

Regional Advisory Group on Learning Disability Services

Choice

Guidelines for Good Practice

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Summary

Underlying Issues

Central to consideration of choice are: legal and human rights; assessment of competence to decide in legal and medical matters as well as in managing day to day affairs; power and the need to even up imbalances in the lives of disabled people; distinction of wants and choices; risk.

Individual Issues

1. All concerned commit themselves to learning to listen to people so as to discover their wishes, dreams, aspirations, preferences and choices.
2. In arriving at any decision it helps if it is based on adequate information.
3. Where it is very difficult to determine a person's preference others will need to act in the best interests of the person.
4. When a major decision is made on behalf of another person then the reasons and implications should be considered and explored by relevant parties.
5. Carers should be aware of the tendency of many people with learning disabilities saying what they think will please those in authority.
6. Where there is a conflict between encouraging choice and another equally valid principle there is a need to explore a variety of approaches to resolution.
7. However unrealistic a person's aspirations seem people should not be slapped down and have their dreams stamped on.
8. Although they should not be imposed upon people with learning disabilities, staff are entitled to their own moral values.

9. Once decisions have been made or preferences expressed and commitments made to implementation which require the action of staff or others there should be follow-up to ensure they are carried out.

Organisational Issues

10. The policy of the service should include a statement of intent supporting the aim of extending personal control over one's life as much as possible.
11. Concerned people and organisations should have access to a local standing ethical committee which includes outside people and which is available to discuss difficult decisions as required.
12. All staff should have opportunities to review choice situations (especially those which give rise to difficulties) in supervision sessions, in staff meetings and ethical committee meetings.
13. Where there is concern about possible damage to a person and an intervention is proposed to prevent or reduce such harm which may go, or appear to go, against the wishes of the person then a planning process is required which includes input from a mix of relevant interests, including the person, family and various professionals and agencies.
14. Managers need to develop a culture of integrity, through their own actions, teaching, supervision and expectations.

Purchasing

15. Purchasers of services should require providers to show clear evidence of substantial effort to implement guidelines such as those above.

Introduction

The topic we are concerned with here is self-determination, control over one's own life, making decisions, indicating a preference, personal autonomy.

Freedom from restrictions in choosing is highly valued in democratic societies. It contributes a great deal to what we think of as quality of life. The more we can control our lives the more satisfaction we are likely to experience. The law recognises important freedoms and is intended to protect them. The UN Declaration on Human Rights exhorts the extension of freedoms to all the world's citizens. The main restrictions on freedoms are to do with limiting the freedoms of others.

A distinction could be made between major, decisions having significant consequences and others having less impact e.g.: where to live, who to live with, which job or day activities? These are all decisions which most of us take time over, even preparing ourselves for years to make.

The emergence of choice as an issue for people with learning disabilities is a response to their common experience of having little control over their lives. Parents and staff have regarded people with learning disabilities as irresponsible and incapable of managing their own affairs. Others, therefore, took decisions for them, gave them little opportunity to learn about making choices and experiencing the consequences.

People considered vulnerable were seen as in need of protecting from themselves, their own perceived inadequacies and poor judgement.

This paternalism showed itself in the big decisions in life. The subjects of marriage and having a job were taboo, simply unthinkable. But in the smaller day to day decisions others took over too, often because of the person's slowness in responding. Impatient and quicker thinking others would jump in to make decisions.

Denial of choice was an indication of the disrespect in which people were held. It also marked the imbalance of power in relationships.

In recent years as this repression has been recognised efforts have been made to reverse the situation and encourage people with learning disabilities to take more control over their own lives. The People First self-advocacy movement has emerged and people are beginning to find a voice. The popularity of the terms empowerment, user participation and involvement grew out of this movement.

There are so many variations in the situations where carers are faced with decisions concerning choice that arriving at useful guidelines is fraught with problems. No set of guidelines can cover every eventuality. Each situation has to be considered with all its complexities. As we struggle to find our way through these complexities we should seek to deepen our wisdom. Often there will not be a right or wrong answer that is clear to us. Sometimes in retrospect we will be shown to have got it wrong. If we act in good faith with the aim of gaining in understanding and good judgement then we are fulfilling what is required of us.

Some staff have unfortunately gone over the top, insisting that a person's choice is to be respected totally even if this results in harmful consequences for them.

Two examples:

- There is a serious fire within a residential situation. A member of staff Joan goes into Mary's room to get her out of the building. Mary refuses to come. The member of staff tries to persuade Mary but is unsuccessful. Joan reports back that Mary wishes to stay where she is. Joan indicates that this is Mary's choice and that she could not bring herself to drag Mary out of the building.
- Alan living in staff supported housing has indecently assaulted a child in the local neighbourhood, as well as female staff members. The police have been involved but did not prosecute because staff have explained that Alan is only expressing his developing

sexuality. The matter comes to a head. Alan moves house but indecently assaults a child in the new neighbourhood. Hospital admission is arranged, and in the meantime staff are asked to prevent further incidents occurring. Whilst waiting for admission to hospital Alan continues to be allowed out of the house because staff feel that they can not interfere with Alan's choice.

In part this problem arises from an oversimplification and misinterpretation of normalisation teaching which rightly emphasises the importance of self-determination.

In part it may also be an oversimplification of the tradition in social services of rightly encouraging people to take responsibility for themselves. It may also be in part, a reaction to the paternalistic tradition of health services, as people moved out of hospitals.

Paradoxically we are in danger of not supporting user choice enough on the one hand and supporting it inappropriately on the other.

Being well informed helps in making wise choices. Carers need to inform themselves and also assist people with disabilities to gain relevant information to aid in making decisions.

Problems arise for people with learning disabilities in making choices:

- **Others may impose decisions regardless of the person's preferences.**

This may be because we do not give priority to the person's concerns over our own or it may be for legal or moral reasons.

- **Others do not listen to the person's choices and concerns even when they are expressed.**

This may be because of our low expectations or assumptions, or because we are impatient.

- **We cannot determine what the person's choice is.**

This may be because of their limited communication or our limited skills in listening or not knowing the person.

- **The person cannot make choices.**

Making a choice requires a person to identify alternatives and discriminate between them, anticipate consequences and indicate or express preference.

Not being able to make choices may be because a person has been denied relevant life experiences. Therefore encouraging their personal development by making opportunities available for broadening their lives will provide more experiences as a basis for making choices.

It may be a result of lack of conceptual and abstract abilities such as looking to the future or judging magnitude. The person simply may not understand the question or the options available.

These guidelines have been written for workers in services, family members, friends and other community members outside paid services. It is hoped that all concerned will have opportunities to reflect on the issues raised here in training events and other discussion forums such as parent groups, self-advocacy groups, management committees, board meetings etc.

Managers should introduce these issues in supervision and ensure that their staff have opportunities to focus on them in training.

Underlying Issues

Rights

Legal rights are entitlements enshrined in law (see notes 1-3 under *Resources*). Human rights are exhortations which may or may not be backed by the law. We may support a 'right to work' but this has no legal meaning. We can say that everyone should have the opportunity to work if they wish. This is no more than our opinion of right.

Competence

Assessment of a person's competence to decide may be required for several purposes. The decision in question can be about marriage, entering into a contract, making a will, voting, managing financial affairs, or agreeing to medical treatment. The understanding (legal capacity) required for each decision will be different in each case depending on the complexity of the information and the legal test (if one exists) to be applied (see note 4 under *Resources*).

Managing affairs - e.g., is the person competent to give their money or belongings away? Unprincipled people may exploit a person's generosity.

Medical matters - is the person competent to give their consent to treatment? Gunn (see note 5 under *Resources*) points out that assessment is required of:

- the person's level of knowledge and understanding of the problem which needs resolution
- the various methods of dealing with the problem, including doing nothing
- the consequences of those various methods.

A decision to accept or refuse treatment must be taken voluntarily and without undue pressure or influence which might include coercion, threats or rewards.

There is a range of disability. Some people with profound disabilities require others to act on their behalf in all decisions. Others with mild disabilities require little assistance. The extent to which a person's competence is limited has to be determined for each person and situation. It should not be assumed that a particular mental age or IQ or the label 'learning disability' implies incompetence. A person may be competent in some things at some times and incompetent in others at other times.

Power

Power means the ability to act. Because of the limitations imposed by their impairments as well as by carers, staff and others, people with disabilities mostly have very little power in their lives. Almost every grouping of people stratifies automatically so that some people are at the bottom of the pile and others at the top. These guidelines are intended to even up the power imbalances inherent in social groupings where disabled people are concerned.

Some people tend to be oriented to achieving status, domination and power possibly at the expense of their connections to people (see note 6 under *Resources*). The focus of other people's lives tends more to be on connectedness and nurturing community and less on hierarchy. Of course these are generalisations. They do however draw attention to the need many people have to exert control over others. If the balance of power is to be evened up some people are going to have to be prepared to give up some of their power over others.

Wants and choices

Wants and choices are not the same. Choice involves selection among available options. You might choose to go to an Indian restaurant rather than a Chinese. Once there your choice is limited

by what is on the menu. You may prefer stir fry vegetables but if it is not available it is not an option. You may not always be able to choose what you want.

Risk

For all of us making choices provides opportunities for learning and development. We have to live with the consequences of our decisions. Risks are involved. We don't always

make the wisest decisions but we often learn from the way they turn out. Denial of choice places restrictions on opportunities for development.

One of the hardest things for carers, whether parents or staff, is to learn when to 'let go'. Overprotection arises from fear of danger and constrains a person's development. Underprotection needlessly exposes a person to dangers. Judgements are needed which leave a carer worrying: 'Have I taken too great a risk?' at the same time as: 'Have I held her back?'

Guidelines for Good Practice

Individual Issues

1. All concerned commit themselves to learning to listen to people so as to discover their wishes, dreams, aspirations, preferences and choices.

Some practical implications

See notes 7-12 under *Resources*.

- Parents can encourage their children to learn from making choices from an early age. This will give them more control over their lives, and more motivation to learn.
- Staff need to get to know the person as closely as possible, exploring all the person's efforts at communication. One thing that a surprisingly large number of carers and staff are not sufficiently aware of is the need to give sufficient time to respond. One has simply to be patient and wait. Continual prompting may actually interfere with the person's ability to respond.
- Job descriptions should emphasise the commitment to learning to listen.
- There needs to be good communication between all concerned so that everyone knows what signals mean. Challenging behaviour is often a signal that a person is dissatisfied with something in their life. Sometimes when a person has a tantrum it may be an indication that the person does not like going to the day centre, or does not like the other people in their group home. Staff may come to understand this but feel that there is nothing they can do about it or that it would be too inconvenient to disrupt the service to meet the person's needs. Another approach would be to explore other options. The supported living movement has grown from the realisation that group homes are not the answer to everyone's accommodation needs.

- Staff need to be aware of their own inclinations.
 - Wanting to exercise control over others or have them dependent on us. For some staff it may be difficult to switch roles from being the one who controls to being controlled.
 - Wanting to be seen to be responsible for others or playing the caring role.

Taking an enabling role rather than taking charge and doing things for the person requires a different mind set. It may require some self-examination and honest feedback from others to see ourselves as we really are.

- There is a need for continuity in relationships so that staff are not moved about unduly.
- Photographs depicting options can be helpful in presenting alternatives.

Examples

- Rachel returned to her group home after a weeks holiday with her parents. When they arrived she cried and said she didn't want to go in. Previously she had always appeared happy to return to her group home. Parents and staff spent several hours trying to figure out with Rachel what the difficulty was. It emerged eventually that she was worried about having put on weight at home and that she would be taken to task by the staff at her group home. When this was cleared up Rachel was reassured and was happy to stay. Her parents were relieved that she really did want to stay.
- Staff might be worried about the people a person chooses to associate with, perhaps they are seen as a bad influence or the person is believed to be at risk of exploitation. It may be that the person is very lonely and eagerly responds to interest from any quarter.

2. In arriving at any decision it helps if it is based on adequate information.

Some practical implications

- Informed decisions are generally more likely to lead to satisfaction than those plucked out of the air or based on whim. This is especially important for major decisions that have significant consequences.
- Information that may assist in arriving at a decision includes:
 - what are the possibilities?
 - what are the currently available options?
 - what are the likely consequences of the options and possibilities in terms of risks, potential benefits, responsibilities and likely effects on others?
 - what are the costs in terms of time, effort and emotion as well as finance?
 - what resources, including personal capabilities, are required?

Consequences may be in the immediate or longer term future. Learning to delay immediate gratification for longer term benefits is a hard lesson for us all. It may be even harder for a person whose grasp of time scales is limited.

- One can never have all possible information but often if the critical information is available that is enough. There might be a danger of decisions not being taken if relevant information is not available. There may be times when it makes sense to act and learn from the experience. It is often more important to be on the field of play than to be a spectator.
- In making a choice we are making a judgement or an evaluation of alternative options. We place values on each possibility available to us and eventually select one in preference to the others usually trying to maximise the advantages and minimise the disadvantages. We may do this quickly or it may take years. We may do it impulsively

with little consideration or we may do it systematically and carefully.

- For each situation we could draw up a balance sheet of the advantages and disadvantages, evaluating each of the available options. When managers do this these days, it is called option appraisal. In our daily lives, of course, most of us don't go into this kind of detail. It might be said that if we expect people with learning disabilities to go through such a procedure we are expecting more from them than we do from ourselves. However, there may be a lot to be said for working systematically at it. The procedure would provide lots of opportunities for learning, by staff and carers as well as those faced with the choices.
- Increasing life experience will help develop a person's ability to make informed choices.
- Informed consent is required before treatment is administered (see note 3 under *Resources*). Legal liability may be incurred if treatment is given or if it is withheld without obtaining consent. Informed consent requires an explanation of the reason for the treatment, the procedures to be followed, expected benefits, risks involved and alternative treatments if available. A person should be told that she has the right to accept or reject the proposed treatment and that if she does accept she may change her mind and withdraw consent at any time.

Examples

- Sarah wants to buy a television she sees in the shop window. She has not got the necessary cash, does not have a credit rating suitable for a hire purchase agreement, or the necessary income for a rental arrangement. Buying the TV therefore is not yet an option for Sarah. She will have to work on her finances before it becomes one.
- Andrew is moving from hospital to community services. Staff take him to view six houses, one of which he may possibly be moving into. It is, however, his choice.

Andrew views the first house. He likes it, he decides that this is the one he wants and refuses to look at the other houses.

In this example Andrew might have found the house of his dreams or might be thinking he had better choose quickly or he may not get out of hospital. There may be other interpretations that we might put on Andrew's actions. How can we be sure that the choice is an informed one? How much will the wrong choice of house seriously affect Andrew's quality of life? What importance does Andrew attach to which house he lives in?

3. Where it is very difficult to determine a person's preference others will need to act in the best interests of the person.

Some practical implications

- For children up to 16 years (with some exceptions, to 19) parents have the main but not total responsibility. A child can be made a ward of court by the local authority under some circumstances. Over the age of 16 years parents do not have a legal right to make decisions on behalf of their sons and daughters. Care workers have no more right than parents. Parents and care workers, however, do have a duty of care.
- The question of 'who owns the person' can give rise to conflict. Often there may be negotiations between service providers and family members. Occasionally these negotiations will break down. Sometimes the dispute can be between different members of the family as to what is in the best interests of the person. An independent person could be sought to speak for the person in the negotiations. An independent person acceptable to all parties could be brought in to act as arbitrator. There may indeed be several parties concerned in decisions about a person with learning disabilities: the client, the parents, other family members, the service, the local authority, an advocate or an advocacy organisation, a friend.

- Assessing competence in choosing is not always easy. It may be required for a court of law but for everyday purposes, generally we should make a presumption of a person's competence. We will often then have to provide support to enable the person to fulfil their decision.
- Where others act for a person they should act in what they see as the person's best interests. Determining a person's best interests requires judgement. Guidance may be sought in the law, the principle of normalisation, the agency's policies, current good practice. Each of these need interpreting in light of the situation.

Example

- Parents of a man living in a group home run by a voluntary agency wanted him to move to provision run by another voluntary agency outside the locality he was familiar with. However, his brother disagreed and strenuously resisted his parents efforts. Both parties sought a judicial review.

4. When a major decision is made on behalf of another person then the reasons and implications should be considered and explored by relevant parties.

Some practical implications

- There will be a need for regular dialogue and consultation between potentially large groups of people but especially between carers at the person's home and those at the person's day activities.
- It is not good practice for major decisions (e.g., sterilisation, abortion, where to live) to be made by members of one profession or agency (see guideline 11).

Example

- A man of 24 with a learning disability (Peter) lives with his mother (Sue). Peter wants to pursue leisure activities during the day (Mon-Fri) with support from Social Services. He

wants to go home at 1.00 p.m., and watch daytime TV. Sue wants him to stay out until 4.00 p.m., she also wants him to spend less time on leisure activities and more on reading, writing, maths and English.

This has been an issue and a source of conflict within the family for the past four years. Sue eventually told Peter he would have to enrol in a class at an education centre for people with a learning disability, which would concentrate on reading, writing, maths and English. If he refused Sue told him he may have to leave home.

5. Carers should be aware of the tendency of many people with learning disabilities saying what they think will please those in authority.

Some practical implications

- People with learning disabilities may say what they think staff, parents and others wish to hear.
- Staff should try to establish more equal relationships with those they serve so that they are seen less as authority figures.
- Staff should look for ways to encourage people to be more confident in their own opinions and preferences. For example, raising the self-esteem of people may help.

See also 8 below.

6. Where there is a conflict between encouraging choice and another equally valid principle there is a need to explore a variety of approaches to resolution.

Some practical implications

See appendix 2 and note 13 under *Resources*.

- When confronted by the dilemma of a person pursuing a devaluing option three principles may help:
 - use persuasion, modelling and other forms of social influence

- impose coercion only where one would do so legally in the larger societal context i.e., where one would do so with other (valued) citizens of the same age such as harming self or others.

- use the least restrictive alternative if one does coerce.

- It is not generally appropriate to forfeit one principle for the other.
- Staff need to be helped to deepen their understanding of normalisation and the balance to be kept between a number of service design principles, through training and supervision.
- Many service managers are uncomfortable with the tensions raised by engaging in discussions with staff on these issues. This is particularly so when it appears that it is not possible to give staff simple solutions and advice.

Examples

- Elizabeth, 45 years, carried a very large cuddly toy with her when she went shopping. Staff were concerned that this would be seen as childish. Eventually she decided to give it away to a four year old child saying that she was grown up now and the time had come to put childish things behind her. This only occurred after she had opportunities to be treated like an adult after years of being treated as a child.
- John wishes to wear his overcoat and hat on a warm summer's day to go to the local park. This would result in John being seen as odd and possibly ridiculed by members of the local community. He might be in danger of being further isolated.
- Tom is very fussy about his food and will only eat sweets, crisps, chips and will not eat 'proper' food such as vegetables, fruit, fish or meat. Staff are concerned that Tom is not having a balanced diet. They are unsure about what their 'duty of care' is.

7. However unrealistic a person's aspirations seem people should not be slapped down and have their dreams stamped on.

Some practical implications

- Carers can use the person's interest as an opportunity for learning and personal development. The person could be encouraged to find out what it would take to pursue their dream. Along the way their aspirations may change but their motivation to explore will have enabled them to grow. This is not a question of humouring people or encouraging them to believe what you consider to be impossible. It is simply a question of following the person's lead.
- It might be useful to explore what it is about the dream that attracts the person. It might be earning some money, having a companion, gaining recognition. This could then be explored using the PATH process (see note 6 under *Resources*).
- Staff may feel that they are wasting time exploring something which they have decided is impossible. But if the person is actively involved in the exploration then this can be a valuable part of their personal development.

Examples

- One person expressed an interest in playing for Manchester United, another in being an astronaut, another in getting married. Each was slapped down and told not to be silly as it was impossible.

8. Although they should not be imposed upon people with learning disabilities, staff are entitled to their own moral values.

Some practical implications

- If a carer does not approve of some aspect of a person's life on moral grounds they may not be obliged to provide the support needed and should discuss their concerns. If conflict becomes severe then it might be sensible to

replace the staff. It is best if mismatches can be avoided at the time staff are appointed.

- It is quite legitimate to use one's influence in teaching, by example and so forth, within the context of good practice and the agency's policies.
- Staff may not feel they are telling the person what to do (see 5 above). They may not like to think of themselves as powerful. Nevertheless, staff need to be aware that they can have a strong influence on clients' choices.

Examples

- One disabled person expressed antipathy in racist remarks about a carer. Another expressed great hostility and prejudice against a gay carer. Should the carers have been moved? Should users who hire staff be allowed to go against equal opportunities policies of service agencies?
- A non-smoking care worker is asked to work in a house where a client smokes.
- A vegetarian care worker is asked to cook meat for a client's meals.
- A client on holiday in Spain expresses a wish to go to a bull fight to a care worker who cannot bring herself to go. This might have been anticipated if there had been a discussion before the holiday.
- A woman care worker objects to a client's soft porn calendar.

9. Once decisions have been made or preferences expressed and commitments made to implementation which require the action of staff or others there should be follow-up to ensure they are carried out.

Some practical implications

- Structures are needed to remind those who have made commitments to keep them and to keep track of actions taken and progress made. Circles of friends and individual

programme planning provide such structures. Group pressures can be especially powerful in ensuring implementation.

- All concerned should help each other in giving reminders, giving recognition for actions taken and celebrating progress.
- All concerned should feel able and ready to ask for help in ensuring actions are taken.
- Tasks should be spread across a number of people so that particular people are not overloaded.
- If participants do feel overloaded then more people should be enrolled to assist (not necessarily paid staff).
- A client may change his mind. Staff need to check from time to time to see whether he still wants to pursue the original choice.

Organisation Issues

10. The policy of the service should include a statement of intent supporting the aim of extending personal control over one's life as much as possible.

Some practical implications

- A board member should have responsibility for ensuring implementation.
- All staff should undergo training so that they are aware of reasons why choice is an important issue: the common experiences of being controlled, having decisions made for one, being considered irresponsible or incompetent and denied opportunities to learn to take responsibility.
- All new staff should be oriented to this aim at induction.
- All staff should be socialised into this policy through training, supervision, staff meetings and by example of managers and board members.
- The organisation should have a risk management policy to give staff guidance on

handling situations where there may be harmful consequences.

- Person centred planning is an approach which focuses on involving the person in making decisions about their life.
- People with learning disabilities should be involved in decisions on hiring of direct contact staff especially those providing support in one's home.
- Facilitated communication has become popular as a way of helping people to communicate. Managers should ensure that guidelines for good practice are adopted and that facilitators are properly trained. Facilitators need to be aware of the pitfalls and how to establish the validity of communications.

Example

David burnt his hand on the cooker when he got up at 5am one morning to make beans on toast. His mother became angry with the instructor at David's day centre who had been teaching cooking the day before.

11. Concerned people and organisations should have access to a local standing ethical committee which includes outside people and which is available to discuss difficult decisions as required.

Some practical implications

- The committee should have diverse representation from different professions. It should include representation of independent agencies which represent the interests of clients and carers.
- Members of this ethical committee need to be recruited and oriented to their responsibilities so that they are well prepared for whenever the need arises for them to be called together.
- All concerned, including clients, family members as well as staff and others should know of the role of the ethical committee and how it can be called on.

Example

- A woman who has had a number of infections and also lost weight gives cause for concern about her health. However, she refuses medical investigations. Staff fear that she may suffer a curable illness or even preventable death. They have tried to desensitise her to get her to tolerate medical examination but without success. They have explored every angle they can think of. The question was discussed at an ethical committee of whether forcing her to undergo a general anaesthetic, to permit the relevant medical tests, was legally justifiable and ethically acceptable.

12. All staff should have opportunities to review choice situations (especially those which give rise to difficulties) in supervision sessions, in staff meetings and ethical committee meetings.

Some practical implications

- There should be a supervision system with regular and routine supervision sessions for all staff.
- Staff should be able to contact a supervisor at any time to discuss problematic decisions.
- Supervisors should raise questions about choices in supervision sessions to see if issues need exploration.
- Supervisors should be trained in supervision.
- Staff sometimes have to make decisions on the spot. Preparation and training may help but sometimes there won't be time to discuss the issue with others. You do the best you can under the circumstances and then review it afterwards to see what lessons there are. Would you do it the same way next time or differently and why?

13. Where there is concern about possible damage to a person and an intervention is proposed to prevent or reduce such harm which may go, or appear to go, against the wishes of the person then a planning process is

required which includes input from a mix of relevant interests, including the person, family and various professionals and agencies.

Some practical implications

- It may be appropriate to refer the situation to the local ethical committee in addition to the planning process referred to in this guideline.

14. Managers need to develop a culture of integrity, through their own actions, teaching, supervision and expectations¹⁴.

Some practical implications

- Managers need to recognise that some people, including staff, may act in a self-serving way rather than in the best interests of those they serve.
- If clients have a network of people who take an interest in them then it is more difficult for staff and others to get away with self-serving.
- Managers should know the people served so that direct contact staff and others would not find it so easy to get away with self-serving.

Example

- Thomas (home leader) indicates to Gill, the Speech Therapist, that Angela (service user) does not want to have speech therapy. (It was an IPP objective). Thomas says - 'It is Angela's choice and we must respect that'. Angela does not receive speech therapy.

Four weeks later the recently in post Assistant Director wishes to visit the house where Angela lives. The Assistant Director is told by Thomas (home leader) that this is inappropriate, because it is their home and it is not a goldfish bowl.

The Assistant Director then asks Thomas if he will ask the service users (Angela included) what their views are on such a visit. Thomas replies that they are quite severely disabled and not capable of making an informed choice about the matter.

Clearly the staff agenda about social role valorisation and people's rights is paramount. Where Angela's views coincide with staff beliefs, she is apparently (in their eyes) capable of making an informed choice. Unfortunately, Angela is not even given the choice of expressing a view where there is a danger that the view would contravene a staff belief system that is considered of great importance.

In this example not only is choice only enabled if it fits with staff beliefs, but Angela's rights are contravened by the people who purport to be upholding them.

- Members of a group home each contributed money to buy a static holiday caravan which was subsequently rented out, when they were

not using it, to bring in extra income for staff.

Purchasing

15. Purchasers of services should require providers, through service quality specifications, to show clear evidence of substantial effort to implement guidelines such as those above.

Some practical implications

- Evidence would be sought in policies, job descriptions, training, supervision, and feedback from clients, family members, advocates, friends and staff.

Resources

1. Ashton, G., & Ward, A., *Mental Handicap and the Law*. Sweet & Maxwell.
2. Wadham, J., *Your Rights*. Liberty: London.
3. *Rights in the Way to Go Series*, 1978, University Park Press: Baltimore.
4. BMA and Law Society, 1994, *Guidance on the Assessment of Mental Capacity*. BMA: London.
5. Gunn, M. J., The Law and Learning Disability. 1990. *Int. Rev. Psychiat*, 2, 13-22.
6. Tannen, D., 1992, *You Just Don't Understand*. Virago: London.
7. Snow, J., Dreaming, Speaking & Creating: What I Know About Community. In Pearpoint, J., Forest, M., and Snow, J., *The Inclusion Papers: Strategies to Make Inclusion Happen*. Inclusion Press: Toronto.

This chapter describes how a young man (Peter), who does not use speech, began to explore life with the help of a support worker who responded to the lead provided by Peter.
8. Pearpoint, J., O'Brien, J., and Forest, M., 1994, *Planning Alternative Tomorrows with Hope (PATH)*. Inclusion Press: Toronto.

This includes a step in the process of encouraging people to dream about possible futures.

Both of the above publications are available from Inclusion Press (UK), 7 Aspen Wood, Godley, Hyde, Cheshire SK14 3SB.
9. Kinsella, P., 1993, *Group Homes*. NDT: Manchester.
10. Kinsella, P., 1993, *Supported Living*. NDT: Manchester.
11. NWTDT runs workshops on:

Being a more effective spokesperson. This is helpful for users of services, family members, advocates, staff and others in lobbying to improve a person's quality of life.

Welcoming advocacy. This is for managers, board members and service staff who might be on the receiving end of lobbying on behalf of service users. It provides preparation so that a satisfactory outcome of the lobbying is more likely.
12. Deacon, J., *Tongue Tied*.
13. NWDT, 1988, *Guidelines for Visitors to People with Mental Handicap in their own Homes*. NWDT: Whalley.

Deals with the dilemma of balancing respect for the person's choice of who they want to visit them, their privacy and the importance of broadening the range of relationships, especially with people who might provide safeguards for them.
14. O'Brien, J, 1994 *Integrity Responsive Systems Associates*.
15. The Law Commission, 1993, *Mentally Incapacitated Adults and Decision Making: Medical Treatment & Research*, Consultation Paper No. 129. HMSO: London.
16. The Law Commission, 1993, *Mentally Incapacitated & Other Vulnerable Adults: Public Law Protection*, Consultation Paper No. 130. HMSO: London.
17. NHS Management Executive, 1993, *A Guide to Consent for Examination or Treatment*. Department of Health: London.

Appendix 1: Working Group Membership

Richard Cafiero	Manager, Learning Disability Services, Rochdale NHS Trust.
Paul Clarke	Member North West Training & Development Team and Training Officer, Bury Social Services.
Marjorie Dickinson	Parent
Wilson Dickinson	Parent and Trafford Community Health Council member.
Chris Gathercole	Working Group Convenor. Member North West Training & Development Team.
Rosemary Ludden	Parent and Mencap District Officer, Greater Manchester.
Paul Sutton	Director, Outreach, Prestwich.

Appendix 2:

What to do when a person pursues a denormalising option

From: Wolfensberger, W., *The Definition of Normalization: Update, Problems, Disagreements and Misunderstandings*, In Flynn, R., and Nitsch, K., 1980, *Normalization, Social Integration and Community Services*. University Park Press: Baltimore.

In this extract Wolfensberger discusses a series of considerations that should be reviewed by a person confronted by the dilemma of a person pursuing a denormalising option.

1. As a precondition to almost any course of action, it is often necessary (especially with adults) to determine whether a person understands the problem that is at stake, the specific aspect of his/her own functioning and identity, the likely (or even quasi-certain) consequences of his/her own behaviour, and the nature of a proposed measure.
2. In order to raise a person's level of understanding, or to move him/her toward a desired course of action, the utilization of *culturally normative informal* avenues or social influence should be explored and applied to the point of grossly diminished returns. Many people who choose non-normalizing options have had little or no relevant education or training, perhaps have never had the opportunity to interact in a positive fashion with a valued and adaptive age peer, and/or have never had the nature and consequences of their choices interpreted to them. Thus, numerous options are typically available for noncoercive change, including systematic and long-term reinforcement for emitting the desired responses. Except in emergency situations, coercion should not even be considered until social influence options have been exhausted - and only too often these have never even been tried in a valid fashion.
3. Particularly where adults of legal age are involved, it is often essential to ascertain a person's level of competency for making important decisions.
4. In instances in which a person does not appear to be competent, it must be determined who is formally responsible for the person under law and/or informally in fact and practice. Here one must not merely be oriented to the formalities of the law, but also to the realities of special social relationships, and an individual who has carried de facto responsibilities for the person in question should be accorded extensive respect and participation in the decision-making process.
5. If a person is a minor without a competent guardian or an adult who is significantly impaired in competence, a guardian should be appointed. This guardian should be a minimal guardian, i.e., the guardianship role should be specified by the court to be no more extensive than the person's impairment warrants.
6. In instances in which shortcomings in competency to understand or act do exist, it then becomes important to determine what has been and can be done to increase competency; whether the measures that have been employed have been adequate; and if they have not been adequate, whether there is a reasonable likelihood that additional measures may increase the person's potential for comprehension and competency.
7. In the case of children, coercive methods applied normatively to valued children (exacting obedience, being under the physical and largely also the social control of parents or parent surrogates, etc.) may be applied, although social influence methods should generally be given priority over coercive ones.
8. Before applying coercion to an adult, it should be determined whether the issue at stake is so important as to warrant the coercion. The

issue should be carefully examined not only in its own right, but also in relation to other issues that involve the person, and that may very well have a higher urgency. An issue that may be important, if it is the only one at stake, may recede into insignificance when it coexists with half a dozen other and even more important ones.

9. It is important that, to the highest degree possible, the person understand not merely the demands made upon him/her by an interventive measure, but also the likely benefits if the measure is successful, or the potentially unpleasant consequences if it should fail.
10. The people in power who are involved should develop a clear picture in their minds just what is at stake in the proposed intervention, what infringement of the person's rights might be entailed, and what the upper and lower limits of the likely outcomes are apt to be.
11. If proper legal and moral means are used to override a client's wishes and rights, the duration of this state of affairs is to be considered. Other things being equal, short-term structures are more defensible than long-term ones.

12. Legalities, lack of resources, the person's condition, etc., may be such as to render effective intervention an impossibility, at least in terms of making a significant difference in a person's life. In some cases, all one can do is to share suffering and walk with a suffering person without effecting more than a moral victory.

The above discussion could continue at considerable length, and many other considerations could be listed. No claim is made that the issue is treated exhaustively; only some of the more common and illustrative points have been listed.

A related consideration here is whether one has to invoke a trade-off or a compromise. Briefly, a trade-off occurs in a situation in which it is impossible to optimize both horns of a dilemma. In contrast, a compromise implies that both horns can be optimized, but that present conditions are such that one must or does sacrifice something that, in theory, is quite obtainable.

Appendix 3: Training

It has only been possible in these guidelines to touch on major issues. To gain a deeper understanding it will be helpful to reflect on these issues in supervision (for staff) and in training, using this report as a basis. Training could be arranged within an agency or unit of service such as a day centre. Better would be to run a workshop with a mix of people including service users, family members, direct care staff, managers and others. These notes suggest some ideas for training.

Ask participants to think of examples from their own experience where choice was an issue.

- Describe the situation relating to the choice.
- Include:
 - who was involved
 - how was the disabled person involved?
 - whose view prevailed?
 - was the outcome satisfactory?

Then consider questions which will help reflection and discussion e.g.:

- What questions does this example raise for you?
- Who else could or should have been involved?
 - how could they have been involved better?
 - what would have helped to involve them better?
- What alternative outcomes might there be?
 - what would have been a more satisfactory outcome?
 - how could this have been brought about?
- Are any of the guidelines relevant?
- Are there implications arising from the example e.g.:
 - for operational procedures?
 - for changes in the law?
- Can you invent another guideline derived from your example?

Please send comments on the guidelines including suggestions for additional guidelines for a future revision to:

NWTDI,
Calderstones,
Whalley,
Clitheroe,
BB7 9PE.