

Self-advocacy in National Autistic Society and affiliated Society services for adults with autism: a change in the balance of power

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(Code of Practice Procedures, Document 2)

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Introduction

A belief in the inherent value of individuals with autism is fundamental to the provision of services for adults. One of the most effective ways of translating this belief into action is the promotion of self-advocacy as a means of enabling adults with autism to make choices affecting their lives. The purpose of this paper is to set out guidelines which will serve as a framework within which staff can develop programmes of self-advocacy for those in their care. In developing these programmes, staff will need to adapt them to the individuals' needs, their level of handicap and the settings in which self-advocacy is taking place. For this reason, this paper describes the principles of self-advocacy as they might apply to people with autism and suggests how self-advocacy might be adapted to meet the needs of adults with autism.

The implementation of self-advocacy for adults with autism requires a realistic assessment of the special nature of the handicap as it relates to the principles of self-advocacy. Successful self-advocacy is highly dependent upon the social and communication skills of the self-advocates, while the impairment of these skills is a primary component of the handicap of autism. Also fundamental to self-advocacy is the ability to make choices and reach decisions, processes which often produce profound anxiety in people with autism. These problems are often compounded by other impairments and may be accompanied by severe challenging behaviour. None of these factors, however, should discourage the implementation of self-advocacy for adults with autism - they simply confirm the need for its introduction to be supportive, careful and cautious, a step by step process requiring commitment and consistency from all concerned.

1. Principles of self-advocacy

1.1 What is self-advocacy?

The general principles of self-advocacy have been developed in the wider context of the normalisation of people with learning disabilities. The concept of self-advocacy

has grown in partnership with the concept of advocacy on their behalf. The two functions are distinct from each other but can overlap in the concept of citizen advocacy.

An advocate is defined in the Oxford English Dictionary as ‘one who pleads, intercedes or speaks for another’. The role of advocates on behalf of people with learning disabilities has normally been exercised by parents, social workers and voluntary organisations, a process which must continue if self-advocacy, which is one of the applications of the principles of advocacy, is to be enabled to flourish. Self-advocacy is defined as ‘people being their own advocates and speaking for themselves’ which implies making choices and decisions with the intent of producing change in one’s life in matters both of immediate concern and also those of broader concern which might affect one’s interests. It is the implication of action which distinguishes self-advocacy from self-expression. Any activity involving self-determination can be called self-advocacy. (Cooper and Hersov, 1988; Crawley, 1988.)

Self-advocacy is part of the developing awareness on the part of people with learning disabilities that they should be enabled to take a full and active part in all aspects of social life and that they have a right to services that meet their needs as they themselves define them. (Clare, 1990.)

Self-advocacy is not, of course, restricted to people with learning disabilities. Every adult has the right to choose what to speak out about, what changes they wish to make in their lives and what action they should take to bring those changes about. It is particularly important for people with learning disabilities, because until comparatively recently, they did not have opportunities to speak out effectively on their own behalf. It should be pointed out, however, that self-advocacy does not offer licence to people to say and do what they like. The same constraints apply to all self-advocates. These are the law, awareness of the rights of other people and good manners, as well as considerations of health, safety and self-preservation. (Cooper and Hersov, 1988.)

1.2 Changing the balance of power

The promotion of self-advocacy has drawn attention to the need to provide opportunities for self-determination, a concept which has brought about a radical reappraisal of the relationship between ‘carers’ and ‘clients’. The majority of people with learning disabilities have, for most of their lives, been under the influence and control of parents and professionals. Self-advocacy, because it is based on the concepts of independence, freedom of choice and group awareness, by its very nature changes this relationship. Staff and parents may feel under threat because their attitudes and behaviour may need to change, but also because of their understandable concerns regarding the risks which independent action might involve for the handicapped individual. If self-advocacy is to succeed, it is important for families and staff to understand what is involved and for those promoting it to seek their co-operation and support. (Cooper and Hersov, 1988.)

It should be said, however, that self-advocacy training does not assume that every adult with learning disabilities can, or should, make major decisions independently.

Few people do. Family, staff and friends may all play a part in helping the disabled person make choices which accord with their own desires and needs. (McTaggart and Gould, 1988.)

1.3 Self-Advocacy and the Principles of Normalisation

The philosophy of normalisation is based on the recognition that each person with learning disabilities is a unique individual with innate value. They have the same human value as anyone else in society and therefore have the same human rights. It follows that the attitudes and expectations applying to all people should be acknowledged as applying to them; they have the potential to develop and change, they have emotions, opinions and interests, and they have the right to dignity and self-respect. (Crawley, 1988.) Also, like other members of society, they have a right for others to recognise any difficulties they may have and respond to them.

The devaluation by society of people with learning disabilities has burdened them with an additional handicap. This handicap can be overcome by enabling them, in so far as possible, to have experiences which are generally valued in society and to enjoy the opportunities taken for granted by those who are not handicapped. The concepts of normalisation and self-advocacy both incorporate the principles that people with learning disabilities have a right to express their views on how they wish to live, have a right to comment on and to influence the services they receive and should be given the opportunity to learn useful and life-enhancing skills. Self-advocacy is an important vehicle for learning skills of communication, assertiveness and competence - skills which award value and status in society. (Williams and Shoultz, 1982.)

1.4 Rights and Responsibilities

Central to the concept of self-advocacy are rights and the exercise of rights - both human and legal. The former are incorporated in the UN Universal Declaration of Human Rights, the UN Declaration on the Rights of Mentally Retarded Persons and the UN Declaration on the Rights of Disabled Persons. Also important are MENCAP's STAMINA papers (Standards that are Minimally Acceptable), in particular, those applicable to residential services for adults. An objective of those concerned with the protection of human rights is to transform these into legal rights and codes of practice. Examples of these are the right of those with learning disabilities to receive services in 'the least restrictive environment appropriate to that particular person' (Jay Report on Mental Handicap Nursing and Care, 1979) and the right to Individual Programme Plans for how services will help to meet their needs. (See Note.) (Williams and Shoultz, 1982.)

The literature on training in self-advocacy includes helpful and easily understood information on basic human rights (for example, the right to life, the right to freedom and the right to make choices) as well as legal rights (education, financial benefits, the right to marry and the right to vote). Also included is information on safeguarding one's rights. (CMH, LASA 1, 1988.)

Awareness of one's responsibilities is also emphasized in the literature on training in self-advocacy; responsibility to oneself, to one's family and friends and one's community. (CMH, LASA 1, 1988.)

Note

The IPP is essentially a written programme of intervention and action which is developed by the people who are regularly involved with an individual client. It defines a continuum of development and, after an initial assessment which tries to determine the degree of the client's developmental deficits, outlines progressive steps which the client can take in each area of development and the supports which will be needed. The overall aim is to enable the client to keep moving towards more independent functioning; IPP's are reviewed regularly, at least once a year.

(Kings Fund Centre, An Ordinary Life. 1987.)

1.5 Forms of Self-Advocacy: Individual, Group and Citizen

Self-advocacy can be undertaken by individuals on their own behalf, or in groups of people who share similar attitudes and experiences. Group self-advocacy is not a substitute for individual self-advocacy. In fact, individual and group self-advocacy reinforce each other. Improvement of self-advocacy skills on an individual basis can benefit a self-advocacy group and the facilitation of group self-advocacy can have a beneficial effect on individual self-advocacy in providing support and learning opportunities. In order to be effective, self-advocacy groups need someone to serve as an advisor whose role is to facilitate and guide, but not to lead.

Essential to the concept of individual self-advocacy is the development of citizen advocacy, which is the linking of non-handicapped people to individuals with learning disabilities so that they can represent their interests as if they were their own. Ideally a citizen advocate is independent of any service directly affecting their partner in order to avoid a conflict of interests, as it may be necessary for them on occasion to challenge service providers. Again, in order to avoid conflict of interests, a citizen advocate should have no familial connection with the individual on whose behalf they are advocating. (Williams and Shoultz, 1982.)

1.6 Topics Discussed in Self-Advocacy Groups

Topics discussed in self-advocacy groups may cover a wide range. Research has shown that the majority of groups in adult training centres and social education centres focus their discussions on social and leisure activities, catering arrangements and fund-raising. A significant number discuss issues relating to mental handicap such as labels, attitudes, services, rights, harassment. Other topics discussed are: discipline, rules and behaviour, the improvement of centre facilities, issues concerning staff such as staffing levels, staff attitudes, complaints about staff and issues concerning the self-advocates' working conditions and future employment. Some groups also discuss centre and county policies and wider general issues such as current affairs, religion and politics. (Crawley, 1988.)

2. Implementation

Appropriate staff attitudes are a basic pre-condition of the development of self-advocacy in services for adults with autism. These include a belief in the inherent value of those in their care and their right to self-determination within their capabilities, as well as their right to express their views on the services they receive and to have these views taken into account.

In theory, both individual and group self-advocacy are self-generated. In practice, however, because of the nature of the handicap of autism, staff must play an active role in the promotion of self-advocacy in services for adults with autism.

In order to equip themselves to implement self-advocacy, staff should familiarise themselves with the principles and practice of self-advocacy in its various forms by joining training courses on the subject and by reading the staff training literature and self-advocacy manuals now available. (Cooper and Hersov, *We Can Change The Future* and CMH, *Learning About Self-Advocacy*. For further details and more suggestions, see References and Other Useful Reading.) To ensure that self-advocacy can be practised with authenticity in services for people with autism, staff must also learn about the nature of the handicap by supplementing careful observation and care experience with attendance at training courses organized by the NAS and reading the literature available. In addition, they must also acquire a profound knowledge of the personalities of the individuals in their care. They will, therefore wish, if possible, to consult their families in order to discover their life histories and the social and cultural influences which have shaped their lives, as well as their interests and their preferences in such things as diet and leisure pursuits. (See Parent and Professional Partnership.)

Because of the many problems which need to be overcome in introducing self-advocacy to people with autism and the risks of failure if adequate groundwork is not laid, staff should introduce it gradually and with caution.

2.1 Component Skills of Self-Advocacy

The skills which should be developed for effective self-advocacy are communication and social skills, the ability to make decisions and the self-confidence and assertiveness both to declare one's goals and to develop whatever additional skills are necessary in order to achieve them. The progress from choice to action requires the ability to know what goals are possible, to make decisions about what goals to pursue, to know when and where to ask for help, to act upon the choices made, to solve problems when they arise and to assess progress. In order to make realistic decisions, it is often necessary for self-advocates first of all to decide what help and/or information is needed and to find out where these can be obtained. As people become more skilled in self-advocacy and the decision-making process, they increase their awareness of their rights and responsibilities. In addition to learning the skills directly bearing on self-advocacy, self-advocates must also learn to cope with frustration and disappointment if it is not possible for them to get what they want. (Cooper and Hersov, 1988.)

It might be said that the disabilities of which autism is comprised - impairment of social interaction and communication skills - as well as difficulties in making choices and lack of motivation - are virtually incompatible with the practice of self-advocacy.

However, all people with autism, no matter how handicapped, can indicate needs, preferences, displeasure and choice. Because the services for adults with autism are all directed towards enabling those in their care to realise their potential as members of society by teaching them the skills which will enable them to do so, the promotion of self-advocacy should be considered part of this process.

The set of five booklets entitled *Learning about Self-Advocacy* published by CMH is a clear introduction to self-advocacy, designed to be read both by people with learning disabilities and those interested in assisting them to become self-advocates. There are also classes in Adult Education Institutes and Further Education Colleges which are intended to enable people with learning disabilities to learn the skills necessary for self-advocacy. Staff might wish to consider whether it would be helpful to encourage those in their care to take advantage of these resources.

2.2 Adaptation of the Concept of Rights

In implementing the practice of self-advocacy in services for adults with autism, it is helpful for staff to understand how the concept of rights can be adapted so as to be more accessible to them. It must, in the first place, be recognised that people with autism have the same rights as all people of their chronological age - the only difference being in their ability to exercise these rights responsibly and with an understanding of their implications. One means of bringing the concept of rights within the range of understanding of people with autism, is to draft a Bill of Rights applicable to their daily lives. These can be set out as part of the statement of the philosophy of an establishment by self-advocacy groups with the help of advisors. An example of a Bill of Rights for individuals with autism is as follows:

If I could speak, I would say these things about myself:

- I have a right to my own dignity
- Even if I do not speak, I still have the right to be heard
- I have a right to make mistakes
- I have a right to be told if I am not doing things properly and a right to receive guidance
- I have a right to be secure and to be cared for
- I have a right to take risks
- I have a right to be taught
- I have a right to a sense of duty
- I have a right to care about others, but I need a chance to show that I care
- I have a right to make friendships
- I have a right to have fun
- If I have a family, they have a right to know what is happening to me
- I have a right to have staff in my home who know what they are doing and care about the way they do it
- I have a right to be me

(Based on a Bill of Rights for a resident of Whitegates Community, Worksop, Nottinghamshire.)

As people become more skilled in the practice of self-advocacy, they increase their awareness of their rights and responsibilities.

2.3 Self-Advocates and Service Provision

A person with learning disabilities has the right to participate in the development of their Individual Programme Plan, together with professional workers, representatives of services familiar with their needs, and their interested family member or guardian. They also have the right to participate in any case conferences and annual reviews in which their care may be discussed. Staff should, however, be aware that despite the existence of these rights, owing to the dearth of appropriate service provision, very few people with autism have been given the opportunity to choose where or with whom they live and, in practice, they have no power or influence over the services affecting them unless staff choose to give it to them.

It should be pointed out, however, that although people with autism have the right to participate in discussions affecting their future, staff may consider that such participation is not in the interest of individuals who react with high levels of anxiety when they hear themselves being discussed. In these cases, it may be preferable to discuss the review beforehand with the individuals concerned on an informal basis, emphasizing the positive aspects, and minimising those which might produce anxiety. The results of the review could be communicated to them afterwards in the same positive and reassuring way. If it is not considered to be in an individual's interests to attend the review, they should, if possible, be represented by a citizen advocate. In all aspects of the annual review, the personality and the level of understanding of the person with autism should be borne in mind. There is no point in raising issues with them if the process of doing so is likely to produce anxiety or distress which cannot quickly be dispelled.

2.4 The Implementation of Individual Self-Advocacy

Individual self-advocacy should be promoted across the whole spectrum of people with autism, from those who are the most severely dependent and those presenting with severely challenging behaviour to those who are capable of virtually independent living, and it should be integrated into all levels of interaction. It is an important means whereby people with autism can achieve self-determination within their capabilities, and it must be carefully adapted to take account of their special characteristics. Because of the nature of autism and the severity of the handicapping features, individual self-advocacy may be the only realistic form of self-advocacy which can be practised in the majority of services for adults with autism.

Individual, as well as group self-advocacy, must be based on certain assumptions - a recognition of rights (see Sections 1.4 and 2.2), including the right to speak up for oneself and the right to make choices with the expectation that these will be taken into account by carers and service providers. These concepts are summarised in the CMH manual (CMH, LASA 1, 1988):

'Self-advocacy means speaking up for yourself so that your life goes the way **you** want it to.

Speaking up means telling other people what you think, how you feel and what matters to you.

Everyone should speak up:

- ** When they think something is important
- ** When they want something to happen
- ** When they want something to stop happening
- ** When decisions are being made about their life

Sometimes other people don't ask us for our views on things that concern us.

Self-advocacy means speaking up even if you are not asked what you think.

Your family, your friends, the people who work around you and the rest of the community, will not know your point of view unless you speak up and tell them what you think.

No-one can read your mind!

People with autism, because of their difficulty in understanding concepts, may find it difficult to understand one of the important components of self-advocacy, a sense of responsibility for self and others (family, friends, those with whom one lives and works), but staff should make them aware of this in so far as it is possible, by practical means of encouraging self-care, sharing in chores and maintaining contact with family. (See Parent and Professional Partnership, Section 10.)

2.5 Staff as Enablers of Individual Self-Advocacy

The role of staff as enablers of individual self-advocacy should be regarded as an integral part of their care responsibilities. Their aim is to guide those in their care towards self-determination, gradually extending the setting in which self-advocacy can take place and increasing the range of options which can be considered. This enabling role involves the provision of an environment offering opportunities for choice and within which the expression of choice is encouraged. It also involves a commitment to helping those in their care to develop the skills of communication, decision-making and social interaction necessary for effective self-advocacy.

Because people with autism often fail to develop a proficiency in these skills, the enabling role of staff involves functioning not only as attentive listeners, but also as skilled interpreters. They need to be able to interpret all the means whereby those in their care may indicate their wishes, either directly or indirectly, from speech and signing, both of which means of communication are likely to be used idiosyncratically - to physical signs such as facial expression, gaze avoidance and withdrawal or diversionary tactics such as aggressive, obsessional or inappropriate behaviour. Family members are often a good source of information on how to discover an individual's wishes. In observing those in their care, staff may need to avoid direct

eye contact with individuals who find this distressing. They should also be aware that facial expression of a person with autism may be misleading - an angry frown may accompany an activity which the individual later recalls with pleasure.

The ultimate objective of the staff's enabling role should be the empowerment of those in their care to take charge of their own lives within their capabilities; in other words, the promotion of self-advocacy which will lead to action or changes desired by the self-advocates. Accordingly, they will need to help the self-advocates to take the practical measures to bring about the desired objectives, if necessary enlisting the co-operation of managers or service providers. Staff, however, must constantly be aware of the constraints which must apply - for example, common-sense, social acceptability and health and safety, so that they do not raise false hopes in the self-advocates. They must also be prepared to deal with the anger and frustration expressed if the self-advocates have difficulty in understanding these constraints, which most members of society take for granted.

Because many people with autism may never be able to function as self-advocates independently, staff may, on a day-to-day basis, need to serve as advocates for those in their care, always guarding against imposing their own views on the decision-making process of those they represent. Staff acting in this advocacy role should, if possible, have regular periodic assistance from independent citizen advocates. The concept of citizen advocacy, as with other aspects of self-advocacy, needs to be adapted to the special handicaps of people with autism.

2.6 Citizen Advocacy

2.6.1 Practice of Citizen Advocacy

In practice, parents have acted as advocates for the large majority of individuals with autism, first in obtaining diagnosis, then in obtaining specialised educational services and later in securing day care, training and employment and often, residential care. Many parents have been fortunate in finding professional partners in their advocacy on behalf of their children among doctors, psychologists, teachers and social workers as well as NAS and affiliated Society executive and care staff. This type of advocacy, with the goal of securing the provision of services, overlaps with, but is not identical to, self-advocacy or citizen advocacy. The service structure is vitally important in determining whether and how these types of advocacy can flourish.

To serve as a facilitator of self-advocacy for a person with autism, - that is as a citizen advocate - it is necessary to have a willingness to learn about the handicap of autism, as well as a personal knowledge of the individual on whose behalf one is acting. In order to function effectively, the citizen advocate must expend time and effort in getting to know their partner well so that they can speak and act on their behalf with confidence that they are genuinely serving their interests. They may need to participate in their care and to share experiences with them over a period of time. Because of the profound communication difficulties of people with autism, it will be necessary not only to learn to frame questions in order to elicit valid replies, but also to 'read' non-verbal signals and clues. In the end, it may be necessary to make decisions on behalf of a person in the hope that one's interpretations are correct. Of course, a citizen advocate will also wish to consult staff and parents in order to learn

their techniques of discovering how an individual's wishes may be ascertained. It is also helpful to know the previous history of an individual and to learn something about the life-style of their family, their cultural background and interests, because the family member with autism is often more comfortable with the customs, practice, habits, diet and leisure pursuits with which they have become familiar when growing up. Family interests and influences are neither an infallible nor an exclusive guide. They should, however, be taken into account by citizen advocates as one of the sources of learning about the interests and preferences of their partners and they might reveal a range of activities in which their partners might wish to participate, if given the opportunity.

2.6.2 Finding Potential Citizen Advocates

The citizen advocate must have the motivation and the time to serve in this capacity on a voluntary basis. They need strong motivation to become involved with a person with autism who may be unable to return affection and whose behaviour may require considerable ingenuity, and even strength to control.

It is hoped that as services for people with autism increase, and as more people benefit from these services or are associated with them as staff or in a voluntary capacity, there will be a growing pool of individuals who might be called upon to act as citizen advocates. Potential citizen advocates might be found among the following:

- ** Professional workers independent of the service caring for the person on whose behalf they will advocate.
- ** Family services committees or advocacy committees.
- ** Members of voluntary organisations in the community.
- ** People in the community who become acquainted with autism through outreach by the caring establishment.
- ** Parents or other relatives of people with autism willing to advocate for other people's family members with autism, perhaps on a 'cross-over' basis.
- ** 'Befrienders'. People participating in 'befriending schemes' might bring with them the additional advantages both of being within the age range of the individuals on whose behalf they would advocate, and of possibly sharing interests with them.
- ** National Citizen Advocacy.

Staff and family services should make every effort to initiate and maintain contacts with potential citizen advocates. They should seek out or actively promote 'befriending schemes' which might produce people who would be willing to serve in this capacity. The selection of citizen advocates should be undertaken with care and should involve both the staff caring for the individual concerned and interested family members. Once the citizen advocate is selected and has indicated a willingness to serve in this capacity, it is important for staff and family members to maintain contact and to consult with him/her on issues affecting self-advocacy. The citizen advocate

should also be invited to participate in case conferences, the formal annual review and any informal review of their partner's care, progress and activities. A citizen advocate can play an important part in averting confrontation between service providers and families. The role of citizen advocates can be stressful. It is therefore advisable for them to receive training and support from an organisation such as National Citizen Advocacy.

In the meantime, until citizen advocates can be found, parents and staff will need to serve in partnership to advocate for individuals who need help in self-advocacy. This partnership might be facilitated by devoting periodic reviews of each individual in an establishment, additional to the formal review undertaken to satisfy statutory requirements, to developing a body of knowledge of how his or her choices and preferences can be discovered and made effective and to monitor the progress of the individual in advocating for themselves.

In some instances, it may be found that a more verbal adult with autism takes on the role of advocating for another or others less skilled in communication. This should always be nurtured and encouraged, providing that it is truly in the interests of the individual or individuals being advocated for.

2.7 Group Self-Advocacy

Group self-advocacy and individual self-advocacy, as mentioned previously, reinforce each other. Group self-advocacy provides a setting in which communication skills and social interaction can be practised; it provides peer models and peer support in decision-making; it creates opportunities for practising leadership and taking responsibility and it also creates opportunities for learning group process skills which may lead to effective participation in other group or community-based activities. (McTaggart & Gould, 1988.)

A very important aspect of group self-advocacy, if not the most important, is that it may be able to influence the delivery and structure of services. Some self-advocacy groups are formed by the election of representatives. Others include all the members of a particular residential or day care unit.

2.7.1 Forms of Group Self-Advocacy

Four types of self-advocacy groups for people with learning disabilities have been identified, each model having its advantages and disadvantages:

(i) The 'autonomous' model is a group independent in time, organisation and finance from professional services or parent bodies. The primary advantage of this type of self-advocacy is that its members are free from any conflict of interests with parents or professionals. The self-advocates can express opinions about services without fear of embarrassment or retaliation. On the other hand, the members of the group must learn to take responsibility for its support, decisions and actions from the beginning. Provided they are able to accept these responsibilities, the members may be more committed to it than members of other types of self-advocacy groups. An autonomous group usually draws its membership from a range of services and settings with the advantage that it can share in a breadth of views and experiences. It is therefore more

likely than other types of groups to escape the parochial concerns of particular services and to be able to campaign for self-advocacy on broader issues affecting those with learning disabilities. Because of its independence, it is particularly important for this type of group to have the services of an independent advisor.

An example of this type of group is People First of the London Boroughs.

(ii) The 'divisional' model is a self-advocacy group formed as a special section of an existing parent or professional group. The chief advantage of this model is that the larger organisation usually provides the resources for the group such as a place to meet, use of telephones, stationery, photocopying and sometimes finance. This type of group provides the self-advocates with an opportunity to educate parents and professionals, and to affect the larger organisation. The main disadvantage is that if a disagreement arises between the self-advocacy group and the organisation, the latter can either ignore or disband it.

An example of this model is the Participation Forum, a section of the Metropolitan Division of MENCAP.

(iii) The 'service' system model, a group which is part of the service system, is based where people with learning disabilities live or work. The advantages of this model are that there can be provision of the same or similar resources as those provided by the divisional model. There are no transport problems and the group can meet when they would normally be on site. As the group is based within the service, members can focus their attention directly on service issues. However, the potential for conflict of interests is greatest for service groups. This can result either in disbandment or in being reduced to a token gesture towards self-advocacy. Examples of this model are the groups based in both day and residential services. The majority of the self-advocacy groups in Great Britain are in service settings.

(iv) The 'coalition' model is based on the bringing together of people with different types of disabilities to form one self-advocacy group. The size and diversity of the group bring with them the advantages of legitimacy, increased political power and a greater ability to generate funds. On the other hand, those with learning disabilities are disadvantaged in that they can become restricted in the extent of their involvement or dominated by more articulate members. An example of this group is the Massachusetts Coalition of Citizens with Disabilities.

(This section is taken in its entirety from Crawley, 1988 - based on a training manual prepared by P. Browning and C. Rhoades following the 1984 International People First Conference.)

2.7.2 Forms of Group Self-Advocacy Accessible to People with Autism

The forms of group self-advocacy accessible to people with autism are the 'autonomous' model and the 'service system' model. The 'divisional' model does not yet exist for people with autism, but may, in time, be developed by the NAS or its affiliated Societies. Certain obvious difficulties stand in the way of this development; the very small minority of people with autism who would be interested in participating in such a forum, the problems involved in making it a representative

body, and problems of transport and escort. The 'coalition' model does not yet exist in the UK and, if it did, the people with autism would be particularly disadvantaged as participants. On the other hand, it is just conceivable that a person with autism might wish to participate in People First, the 'autonomous' model. Any person with autism who is capable of understanding the principles of self-advocacy for people with learning disabilities and who could find fulfilment in participating in the broader issues addressed by People First groups, should be encouraged to join one of them. (See Note.) The large majority of people with autism are unlikely, because of their impairment of social interaction and awareness, to have any interest in participating in group self-advocacy unless they can be persuaded to do so in a familiar setting such as their workplace or residential hostel. Depending upon the degree of handicap of their residents, staff in establishments for adults with autism might wish to consider setting up 'service system' self-advocacy groups. If such groups were to be formed, because of the small scale of some of the establishments involved and the fact that the larger establishments are divided into smaller units, all residents could be enabled to participate directly rather than through elected representatives which might, in any case, be a concept which most of them would find difficult to comprehend. It might enhance communication skills in both writing and speaking if a number of residents could be taught to manage the procedures of electing officers of their group, writing agenda, and recording the proceedings of the meeting.

Note

A number of People First groups are not 'autonomous' but are service based.

2.8 Staff as Enablers of Group Self-Advocacy

2.8.1 Steps in Setting Up a Group

The role of staff as enablers, encompasses group as well as individual self-advocacy. There are significant factors which might discourage the promotion of group self-advocacy in services for people with autism; the nature of the handicap and the fact that people with widely varying degrees of handicap may be cared for in one establishment. However, staff in the NAS and affiliated Society services will wish to consider seriously whether the promotion of group self-advocacy is feasible in the setting in which they are working. If it is considered feasible, it is likely that in order to be successful the number in the group should not exceed six or seven because of the handicaps of communication and social interaction, particularly with their own peer group, characteristic of people with autism. Staff members wishing to promote group self-advocacy will need to follow a stage by stage process, the timing to be determined by the level of understanding and co-operation of the participants. These stages, inevitably, overlap with each other and are as follows:

- ** Encourage group awareness

- ** Encourage members of the group to contribute

- ** Decide on the role of the group

- ** Decide on the structure of the group

**** Train group members to take control**

**** Decide on appropriate staff roles**

Staff may find that it is advisable for two of them to act together in establishing the group.

Throughout all these stages staff will wish to bear in mind that, in order to be successful, group self-advocacy should grow organically, so that it is always consonant with the level of understanding and capabilities of the group members. In their role as enablers, which denotes a commitment to helping those in their care to develop self-advocacy skills, staff will wish to extend this commitment to helping them to develop the interactive skills which could lead to the formation of a self-advocacy group.

Encouraging group awareness

If the members of the group with which the staff members are working have been living or working together for a period of time, it is easier to establish group awareness than if the members are new to each other. If the latter, it may be necessary as is so often the case when working with people with autism, to begin with basic simple steps, such as persuading pairs of individuals to interact with each other. Ingenuity must be employed in order to bring this about, such as getting them to walk side by side on outings, to play games together, or to share chores such as washing-up together. Gradually the interacting pairs can be combined with each other in the hope, eventually, of widening the circle to include the whole self-advocacy group. Even if a group has been living or working together for some time and its members have become used to sharing household chores, work or leisure activities, in order for them to function as a self-advocacy group, peer interaction should be developed to the point where, without prompting, they direct questions and comments to each other instead of to or through staff and they can turn to their peer group for support and help, at least some of the time.

It may be that staff consider that it is not feasible for the group to progress from group awareness to formal group self-advocacy. Even so, group awareness can provide a valid setting for group self-advocacy on an informal basis and staff can introduce for discussion and decision topics affecting group members' lives within the service and, depending on the success of this approach, gradually broaden the complexity and number of topics discussed.

Encouraging members of the group to contribute

The next stage is to transform group awareness to participation in group discussion with the expectation that each member will contribute their views either verbally or non-verbally, on what is important to them and that their contributions will be valued, even if they appear to be irrelevant or of no particular interest to the other members of the group. Perhaps for some of the group members such contributions may need to be prompted by staff on a very basic level, for example, by providing lists of options, possibly accompanied by pictures or drawings, relating to concerns affecting their daily lives such as food, activities or outings. These measures may need to be

undertaken repeatedly until group members learn to initiate topics of interest to them which might, in due course, become the basis for group discussions.

Deciding on the role of the group

If, at this stage, staff members become confident that the group dynamics are well enough established to sustain a formal self-advocacy group, they will need to help to determine what the role of the group should be. The setting up of a self-advocacy group is, in itself, a recognition that the group's concerns about the establishment in which they lead their lives should be discussed freely and deserve to be taken seriously. Its role could be significant in affecting policy in a hostel for more able people with autism, but in establishments for the less able it would, initially at least, be confined to discussions and decisions about social and leisure activities, holidays and amenities, although its discussions might become more comprehensive as the group gained experience. Areas which cannot be changed in the light of group discussion should be decided from the outset.

Deciding on the structure of the group

Before the first formal meeting, staff will need to decide where meetings will take place, the timing and length of meetings, how the group might realistically be structured (officers and constitution), how an advisor should be chosen and how progress will be monitored.

Training group members to take control

In the beginning, a staff member will need to call the meeting to order, ensure that each member participates and set the agenda. If the group members clearly show no motivation to progress to the stage where they are able to control the meetings, staff will need to continue in this leadership role. If, on the other hand, group members can be motivated to take control of the group's activities, staff will need to teach them how to go about it, explaining the role of officers and how the group should function. At this stage, the CMH *Learning About Self-Advocacy* manuals could be very helpful, or staff may wish to get group members to join with them in writing their own manual appropriate to their particular circumstances.

Deciding on appropriate staff roles

If a group is able to take over control of its own activities, the staff involved in setting it up will need to change their roles to facilitators or advisors rather than leaders. If two staff are involved, it may be possible for one of them to cease their connection with the group and the other to act in the role of advisor in co-operation with an advisor who is independent of the establishment. The transition to a different type of role may be difficult but should be attempted if the group is to function as a self-advocacy group in the true sense of the term.

2.8.2 Action Following Group Meetings

Both group and individual self-advocacy carry the implication that, within the prevailing constraints, action will follow the choices or decisions made by the self-

advocates. Therefore staff need to ensure that the decisions of group meetings are recorded and communicated by a representative of the group to staff members or members of the management team whose areas of responsibility are relevant to the issues discussed. It is then their duty to respond.

2.9 Advisors

2.9.1 Role of Advisors

An advisor to a group may be any person - staff member or volunteer - who is sympathetic to the concepts of self-advocacy. It is recommended that a group have two advisors to share the work and support each other, particularly if one is a member of staff who may be exposed to a conflict of interests between the management and self-advocates. The role of advisor, which is critical to the outcome of a self-advocacy group, is to support, encourage, facilitate and guide, but not to lead. They help the group members to learn the skills necessary for self-advocacy and they foster their self-confidence. A successful advisor is someone who listens carefully, helps when necessary, tries to understand what the self-advocates feel and enables them to indicate what they feel. They also help to ensure that the expectations of the group are realistic. They advise on how to run meetings and, depending upon the abilities and expectations of group members, they may help them to write letters and advise on raising and managing money. They may also help members in obtaining information relevant to their deliberations from libraries, travel centres, legal advice centres, Citizens Advice Bureaux and other organisations. The role of an advisor is never static; they must be willing to review continually their level of involvement and to decrease it as the members of the group develop their self-advocacy skills. It is important, if an advisor is to be effective, for them to be able to continue in this role with the same group for some time. (Wertheimer, 1987; Crawley, 1988; CMH, LASA 2, 1988.)

2.9.2 Finding Advisors

It is generally agreed that advisors to service-centred self-advocacy groups should, if possible, not be connected with the service responsible for the group members, in order to avoid a conflict of interests. On the other hand, it might be very difficult to find people to act as advisors and who understand autism sufficiently to be effective, who are not employed by the establishment. It might be possible to recruit advisors from public sector services, the staff of which are familiar with autism, from other NAS or affiliated Society establishments in the area, or from Family Services Committees concerned with people with autism. It is usually recommended that there be two advisors so that they can support each other, in which case, one might be an employee of the establishment and the other independent of it. It is also recommended that advisors have independently-based support groups, as the role of advisor is not an easy one. In discussing the choice of advisors, the manuals on group self-advocacy assume that the choice would be made by the group members themselves. However, in view of the special nature of the handicap of autism and the comparatively few people who would be either able or willing to serve as advisors for self-advocacy groups of adults with autism, it is unlikely that this would be a realistic possibility.

2.10 Managing Group Self-Advocacy Meetings

2.10.1 Importance of Involving All the Members of the Group

Many establishments set up for adults with autism include those of a wide range of capabilities from the fairly able to those who are highly dependent. In addition, some may be mute and some may exhibit challenging behaviour. If, despite these difficulties, it is considered feasible to set up a self-advocacy group, it is important to bear in mind that the ultimate objective should be that all, even the most handicapped, should be enabled to take part. The CMH manuals, *Learning About Self-Advocacy*, include practical suggestions for encouraging the participation of all members of a group, communicating (including use of body language and signing), making the most of everyone's skills, listening and taking turns - all with the purpose of drawing people into group self-advocacy. If, however, staff know in advance that a certain individual will be persistently disruptive to the group, they will need to work out positive ways of dealing with this, although at times it may be necessary to make alternative arrangements in the interests of other group members. For example, a member of the staff could talk separately with the individual concerned and bring forward their contribution to the group meeting. (Cooper and Hersov, 1988; CMH, LASA 1 & 2, 1988.)

2.10.2 Meeting Procedures and Activities

The CMH manuals also give clear advice on procedures for election of officers (chairperson, deputy chairperson, secretary, treasurer), the purpose and content of agenda, minute-writing, correspondence, handling money and voting for officers and on issues. Further advice is given on how to produce a newsletter, organise a conference, speak in public and how to obtain publicity, find and collect useful information on leisure activities, adult education institutes and further education colleges, transport, rights and legal matters. (CMH, LASA 2 & 3, 1988.)

It should be pointed out that in services for people with autism, the use of tape to record the main issues raised and decisions made at a meeting may be found to be more appropriate than written minutes.

2.10.3 Rules and Constitutions

It may be necessary for self-advocacy groups, whatever form they may take, to establish rules at the outset in order to ensure that each participant may be confident that they will be treated with respect by other members of the group. One method of establishing rules is for the group leader to propose that members make up and agree to some rules for how they will act towards each other, perhaps giving some examples. Once some concepts have been agreed, they can be reworded as rules and written down. Members could then be asked to acknowledge agreement to following the rules. The consequences of violating the rules must also be agreed. (McTaggart and Gould, 1988.)

A self-advocacy group may develop to the point where the members wish to have a written constitution. The CMH manual includes a useful chapter on the content and purpose of a constitution summarised as follows:

'A constitution is a list of:

- things the group wants to achieve
- the kind of things the group will do
- the rules of the group
- the jobs of particular people

The constitution helps:

- to explain what the group is for and what it does
- to make sure that the members agree with this
- to make sure people in the group know what jobs to do
- to make meetings run smoothly

The constitution should contain a list of things the group believes are important.'

(CMH, LASA 3, 1988.)

2.10.4 Practical Measures for Maintaining the Momentum of a Service-Based Self-Advocacy Group

The momentum of a service-based self-advocacy group is largely dependent on the skills - mainly communication skills - and enthusiasm of the participants. The survey by Bronach Crawley of the development of self-advocacy in services for people with learning disabilities concluded that groups failed largely because of the lack of skills of the self-advocates, closely followed by 'staff-related problems' which included the inability of advisors to help a group to overcome its problems, the lack of support from staff and managers and staff changes. (Crawley, 1988.)

Those involved in setting up a group need to be aware of the factors which might lead to failure and also of the techniques for the maintenance of momentum. For example, priority needs to be accorded to self-advocacy sessions. This principle is particularly important in service settings where, unless priority is agreed by management, the group's meetings might be cut short or cancelled to make way for other activities, thus losing value in the eyes of the participants. Meetings should occur at a regularly scheduled time and place and for a set period, and participants should be released from other activities to attend them. Participation should always be voluntary. Staff not participating should neither interrupt nor attend meetings without the group's permission. Group decisions should be taken seriously, and, if possible, be followed by a positive response. (McTaggart and Gould, 1988.)

3. The characteristics of autism as they relate to self-advocacy

In addressing the problems of the adaptation of the principles and practice of self-advocacy to people with autism, the handicaps associated with autism have been referred to in the context of the implementation of self-advocacy in its various forms. At the risk of repetition of some of the ideas discussed in earlier sections, the following sections of this paper focus attention on the disabilities of people with autism, discussing how they might affect the implementation of self-advocacy and offering some suggestions on how they might be circumvented.

3.1 Problems of Communication

One of the basic components of self-advocacy is communication skills, the lack of which is a fundamental indicator of autism. This underlies the need for citizen advocates, staff and advisors to cultivate their powers of observation so that they can interpret the means whereby individuals with autism indicate their needs, desires and preferences. Both day and residential care staff will wish to give constant attention to developing communication skills in those in their care by encouraging those who are able to talk to express their wishes and feelings by use of language, and those who are non-verbal, to express themselves by signing. Writing skills should also be encouraged as an adjunct to daily living, like writing diaries, shopping lists and letters to the family.

3.2 Resistance to Change and Problems of Decision-Making

Another skill which is considered to be a basic component of self-advocacy, is decision-making, a process which can be difficult for those with autism. They are self-directed in their attachment to routines and obsessions, but they have difficulty not only in the communication of choice, but in actually making choices when being presented with them by someone else. In fact, a request to make a decision may raise their anxiety level to such an extent that they resort to diversionary behaviour, such as temper tantrums or a retreat into obsessions. This anxiety arises perhaps because choice and change are so often closely related and people with autism often find change threatening, particularly in a familiar environment, preferring to adhere to habitual routines in order to maintain predictability. Therefore, even changes desired by the self-advocates may need to be introduced with caution.

In order to enable those in their care to make meaningful choices and to familiarise them with the process so that it is transformed from a threat to a habit, staff need to introduce the concept by means of easy steps, at first setting out simple concrete choices restricted to only two alternatives. For example, with clothing they can lay out two shirts, gradually moving towards setting out two outfits appropriate to the season from which a choice can be made from each category of clothing. Later a greater breadth of choice can be encouraged, if necessary, limiting it by putting away clothes not appropriate to the season. The use of photographs or drawings can be a helpful means of presenting choices, particularly of menus and activities.

Staff are aware that to offer a new activity to a person with autism often results in a negative response ('Like do nothing best') unless they word their offer in such a way as to preclude the negative response, in other words 'Come on, we're going dancing', not 'Do you want to go dancing?', which will invite the answer 'No'. Part of the process of normalisation is gradually to offer people with autism a range of experiences and options. It will become clear over time where their preferences and interests lie, and skilled staff can then distinguish between true preference ('Don't want to go swimming today') which should be respected, and 'autistic negativism' which should be discouraged.

Another characteristic reaction is to reply affirmatively to two questions when the actions involved are mutually exclusive. ('Do you want to go to church tomorrow morning?' - 'Yes'. 'Do you want to go to the club tomorrow morning?' - 'Yes'.) Staff need to learn to avoid open-ended questions and to word them in such a way as to

ensure that the answer is a specific noun or verb, not a positive or negative. ('Do you want to go to church or to the club tomorrow morning?')

3.3 Obsessional Behaviour

One of the main tasks of staff caring for adults with autism is the management of obsessional behaviour. Although obsessions can be used constructively as a means of motivating learning, if unchecked, they can become a source of anxiety and a barricade against learning the skills and competence which can enhance the individual's quality of life. In implementing self-advocacy staff need to enable people with autism to use their obsessions constructively, redirect them, or hold them in check in the interests of normalisation.

3.4 Challenging Behaviour

People with autism who present challenging behaviour are particularly difficult to bring within the orbit of self-advocacy. It may be necessary, in order to protect others in the residential or work setting, to make alternative arrangements for individuals with challenging behaviour, and they may have to be controlled, not only by restricting their movements, but also by medication which may dull their perceptions. Within services for people with autism, however, the aims for those with challenging behaviour are the same as for others in their care, and it is therefore necessary to adapt the techniques of self-advocacy to them. In learning the causes of the challenging behaviour - which may be varied and numerous, staff may find that these are clues to a person's preferences and needs. For example, the behaviour which is often a compensation for a lack of communication skills may signal discomfort, fear, a wish for attention, dislike of noise or change, a cry for help, a memory of a past unpleasant incident, task failure, etc. If the behaviour can be controlled and communication skills improved, there is a greater potential for an individual to practice self-advocacy constructively.

3.5 Lack of Motivation

Implicit in both group and individual self-advocacy is the assumption that there is motivation to make decisions and communicate them to others in order to influence one's own life. Although people with autism are self-directed in matters of routine and in regard to their obsessions, they often, particularly in adulthood, lack motivation; some of them to such a degree that, unless prompted or persuaded, they would spend the day lying in bed, sitting in a chair or occupied with their obsessions to the exclusion of any other activity. Because its results are often immediately apparent, a person with autism can be motivated to practise individual self-advocacy, at least to some extent. Group self-advocacy, on the other hand, is more difficult to introduce because it includes the concept of group decisions, which is not easy for people with autism to understand, particularly since the results of these decisions may often be deferred. Moreover, many people with autism become impatient with discussion of subjects not of immediate interest to themselves and their handicaps of social interaction may inhibit motivation to join in activities requiring such interaction. As was mentioned previously (Section 2.8.1), before staff can introduce group self-advocacy successfully, they need to promote group awareness and group interaction.

3.6 Handicaps of Social Interaction

Self-advocacy is an important means of bringing about the social integration of people with learning disabilities. Because the impairment of social interaction, characteristic of the handicap of autism, can lead to social isolation, staff need actively to intervene to prevent this by developing not only the communication skills of those in their care (see Section 3.1), but also their social skills both within the service setting and within the wider community. Important in the development of social skills are the maintenance of high standards of personal care, appearance and demeanour and the encouragement of good manners and appropriate social behaviour. (See CMH, LASA 5, 1988 concerning communication and social skill.)

Maintenance of high standards of personal care, appearance and demeanour

One aspect of the impairment of social interaction of people with autism is a lack of awareness of other people's reactions to them so that they are unaware that they may be offensive to others. Some may, without prompting, fail to take even the most basic measures such as minimising body odours by washing, use of deodorants and frequent changes of clothing. They also, unless supervised, may dress sloppily or inappropriately. They may slouch when standing, stand too close to people or sprawl when sitting. Staff must be prepared to intervene sensitively and consistently so that habits of personal care are developed to the point where intervention can be reduced or withdrawn. They should also actively encourage those in their care to take a pride in their appearance, by helping them choose appropriate clothing, attractive hairstyles and make-up. Good habits of posture, body control and awareness of other people's personal space should be developed, perhaps with the aid of physical exercise such as keep fit and dancing.

Encouragement of good manners and appropriate social behaviour

Many people with autism are unaware of the importance of social integration and therefore lack the motivation to achieve it. Considerate social behaviour not only helps to maintain happy relationships within the service setting, but is essential if people with autism are to become integrated with the wider community. Staff therefore need to ensure that those in their care behave with consideration and good manners towards members of the public.

Some people with autism may make inappropriate advances to strangers - grabbing, stroking or even kissing - which can be very frightening for the recipients of these attentions, especially if the perpetrator is a grown man. Personal comments ('Is that lady dead?'; 'Fat man', etc.) can cause embarrassment or hostility. Alternatively, people with autism may appear to be so unaware of the presence of others that they let doors slam in the faces of those following or walk in such a way that others have to take evasive action. In the long-term, the aim of staff should be to enable those in their care to replace socially unacceptable behaviour with good manners. In the short-term, they should anticipate and prevent anti-social behaviour. A few of the more able people with autism may wish to participate in social relationships but are incapable of knowing how to go about it. In these cases staff should be supportive and helpful, but it requires patience and discernment to teach behaviour which is based in great part on

an understanding of people's reactions to each other, which is often difficult for people with autism to achieve.

3.7 'Autistic Vulnerability'

Because people with autism are unaware of the clues to other people's motivations, which even those not suffering from autism can on occasion misinterpret, they are particularly vulnerable to exploitation by the unscrupulous or by people who are simply serving their own interests. People with autism take others at their face value. Anyone who seems to be friendly is regarded by them as their friend, so they may, for example, willingly lend large sums of money or agree to buy something without critical examination of the transaction. Staff need to be particularly vigilant in respect of the more able person with autism who is more likely to be involved in such transactions, and should therefore establish easily understood rules such as an obligation to consult them on any transaction involving a sum of money in excess of a stated amount. (Dewey in Schopler and Mesibov, 1983.)

4. Constraints on the self-determination of adults with autism

As mentioned previously, there are certain general constraints which apply to all self-advocates; the rights of others, the law and considerations of health, safety and self-preservation. Related to these, but more specific, are constraints which need to be taken into account by those who wish, through self-advocacy, to promote self-determination of adults with autism. They should not be considered as deterrents, but should be understood and accepted as defining the boundaries within which realistic self-advocacy can be practised.

There are constraints deriving from the circumstances of living within a protected community (practical and social constraints), the need to maintain health and hygiene, and the need to assess and avoid risks which might lead to damaging consequences.

4.1 Practical and Social Constraints on Self-Advocacy

All care services operate within limitations imposed by annual budgets, staffing levels, staff rotas, availability of transport and safety regulations. Other constraints derive from the inclusion in the establishment of people with widely different levels of handicap. For example, although it may not accord with the principles of independent living and normalisation to lock the front gate, it may be necessary to do so in order to avoid endangering those who are likely to escape or whose road sense is not reliable. Further practical constraints of self-advocacy arise from living within a community or hostel, most of which exist within the normal family unit - consideration for other people's property, their private space and personal privacy and consideration in regulating noise levels. Another type of practical constraint which also applies to those without learning disabilities, is the need for a structured life if the individual is to realise their potential. Some self-advocates resist the notion of regular hours for going to bed, getting up in the morning or meals at appropriate times. However, although some flexibility and personal choice can be allowed to individuals within a residential establishment, especially at weekends, there are impediments to total permissiveness in this respect, not only because of the disorienting effects on the individual, but also because of inconvenience to other residents and to staff. It could

be argued that the principles of normalisation imply adherence to regular hours, as is the case with most members of society.

It should be remembered that most people with autism not only have no choice of where they live, but also with whom they live. Sometimes certain individuals cause acute distress to others over a period of time by reason of their personalities or habitual behaviour. In such cases staff should make every effort to arrange for the people involved to come into contact with each other as seldom as possible, although this may be difficult if the establishment is a small one and there is no prospect of a suitable alternative.

4.2 Need to Maintain Health and Hygiene

Staff need to be vigilant in ensuring that obsessional behaviour or the failure of people with autism to judge the consequences of their actions do not lead to adverse effects on health. A number of adults with autism can be obsessional about food, either becoming addicted to sweets or simply over-eating, and staff have been able successfully to set rules and limitations in the interests of maintaining the health of those in their care. Others have become addicted to tobacco or alcohol. (A tragic example of this is described in a moving article in *Communication* of December 1989.) With care and foresight these can be prevented.

An additional limitation on self-determination is the need, especially in establishments caring for highly dependent persons with autism, to invade the privacy and autonomy of individuals in the interests of health and personal hygiene. As part of their care responsibilities, staff may need to toilet, bath and shampoo residents and clean or change items like toothbrushes, hair brushes and shaver blades on a regular basis, as well as ensure that clothes are changed and laundered regularly. Staff may need to carry out some of these routines, including shampooing and bathing, for the more able people in their care until they are able to reduce their role to monitoring these procedures. In order to increase autonomy in personal care, staff may wish to devise personal care plan charts which will enable individuals to monitor their own care programmes.

Staff also need to be aware of the fact that people with autism may have an abnormal reaction to pain and are unable or unwilling to draw attention to it. Consequently, they are unable to advocate for themselves in matters concerning health care. Staff therefore need not only to ensure the provision of all the components of healthy living for those in their care, such as appropriate diet and exercise, but also to arrange for six-monthly dental checks, regular inspections by a chiropodist, and possible annual pre-emptive physical check-ups by a doctor or nurse. It is also advisable for staff to undertake weekly health checks including inspection of body surfaces in order to detect any problems such as rashes or infections in their early stages. Experienced staff have found ways of undertaking these inspections unobtrusively either at bath times or at the swimming pool or gym.

Staff should use their powers of observation to detect any unusual reactions by an individual (unusual lassitude, unwillingness to chew, continual rubbing or scratching) which might signal that they are unwell or in pain, so that they can take the necessary action. Some people with autism will persist in carrying out their daily routines of

getting up and going to work despite pain or illness, and staff may need to intervene in order to prevent this.

4.3 Assessment and Avoidance of Risk

People with autism are, because of their handicap, particularly vulnerable to a variety of risks. Not all of these can be predicted with any reliability as they can result from obsessional behaviour, immature emotional and sensory development, difficulty in transferring taught skills from one setting to another, inability to interpret the motivations of others (leading to particular vulnerability to manipulation by others), difficulty in understanding cause and effect, and foreseeing the consequences of their actions. Because the choices made by self-advocates may sometimes involve risk, staff need to become skilled at risk assessment and in avoiding exposing those in their care to risks which may result in injury or long-term harm. For example, teaching independence skills (road sense, how to use public transport, cooking, shopping), staff need to have a profound understanding of an individual's personality and capabilities. There are implications for supervision associated with those who are likely to suffer from convulsions.

4.4 The Need for Structure in Which to Practise Self-Advocacy: Rules and Goals

It is commonly accepted that people with autism need to live within a structured environment which can serve as a supportive framework within which they can develop and flourish. The promotion of self-advocacy does not challenge this assumption, but it does require the structure to be managed in such a way as to offer a greater range of options as the clients' capabilities develop and to take account of their needs and desires. Because anxiety is characteristic of the majority of people with autism, a supportive structure is necessary if they are to practise self-advocacy with confidence.

The need for structure means that a groundwork of rules and routine needs to be maintained within the services caring for them. At times, they need firm guidance if they are likely to expose themselves to unacceptable risk or if their obsessions are too overpowering. It should be made clear that 'No' means 'No'.

It has been found, particularly with the more able person with autism whose inability to grasp the unspoken assumptions which govern normal social interaction linked to their wish for independence makes them particularly vulnerable, that it is necessary to lay down very clear rules, as it is often impossible to teach them judgement. They may consider that adulthood is saying and doing what they like, but it is difficult, except at the most concrete level, to explain the constraints non-handicapped adults take for granted. Instead of arousing their anxiety levels by what may turn into long philosophical discussions, it may be best for staff to be decisive in bringing the discussion to a close by giving a simple explanation, then asking the person involved to repeat it in their own words, or, as a last resort, to say 'I have given a reason, and that is the end of it'. (Taylor, 1987/88.)

On the other hand, as a means of controlling a particular aspect of unacceptable behaviour, it may be helpful to set clear goals and to negotiate a programme of action agreed both by the person with autism and staff. Agreement can also be reached on

how the programme can be monitored. A careful use of a system of rewards can also be a useful means of controlling behaviour as can goal charts on which successes can be noted by the individual involved. Such programmes of negotiation and agreement on goals can lead to a reduction of time, money or energy spent on a particular obsession or behaviour, thus enabling these resources to be directed towards more constructive pursuits. (Howlin, 1988 and Tantam, 1988.)

5. Staff attitudes

In their efforts to guide, instruct and encourage, as well as to control, if not eliminate, anti-social behaviour, staff can have a considerable influence on those in their care. They must be constantly vigilant, particularly in the promotion of self-advocacy, in avoiding manipulation and the planting of ideas. Staff attitudes should always reflect their belief in the value and dignity of the individual with autism as a person with equal rights and equal worth, with abilities as well as disabilities.

Because self-advocacy is, by its nature, an agent of change, staff need constantly to exercise **flexibility** in reassessing their role in response to the developing independence of those in their care, and to exercise **judgement** in knowing when to intervene to reduce anti-social behaviour or to avoid risks with damaging consequences.

Self-advocacy is a challenge, both for the self-advocates and for their carers as they work in partnership to redress the balance of power.

References and Other Useful Reading

Below is a list of books and articles used in the compilation of this document. Most of them can be obtained direct from their publishers. Otherwise they can be borrowed from specialised libraries or by means of an inter-library loan. Prices may need to be confirmed before ordering for purchase. The starred items are particularly useful for those wishing to develop self-advocacy.

Butler, K, Carr, S and Sullivan, F, *Citizen Advocacy: a Powerful Partnership*. National Citizen Advocacy, 1988. £6.00 incl. p&p.

A comprehensive guide to citizen advocacy from principles to practical problems on setting up and running schemes.

Clare, Mariette, *Developing Self-Advocacy Skills with People with Disabilities and Learning Difficulties*. FEU (Further Education Unit), 1990. £8.00 incl. p&p.

This report takes the view that disabled people are potentially the best experts on themselves and their disability and shows how self-advocacy can become the basis for learning independence skills. It describes the consequences to professionals of scrutiny of their own practices and of putting the learner at the centre of a learning programme.

*CMH (Campaign for Mentally Handicapped People, now Values Into Action), *Learning About Self-Advocacy*, a set of 5 manuals, 1988, £14.50 incl. p&p.

Five manuals covering all the tasks involved in operating a self-advocacy group and the basic skills which self-advocates need to develop. The pack is aimed at self-advocates, but professionals will find it equally helpful. The text is in simple language with illustrations.

*Cooper, Deborah and Hersov, John, *We Can Change the Future, A Staff Training Resource on Self-Advocacy for People with Learning Difficulties*. SKILL (National Bureau for Handicapped Students), 1986, revised 1988. Book £7.50. Video £12.50 incl. p&p.

The book is part of a self-advocacy pack, the components of which can be ordered separately or together and include a video and transcript of the video. Staff at all levels will find the pack useful, both as an introduction to self-advocacy and as the basis of a staff training programme.

*Crawley, Bronach, *The Growing Voice: A Survey of Self-Advocacy Groups in Adult Training Centres and Hospitals in Great Britain*. CMH (now VIA, Values Into Action), 1988. £3.95 incl. p&p.

Based on a postal survey, this report shows that some form of self-advocacy group is now fairly common in ATC's and hospitals. It reveals how much the style, scope and achievements of groups vary, and the obstacles they face. There are interesting sections on the topics discussed by groups and reasons for failures. It highlights changes and challenges facing staff and self-advocates.

Department of Health, Social Services Inspectorate, *Inspection of Day Services for People with a Mental Handicap, Individuals, Programmes and Plans*, 1989. Obtainable from Department of Health.

Report of an SSI inspection of day services in 13 representative Local Authority areas and a sample from the voluntary sector. Chapter 5 includes paragraphs on self-advocacy. Services were found to be at varying stages of thinking about how to help clients to influence service design and delivery.

Dewey, Margaret A, Parental Perspective of Needs. In: Schopler, Eric and Mesibov, Gary B, *Autism in Adolescents and Adults*. Plenum Press, NY and London, 1983.

Description of the needs of adults with autism using as an example an able young man, thereby clearly illustrating the 'autistic mind-set' - difficulties of social interaction and of interpreting spoken and unspoken communication. The author concludes that even an able adult with autism needs continual supervision and counselling and should be taught that willingness to consult others is a sign of strength.

FEU (Further Education Unit), *Self-Advocacy and Parents, the Impact of Self-Advocacy on the Parents of Young People with Disabilities*. Study undertaken by Alison Wertheimer, 1989. £4.50 incl. p&p.

The introduction includes an excellent description of self-advocacy, its history and implications. The report offers case studies, discusses issues arising from these and makes recommendations for further education providers, agencies and professionals. Included in its recommendations are the need of support for parents and for enlisting their support for self-advocates.

Howlin, Patricia, *Helping the More Able Autistic Individuals in Selection of Papers Presented at a Seminar on Asperger Syndrome*. 1 June 1988, The National Autistic Society, 1988. £1.60.

Practical advice is offered for helping the able person with autism, much of which can be adapted to the less able. Advice includes help with language problems, the complexities of social interaction, the constructive use of obsessions and increasing skills.

Kidderminster People First Group, *Self-Advocacy, Speaking for Ourselves*. January 1989. £2.00 incl. p&p.

A book written by and for self-advocates. Words and pictures tell about self-advocates' views on labelling, jobs and leisure.

*Kings Fund Centre, *An Ordinary Life, Comprehensive Locally-Based Residential Services for Mentally Handicapped People*. Project Paper No. 24. First printed 1980, most recent reprint 1987. £1.50 plus 10% p&p.

This paper is the result of an inter-disciplinary working group's study of the development of comprehensive local residential services for people with learning disabilities. It is invaluable in setting out clearly the basic principles of a residential service, how it should be planned, the role of individual programme plans, types of housing and how the service should be evaluated.

Kings Fund Centre, *Facing the Challenge, an Ordinary Life for People with Learning Difficulties and Challenging Behaviour*. Project Paper No. 74. Edited by Blunden, Roger and Allen, David, 1987, third impression 1989. £4.00 plus 10% p&p.

The provision of community-based services for people with challenging behaviour is believed to be a key test of the quality of community care. Valuing clients, designing services around their individual needs, ensuring availability of resources, training and support of staff are all essential if the needs of people with challenging behaviour are to be met. Based on contributions from a comprehensive working group, the issues involved in establishing services for this client group are explored.

McTaggart, Nancy and Gould, Martin, *Choices and Empowerment Towards Adulthood; A Self-Advocacy Manual for Students in Transition*. Sponsored by the US Department of Education, Office of Special Education and Rehabilitative Services, unpublished, 1988.

A manual providing information and guidance to enable the reader to assist students with disabilities to form a self-advocacy group. The ultimate aim is to enable the

students to make realistic decisions about their future activities and arrangements and how to translate these into reality.

National Autistic Society, *Parent and Professional Partnership in Caring for Adults with Autism in National Autistic Society and Affiliated Society Establishments*, 1990. 50p.

This paper provides guidelines for co-operation between families of clients in services for adults with autism and the staff caring for them.

*O'Brien, John, *The Principle of Normalisation - A Foundation for Effective Services*. VIA (Values Into Action), 1981. £3.45 incl. p&p.

Explains the principle of normalisation, important because it furnishes a tool for identifying and reversing the vicious circles trapping people with handicaps. It shows how normalisation increases the probability that handicapped people will live as valued neighbours rather than devalued clients. Practical advice in achieving this is offered.

Pelmar, Doreen, *The Problems of Living Alone in the Community in Communication*. The journal of the National Autistic Society, Vol. 23 (3), December 1989.

The mother of an able young man with autism writes of the pitfalls of normalisation. She concludes '... we seem to have created new (problems), more dangerous to himself and causing more distress to both myself and to the community into which I tried so hard to integrate him'.

Sand, Bob and O'Brien, John, *Advocacy, The UK and American Experiences*. The Kings Fund Centre, Project Paper No. 54, 1989. £3.25 plus 10% p&p.

The first part of this report describes the history and activities of the Advocacy Alliance founded in order to provide citizen advocates for people with learning difficulties in long-stay hospitals in the UK. It includes the principles of citizen advocacy; recruitment, training and support of advocates are discussed as well as their role and purpose. The second part of the report describes the development of citizen advocacy by the Georgia Advocacy Office in the USA.

Tantam, Digby, *A Mind of One's Own, a Guide to the Special Difficulties and Needs of the More Able Autistic Person*. The National Autistic Society, second edition 1991. £1.50.

A very clear analysis of the handicap of autism and its implications with an emphasis on the more able person. Practical advice is given on how parents and professionals can help.

Taylor, Jill, *unpublished paper* 1987/88.

Miss Taylor, former principal of an NAS school, describes the difficulties of the able autistic young person in learning independence and social skills and how staff can

help. 'Autistic vulnerability' can to some extent be minimised by careful counselling, role play and constant staff support.

Wertheimer, Alison, *Self-Advocacy Skills Training; A Report of Two Workshops Held Between April and September 1987*. The Kings Fund Centre, 1987. £2.00 plus 10% p&p.

A book to help self-advocates and their advisors/supporters learn more about self-advocacy skills and run their own self-advocacy workshops.

*Williams, Paul and Shoultz, Bonnie, *We Can Speak for Ourselves*. Human Horizons Series, Souvenir Press, first published 1982, reissued 1991. £8.95.

Describes the growth of self-advocacy in Britain and the USA and offers practical advice to those who wish to develop self-advocacy. The appendices include valuable material on rights, indicating their practical applications.

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