

Does Advocacy Have a Future?

Robin Jackson

Abstract

This paper seeks to question whether advocacy services for people with developmental disabilities have a future. Attention is drawn first of all to Wolfensberger's view that the effectiveness of advocacy services has been seriously impaired by the strident message uncritically proclaimed by certain sections of the Self-Advocacy Movement. It is the contention of this paper that advocacy services have only an ephemeral existence. Once the statutory agencies which fund the advocacy services realize the challenge that independent advocacy services pose, they feel obliged to react. Examples are cited of statutory agencies in the U.K. which are now developing their own in-house 'independent' advocacy services. The continuing difficulty of citizen advocacy schemes in recruiting sufficient volunteers, when coupled with the in-built capacity of self-advocacy groups to self-destruct, means that parent advocacy is likely to remain the only form of lay advocacy able to bring about significant changes in the quality of services for people with developmental disabilities. Plus ça change, plus ç'est la même chose.

The question posed in the title is not a rhetorical one. For reasons outlined in this paper there are serious doubts whether advocacy can contribute to the quantum leap required if there are to be significant and lasting improvements in the quality of services provided for children and adults with a developmental disability.

In characteristically forthright fashion Wolfensberger (2003) has identified some of the problems that currently hinder progress. He has acknowledged that the 'community living' revolution that started in the late 1960s has opened up innumerable opportunities to impaired persons, and has conveyed many of the good things of life to many of them. However, in his opinion, one of its greatest shortcomings has been that a large proportion of adults

who have been impaired since childhood do not have much opportunity for genuine community participation: they have few or no real friends, or they associate almost entirely with other people who are societally devalued themselves, and/or with paid caretakers.

In the 'bad old days', according to Wolfensberger (2003), there were few services and many people got none, or next to none. If people with an impairment were placed in an institution, they tended to stay there because institutions rarely went out of business and only let their inmates out reluctantly. The situation is quite different today. Wolfensberger points out that we are awash in services but services that are very unreliable in a number of ways: (1) they are normatively of very low quality; (2) if they are of satisfactory quality, this quality rarely lasts; (3) they make promises that they cannot keep; (4) they have high personnel turnover; (5) they provide poor continuity of experience for clients and their families; and (6) the very existence of many is discontinuous. Clearly, this negative portrayal of the quality of current services for people with developmental disabilities is not one that would gain universal endorsement.

It is Wolfensberger's view that many of these problems have occurred because of the advent of the ideologies of radical individualism coupled with radical self-determination and the derivative constructs of 'choice', self-advocacy and empowerment. As a result of these ideologies, many people who have a developmental disability are today turned loose without any, or without sufficient, supports, guidance, tutelage, or outright controls.

No matter what laws are in place, what rights have been defined or how much money is being spent on services, Wolfensberger argues that there is no substitute for having one and preferably more persons in the life of a vulnerable individual who have made a voluntary personal commitment to that individual, who have no conflict of interest that would undermine that commitment and who will be by that person's side when that person is in difficulties.

Citizen Advocacy

In citizen advocacy, which has been actively promoted by Wolfensberger for the past four decades, the advocate is a committed member of the wider community (usually a volunteer). This one-to-one relationship was seen as a step in the empowering process for the person with a disability, a way to encourage the strengthening and acquisition of skills by that person while acting as a safety net for the person with the disability.

The rapid appearance of citizen advocacy programmes throughout the U.S.A. resulted largely from sponsorship by the Association for Retarded Citizens and its various state and local affiliates. As a result of financial assistance from the federal government, the Association was able to establish a National Citizen Advocacy Office that prepared and distributed guidelines for recruiting, screening and training volunteer advocates (Scheerenberger, 1987).

Studies of citizen advocate programmes in the U.S.A. have found citizen advocates successfully undertaking a number of distinct roles (Danker-Brown, Sigelman & Bensberg, 1979). What is of particular interest is the assumption by citizen advocates of a defender role that is assertive, proactive and interventionist in character. All of these programmes satisfied one essential component of the citizen advocacy model in that they were not operated by agencies or professionals acting in professional roles (Wolfensberger & Zauha, 1973).

While citizen advocacy has proved successful in many ways, a review undertaken in 1983 produced some significant exceptions (Wolfensberger, 1983). It was reported that very few individuals with a severe or profound developmental disability were receiving any form of advocacy service. The failure to extend citizen advocacy programmes into the area of guardianship for such individuals hindered efforts to assure ageing parents that such services would be available for their offspring when needed. One of the main reasons for this shortcoming was that most citizen advocates had difficulty with, or little enthusiasm for, working with individuals with a severe or profound developmental disability for whom a meaningful and reciprocating relationship could not be established. It was strongly urged that advocacy groups should reach out and provide services in these neglected areas.

There have been instances where funders either have refused or have shown reluctance in supporting advocacy schemes which represent people with a severe or profound developmental disability who are unable to act or speak for themselves. In justification it has been argued that there could be a risk that advocates would second-guess what the person with a severe or profound developmental disability wanted or needed or would impose their own views which might be at odds with what the person represented actually desired. Whilst this argument may have some validity, it could equally apply to professional workers (e.g., social workers; nurses) whose views might be influenced by commitment to a particular ideological stance that rendered them incapable of arriving at an independent and objective assessment (Jackson, 1999a).

If most advocates are aware of the codes of practice applicable in day, residential and other services and the standards of performance that services are expected to uphold then any breach of these codes and standards, as far as they affect a client, should be evident to the advocate. In other words, there are objective measures by which to judge whether or not a client's rights are being ignored or injured. It is not, therefore, a subjective judgement on the advocate's part. If people with a profound or severe developmental disability are excluded from the remit of an advocacy service then one of the most disadvantaged groups in society is further disadvantaged. This would constitute an unfair and indefensible form of discrimination (Jackson, 1999a).

Does Advocacy Have a Future?

Peters (1995) has offered a number of arguments to explain why, in its philosophy and practice, advocacy will continue to swim against the tide of dominant values in our culture. First, it can be argued that our society increasingly condones the selfish pursuits of individual interests to the detriment of others' well-being. In such a self-centred social environment, advocacy stands out by appealing to people to be 'others-centred'. Second, our society places high value on such characteristics as wealth, health, physical beauty, youthfulness, intellectual ability, independence and productivity. As a consequence, people who possess such socially desirable characteristics are valued. In contrast, those who personify the opposite of the qualities become devalued. The fact that people with developmental disabilities are devalued means that there are likely to be few citizens who will come forward and act as their allies.

Third, our society is currently witnessing the growing professionalization, formalization and bureaucratization of human services. Increasingly we are led to believe that ordinary human needs are best met by formal services utilizing impersonal and technological means. An outcome of this trend is the emergence of the cult of the human service 'expert' who is thought to know best and to whom we must defer. Thus the contributions of friends, neighbours and concerned citizens are overlooked because such persons are regarded as 'unqualified'.

Fourth, we live in an age in which science has been elevated almost to the level of a religion. In the same way that science demands material proof as validation of its hypotheses, we look for evidence of success in terms of the tangible outcomes. In human services, the criteria of quality may include

such outcomes as the successful completion of individual programme plans, the frequency of community outings, and the number of beds which are filled in a residential facility. In advocacy, whilst support provided by advocates may be practical in nature, other characteristics of citizen advocacy relationships – such as love, friendship, acceptance, respect and inclusion - are not so easy to assess and measure. In this context, researchers in the advocacy field could benefit from the valuable work undertaken by those who have developed instruments for assessing and measuring the quality of life of people with developmental disabilities (Brown & Brown, 2003; Brown, Raphael & Renwick, 1998; Cummins, 1993; Goode, 1994).

Funding

A further problem for most advocacy schemes is that they are usually dependent on statutory sector funding from health authorities and/or social work departments. Although this financial support is welcome and serves to provide stability and security to local advocacy projects, there are inherent dangers in relying too heavily on such funding. A particular concern in the U.K. is the trend for advocacy schemes to be funded through contracts rather than grants. The Scottish Executive (2001) has noted that the tendering process is not a creative way to achieve the effective provision of advocacy.

- It requires the commissioners to specify in considerable detail what is to be provided. However, a better picture of what people need most from advocacy emerges more clearly over time.
- It sets up the purchaser-supplier dynamic, where the advocacy scheme is expected to see itself as delivering a service on behalf of the commissioners, not in response to the people who need advocacy. This compromises an agency's independence.
- It encourages advocacy schemes to be dependent on the funding provided by the commissioners, so that the advocacy only happens if this funding continues to be provided. By definition, advocacy means a continuing commitment to people over time and not abandoning that commitment in difficult times.
- It tends to encourage the choice of the larger, national advocacy agencies which can present bids, demonstrate a track record and negotiate contracts. This makes it harder for advocacy to become genuinely rooted in the community.

The tendency for statutory service funders in the U.K. to impose service agreements is undesirable for the following reasons:

- They present a direct challenge to the integrity of advocacy schemes
- They can lead to subtle or blatant pressures on advocacy schemes to disclose confidential information
- They can accentuate the bureaucratization of the service provided
- They permit the funder to retain control and place a check on the process of client empowerment.

(Jackson, 1999b)

Kendrick (2002), too, has noted that one of the principal sources of funding for advocacy groups in the U.S.A. comes directly from statutory mandates. Much of the advocacy that is undertaken independently in the U.S.A. owes a debt to the good faith of legislators and to a degree, public bureaucrats that respect the need for advocacy to be independent. This support cannot be taken to be a permanent right. In Kendrick's opinion, if funding were to disappear, so would the advocates, and possibly the organizations themselves, given the reliance on paid or professionalized advocacy in the U.S.A. As paid advocacy has largely displaced unpaid citizen advocacy, there has been no significant development of a voluntaristic network. The failure of citizen advocacy schemes to recruit sufficient volunteers to sustain a viable advocacy network coupled with the increasing evidence that other kinds of formal advocacy are being slowly transmuted into quasi-statutory services may explain why increasing attention has been directed to the role of self-advocacy.

One recent development in England gives cause for particular concern (Gould, 2003). The government has decided to abolish Community Health Councils, the long established voice of the health service user, and to replace them with a bewilderingly complex bureaucratic edifice comprised of:

- Patients' Forums which will be based in every primary care trust and National Health Service trust. They will be funded by the Commission for Patient and Public Involvement in Health and monitor and review services arranged or provided by the trust. They will seek the views of patients receiving services, inspect premises and make reports and recommendations to trusts.
- Patient Advice and Liaison Services (PALS) which will be provided in every trust to resolve problems on the spot; provide information to patients, carers and families; put people in contact

with local support groups; and tell them how to access the complaints procedure.

- Patients' Forums will also provide an Independent Complaints Advocacy Service (ICAS) to enable anyone to make a complaint about NHS services. ICAS will offer free impartial confidential support; information about complaints procedures; assistance with letter writing; support at meetings and has a brief to listen and act on the patient's behalf. ICAS will also help and guide a complainant through the whole process from local resolution to formal investigation.
- The operation of the Patients' Forums and ICAS will be monitored by the Commission for Patient and Public Involvement in Health (CPPIH). It will be the funding body for Patients' Forums and ICAS and submit reports to the Secretary of State for Health on how the system of patient and public involvement is working.

The problem here is that the advocacy element in this arrangement will be owned by the hospital trusts it exists to monitor and challenge. The high profile adoption of this model will hinder rather than help the development of an independent advocacy culture since it will give a tacit nod to other large service organizations which would be only too happy to create 'in house' advocacy for their users and to dispense with the rigours of independent scrutiny. The ethics of the market place when combined with an emphasis on clinical outcomes will inevitably lead to a form of advocacy that does not differ significantly in its mode of operation from the service that it is monitoring. The neutering of advocacy services in this way communicates a damaging image to both public and professional audiences of the integrity, value and purpose of advocacy. Such an image is likely to act as a deterrent to any potential user considering approaching such a service. Recruitment of advocates, too, could be adversely affected by this negative image.

A further example of the way in which advocacy schemes can be absorbed into the statutory system is provided by the introduction and implementation of the Mental Health (Care and Treatment) Act 2003 in Scotland. The primary objective of the Act is to ensure that people with mental disorder – defined as covering mental illness, personality disorder and developmental disability – can receive effective care and treatment.

This Act enshrines the right of access of a 'patient' to advocacy. It places a duty on each local authority and health board in Scotland to ensure the provision of independent advocacy services to any person with a mental

disorder within their area. In other words, a local authority or health board has a statutory obligation – a legal duty – to involve an advocacy service and the advocacy service has a duty to respond. If representation is sought then there will be an expectation on the part of the local authority, health board and client that the advocate appointed will be thoroughly familiar with:

- all the principles, roles and responsibilities involved in the implementation of the Act
- the range and nature of the powers relating to compulsory treatment and detention
- the law concerning people with a mental disorder who enter the criminal justice system and
- knowledge of a person's rights and safeguards in accessing mental health services.

If for any reason an advocacy scheme is not able to offer representation then this could lead to the withdrawal of funding because of the failure by the service to meet its obligations.

Representing a 'patient' may result in the advocate making an appearance before a Mental Health Tribunal where the advocate is likely to be 'opposed' by a professional who will be familiar with the legislation or will have been briefed by legal officers from either the local authority or health board. If 'patients' are not be disadvantaged then advocates will need to be thoroughly grounded in the relevant law which means that some form of specialist legal training will be required. It is open to question whether there are many volunteer advocates who would have either the competence or confidence to act in such a capacity.

Training

There are those who believe that the provision of training runs the risk of 'professionalizing' the role of the advocate and transforming their identity to that of a quasi-human services worker (Peters, 2000). It has been argued that one of the main strengths of advocacy is the independence of representation provided by advocates to their clients. In representing their clients advocates are asked to act as 'free agent' citizens unencumbered by significant conflicts of interest. However, if advocates undergo training – it is possible that the content of the training – whether intended or not – can serve to control their actions. The training may impart knowledge of a highly prescriptive nature which can discourage advocates from exercising common sense, initiative

and flexibility – the essential qualities sought in the ideal advocate. Peters (2000) contends that the case against the provision of advocacy training is that it is incompatible with, and even destructive of, the identity of advocacy.

Advocacy Movement

There is a further reason why the future of advocacy is clouded. If advocacy is viewed as part of a Movement then it has to be recognized that 'Movements' usually lose the force of that original impulse which brought them into being and other new issues emerge which generate new Movements. These new Movements may attract to them those whose allegiance had formerly been given to advocacy. As there is a finite pool of citizens who are prepared to volunteer their services, there could well in the future be a contraction in the number of people coming forward to act as advocates.

The life span of advocacy schemes may be shortened for other reasons. It has been suggested that advocacy schemes have an ephemeral existence passing through a four-stage life cycle (Jackson, 1999b).

Initial phase: a short period characterized by general enthusiasm for the idea of advocacy

Awareness phase: when statutory services begin to realize the potential threat that independent advocacy poses

Containment phase: when efforts are made 'to rein in' advocacy schemes as the performance of local authorities and health boards funding the schemes comes under increasing critical scrutiny; and

Final phase: when the integrity of advocacy schemes is progressively subverted either through their absorption into the statutory structure or through the imposition of contractual arrangements that limit operational freedom.

Self-Advocacy

The failure of citizen advocacy schemes to recruit sufficient volunteers to sustain a viable advocacy network coupled with increasing evidence that other kinds of formal advocacy are being slowly absorbed into the statutory system may explain why increasing attention has been directed to the role of self-advocacy. Self-advocacy has been described as the process of

development through which individuals acquire the skills and confidence to voice their own views and concerns. However, it can also refer to the activities of groups of people who have come together to voice their collective concerns.

Whilst the growth of a vibrant self-advocacy movement over the past few decades has generally been welcomed, some reservations have been expressed. In Wolfensberger's opinion, the adoption by the People First Movement of 'the pernicious new ideology of radical individualism and self-determination' threatens to antagonize and alienate those whose support is vital if appropriate services are to be developed (Wolfensberger, 2003). In the U.K. particular frustration has been expressed at the way in which research on inclusion has been hampered by certain self-advocacy groups dogmatically committed to the principle of 'Nothing about us, without us'. Researchers have urged this lobby to give them the freedom to discuss issues relating to inclusion and not seek to determine the scope and direction of that research (Walmsley & Johnson, 2003).

The aggressive manner in which these activist groups pursue their interests was shown when they gave oral evidence to the Joint Parliamentary Committee on the Draft Mental Incapacity Bill in October 2003. Representatives of People First, Changing Perspectives and Values into Action, all organizations promoting collective self-advocacy for people with developmental disabilities, vigorously challenged the right of parents and relatives to have any say in the key decision-making affecting their children's future. The overwhelming impression of parents and relatives, portrayed by these organizations, was an entirely negative one. They were characterized as self-centred, over-protective and controlling. For their part the parents questioned the authority of these organizations to speak on behalf of all children and adults with a severe or profound developmental disability and they challenged the assumption that there were any people who were better equipped to represent their children than themselves. The evidence of the last decade suggests that government departments have tended to listen more attentively to the views of these self-advocacy collectives than parents and relatives in the mistaken belief that they present the authentic voice of people with a developmental learning disability.

Conclusion

There must be some doubt as to whether advocacy has a future. First, it is clear that there are too few volunteers in our communities to make citizen advocacy a viable option. Second, the statutory services have seen the potential threat that independent advocacy poses and have succeeded in introducing measures to nullify its impact. This has been done by: (1) funders imposing tight contractual arrangements which limit the operational independence of advocacy schemes; (2) a process of assimilation whereby advocacy schemes are absorbed within the statutory system; and (3) according advocacy token not substantive recognition. Third, the abrasive manner in which self-advocacy organizations have pursued their narrow radical agenda has alienated support for advocacy. Fourth, the pressure on advocacy services to become increasingly professionalized and bureaucratic is likely to discourage volunteer advocate recruitment. Fifth, as other priorities are identified advocacy will slip down the political agenda of national governments and organizations. This means that less money will be directed to already financially over-stretched advocacy schemes reducing further their capacity to offer a worthwhile service. If this forecast proves accurate it will mean that the burden for advocating for the rights of children and adults with a developmental disability will once again fall on parents and relatives. However as the history of the last half-century has shown, much of the current provision for children and adults with a developmental disability in the U.K. and North America has resulted from the resource, resilience and resolve shown by parents and relatives. Parent advocacy is likely to continue to remain one of the most potent forces for effecting change in philosophy, provision and practice (Jackson, 2004).

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Correspondence

Robin Jackson
Camphill Rudolf Steiner Schools
Murtle House, Bieldside
Aberdeen, SCOTLAND
AB15 9EP
(44) (01330) 811264

robin@dalmaik.demon.co.uk