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FROM EXCLUSION TO INCLUSION: INVOLVING PEOPLE WITH INTELLECTUAL DISABILITIES IN RESEARCH

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Abstract

The de-institutionalisation of the last two decades brings a poignant focus on social inclusion, exclusion and how to facilitate informed lifestyle choices among people with intellectual disabilities. This study explores some of the developments and challenges in participatory inquiry involving lay experts such as people with intellectual disabilities, their advocates and service staff in sheltered occupational sites. The core outcomes in this study are the collaboration between all involved actors identifying and implementing the service improvements needed. It was concluded that an inclusive joint research methodology may be a key and fundament for the development of supporting and empowering social care practice for this said population.

KEY WORDS: vulnerable population, learning disability, social inclusion, collaboration, inclusive research, occupational programs.

Anotacija

Pastarųjų dvejų metų deinstucionalizacija atkreipia išskirtinį dėmesį į socialinės atskirties ir socialinės įtraukties problemas, siekiant padėti protinę negalią turintiems žmonėms. Straipsnyje pristatomas tyrimas atskleidžia problemas, kurių kyla neįgaliosiems aptarnaujančiam personalui, tarpininkams. Tyrimo rezultatai pagrindžia visų tyrime dalyvaujančiųjų bendradarbiavimo būtinybę teikiant paslaugas, kurios gali padėti spręsti problemą. Tyrimas dalyvaujant gali būti pagrindinė metodologinė prieiga plėtojant ir tobulinant įgalinančią socialinės pagalbos praktiką šios rizikos grupės asmenims.

PAGRINDINIAI ŽODŽIAI: pažeidžiami asmenys, mokymosi negalia, socialinė įtrauktis, tyrimai dalyvaujant, profesinės programos.

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Introduction

In Sweden, as in many other western countries, the past decades have seen changes in the provision of care for those with developmental and intellectual disabilities (LD). A key element has been the move towards ensuring engagement as full members of the community for this population group (Nirje, 1969; Wolfensberger, 2000). This has resulted in the integration of services for those with LD into generic social services programs (SFS, 1993; Socialstyrelsen, 1997) as a part of the move toward normalisation. Current service provision includes group homes for adults, who are unable to be independent and live on their own, access to day activity centers, sheltered work placement, and personal support services (Dychawy Rosner, 2008). Previously, traditional institutional practices have been supported

by basic knowledge in the medical and biological sciences and there has been some discussion of its unsuitability for providing service to persons with LD living in the community (Googley, 2001; Verbrugge, Jette, 1994). A number of studies have emphasised the importance of taking service users' view into account in tailoring and developing good practice (Schraivesande, 2000), as well as involving the parents in the research, and the development of new methodologies and service planning (Schwartz, Rabinovitz, 2003).

Thus, the development, improvement and delivery of intervention care programs of this population require an approach to social services practice that ensures that all involved actors' voices are heard, including that of the learning disabled persons themselves. The object of this article is to illustrate an example of using participatory action research (PAR) to develop best practice in occupational day care programs in collaboration with people that are connected to the care process. First, this paper will introduce the philosophy and approach of PAR. Then an overall description regarding pathways of inclusive inquiry in this study will follow. Finally, some reflections on the outcomes of the process will be presented.

1. The participatory action research

The underlying principles of PAR emphasise on valuing various forms of knowledge and engaging in research in a democratic, empowering and life enhancing way, thus, engendering a sense of togetherness that creates the basis for effective and productive relationships in a number of areas of work (Gilbert, 2004; Welch, Dawson, 2006). The inclusive research methodology of PAR is growing and iterative whereby research questions are developed in collaboration and may continuously change as new directions of research arise and new actions are started. Although sharing a paradigmatic and epistemological basis similar to interpretivism, PAR has no prescriptions or restrictions on what constitutes legitimate research methods. A variety of research methods may be used, *e.g.* quantitative such as quasi-experimental, or qualitative such as participant observation, or interviews etc. No matter what research method being used, the question of validity and reliability is raised accordingly to accepted methodological standards (Walmsley, Johnson, 2003). However, the emphasis throughout is on the dialogical process. Kurt Lewin (1946), generally acknowledged as the first to use an action research approach, proposed the cycles of analysis, fact-finding, conceptualisation, planning, implementation, and evaluation to simultaneously solve problems and generate new knowledge. PAR as a research practice is normally carried out by a team encompassing a researcher and members of an organisation or community seeking to improve their situation. It promotes broad participation in the research process

where the researcher and the stakeholders define the problems at hand to be examined, generate the relevant knowledge about them together, and then take action accordingly (Walmsley, Johnson, 2003).

In recent years, PAR, as an inclusive and collaborative method of inquiry, has gained increased interest from both researchers and practitioners in the field of LD (Chappell, 2000). It is considered that this context acknowledging philosophy of investigation may be, with its focus on the importance of insider knowledge, a useful tool for service development and generation of knowledge for the implementation of change. An attempt at participatory action inquiry has been reported in the area of service user and professional issues (Chappell, 2000; Ham et al., 2004; Schwartz, Rabinowitz, 2003), but there are still few published examples of how to use PAR as a method to facilitate daily activity support in the daily care of people with developmental disabilities and accompanying intellectual impairments.

2. Developing inclusive inquiry

The PAR inquiry was conducted at four sheltered occupational sites for persons with LD in an urban municipality in south of Sweden. The project started in an up to down structure. The administrative officer and service manager initiated and invited the researchers at the university to participate in facilitating the involvement of service users, their families and staff in developing a new approach to occupational program designs. The involved services were providing supported employment and sheltered work placements including social, emotional and academic support to aid the individual in becoming productive members of society. The services contained a car repair shop and garage service, bicycle repair, gardening, and a handcraft shop. Since an informed consent and agreed participation are essential according to ethical approval regarding vulnerable populations, as well as for the quality of this project (Gilbert, 2004; Ham et. al., 2004), only service users and their relatives or legal representatives, staff, or other actors that were willing to take part were included. Participants in the study were managers and field officers ($n = 8$), support workers and rehabilitation staff ($n = 27$), service users ($n = 27$) and their relatives ($n = 13$). The service users had varying levels of disabilities, ranging from moderate to profound and multiple intellectual disabilities. All staff volunteered to have their practice questioned however, not every service user volunteered and thus, was naturally free to depart from the research process.

The conducted research process included phases of problem identification and planning, committed actions, and finally a phase of implementing improvements. The entire research process involved all participants who were working together in mixed groups identifying goals and available resources, and developing data col-

lection procedures. Since the primary goal of the inquiry was to improve occupational programs, the questions that were collectively raised and developed to guide the research process were as follows: How are the occupational training services perceived by the service users, their relatives and by the staff? How can the programs be improved? What could be done to increase the service user's participation in decision-making about the content, goals and realisation of the programs?

3. Pathways of inclusive inquiry in the study

After a collaborative consensus was reached in all groups regarding the research questions and methodology, the staff from each service site made participant observations and face to face interviews with staff and service users at each other's facilities aiming to conduct collegial examinations. The object of the process of this data collection was to enable all participants, including people with LD, to collect images of facts, experiences and ideas about the target services. It was assumed that by identifying both the good and bad experiences may aid reflexivity and facts that would make up a collage that depicts services given by all the stakeholders at the same time. All service levels ranging from first line workers, service users relatives and managers were included. When necessary, the service users were offered support and assistance from their relatives, significant others, or the staff. The experiences of the participants were further discussed in all the assembled groups and served as a starting point for suggested program changes and improvement. Table 1 presents examples of identified and implemented improvements.

The main outcome of this research process was that both the staff and the service users were fully engaged and experienced learning about how to research and develop their own best practice (see Table 1).

The themes, which emerged on the shared stages of the process generating knowledge, included concerns that the occupational programs did not always meet the social, communicative and physical needs of the service users. They articulated improvements issues in examples such as: "My group wanted to work with communication, Anna (staff) informs us in the mornings [...] when she is away no information is given. I suggested a board with pictures of what is going on [...] but I wanted Anna to go on with the information anyway". Another service user's voice about involvement in an inquiry: "My parents helped me with the answers and all the difficult words during cross groups discussions. I don't like changes [...] and here I was supposed to have an opinion on what to change, however, I don't think we should change anything!" Further voices about having an influence on

decisions on the service development process can be exemplified by the following opinion of one of service users: “It’s always the staff telling us what’s going on but my friends thinks that is wrong, so we told them that we wanted to change this.”

Table 1. Examples of identified and implemented improvements in programs supporting-daily occupations for people with intellectual disabilities.

| | Outcome | |
|--|---|---|
| Method of data collection | Examples of identified areas of improvement | Examples of implemented service improvement |
| Participant observations (four half working days at each unit) | Inadequate working structures such as responsibilities, work roles and work strains. A need for better communication boards displaying daily schedules. Absence of work instructions adopted for the specific intellectual disability. Low accessibility for people with transportation problems. A need for various aids in regards to the specific learning disabilities. Service user’s wishes to try out new tools in their work | New work schedules. Incorporating information meetings and information boards at the workplace. Environmental adaptation. Integrating pedagogical and educational aid, instructions and operational descriptions into the work process |
| Semi-structured interviews conducted with the service users (<i>n</i> = 16) relatives and legal representatives (<i>n</i> = 13) staff (<i>n</i> = 12) | Deficiencies of co-ordination between the various staffing groups around the service user The service user’s desires to have more influence on the services The service user’s desires of increased participation when planning services | New trainees programs have been developed. Field visits too pen market service companies. Clearer information to the clients and established work place meetings |
| Documentary review and analyses | Shortfall of rehabilitation plans. Vague goals of the service unit. Lack of plans for staff development. Absence of documented individualised care plans | Improved description of the services’ ambition, goals and mission. Extended marketing of the services. Questionnaire survey to the public clients using offered services |

| | Outcome | |
|--|---|---|
| Method of data collection | Examples of identified areas of improvement | Examples of implemented service improvement |
| Reflective cross-group discussions and collaborative problem solving | <p>A need for educational and training days for the staff about the specific learning disability and training methods.</p> <p>Increased use of sign language.</p> <p>A need for increased participation and involvement of all stakeholders</p> <p>Needs for a strategy advance on collaboration with parents and legislative representatives</p> | <p>Structured educational days for the staff about various intellectual disabilities.</p> <p>Field visits and exchange seminars with other municipality units.</p> <p>Individual rehabilitation plans have been developed.</p> <p>New programs have been developed.</p> <p>New co-operation strategies with service users and their relatives</p> |

As showed in Table 1, there was also a need for environmental adaptations that are adjusted to occupational performance and the different levels of disability of the service users and a need to offer varying program content. In conducting the interviews with the service users and their parents, the service providers became more aware of the service user’s individual interests, needs and concerns, and they began to see the client from a more holistic perspective. This can be exemplified by expressions such as: “As a matter of fact, I want to know what my clients think about working in the store”; another statement was pointing to the issue in this way: “I thought of social training as something not working so well. Maybe service users in my group would like to have a more equal discussion before any decisions are made [...] maybe they would like to go out and eat downtown more often”. This more open minded way of thinking, reinvigorated the staff’s interest in new management strategies and solutions to what was initially perceived as static and routinized conditions. This in turn assisted the staff in developing more individualised management plans and activity options for the service users.

Another significant outcome was that the impact of the actions being developed as are sult of the research had a domino effect at a number of various organisational levels. Inspiration derived from a variety of practice and ideas shared by others led to changes in occupational programs that encouraged service users to train for other kinds of sheltered work settings, which in turn resulted in yet more occupational programs. Moreover, the staff of the units and the service users’ relatives began to understand the very close connections they indeed have while providing care. This refreshed the relationships with the service users, it supported

networks, and resulted, among other things, in the development of an extensive information folder to the service users, their relatives and significant others and new routines regarding telephone contacts as well as designated open information days within each occupational unit.

4. Reflections on the process

The participatory process that took place in this study provides a framework for how to engage service providers, service users and community members in research that potentially includes service improvement. Contemporary research have reported that the drive towards supported and community based service provision may also result in greater levels of vulnerability and that social services need significant improvements (Hall, Hewson, 2006). The core research process searched for and consequently promoted social involvement of the service users. More critically, it identified the need for service development. The service users and their legislative representatives constituted an important reference for grounding service improvements by not only bringing their insights, but also influencing the direction of facts sampling, analyses and implementation of these improvements. Initiating change in service delivery is often considered as one of the most difficult aspects of service development (Chappell, 2000; Gilbert, 2004). In the actual practice, the immediate physical environment and individual occupational performance received most attention from the staff, and rather little attention was given to the complex environmental systems, *e.g.* political or institutional systems that have impact on the service user's health and well-being, or exclusion from employment and the job market. By having dialogical meetings across all institutional levels and also by sharing perceived realities, the involved actors were able to acknowledge greater organisational perspectives and to recognize different values of service provision. This helped them to shift their professional strategies from the service user's performance components to the person's participation and the need for support for social inclusion.

An important and enabling factor in the success of this study was that the participants were co-operating when doing the inquiry as well as in the reflection phase, the analysis and when outlining an activity plan for implementation of the improvements. However, as it has been shown in other studies (Koenig, 2011; Ward, Townsley, 2005), building up social inclusion and a purposeful kind of community collaboration were the most challenging aspects of this research. Increasing family involvement in the care and service evaluations was sometimes perceived as an erosion of the professional influence. This was potentially uncomfortable for some of the staff members since it differed from conventional service

development. Moreover, there was also a cultural conflict between the professional culture and the culture within an individual life sphere, *e.g.* the immediate family. There were also problems concerning with how practitioners can overcome their preconceptions of a situation that related to norms and values of which the member of a said culture may not be aware of. These conflicts were handled through the growing trust and confidence built up and established during the large number of meetings and taking action together, *i.e.* through creating a space for mediating discourse. A direct consequence has been their creased staff awareness of institutional issues and framework within which the service users are now playing a more active role. Thus, the staff shifted their intervention from having a strong focus on established and set ways of steering and service management to a care management that is more concerned with including the service users by inviting them to present their own ideas and suggestions of service improvement, and to then implement their voiced wishes. This has, among others things, resulted in changes such as an increased possibility for the service users to choose among various trainee placements in a variety of community facilities and integrating the work placements into mainstream sheltered work provision in the community.

Historically, people with intellectual disabilities have been subject to a number of various disadvantages, social exclusion and poor quality of life outcomes (Verbrugge, Jette, 1994; Wolfensberger, 2000). To increase a sense of power and participation, it was necessary in this research to create an atmosphere that made inclusion apparent. Especially interesting were those positions that were influenced by the service organisation and the context in which this service existed, *e.g.* the institutional order, expectations and attitudes as shared by all the participants. The findings showed that the service users' participation was not only a question of right-to-service, but also a question of being allowed to express a specific role, *e.g.* as an evaluator or co-researcher. The products of the research process and its results revealed that not only the experts but non-professional researchers such as people with learning disabilities and care staff as well are capable of sharing responsibilities and to be exposed to the complexity of a research design and research process. Consequently, involvement and inclusion should be seen as something more than merely a problem – a hindrance – for researchers in their attempts to find adequate participants to enable them to undertake specific projects. If the research is to have relevance for people with LD, it requires that it takes the aspects and opinions of this group and their significant others into account. However, the retrospective overview as regarding to the research cycle indicates that the powerful stakeholders are maintaining their dominance over core decisions, *e.g.* economical resources and decisions involving resources of time.

Other essential findings were those associated with the nature of LD itself, and the ability to understand and communicate with others (Schraivesande, 2000; Ward, Townsley, 2005). There is an assumption underlying the concept of voluntary participation that people can have free choices and are capable of making them. This belief does not take into account the different conditions of people's lives, material situation and understandings. The long history of the marginalisation of intellectually disabled people may influence their self-selection of enrolling in participation as they may have a low trust in their own capability to communicate their own experiences and desires. Nevertheless, different communication strategies were used during dialogical process in this study, such as using a clear and simple language, symbols, photographs, images and personal support to minimise confusion (Ham et al., 2004; Ward, Townsley, 2005). Moreover, those clients who were able to participate in the process, even partially, claimed that they had gained benefits through the sense of belonging and the companionship offered by others.

Concluding remarks

This research process, which focusses on inclusion and involvement of service users, has shown to be an important instrument in providing the humanistic set of values, which shows that people with LD really have a voice in events that affect their lives. The central tenet of this research focusing on inclusion and involvement proved that people with LD could participate, and were in control of the research process. Further, sharing the social experiences of disability caused a perspective replacement and changes in structural relationships between people with disabilities and non-disabled people. Thus, it is concluded that the development, improvement and delivery of an intervention program in care services for people with learning disabilities require an approach to practice that ensures that all the involved stakeholders' voices are heard, including that of the learning disabled persons themselves. Having claimed this; it is not sure, however, that such positioning of people with intellectual disabilities will actually lead to enhanced quality of interpersonal relationships, or the feeling of being accepted. In the future, there are much potential for exploring the use of participatory inquiry to view questions about the efficacy of current practices and integrative service philosophy within other social care practices and social inclusion for this population.

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