policy-makers may be more likely to take notice than if delivered by academic researchers (Delman, 2007).

SURs can effectively determine how best to disseminate findings to community stakeholders (e.g. service users), often through community forums. Many SURs have had advocacy experience and/or are connected to service user advocacy groups, an important action point for the findings.

Stigma reduction

Service users are often generalized to be lacking in judgment, unpredictable, unreliable, cognitively challenged, or any combination of the above (United States Public Health Service Office of the Surgeon General, 1999). When projects are done well, SURs are full participants in a complex and lengthy research process. Full participation is likely to have an impact on the stigmatizing views of academic researchers and perhaps the self-stigmatizing views of the SURs (see Wyatt *et al.*, 2008). In addition, conference presentations and reports on the process and effects of involving SURs can make other community members aware of service users’ potential

Researcher education

The education of senior researchers, particularly academic researchers, about the lives, experiences and knowledge of service users is an additional benefit of SUR involvement (O’Donnell and Entwistle, 2004; Wright *et al.*, 2006). Senior researchers and SURs cross-

training each other presents an additional opportunity to learn about SUR lived and learned knowledge. (See Israel *et al.*, 2004.)

Service user skill development

Service users have the opportunity to gain valuable skills, including (but not limited to) data entry, transcription, data management, research literacy, team building following protocols, and leadership.

Challenges to the active service user involvement

The hiring of service users challenges the typical way of conducting research in academic institutions.

Differing expectations and competing demands

While senior researchers and SURs may share expectations for the research process, some of their expectations are likely to be different. First, researchers and service users will probably have differing perspectives on what the highest priority research topics are (Faulkner, 2004). Second, service users tend to focus on the impact research will have on their daily lives (including provider practices). This focus conflicts with the demands of academic appointments such as timely publications in academic journals, accountability to funders, and a focus on the next potential research project (Griffiths *et al.*, 2004). Finally, some academics may be concerned that service users will introduce personal biases or a 'hidden' advocacy agenda to the study, and service users may have their own negative biases with regard to the intentions of academic researchers, creating trust issues (Beinecke and Delman 2008). All of these differences can lead to sustained tension. (Wyatt *et al.*, 2008; Faulkner, 2004).

A very good example of this misalignment of expectations relates to data dissemination. Academics tenure decisions are based largely on publication of research articles in peer-reviewed journals. In addition, successful publication in the most prestigious journals is often based on the rigor of the research. This publication focus can run in contrast to service users' focus on research for social policy change. Thus, service users are often more interested in producing documents that are written both for their fellow service users and for policy-makers. The differences here can affect plans for research design as well resources developed to writing about data.

Imbalance in knowledge, experience and resources

The imbalance in knowledge, experience and resources between academics and the service user community is substantial. Academic and other research institutions usually have a built-in infrastructure to assess funding opportunities and write grant proposals, something service user organisations usually do not have. A large majority of SURs have had little experience conducting research, and many have limited general education and/or

employment experience. The research jargon used thus presents a real barrier for many SURs to intelligently discuss the research, unless researchers explain terms as they go along (Faulkner, 2005). This means that the research process must include an investment in bringing service users 'up to speed' through training and education (Wright *et al.*, 2006).

That unsteady feeling service users have working in academia

Service users signing on to be paid research workers often have an unsteady feeling related to their new employers/employment. Many service users who have answered the academic call for involvement in research in the past have found a lack of both opportunity and support/training to influence the process. Academia is often hierarchical in nature, which may present a difficult challenge to those who have not worked recently, or who have been involved in consumer organisations, which tend to have less structure (Faulkner, 2005). When service users are hired to work on a particular project (as opposed to regular employees), they may at times feel that 'that they are seen as products with limited shelf lives. As a result, service users may constantly be wondering what's going to happen next' (Stevens *et al.*, 2003).

Lack of infrastructure and/or funding for bridging the gap

As will be discussed in more detail below, it is necessary for a research group or project to assign resources to achieve successful employment of paid service user researchers (Faulkner, 2005; Stevens *et al.*, 2003). If an institution takes on user involvement on a project-by-project basis, they will need to build that support into each project, which is difficult when a funding organisation does not value that level of support. The research institution may then want to reconsider their overall policy of service user involvement and hiring in order to build a mission and infrastructure that will survive individual grants. The barrier here is ongoing challenge of institutions ability to transform themselves.

Principles for the active involvement of SURs

We recommend the following nine key principles as a framework for the active involvement of paid service users working on research projects in academic and other institutional settings. An understanding of these principles for both senior researchers and service users is essential for overcoming the barriers to success noted above and to attain the substantial benefits.

1. Personal commitment
2. Inclusion
3. Clear communication
4. Respect
5. Education/training
6. Effective hiring practices
7. Individualized attention

8. Supportive infrastructure
9. Additional resources and project flexibility

These principles are based on the research literature, working guidelines for mental health service user involvement in research, and our own experience (see, for example, Faulkner, 2005). With regard to the literature, several of the articles we cite have effectively documented the experience of service users with other health difficulties (e.g. cancer); these articles reflect our experiences and are consistent with mental health literature and guidelines. Regarding our experience, author Delman has directed a not-for-profit user-led research organisation for nine years, has hired and worked with many paid service users over that time, and has consulted with universities to achieve the active involvement of service users in research (see Delman, 2007). Author Lincoln has hired SURs directly as principle investigator of a National Institute of Mental Health (US) participatory-action research project.

Personal commitment

Senior researchers *and* SURs should be committed to both active SUR involvement and learning about the other's perspective. (See Wyatt *et al.*, 2008; Faulkner, 2004.) Without that commitment, the natural frustrations that accompany the research process and the differing viewpoints on the project's direction may undermine the process.

This commitment on the researcher side is usually based on a belief that active service user involvement will add value to the research process (Wyatt *et al.*, 2008). Without that belief, there may be little motivation to commit the time and resources to develop the researcher-user working relationship. As such, when researchers are hiring SURs only because of a funding mandate, that commitment is likely to be lacking. When senior researchers would like to work with SURs for the first time, they should first consider observing or participating in such a project, attending service user involvement trainings, and hiring an experienced consultant (see Faulkner, 2004).

When hiring SURs, an important consideration is the service user applicant's belief in the importance of the research topic and the potential for findings to affect policy. The SUR's commitment is important since the research process does not always go according to plan, and patience is required to see the project through. In addition, researchers may be learning about SUR involvement as they go along. SURs dissatisfied with an aspect of the project should not assume that researchers are aware of this, and should attempt to address it with them directly.

Inclusion

The SUR should have a sense of belonging to the research team. Thus, SURs should have the opportunity to be involved in all aspects of the research process, from issue determination to dissemination (Wright *et al.*, 2004; Wyatt *et al.*, 2008). (If not so included, the reasons should be made explicit – Faulkner, 2005). For this involvement to be active, the service user's contributions will need to be valued, encouraged and acknowledged (Faulkner, 2005). Regular (eg., weekly) meetings of the research team, including users, are critical to build

camaraderie and the sharing of updates and plans. Regular group emails can buttress the meetings.

In order to provide a basis for SURs to trust researchers, the differences in experience, background and expectations between the groups should be openly acknowledged early in the project (Faulkner, 2005). This allows SURs to openly discuss their support needs and senior researchers to clarify their expectations.

Wyatt *et al.* (2008) found that physical proximity of senior researchers to SURs is important and can result in off-line 'get to know you' conversations; these events are important because the researcher and service user begins to see the other as a human being. 'Social bonding and fun' can also result from attending conferences, trainings and site visits together (Faulkner, 2004).

Inclusion also requires that materials and meeting locations be made accessible to people with different disabilities and other needs. For example, for someone who has difficulty climbing stairs, it is important to have meetings at a location's first floor or have lift access.

Clear communication

As noted by Faulkner (2005), senior researchers need to be clear with service users on what they wish to accomplish with the research project, their reasons for paying service users, and 'the roles and responsibilities of all parties' (including limits to their involvement). This includes clarity on compensation, training, support, and supervision (Faulkner, 2004).

A major challenge for researchers when collecting data is the ability to stay true to the projected time frame. As noted above, the researchers should clearly communicate this and keep SURs updated on changes.

SURs should be clear with the senior researchers on what their needs and expectations are. This clarity is not a one time event, but must be maintained on a regular basis to avoid misunderstandings. And if not feeling well or dissatisfied, SURs should address their concerns directly with the research director and/or leaders to attempt to negotiate a satisfactory solution, instead of just dropping out.

A contract stating the participants' respective rights and responsibilities may provide more clarity (Faulkner, 2004).

Respect

All parties should respect the others' right to present their own, perhaps opposing, point of view (Wyatt *et al.*, 2008). With the potential for discussions to become heated, there should be at least one participant, such as a project director/co-ordinator, who is seen as a moderating influence. That person will need the caring support of the senior researchers to be able to address needs and resolve difference (Faulkner, 2004).

Senior researchers need to have respect for the hard earned expertise of SURs, and SURs for the academic experience of the researcher (Beinecke and Delman, 2008). While the SUR's expertise may be in recruiting people for a study, a researcher may have much more experience getting a research protocol through a human subjects review board (see Wright *et al.*, 2006). That means listening to opposing points of view, considering them as a reasonable approach to a situation, and at times deferring to expertise.

Education/training

Effective training is a critical element for successful SUR involvement in the research production process. When people lack familiarity with research terminology and processes, they quickly become discouraged from participating (Stevens *et al.*, 2003). A good training program not only builds knowledge, but also generates excitement about the research process and the potential policy implications of the work.

Preparing new researchers to engage in the research process is best done through a combination of didactic learning, observation, role-playing and feedback (Elliot *et al.*, 2002). The initial training should present at a minimum an introduction to research, research ethics, information on the subject matter (including previous research) of the research, and research interviewing. Interview guide and analysis training is best addressed as that work is actually being carried out.

The training should have a strong cross training component (Israel *et al.*, 2003). SURs can present to senior researchers on their relevant areas of expertise; we have had SURs present on strengths-based care, person-first language, and the advocacy work of the user group to which they belong. Senior researchers should also take a flexible approach to the training schedule (Wright *et al.*, 2006). When one of our service users missed several trainings in a row, we caught her up on a one-to-one basis.

The training should include sessions on the practice and policy context of the research. We have had governmental policy-makers discuss with service users their own roles in policy-making, and the benefits research findings will have to them. And we've had providers discuss the specifics of how a particular service works. These discussions provide an additional impetus for the SURs to carry on the research, as they know there will be an audience for the findings.

The training should include a team-building process to create a mutually supportive atmosphere (Israel, 2003). We have also found it advantageous on several levels to have service users demonstrate their new competencies through an exam process.

Effective hiring practices

The service user hiring process should be carried out carefully. Clear job descriptions should be developed based on the essential job functions and minimum qualifications. To attract a diverse group of candidates, the job description should be distributed widely, including to service user groups, vocational programs and universities. Oral presentations by researchers to these groups can boost recruitment.

Upon the receipt of expressions of interest and resumes, researchers should examine the application to detect an interest in the research topic and a desire to work in research. It is best for researchers to interview in teams to counteract possible prejudices (e.g. race, class); a service user ideally should be one of the interviewers.

And as explained in the "support" section, it is beneficial to hire in groups (Faulkner, 2005). There are some service users who would prefer not to work full-time, and it's likely that at least one SUR will leave (see O'Donnell and Entwistle, 2004). In our work we aim for diversity with regard to at least age, gender, race/ethnicity, and experience with the mental health care system.

Individualized attention

SURs bring different interests, skills and needs to the table, and it is important to attend to that individuality for the purpose of motivating SURs whose commitment is wavering (Delman, 2007).

SURs may go through periods of poor health during the course of their employment, and the research leaders should make every attempt accommodate these special needs (Beinecke and Delman, 2008). People who are depressed and having difficulty attending meetings may require extra encouragement and/or 'reminder' calls. Some people may need to work fewer hours or take a break from the process to maintain their mental health; this can often be accommodated when there are other service users to pick up the slack.

If a SUR is not performing essential job functions well, the supervisor should work with him/her to consider a reasonable accommodation, such as extra training or a job coach (Beinecke and Delman, 2008). If a person is unable to perform essential tasks with accommodations, it may make sense for the employment to end until the SUR's health improves.

Building on a SUR's strength is also important, particularly when his/her interest in the project is wavering. One way we do this is by matching the SUR's strengths to a particular research stage. I (Delman) employed a SUR who was most interested in the political implications of the research, so we had him meet with policy-makers to discuss the research and to present the findings. Another SUR was particularly interested in 'creative writing'. Thus, we secured a small grant for her to develop a booklet containing first-person accounts of women ageing out of the adolescent system.

Supportive infrastructure

Several reports have noted that practical, emotional and research supports are critical ingredients of success (Faulkner, 2004; Wright *et al.*, 2006). This support should happen on an individual basis and in groups. The practical support may relate to transportation, accessible space, regular supervision, and an 'open door' communication policy with senior researchers and the project director (Faulkner, 2004).

The emotional support is necessary to build the SUR's confidence and to address triggering experiences that may occur because of the research (Faulkner, 2004). Active listening and encouragement are important aspects of support. SURs may develop their own emotional support network, working through challenging issues together. They are also likely to each bring in new types of knowledge, enhancing SUR researcher capacity.

Additional resources and project flexibility

The employment of SURs for active involvement requires resources in addition to what's ordinarily provided for a research project. Training, team building, supportive infrastructure and the establishment of clear communication channels will require additional funding, extra time, and flexible deadlines (Faulkner, 2005). If SURs' input is to be taken seriously, there will need to be flexibility with regard to research methodology and methods (Faulkner, 2005).

The project's budget should take into account SUR wages, including training time. Other considerations for a budget include a user involvement consultant, a portion of the project director's time, additional computers, job coaches, and accessibility items for people with physical disabilities.

Good practice guidance

Below are some basic steps that senior researchers can take to achieve the active involvement of SURs.

Researcher preparation

1. Develop relationships with service user groups well in advance of hiring paid service users in order to identify key community issues and to identify service users interested in research.
2. If inexperienced in the active involvement of SURs, attend a relevant training, observe or participate in such a project, and hire an experienced consultant to help develop the project.
3. Work internally and with funders to develop a flexible budget and timeline for the hiring of SURs.
4. Identify the concerns the human subjects board may have with SUR involvement (particularly as interviewers), and be prepared to defend that involvement.

Hiring service users

1. Develop a clear job description, highlighting the essential job functions and minimal qualifications necessary.
2. Hire SURs in small groups and from diverse backgrounds.
3. Distribute the job notice widely; include user groups and different multicultural groups.
4. Interview job applicants in teams.

Compensation

1. Pay SURs the prevailing market wage for their time, consistent with other project/organisational staff.
2. Communicate clearly to the SURs the activities for which they will and will not be paid, particularly if the person is paid hourly (this should include the training time). Relevant out of pocket expenses should be reimbursed promptly.
3. Co-ordinate early on with the finance department.
4. Prepare to connect SURs to a public benefits counsellor.

Training

1. Focus the training on a specific project to provide trainees with a clear goal.
2. The training should be interactive, with discussion, role plays, and visits to relevant programmes.
3. SURs and senior researchers should cross train each other.
4. Develop presentations and materials that use clear language, with jargon minimized but defined if used.
5. Be flexible and prepared to adjust the training in response to the expressed needs of the SURs as a group, as well as to an individual SUR, based on informal feedback and formal evaluations.

Supervision

1. Clearly communicate to SURs the reasons for including them and the manner by which the research topic was chosen.
2. Develop an individual and group supervision process. Supervisors and SURs should discuss their respective roles, responsibilities and expectations.
3. Provide to the SUR *at least* one direct supervisor, often a project director or research co-ordinator. That person should have the support of and regular contact with senior researchers.
4. Provide direct supports for aspects of the research process a SUR finds particularly challenging.
5. Group supervision should include regular group meetings involving SURs, the project director *and* the senior researchers. The project director should not serve as the sole connector between SURs and researchers. Supplement the meetings with written communications (e.g. email) on research progress issues and other updates.
6. Extra supervisory attention should be given to research activities that happen outside group processes and/or which could be triggering, such as research interviewing. This could include the review of interview transcripts.

Support

1. Provide emotional, practical and research support.
2. Make every effort to accommodate service user's needs, particularly in relation to health difficulties. When a SUR returns after taking time off, senior researchers and the project director should take the time to bring him/her 'up to speed' and to assess the need for job accommodations.
3. Encourage SURs to communicate clearly to their supervisors the need for an accommodation.
4. Identify the strengths and desires of each SUR; encourage SURs (particularly those who are discouraged) to focus on the research stages that excite them most.
5. Openly appreciate and acknowledge the SUR efforts and contributions. Consider group celebrations for significant achievements (e.g. completing a research report).

6. Provide SURs the space and equipment (e.g. computer) to accomplish their work.
7. Encourage and nurture peer-support among the SURs.
8. Make meetings and materials accessible to all SURs, including assistance with transportation, flexibility with locations of the meetings (including the use of teleconferencing and Internet forums) and large print text.
9. Work with user-led organisations to support SURs.

Team building

1. Create a 'space' for participants to acknowledge the differences in experience and backgrounds between SURs and senior researchers.
2. Engage in several team-building exercises so that research participants can begin to know one another beyond their labels/diagnoses ('service user' or 'researcher').
3. Develop with the SURs a conflict-resolution plan.
4. Work in close physical proximity to the SURs at least some of the time.

Opportunities for involvement at all stages

1. Build connections to user-led organisations.
2. Prepare the SURs to be primary presenters of the findings to policy-makers and community members.
3. Create opportunities for SURs to be a primary or co-author on a research paper and/or to present at conferences.
4. Do not require that SURs participate at every stage of the project.

Additional resources (time, funding)

1. Assess the types and costs of the additional resources required.
2. Negotiate with the funding agency for additional funding, a realistic project completion time-period, and flexibility with both budget and timeline.
3. Other budgetary line items will include:
 - training for senior researchers on SUR involvement
 - SUR involvement consultant to project
 - accessible training materials
 - a portion of the project director's time to co-ordinate and supervise SURs
 - service user compensation costs
 - physical resources, such as computers and tape recorders.

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