

# Building creative tension

The development of a citizen advocacy  
programme for people with mental handicaps

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In this text, 'services' or 'human services' can be taken as the equivalent, in a UK context, of the wide range of services provided by health and local authorities and voluntary bodies, including health, education, social services, housing and others.

'Service workers' includes people at any level working in any or all of these fields.

# Introduction

‘Beware thinking of systems so perfect that nobody will have to be good.’  
– Gandhi

How does one measure social progress? If the increasing investment of public resources, the development of new services and methods of assistance, the entry of growing numbers of professionals into ‘caring’ careers, and public statements of rights and entitlements are valid criteria, the past twenty years have witnessed a transformation in policy and potential for people with special needs. But the daily experience of many people shows the transformation to be incomplete in practice. Large numbers still live in institutions; much ‘deinstitutionalisation’ has been a matter of swapping larger older institutions for smaller newer ones; many people still do not receive technically competent assistance; and rights to services and protections are hard to enforce.

The gulf between promise and common practice is sobering, but it need not be cause for cynicism or defeatism. It can motivate constructive action on the part of ordinary citizens and the professionals who serve their communities.

Citizen advocacy is one channel for constructive action. An ordinary citizen develops a relationship with another person who risks social exclusion or other unfair treatment because of a handicap. As the relationship develops, the advocate chooses ways to understand, respond to, and represent the other person’s interests as if they were the advocate’s own. Their relationship is arranged and supported by a citizen advocacy office which operates independently from service providing agencies. Such relationships build creative tension around the service experience of particular people. Resolution of the tension introduced by citizen advocacy relationships can lead to changes in understanding and reorganisation of action on behalf of people with handicaps. Some of these changes will be within service programmes; others will touch the life of the wider community.

This paper describes the role of the Georgia Advocacy Office, as I see it – how it sets about planning and implementing methods of representing the interests of individual Georgians with special needs. (For a brief description of the Georgia Advocacy Office (GAO), see Box 1.) Citizen advocacy is the key factor in GAO’s protection and advocacy strategy.

Some of the details of GAO’s operation are specifically American in legal and social context. But many of the decisions and principles which shape the growth of GAO are, I believe, relevant to developed countries with a substantial investment in organised health and social services.

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## Box 1

### A BRIEF DESCRIPTION OF GAO

The Georgia Advocacy Office serves the south-eastern state of Georgia, which has a population of about five and a half million people. A little more than a third of the state’s population lives in the Atlanta area. The state covers 48,000 square miles.

GAO is a private, non-profit agency which was planned by a state-wide network of concerned citizens during 1976 and began operating in 1977. It is designated by Georgia’s governor as the state’s protection and advocacy system, in voluntary compliance with the federal Developmentally Disabled Assistance and Bill of Rights Act (Public Law 94-103, II: 113). Official designation

makes GAO eligible for federal funds but does not confer any special powers or sanctions. Volunteers and staff working on behalf of people with developmental special needs have access to the same administrative and legal recourses as any other citizen.

In 1982, GAO's working budget was approximately \$387,000, of which \$172,000 was provided by the federal Department of Health and Human Services. Federal law does not require states to share in the funding of protection and advocacy systems, and GAO enjoys an exceptional level of legislative support in comparison with designated agencies in other states.

GAO has as its headquarters a state office. The staff includes an executive director, a staff attorney, two staff advocates, a state citizen advocacy coordinator, an office manager, and an administrative assistant. The staff advocates and the staff attorney deal with a wide variety of requests for assistance from people with special needs, and their families, throughout the state. Their role is a supportive one: to help people with special problems and handicaps, as well as their families and other concerned citizens, to cope with problem situations in a manner that respects the handicapped persons' rights, interests and human dignity. GAO itself has not made use of the courts. When it appears that a lawyer could help, the staff attorney can help a client to find one. The staff attorney also acts as a link with lawyers representing people with special needs.

The citizen advocacy coordinator supervises the running of six local citizen advocacy offices, each of which is staffed by a local coordinator and an administrative assistant. These local offices, which are funded by the state legislature, are the heart of GAO's strategy for advocacy.

Local office staff do not themselves represent people. They match people with special needs, who require person-to-person relationships, with citizen volunteers who undertake to respond to them as people and be their allies in improving their situation in life. Some of these relationships are relatively brief and focused on a particular situation. A growing number have lasted for more than three years, and some people say they regard their relationships as for life. GAO staff are at hand to support the relationships they initiate, and may provide citizen advocates with help in identifying options for constructive action.

Each local office is supported by an advisory board of local citizens and a group of advocate associates. Associates include lawyers, local politicians, and experts from the 'caring' professions who volunteer their skills and knowledge to assist advocates.

Local offices also train people to form a clearer understanding of the difficulties faced by people with handicaps and encourage citizens to expect high standards from their community health and social services.

The six local offices were opened, one at a time, between 1977 and 1981. By January 1982, well over 600 relationships had been established by local offices and more than 300 relationships are currently active. Over 2500 citizens have attended training programmes.

All of the American states and territories have chosen to participate in the federal programme which requires a protection and advocacy system; but they vary substantially in the way they organise and operate the system. Most states rely much more heavily on staff attorneys and staff advocates than does GAO. Georgia, Wisconsin and Vermont have made citizen advocacy a basic component of their approach. GAO is, however, unique in the amount of resources it invests in citizen advocacy.

# Design principle 1

Develop an agency that can learn. State assumptions clearly and test them against experience.

Standing up for people with handicaps is nothing new. Concerned people, especially parents, have long experience as advocates. A publicly funded, independent agency mandated to protect, and advocate for, the individual rights of everyone in the state with special disabilities, *is* something new. At the time GAO was planned there were many opinions about how best to 'do advocacy' but no functional models that met the criteria specified in the law which stimulated its creation. Then, as now, there was no research to inform the debate. In the absence of a validated method, GAO planners decided to invest in an organisation designed for learning.

Like any organised way to help, an advocacy programme is formed by a set of assumptions about

- the nature of the community in which it operates
- the nature of the service system to which it is related
- the situation and most important needs of the people it will (potentially) serve
- the most effective strategies for making necessary changes.

These assumptions may be openly discussed and agreed upon, or may remain implicit in the operation of an advocacy programme. In either case they influence the way in which a programme deals with problems and manages constraints. Clearly stated assumptions can guide management decisions and can be tested against accumulating experience.

GAO has committed a substantial amount of resources to clarifying and testing its assumptions. Wolf Wolfensberger – an expert in advocacy, voluntary association dynamics, and human service design and evaluation – was commissioned to review the available literature and provide the planners with a description of a comprehensive advocacy and protection system<sup>1</sup>. More than 500 people with many different viewpoints were consulted in the planning process. Board and staff members periodically set aside time to reflect on and revise the assumptions, strategies, and tactics expressed in the original plan. Regular surveys of consumer satisfaction, and annual evaluation and consultation with outside experts, provide a wide spectrum of views on the quality of GAO's activities and the usefulness of its assumptions. Regular contact with representatives of other advocacy organisations invites comment and criticism. This effort does not necessarily make our assumptions correct; it does make many of them explicit.

Modest expectations are justified. Any contemporary advocacy agency lacks resources proportional to the task. In 1982 Georgia will spend \$50 operating the smallest of its seven institutions for each dollar in GAO's total budget. Moreover, there is no sure-fire approach to advocacy. The temptation must be avoided to promise oneself, and others, that the programme will deal effectively with the problems of everyone in need. So, do not promise to get it perfect the first time. Build a constituency for a learning, changing organisation.

Pick an overall advocacy strategy, define it as clearly as possible and commit yourself to developing it. (GAO's approach to citizen advocacy is operationally specified in CAPE: Citizen advocacy program evaluation standards.<sup>2</sup>)

State the limits and disadvantages of the strategy clearly and publicly. Plan to stick with the basic strategy at least until the agency has learned to implement it. This means absorbing development costs, involving some disadvantage to people with handicaps. One very likely price to pay for clear focus and acknowledgment of limits is strong criticism and

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opposition from others who prefer another advocacy strategy.

Grow slowly, in a piecemeal fashion, rather than trying to implement a big system all at once. Phased growth allows for repair of design errors and gives later beginners the advantage of learning from earlier starters.

If large sums of money are offered on condition of rapid growth, resist.

Invest in organisational learning: consultation, external evaluation, board and staff training, and board and staff reflection and planning time.

Budget to allow reserve funds to repair errors or develop new opportunities. Resist the understandable pressure to spend every available bit of money on 'doing advocacy'. Spending without reserve staves off (self) criticism for 'sitting on money while people suffer violation of their rights'. But it rapidly causes a programme to outrun its resources and fall into the panic of over-commitment, leading to deeper and more justified disappointment.

## Design principle 2

Respond to reality in the community in order to shape the best possible response to people with handicaps.

The way advocacy programme designers and operators view natural communities and ordinary citizens will make a major difference to their choice of advocacy strategies.

Some advocacy programmes act as if they believe that natural communities are essentially accepting towards people with special needs. They conceive the advocacy problem as one of getting good information across to the public, usually through the mass media or educational programmes for community groups. Once people are informed they have the means at hand to respond positively, out of natural benevolence. Discrimination against people with handicaps is individual, exceptional, and unintentional. The rest of us can and will stop discriminating if we are simply told how our behaviour adversely affects people with handicaps. An informed person who persists in negative behaviour towards a person with a handicap places himself at odds with his community. He can usually be called to order by an appeal to the community at large. Very rarely, an advocate may have recourse to the courts to deal with an unusually recalcitrant person. When this happens, the court will represent the positive element in the community and intervene to protect the handicapped person.

At the other extreme are advocacy programmes which appear to regard natural communities as essentially rejecting of people with special needs. The problem is to create a protected environment and special provision for people that nobody really wants. Ordinary people will, at best, be indifferent; often they will be cruel. Guilt may motivate some to say that they would like to act positively towards people with handicaps but, faced with them, they will react negatively. In the long run, the only people who can be trusted are those who are insulated against common rejection patterns by a special role: that of a professional service worker, a handicapped person with the same handicap, the devoted parent of a person with a handicap, or an (aspiring) saint. If conditions inside a special programme become abusive, the solution lies in increasing the amount of money available and providing more effective insulation by further 'professionalising' those involved. The advocate's role is to get people with handicaps into special programmes and places. Once they are there, the advocate supports the programme organisers by helping clients adjust to the realities of their status as rejected people, and lobbying decision-makers for additional funds. Advocates have no business interfering with professional prerogatives, especially clinical judgments

**The accepting  
community**

**The rejecting  
community**

## The community with potential for transformation

about what is best for people. Indeed, if advocates undermine the status accorded to the community's caretakers, the people who depend upon them will suffer.

We see an ambiguous situation in Georgia's communities. There is clear evidence of rejection. Segregation on the basis of handicap is the general, and generally unquestioned, rule within the organised services. Large numbers of people have no alternative but to live in public and private institutions. One can read a depressing collection of press clippings in which people proclaim support for group residences in general, 'but not in my neighbourhood.' But there are equally clear examples of community acceptance. A small but growing number of professionals all over the state have won community support when they have organised services encouraging the participation of people with handicaps in ordinary living, learning, and work places. The state's leaders have declared a policy of alternatives to institutionalisation, supported by legal and (partly) budgetary decisions. After one upper-middle class neighbourhood demonstrated public opposition to a home for three men with special needs, several similar neighbourhoods welcomed the home. Our communities have potential, therefore, for both acceptance and rejection. People with handicaps substantial enough to need very special accommodation evoke an ambivalent response from their fellow citizens.

Discrimination on the basis of handicap is woven into the fabric of community life. People with significant handicaps are very likely to occupy a devalued social role, which exposes them to risk of social exclusion and unfair treatment. Discrimination is masked and justified by such common myths as 'they really don't experience situations as the rest of us do', or 'nothing can be done for people like this', or 'people who need help should be grateful for what they get', or 'people like this are happiest living with their own kind'.

A community can take affirmative action to include people with handicaps and encourage them to assume positive roles, but it will not always be simple. Change will require more than good intent. Some community members may be disadvantaged by changes and there will often be conflicts of interests. While the courts may provide a forum to deal with some of these conflicts, many situations appear beyond their ability to resolve.

Georgia communities can draw on a tradition of community action to change unjust conditions and deal with unfair circumstances. But people with special needs are usually cut off from this tradition and most of their fellow citizens have no person-to-person contact with them. When contact does occur, it is generally with a faceless group seen to need pity or charity. ('Help with the handicapped. Donate your spare change.')

Most people think: 'Those people are well taken care of. We pay taxes and make donations to provide special centres and homes for them. They don't need anything else from us.'

The growth of professional services leaves many citizens confused about how to go about influencing this vital sector of their community. In providing for ever-increasing numbers of people, today's complex, bureaucratised services have outgrown citizen control. This imbalance strains the very meaning of citizenship. Ordinary people who want to change things have to organise and invent new ways of influencing services.

GAO assumes that there are significant numbers of ordinary citizens who are variously motivated to become personally involved with people with handicaps and to work to protect their interests. Over a period, a pattern of relationships which gradually weaves itself into the fabric of the natural community will be a force for transformation. Such relationships do happen spontaneously, but many more are likely if the community has resources dedicated to their initiation and support. These

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relationships can be important for people with special needs; they are also important in forming more just and more competent communities. Think of an advocacy office as a catalyst, a source of energy. Think of it as linking ordinary citizens with people who are handicapped, so that they may act together on behalf of people who are handicapped. This is different in concept and practice from running a volunteer bureau to supply a low-cost supplement to the professional, statutory service workforce.

Measure success in terms of the varied networks of ordinary citizens linked together by the office; the extent to which these networks come to include people with handicaps in their everyday life; and the extent to which the situation of people with disabilities becomes the occasion for action and learning within them. Expect these fundamental changes to take time. Growth will be organic and slow at first.

Situate advocacy offices so that networks of ordinary people can easily relate to them. State-wide is too wide; so are regional offices based on the human service system's map; and so is one office for a large metropolitan area. What is just right is hard to say, but when networks of ordinary people cannot relate to an office, most supporters will be professionals and volunteers already involved.

Convene a local group whose members have wide personal contacts throughout the community. Count on this group to identify and support people they know who could become advocates. To broaden the programme's reach, avoid recruiting too many people already involved with human services.

Hire staff with community roots and expect them to pick out and support advocates within their own familiar environments, for example through churches, civic organisations, neighbourhood clubs, pubs and so on. If resources allow more than one member of staff, hire people whose contacts are complementary rather than overlapping. This is as important for people who do ancillary and clerical work as for 'professional' staff.

Arrange and support personal relationships with a wide range of people. Include people of different ages, abilities and circumstances. People volunteer to a person, not an agency or a problem. Cultivate the expectation that an advocate will learn to know the other person by working to understand, and change, that person's situation. Also that, as the relationship grows, the person will become more and more a part of the everyday life of the advocate and of the advocate's social group.

Position the advocacy office as a support to citizen networks rather than as one more human service or as a place to go if one has problems with human services.

Responsibility for action rests with citizen volunteers who, as a group, will become more effective with experience in dealing with the problems created by human service agencies.

Avoid competing directly with service agencies for funding.

Don't depend on services to pinpoint the people with whom citizen advocates will form relationships by seeking referrals through official channels. Develop a strategy for identifying and making contacts with a wide range of people with handicaps in a variety of social settings. To begin with, liaison with service workers will help, but as the number and variety of relationships grow, people who form relationships will pick out others who need them.

Matching is a person-to-person process. Rely on expanding personal contacts to recognise potential advocates, rather than 'marketing' people with handicaps as a group in need through mass media appeals for a group of volunteers.

When planning, accept the fact that citizen advocacy is unlikely to cover all of the people with handicaps who need personal representation. Because a citizen advocacy network grows slowly, this shortfall will be most acute in the first year of an office's operation. Supporters and staff should avoid promising, or expecting, too much.

First phase funding should not depend on the number of relationships formed or problems successfully solved.

## Design principle 3

Bear in mind the realities of the existing service system in order to improve the quality of life for each person with a handicap matched by the programme.

### A question of perspective and focus

Most of the people who call on GAO need special support if they are to develop. At present, society allocates resources in such a way that providing support is the designated responsibility of one or another organised statutory service. The past generation of political advocacy for people with handicaps has promoted a policy of replacing care with service: what families cannot do, services should. Many people with handicaps rely on organised services for such life defining functions as a place in which to live, work and learn. Beyond this, the real nature of services is a matter of perspective.

Many staff and advocates look at the service system as a whole from the point of view of service providers. They point with justified pride to a record of steady progress. More services than ever are available and, compared with the past, quality is good and getting (slowly) better. Better services will continue to evolve through a political coalition of professionals and organised consumer advocates. If progress lags, litigation on behalf of deprived classes can help. Many people who seek change from this perspective define their work as 'systems advocacy'.

GAO looks at the service system as it affects the experience of particular people. It looks at their natural support and their home communities. Our mental perspective at GAO is formed by a studied commitment to the principle of normalisation<sup>3,4</sup>. From this point of view, there are more services than ever, but many people still do not get what they (or those intimately concerned about them) believe they need. Their development is retarded if we do not make allowance for their (often) horrific past. Efforts to change the system as a whole from the top down continue to yield important gains, but are necessarily out of phase with the immediate needs of many people. More fundamentally, service (what organisations do for people) is no substitute for care (what people do for one another). Indeed, growing public investment in service may have the reverse effect of driving out care by weakening the structure of voluntary action by citizens.

Georgia has a number of active 'systems advocacy' organisations, some with an enviable history of success in influencing legislation. GAO chooses and maintains what it believes is a complementary focus, working with a relatively small number of people to create change in their relationship with their community and its service system.

### Different ways of thinking

Advocates can start by seeing things from the service point of view, or from the point of view of those who rely on services. Either way, the advocate is likely to encounter people who regard the service system as if it were a perfectible machine. It is important for those who plan and implement advocacy programmes to consider the consequences of this way of thinking and to shape alternative metaphors.

### The perfect(ible) service machine

Many American human service administrators like to think of their work as the assembly, operation, and maintenance of a complicated set of machines. Here is a caricature of this way of thinking.

An alliance of rational planners and specialist lobbyists in federal and state capitals provides brain and muscle to blueprint and implement an increasingly comprehensive array of service programmes based on progressive principles. Computerised 'needs assessment' surveys identify gaps in service. The planning and budgeting process converts



these into programme 'slots', 'seats', or 'beds'. An ever-increasing army of laws and regulations divides the work between the various service agencies; coordination is achieved by joint committees. Major coordination problems are solved by reorganising the bureaucratic machine to achieve more rational integration.

Interdisciplinary teams produce individual service plans based on objective client assessment. Case managers introduce clients to service 'packages' through which they will be able to reach independence.

From time to time the service machine malfunctions. Incorrect application of eligibility criteria causes denial of service. Human or machine error causes a benefit cheque to go astray. Failure to heed good individual programme planning procedure leads to misclassification or inappropriate placement. Breakdown of management control at the programme level results in staff abusing clients in violation of written policy. These accidents present well-structured problems which are solved through a variety of administrative appeal procedures. Error is proven; responsibility is established. Redress follows according to regulation. Those who cannot represent themselves effectively have agency-paid internal advocates and ombudspersons to assist them.

From this point of view, personal advocacy is one more component of a comprehensive system of services. Advocates solve routine problems by applying defined rules. Advocacy serves as a stabiliser by providing feedback to those who operate the system. If change is required, managers will make it through established channels. Managers have the big picture required to make balanced decisions; advocates feed information about system performance discrepancies into managers' big picture files.

The limits of effective advocacy are the limits of the service system. When the system is unable to provide what a person needs for good reason, the advocate's role is to help the person adjust to the realities of the situation. Good reasons mostly have to do with resource shortages beyond the control of the managers. 'Fred can't have an electric wheelchair because the severely retarded are low priority for the few chairs available'. 'We can't design a mealtime programme for Alice because we are unable to recruit occupational therapists out here'. 'The authorities won't raise enough money to develop community homes for people like George'.

## A herd of clumsy dinosaurs

The service system GAO has to deal with seems more like a herd of clumsy dinosaurs than an almost perfect machine. It dwarfs the many people who depend on it for housing, jobs, education, recreation, and health care. At times it inadvertently squashes smaller creatures. It has a significant impact on its environment because it consumes great quantities of resources and moulds society's response to its vulnerable members. It is not noted for its subtlety of response to small differences or for its ease in steering. And it faces a crisis of adaption to change, against which its bulk and power may insulate until too late.

Many dinosaur tales are swapped when advocates gather. Here are three, to illustrate the setting in which GAO works.

One of Georgia's dinosaurs is its Department of Mental Health and Mental Retardation (DMH/MR). Since 1972 DMH/MR has had legislative mandate to provide all Georgians with community alternatives to institutionalisation. In 1982, the Mental Retardation Division of this beast consumed about \$75,718,000, allocating \$8.50 to institutionalisation for every dollar spent on community programmes. 3,500 people still have to live in institutions, though the department itself has recently identified 600 as currently ready to move into other types of accommodation. Throughout the state, only 300 people are supported in community residences. In short, everyone talks about a continuum of service; but hardly anyone flows through it. All the laws, plans and coordinating council minutes make cold comfort to those still waiting for a decent place to live.

The herd moves slowly even under the goad of law. In 1976, federal

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law said that each school district was responsible for providing a free and appropriate public education for all children, no matter what the nature or severity of their handicap. In 1981 there were still 600 school-age children included with adults in DMH/MR programmes because of an inter-agency coordination agreement ruled illegal in 1979. The use of fiscal sanctions, provided in law for recalcitrant education agencies, has never even been threatened. Passing progressive laws is not sufficient to ensure a good place to learn for everyone.

Many dinosaurs seem to have a learning disability. Georgia's Vocational Rehabilitation Agency heralded the implementation of a comprehensive appeal system – an unparalleled opportunity to identify and solve problems. In its first year of operation, a grand total of five appeals was processed; the agency was right, the client wrong one hundred per cent of the time. People and advocates who rely on the rehabilitation agency for employment training find the maze of forms, procedures and deadlines which protect their rights so confusing that they do not know how to complain.

Concentrate on changing the personal experience of a variety of individuals who rely on the service system by involving a variety of people one-to-one in their situations. This offers many options for solving problems, reframing situations to allow creative action, or, if other measures fail, compensating somewhat for the pain of unresolvable situations.

If you manage to approach people's problems from many angles expect some adverse reaction from service managers – especially those who think of their work in mechanical terms. An advocacy strategy that demands more varied responses from staff in a programme may seem to them inconsistent, unpredictable and uncomfortable. Workers may press the advocacy office to define itself more clearly – that is, to specify limits on what advocates may do. This should be an ongoing source of tension and negotiation between the programme and the service system.

Advocates and people with handicaps will need ongoing support in a cyclic process of social learning. They will have to cope with the contradictions in services, as experienced by people with handicaps. This can lead to expanded awareness of the needs of the person for whom the advocate is concerned, and of the realities of a heavily-serviced society. Heightened consciousness reframes situations and inspires renewed action by citizens. Action transforms situations, usually in unpredictable ways. The social learning cycle is renewed as action reveals new possibilities and contradictions.

Advocacy based on a social learning cycle includes routine problem solving, but goes beyond it. The social learning cycle changes the terms of the problem and reveals new options. It also calls for an ongoing relationship to contain the uncertainty it releases.

The social learning cycle is interrupted if an advocate takes a narrow view of the situation. Thus, the programme will have to support advocates and people with handicaps as they clarify the situations in which they are involved.

The most common way to simplify contradictions is to blame the victim. Things that seem wrong are explained away by claiming that the person's handicap justifies the abnormal situation: 'Retarded people don't mind living six people to a bedroom'.

It seems reasonable, but is frequently unhelpful, for advocates to assume that those who provide services know best. 'This seems unreasonable to me, but if qualified staff are doing it, it must be right'. Effective advocates are good at raising questions that challenge the usual perspectives and flatten hierarchies.

Advocates and people with handicaps gain support from others concerned with similar situations. The advocacy office may bring people together to explore themes like: 'Improving living arrangements'

and 'Better schooling', or provide training sessions, or put people in touch with professionals who volunteer their skills as advocate associates.

## Discovering new possibilities

No relationship can be described solely in terms of discrete activities and accomplishments. Within these limits, the following summarises some examples of action by citizen advocates.

Some citizen advocates simply – and importantly – provide a relationship with a person with a handicap. Some citizen advocates represent, or work with, the person for whom they are concerned to solve routine problems through routine bureaucratic means. Some citizen advocates adopt a role defined by the service system, for instance as trustee for a person's funds, or monitor of an individual programme planning process. Some citizen advocates seek legal definition of their relationship as adoptive parent or guardian. But no matter how a citizen advocate sees his role, there is a good chance that he will experience creative tension from time to time.

Becoming a citizen advocate does not give a person special access to the truth about a person with a handicap. It does provide a special perspective and platform for action: a citizen advocate only relates to one person, and can look at things from that person's point of view. Service workers spend almost all their time working with a person as one of a group. Even individual programme planning coordinators experience a person as a case-load. But a citizen advocate has many ways of spending time with the person he is concerned about: within the rules, he can take a person home, on a trip, or to a new place. Official staff are nearly always limited by routine.

A citizen advocate can take time and decide how much responsibility to take for a person with a handicap. As a volunteer the advocate can choose to accept formal responsibility for a person, bring the person back to the programme if time is short or problems become unmanageable, or even choose to terminate the relationship with the minimal cost to the advocate. Professional staff have a different accountability. They are more likely to be punished for failing to prevent a problem than rewarded for taking a risk. They may even be held responsible for what a citizen advocate does with a person.

Many citizen advocates lack the socialisation experience that shapes service workers' perceptions of a person with a handicap. They often lack information about a person's history and the official 'prognosis' for his growth. This naivety might lead a citizen advocate to over-estimate a person, but it can also be the basis for new expectations and experiences.

The different perspective a citizen advocate brings can form the basis for constructive action if others involved can negotiate through creative tension. Creative tensions spring from a new sense of potential; they are experienced by the person and his widening social circle – the citizen advocate and the support network, service workers and their organisations, family, and often other ordinary citizens – and their resolution evokes new learning through action.

Most citizen advocates lack expert knowledge of human services; thus, their new expectations often emerge from unique personal knowledge. With support to identify with the person's interests, getting to know a person with a handicap will probably lead to a new appreciation of that person's situation. This appreciation develops along two lines. The citizen advocate gets a feeling for the person's undeveloped potential. He may decide that the person could communicate better, be more mobile, learn more functional skills, be more productive, or relate to a greater number of ordinary settings and ordinary people. He may see a person

currently engaged in 'work activities' as a job holder or a person living in a residential centre as a potential friend, neighbour or member of the family.

The citizen advocate believes that what others accept as part of a person's situation is unacceptable. He may conclude that there is nothing inherent in a person's handicap that justifies poor food, insufficient choice of clothing, overcrowded living quarters, work without pay, denial of necessary services, inactivity, or being moved from place to place without being consulted.

These perceptions become the basis for action. At first, this seems to the citizen advocate a straightforward task of clear communication. Others need to be informed and, once informed, they will either help change things or offer better ideas to work on. But many straightforward tasks become convoluted because of the resistance the citizen advocate encounters. Resistance comes from outside – the 'dynamic conservatism' of service organisations – and from within, coming to terms with his own confusion and conflicts.

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## BOX 2

### EXAMPLES OF CITIZEN ADVOCACY ACTION

A citizen advocate who has known a man with mental retardation for more than five years recently concluded that the adult training centre was under-estimating his ability and failing to provide relevant training. The advocate informed himself about personalised vocational services, used his business contacts to find the man a job, and found help to teach the person to get to, and perform, his job competently. Despite staff scepticism that the man is 'too low-functioning to be employed', he has worked successfully for over a year, earns a minimum wage, and provides health insurance for himself and his elderly mother.

A citizen advocate met a ten-year-old boy who had been institutionalised for most of his life because of mental retardation and severe behavioural problems. The citizen advocate visited regularly and put pressure on staff to pay more attention to the boy. His grooming and speech improved and behavioural problems decreased. Far from satisfying the citizen advocate, these successes led him to decide that institutionalisation was inherently destructive. After personal struggle and working through a complicated tangle of procedures, he became the boy's adoptive father and offered him a home.

Over a year ago a citizen advocate became involved with a man who had been placed by the authorities in a 'board and care' home, in poor conditions. The advocate was initially appointed to manage the person's funds, as he was judged incapable of doing this for himself. As their relationship has developed, the advocate has helped the person find part-time work and move into much better accommodation. A dentist by profession, the advocate has also performed necessary dental work which the service system had neglected.\*

A citizen advocate has known and represented a child with mental retardation since 1978. When they met, the child was living in an institution. She felt he could live with a foster family. As the months passed, the citizen advocate knew that she would have

\*Most Americans rely on themselves, or on private insurance plans to meet their medical expenses. The examples just quoted show that the poor rely on a confused, limited patchwork of benefits.

to act if this was to happen, so she wrote letters, made telephone calls, and attended meetings persistently until he moved in with the foster family with whom he has lived since late 1979.

Another advocate has known a woman with mental and physical handicaps since 1979. The citizen advocate decided that an electric wheelchair would improve her mobility and her options. When she was told that the service system would not provide an appropriate chair, the citizen advocate raised funds through local civic organisations and bought it.

Another person, known to a citizen advocate for over a year, is a woman with mental retardation who lives in a private nursing home. The woman's sister, her legal guardian, has instructed the staff that she is forbidden to leave the building. The citizen advocate, who lives nearby, has observed the sister's rule and visits regularly, frequently bringing her other friends. The citizen advocate has decided that she now has a strong enough relationship to begin to negotiate new rules.

A citizen advocate met a young man of 18 with cerebral palsy who was living in a home for unmarried mothers, his fifteenth 'placement'. While pressing the services to find him somewhere more suitable to live, the citizen advocate came to know the young man and decided to invite him to share his home. They enjoy the arrangement and say they intend to live together 'long-term'.

A citizen advocate decided to buy batteries for a man with mental retardation living in a nursing home, so that the man can now listen to his portable radio.

A fifteen-year-old, who had lived in an institution for most of her life, was visited every week by the citizen advocate. Through family and other community contacts, the advocate developed a support network. This allowed the family to bring their daughter home.

A married couple met a young woman who had lived all her life with her elderly mother before her recent placement in a local group home. The young woman had led a very sheltered life and missed many of the ordinary experiences of growing up. The citizen advocates involve her in a wide variety of everyday activities: cooking meals, shopping, attending movies and concerts, and just visiting.

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## Meeting resistance

### Resistance from 'outside'

Sometimes a citizen advocate's sense of potential communicates itself easily to others. They come together to make the necessary changes and learn the implications of the new concept. For instance, adult training centre staff were certain that George could never be employed. George's citizen advocate felt that he could be. Institution staff were convinced that it was unrealistic to find Ken a foster home; his citizen advocate decided that one should be found. The 'board and care' home manager was sure that no one who did not benefit financially would bother with Tom's financial situation; his citizen advocate was willing to try.

But not all service workers are ready and able to cooperate with a citizen advocate's notion of what might be. Service workers who do not want to engage a creative tension control important resources which they can use to neutralise a citizen advocate's concern. Public faith in professionalised service is a very important resource, which can be used at little cost and often with powerful effect. 'We appreciate your interest. But we experts can explain why what you want is not really in the person's best interests.'

Most citizen advocates want to be seen as reasonable, well-mannered people. But even when a request for change is respectfully made, that request often challenges everyday assumptions and practices. Service workers may therefore interpret a citizen advocate's statements as 'aggressive', 'unconstructive', and 'confrontational'.

Red tape is always a reality; even under the best conditions, it can discourage a determined advocate. At worst, red tape can snarl up an effort to change things, and sap a citizen advocate's strength.

Service organisations are complex hierarchies and there can always be somebody 'up there' or 'down there' who will not cooperate.

Service programmes are responsible for many people, not just the person for whom the citizen advocate is concerned. It may be that investing in a change to benefit one person will disadvantage others, at least in the short run. Even when creative effort could improve things for everyone in a programme, service workers can react to a demand for change by appealing to the citizen advocate's sense of fairness. 'If we pay special attention to *your* request, the other people we serve won't get what they deserve.'

Staff who are cooperative can share their skills and lend their resources to solve the inevitable problems involved in change. Those who simply remain passive, and let problems develop, can almost guarantee that negative prophecies will be fulfilled.

Some citizen advocates are vulnerable in other ways. A college faculty member was told by her profession of complaints of 'unprofessional conduct' arising from her efforts to represent a handicapped person's interests as she saw them.

Many programmes control access to a person who is handicapped. If other means fail, a citizen advocate can be 'cut off'. This obstruction can be subtle, as when schedules are adjusted so that a person is 'unfortunately in speech therapy' when the advocate arrives. It can be more overt, as when a citizen advocate is barred from seeing a person 'because he is upset when the citizen advocate brings him back.' There have even been threats of arrest for trespass. Each of these controls has some legitimacy, and most service workers feel justified in using them instead of more open, time-consuming ways to deal with disagreement which might produce changes. Since many citizen advocates often feel insecure, they frequently withdraw for a time to reconsider their position when service workers under-value their perspectives on a person's situation.

## Resistance from 'inside'

Not all resistance is external. Creative tension is experienced by the citizen advocate as well. The advocate, too, has grown up in a culture that devalues people with handicaps and is as likely to confront prejudice within himself as among service workers or uninvolved fellow citizens.

Beyond prejudiced attitudes, involvement with people who have substantial handicaps raises powerful issues which are unresolved for most of us. Many of us live most of our lives out of contact with sustained suffering, real physical and emotional dependency, violence, and mortality. A citizen advocacy relationship can disorganise personal defences. Disorganisation may lead to personal growth or to withdrawal through rejecting the relationship ('I'm not strong enough or good enough to relate to her', or 'He really isn't worth my time', or 'I don't know what happened, I just got busy with other things and we drifted out of contact'). Disorganisation can also be avoided by denying a person's disability and its implications for others ('He really isn't handicapped at all'). Getting a proper sense of a real person with a handicap without retreat into denial of potential, or denial of inability, is difficult for most of us<sup>5</sup>.

Any relationship takes time and care. A relationship with a person who relies on a time-controlling service programme is often additionally complicated by the need to accommodate unusual schedules and rules. Involvement with most people who have handicaps means involvement with people who have professional status, and substantial

power over handicapped people's lives. It is challenging to establish a constructive relationship with people in authority who can assist or frustrate a citizen advocate's plans. A citizen advocate may find himself reacting to authority with submission, unquestioning dependency for guidance, or rejection out of hand. Some citizen advocates fear that taking positive action may lead those in authority to cut off the advocate's contact or even punish the handicapped person. Sorting out situations like this is more difficult when authority relationships are confused.

Then again, citizen advocates often face complex bureaucratic problems. They may find themselves struggling to make sense of confusing and contradictory regulations and procedures. As one citizen advocate said, 'I used to think my income tax forms were threatening until I got involved with Jane'. In many situations, it is hard for a citizen advocate to decide when to stop. If a particular problem isn't resolved at one level, a citizen advocate faces a choice. For instance, if ward-level staff turn down a request or fail to follow it through, will the citizen advocate take the matter up with people further up the hierarchy? If this is unsatisfactory, will the citizen advocate initiate a formal complaint or appeal? If mediation fails, will the citizen advocate go to court? When should a citizen advocate involve advocate associates or an attorney?

Where is compromise possible and when does compromise become a sellout of a person's rights and dignity?

Once one problem is resolved will a citizen advocate declare victory and take a well earned rest, or look for a new problem?

Many people with handicaps have limited ability to state their own preferences and desires. Sometimes this is because of inability to communicate effectively. Often, and more ambiguously, it stems from lack of experience of real alternatives. It can be hard for a citizen advocate to be confident that he is working for the best interests of a person who depends on him to interpret his or her wishes, or say what is best.

A growing number of citizen advocates conclude that the service system cannot meet a person's basic needs for a home and an occupation. This creates a new challenge – defining the limits of personal responsibility. Some citizen advocates, as we have seen, respond by going outside the system and sharing their own home or using their network of relationships to find a person a job. This creates new uncertainty. How long can this arrangement last? If it falls apart, who will pick up the pieces and what will be the consequences for the person with a handicap? Do I as a citizen advocate have a personal network which will support my commitment? Can I rely on the service system for support?

Citizen advocates who decide to do for a person with a handicap what might reasonably be expected of the service system may face a dilemma. 'If I find her a job or pay for her medical care or buy her basic clothing, I'm taking away a source of pressure to improve services. But if I don't, it looks like the service system will delay matters forever'.

None of these sources of tension is simply removed once and for all. There cannot be a citizen advocate's manual of answers. With the support of allies who listen, clarify, and respond to requests for joint action, each citizen advocate works out personal responses in the context of a unique relationship.

# Constructive action

Action by citizen advocates reorganises the situation surrounding a person with a handicap. This reorganisation may not lead directly to the expected result. A citizen advocate who sets out to get a person referred to a group home ends up sharing his own home. It may not even lead to a solution. A citizen advocate may decide that he can do no more – and no less – than spend time with a person who acts violently and actively rejects the demands of structured contact.

People with mental retardation in a community which supports citizen advocacy relationships can expect a variety of responses to their situation. Those who are part of a citizen advocacy relationship should experience

personal concern for their individual experience, which can lead others to notice, and pay more attention to, their uniqueness;  
respectful interaction – and often genuine affection – which can change other people's evaluation of them;  
individual experience of new places and people in company with someone who knows the way;  
positive contacts with a broader network of people which can provide support and an increased sense of personal security;  
active help in defining their personal interests and concerns, and representation to help solve problems in a way which will serve their interests;  
monitoring of the programmes handicapped persons rely on;  
(occasionally) direct care in the form of a job, a home and family life.

Not every relationship provides all of these benefits. And because citizen advocates are not service workers, benefits cannot be planned, managed and charted. The effects of citizen advocacy can best be measured in terms of the stories of citizen action generated by groups of advocates.<sup>6</sup>

Citizen advocacy is one way in which ordinary people, and people who rely on service programmes because of mental retardation, can work together to explore the meaning of citizenship. Not all the lessons of citizen advocacy action are easy. Not all of the stories have happy endings. But every person who becomes involved and acts can grow and promote growth.

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