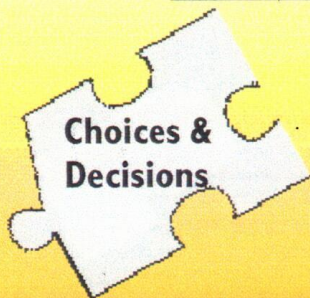
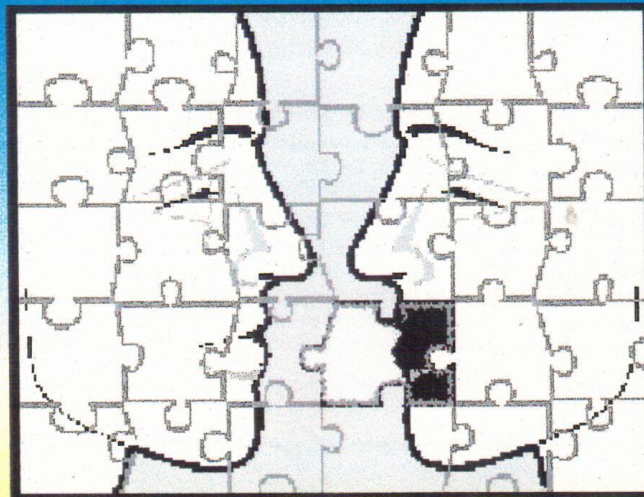


Speaking Up, Speaking Out

Pathways to Self Advocacy

Handbook



United Kingdom Chapter of the International Society for Augmentative and Alternative Communication

COMMUNICATION MATTERS

About Communication Matters

Communication Matters is a UK voluntary organisation which focuses upon the needs of people with severe communication difficulties, who may benefit from special communication systems to maximise their opportunities and enhance their life.

The aims of Communication Matters are:

- to increase awareness, understanding and knowledge of good practice in the field of augmentative and alternative communication (AAC).
- to provide a forum for the exchange of information and ideas between professional workers, AAC users and their families.
- to promote the positive role of AAC in the empowerment of people with severe communication difficulties in society.

Communication Matters is the UK branch of the International Society for Augmentative and Alternative Communication (ISAAC).

About this Advocacy Pack

This Advocacy Pack has been produced by members of the Communication Matters Advocacy Project Steering Group. As members of ISAAC and Communication Matters we want to do what we can to make sure that people who use different or additional forms of communication have the chance to make their views and feelings heard. We want to help people speak up and speak out for themselves. This pack is about communicating with AAC users; it is about advocacy; it is about self advocacy. The project steering group has run pilot courses using materials in this pack and we are grateful to the participants on these courses for their comments and feedback which have been integrated into this final version. The steering group would also like to thank the members of Chatterbox User Support Group (Scotland) for their insightful comments on advocacy.

For more information on Communication Matters or this advocacy pack, contact the Communication Matters Information Line on (0870) 6065463.

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United Kingdom Chapter of the International Society for Augmentative and Alternative Communication

COMMUNICATION MATTERS

Speaking Up, Speaking Out

Pathways to Self Advocacy

Handbook

This handbook is divided into eight sections:

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3.	Advocacy for people with communication difficulties	... 12
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Introduction

Speaking Up, Speaking Out consists of a Handbook and Practical Guide. You do not have to know about augmentative communication or advocacy in order to use this package. We want to help people speak up and speak out for themselves and that is what this Handbook and the accompanying Practical Guide are about. It is about communicating with people with severe communication difficulties; it is about advocacy; it is about self advocacy.

Why?

As members of ISAAC and of Communication Matters we want to do what we can to make sure that people who use different or additional forms of communication have the same chances as everyone else to make their views and feelings understood. We want to give them the opportunities to make choices and decisions about how they want to live and what they want (or don't want) to do.

Who is this handbook for?

We have developed **Speaking Up, Speaking Out** for anyone who on a day to day basis supports and works with individuals who have severe communication difficulties. Communication partners (parents, family members, friends, key workers, care workers, volunteers etc.) are very important.

Strictly speaking, an advocate should be someone who is not involved in any other way with the person for whom they are advocating. However, there are practical reasons for addressing this package to the people who are constantly communicating and in daily contact with persons with severe communication impairments. They are very important for the following reasons:

- It takes a long time to develop an effective communication partnership and to have the background knowledge and understanding to realise that something needs to be communicated.
- People with communication difficulties need lots of time to get their messages across and may transmit important information at unexpected times. In practice, carers are most likely to 'be there for them' at the right time and for long enough periods of time.
- Family, carers and day to day workers are often not recognised or supported in their role as advocates. They themselves may need information and support.
- In the real world, independent advocacy services are not always available locally. Where they exist, these services may have little experience of advocating for people with communication difficulties.

Introduction

How to use it!

The Handbook provides detailed information about advocacy and communicating with people with severe communication difficulties. You can read this Handbook on its own just like any other book. However, if you are involved in training or are a member of an existing advocacy service, the Practical Guide will identify key points for activity sessions or group discussions. If you are a key communication partner for someone with a communication difficulty, you could use the package to help you develop a realistic advocacy action plan for the person who you are supporting. The coloured pages in the Appendix and duplicated in the Practical Guide will allow you to create a personal advocacy plan for an individual you are working with.

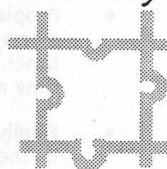
This Handbook and Practical Guide are both divided into the following sections:

1. Introduction
2. What is Advocacy?
3. Advocacy for People with Communication Difficulties
4. Communicating Effectively
5. Towards Self Advocacy
6. Ethical Issues
7. Who Supports the Supporters?
8. Conclusion

Each section in the Handbook is accompanied by Case Stories. These case stories illustrate key issues and the questions raised in each section. The case stories are designed to be used either for small group discussion or as part of an individual learning plan.

We hope that **Speaking Up, Speaking Out** will help you to help your communication partners out of immediate difficulties and also to help them to develop their own advocacy skills. In this way, we hope, people with communication difficulties will gradually become more able to communicate and advocate for themselves and will become less dependent on others to advocate for them. Through using this package you will be able to build realistic advocacy action plans which will help your communication partners move towards greater confidence in their own decision making, greater independence and greater self advocacy.

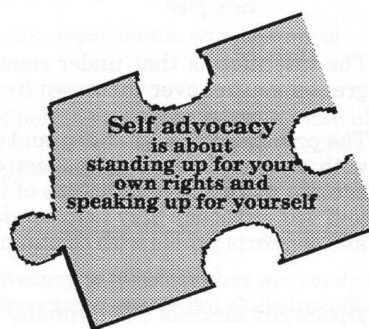
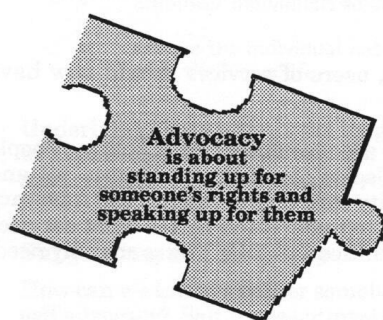
Summary



What is Advocacy?

This section will cover:

- The context for advocacy services
- Examples of recent advocacy developments
- Different models of advocacy and advocacy services
- The aims of advocacy
- Supporting self advocacy



The context for advocacy services

Two recent developments have helped to make advocacy services for people with communication difficulties a priority. The first is a development which has its roots in the everyday practice of workers and carers who support people with communication difficulties; the second is a direct result of central government policy. These two developments are:

- The emergence of the inclusion movement.
- The introduction of care in the community.

The **inclusion movement** argues against any form of segregation and against the notion that some people have deficits. It stresses the right of everyone, regardless of their ability, to have a say in their life choices, to be an active and contributing member of the community. Providing the appropriate supports to enable all people to live actively and participate in their community is what inclusion values. It wants society to move away from providing special treatment or care which separates and hides away whole sections of the population.

What is Advocacy?

Care in the Community was developed in the early 1990s. A fundamental principle of this approach is that local authorities should consult with, listen to and take account of the views of service users when drawing up and putting into practice their community care plans for an area.

Consultation with the users of services takes place at two levels:

- At a collective level - in relation to care planning for the local community as a whole.
- At an individual level - in relation to drawing up an individual's community care plan.

The intention is that under community care, users of services should now have greater control over their own lives.

The principles of user choice and consultation are now government policy. People with communication difficulties can be enabled to speak up for themselves and become more active members of the community care planning process. Advocacy and self advocacy may help service providers to understand better what services and supports people with communication difficulties and their carers actually need.

Different models of advocacy and advocacy services

A range of advocacy services has been developed to assist those individuals who find themselves in circumstances or situations where it is difficult to speak up for themselves and be heard. A few examples are:

- Advocates for people receiving hospital care known as Patients' Supporters.
- Advocates for parents whose children are being assessed as having special educational needs known as Named Persons.
- Advocates for people with mental health problems and people with learning difficulties, in their communications with the police known as Appropriate Adults.

Advocacy services work in many different ways. Sometimes advocates are paid; sometimes they give their services on a voluntary basis. Sometimes a person's need for advocacy is a short term one to help over a crisis. However, in most cases, advocates need to be available to those they are supporting over a longer period of time.

Underlying most advocacy services is the hope that through being advocated for by someone else, individuals will learn how to be better at advocating for themselves. Good advocacy should enable individuals to grow towards self advocacy.

What is Advocacy?

The aims of good advocacy are to:

- Enable all individuals to be treated with equal respect and equal consideration.
- Enable all individuals to have access to information about their rights in a form that they can understand.
- Increase the ability of all individuals to make informed choices and decisions based on their own wishes.
- Empower individuals to be more able to do things for themselves.
- Ensure the individual has real and relevant opportunities to take control over their own life.

Underlying these aims is the long term goal of helping a person become more able to speak up for themselves and move towards self advocacy. Good practice in advocacy can lead to increased readiness to self advocate.

Supporting self advocacy

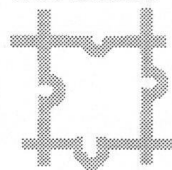
How can we know whether somebody needs advocacy or whether they are ready for self advocacy? Self advocacy involves many different and important skills including:

- Being able to communicate and get your message across.
- Making decisions.
- Doing something about your decisions.
- Knowing what your rights are.
- Knowing your responsibilities.
- Asking for help when you need it.
- Feeling good about yourself.

Worksheet

Using the points above, think about people you know and consider whether they might benefit from advocacy support.

Checklist 1: Personal Skills to Support Self Advocacy will help you to identify the skills necessary to move along the pathway to self advocacy.



Self advocacy and being able to move towards it are particularly important for people with communication difficulties. In the next section we explain why, and we consider some of the special challenges that advocacy work presents to those supporting people with communication difficulties.

Case Story 2.1

The facts:

Ryan is a 25 year old man with cerebral palsy and moderate learning difficulties. Because his speech is difficult to understand, he uses a picture communication book. He lives at home with his elderly mother who feels she knows what is best for her son. Ryan has been attending a local further education college for the past 3 years. The college lecturers now feel they have nothing more to offer Ryan and have asked for a reassessment of his placement by the Social Work Department. This has not been discussed with Ryan. The Social Worker has completed her assessment and has concluded that a placement in a local day centre would be most appropriate. The Community Medical Officer in charge of Rehabilitative Medicine has also been involved with this family for many years and feels that Ryan would be better off in a residential setting where he might learn to become more independent. Ryan has been very open about his wishes and he wants to stay at college.

There has been heated debate at many case reviews among all the professionals and Ryan's mother as to what is the best placement for Ryan. Ryan has not been in attendance at any of these discussions.

The questions below are offered to help groups get started in discussion about the case presented. Please add any additional questions your discussion group raises in the space provided. As these cases are examples of real situations, we have provided you with what really happened on the following page. You may want to look at this after your group discussion.

Discussion questions:

1. How might an advocate start to help Ryan?
2. What can an advocate or advocacy service offer Ryan?

Additional questions raised by the group:

--

Key issues:
user consultation, participation,
advocacy support, empowerment

Case Story 2.1

This is what really happened! Your discussion group might have come up with a different scenario. There are no right or wrong answers.

An advocate has been made available to Ryan to help him become part of the decision process and to ensure that his wishes are taken into account at every step of the way. The advocate initially has met with Ryan to identify what he wants and how he can help him to speak up for himself. A written record of Ryan's wishes is made and Ryan and his advocate are scheduled to attend the next case conference. The advocate also helps Ryan to explore what he may want to study if he continues at college and help Ryan to put it in a form that he feels comfortable with to explain to the professionals. The outcome of the meeting is that Ryan will continue at college for the next term and Ryan, his advocate, and the college staff will meet regularly to plan an appropriate course.

Case Story 2.2

The facts:

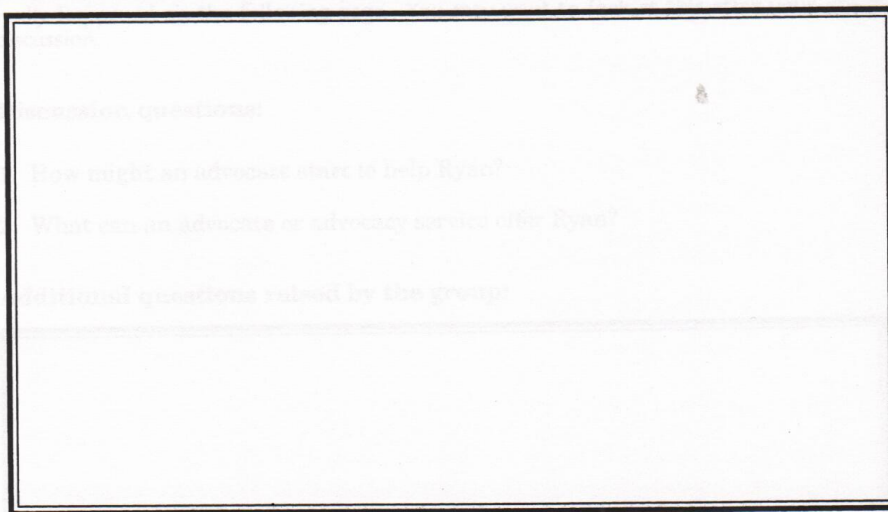
George is a 19 year old man who uses a communication aid. George has been attending a residential college for the past 2 years and his course is due to finish in a few months time. George is hoping to return to his home area and live in an adapted bungalow. He wants to take responsibility for his day to day needs as much as possible and make his own decisions. However he has never lived on his own and is not sure what to expect. He is also not sure whether he will be able to communicate all his wishes to the professionals and his family.

The questions below are offered to help groups get started in discussion about the case presented. Please add any additional questions your discussion group raises in the space provided. As these cases are examples of real situations, we have provided you with what really happened on the following page. You may want to look at this after your group discussion.

Discussion questions:

1. What would be the priority tasks for an advocate at this time ?

Additional questions raised by the group:



Key issues:
informed choice, advocacy support,
access to information, empowerment

Case Story 2.2

This is what really happened! Your discussion group might have come up with a different scenario. There are no right or wrong answers.

George has been put in touch with a local advocacy service and an advocate has been provided. George is able to discuss his concerns and plans are made to outline all the decisions George feels he can make for himself. Using this outline, George and the advocate can detail realistic ways to help George make his own decisions. A meeting is set up with the professionals and George's family to discuss these. The advocate has also arranged for George to visit the local community and talk to other young people who are living independently. George feels he is now part of the planning process and has a better idea of what to expect when he moves.

Case Story 2.3

The facts:

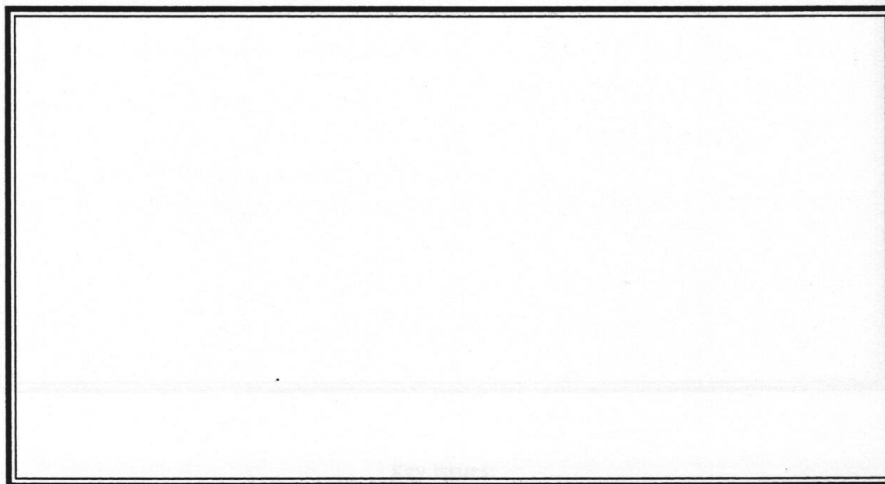
Jenny is a 21 year old woman who has been using a Lightwriter communication aid for the past 4 years. Although Jenny lives with her mother, she has always strived to be as independent as possible. Jenny makes her own plans and is now concerned over one aspect of her life. Jenny needs to attend her doctor regularly and is becoming increasingly upset because she feels she should be able to see the doctor on her own without her mother present. She is not sure how her mother will react if she suggests this. Jenny has decided to confide in her Social Worker and asks her what she should do. Jenny's social worker has recently heard about a new advocacy service in their area and wonders whether an advocate might be a good idea for Jenny. The Social Worker tries to persuade Jenny that she could refer her to this new advocacy service. Jenny is very doubtful about how helpful an advocate might be as she wants to try and settle this with as little fuss as possible.

The questions below are offered to help groups get started in discussion about the case presented. Please add any additional questions your discussion group raises in the space provided. As these cases are examples of real situations, we have provided you with what really happened on the following page. You may want to look at this after your group discussion.

Discussion questions:

1. How might Jenny resolve these issues without a referral to a formal advocacy service?

Additional questions raised by the group:



Key issues:
control, support

Case Story 2.3

This is what really happened! Your discussion group might have come up with a different scenario. There are no right or wrong answers.

Jenny is adamant that she wants to try and settle this on her own and she fears that bringing in an advocate might inflame the situation. Jenny and her social worker then discuss other ways that Jenny might handle the situation. Jenny has decided to first speak to a few of her friends when she sees them at the local support group. She is sure that others must have come across this problem and wondered how they have handled it. She has also decided to have an informal talk with her mother and suggest that her mother take her to the doctor's office and wait in the waiting room for her. Jenny's mother agrees to try this at her next appointment. Jenny promises to inform her mother on everything that is discussed with the doctor. This works well and Jenny and her mother continue this for all her subsequent appointments.

Advocacy for People with Communication Difficulties

This section will cover:

- The barriers to self expression faced by people with communication difficulties
- The balance of power and giving power back
- The possible tensions and role conflicts professionals and parents may face acting as advocates.
- When advocacy is most necessary
- Advocacy challenges

Everybody needs opportunities to develop the ability to speak up for themselves. Some people find it easier than others to get their voices heard. People with communication difficulties face particular barriers.

Attitudes and perceptions

One of the greatest barriers facing people with communication difficulties is how other people see them. Communication disability is not well understood. It is an invisible disability and is not formally recognised like a visual or hearing impairment. The role of an advocacy worker may therefore include information provision and awareness raising in the whole area of communication disability.

User's views

People often think that a person with disabilities should be protected from situations in which they may be at risk e.g. going to the shops in their powered chair and having to cross a busy road or attending a local school where bullying is a possibility. But life is a risky business for everyone and it is no different for people with disabilities.

Don't wrap me in cotton wool!

Sometimes we try to protect people with disabilities from hurtful or distressing information: the death of a close relative, the detection of a serious medical condition, the loss of someone loved. These are upsetting situations for all of us and we all need the support of friends and families to work through them. Such news should not be held back from people with communication difficulties.

I'm entitled to know information.

Young people with communication difficulties face all the same potential conflicts with their parents as any other young people. They will want to choose where they live, what they do in their free time, and with whom. They will kick against parental authority as a way of finding out who they are.

Let me grow up!

*Let me pay my way &
buy a round.*

While financial circumstances may limit the generosity of a person with a disability, it does not stop them wanting to give to others. Everyone has the right to give as well as to take.

*People stare at me or cross
the road rather than talk to me.*

People with communication and physical difficulties may look different but they are not from another planet, nor are they contagious - you can't "catch" disability. Once you get to really know someone you'll forget about any disability and see that they have similar hopes, worries, and hates as everyone else.

Like everybody else, people with disabilities want to have an active social life that they can share with friends. They want to go out with friends, to eat with friends, to travel with friends. However, this can present many very real practical problems - public transport is not accessible, nor are many public places - so some people with disabilities get out far less than they would like and are far less visible as a result. And that brings us to the barrier of limited life experience.

*I just want to go out and
about like anyone else.*

Limited life experience

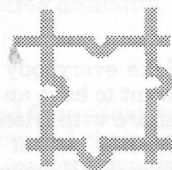
People with communication difficulties will often have far less experience of everyday contacts, such as speaking to bus conductors, supermarket check-out staff, neighbours etc. This is partly because it is often harder for people with disabilities to get out and about. It is also harder if the person has a communication difficulty since it is more difficult to start and sustain a conversation. Other people may think that communication is going to be difficult and may therefore avoid attempting it, often because they are afraid they will somehow look foolish or do the wrong thing. As a result it is hard for people with communication difficulties to experience communicating with others.

Furthermore, people with communication difficulties will often have many years of experience of letting others do the thinking and the talking for them. Sometimes, this is because they have had no easily recognised and understood way of communicating and so they have had no choice but to leave others to speak for them. Sometimes other people have just got into the habit of doing all the talking, even though the person with communication difficulties could communicate by themselves. Sometimes, it is because they take much longer to communicate than people around them allow time for.

It may be beneficial to look at the types of people in the environment which you and a person with communication difficulties might come into contact with on a daily basis. The various people you come into contact with in your everyday life - family, friends, acquaintances, people paid to be in some sort of contact with you (e.g. doctor, electrician, etc.) - all have a specific kind of relationship with you. With some people you may have a close, loving relationship, with others it may be a brief, business-like contact, with yet others it may be somewhere in between. On the whole these relationships will be based on an ability to communicate and on an ability to get around and meet people. It is possible to think of these relationships in some sort of hierarchy - with yourself at the centre and the various people radiating out from you like ripples in a pond. People you have an emotional bond to are likely to be closest to you and people who you only have a fleeting contact with are likely to be considered at the farthest point away from you.

Worksheet

At the end of this handbook, you will find the **Worksheet 2: Circle of Friends**. This will help you to identify the different types of people who communicate with yourself and the people for whom you advocate. It may be helpful to compare your circle of friends and those of the people you are considering advocating for.



In general people with communication difficulties often have lots of people in their outermost circle but fewer people in the inner circles. This is usually reversed for people who do not have difficulty in communicating.

This double barrier of other people's attitudes and their own limited life experiences makes it crucial for people with communication difficulties to speak up for themselves. The life experiences of people with communication difficulties will only be enriched if those supporting them consistently try to provide support to enrich their inner circles and allow self experience and self confidence to grow.

The balance of power

People with communication difficulties are at risk of feeling powerless in the face of powerful others (e.g. key workers, support staff, social workers, and other professionals) who can control their lives. They often need advocacy support to shift the balance of power and get more control over their own lives.

There are many reasons why people with communication impairments may feel powerless. These include:

- Others tending to speak for them.
- Lack of experience of success leading to a lack of confidence.
- Being told they cannot do things.
- Not having adequate communication skills.
- Not being sure that people will understand their communication attempts.
- Being unsure that people will be patient and give them sufficient time to communicate their needs and wishes.
- A lack of positive role models.

If we want to help our communication partners to have more control over their lives we have to think of ways to give power back to them.

Professionals as advocates for people with communication difficulties

Limited life experience of people with communication difficulties, combined with the general lack of independent advocates, means that more often than not professionals involved in supporting people with communication difficulties - speech and language therapists, teachers, social workers, care staff - will find themselves in situations where there is no-one else to advocate for the person they are supporting.

Immediately, this creates problems. Role confusion and role conflict are likely.

There is a problem for the professional, stepping outside their 'normal' role and having to follow a different set of principles and guidelines. For example, they might have to switch from being quite directive and being the one to set goals, to taking a back seat and learning to wait for the person him or herself to ask for advice or help or more time.

Equally, the person being advocated for might find it difficult to grasp that their supportive professional has switched hats, and will no longer tell them what to do, will no longer organise their social timetable and organise transport for them etc. but is in fact waiting for them to say where they want to go when, to ask for another appointment, and so on.

Other people involved may have difficulties in realising that a particular professional is temporarily switching roles, perhaps appearing less supportive than usual of parents' views.

A typical example of when role conflict and confusion occurs is when young people with communication difficulties are going through the process of deciding what to do once secondary education ends. All the professionals involved, the parents/carers and the young person will meet together to discuss the options. The way the young person's teachers, parents and social workers look at the options might be quite different from each other. Where does this leave the young person? Who has the greatest right to speak up for him or her? Will all the professionals involved agree on how much say the young person should have? Or does the young person need an advocate who is independent of all of those different opinions? Who can help the young person think through the issues and support them through this period?

Family members as advocates for people with communication difficulties

If professionals sometimes experience role conflict and confusion when they are acting as advocates, the potential tensions and role conflicts between parents and children and between parents and professionals are even harder to resolve. Children and adults with severe communication difficulties may have relied all their life on their parents / family to speak for them and to interpret their wishes and needs, on both trivial and important matters. Family relationships are complex for everyone. It's never easy for any young person to move from a child-parent relationship to an adult-adult relationship. But when one family member has a greater degree of dependency on others in the family, then those relations become even more complicated since much of the family life will have revolved around that person, with dependency being their primary role. Moving from that deeply entrenched role towards independence will be difficult. As the young person tries to develop a sense of self and to "separate" from the parent/family, the parent/family might feel the established relationship is under threat. It might be especially painful for parents of a disabled child to 'let go'. It might be very hard for the child (or adult) with the communication difficulty to make and stick to a choice that he/she knows the parents and family will be unhappy with.

Very real difficulties lie in the tension between parents' responsibility to care for and protect the young person/adult with communication difficulties and their responsibility as advocates to be helping their son/daughter to make choices about their lives and to move towards greater self advocacy. Careful thought and consideration need to be undertaken before taking on an advocacy role.

Here are some questions to consider before becoming an active advocacy partner:

- Does your communication partner want you to be involved in advocacy work with them?
- What tensions may be created if you hand over more control to the person you are supporting?
- Are there other people involved with the person you are supporting?
- How do you let those people and your partner know of your change of roles?

When is advocacy most necessary?

Advocacy is most necessary at times of transition when major life choices and decisions have to be made: leaving home to go to school, leaving school to go to college, leaving college to go on to training or to work, leaving home to go into care, leaving home or care to go in to supported accommodation. People with communication difficulties are often extremely vulnerable to decisions made on their behalf. Sometimes the decision makers are hard to identify and often people with communication difficulties will have little influence over them. An advocacy worker should anticipate well ahead when such changes are coming up, explore the possibilities and options, and work to prepare the person with the communication difficulties for the implications of these changes.

Advocacy challenges

Doing advocacy work with people with communication difficulties will be challenging. The primary challenge and consideration for anyone involved in advocacy work with people with communication difficulties is to make communication a priority. This will involve:

Time challenges:

- The amount of time needed for your partner to respond.
- The amount of time needed for feedback. It can take a great deal of time to interpret words/gestures/sounds into meaningful statements and to check with your partner that your interpretation is correct.

The challenge of familiarity

- Knowing your partner very well over a long period of time can sometimes be a disadvantage as well as an advantage. You may presume that you know what they think and feel and how they will respond, and be unaware of changes that are taking place in their thinking. This is a trap you need to be aware of and avoid falling into.

Challenge of decision making

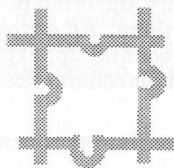
- Limited experience in making decisions can make it difficult for a person with severe communication difficulties to exercise choice and control over more important matters in life. This may also mean that they have little or no experience of learning about the consequences that come from having made a decision.

Challenge of appearances

- People with communication difficulties are often seen as passive. Because they can't easily speak for themselves they are often not given the opportunity to put forward their ideas. They eventually come to accept that their role in life is to be a spectator only.

- Just because a person can't speak doesn't mean they can't understand what you say - often they can. However the opposite is also true - just because someone seems to understand much of what you say doesn't mean they understand all of what you say.

Remember



The primary consideration is to make communication a priority.

The next chapter identifies and discusses how people can communicate effectively using augmentative and alternative communication systems and how you as a listener can facilitate communication.

Case Story 3.1

The facts:

Terry is a 26 year old man with cerebral palsy and moderate learning difficulties. He communicates using some single words and uses an Orac communication aid via a single switch to backup his speech. He lives at home with his parents.

Terry attends a local day centre where he has attended for the past 8 years. Terry has been able to go to a few outside activities such as a Social Life skills course at a local college. Both the staff and Terry have been concerned for some time as to the appropriateness of his day centre placement. The centre is small and cannot offer Terry a range of activities. He is now becoming interested in computer technology and would hope to be able to put together a newsletter. He is also interested in exploring other placements including those which may involve moving away from home. He has spent eighteen months investigating various living situations with the help of his Social Worker. His parents have not been keen on this from the start but have allowed Terry to continue his investigations. Terry has now decided on a residential placement approximately 40 miles away from home. This placement offers Terry a wide range of choices of daily activities including links with the local Further Education College and its computing department. All the plans are made and Terry is due to move in 6 weeks time. However, during a subsequent discussion with his social worker, Terry says he no longer wants to move and will just continue at the day centre.

The questions below are offered to help groups get started in discussion about the case presented. Please add any additional questions your discussion group raises in the space provided. As these cases are examples of real situations, we have provided you with what really happened on the following page. You may want to look at this after your group discussion.

Discussion questions:

1. How might an advocate have helped Terry during his initial investigations?
2. What might an advocate do now to help Terry in planning for the future?

Additional questions raised by the group:

--

Key issues:
transition, balance of power,
choice making

Case Story 3.1

This is what really happened! Your discussion group might have come up with a different scenario. There are no right or wrong answers.

Terry has continued to feel bad about not moving away from home but feels he cannot really talk to anyone at the centre or at home. He feels he has let them down. Terry is put in touch with a local advocate and he begins to explore and record what he really does want to do in the long term and his reasons for staying at home. The advocate helps Terry to discuss this with his family and the centre staff and plans are then put into action to find an appropriate placement for Terry in his community. The advocate and Terry also begin to draw up a list of choices and decisions that Terry will have to make and their possible consequences on Terry and his family. Terry has very strong feelings on the kinds of activities he wishes to pursue and these are written down. Terry is accompanied by his advocate on visits to other centres and key questions are posed by Terry to ensure all his needs will be met.

The questions below are offered to help groups get started in discussion about the case presented. Please add any additional questions your discussion group raises in the space provided. As these cases are examples of real situations, we have provided you with what really happened on the following page, for you to look at after your group discussion.

Discussion questions

1. How might an advocate have helped Terry during his initial investigations?
2. What might an advocate do now to help Terry in planning for the future?

Additional questions raised by the group



Key issues
Transition, balance of power
Choice making

Case Story 3.2

The facts:

John is sixteen years old and has good understanding of speech. He has always preferred using unaided methods of communication. He uses eye-gaze and several hand gestures to signal to his listener what he wants to say. At times, these attempts can go unnoticed by John's parents and school staff. John is being asked to consider a change of placement to a new school. A meeting has been called to discuss this with John and his parents and for all parties to be able to explain what they feel about the plans. John is concerned that his communication attempts might go unnoticed and has asked his Speech and Language Therapist to accompany him to the meeting to make sure his communication attempts are recognised.

The questions below are offered to help groups get started in discussion about the case presented. Please add any additional questions your discussion group raises in the space provided. As these cases are examples of real situations, we have provided you with what really happened on the following page. You may want to look at this after your group discussion.

Discussion questions:

1. What factors should the Speech and Language Therapist take into account when agreeing to do this?
2. What role will the Speech and Language Therapist be taking on during this meeting?

Additional questions raised by the group:

is more important than the words themselves. The words are only a vehicle for the message. The message is what counts. The words are only a vehicle for the message. The message is what counts. The words are only a vehicle for the message. The message is what counts.

Key issues:
transition, role conflict,
power, control

Case Story 3.2

This is what really happened! Your discussion group might have come up with a different scenario. There are no right or wrong answers.

The Speech and Language Therapist has sought permission from the school and John's parents to be present at the meeting. She makes sure that all involved know what role she will be performing. She is not there as a professional to give her opinion on the new placement, but rather to ensure that John's opinions are taken into account. At the beginning of the meeting, she informs all present how she will let them know when John has something to say and she ensures that ample time is given for John to explain his feelings. This works well and John feels that he has had his feelings taken into account.

Communicating Effectively

This section will cover:

- The nature of communication and its effectiveness
- What AAC or augmentative and alternative communication means
- Differences between AAC and natural spoken communication
- Techniques and strategies to facilitate effective communication
- Making written communication accessible
- Enabling advocacy by communicating effectively

Communication is more than just speech

We often take it for granted, but communication is an active and very complex process. Communication is a two way process. It is about the expressing and receiving of messages. Both partners have responsibility for making sure that messages are sent and understood. In this section we will be thinking in some depth about what is involved in communicating effectively.

We communicate with each other every day in many different ways, for instance - speech, tone of voice, facial expression, gesture, body posture and body movements, eye-pointing, touch, etc. We often use several of these at once to get a full message across. Communication can be immediate or delayed, fleeting or long-lasting, private or public, between two people or in a group, face to face or across a distance. As well as using our voices and our bodies, we also use communication tools such as pencil and paper, tape-recorder, typewriter, computer, telephone, or fax machine to communicate. However, for communication to happen there must be someone or something to receive and understand the message.

The most commonly used tools for everyday communication in our society are combinations of facial expression, voice, tone, speech. We receive messages through our eyes and our ears. Speech is not the only means of communication, although for many people it is the main one. Some messages can be conveyed quite easily without speech. A frown can send the message that the person you are talking to is not very happy with something; a yawn or a sigh that they are tired or bored.

Communicating effectively with people who do not use familiar communication channels presents all of us with a real challenge. Patience, sensitivity, imagination and the skills of careful observation, listening and paying attention become even more crucial if the exchange is to be successful. Communication is complex. It can easily go wrong even between people who know each other well. It can go wrong even more easily if any of the familiar means of receiving and understanding messages are missing.

Some people with disabilities cannot rely on speech as their main means of communication, so they may use special techniques or technologies as well as facial expression, gesture, eye contact etc. These special techniques and technologies are referred to as Augmentative and Alternative Communication (AAC) techniques.

The aim of this section is to explain what AAC is and to discuss some of the ways AAC conversations can be different from "natural" spoken communication.

What does AAC or augmentative and alternative communication mean?

Quite simply it means any methods of communicating that can replace or be added to the ordinary methods of speech and handwriting, where these are impaired. There are times when we all use aspects of AAC, for example gesturing across a noisy pub to a friend for a drink. Some people rely on AAC all the time.

The aim of AAC is to give the power of communication to people who can't speak or write in the usual way. AAC helps to support and to improve communication, learning, participation, degree of independence and general quality of life. AAC can help someone to do more in life, by providing him/her with a greater level of independence. McFadden (1995) says *"...to me and others like me being able to communicate puts us into society. It lets us have a voice... For me having a Liberator has changed my life completely."*

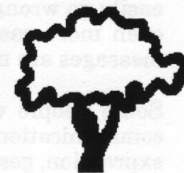
The term "AAC" includes four inter-linking strands (RCSLT, 1996):

1. The **communication medium** - how the meaning of the message is being sent. The communication medium can be unaided meaning that no additional material or equipment is used. Essentially, this means gesture, facial expression and/or manual signing. The biggest advantage of gestures and signing is that they are quick, immediate and practical. You can't forget to take these systems with you; you can use them wherever you are; you don't need any expensive or cumbersome equipment; they can't break down.

The communication medium can also be aided which involves some additional physical object or equipment such as symbol charts or books, or microelectronic devices (also called communication aids). An aided communication system can be something very simple e.g. the alphabet written on a plain postcard. These are described as low-tech aids. Alternatively, an aided communication system may involve a sophisticated computer based system specially programmed with a large vocabulary. These are described as high-tech aids.

2. A **means of access** to the aided communication medium - this may be via a keyboard or touch screen, or by using a mouse, joystick, or switch to scan from an array of letters / words / pictures.

3. A **system of representing meaning** - when people speak their meaning is represented by spoken words. Words are a form of symbols; the word 'tree' is a symbol for the real tree that grows in the park. Where a person is unable to speak, their meaning has to be represented by a different set of symbols. These symbols may be letters that are built up into written words or they may be a set of pictorial symbols (e.g. Picture Communication Symbols™).



4. **Strategies for interacting** with a communication partner, for example being able to start up a conversation: *"Hello, I haven't seen you for ages!"* Or being able to sort things out when the other person does not understand: *"You haven't understood me right."* or *"I'll point to something like the thing I mean."* Another example is closing a conversation such as *"See you around, bye!"*.

Some differences between AAC and "natural" spoken communication

The experience of talking can be very different for someone who is able to speak clearly as compared to someone who has no speech and who uses AAC techniques. "Natural" speakers take it for granted that they will be able to say what they want to say and that people will understand them. They think more about the content of their message than how they say it.

This can be different for some people who use AAC. They may be unsure of how to say what they want to say with their AAC system. Their experience of speaking up for themselves may be very limited. They are aware that their method of communication is different and that people may not be sure of how to react or may not give them enough time to say everything that they are trying to say.

The exchange between an AAC user and someone who is able to speak naturally may be different from that between two natural speakers. The end result may well be the same: - a shared joke, a chat, a request for help but there will be differences in how this is achieved.

Differences: Time

Conversations are usually slower. AAC users in general take longer than natural speakers to get started and be understood. As a result, there tends to be lots of silences or gaps in the conversation.

Silences in a conversation usually have some sort of meaning (often negative) - perhaps that one person has not been listening, or that they are bored, or that they disagree with what is being said. Silences in a conversation between an AAC user and a natural speaker can be meaningful, but they are often simply caused by the AAC user needing time to respond and to produce a word or a phrase.

Do

- Allow plenty of time for a conversation. If time is limited, tell the person this straight away and come back later to continue the conversation.
- Wait and give the AAC user a chance to start the conversation off.
- Stay relaxed and wait for the AAC user to say what they are going to say.
- Allow 10 seconds before asking another question or making a comment.
- Ask the person whether they have finished or if they have more to say.

Don't

- Feel embarrassed by long silences.
- Feel you have to fill up silences by 'chat'. This might put the AAC user off what they're trying to say.
- Change the topic of conversation, having assumed that silence means the person has finished saying all they have to say on the previous topic.

Differences: Control of the conversation

Because natural speakers can communicate more quickly than AAC users, and because they may have more experience of being involved in conversations, it is all too easy for them to control or dominate conversations with AAC users. This may be quite unintentional. The person who controls a conversation may decide what is discussed, may be able to get his/her ideas across more strongly, may decide when the conversation is finished or when the topic of conversation has changed. The AAC user may not get much of a chance to talk about what he or she has in mind.

Do

- Remember to wait and leave plenty of time for the AAC user to speak.
- Ask the AAC user what they want to talk about.
- Give AAC users plenty of chances to ask questions themselves, and to make comments as things go along.

Don't

- Start a conversation assuming you know what the AAC user wants to talk about.
- Assume you know what the AAC user's views are.
- Bombard the AAC user with a series of questions one after the other.
- Flit from topic to topic just as the user is getting going on one.

Differences: Misunderstandings

Misunderstandings happen when one person fails to understand what the other is saying. These tend to happen more often, and be more problematic, in conversations with an AAC user than in conversations between two natural speakers. Any problems which occur in conversations might be seen as being caused by the person with the communication difficulty. But communication is a shared process, relying just as much on the listener as on the speaker. Both partners have responsibility to try to work out what is being said.

Techniques which can be helpful in reducing the problems caused by misunderstandings include:

Do

- Check that you are understanding correctly what the AAC user is saying.
- Look for clues in the AAC user's non-verbal communication; they may be indicating by their facial expression that you have not understood.
- Say something like "I'm sorry, I can't get that". Say out loud what you think you heard to help identify where there was a break down in communication.
- Try asking the AAC user to repeat. Ask them to say it in a different way; to give you a clue by pointing or looking or gesturing or saying a similar word.
- Check whether the issue is really important to the user, or whether it can be laid aside. If it is important, try to find somebody else who might interpret, or agree to come back to the topic another time soon.

Don't

- Pretend that you have understood when you have not.
- Let misunderstandings become upsetting. They do not mean that the content of the message was poor or that the user has failed, just that the process of transmission has not worked

The power of communication

Being able to communicate gives us the opportunity to influence and change our environment. It enables us to interact with others and so to broaden our experience and our understanding of the world. It allows us to express ourselves, to make our own choices, declare them, and to be in control.

McFadden (1995) points out "... you now have hundreds maybe thousands of people with new opinions, new wants, not willing to sit back and accept what goes on around us but stating opinions... As people it is our right to use our new found voice or not to use it. We may say things that people do not want to hear."

Whatever the nature of the message, communication is about exerting power and control. For that reason being able to communicate effectively with others is an essential human need.

Next you will find some ideas for strategies and techniques which might help to make the process of communication go smoothly.

Techniques and strategies for effective communication

As technology has improved, more and more people with severe communication difficulties have access to speech via an AAC system. It is important to remember, however, that people communicate with each other, not with machines! No matter how sophisticated the communication aid, it cannot speak on its own! A successful conversation with someone using AAC technology will depend on many things: your communication style when you talk with a person using an AAC system; your attitude towards that person; the opportunities that person has for real conversation; the amount of training and support the AAC user gets; the amount of training that you as a communication partner get. All of these things are vitally important in determining how effective the use of AAC technology will be for the user.

All AAC users need something to talk about and somebody to talk to. They won't learn to be effective communicators without practice.

As well as general guidelines, it can be helpful to look at some more specific techniques.

Asking questions

There are many different types of questions that can be used. For example, closed questions such as yes/no, open questions, and non-questions.

The most basic communication strategy of all is to establish how the AAC user indicates **yes** and **no**. Some people will use their AAC system but many others will use other means such as facial expression, looking up for yes and down for no, or blinking once for yes and twice for no. Ask the person *"Please show me how you say yes"*, *"Please show me how you say no"*, or check with someone who knows them well.

If a person can indicate yes and no reliably then they can make their needs and choices known and can answer questions, so long as the questions they are asked are in a suitable format.

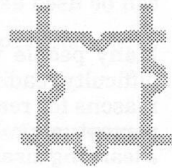
Often people think they know what the person is likely to think or want to say and they ask a question that simply invites the person to confirm or deny it by saying **yes** or **no**. For example, *"You're always hungry after swimming, aren't you?"* or *"It's raining, you'll want to stay in this morning won't you?"*. These may appear at first glance to be genuine yes/no questions but they are in fact closed non-questions that don't really need an answer at all. Using these types of questions makes it hard for the AAC user to say anything much.

A more productive strategy is to use genuine yes/no questions like *"Do you want a cup of tea?"*. These are quick questions to use because they demand very little communicative effort. But they are closed questions and therefore are quite limiting. They do not allow for any sort of response other than yes or no.

Another type of question is the **open question** which lets the AAC user answer in whatever way they want. For example, *"What are you doing at the weekend?"* This technique is higher risk for both communication partners in that the AAC user may find it difficult to answer or the listener may not understand the answer. It is potentially much richer, however, in that new information can be brought in independently by the AAC user.

Checklist

At the end of the handbook, **Checklist 3: Different Types of Questions**, will give you the opportunity to practice and explore different types of questions.



Forced alternatives

Another common technique is to give a choice of only two alternatives. For example: *"Do you want tea or juice?"* This is often highly practical in everyday situations where time is limited.

Ideally, mix different techniques. Start with open questions. Once the topic of conversation has been definitely established and the main area of discussion has been identified, using yes / no questions can be very useful to narrow down a range of options.

Feedback

It may be helpful for an AAC user to get some feedback to reassure them that they are managing to make themselves understood as they go along, especially with a long and complicated message. This can prevent or reduce misunderstandings. Feedback may be by saying out loud each letter they spell out from an alphabet chart (and it might also be helpful to write down the words as they emerge); or each word, phrase or sentence indicated on a communication board.

It's best to check if and how each user prefers to operate. Some people don't like feedback as this interrupts their train of thought or seems patronising or odd.

Guessing

AAC users vary. Some are happy for listeners to guess what their message is, realising that it is a quick way of communicating. Others hate listeners who guess and do not let them finish. Often it boils down to how well people know each other and how good listeners are at guessing. Always ask *"Do you want me to guess if I think I know what word you're saying. Do you want me to wait until you finish?"*

Communication is more than just writing

Both for daily communication and in an advocacy situation it may be useful to use written forms of communication. Writing can be used as an outline or agenda of what might be discussed at a meeting; as reminders for yourself and/or your communication partner; as a record of what was discussed or agreed during a conversation, etc. If face to face communication is difficult or time consuming, writing can be used as a back up to avoid having to repeat the communication process.

Many people who have difficulties with spoken communication may also have difficulty reading and understanding written material. There may be many different reasons for reading difficulties. These may include difficulties at school, visual or perceptual problems, the loss of the ability to read following a head injury or stroke, a learning disability, a specific language disorder or a learning difficulty e.g. dyslexia. You will need to find out whether your partner can or can't read, and at what level.

The most important aspect of making written material accessible is to get the language right. You will want to keep all written material short and simple:

- Think about what you are saying and why you are saying it.
- Think about what your communication partner needs or wants to know.
- Think about the words you use. Would your communication partner understand them if you spoke them to him/her?
- Think about the grammar of the sentences. Only write down sentences that are easily understandable when you say them out loud and quickly.

For readers

If your communication partner can read, but not easily, then there are some things you can do to make written materials more accessible:

Do

- Check with your communication partner whether he/she finds upper or lower case easier to read. Lower case writing is easier to read.
- Print clearly and use a basic font e.g. Times New Roman.
- Try out different colour contrasts. Some people find black writing on yellow paper easier to read, others prefer red writing on white paper.
- Use the simplest words you can to say what you have to say.
- Use short, simple sentences.
- Make the length of the lines short and have wide margins. Small chunks of text make it more manageable.

Don't

- Use joined up writing or fancy letters, just print.
- Use a fancy font or italics, they can be very difficult to read.
- Use jargon or long words.
- Use abstract concepts; actual information is much more understandable.
- Use long, complicated sentences.
- Use too large a font. It can appear childish and isn't necessarily easier to read.
- Fill up the whole page with writing.

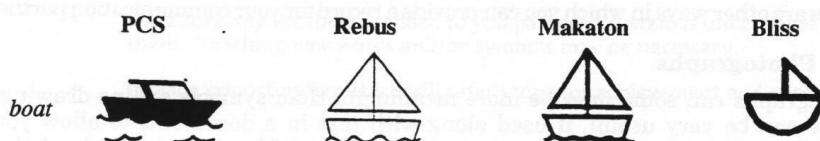
For non readers

If your communication partner is unable to read, then making the text bigger and writing in short simple sentences will not help at all. You may have to think about making your written information available in other formats. It may be helpful to give your communication partner written information in a variety of ways:

Pictures and symbols

Simple line drawings can be a quick way of graphically representing what you want to say. It doesn't need to be fancy, you can just do 'stick figures' and simple outlines of buildings etc. For abstract concepts, like "waiting" you will have to use your imagination - for example, waiting a short time might be a drawing of one clock, while waiting a long time might need five clocks! If possible talk through each drawing with your partner so that they know what each picture is meant to represent. If they can't be there as you draw, go through it with them afterwards bit by bit, as if you were just drawing it again. You cannot assume that they will just understand the pictures on their own.

There are also a number of pictorial symbol systems currently in use in the UK: Picture Communication Symbols™, Rebus™, Makaton™, Bliss™. All are similar in that they are a way of representing meaning in a graphic form, some are more pictorial than others but all rely on the user being able to assign meaning to the symbol and remember it over time.



Adapted from Augmentative Communication in Practice: An Introduction (1994).

Communicating Effectively

Before choosing to use a symbol set, you need to check if your partner has ever used symbols before. If they have, use the symbols they are familiar with. If your communication partner is new to symbols, it may take time to learn their meaning.

Computer programs are available which can take a sentence, or a page of text and convert it into symbols. The text and symbols can then be printed. It is important to realise however that this will not necessarily result in a document which is any easier for a non-reading person to understand. A page of computer printed symbols can make the page look even fuller and more cluttered, making it visually distracting and more difficult to read. Symbols and line drawings, used correctly, can be a very useful way of making some written information more accessible. If using symbols or line drawings:

Do

- Make sure that your communication partner knows and understands the symbols used.
- Teach your communication partner the meaning of the symbols you are using, if they are new to him / her.
- Make sure that you are using the right level of language.
- Use symbols to convey the key words in your message.
- Space out your sentences, have wide margins so that the page does not just become a dense jumble of words and symbols.
- Place symbols near to the appropriate text or on the opposite page.

Don't

- Assume that your communication partner will understand symbols. Check that he/she is familiar with the symbols you are using.
- Translate the whole sentence word for word into symbols.
- Feel that a symbol program on a computer will solve your problems of making written information accessible - it won't!
- Over fill your page with words and symbols.

There are other ways in which you can provide a record for your communication partner.

Photographs

Photographs can sometimes be more meaningful than symbols or line drawings. These can be very useful, if used along with text in a document, to allow your communication partner to discuss aspects of his/her weekly routine, to make choices about where he/she would like to live, what he/she would like to do at work, etc.

Video

There may be occasions when videoing a place or situation could be useful as a means of recording an event, providing a focus for later discussion. Videoing your communication partner in different living situations could help him/her make a more informed choice about where he/she would like to live, for instance.

Audio-recording

For some people it may be useful to audio record a meeting, or to make up a summary tape of the main points. Your communication partner can then listen to the tape in privacy using a personal stereo to remind himself/herself of what was agreed, what his/her action plan is, etc. For people whose first language is not English, providing information on audio tape in the appropriate language may be a useful way of overcoming a communication barrier.

Enabling advocacy by communicating effectively

It is important to learn the basics about communicating with AAC users for yourself and to practise them. People with communication difficulties usually find it easier to communicate more successfully with some people than with others. It is important to learn about good communication techniques and how to facilitate communication.

Enabling advocacy for people with communication difficulties includes ensuring they are being presented with information in a form they can understand. Remember that people with communication difficulties may need a lot of time to process what is said to them and need to think about things for a while before they come up with ideas and answers. Often people with communication difficulties can't write things down easily. They have to hold everything in their memory most of the time. This can be a strain and things may be forgotten. They may need several and frequent reminders and reinforcers.

The following is a summary of key points to remember to help enable and empower your communication partner to speak up for themselves:

- Find out how your advocacy partner communicates.
- Find out how they like to learn new information.
- Develop your skills in listening to a person with communication difficulties.
- Liaise with others and work with your partner to develop a communication system with vocabulary which meets their current needs.
- Make sure any vocabulary added to your partner's system is understood by them. Teaching new words and/or symbols may be necessary.
- Provide opportunities which will offer scope for achievement and success.

How you go about developing your and your partner's communication skills to help them speak up for themselves is explored in Section 5.

Case Story 4.1

The facts:

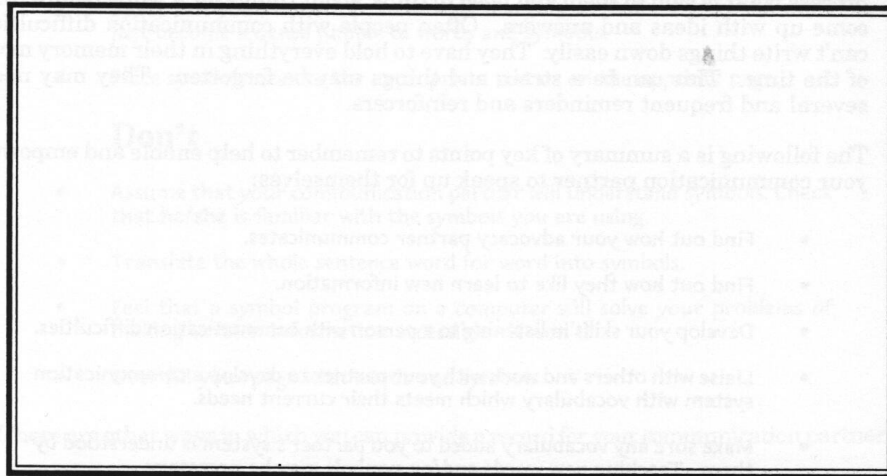
Laura is an 89 year old woman who has recently moved to a nursing home. Laura has a degenerating hearing loss and now is completely deaf. The nursing home staff and the Social Worker are keen for Laura to be an active participant in her proposed care plan for the future. However, they are finding it very difficult to communicate with Laura as they are having to write everything down they say word for word on a blackboard. This slows the process of discussion down and Laura often gets tired and loses attention.

The questions below are offered to help groups get started in discussion about the case presented. Please add any additional questions your discussion group raises in the space provided. As these cases are examples of real situations, we have provided you with what really happened on the following page. You may want to look at this after your group discussion.

Discussion questions:

1. How can the staff and the social worker make the information more accessible to Laura to ensure that she understands what is being discussed at regular meetings?

Additional questions raised by the group:

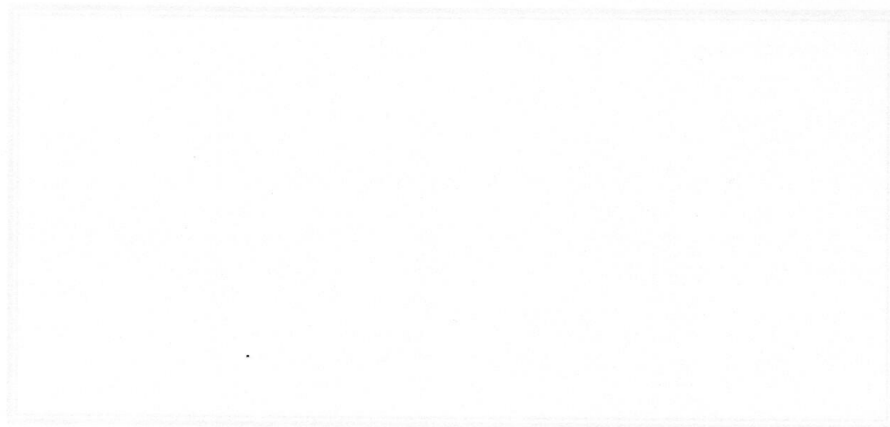


Key issues:
strategies, accessible information,
effective communication, time

Case Story 4.1

This is what really happened! Your discussion group might have come up with a different scenario. There are no right or wrong answers.

Laura's social worker has outlined the key issues to discuss at the next care plan meeting. The staff have constructed a word board with appropriate key words so that the staff can identify for Laura the topic being discussed as well as to remind Laura what they are discussing during the course of the meeting. Key choice responses are also presented on the back of the word board to remind Laura of her choices when making decisions. The use of the word board and the key topics are discussed with Laura before the meeting to ensure that she understands how the word board will be used. Additional blank spaces are left on the board to write in any particular topics that come up during the care plan meeting.



Case Story 4.2

The facts:

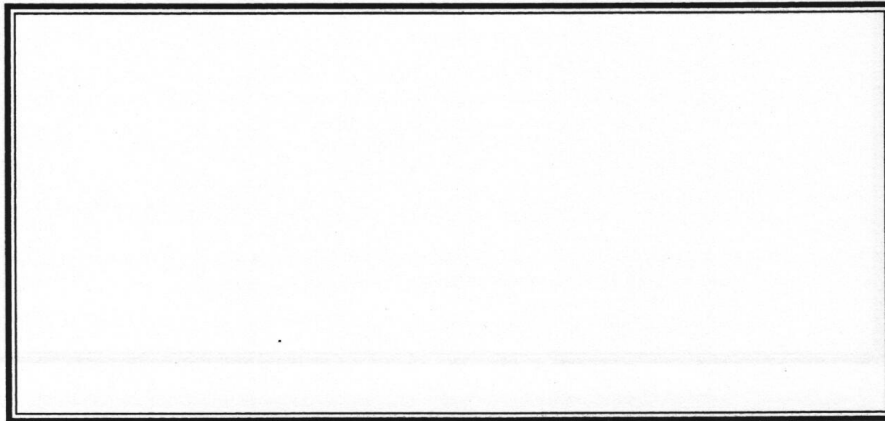
Simon is a twenty year old man. He has no understandable speech and mainly communicates by answering yes and no to questions posed to him. He is dependent on others to meet all his physical care needs. His family have made great strides towards recognising his adult status and his right to make his own decisions. Simon has to undergo major surgery and it may be necessary for him to have a blood transfusion during his hospital stay. His family are Jehovah's Witnesses but Simon wishes to consent to being given a transfusion if absolutely necessary. He is frightened of the possible alternative. He feels distressed that his family may not understand his wishes or attempt to override them. Simon feels he is unable to explain his feelings to his family or the medical staff. Simon has been involved with an advocate for the past year and they have been working together with Simon's Speech and Language Therapist on developing a communication system for him.

The questions below are offered to help groups get started in discussion about the case presented. Please add any additional questions your discussion group raises in the space provided. As these cases are examples of real situations, we have provided you with what really happened on the following page. You may want to look at this after your group discussion.

Discussion questions:

1. What can Simon and his advocate do to try and resolve this situation?
2. What will Simon need in his new communication system to discuss these issues?

Additional questions raised by the group:



Key issues:
effective communication,
strategies, control

Case Story 4.2

This is what really happened! Your discussion group might have come up with a different scenario. There are no right or wrong answers.

Through discussions Simon and his advocate have decided to include words in his communication system for feelings that he wants to communicate to both his family and the medical staff. In addition, questions that he may want to pose to the doctor are included in his communication system. The advocate and Simon have arranged for Simon to meet with the medical staff to discuss the procedure and Simon's feelings about the blood transfusion. Simon also has had many discussions with his parents about his concerns and although they do not agree with him, his parents have decided that he should be allowed to make his own decisions with regard to his health care.

Towards Self Advocacy

This section will cover:

- The relationship between advocacy and self advocacy
- How advocacy can lead to self advocacy
- What can be done to encourage self advocacy skills to develop
- How to draw up an advocacy action plan
- Judging how much control your partner currently has over their life, and what areas they need to work on
- How to record choices, decisions and other significant self-expressive information
- Planning and preparing for formal advocacy situations

Advocacy support and self advocacy skills help people with communication difficulties to express themselves - to give important messages about their own needs and wishes to others who may influence or control their lives. In Section 4, we looked at helping the development of effective communication and at different ways of making information more accessible to people with communication difficulties. In this section we will look at how to work out what stage people are at on the road to self advocacy; how best to record the self-expressive information people with communication difficulties build up in the process of working towards self advocacy; and how to plan and prepare for advocacy and self advocacy situations.

Drawing up an action plan

Moving towards self advocacy is a long process, not a single step. Like any long term goal, it requires careful planning. An advocacy action plan should:

- Follow agreed aims and principles.
- Include opportunities for developing choice and decision making skills.
- Have an agreed record keeping system.
- Include time for preparing for formal advocacy situations.

At this point, you should be beginning to think of the practicalities of developing an advocacy action plan for yourself and a communication partner.

The following planning stages might help:

- Stage 1: Aims and Principles
- Stage 2: Choices and Decisions
- Stage 3: Setting Targets
- Stage 4: Keeping Records
- Stage 5: Preparing for Formal Advocacy Situations

Stage 1: Aims and principles

The first step is to establish some general aims and guidelines. As communication and advocacy partners we should remember to:

- Involve the person with communication difficulties in making decisions and choices. This should begin as soon as possible, starting with simple straightforward choices e.g. choice of drink, clothes to wear and gradually moving towards choices which affect quality and/or control of life.
- Include the person with communication difficulties in any discussions regarding choices to be made. We should always talk with and not at our partners.
- Encourage people with communication difficulties to express their own opinions. We should remember that individuals with significant communication difficulties need to be given time to contribute to and participate in decision making. They need to have an understanding of any special vocabulary being used in these situations. They also need access to a means of expressing their own thoughts and ideas.
- Help our partner to be well-prepared and well-informed in advance of any new challenges or experience. Everyone involved in formal situations needs opportunities to practice and rehearse their roles.
- Help our partners to develop an awareness and understanding that having rights involves responsibility and commitment.
- Empower people by allowing and encouraging them to take risks. Sometimes the activities our partners choose may involve a degree of risk. We need to accept that risk taking is a natural and necessary part of gaining life experience and developing as an individual. We need to explain that any risk taking should be legal, reasonable, practicable and appropriate. It is important to provide a supportive framework and give support when our partners do decide to take risks.

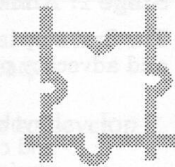
Stage 2: Choices and decisions

We know that for many people with communication difficulties, their experience of life will not have included many opportunities to make choices (simple or complex) about their life and the environment they live in. Having little or no experience of making choices, they may also lack any understanding of living with the consequences of their choices and actions.

Regular daily opportunities for choice and control and decision making in everyday life - with the opportunity to follow through the consequences of each decision - should be presented to your partner. The level of choice and control needs to be gradually increased. Without this experience, they will find it hard to gain the self-confidence to express choice and make decisions either at the significant transition points in their life or in formal advocacy situations.

Checklists and Worksheets: 4 to 8 are provided at the end of this handbook. They will help you to identify choice and decision making opportunities for an individual. You can then get a clear idea of what level of decision making they are used to and what kind of new choices and decisions need to be introduced before they will be ready and able to cope with major life changing decisions. It is important to set clear and realistic targets for developing choice and decision making skills.

Worksheet



At regular intervals (perhaps 3 or 6 months) it is wise to repeat the process of filling in the checklist. Compare the old and the new one, and discuss progress. Offer encouragement to your partner by emphasising successes and keep old checklists to look back on later to see how far they've come.

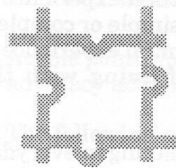
Progress must always be built upon simple basic choices moving towards independence through choice making. It should be stressed that it is not necessarily the number of choices and decisions presented that matter - it is the quality. A few real and meaningful choices are of more value than dozens of more empty choices.

The more we give our partners the opportunity to make choices and decisions of their own, the more their confidence increases and their ability to communicate improves. Through handing back some of our power to them, they become more powerful and feel more in control of their lives. Providing supportive advocacy means consciously giving power back.

Stage 3: Setting targets

Once you have identified choices and decisions that need to be made for now and for the future, it may be a good time to start setting some short and long term targets. Remember to make sure your targets are realistic and achievable. Often people find it easy to identify single targets but it is more difficult to see how to build up these targets for choice into a progression. Planning targets in stages will lead to greater independence.

Worksheet



At the end of the handbook we have provided **Worksheet 9: Moving Towards Independence Through Choice Making**. Filling in this worksheet will allow you and your partner to list the areas of choice making needed to be offered and experienced along the pathway to self advocacy.

Stage 4: Keeping records

It should be becoming clear that being an advocate is much more complex than just being a mouthpiece or an interpreter and simply transmitting information. There are many stages in the advocacy process. Helping the person to get better at making choices and decisions is one; keeping track of the choices and decisions made and helping to ensure that they are carried through is also important. The process may stretch over a long period of time and it may not be appropriate or possible for everything to take place on a here and now, face to face basis.

One of the roles of an advocacy partner may include a responsibility to record significant information, if the person wishes it and if they cannot do it for themselves. Information such as feelings, views, likes, dislikes and problems should be recorded. A written record can be a powerful tool as it gives value to what has been said. It also can provide an aid to memory and provides a permanent record of what transpired during any communication interchange.

Permission to record self-expressive information

The first thing you must do is make sure your partner understands that you are acting as an advocate and you want to help them express themselves. You need their permission to record information they may give you. Some people may at first not have a sense of what the purpose or potential usefulness of writing things down is and may need time to think about and discuss the matter. It is not acceptable to record material against the wishes of the person concerned.

If it is not possible for your communication partner to give meaningful permission, you may decide to keep a written note as a private memory jogger for yourself.

The advantages of recording

Your communication partner will benefit from discussion and explanation of the values of recording. A written record could be very empowering for your partner. It will give value to what your partner is saying. In the early stage where trust is being built up, writing down discussions with your partner shows that you are taking the discussion seriously and intend to remember it. If there are staff changes, and past discussions are lost, the availability of a written record could help the user to make their views known. To rely on memory alone for the content of important discussions is not satisfactory; it is easy to forget or to remember things falsely. Recording can ensure accuracy and act as an aid to memory.

When and how to record

A written record will, in most cases, be the most likely method of recording. Writing is a good way to record information simply because it is the most 'ordinary' way. It doesn't require too much time, or special skills or equipment so you are more likely to record than not. Things that are written can be easily shared with all sorts of different people.

Towards Self Advocacy

Video recording may also be an option, and can be particularly useful where people use a number of different modes of non verbal communication. This kind of recording is particularly powerful if used later as evidence when your partner is trying to express significant information to very powerful others, or when the authenticity of the advocate's interpretation is in question.

Photographs and rapid line drawings/diagrams can also be useful, especially to illustrate a physical problem, difficulty with access or equipment, or a concern about physical care described by your partner.

Photographs, pictures, symbols and line drawings can help people who have problems understanding writing but who can decode symbols or drawings. It may be a good idea to include at least some pictures, symbols or line drawings in the record so that your partner can read it back for themselves, and check it is accurate.

The following points need to be remembered when keeping records:

- Written records should only be kept with your advocacy partner's permission.
- Written records should be an exact record of what is said even if it is not grammatically correct.
- Record every type of communication used even if it is not understood.
- Record all non verbal communication such as gestures and facial expressions.
- Record what you say as well as what your communication partner says.
- Show and read back to your partner what you have recorded.
- Make sure the written record is understood and agreed by both yourself and your advocacy partner.
- Sign and date the written record.

There are reasons for all these suggestions. When people have communication difficulties, the question can easily arise as to who has said something: Was it the person or the person's advocate who has said this? In cases of law it has been known that expert witnesses are called to testify as to whether the non verbal person, in their view, is capable of expressing such thoughts. In such cases, it is particularly important to have followed the recording procedures outlined above.

Where there are serious criminal, legal or financial implications it may be advisable keep evidence that your partner has been involved in not only generating but also validating the records. Ask your partner to mark each page as you go over it, to show they have agreed to it as a true record. You can ask another person to attend and sign, as a witness, that the record was checked and accepted by your partner.

A well kept record book could make all the difference between someone winning or losing a court case, and gaining control over their life. Lawyers might call in experts in linguistics to check consistency of vocabulary and grammatical construction. For example, if the person has very limited language this should show up clearly in the record; the advocacy partner's interpretations must be kept separate. It is therefore important to record precisely what your partner said including gestures and facial expressions and to record separately your interpretation of what was said.

Whose self-expression?

Recording your communication partner's self-expressive information is a valuable service for you to perform but it does give you a kind of power. When you are working together towards greater self advocacy, you need to consciously try to keep giving this power to your partner. Here are a few suggestions about how to do this:

- Review carefully the issue of where any records are to be kept, bearing in mind issues of vulnerability, confidentiality, security etc.
- Help your partner to understand the importance of keeping track of and looking after the record. Learning to keep something safe is a worthwhile skill very relevant to the progression towards self advocacy. Most people will be able to take some degree of responsibility for their records though safeguarding steps may need to be taken.
- Keep stressing that the record belongs to the person with communication difficulties (not to you) wherever it is physically kept.
- Remember that restricted life experience may mean that your partner does not have a concept of privacy. They may have no experience of judging when it is appropriate to show certain types of information to others. You may need to prompt them to show the record to others or not to show it.
- Make sure your partner is clear about what information has been recorded and what has not. This may take several readings and discussion.
- Give your partner the chance to alter the record at any time.
- You may also need to decide what other communication partners should be involved in the record keeping and how they should be involved.
- Depending on how care policies have been devised and implemented, you may need to explain to staff that your partner has rights to privacy and self-determination.
- From time to time it might be useful to copy portions of records for specific situations - e.g. case conferences or Community Care Assessment
- If you are worried about your partner losing his/her record then think about keeping two - a working copy and a master copy. There may also be situations where it would help to have one self-expression record for home and one for where your partner is during the day.

Towards Self Advocacy

Every situation is different. It will be up to you and your partner to decide who contributes to the record, who keeps the record and how. Do not underestimate your partner and their capacity to learn that the record is theirs - learning this is a step towards self advocacy.

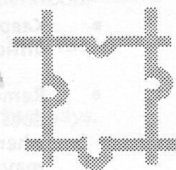
Good practice in day to day advocacy work will lay the necessary foundations for self advocacy as well as building up your partner's self-expressive abilities and through that their self-esteem.

Stage 5: Preparation for formal advocacy situations

Planning and preparation for meetings is essential both for you and your communication partner. It is likely that your partner will be going into situations where the other participants may have little or no experience of communicating with an augmentative communication user. Together with your partner, you need to formulate a plan for how you will co-communicate with these key other people. Good advance planning and careful preparation is the key to success 'on the day'. As an advocacy partner, your role in the planning and preparation process is very important. For some communication partners who are more advanced towards self advocacy, this early backstage work may be the most important thing you can do, and your role on the day may be much less important or even non-existent.

Worksheet

Worksheet 10: The Formal Advocacy Worksheet will allow you to consider important points and discuss them with your communication partner when preparing for a special meeting.



The following are important points to consider:

What roles will you be taking? Are they understood and agreed by your communication partner?

You could be undertaking a number of roles on behalf of your partner: are you going to be an information gatherer; an enabler; an interpreter; a trouble shooter; a formal advocate; a friend; an exponent of AAC to naive listeners? You may have a different role at various points in the meeting.

How will the introductions be done and by whom?

People who have little or no experience of communicating with people with communication difficulties will need some background information about the person with disabilities that they are communicating with. This will help the "new" listeners to know what to expect and to be more confident that they have understood something about the person's abilities and disabilities, of how their communication systems work, and how to behave appropriately in interactions with the person.

It can be difficult for a non-speaking person to put this information across by themselves, and it may not be appropriate to do this at the first meeting. It is probably better to have this sort of background material prepared in advance and perhaps distributed to people who will attend the meeting. It should be in an easy to read format like a "personal passport". This will give your partner a positive advantage in the interaction showing that they are self-reliant, well organised and considerate of others' information needs.

How many listeners will there be and how much experience will they have of AAC?

Knowing the size of the group in advance will avoid panic or problems on the day.

What facilitation techniques will be used?

There may be differences in how you facilitate communication for your partner depending on whether a high tech communication system with voice output or a silent low tech system is used. With the latter, your partner may want you to provide the voice while they communicate, especially when communicating in a group situation.

However much planning and preparation you and your partner do, things may come up which you were unable to plan for. Before the meeting you both need to identify simple non verbal cues to indicate that something is not right to ensure communication continues e.g. a glance to a certain position, eye pointing or a number of eye blinks. You should also discuss how your partner will indicate if they need a break or time to consider an unexpected issue. A non verbal gesture may indicate this.

Is there a back-up communication system?

If your partner uses an electronic aid then breakdowns can occur. You need to agree on a back-up system e.g. a low tech communication board, manual signing, pen and paper. If you are using an electronic system do not forget to charge its batteries fully the night before. Remember to take switches and the charger with you and the agreed low tech system, if there is one.

What material should be prepared in advance?

Whatever the topic under discussion is, it can take a long time for an AAC user to get a message across and this can unbalance the process of information exchange and personal interaction. In certain types of situations time is limited - e.g. a brief interview granted with an MP, or health board or council official and it may be impossible or inefficient for the person to try to say everything word by word in real time. Your partner may want to prepare some material in advance and have this pre-stored under one, or a few keys, or printed out on paper.

Will any specialised vocabulary be needed?

One of the major considerations will be the vocabulary needed for the event. It may be that specific vocabulary items will need to be added to the person's communication system beforehand. You and your partner will need to know what items are on the agenda for that event so that you can discuss the new vocabulary that may be needed and to ensure your partner is able to access it. If time is a factor at the event then you may both decide to opt for pre-stored messages.

Where will the event be taking place? How will the room and seating be arranged?

It will be useful, if possible, to visit the setting prior to the event in order to get an idea of the environment and layout of the meeting. If you've been there before, it can also make the event feel less threatening, e.g. prior to attending an Industrial Tribunal, you and your partner could arrange to sit in on a case being heard. If you can visit beforehand discuss where you and your partner wish to sit. Your partner may want to sit in a particular place to avoid glare. In any case, discuss where to sit in relation to each other. Is it important for you to be able to see each other face on? It may be better if you position yourself to the side/back of your partner as this should indicate that you are a facilitator and not a main contributor. If you take a prominent seat at the table the other meeting participants may feel that you are the individual to whom they are speaking and not your partner.

What is the likely agenda?

As previously discussed, you and your partner will need to try and find out the agenda. Remember it will be impossible to cover all topics/discussion points that may come up. It is important, therefore, that you have established some form of communication for your partner to indicate that they need time to think, or need a break in order to gain time to discuss options with you.

What are my partner's desired outcomes and are there any compromises he/she will accept?

You both need to know exactly what the desired outcomes from the meeting are and what compromises if any might be acceptable. That means having frank and honest discussions prior to the event. Should unexpected items come up during the interaction, time may need to be taken out to discuss these with your partner. Do not be frightened to ask for some time during the meeting or to arrange another meeting to give your partner time to explore the options.

The next section will deal with some of the more complex ethical considerations including the question of confidentiality and trust.

Case Story 5.1

The facts:

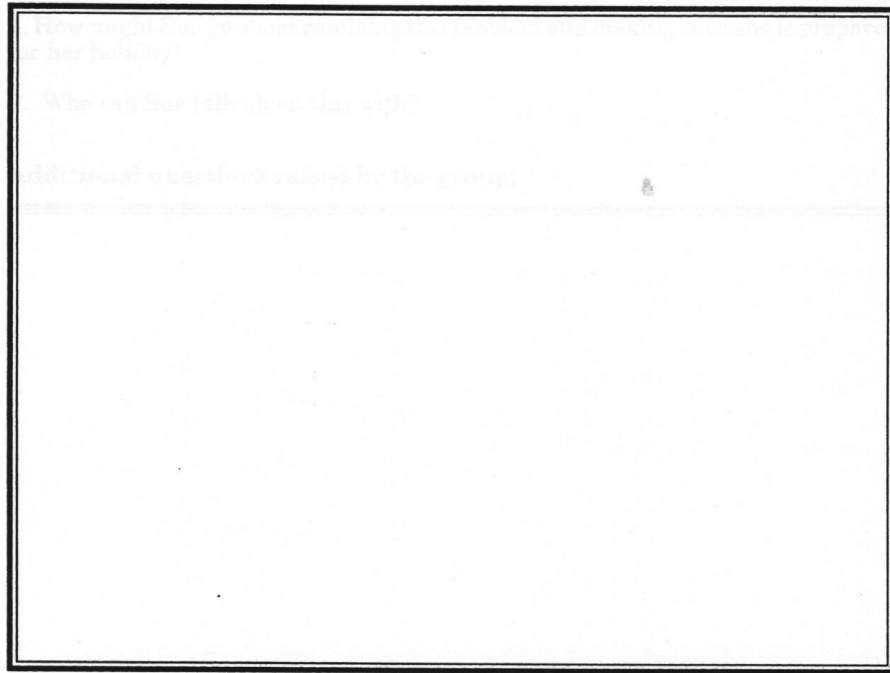
Yvonne is a thirty six year old woman with cerebral palsy. She communicates well using a Liberator communication aid. Yvonne is a sociable person who lives in a residential home. Yvonne wants to be more independent and in discussion with the staff decides that she should take more responsibility for organising her life.

The questions below are offered to help groups get started in discussion about the case presented. Please add any additional questions your discussion group raises in the space provided. As these cases are examples of real situations, we have provided you with what really happened on the following page. You may want to look at this after your group discussion.

Discussion questions:

1. What steps should Yvonne and the staff take to put their plan into action?

Additional questions raised by the group:



Key issues:
power, control,
recording, preparation

Case Story 5.1

This is what really happened! Your discussion group might have come up with a different scenario. There are no right or wrong answers.

Both Yvonne and the staff realise that this may be a long step by step process. They first decide together what activity Yvonne would like to try and organise for herself. Yvonne and the keyworker decide to start with activities which she does on a regular basis. Since Yvonne visits her sister every Thursday night this activity was chosen. At the moment, the keyworker makes all the arrangements for her regular visits to her sister's house. Yvonne and her keyworker start by drawing up a plan which includes what things Yvonne would need to arrange and what information she will need. This is written down in a planner so Yvonne can refer to it during the next week. Every time Yvonne completes a step, her keyworker can place a tick mark next to it. This serves as an indicator for Yvonne that she can now proceed to the next step. Because Yvonne and her keyworker have been doing this together, Yvonne feels that she can ask for help when she needs it. This has helped to avoid feelings of frustration. Yvonne has managed to arrange her weekly visits on her own. Yvonne and her keyworker are now looking at other situations and activities that Yvonne can plan independently.

Should indicate that you are a facilitator and not a main contributor. If you take a prominent seat at the table the other meeting participants may feel that you are the individual to whom they are speaking and not your partner.

What is the likely agenda?

As previously discussed, you and your partner will need to try and find out the agenda. Remember it will be impossible to cover all topics/discussion points that may come up. It is important, therefore, that you have established some form of communication for your partner to indicate that they need time to think, or need a break in order to gain time to discuss options with you.

What are my partner's desired outcomes and are there any compromises he/she will accept?

You both need to know exactly what the desired outcomes from the meeting are and what compromises, if any, might be acceptable. That means having frank and honest discussions prior to the event. Should unexpected items come up during the interaction, time may need to be taken out to discuss these with your partner. Do not be frightened to ask for extra time during the meeting or to arrange another meeting to give your partner time to explore the options.

This next section will deal with some of the more complex ethical considerations including the question of confidentiality and trust.

Case Story 5.2

The facts:

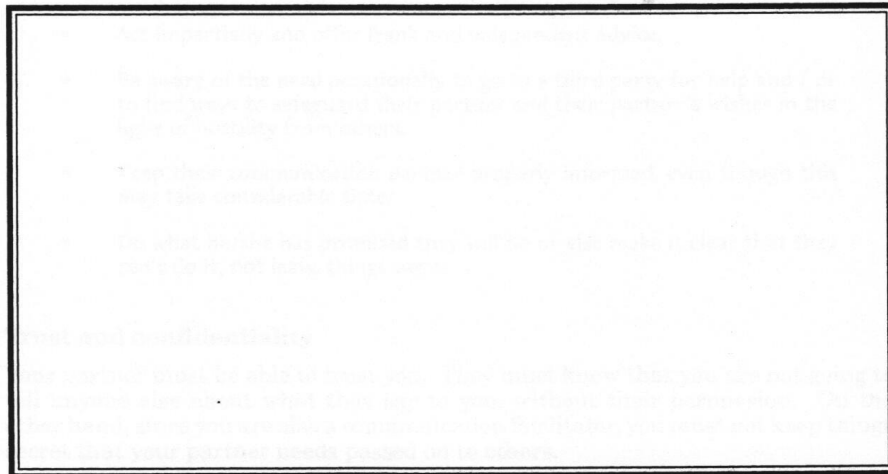
Sue is 29 years old and was involved in a car accident two years ago. Sue has always lived on her own and continues to do so with the help of her home help, family and friends. She communicates very well using a Lightwriter communication aid. Sue's home help does all her shopping for her and Sue rarely has an opportunity to buy anything for herself. Sue has now been asked to go on a two week holiday with her friend. They will be staying in a self catering apartment and Sue feels she wants to be able to "pull her own weight" when it comes to buying and preparing the meals.

The questions below are offered to help groups get started in discussion about the case presented. Please add any additional questions your discussion group raises in the space provided. As these cases are examples of real situations, we have provided you with what really happened on the following page. You may want to look at this after your group discussion.

Discussion questions:

1. How might Sue go about resolving this problem and making sure she is prepared for her holiday?
2. Who can Sue talk about this with?

Additional questions raised by the group:



Key Issues:
power, control,
preparation

Case Story 5.2

This is what really happened! Your discussion group might have come up with a different scenario. There are no right or wrong answers.

Sue discusses this with her Social Worker who organises all her support. The Social Worker and Sue decide that Sue should approach the home help to start taking a more active role in the shopping. Sue and the home help decide that Sue will draw up menus for the next three days and then they can together decide what needs to be purchased. Sue can make a list using her communication aid of what they want to buy. Preparations are made for Sue to accompany the home help on her weekly shopping expedition. The home help can advise Sue as to what to expect when she gets to the supermarket and where items are located. The supermarket has instituted a new way of keeping track of your shopping and Sue has decided that this is an ideal way for her to identify how much money she is spending during the shopping trip. After a few weeks, Sue feels more confident about being able to shop for herself and is less worried about her holiday.

Ethical Issues

This section will cover:

- Guidelines for good practice and ethical conduct for advocates
- Trust and confidentiality within an advocacy situation
- Ethical dilemmas that can occur in advocacy and self advocacy situations

People with disabilities of any sort, and perhaps especially those with communication disabilities, are very vulnerable. Those working with them in an advocacy role must maintain some basic principles of ethical conduct.

An advocate should:

- Always act in the best interests of their communication partner.
- Accept the fact that there may be conflicting views about the best interests of their partner.
- Act in accordance with the wishes of their communication partner insofar as this is possible without leading to danger for them or others.
- Always maintain the rules of privacy and confidentiality, unless asked or permitted by their partner to transmit specific information.
- Have an awareness of communication disability and AAC issues, and have competence in AAC communication partner strategies.
- Act impartially and offer frank and independent advice.
- Be aware of the need occasionally to go to a third party for help and / or to find ways to safeguard their partner and their partner's wishes in the light of hostility from others.
- Keep their communication partner properly informed, even though this may take considerable time.
- Do what he/she has promised they will do or else make it clear that they can't do it, not leave things vague.

Trust and confidentiality

Your partner must be able to trust you. They must know that you are not going to tell anyone else about what they say to you, without their permission. On the other hand, since you are also a communication facilitator, you must not keep things secret that your partner needs passed on to others.

Ethical Issues

Sometimes people with communication disabilities are inexperienced or don't understand about privacy and about giving and withholding permission, and find it difficult to judge who needs to know what information. The advocate will have to set and keep ethical standards.

Do

- Check with your partner how private or public information is, and which listeners he/she has in mind.
- Check with yourself if passing on information could do any damage.
- Ensure that written material is stored safely and kept confidential.

Don't

- Say anything about your partner when they are not there to hear what you say.
- Leave records lying around.
- Make or give away any copies of records without permission.

Ethical questions

There are many questions around advocacy and self advocacy for people with communication difficulties. Below are some questions to consider:

- Should advocates be paid or unpaid?
- How should volunteer advocates be recruited and trained?
- Is being an advocate just a mouthpiece for someone or is it something more?
- What do you do if your partner refuses to give you permission to reveal what she/he has said?
- What happens if important cultural, religious or moral principles of an advocate conflict with those of your partner?
- Is advocacy always appropriate for everyone and in all situations?

In addition, helping someone to be more independent and to develop self advocacy skills may lead to risks. Here are some more questions you may want to consider:

- Does the person really understand the risk they are proposing to take?
- What does "really understand" mean when someone has limited experience of the world and limited communication skills?
- How can we be sure that someone has all the information they need and has enough experience to think through all of the long term implications and outcome possibilities of dangerous situations?
- What if the person doesn't understand the risk?
- Should the advocate prevent them from taking the risk or try to educate them about the risk and then let them choose to take it or not?

As we have said already, supporting someone with a communication impairment can be rewarding and challenging. The next section discusses how you as an advocate can find support for your work.

Case Story 6.1

The facts:

Joanne has worked as a secretary in the local Social Services office for the past 5 years. She has just decided to become involved in an advocacy service and has agreed to become an advocate for a young girl named Sally. Sally is appealing against the decision of another social services' district about her future placement in a group home. Sally feels that the recommendations being offered are unsatisfactory and would like to live in a flat. Joanne attends a meeting with Sally and after the meeting, Joanne is approached by Sally's Social Worker seeking information about Sally's reactions and feelings towards the proposed placement.

The questions below are offered to help groups get started in discussion about the case presented. Please add any additional questions your discussion group raises in the space provided. As these cases are examples of real situations, we have provided you with what really happened on the following page. You may want to look at this after your group discussion.

Discussion questions:

1. How should Joanne react in that situation?
2. What conflicts might Joanne face in this situation?

Additional questions raised by the group:

Key issues:
confidentiality, trust and respect,
role conflict

Case Story 6.1

This is what really happened! Your discussion group might have come up with a different scenario. There are no right or wrong answers.

Joanne is quite surprised when she is approached by the Social Worker and feels it is inappropriate to be discussing Sally's feelings without her. Joanne discusses with the Social Worker that her utmost priority is to Sally and that she cannot violate the trust and confidence that Sally has in her. She suggests that the social worker set up a time to meet with Sally and herself and that these questions can be put to Sally herself.

Case Story 6.2

The facts:

Sam is acting as an advocate for Stuart, a 16 year old man. He has cerebral palsy and his speech is difficult to understand especially when he feels under pressure or stress. During the course of their relationship, it has come to light that Stuart does not want to continue being a vegetarian like his parents and wants to eat meat during the week at school. These wishes have been recorded down in a diary that only Sam and Stuart can look at. Stuart feels that if his parents see his diaries they will be angry with him.

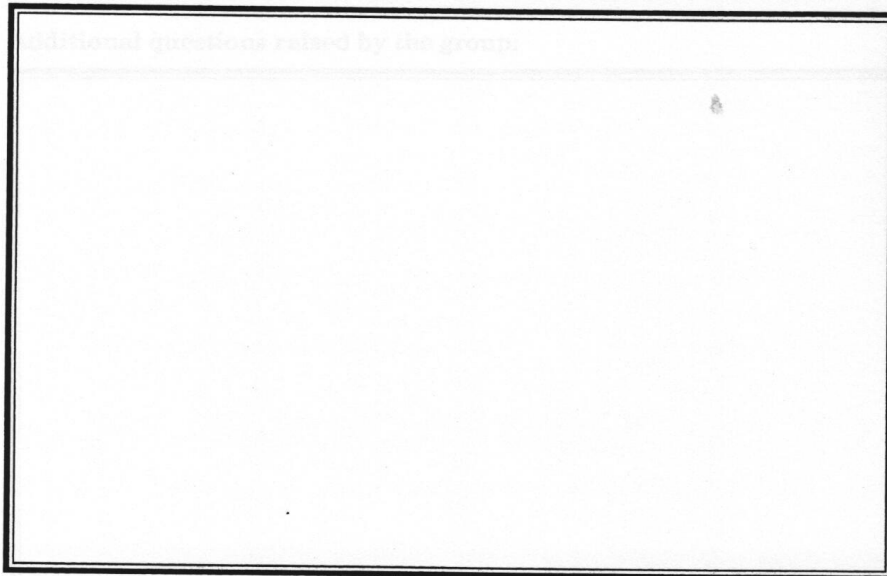
The questions below are offered to help groups get started in discussion about the case presented. Please add any additional questions your discussion group raises in the space provided. As these cases are examples of real situations, we have provided you with what really happened on the following page. You may want to look at this after your group discussion.

Discussion questions:

1. How can Sam help Stuart to discuss this topic with his parents and the school?

Additional questions raised by the group:

Additional questions raised by the group:



Key issues:
confidentiality,
privacy, respect

Case Story 6.2

This is what really happened! Your discussion group might have come up with a different scenario. There are no right or wrong answers.

Sam and Stuart talk about what is contained in the diary and how this might help Stuart explain his feelings to his parents. Sam reassures Stuart that nothing will be revealed from his diary without his permission. Initially Stuart uses his diary when his parents come to pick him up for the weekend to let them know what he wants to do. After several weeks, Stuart agrees for one other staff member to read his diary and discuss his choice of food with him. Stuart is surprised and encouraged when the staff member does not get angry with him but is willing to help Stuart approach his parents about this. Stuart then agrees to discuss his choice of food with his parents during a supportive meeting with Sam and staff in attendance. Stuart and his parents decide that Stuart can choose what kind of food he wants to eat during the week at school, but they would still expect him to refrain from eating meat at home during his weekend visits.

Who Supports the Supporters?

This section will cover:

- Possible conflicts when advocating for a person with severe communication difficulties
- Sources of support

Providing advocacy support for a person with communication difficulties can be very rewarding. It gives you the opportunity to get to know someone you might not normally come into contact with. By working with a person with communication difficulties you may acquire new knowledge and develop additional skills. It can give you insight into another person's life, which is a privilege in itself, and this knowledge and information may influence other aspects of your life and work.

However this type of work can be very demanding and frustrating. There will be times when you will require support. You may experience both personal and professional conflicts.

- **Personal conflict** - The issues involved can be very personal and emotional, and it is important to remember you are representing someone else. You may be required to advocate for someone on an issue you disagree with; you might disagree with how the person you are supporting wants to go about it.
- **Social conflict** - You may feel the choices of your partner involve risk to him/herself and to the wider community. Where do your responsibilities lie?
- **Role conflict** - If you are also employed by an agency involved with people with disabilities there may be conflicts at times between the interests of your employer, your own interests as an employee, and the interests of the person with communication difficulties you are representing.
- **Time conflict** - Supporting a person with communication difficulties can be very time consuming and it could quite easily take over your whole life. It is therefore important to be able to set limits and to allocate appropriate time to the task in consultation with the person with communication difficulties.
- **Moral conflict** - You may feel that your own moral and cultural feelings and convictions are at odds with the person whom you are advocating for.
- **Employment conflict** - If you are a professional also providing advocacy support to a partner, you may feel that your loyalties are being questioned between your employer and advocacy partner.

Who Supports the Supporters?

It is important to have a final goal in sight, and to strive towards it, but there may be several steps before you are able to achieve that final goal. Always try to be realistic in what you are able to achieve. There may be times when you find that it is difficult to know where to go next, what the next stage is, who you should contact. You may feel a bit isolated in this work, and feel like you need a bit of support. Because of the demanding nature of the work it is important that there is support available for you, both for your own sake and to help you provide a better service for your communication partner, in the long run.

We have listed below some examples of the kind of support that should be available to you, and relevant sources of help.

Sources of support for you relating to your partner's communication difficulties:

- If you would like more information about how the person for whom you are advocating communicates, contact his/her local Speech and Language Therapist if they have one. Contact the Speech and Language Therapist if you would like help in communicating with him/her; if you would like more information about AAC; if the AAC aid is broken; or if you feel the person might need a new communication aid. If you do not know who or where to contact that person, ask your local Hospital or Health Centre. They should be able to put you in contact with the local Speech and Language Therapy Service.
- If the person for whom you are advocating does not have a Speech and Language Therapist and you would like information about AAC; or if his/her AAC aid has broken down; or if you feel he/she might need a new aid; contact the nearest AAC Assessment/Resource Centre. The local Speech and Language Therapy Service or Disability Resource Centre should be able to give you the address to contact.
- If you are not able to get any help locally, contact the Royal College of Speech and Language Therapists or the Communication Matters Information Line and ask them to help you identify a local contact (either Speech and Language Therapist or AAC Centre).

Sources of support for you in your advocacy role:

- It will be useful for you to make contact with a local Advocacy Service if there is one. They might give you information about training opportunities on offer. They might provide general support and advice in your advocacy role, for instance chatting through with you what your role in a meeting might be, identifying the procedures for helping someone to move from a residential setting to independent living, etc.

Who Supports the Supporters?

- If you do not know of a local Advocacy Project, contact your local Social Work/Services Department and ask for their Advocacy Service Worker or Officer for people with physical/learning disabilities, who ought to be able to give you some local contacts in the advocacy field.
- You could also contact a Voluntary Organisation/Charity which is involved with disability, e.g. Enable, Mencap, Capability Scotland, or SCOPE and ask if they have/know of an Advocacy Project local to you. This might be a useful source of information if the person you are advocating for is already involved with one of these organisations.
- If you still are not able to find an appropriate Advocacy Project locally, contact the Nuffield Centre for Community Care Studies and ask if they can send you a list of Advocacy groups in your area (printout from their Community Care Works database).
- You may also find it useful to talk informally with someone else in a similar position about the specific problems of advocating for someone with communication difficulties. The local Speech and Language Therapy Department, AAC Centre, Social Work/Services Department or Advocacy project may be able to put you in contact with other people in your area who are advocating for people with communication difficulties.

Useful addresses

Royal College of Speech and Language Therapists
7 Bath Place
Rivington Street
London EC2A 3DR
Tel. (0171) 613-3855

Communication Matters Information Line
c/o ACE Centre
Ormerod School
Wayneffete Road
Headington, Oxford
OX3 8DD
tel. (0870) 606-5463

Nuffield Centre for Community Care Studies
University of Glasgow
7 Lilybank Gardens
Glasgow G12 8RZ
Tel. (0141) 330-5600

Conclusion

We hope this handbook has helped you to a greater understanding of how to support people with communication impairments and to ensure their voices are heard. We want to help people **Speak Up and Speak Out** for themselves.

Here is a summary of key points to remember:

- People with severe communication difficulties and who use augmentative and alternative communication often have great need of advocacy support.
- Advocacy is a continuum. At one extreme is speaking for someone else. At the other extreme is people speaking up for themselves. In the middle, there are many ways in which others can offer support. The aim is always to help people towards self advocacy, not to lock them into dependency on others.
- Advocates need a good understanding of communication impairment, and of the range of communication strategies and AAC techniques for people with disabilities and their communication partners.
- Advocacy may demand a commitment of considerable time, over a long period.
- Advocacy needs are greatest at periods of transition and life change.
- Conflicts can occur within advocacy - parental, professional, moral and ethical.
- Advance preparation and role rehearsal are essential elements of advocacy and self advocacy.
- Good record keeping is important.
- Confidentiality and high standards of conduct are essential at all times.
- Advocates need a good back up support system for themselves.

Reading References

McFadden, D. (1995) *AAC in the Community - A Personal Viewpoint* in Millar, S. & Wilson, A. (Eds) *Widening the Perspective*, CALL Centre, University of Edinburgh, ISBN 1 898042 07 1.

RCSLT (1996) *Communicating Quality 2: Professional Standards for Speech and Language Therapists*, Royal College of Speech and Language Therapists, London, ISBN 0 947589 04 X.

Millar, S. & Wilson, A. (Eds) (1994) *Augmentative Communication in Practice: An Introduction*, CALL Centre, University of Edinburgh, ISBN 1 898042 03 9.

Further reading and resources relating to communication and AAC

ACE Centre (1997) *In Other Words: An Introduction to Augmentative and Alternative Communication* (video), ACE Centre, Waynflete Road, Headington, Oxford OX3 8DD.

Murphy, J. & Scott, J. (1995) *Attitudes and Strategies Towards AAC: A Training Package for AAC Users and Carers*, Department of Psychology, University of Stirling, Stirling FK9 4LA, ISBN 1 85769 028 1.

Murphy, J. & Scott, J. (1997) *Talking to People with Severe Communication Difficulties: An Introductory Training Video*, Department of Psychology, University of Stirling, Stirling FK9 4LA.

Moffat, V. (1996) *Life Without Jargon*, Choice Press, ISBN 1 900532 01 8.

Millar, S. & Wilson, A. (Eds) (1996) *Communication Without Speech*, CALL Centre, University of Edinburgh, ISBN 1 898042 10 6.

Glennan, S. & DeCoste, D. (1997) *Handbook of Augmentative and Alternative Communication*, Singular Publishing, London.

Further reading and resources relating to advocacy

Cooper, C. & Hersov, J. (1986) *We can change the future: self advocacy for people with learning difficulties: a staff training resource*, SKILL, London SW9 7AA. ISBN 1 8699650 51 5.

McKay, C. & Patrick, H. (1995) *The Care Maze: the law and your rights to community care in Scotland*, ENABLE and the Scottish Association for Mental Health ISBN 1 874004 06 4.

Department of Health and Scottish Health Advisory Service, (1997), *Advocacy: A Guide to Good Practice*, Scottish Office, Edinburgh.

Additional sources of publications on advocacy and self advocacy

BILD Publications, available from BILD, Wolverhampton Road, Kidderminster, Worcs. DY10 3PP.

EMFC Publications, available from EMFC, Robins Wood House, Robins Wood Road, Aspley, Nottingham NG8 3NH.

Kings Fund Publications, available from Kings Fund Centre, 126 Albert Street, London NW1 7NF.

People First Publications, available from People First, Instrument House, 207-215 Kings Cross Road, London WC1X 9DB.

Skills for People / Speak for Ourselves Publications, available from Skills for People / Speak for Ourselves, Haldane House, Tankerville Terrace, Newcastle upon Tyne NE2 3AE.

Values into Action Publications, available from Values into Action, Oxford House, Derbyshire Street, London E2 6HG.

Personal skills to support self advocacy

Checklist 1

Name: _____

Date: _____

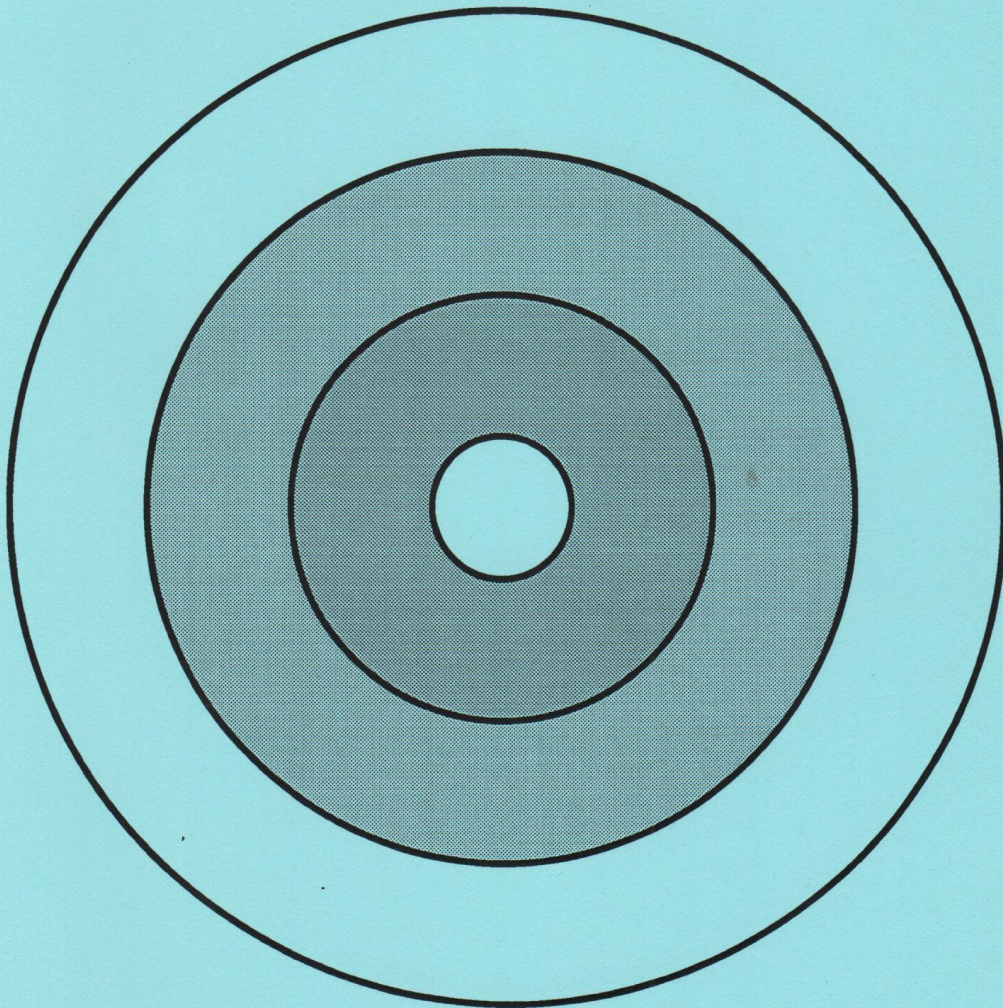
	can do	can do with support	is not yet able to do
-is able to get a message across <i>in what situations?</i>			
- can make choices and decisions			
- can carry through decisions <i>write examples on the back of this sheet</i>			
- can ask for help appropriately			
-know their rights <i>in what situations?</i>			
- can take responsibility for own actions			
- can be confident in familiar situations			
- can cope in unfamiliar situations			

This form was completed by: _____

Circle of Friends

Name: _____

Date: _____



Different types of questions

Checklist 3

Name: _____

Date: _____

Decide whether the following questions are open, closed (yes / no) or 'non-questions'. Tick the appropriate box.

	open	yes/no	non
Did you talk to Mrs. Brown the Social Worker again?			
What has happened?			
Why don't you put on that nice blue shirt?			
You'll be ready for bed now?			
Shall we go to the pub?			
What do you want to talk about?			
How are you feeling this week?			
Anything on your mind?			
It's time for Coronation Street. Are you wanting me to put the TV on?			
Do you feel angry about that?			
How do you feel about that?			
When do you want to talk again? - tomorrow? next week?			

Communicating Choices

Worksheet 4

Name: _____

Date: _____

How I indicate my choice

e.g. give choices one by one, smile for yes and raise my eyes for no

How I like to have choices presented

e.g. given 2/3 things to choose from, left alone for a few minutes, then give me the choice again

People who help me to discuss and think about my choices and decisions

e.g. my mum

The kind of choices I like to have written down

e.g. things it takes a long time to explain and think about

This form was completed by: _____

Making Choices

Checklist 5

Name: _____

Date: _____

	easy to choose	difficult to choose	not allowed to choose
- clothes to wear everyday			
- what to do at the weekend			
- where to go on holiday			
- who I like being with			
-			
-			
-			
-			

This form was completed by: _____

Decisions: Present and Future

Checklist 6

Name: _____

Date: _____

	decisions to make now	decisions for next year	decisions for the future
- where to live			
- what to do at the weekend			
- where to go on holiday			
- what to study			
-			
-			
-			
-			

This form was completed by: _____

Analysing Choices and Decisions

Worksheet 7

Name: _____

Date: _____

Now that the choice making and decisions checklists are filled in, spend some time analysing them.

List three areas where choices and decisions need to be presented, practised and carried through.

1. _____

2. _____

3. _____

Which decisions need to be made first?

Are there any areas where it is unrealistic to expect your partner to make life changing decisions without support and time to consider the consequences?

Discuss the checklists with your partner and any other relevant people. It is time to set some targets for the short term.





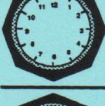
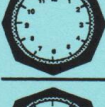

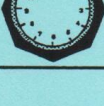
This form was completed by: _____

Daily Record Sheet

Sample

Name: A. User

Date: _____

Time	Activity	type of choice	who chose	how was choice made
 7 am	Getting up	sleeping in	carer	alarm clock
 9.15	Coffee time	what to drink	user	eye pointing
 10.30	Walking	route to follow	carer	discussion
 noon	Buying socks	type to buy	user	vocal noises
 1 pm	Lunch	what to eat	cook	served up
 3.30	Movie going	what film	user / carer	discussion
 8 pm	Dancing	whether to join in or not	user	answer yes or no
				









This form was completed by: _____

Daily Record Sheet

Worksheet 8

Name: _____

Date: _____

Time	Activity	type of choice	who chose	how was choice made
				
				
				
				
				
				
				
				

This form was completed by: _____

Moving towards independence through choice making

Sample

Name: A. User

Date: _____

In the table below list the area of choice and choices to be offered / experienced along 'the pathway to self advocacy'.

Area of choice	Stage 1		Stage 2		Stage 3	
Personal Care/ image	<i>bath or shower</i>		<i>choosing own time for bath / shower</i>		<i>choosing own hair style / clothes</i>	
	date started	date achieved	date started	date achieved	date started	date achieved
Food and diet	<i>fruit or cake for snack</i>		<i>choosing time for meals</i>		<i>choosing menu for meals</i>	
	date started	date achieved	date started	date achieved	date started	date achieved
Leisure	<i>swimming or drama</i>		<i>choosing how often</i>		<i>choosing who to go out with</i>	
	date started	date achieved	date started	date achieved	date started	date achieved
Living	<i>choose own bedroom</i>		<i>choose colour / decor</i>		<i>choosing who to live with</i>	
	date started	date achieved	date started	date achieved	date started	date achieved

Name: _____

Date: _____

In the table below list the area of choice and choices to be offered / experienced along 'the pathway to self advocacy'.

Area of choice	Stage 1		Stage 2		Stage 3	
	date started	date achieved	date started	date achieved	date started	date achieved
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						

Formal Advocacy Situations

Worksheet 10

Preparation and rehearsal

For an important meeting these worksheets provide some questions which may be helpful for a person with communication difficulties to consider. These worksheets will help you to set the scene and identify key points to think about beforehand. Advocacy partners should complete it together well in advance of any meeting.

Setting the scene

The meeting is to be held

on _____

in _____

at _____

The purpose of the meeting is _____

We will talk about _____

There will be _____ people there. List their names and circle those people that are known:

Will they know how I communicate? _____

Do I need to visit the place where the meeting will be held beforehand? _____

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Handbook**

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United Kingdom Chapter of the International Society for Augmentative and Alternative Communication

COMMUNICATION *MATTERS*
