

# Agencies & Advocacies

Experience in the North West

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Working with local services in Cheshire, Greater Manchester, Lancashire, Merseyside and South Cumbria in moving towards better futures for people with learning disabilities.

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## Introduction

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Interest in advocacy, in all its different forms, has been growing. In the North West there have been a number of innovative projects stimulating the development of self advocacy, leisure advocacy, citizen advocacy and collective advocacy. Service agencies have appointed advocates to assist in improving services for individual people, and have been at the receiving end of representations made by family advocates, independent advocates and legal advocates.

Both provider and purchasing agencies have been touched by the expanding advocacy movement. Inevitably, with a rapid expansion of activities directly relevant to both learning disabled people and service agencies, tensions have arisen, confusion has emerged and some professionals feel under attack. If agencies are to remain open to the positive possibilities for change suggested by advocacy it will be necessary to gain some clarity about its different forms and to explore the possibilities for further development.

This report summarises some of the key features of different forms of advocacy. It then goes on to present the results of a survey of provider and purchasing agencies involvement in advocacy. Short case studies of successful and unsuccessful advocacy are presented in order to highlight the advantages to both disabled people and service agencies of effective advocacy. The report is offered as a discussion document for agencies to:

- use in interrogation of the extent to which their own practices and procedures support or obstruct the growth of effective advocacy
- help in examining the opportunities for stimulating further development of advocacy, particularly for those with profound and multiple impairments, and in ways that are independent from services

It is recommended that resources are clearly allocated to the development of diverse forms of advocacy throughout the region.

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## Overview of Advocacy

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A recent discussion of the relative merits of different forms of advocacy for people with disabilities<sup>1</sup> suggests that advocacy ‘involves a person(s), either an individual or group with disabilities or their representative, pressing their case with influential others, about situations which either affect them directly or, and more usually, trying to prevent proposed changes which will leave them worse off. Both the intent and outcome of such advocacy should increase the individual’s sense of power; help them to feel more confident, to become more assertive and gain increased choices’.

More formally, a dictionary definition<sup>2</sup> of advocacy is:

‘active support especially of a cause’.

The same dictionary defines an advocate as:

To support or recommend publicly; plead for or speak in favour of.

a person who upholds or defends a cause; supporter.

a person who intercedes on behalf of another.

a person who pleads his client's cause in a court of law - (see also barrister, solicitor, counsellor).

Scottish law, the usual word for counsel.<sup>3</sup>

Advocacy, here, means speaking up on behalf of a person or an issue.<sup>4</sup> When advocacy is in relation to one person, it is to safeguard that person's interests and rights e.g. to protect the person from abuse or to present their vision of a future if they are unable to do so themselves.

When advocacy is in relation to an issue, it would usually benefit anyone affected by that issue e.g. persuading the health authority to

close a long-stay hospital and move the residents to homes of their own.

Wolf Wolfensberger<sup>5</sup> proposes that advocacy has three additional points:

- advocacy requires vigour and vehemence. So, an advocate must ensure their message is given loudly, clearly and at least as vigorously as she would speak for herself.
- advocacy implies a distinct cost to the advocate. This is in terms of time, stress, money and emotion. If it is too easy, then it probably isn't advocacy. Taking on the role of advocate is not a soft option.
- advocacy must also be structured so as to be maximally free from conflict of interest. The advocate must be in a position to say and do what is necessary.

### Who needs advocacy?

At different times in our lives we may all need paid advocates such as solicitors, trades union representatives, and so on. Family members and disabled people themselves have spoken out, long before the terms ‘advocacy’ and ‘self advocacy’ were introduced to services.

Vulnerable people, however, need others with more powerful voices to stand with them and lend their influence to their attempts to fulfil their rights to full citizenship. Often they are devalued, seen as second class citizens and experience unfair discrimination and rejection by society. They may be treated without respect, left out of ordinary community life, experience physical or emotional abuse, exploitation or neglect. Their opportunities are unfairly limited by the way other people see them. People with these experiences may include those who have:

- a learning disability
- mental health difficulties
- physical impairments

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<sup>1</sup> Brandon, D., Brandon, A., & Brandon, T., *Advocacy: Power to People with Disabilities*.

<sup>2</sup> Collins English Dictionary.

<sup>3</sup> Thanks to Judi Stewart for the clear and concise descriptions of different forms of advocacy contained in this section of the report.

<sup>4</sup> Gathercole, C., 1987, *Forms of Advocacy*, NWTDT.

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<sup>5</sup> W Wolfensberger, 1977, *A Multi-component Advocacy/Protection Schema*, Canadian Association for the Mentally Retarded: Toronto.

- sensory impairments
- and people who are:

- older
- homeless
- poor.

## The nature of advocacy

Advocacy is a well-established concept in many different settings and cultures throughout the world. It is a relatively new concept in human services, being rarely used in human services literature prior to the 1970's.

Solicitors, and barristers are recognised as Legal Advocates. Accountants, Welfare Rights Officers and Trade Union representatives put forward cases for fair treatment daily. These people are paid, trained, competent and familiar with the system within which they are working.

Service workers (i.e. social workers, doctors, nurses et al) have been expected and are accustomed to speaking on behalf of people who have special needs over many years.

Family members have represented their views and those of the person in need in a variety of settings over the centuries.

People who have special needs are discriminated against in many different ways and have to fight to gain basic rights - to be treated as other members of society in education, employment, housing, relationships, health services, transport and access. Some people with disabilities speak for themselves in all situations, others need help to express opinions and to have them heard.

Groups of people who have similar experiences or difficulties come together to focus on general issues and to challenge the system, and lobby M.P.s etc.

Particularly within services for people with mental health difficulties there is a movement towards other service users, either current or past, representing the views of someone whose interests need safeguarding.

There are organisations (e.g. MIND, Values into Action and MENCAP) who take up issues

at a national level, influence government policy and lobby for new legislation.

## Forms of advocacy

It is useful to describe different forms of advocacy. Whilst different writers may describe the various forms slightly differently, the following discussion will consider self advocacy; peer advocacy; advocacy by families; in-house representation; independent advocacy; professional advocacy; legal advocacy; citizen advocacy; and collective advocacy.

Each form of advocacy may subsume or overlap with each of the others and so cannot always be clearly separated. It is, however, useful to clarify the purpose and limitations of each form.<sup>6</sup>

'We have become familiar with the notion of comprehensive services. We also need comprehensiveness in advocacy forms which will complement both service provision and each other. There is much to be said for each form of advocacy restricting itself to its own function and not attempting to take on other forms. Basic rules of citizen advocacy, for example, are that it should not take on collective advocacy and staff should not take on staff advocacy functions. Clarity of purpose helps all concerned to focus their efforts most effectively and avoid dissipating energies.'

## Self advocacy

Self-advocacy is a term used in two different and separate ways.<sup>7</sup>

- Self-advocacy can be how a person develops and gains confidence and abilities to express his or her own feelings and wishes

and

- Self advocacy can mean groups of people getting together to collectively speak out about joint concerns

but, inevitably the two are interwoven<sup>8</sup>.

<sup>6</sup> Gathercole, C., 1987, *Forms of Advocacy*, NWTDT.

<sup>7</sup> Based on work by K Simons, *Sticking Up For Yourself*, Joseph Rowntree Foundation and Community Care, November 1992.

Many self-advocacy groups have been initiated by staff. Early studies by Bronach Crawley<sup>9</sup> suggest that only 9.3% of groups were formed following requests from people with learning disabilities themselves. However, by 1989, Andrea Whittaker<sup>10</sup> found that this figure had risen to about 33% of groups.

There are probably many good reasons for staff setting up self-advocacy groups but they have a responsibility to consider what is happening now within that group, to listen to the group members and to evaluate with the group their role (if any). Steve Dowson and Andrea Whittaker<sup>11</sup> look at the role of the advisor in supporting people with learning disabilities in self-advocacy groups and pose a series of questions for study and discussion at the end of each chapter.

The self advocacy movement within Mental Health Services has developed from patients', clients' or residents' councils which are the terms used to describe a meeting of people using services within a day centre, unit, residential setting or hospital ward.

As seen in the definition, self advocacy is a term which is used in two different and separate ways - individually or collectively.

Self-advocacy groups are run by the members, and they determine the direction and purpose of their activities. Ken Simons<sup>12</sup> identified a range of models of self-advocacy groups, including:

- discussion groups in adult education settings
- service-based groups, like elected centre committees

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<sup>8</sup> J Skelton, 1996, *Exploring Issues Surrounding Self-Advocacy by People with Learning Difficulties via Participant Observation*, Unpublished MSc Thesis, Manchester Metropolitan University.

<sup>9</sup> B Crawley, 1982, *The Feasibility of Trainee-Committees as a Means of Self-advocacy in Adult Training Centres in England & Wales*, Hester Adrian Research Centre, Manchester University.

<sup>10</sup> A Whittaker, 1989, *How Are Self Advocacy Groups Developing?* Kings Fund Centre.

<sup>11</sup> S Dowson and A Whittaker, 1993, *On One Side*, Values Into Action in association with the Kings Fund Centre.

<sup>12</sup> K Simons, November 1992, *Sticking up for Yourself*, Joseph Rowntree Foundation and Community Care.

- independent People First groups.

## Peer advocacy

Peer advocacy involves one to one support by a service user, past or present, to help another to express and fulfil his/her wishes.

'Effective peer advocacy is grounded in group self-advocacy, and is best linked to it. This can ensure both its accountability to local service users, and that all the services which people with mental health problems use are changed for the better, by making them more accountable and responsive to the people who use them.'<sup>13</sup>

People who have experienced the same or similar problems are uniquely qualified to support an individual through a time of crisis. Peer advocates are encouraged by Edna Conlan<sup>14</sup> not to give advice but to introduce people personally to the appropriate agencies in the community who can give the most up-to-date information.

User-run peer advocacy is seen as an empowering model for an independent, individual advocacy service.

A peer advocate can bring empathy and strength to a service user. This empowers the service user in ways that are different from an independent advocate.

However, staff attitudes have to continue to change, adjust and develop to new relationships with service users to ensure peer advocates have the maximum impact.

Peer advocacy is developing and there are many issues being explored, particularly in relation to training (about service systems, about aspects of mental illness, drugs), support, remaining independent and not becoming 'professionalised' by the services which they are challenging.

## Advocacy by families

Family members will have many years experience of asserting the rights of their children (even when they are adult) to services and to a decent standard of living and life

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<sup>13</sup> E Conlan, 1994, *Peer Advocacy*, Chapter 3, Advocacy - a Code of Practice UKAN.

<sup>14</sup> E Conlan, 1994, *Peer Advocacy*, Chapter 3, Advocacy - a Code of Practice UKAN.

opportunities. As Brandon et al<sup>15</sup> point out they ‘get no training or payment and bring considerable concerns, intimacy and passions to the process of representation as well as despair and exhaustion. Often they are uniquely qualified and involved to make strong cases’.

Despite this, it will not always be in the disabled person’s best interests to have their family members advocate on their behalf. Some relatives have different concerns from their disabled members and they are not always able to disentangle them. More importantly, ‘families can be a source of oppression, depending on the sorts of relationships people have developed and their understanding of the meaning of disability’<sup>16</sup>.

Conflicts may arise between disabled people, speaking for themselves and family members or between other advocates for the disabled person and their family members. Of particular difficulty for many family members are the issues connected to personal relationships, sexuality, independence and risk. All of these issues highlight the competing drives of protection and liberation experienced by many family members.

Notwithstanding the difficulties and tensions inherent in advocacy by family members, it can sometimes be difficult for welfare services to open themselves to this form of advocacy, and to value the contributions that family members might make to their sons’ and daughters’ lives.

Carers are seen as (a) a resource to be exploited; (b) as partners in providing care; (c) as clients in their own right; or (d) as a barrier to independent living<sup>17</sup>. It is often as barriers to independent living that carers advocating on behalf of their disabled family members are seen.

A recent innovative course has been introduced in the NW<sup>18</sup> that helps family members become effective advocates for their disabled members and for disabled people in general, underpinned by a thorough understanding of civil rights, values and beliefs underlying supported living, and the service system.

## In-house representation

In-house representation is seen as part of the responsibility of social workers, nurses and others to speak up for individual service users. Clearly, this is vital but there is a conflict of interest as the worker is often paid by the organisation he/she is taking issue with.

Many paid staff working in human services (statutory and voluntary sector) have a significant role to play in representing individuals whom they are working with in a variety of situations. This is an integral part of the role of social workers, nurses and others. To avoid confusion, this work is best called representation, not advocacy.

Paid service workers have a responsibility to ensure that each individual they are working with receives help which meets his or her needs, taking account of the person’s wishes. However, service workers are responsible for many clients at one time, have to take account of organisational pressures, are influenced by personal interests and are accountable to managers. These factors create a conflict of interest. Paid staff can only go so far in their representation of an individual, particularly if it is within their own organisation. Paid staff have a responsibility to represent their clients which they cannot avoid but should recognise their conflicts of interest and work with independent advocates to ensure individual needs are met.

## Independent advocacy

Independent advocacy is often undertaken by volunteers. It offers a one-to-one relationship, with advocates assisting disabled people to express their wishes and feelings. Sometimes it

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<sup>15</sup> Brandon, D., Brandon, A., & Brandon, T., *Advocacy: Power to People with Disabilities*, p.47.

<sup>16</sup> Brandon, D., Brandon, A., & Brandon, T., *Advocacy: Power to People with Disabilities*, p.49.

<sup>17</sup> Twigg, J., & Atkin, K., 1994, *Carers perceived: policy and practice in informal care*, Open University Press.

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<sup>18</sup> Gathercole, C., & Elwell, L., 1997, *Partners in Policymaking: The first UK course*, NWTDT.



may be necessary for the advocate to speak for the person. Independent advocacy has some of the elements of citizen advocacy but does not adhere to the criteria laid down (see below). Individual (volunteer) advocacy often has some elements of professional services i.e. record keeping, accountability to a co-ordinator, supervision of advocates, and payment of expenses, but is undertaken by volunteers. This form of advocacy appears to have developed

- in response to statutory services procedures which require the use of advocates
- as voluntary organisations respond to the needs of the people they are already working with
- alongside citizen advocacy and the self-advocacy movement.

There is a dilemma about the real independence of agencies providing advocacy services, when much financial support is from statutory services.

Increasingly, services specifically recruit an independent advocate to represent the best interests, or even the perspective, of a disabled person who cannot speak for themselves. This is often done in the midst of conflicting views above what is best for the person, between different professionals or between family members and professionals. This form of advocacy is best undertaken by a person who is skilled in interpreting behaviour and in communicating with severely impaired people, and who has the investigative skills to gain information about what the person's life might be like now and in the future, as well as a thorough understanding of the values and practicalities of independent living. He or she should be able to assess the adequacy of professional interventions and to understand the service system. As this type of advocacy role is commissioned and often time-limited, it is best thought of as quasi-advocacy.

Quasi-advocacy is a relatively weak form of advocacy and depends on the willingness of those who commissioned the work to listen to and take account of the advocate's views. It will often develop into either independent or citizen advocacy, if the advocate is not taken

seriously. There is a tendency for commissioning agencies who do not like either an independent or quasi-advocate's views to dismiss her or him and appoint another. This, too, can give rise to the first advocate becoming a citizen advocate and contesting the views of a newly appointed advocate if they are different.

## Professional advocacy

Professional advocacy involves a paid person working **independently** of services, representing the interests of a person. (This is different from services staff speaking up on behalf of a service user which should be seen as in-house representation to avoid confusion). Community Health Councils and Citizens Advice Bureaux are both agencies which might be said to engage in professional advocacy.

In the Netherlands, the Independent National Foundation for Patient's Advocates employ and manage patient advocates for all the Dutch psychiatric hospitals. The hospitals are obliged to pay a fixed amount towards funding the advocates. There is training, a published manual, standardised duties and working methods for the advocates. The advocate's role is to take up issues for and with individual patients, not to look at wider issues.<sup>19</sup>

Edna Conlan<sup>20</sup> suggests that professional advocates sometimes adopt an expert model of advocacy which involves them in giving advice, prioritising options, counselling and mediation. These activities may not encourage empowerment through advocacy.

Where there is funding by statutory services for advocacy workers, there is a danger that the workers have the same clash of interests as paid service workers. A professional advocate must be working with and for their partner and not as an additional worker for statutory services.

A particular and specialised form of professional advocacy is legal advocacy.

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<sup>19</sup> D Brandon, 1991, *Innovation without change?* Macmillan.

<sup>20</sup> E Conlan, 1994, *Advocacy in Mental Health*, from *Advocacy - A Code of Practice*. UKAN.

## Legal advocacy

Legal advocacy is representation by legally qualified advocates, usually solicitors or barristers.

Advocacy is probably most commonly understood in relation to legal advocates and continues to be the basis of the Scottish legal system. Many citizens will require the use of a legal advocate at some time, to move house, to make a will or to represent them in court.

In 1989, the Law Society initiated a general debate about the law relating to vulnerable people, by publishing a document on mental incapacity and decision making.<sup>21</sup> It suggested that advocacy schemes should be developed and that statutory services and courts should recognise advocates acting with or for a dependent person. The Law Commission subsequently published a paper<sup>22</sup> acknowledging that there was growing support for the role of independent advocates.

## Citizen advocacy

Citizen advocacy is a one-to-one, long-term partnership between a service user and a citizen.

The citizen advocate's commitment is to the person with a disability. She or he gives his/her time without pay and is not connected to the disabled person through a service role. Where necessary the non disabled person helps the disabled person to speak up for him or herself and /or to speak for them if appropriate.

Citizen advocacy is based on the belief that all people have values and rights, irrespective of their disabilities. Citizen advocacy's objective is to **empower** those people who have been excluded or kept powerless by linking them to a valued citizen and bring them into full membership or the community.

John O'Brien sees a valued citizen as someone who is 'connected to the networks of people

and associations that make up community life and willing and able to act with - and perhaps for - another person'.<sup>23</sup>

Citizen advocacy relationships are, therefore:

- **Unpaid.**
- **With minimal conflict of interest.** The advocate's loyalty is to the person he/she represents and is central to the success of the relationship.
- **One to one relationships.** The focus is on one individual who is in a relationship with a person who is not disabled. This starts to ensure positive interactions with, and interpretations of people who have disabilities.
- **Sustained relationships.** The relationship between an advocate and the person represented should have the capacity to develop over a long period. This is important as people who have disabilities often have to cope with frequent staff changes.<sup>24</sup>

Citizen advocates are recruited through a citizen advocacy scheme which is independent from service providers in administration, funding and location to ensure that conflicts of interest are minimised. A citizen advocate is recruited for a specific disabled person. Each relationship will, therefore, be unique and different roles will be undertaken by citizen advocates.

Advocates may help to solve practical or material issues e.g., help with shopping, voting, claiming DSS benefits or representing the person at an Individual Planning meeting (this is seen as the instrumental role). The advocate is likely to be involved in meeting their partner's need for communication, love and support (expressive role) by sharing significant activities and events, family and friends and by offering support during a crisis. An advocate could be involved in either of these roles or a combination of both.

<sup>21</sup> Law Society, 1989, *Decision making and mental incapacity: a discussion document*, Law Society's Mental Health Sub-committee.

<sup>22</sup> Law Commission, 1991, *Mentally incapacitated adults and decision making: an overview*. Law Commission Consultation paper no2 119, HMSO.

<sup>23</sup> J O'Brien, 1981, *Learning from Citizen Advocacy Programs*. Georgia Advocacy Office, Georgia, USA.

<sup>24</sup> Based on N Carle, 1984, *Key Concepts in Community based services - Citizen Advocacy*, CMH.

Some advocates undertake formal roles, which could include - Appointee (for DSS benefits); Receiver (for Court of Protection); Attorney (Power of Attorney); Guardian (Mental Health Act 1983); Responsible Adult (Police and Criminal Evidence Act (PACE) 1984).

Whatever tasks are undertaken, the advocate must undertake them vigorously, ensuring that they define situations from their partner's point of view and that their views carry as much weight as others.

Citizen advocacy is NOT a befriending scheme; in-house representation; group advocacy; nor an extension of services.<sup>25</sup>

## Collective advocacy

Collective advocacy is when a group of people come together to pursue an issue which affects more than one individual. This concept overlaps with the work of self-advocacy groups. Class advocacy refers to representation affecting a certain group of people, such as homeless people, and may be undertaken by the people themselves or by a campaign group on their behalf.

Collective advocacy is 'not concerned with individual grievances, but with **patterns** of problems, difficulties, shortcomings, and possibly with class needs.'<sup>26</sup> Wolfensberger argues that collective advocacy bodies should be independent of direct service provision.

Collective action contrasts with individuals working in isolation. Collective advocacy focuses on general issues rather than individual difficulties. The skills needed in collective advocacy are different from those used in working with individuals. They would include committee work, managing finances, planning press handouts, the use of the media to influence policies, and campaigning.

There is considerable confusion between the collective and self-advocacy processes as much

of the work undertaken in self-advocacy groups could be described as above.

The power of people undertaking collective advocacy can be seen in the amendments to the recent Disability Discrimination Act. Different campaigning groups worked together, presenting a united front on a single issue. They lobbied M.P.s, attended meetings, held demonstrations, organised petitions, wrote thousands of letters, made thousands of telephone calls and used the media at all opportunities to press their case for major reforms.

Difficulties exist for collective advocacy groups as they have to get close enough to the system to influence its activities but if they get too close, they are in danger of losing their independence and being co-opted into the system they seek to change.

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<sup>25</sup> Wolfensberger, W., & O'Brien, J., 1979, *CAPE - Standards for Citizen Advocacy Program Evaluation*, NIMR, Toronto.

<sup>26</sup> W Wolfensberger, 1977, *A Multi-component Advocacy/Protection Schema*, Canadian Association for the mentally retarded.

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## Survey of Advocacy in the NW

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In order to get some idea of the extent and nature of advocacy throughout the North West, a survey was carried out at the beginning of 1996. Questionnaires were sent to all provider service managers in health and social services, to independent organisations concerned with providing care and concerned with advocacy, and to commissioning agencies in health and social services. Replies were received from 28 social service agencies operating in six districts in Lancashire, Wigan, Oldham, Trafford, Rochdale, Bolton and Wirral; six health providers from Trafford, Lancaster, Warrington, Rochdale and the Royal Albert Hospital; one private provider; three independent agencies concerned with advocacy;

one social service commissioner and six health commissioners from Manchester, Trafford, East Lancashire, South Lancashire, Lancaster and Wirral.

It is impossible from these replies to gauge the extent of advocacy throughout the region. However, some patterns in the practice and experiences of advocacy can be discerned.

Of all the people with learning disabilities involved in some advocacy activities in social service agencies, 40% receive advocacy from a staff member, and 31% are involved with self advocacy groups. Only 3% receive advocacy from an independent person and 1% as part of citizen advocacy (see figure 1).

### **Figure 1: Percentage of people with learning disabilities involved with different types of advocacy: Social Services (N=28)**

The picture is similar within health services, with proportionately more people involved with self advocacy groups (59%) and 20% with advocacy from a staff member. Still a

relatively small percentage of people are involved with citizen advocacy (6%) or with an independent person (7%) (see figure 2).

### **Figure 2: Percentage of people with learning disabilities involved with different types of advocacy: Health Services (N=6)**

At least two of the three voluntary organisations are primarily concerned with advocacy activities. The situation for those people involved with advocacy within these

voluntary organisations, is quite different. 68% of people are involved with citizen advocacy and 27% with advocacy by an independent person (see figure 3).

**Figure 3: Percentage of people with learning disabilities involved with different types of advocacy: Voluntary Organisations (N=3)**

There were insufficient data from the private sector to present. It seems, therefore, as if statutory provider agencies have supported the growth of self advocacy (especially group self advocacy). Furthermore, staff consider themselves to provide widespread advocacy. They have not, however, been successful in stimulating the growth of independent and citizen advocacy from within their services. If these types of advocacy are to grow, advocacy services contained within the voluntary sector will need to develop. This view is supported by

the information available about who is doing the advocacy work within the different types of agencies.

Within health and social services, 81% of advocates are staff members, and only 11% of advocates are independent people, with a further 6% of advocates acting as independent facilitators of self advocacy groups. 1% of reported advocates are lawyers and 1% of advocates belong to independent groups (see figure 4).

**Figure 4: Percentage of advocacy activities undertaken by different groups of people: Social Services, Health Services (N=28 social services and 6 health services)**

In contrast, the independent agencies report 76% of advocates being independent, with a further 10% belonging to independent groups

(see figure 5). It is difficult to draw many conclusions from this, as only three independent agencies returned questionnaires.

**Figure 5: Percentage of advocacy activities undertaken by different groups of people: Voluntary Organisations (N=3)**

The bulk of the resources provided by the statutory agencies for advocacy focus on the training of people with learning disabilities (21%), providing a venue for groups (18%) and the training of self advocates (13%). Only 8%

of resources are directed at the recruitment of advocates, 6% for the production of guidelines for independent advocates and 7% for the training of advocates and family members (see figure 6).

**Figure 6: Resources provided by agencies for advocacy (percentage of total resources identified by activity)**

All the statutory services encourage advocacy that represents the person's best interests and seeks to represent the person's views. Advocates are also used widely to obtain people's views, enable participation, provide criticisms of the service as means of eliciting

complaints, consultation and in the assessment of need. As Figure 7 shows, relatively few services encourage advocacy as part of criminal proceedings, the inspection of services and for enabling collaboration.



**Figure 7: Issues featured in the practice of advocacy by health and social services (number of services identifying particular issues N=28 Social Services; 6 Health Services)**

The only issues reported not to be taken up by voluntary agencies, were service evaluation, the inspection of services and criminal proceedings. The private agency in the survey advocated on the following issues: complaints, representing the person's views and best interests, assessment of need, obtaining person's views,

consultation, resolving disputes between family members and the service, information and advice and criminal proceedings. 40% of all advocacy within the private agency was provided by a staff member and 50% by another professional.



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## Case Studies of Successful Advocacy

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All agencies were asked for an example of successful advocacy. The examples are reported from the point of view of the person completing the questionnaire, and may not reflect all interested parties' views. The advantages to the individuals include the gaining of civil and legal rights, the maintenance of financial rights, support for independence, increased ability to make choices and to be heard in relevant decision making, the development of relationships and support of existing relationships, the enhancement of self esteem and improved quality of life. The advantages for agencies of welcoming advocacy are in terms of promotion of civil and legal rights, reducing conflict at the interface of the family and the service, the execution of high quality professional practice, the development of service procedures and policies and progress in public education.

### Promotion of civil and legal rights

Advocacy can serve a vital role when service agencies fail to uphold learning disabled people's civil and legal rights. This example addresses a number of rights and shows how even if the original wrong cannot be righted, future rights may be protected.

An advocate supported a lady with a learning disability who is the natural mother of a young child at the Children's Services Planning meeting. The child is in foster care. The foster parents plus the children's services planned and carried out the child's christening without taking into account the views of the mother. The child was christened in a Church of England church and not as the mother had requested, in a Catholic church.

Although the events had occurred, the advocate obtained an agreement on behalf of the young lady (mother) and all future decisions relating to her child should include her points of view and aspirations for the child's future. The agreement was sought and obtained. The mother and her advocate have been invited to all relevant meetings since. (Independent advocacy agency).

Financial rights are often found to be jeopardised.

Residents were not receiving all the benefits to which they were entitled. Contact was made with the relevant authorities and the monies due were traced. Residents successfully claimed their Disabled Living Allowance entitlements. (Private residential service).

Some people may need help in dealing with the ordinary legal procedures of everyday life.

One client on a specialist adult placement used the centre for meetings with an advocate who was assisting in the making of a will. (Social Service Day Centre).

At times, family disputes may indirectly affect the legal entitlements of disabled people, and advocates may have a role in upholding their rights.

There was a financial dispute between two family members regarding an inheritance. This squabble between relatives indirectly affected the service user in so far as an amount of money left in a will had not been received. The matter was brought to our attention by one of the parties involved in the dispute. The issue was passed to the local advocacy service as a specific item to be dealt with along with copies of paper proof of entitlement. The service also took up the matter and wrote to the executor of the will (who was the other party involved in the dispute). Correspondence continued with the service user being represented and a stance being taken that representation was for the service user, and neutrality was maintained in order to ensure family contact with him from both parties.

The inheritance was received with interest and both parties have still maintained links with the service user. All staff members providing support to the service user were able to stay on the periphery of things. (Social Service residential network).

### Family service interface

A number of examples arose, whereby an advocate had worked at the interface of the family and the service, in the best interests of the service user. Some involve staff members helping the person to assert their own wishes:

We encourage advocacy through advocacy groups/user group. We act upon service user's wishes so that service users become more confident in speaking up for themselves. One

service user was not happy at home. This person gained confidence within the group and eventually through the relationship he developed with his key worker he had enough trust and confidence to bring to light issues in his personal life. The service user was offered short term care. During this stay he was very happy and did not want to return home. The adult placement team became involved, leading to the person having a foster family.

He is now more confident, has more independence, has some control of his own finances, is making more choices, outlook on life is broader, communication has improved, appearance (personal care, dress etc.) is excellent, he is more adult in his ways, he is now living a more valued life, he has opinions and is not frightened of speaking out. He accepts consequences better. (Social Service Day Centre).

**In a similar vein, support for a person in asserting their needs can be helpful:**

An independent advocate supported a service user in talking to family: this enabled the service user to have an assessment for sight impairment when family were reticent about this. Discussions were held between service user, advocate and family. The outcome was that the service user had an assessment and consequent training to enable his independent mobility. (Social Service Day Centre).

An independent advocate was involved with a person leaving hospital. The advocate enabled the person to express their views to a dominating relative who did not always represent the person's best interests. The person is now more confident about expressing views to the relative. (Community Health Team).

**Times of transition are often particularly vulnerable times and advocates play a useful part in representing the person's best interests.**

A friend of one of the residents was involved in helping him to resettle from the long stay service in the hospital to his local community. The friend was involved in all planning and project meetings and assisted in looking for suitable housing. The process is still continuing, but a successful resettlement for the client into an ordinary house and with appropriate support looks likely to be achieved. (Long Stay Hospital).

**It is not just for the learning disabled person that advocacy can help assert needs. This example shows how the support of an advocate**

**can help family members assert their needs and continue to carry on providing care for their sons or daughters.**

A young woman with a severe learning disability living with her elderly carer was informed that her support from the Community Healthcare Trust would be replaced by a home help who was not trained to deal with her behaviour. The advocate helped the carer to voice her concerns and the service was immediately restored. (Voluntary Sector Advocacy Service).

**Family members may need to be reassured that their wishes will be met sometime in the future:**

A local independent advocacy service was involved in passing on a family member's request for the tenant's future after she had passed away and a good result achieved. (Social Service Day Centre).

Thus it can be seen that advocates can be helpful in bridging between families and services, enabling better working relationships between the two and positive gain for people with learning disabilities.

## **Advocacy as part of professional practice**

At times, staff members have to advocate on behalf of the person in negotiations with other family members. Whilst they are advocating on behalf of the person's best interests, this advocacy is part of the professional role and should not be considered exceptional.

A service user was expressing a wish to go to college. Parent was anxious and resistant giving several reasons why the service user could not go, such as: 'cannot use transport safely to get there and back; is anxious and not sleeping well; has medical condition which needs monitoring'. A meeting was held which gave the parent opportunity to discuss their reasons and an individual programme was designed to address the issues: community support officer was to travel on the public transport with the client until competence achieved; a management programme for medical condition and anxiety was introduced. The service user now attends college and is able to get there on the bus but uses a taxi for the homeward journey and does not require any other support. (Social Service Day Centre).

A health professional was involved with a social worker, case assessor and client in obtaining a satisfactory residential placement. Personal and

written representations were made to advocate the client's right to choose the placement. The client was placed at the establishment of their choice, meeting their needs adequately. (Community Health Team).

Sometimes, learning disabled people need help and support in identifying their wishes and in speaking up for themselves at home. This may be about dissatisfaction with current living arrangements.

A man was living in a shared house in our service. Staff members felt this man would benefit from more independent living but no such project was available in our service. The man's name was put forward for a Mencap project. He was supported throughout this process and eventually moved into his own flat supported by Mencap. He still sees original staff on a social basis. (Community Health Team).

It is not always clear what is causing the dissatisfaction:

A young lady (35) attending local college became unhappy: health and mobility decreased and she started behavioural problems. College and health staff (Physiotherapist) encouraged open conversation and discovered the situation at home was very poor - no choice, freedom, privacy, independence. She lived with elder sister and foster children. The staff enabled the young lady to speak up for herself and give reasons for her unhappiness. She spoke to the sister with support from her college staff.

The sister became more aware of her younger sister's rights and feelings. She was given a private bed-sit room of her own in the house and more freedom and choice. Her health and mobility improved the behaviour problems disappeared and she became a happy contented secure person. (Physiotherapy Team).

Not all advocacy has to respond to situations where something is wrong. Self advocacy, in particular, may be facilitated in order that service users can give continual feedback about the services they receive.

An advocacy group was set up by myself in the network in which I used to work, for service users who lived in supported houses. The aim was to provide individuals with the necessary training to develop self advocacy skills with a view to enabling people to voice an opinion about our service. The training skills groups ran for 12 months and from this some people moved on to a self advocacy group.

Using knowledge of other materials, I devised a basic training skills pack which was used with the group. The groups met once a week in the evening away from their homes and were supported in the evening away from their homes and were supported by myself and other support staff. The training developed each individual's skills including self awareness, confidence, interpersonal skills, communication, meeting practice and group building. We also used an independent trainer who came in and provided the group with a six week assertiveness skills course without staff input.

The effects were: Positive feedback from service users - they felt more confident etc; feedback from others - service users became more assertive at home; group voiced some opinions about service e.g., charging policy; service users are now aware what self advocacy means, something of which they had no previous knowledge; some people went on to join other larger groups. N.B., sadly this group has dispersed since I left the network. (Social Service Day Centre).

Independent assessments of people's situations by an advocate can contribute to rapid changes in the supports available to people.

A member of staff called a review on a service user due to concerns regarding his coping skills and health issues. To help address the issues the advocate was asked to a meeting and met up with the service user and care manager/social worker. The advocate supported the service user and was able to make an independent assessment of the situation, as well as liaise with the Centre and Care Manager. A report was prepared with the service user to help bring about a change in his living situation. The advocate's report helped to arrange an emergency respite family/adult placement due to the risks to the service user that had been uncovered. The review confirmed the change in needs and coping skills. (Social Service Day Centre).

Equally, the initial catalyst for change may be a professional, but advocacy and self advocacy functions to support the person through major life changes.

A client was very unhappy with her living arrangements and was expressing anxiety in a variety of ways including screaming and emotional outbursts. The social worker referred her to the independent living project. Key workers and independent living scheme workers met and discussed the issues with the client. The client joined self advocacy groups and a women's studies programmes and was supported individually by key worker counselling

sessions. As a result, the client was helped to move into alternative living with ongoing programmes and advocacy groups assisting her in beginning to make choices and decisions in new situation.

A radical change in the client's life was achieved. She now presents as a mature and responsible lady, far more competent at making decisions. (Social Service Day Centre).

## Development of service procedures and policies

In less dramatic ways, advocacy and self advocacy can bring about change in service procedures. Sometimes these changes are limited to those actively involved in the self advocacy process and does not extend to others using the service.

Discussions were held between the advocacy group and management regarding the appropriateness of 'taking register' in a mainstream unit. The group felt it was childish. Consequently, a new register was produced for the advocacy group and they were given the responsibility for managing it. The group organised a rota, enhancing self esteem and encouraging independence. (Social Service Day Centre).

At other times the results of self advocacy has effects that reach all service users.

Service users (representatives on management committee) wanted a new minibus with seat belts. They asked management and local councillors and were eventually successful. (Social Service Day Centre).

By expressing their views about current services, people with learning disabilities can contribute to changes in practice and in the development of policies.

Our service user's group is supported by an independent facilitator from the Local Disability Alliance group, and a local staff member.

(i) Service users complained about having to collect lunches from kitchen in heated trolleys and eating them in their base rooms. They wanted a more flexible restaurant self service system where people could come in from outside the centre.

(ii) Service users with assistance made a video of the problems of the present system. Invited assistant director of social services and head of

adult services to watch and discuss the problems. Also spoke to people from building and technical services about what would be involved. After several months money was made available to improve kitchen and dining facilities. A self serve restaurant system was agreed but not opened to the general public at the time. Money was also made available to upgrade toilet facilities and improve wheelchair access. Service user's groups was given a decisive role in how O... 's budget is to be spent (furniture, recreation and painting and decorating). (Social Service Day Centre).

Advocacy is not only in verbal or written form. Both the above example and the ones below show the power of using video to influence a consultative process.

In the context of the Joint Advisory Group consultation process a video was made of people's views of services - what they like or are unhappy with. People who use the service interviewed other people who use services. JAG, with service users as group members, watched video and incorporated comments in their report. The process of making the video was initiated and facilitated by non-disabled group members who work for the local authority but also work with the Civil Rights group independently. (Social Services - Agency Unknown).

We have a local video project. It is co-ordinated by a person from the voluntary sector, and chaired by someone from a self advocacy group. Service users from the day centres attend but the staff do not. The group meets once a fortnight in a community venue. They are working to produce a video aimed at assisting people with a learning disability to know about the complaints procedure and how to complain via the proper channels should they have a complaint regarding the service they receive. £5000 was to be provided by social services to enable this video production, which is still in progress. 9 people from the centre were involved, but for various reasons, only 2 remain. Time will tell if it is of use, although all the people involved have enjoyed the project. (Social Services Training and Development Centre).

## Public education

When people are supported in making their views more widely known, there may be some spin offs in terms of general public education.

A Quality Action Group (QAG) was set up with a total of 8 service users and initially 2 members of staff to facilitate. Over a period of 3 weeks the group was asked 4 questions about the service:

- (i) do you feel the need to change the way we run W... House;
- (ii) how would you change the way we run W... House;
- (iii) what do you like at W... House;
- (iv) what do you not like at W... House?

All the members contributed. E... was invited to join the Quality Action Group and spoke about what he liked and disliked about the service provided at W... House. The group facilitator asked E... if he would represent the group at a conference on short term support and respite. E... was chosen by the group members to speak. The facilitator helped E... rehearse for the conference. E... spoke about the way the QAG helped him to speak up for himself and make changes in the service he received.

After the conference all the other groups of delegates congratulated our team for including a service user to speak up for others. Our group was then invited to repeat our presentation at Oldham Civic Centre at a meeting of councillors and members of social services. The councillors were impressed that we had a service user speaking up for himself and we were reacting to what the people who use our service wanted and not what parents or carers thought they wanted. This has led to more service users wanting to join the QAG and the councillors listening to our service users and knowing we are too. (Social Services).

The very nature of the work of an employment service, in advocating for people's rights for employment, serves as a public education role:

As an employment service we are advocating on behalf of clients every time we approach an employer. Also with benefits agencies etc. We approach an employer before attending an interview with a person, helping employer to realise that the person could be a useful member of the workforce. We have several examples of people now employed in integrated setting. (Employment Development Service).

The process of advocacy itself has spin offs for not only the person, in terms of particular activities, but for the person and the advocate in terms of enhancement of relationships.

An advocate (ex staff member) was involved with a client who lives in a community home. He worked very closely with the client and the staff who worked in that particular home. He was also very much involved with the advocate's family and social circle. The main role of the advocate was to introduce outside interests (or to develop his interest or hobby, which was mainly trains). It was also for the client to have his own 'special friend' someone who came to visit him in his own home as he had no family and very few outside contacts. The client particularly enjoyed being introduced to the advocate's family, which gave him a sense of 'belonging'.

The client's quality of life improved immensely. As stated above, he developed a sense of belonging. The client looked forward to weekly visits to his home and his social life improved. He was also communicating with other people as he had developed interests apart from the day centre. The main effect was that the client gained a friend of which he was very proud. "Somebody to send a postcard to while on his hols" and to receive one from. (Social Services).

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## Case Studies of Unsuccessful Advocacy

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The consequences for individual people of advocacy that is unsuccessful include restrictions on their lives in terms of lack of opportunity to use ordinary facilities along with the rest of us, fewer opportunities to meet with non-disabled people and to work, fewer financial resources, limited leisure opportunities, continuing to live with people they do not like, over protection and few choices.

Unsuccessful advocacy presents major challenges to agencies. It highlights the extent to which the service system obstructs advocacy and may raise conflicts of interest that may inhibit advocacy; some of the difficulties of working with families and other agencies; unhelpful practices and procedures; and the need for more public people with learning disabilities and the principles underlying the services supporting them.

### The service system

If the service system, itself is inadequate, advocacy can do little in supporting people to use it effectively. For example, advocates can help people use complaints systems, but if these are weak, nothing much will follow.

A member of staff supported a service user in bringing a complaint against another service provider, due to bad practice/neglect. They were helped to prepare a written complaint and to gather evidence to support the letter. The service user complaint was looked into by a senior member of staff from the service provider. A written note was received which did not address the complaint but simply stated their policy and procedures. It is extremely difficult for service users to tackle complaints without an independent advocate to provide support or backup once a complaint has been made, it is hard to explain the outcome to the service user with limited literacy skills. As a result of this the staff member felt frustrated. (Social Service Day Centre).

Staff may feel frustrated at the perceived inadequacy of the service system. This seems particularly so when service users have limited communication skills and staff find themselves in the position of advocate.

I acted on behalf of service users trying to improve care provision or meet their needs. These service users were unable to communicate this for themselves. I liaised with main carers - with poor results. I then liaised with my line manager - with fair results as my line manager took this further, but too many service issues stood in the way of progress. There was lots of conflict regarding opinions etc., which meant before advocacy could take place, relationships between different parts of the service needed to be built further. This is still progressing very slowly on behalf of service users. It has become an 'uphill struggle' and puts lots of pressure on myself and others. I have to ask 'is it worth the effort?' (although I do not give up that easily). (Social Service Day Centre).

Sometimes, staff come up against what appear to be blocks linked to inadequate resources.

A letter from staff and an independent provider was sent saying that the client had asked for a move. We were already aware of the circumstances and continue to say an alternative placement will be offered when resources and other demand permit. To date the person remains in current placement. (Social Services).

At other times, the service itself can offer a compromise on advocacy. If resources for independent advocates are unavailable, a social worker may serve the function.

An attempt was made to obtain an advocate to assist a client in a domestic situation. Due to costing considerations this did not come to fruition. A social worker resolved the situation. (Social Services).

The limitations of the service system extend to its capacity to work with families and other agencies in the best interests of the client.

Advocates may be unsuccessful in bridging the gaps between client and worker, service requirements and family concerns. Independent advocates have sometimes found that services capitulate to parents wishes to the detriment of the client. In this case, the client wished to move from home in order to live a more varied and stimulating life.

A service user wanted to do things other people his age are doing. He is very able and has 2 brothers. He sees his 2 brothers going out and enjoying themselves, although there is some

restriction at home such as money. Service user, because of his limited freedom, wants to move out of his house away from Mum but not lose contact. After several meetings with the service user, centre staff, key worker, centre manager, it was decided to take it further.

Other meetings were arranged: involved were an independent advocacy service and People First. The key worker referred the service user to an independent counsellor (Mum was invited but usually would not attend - she was informed throughout). Mum would attend small meetings at the centre which continued to receive negative feedback from her. Meetings are still in progress.

Service user still has not achieved his goal and continues to lead a restricted life, due to lack of parental permission. There are some behavioural effects on service user, as his behaviour has begun to deteriorate. (Social Service Day Centre).

Restrictions by parents can also be imposed in terms of relationships, particularly close relationships.

A couple with learning disabilities had been resettled in the community from an institution. Previously they had had a very close, full relationship for 10 years. Her family refused permission for them to live in the same house, would not allow outings or holidays together and discouraged contact. Her family was very threatening, saying that mother's dying wish was for her to be fully cared for by staff. Staff in her house became unhelpful to the relationship - they were obstructive and frightened of her family and trouble they caused. Staff in his house tried to enable the relationship with no effect. (The young lady had some speech and hearing problems, so could not fully understand and speak up for herself).

Several meetings were called but the situation remained very difficult. A speech therapist demonstrated that the lady was communicating and that she wanted the relationship, but her family refused to consider any evidence. Her staff continued to overprotect her.

The young lady continued to do as she was told but had some behavioural problems. The young man had severe behavioural problems and became very withdrawn and unhappy. (Physiotherapy Team).

Financial pressure on families is at the root of some conflicts that advocates try to resolve, either from within and outside the service.

A particular client was interested in joining a voluntary work opportunity with the YMCA. Keyworker, family, employment placement officer and community support officer all agreed the value and mechanisms for joining this scheme. The client was positively motivated and excited to have the opportunity. At the 11<sup>th</sup> hour parents pulled the rug - deciding that this would lead to a loss of benefit.

Meetings with parents and client were held. Keyworker support meetings with client held. Reinforcement of the values of the opportunity were made. Details regarding benefits and how voluntary work was considered by EPO sought. Client suppressed her wishes to go on voluntary placement and began to actively reinforce what her parents were saying about not seeking work. (Social Service Day Centre).

Sometimes family members are not willing for their disabled members to suffer what they perceive to be indignity at the hands of others. In this case, the staff member acting as advocate is seeking to balance expansion of opportunities with possible lack of dignity.

A service user wanted employment and was supported by centre staff in work experience. A practical joke on the service user by other employees (considered by staff to be acceptable as part of 'apprenticeship' and not upsetting the service user) caused the family to prevent the person continuing their work experience.

Staff member had lengthy discussion with family, including an 'appraisal' by employer. However, the service user ? the work experience. He has since said that he wants to undertake further work experience. (Social Service Day Centre).

Here, there appeared to be a conflict between what the family and centre staff thought to be acceptable practice. At times it is the practice itself that is the focus advocacy. Resources, again, appear to be the reason why this advocate was unsuccessful in developing a more appropriate response from service workers. It also highlights some of the risks in trying to mediate on behalf of clients.

A client had been stopped from attending a SEC due to restraint being used. I contacted a citizen advocacy group to help us secure extra support for this man to attend the SEC without restraint being used.

The advocate met with our service, the centre, local MPs and parents to try to get extra funds.

No such extra support was available. MPs would not get involved. This man was off work for over 12 months. His behaviour deteriorated. As we had limited reserves to support this man whilst he was off work, his quality of life deteriorated. His advocate was accused by the client's parents of gossiping about them and eventually stopped being the advocate. The client returned to the centre with no extra support in place - but the times he is in restraint (in his wheelchair with a strap across his lap) has been dramatically reduced with continuous monitoring. (Community Health Team).

Some agencies have demonstrated that for effective advocacy and self advocacy, skilled methods of enabling participation must be used. Without these the advocacy may be reflective and, further, be perceived to be unnecessary. Formal review meetings may disable, not enable clients:

Two service users were placed together in a house with a joint tenancy as part of a dispersal from a residential hostel. One of the service users was expressing serious complaints about the other and wanting to move out. Both service users have the same social worker and a conflict of interests was apparent at reviews. Then complaints were minimised and the service user was made to feel guilt about complaints, with emotional, exploitative statements from the social worker, and confusing questioning which placed the service user in an untenable situation, being asked to make uninformed choices (e.g., where would you live? Who would you live with? Etc). All of this was in a very threatening formal review meeting with a large group of professional workers.

Management and staff member followed up the review with the social worker, taking up the issues of listening to the service user. A smaller meeting on an informal basis was arranged with the social worker, keyworker and client, to discuss the issues informally. Then social worker agreed to work towards seeking alternative accommodation and look at each of the two service users' needs in isolation from each other. The service user would be helped to identify someone else to live with (the client wants a companion).

Various delay tactics have been put into place. The service user's complaints were made available to other client's parents and the home help. All of these people are putting pressure on the person not to move, all the negative possibilities of moving are being put forward. Even so, the service user continues to want to move and we are still supporting her wishes and

working on representing her views. (Social Service Day Centre).

Even more informal, self advocacy groups require some support if they are to work effectively.

Self advocacy group with representatives from day centre is not representing people's views adequately.

Previously minutes of the last meeting were given out at each fortnightly meeting. These were good quality, using words and graphics. However, the person who used to produce them left and no minutes have been produced for the past year.

There is now a lack of feedback regarding issues discussed. The service users who attend fail to pass on verbally any information discussed at the meetings. They seem to treat the meetings as a social gathering where they meet friends rather than as representatives of our day services, responsible for representing the views of fellow service users and feeding back information to them. (Social Service Training and Development Centre).

Although this self advocacy group was perceived to be reflective it did highlight the interest members had in opportunities just to meet and talk. A further service deficiency would be revealed if this point were not to have been taken up by the agency. If agencies cannot recruit and support advocates, or offer feedback to advocacy agencies, the advocacy may disappear and advocates get a bad name. In what follows, the advocate did not fulfil her or his role:

A volunteer from an independent advocacy service came to see a service user twice then nothing was heard from them again. Minimal effect! (Social Service Day Centre).

Lack of flexibility of the service system may prevent people's needs being met. Here, a service user is attempting to make her needs known. The rigidity of the system was unhelpful and she was not directed to alternative routes to the support she required.

A service user required counselling regarding personal problems. The key worker was involved and the service user asked for a consultation with a psychiatrist but requested total confidentiality. Referral was made to a social worker who followed throughout the request and advised contact with the service



user's GP. Service user withdrew request. (Social Service Day Centre).

Reluctance to suggest alternative forms of support available to other people, outside the learning disability service may be due, in part, to the lack of access and understanding of these other agencies. Examples of unsuccessful advocacy might highlight the need for more public education.

## Public education

Advocates can play a vital role in helping people use ordinary facilities and procedures. They draw attention to the need for other agencies to provide the means for full participation in procedures, as in this example of a disciplinary/grievance procedure at work.

An advocate supported a person with learning disabilities at a grievance/disciplinary hearing. The advocate put across the person's point of view. The advocate asked for time for the person to respond to questions and that people stopped using jargon. Advocate asked for re-location of work site rather than dismissal. However, the person, due to the seriousness of the offence at the workplace, did lose their job. (Independent Advocacy Service).

Access is not only to procedures, it is also to buildings and facilities.

A service user complained to the service user's group that as a wheelchair user she could not use the same changing facilities at the sports centre to access the swimming pool as everyone else. Members of the service user group were helped by an independent facilitator to write an official complaint/suggestion form and contacted a representative of leisure services asking for a meeting at the sports centre to discuss and highlight the problems.

A meeting took place and several suggestions were made, e.g., ramps, wider changing bench, larger family style changing cubicles etc. Whilst the representative seemed genuinely sympathetic to the issues, the formal response was that the changes necessary would be too costly, or after consultation with building/technical services, impractical. The service user's group agreed to keep lobbying for better facilities for wheelchair users and or people with severe disabilities. (Social Service).

Lack of access to ordinary facilities extends to education and employment. It is largely through lack of wider public education and

knowledge that attempts to include learning disabled people in education and employment often falter.

Although this example is not a part of our service, it was done in the worker's own time and demonstrates significant difficulties faced by people with learning disabilities and their carers. A number of young people have not been listened to in terms of education provision, particularly for young people wanting to remain in the mainstream educational system. The Education Authority insisting they are segregated into special provision.

Letters have been sent to the local authority education authority, councillors, MPs, etc. Meetings have been held with the Chief Education Officer and Special Needs Manager. Publicity has been produced and awareness raised.

To date there is no success. This demonstrates the discrimination against children with learning disabilities. Able bodied children are deprived of the invaluable experience of getting to know disabled children. The stress and upheaval caused to families concerned is considerable. (Voluntary Sector Advocacy Service).

Approaches to employers are often unsuccessful - that is they are not prepared to give a person a chance even though a vacancy exists. (Employment Development Service).

Lack of understanding may extend to advocates, themselves. If they do not understand people with learning disabilities and the principles underlying support services, they may not be able to offer effective advocacy.

A representative of a voluntary organisation became involved with someone with sensory impairments. As the advocate did not understand ordinary life principles there were various discussions about why could the person not use children's toys and otherwise be treated like a young child. It felt like moving backwards instead of forwards. (Social and Health Joint Learning Disability Service).

Whilst this might illustrate a need for public education it might also reflect a need for services to develop and support advocacy and advocates. At the moment, provider agencies put relatively few resources into supporting independent advocates or into advocacy training (see Figure 6 above). If provider agencies are doing little, perhaps it is

commissioners of services whose responsibility

it is to stimulate effective advocacy.

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## Commissioning Advocacy

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Questionnaires (see Appendix) were sent to all Health and Social Service Commissioners in the north west. Replies were received from one social service authority and six health authorities, although one of these had no responses to make on the questionnaire. It is unclear whether this reflects the extent of interest amongst commissioners in advocacy or not.

Some advocacy functions have been commissioned in the last two years.

The social service authority has commissioned specific advocacy for an individual and self advocacy as part of a wider contract. It has also commissioned civil or disability rights groups. Preference is clearly for commissioning generic advocacy services to which people with learning disabilities can apply, and not for exclusive learning disability advocacy services. Resources available for the development and practice of advocacy are: finances to cover expenses of advocates and service users; resources for local project developments; contract specifications for effective advocacy and guidelines for providers on good practice in advocacy.

The health commissioners vary in their contracting for advocacy.

One has not included advocacy as part of wider contracts but has contracted specifically for

self advocacy groups, individual advocacy and civil/disability rights groups.

Another has contracted just for specific individual advocacy and carried out by a person independent of services in relation to resettlement for one client. A third agency has added to this, advocacy by staff members as part of a wider contract.

The last health commissioning agency has included group self advocacy, individual advocacy and advocacy by staff members and other professionals (social worker and psychologists) as part of a wider contract whereas advocacy from a person independent of services has been commissioned specifically.

It seems, then, as if commissioning agencies are not putting significant resources into contracting for the development of independent advocacy with the required training and support, unless this is specified in a wider contract. From what provider units report, it is not.

### Outcome indicators

If commissioners are to contract for advocacy they will have to define some outcome indicators for monitoring and evaluation purposes. The outcome indicators identified are summarised in Table 1.

Agency	Outcome indicators
<b>Social Services</b>	<ul style="list-style-type: none"> <li>- Objective appraisal of situation.</li> <li>- Only doing what is commissioned and <b>not</b> straying into other issues.</li> <li>- Identifying for commissioning agent associated issues not specifically contracted that may need to be addressed.</li> <li>- Service user getting appropriate service or need addressed ('wish lists' excluded).</li> </ul>
<b>Health</b>	<ul style="list-style-type: none"> <li>- To initiate new self advocacy groups.</li> <li>- To recruit, train, supervise volunteers to support groups.</li> <li>- To develop new models of self advocacy i.e., relevant to ethnic minority communities.</li> <li>- To contribute to the development of People First.</li> <li>- To stimulate and support statutory and voluntary sector providers to develop the involvement of service users in service planning and to raise awareness about advocacy to staff, managers, etc., in statutory and voluntary sectors.</li> <li>- Facilitation of resettlement.</li> <li>- Number of face to face contacts made.</li> </ul>

**Table 1**  
**Outcome indicators from contracts for advocacy as reported by commissioners**

Two authorities did not list any outcome indicators.

Commissioning agencies have, themselves, been at the receiving end of advocacy in relation to the following issues:

- complaints
- criticism/service
- obtaining peoples' views
- representation of peoples' views
- consultation
- enabling collaboration
- assistance in developing policies, (procedures) and priorities
- information and advice
- criminal proceedings
- service evaluation
- lobbying for change
- quality of service.

## Successful and unsuccessful advocacy - commissioners

Each commissioner was asked to outline an example of successful advocacy. This question prompted one agency to list the few independent agencies they find useful including a general advocacy service, a CVS and two Community Health Councils.

Three examples of successful advocacy were offered. The first highlights a familiar theme, that of family-service interface.

An advocate assisted a family in negotiating with us a preferred supported tenancy option. Both parents' views were given to us and the advocate was able to interpret our position objectively to the parents. (Social Service Commissioning Manager).

The second example highlights the strengths of collective advocacy, and although offered by a health commissioner focuses entirely on its impact on social services.

A mass complaint by some service users about the charging policy. The charges could not be prevented, but social services were forced to

assess everybody individually and ensure all benefits were being claimed. The experience was very powerful for many people and ensured that the council had a much more effective consultation when charges were proposed to be extended including a specific, tailored consultation for people with learning disabilities. (Health Commissioner).

The last reported example drew attention to the constructive participation of an independent agency in a review of services for children with learning disabilities.

Conflicts of interest in one form or another characterised three of the four illustrations of unsuccessful advocacy.

We asked an advocate who normally advocates for service users to advocate for a carer who had been treated fairly badly by the system. Inevitable conflict arose between the needs of the user and carer: the poor treatment of the carer over the years could not be alleviated so easily by an advocate now, and it was an unfair situation to be put in. The negative feelings of staff to the carer were too difficult to counteract. (Health Commissioner).

Whilst role conflict for the advocate may cause difficulties, so too does conflict between agencies.

An advocacy agency became involved in a dispute between the purchaser (me) and provider (a private 6 bed unit) regarding charges for services. I thought it inappropriate for a provider agency to contact the advocacy service regarding this issue and more inappropriate that the advocacy service accepted the referral. The

service user was not in danger of losing a placement - provider wanted substantially more money for no additional service. (Social Services Commissioning Manager).

Conflicts of interest also arise between the advocate's agency and the person he or she is working for.

Services which were not 'independent', i.e., where an organisation provides other services which an individual questions, leads to a conflict of interest for the advocate and the person he or she is working for. Not all organisations in either the statutory or, in this case, the voluntary sector, are willing to accept criticism, especially if they have seen themselves as having the role of 'watchdogs' for a specific client group. In this instance, they saw criticism as 'biting the hand that was feeding the individual'. The contract was to the local CVS which has a more generalist role, and is overseen by the local advocacy service, which is more at arms length. (Health Commissioner).

Whilst most advocacy in provider units is undertaken by members of staff, such potential conflicts of interest are highlighted by commissioners who contract for advocacy, sometimes, within a more general contract, thus supporting the potential conflicts.

## Resources for advocacy

Commissioners may be in a position to allocate resources to the development or provision of advocacy. When asked about this, commissioners identified a range of resources, as indicated in Table 2.

Agency	Resources
<b>Social Services</b>	Finances to cover expenses of advocates and service users; resources for local project developments; contract specification for effective advocacy; guidelines for providers on good practice in advocacy.
<b>Health</b>	Finances to cover expenses of advocates and service users; resources for local project developments; contract specification for effective advocacy; guidelines for providers on good practice in advocacy, training workshops to stimulate advocacy developments amongst providers, quality indicators for advocacy services and advocates, development of district wide advocacy strategy across all user groups.

**Table 2**  
**Resources made available for the development and practice of advocacy by commissioners**

## Further issues - commissioners

Commissioners raised a number of other issues connected to advocacy. These included:

- There is a need to explore the issues within a broad range of advocacy from self to citizen advocacy.
- Advocacy should have to be top sliced from the resettlement programme - any review of services should insist that funding advocacy is a 'must do'.
- Infrastructure is required. We need to be able to recognise the commonalities of advocacy across client groups, such as training for staff, recruitment of volunteers, administration, fundraising and management of projects. Joint infrastructure would make things cheaper and the importance of advocacy would not be dependent on one purchaser.
- Advocacy projects do not see commissioners as 'independent' and that has to be thought through for advocacy to work. If inspection and registration units and complaints procedures could be genuinely 'arms length' here may be a way forward.
- Independence with appropriate standards is immensely important if any form of advocacy is to be effective.
- Employing an advocacy development worker who recruits, trains and supervises volunteers can also contribute to an effective model which can encompass the diversity of skills required and ensures better coverage than an individual can provide.
- We have a local advocacy project, funded from joint finance as well as health and social services. It works to a service level agreement which ensures the service is accountable and professional, but is able to operate at arms length.
- Any authority which embarks on advocacy without understanding the importance of independence is likely to undermine the individual's rights and conflicts will emerge unless the organisation is mature enough, and the senior officers stable enough in terms of tenure of office. There is a particular problem where there is a high turnover of staff and where volunteers come and go without any rigorous evaluation of their understanding of the role of advocacy.

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## Conclusion

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It is evident that agencies are beginning to grapple with the issues raised by the need for and practice of advocacy.

Relatively little seems to be being done to stimulate new models of advocacy, especially those independent from services. Little is being provided in the way of training and support for independent advocates and commissioners are not stimulating developments to the extent that they might.

A range of issues for people using services are being addressed through advocacy, although it is not clear that the mechanisms for receiving advocacy are enabling or clear. For example, organisations are able to resolve some issues for individuals; however, they may or may not learn from this to change their policies and practices more generally. The one example given of collective advocacy did lead to a district wide change of practice. Organisations could also learn from individual advocacy issues.

Most advocacy in provider units is self-advocacy and undertaken or facilitated by a staff member. Commissioners, however, favour independent advocacy. These different agendas could lead to a dilution of resource and expertise if skilled internal practice is not recognised and developmental resources are targeted outside provider agencies.

Family-user conflicts remain some of the most intractable areas around which to advocate for and with learning disabled people. They can also have some of the most far reaching effects on individuals, either in terms of upholding their rights or denying them and sometimes greatly restricting people's opportunities. In part this will be due to the lack of faith some families have in services, borne out of their negative experiences in the past. However, we need to explore more models of successful advocacy where conflicts with family members arise in order to build on such good practice.

As we learn more about and become more skilled in listening to people, in a truly participative way, throughout their time being supported by services, the need for advocacy may decrease. There will, however, always be the need to safeguard the interests of the most vulnerable people who cannot represent themselves. Perhaps this is where the most innovative developments in advocacy practice could be stimulated and developed and this will, inevitably, require many more resources directed at the education of people outside services, including enabling family members and the general public to take a more active part in the lives of severely disabled people.

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## Further Reading

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Brandon, D., Brandon, A., & Brandon, T., 1995, *Advocacy: Power to People with Disabilities*, Venture Press, Birmingham.

Miller, A., & Keys, C., 1996, *Awareness, Action and Collaboration: How the Self-Advocacy Movement is Empowering for Persons with Developmental Disabilities*, Mental Retardation, October 1996.

NISW, 1993, *Complaints: Getting Heard and Getting Things Changed*, Policy Briefing No. 2, NISW, London.

Public Law Project (with UNISON), 1994, *Challenging Community Care Decisions: A briefing by the Public Law Project*, London.

Tyne, A., 1994, *Welcoming Advocacy: Changing the Pattern*, NWTDT, Whalley.

Wolfensberger, W., 1977, *A Multi-Component Protection/Advocacy Schema*, Toronto: NIMR.



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## Appendix 1: Questionnaire for Providers

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### North West Training & Development Team Agencies & Advocates - Provider

This survey is in order to describe the extent and nature of advocacy for people with learning disabilities in the north west.

*Please return questionnaires with as many sections completed as possible to:*

*Carolyn Kagan  
NWTDT  
Calderstones  
Whalley  
Clitheroe BB7 9PE*

*by the end of February 1996.*

Name: \_\_\_\_\_

*(this is optional but will enable me to contact you again for further details if required. All information will remain confidential and anonymous).*

Work Address: \_\_\_\_\_

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Agency:	Social Services	<input type="checkbox"/>
<i>(please tick)</i>	Health Trust: hospital	<input type="checkbox"/>
	community	<input type="checkbox"/>
	Education	<input type="checkbox"/>
	Voluntary	<input type="checkbox"/>
	Housing	<input type="checkbox"/>
	Private	<input type="checkbox"/>
	Other: Please specify _____	<input type="checkbox"/>

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1. Approximately how many people with learning disabilities have been involved in the following types of advocacy in the last 2 years:

Self Advocacy Group(s)	
Self-Advocacy (individual)	
Advocacy by staff member	
Advocacy by other professionals <i>(please list type of professionals)</i>	
Citizen Advocacy	

Civil/Disability Rights Groups	
Advocacy by person independent of services	
Other ( <i>please specify</i> )	

2. Please estimate the number of:

Staff involved in advocacy	
Independent advocates in touch with your service	
Independent advocacy group facilitators in your service	
Lawyers involved with advocacy	
Groups involved with advocacy (e.g. Mencap) ( <i>please specify</i> )	

3. What issues have featured in advocacy practice: (*please tick*)

- Complaints
- Criticism of service
- Compliments of service
- Representation of person's views
- Assessment of need
- Service evaluation
- Lobbying for change
- Representing person's best interests
- Obtaining people's views
- Enabling participation
- Consultation
- Enabling collaboration
- Quality of service
- Resolving dispute between family and service
- Assistance in developing policies, procedures and priorities
- Inspection of services
- Information and advice
- Criminal proceedings
- Others: (*please list*) \_\_\_\_\_

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4. Please outline one example of successful advocacy.  
Who was involved with whom? (names not required).

What was done?

What was the effect?

5. Please outline one example of unsuccessful advocacy.  
Who was involved with whom (*names not required*).

What was done?

What was the effect?

6. What resources does your service provide to stimulate and encourage advocacy?  
(please tick)

- Finances to cover expenses
- Recruitment of advocates
- Training of advocates
- Training of family members
- Training of people with learning disabilities
- Training of staff advocates
- Administrative support
- Venue for groups
- Policy statement of commitment
- Guidelines for independent advocates
- Others (please specify) \_\_\_\_\_

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7. Any other issues: Please outline any other issues arising from the practice of advocacy for your service.

*Please return to:*

*Carolyn Kagan  
NWTDT  
Calderstones  
Whalley  
Clitheroe BB& 9PE*

*by the end of February 1996.*

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## Appendix 2: Questionnaire for Commissioners

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### Agencies & Advocates - Commissioner

*Please return questionnaire with as many sections completed as possible to:*

*Carolyn Kagan  
NWTDT  
Calderstones  
Whalley  
Clitheroe BB7 9PE*

*by the end of February 1996.*

Name: \_\_\_\_\_

*(this is optional but will enable me to contact you again for further details if required. All information will remain confidential and anonymous).*

Work Address: \_\_\_\_\_

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Agency:	Social Services	<input type="checkbox"/>	
<i>(please tick)</i>	Health	<input type="checkbox"/>	
	Housing	<input type="checkbox"/>	
	Education	<input type="checkbox"/>	
	Other: Please specify		_____

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1. Have you contracted for any of the following forms of advocacy for people with learning disabilities in the last 2 years: (please tick and indicate if this was a specific contract or specification within a contract)

	specific	part of wider contract
Self Advocacy Group(s)	<input type="checkbox"/>	<input type="checkbox"/>
Self-Advocacy (individual)	<input type="checkbox"/>	<input type="checkbox"/>
Advocacy by staff member	<input type="checkbox"/>	<input type="checkbox"/>
Advocacy by other professionals <i>(please list type of professionals)</i>	<input type="checkbox"/>	<input type="checkbox"/>
Citizen Advocacy	<input type="checkbox"/>	<input type="checkbox"/>
Civil/Disability Rights Groups	<input type="checkbox"/>	<input type="checkbox"/>
Advocacy by person independent of services	<input type="checkbox"/>	<input type="checkbox"/>
Other <i>(please specify)</i>		

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2. Please list the outcome indicators you would require from contracts for advocacy.

3. Has your purchasing organisation been on the receiving end of advocacy? *Yes / No*

If so, please tick the issues raised by the advocacy process.

- Complaints
- Criticism of service
- Compliments of service
- Representation of person's views
- Assessment of need
- Service evaluation
- Lobbying for change
- Representing person's best interests
- Obtaining people's views
- Enabling participation
- Consultation
- Enabling collaboration
- Quality of service
- Resolving dispute between family and service
- Assistance in developing policies, procedures and priorities
- Inspection of services
- Information and advice
- Criminal proceedings
- Others: *(please list)* \_\_\_\_\_

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4. Please outline one example of an effective advocacy service or relationship you have purchased  
(names not required, just general information).

5. Please outline **one** example of an ineffective advocacy service or relationship you have purchased  
(names not required, just general information).

6. What resources do you make available for the development and practice of advocacy?  
(please tick)

- Finances to cover expenses of advocates/service users
- Resources for local project developments
- Contract specifications for effective advocacy
- Guidelines for providers on good practice in advocacy
- Training workshops to stimulate advocacy development amongst providers
- Quality indicators for advocacy services and advocates
- Others (please specify) \_\_\_\_\_

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7. Please outline any other issues arising from the commissioning of advocacy work for people with learning disabilities.

*Please return to:*

*Carolyn Kagan  
NWTDT  
Calderstones  
Whalley  
Clitheroe BB& 9PE*

*by the end of February 1996.*