

“RESPECT” IN RESEARCH WITH PEOPLE WITH LEARNING DISABILITIES

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Abstract. There would be broad agreement with the need to address the issues put forward by Clements, Rapley and Cummins amongst service providers and researchers in learning disability. However, these authors’ presentation of their arguments may well unnecessarily antagonize both groups. Additionally, it is suggested, the authors fail to identify the different paradigmatic bases of their proposals and thereby miss the opportunity to air genuine ethical dilemmas in learning disability research.

Keywords: Learning disability, research paradigms, ethics of research.

Introduction

The general arguments put forward by Clements, Rapley and Cummins (1999) are important and interesting and are arguments that, in the main, also represent my own views and convictions. They flag up real problems and dangers that everyone from research funding bodies to the reviewers and editors of journals either need to take into account or already take into account in funding and publishing research findings.

I have, however, several problems with the authors’ approach, including their attacks on other professionals and their oversimplification of the complex issues that surround research. My main problem with their paper is, however, that the style that they adopt leads them to fail to distinguish amongst the various paradigms for research with people with learning disabilities, and therefore to leave the reader in some confusion about their fundamental position.

Attacks on researchers and service providers

The authors’ views expressed about other researchers and about service providers are sweeping and on many occasions offensive (they admit to a deliberately polemic style). Their view of the “scientific community”, which they appear to see as some kind of “entity” acting with a common psyche, is that it bears down on the “vulnerable” to its own benefit. Vulnerable people are at risk from it either through “acts of commission and acts of omission” (p. 104), “. . . powerful individuals and interest groups can easily be careless with the lives of powerless people” (p. 105), and the powerless are seen by some interest groups as “less and less worthy of support or even life itself” (p. 105).

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The “objectivity claimed by (the scientific) constituency cannot be relied upon to protect people who are vulnerable” (p. 109). Ethical standards have, to date, involved a “relative free-for-all” (p. 108). Subjects for research studies are selected because of their “easy availability” or because they are “particularly powerless” (p. 113). Research reports which do not “witness” the disgraceful settings in which people live “colludes with the serious violations of human rights that have been the lot of many vulnerable people” (p. 105) and “silence implicitly condones these conditions” (p. 112). “Collusion may stem from a desire not to incur the displeasure of professionals who allowed access to the research sample. . .” (p. 105). The accrual of benefits from research has “heretofore been largely one way” (p. 110) and researchers do well out of research in terms of “jobs and status” (p. 113). They “enjoy high status” (p. 105) and “collectively constitute a powerful lobby” (p. 105), which is answering “the siren call of ‘accountability’” (shared by others receiving public funding) (p. 108), with their status being made “dependent on ‘measurable’ output” (p. 105) with the apparent implication being that ethical standards are less and less important to them. A special reference is made to multi-component interventions that are required to service situations rather than the isolated interventions “beloved by behavioural researchers anxious to ‘control’ extraneous or ‘confounding’ variables” (p. 113).

The authors’ views on service providers are less fully articulated but equally vigorous. In relation to the vulnerable person they are seen as having a “self-serving bias”. Someone should give consent to involvement in research in the person’s best interest “but *not*, and we stress this, current or previous service providers” (p. 111).

Clearly, what I have done in the preceding paragraphs is to quote isolated phrases from the overall argument and, to be fair, the authors do suggest that “research has made many positive contributions” (p. 105) and that there is “no doubt that much research does actively assist the well-being of marginalized and devalued people” (p. 107). However, whether or not it was the authors’ intention, a picture of blinkered, uncaring and self-interested researchers acting as the agents of malign forces, and of self-serving service providers, is the one created. Insulting a substantial proportion of your audience is hardly a good framework in which to develop serious arguments.

The reality of research in learning disability

For researchers and the majority of service providers learning disability is not a field in which there are rich pickings to be had in terms of high status and financial gain. Although there clearly must be exceptions, and degrees of commitment, people who become involved in research with people with learning disabilities usually do so because they want, in some way, to improve the lives of those people. Almost certainly their philosophical views would classify them as “liberal humanists”. The majority of researchers whom I know in the learning disability and related fields would dearly cherish the idea that their research would lead to “immediate improvements in the material conditions of life for disabled research subjects” (Oliver, 1992; p. 109). Similarly, from my own experience and the experience of colleagues working in learning disabilities research, the majority of service providers, at whatever level, are committed to the best interests of their clients. In terms of consent to involvement in research, service providers may indeed be extremely protective. In a recent study in this Centre

a group of care workers seriously questioned whether they should complete schedules describing the behaviour and characteristics of people with profound learning disabilities, on the grounds that the people themselves could not give them consent for this information to be provided for research purposes.

The classic image of a researcher is of a person who, because of academic or scholarly interest, chooses a research project, undertakes it, analyses data and publishes an objective account of his or her findings, drawing only those conclusions that are thoroughly merited by the data. This, of course, is a simplistic view, especially with researchers in a field such as learning disability. Researchers operate against the background of services and public attitudes that pertain at the time and, as such, have limited scope for realizing those beliefs in their work. In the current political and economic climate researchers are not in control of the research agendas set by funding bodies and funding bodies are increasingly proactive in setting these agendas. In an article entitled "Confessions of a jobbing researcher", Parker and Baldwin (1992) point out that the freedom to shape policy makers' agendas or to do research that researchers want to do is therefore constrained.

Nonetheless, research is a politicized activity and the underlying philosophy of researchers can and does find expression. Researchers are free to reject research commissions (although this may, at times, imperil their employment). My own Centre rejected out of hand a commission from an agency, strapped for cash for services for people with learning disability, when we found that the issue that the agency was interested in was whether their clients would prefer reduced but free day services or whether they would prefer to pay for their services.

Similarly, by the selection of measures within research projects, researchers can at least highlight aspects of interventions or services that they feel are particularly good or particularly poor. This can and often is accomplished without violating "objectivity" in research. Hatton and Emerson (1994), whom the authors quote with approbation, were able to question the acceptability of the quality of life of people with learning disability compared to the general population because the majority of studies on institutional versus community provision have used parallel quality of life measures. Hatton and Emerson may well, privately, "protest" the conditions in institutions, but they were staying well within the rules of scientific analysis and, in effect, asking a new research question based on existing research. Additionally, researchers can and do go beyond the rubric of only drawing conclusions based strictly on empirical data to conclusions based on their experience in undertaking a research project. This practice is completely acceptable, provided there is a clear distinction between the two types of conclusion.

Publication of a research report is, however, the equivalent of letting a genie out of a bottle. Researchers cannot control and sometimes cannot even imagine the way in which their research might be used in policy making or by interest groups. Historical examples include the splitting of the atom and the invention of the stored-program computer, where the researchers involved could not predict the applications of their discoveries. In the learning disability field research on the persistence of severe challenging behaviour that documents the costs of services may lead to a *reduction* in funding for such services by cost-benefit sensitive planners, on the grounds of a better return for spending on other client groups. Research on the genetic anomalies underlying

syndromes associated with learning disability may, as the authors envisage, see their work leading to “refined prenatal testing and the *likelihood* (my italics) of large scale termination of fetuses identified as genetically different” (p. 107). The researchers themselves may see their work as furthering understanding of syndromes (with the possibility of better management and eventual “cure”) and as allowing potential parents of affected fetuses opportunities to make informed choices. It is worth pointing out that work on genetic anomalies underlying specific syndromes is not infrequently advocated and sometimes funded by parent groups organized around particular syndromes (Hunt, 1998), instances of the type of “constituency” determination of research of which the authors approve.

Maintaining respect in research

The main thrust of the arguments of Clements et al. is around the area of encouraging researchers to be more aware of the need to show a respectful and responsible attitude to people with learning disability in their research. However, although individual points come across clearly enough, the absence of a coherent framework for their arguments left me rather unclear as to what precisely they were arguing for.

Several paradigms for disability research have been offered in recent years as alternatives to traditional positivist research, the paradigm that the authors appear, overall, to adopt. The traditional paradigm assumes that the social world can be studied in the same way as the natural world, can be value-free, that causal explanations can be provided and that findings are independent of underlying assumptions and of methodology (Oliver, 1992). According to critics positivist research also embodies a divide between “researcher” and “researched” and, in particular, a divide that constitutes a power difference between the “powerful” researcher and the “powerless” subject to the point of “alienation” of people with disability (Rowan, 1981).

There is no question that traditional research paradigms run the risk of exploiting this power relationship and many of the suggestions made by Clements et al. can be interpreted as safeguards against alienation within the positivist paradigm. They suggest that more use should be made of self-advocates, advocates, campaigning organizations, family members and family organizations in approval of research and in consent for participation in research projects. There is, of course, the need to consider the appropriateness of such involvement depending on the specifics of projects. Projects can be seen as lying on a continuum from those that use procedures that involve individuals directly, for instance drug trials, to those where data are collected about individuals from third parties. Existing procedures ensure ethical scrutiny of all projects along this continuum, but it is reasonable to suggest that the need for involvement of additional groups in giving consent is less for projects where individual participation is not directly involved.

Incorporating the authors’ suggestions relating to consent might ensure that aspects of the authors’ pleas for “respect for persons” and “beneficence” are met, as could other aspects of their case. For example, the recommendation that subjects be paid for participation in research projects could be met (although funding bodies may balk at increased costs of projects). Additionally, researchers could add a section to their reports that outlined the steps taken to try to ensure that the proposed benefits of

participation in a project had been realised. However, since the impact of many projects lies in their appropriate dissemination, listing these activities in traditional journal articles might be seen as rather an odd and inappropriate procedure. In the case of policy related research, impact is also very difficult to assess, and actual impact is notoriously outside the control of individual researchers or research teams (e.g. Tizard, 1990).

Other suggestions made by Clements et al. are more difficult to interpret within the traditional positivist research paradigm and reflect radical paradigms that they appear to reject when offering their arguments for improvement in practice. The most radical alternative has been termed the “emancipatory paradigm”. Oliver (1992) argues that the attempt to objectify social research ignores the fact that such research is always fundamentally political. Given this fundamental proposition he argues that the function of research in relation to oppressed groups, including people with disabilities, should be to bring about change that they feel is relevant to themselves. To this end they should be in control of the research process from the inception of projects through formulation of research questions, selection of methodology, conduct of projects, analysis, interpretation and dissemination of outcomes. In this context “researchers have to learn how to put their knowledge and skills at the disposal of their research subjects, for them to use in whatever way they choose” (Oliver, 1992, p. 111). Oliver and others also argue that this control over the research process should extend to control of funding of research. For example, Ramcharan and Grant (1994) suggest that only when disabled people and their organizations are at the apex of the research hierarchy, including the control of the financing of research, can research be deemed “emancipatory”. Zarb (1992) has also argued for the adoption of an alternative paradigm, the “participatory paradigm”, which, although less radical in its aims, also argues for research which is funded and controlled by people with disability.

Clements et al. make a number of suggestions that could only be fully realized if these alternatives to the positivist paradigm were adopted. In their discussion of justice they suggest that more research should address issues “most significant from the perspectives of vulnerable people themselves” (p. 113). In line with such paradigms they suggest that “research funds could be channelled direct to (vulnerable people) so that they can determine how they are disbursed” (p. 113). These arguments, and the earlier suggestions that self-advocates and others should be able to withdraw consent at any time and, moreover, should have editorial power over research reports (p. 111), can only be realized if researchers adopt paradigms that transform research into an overt arm of activist endeavour. Such a shift is also suggested by the authors’ plea for “the requirement for researchers to add a witnessing component to their work” (p. 111).

Activism and beneficence

Clearly the research developed using the participatory and emancipatory paradigms is an avowedly political activity and, as such, has objectives that would run counter to the objectives of many funding agencies (Barnes, 1996). Such research, by its nature, runs the risk of criticism on the grounds of lack of objectivity. For instance, research

on parents' preferences for village communities rather than community residential provision undertaken by groups campaigning for village communities might well be questioned. Researchers have always staunchly resisted suggestions from Government funding bodies that they should have editorial control over research reports and suggestions that other interest groups, of whatever kind, should exert such control similarly put at risk the academic independence of researchers. Research within these paradigms runs the serious risk of confusing the roles of researchers as academics involved in academic endeavours with that of activists seeking to promote "political" change (Shakespeare, 1996). Moreover, the skills of researchers do not necessarily equip them to be activists. If they are to make a contribution to improvement in services, it is more likely that they will be successful by effectively fulfilling their role as researchers rather than trying to occupy roles in which they are uncomfortable.

However, researchers could well make their work more meaningful and valuable by undertaking research that genuinely involves people with learning disability in the research process. Parker and Baldwin (1992) conclude that the normal practice of involving disabled people in pre-piloting and piloting phases of the research process is not enough. They suggest that they should be involved in such a way that they can be framing and elaborating research questions, seeing this as a way in which the non-disabled researchers can be made "fully aware of issues which are currently 'live' among disabled people" (p. 201). They also suggest that people with disability should be represented on research advisory groups, and that they should be trained as social researchers. Ward (1998) reports that, following the official commitment to "user involvement" signalled by the NHS and Care in the Community Act, the Joseph Rowntree Foundation adopted the requirement that all proposals should strive for appropriate user involvement at all stages of the research and development process, and that there was at least one person on the Committee handling proposals who was a disabled person with relevant experience. The Foundation has a general commitment to only funding projects that have "a clear potential for bringing about policy and practice changes which will be positive for people's lives" (p. 34) and also insists that there is evidence of a "proper partnership with organisations of disabled people" (p. 35) where proposals originate from non-disabled researchers. In other terms, the Foundation has its own agenda for research that differs from that of other funding bodies.

These examples represent coherent strategies for creating a more equal "power relationship" between researchers and researched. The feasibility of these approaches is underlined by the growing body of literature which demonstrates the value of interviewing people with learning difficulties about their lives and the services that they receive (Stenfert Kroese, Gillott, & Atkinson, 1998). Although much of this literature relates to people with mild to moderate learning difficulties and relatively good communication skills, sensitive methods have been developed that now allow researchers to involve people with limited communication skills more actively in the research process.

Nonetheless, there remain serious problems about the extensive involvement of people with learning disability (or, where appropriate, their informal carers) in all phases of the research process. The studies cited in the preceding paragraphs suggest that their involvement in the development of research questions, interviews and other measures, can and should be increased. Coupled with extensive participant observation this should benefit researchers in that they would, in Parker and Baldwin's terms, "be fully

aware of issues that are currently 'live' among disabled people". However, even taking into account studies that indicate that people with poor cognitive and communication skills can provide their views, it is hard to escape the question of who speaks for people with severe to profound disabilities. One suggestion would be that self-advocacy groups should be involved. This suggestion begs the question of whether members of such groups would be in a better position than anyone else to identify the needs and aspirations of people with more severe disabilities. Similar questions could be raised about the ability of parents to speak for their sons or daughters. In the example quoted by the authors (Turnbull & Ruef, 1996) parents were speaking for themselves about the difficulties that *they* experienced and the services that *they* wanted rather than about the wishes of their sons and daughters. Parallel issues apply to other aspects of the research process. Are self-advocacy groups and parents realistically in the position to consent to the involvement of people with more severe disabilities in research? Issues concerning limited cognitive and communicative capacity also apply to Parker and Baldwin's suggestion of training people with learning disability as social researchers. One of the projects described by Ward (1998) used this strategy; in other projects cited by her people with learning disabilities acted as consultants and advisers.

These questions relate to the issue of beneficence, which the authors refer to but do not fully explore. Beneficence relates to the duty to maximize good and minimize harm in interventions. A further principle, autonomy, suggests that a person should be seen as rightly self-governing if they are judged to be competent in being able to form reasoned judgements. If they are then they can decide on their participation. On accepted criteria for judgement of competence, people with severe and profound disabilities would not be viewed as autonomous decision makers in situations beyond expression of limited choices in immediate situations (Kiernan, 1991). Under these circumstances, informal carers and service providers are required by their duty of care to exercise "weak paternalism" in making decisions, for example about the management of self injurious behaviour in the interest of their long term good, which may override the apparent wishes of the person concerned.

This situation also applies, albeit arguably to a lesser extent, with people with less severe disabilities. Clements et al. quote studies demonstrating the tendency toward acquiescence among this group, arguing, quite correctly, that this requires enhanced effort on the part of researchers in seeking informed consent. However, people with mild disabilities are increasingly referred to services because their behaviour is dangerous to themselves or others, or risks their involvement with the criminal justice system, with services being given the responsibility for managing their lives in such a way as to reduce risk and educate or otherwise prevent recurrence of such behaviour.

Clements et al. clearly accept that researchers and others should act beneficently. However, in extending their arguments to principles underlying the alternatives to the positivist paradigm, they fail to acknowledge the limitations of autonomy of people with learning disabilities and therefore confuse real issues that need to be fully addressed.

Conclusion

Clements et al. draw attention to issues that need to be discussed. However, a more articulated and less impassioned approach might have been more helpful. A closer

examination of the issues suggests that, in particular in learning disability research, easy solutions to the problems that they raise are difficult to come by. More reasoned discussion may reveal fundamental dilemmas at the heart of such research.

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