SECTION 6: WORKING TOGETHER TO MEET NEEDS

SECTION 17: TEAMWORK

Reading and Looking Things Up
In these final four related sections, our interest is in working together to meet the needs of adults with severe and profound learning difficulties. The first of the four is about teamwork between the people who work together on a daily basis. The principles could equally be used in a college, short breaks service, residential setting, or in day or enabling services, anywhere where there is more than one member of staff working with the same people. In the next section we consider a multi-agency partnership between carers and therapists and in the section after that we will add families to the team. We finish the whole induction pack where we started, with the people with SLD/ PMLD and how staff can listen to their voices in an effort to work with them in all areas of their lives.

Team members are expected to work together very closely in services for adults with SLD/ PMLD. Sometimes the focus will be on supporting small groups or on individuals. What is most important is that team members keep each other constantly informed, sharing information and insights. One of the most useful skills that teams can develop is that of communication. However, the ability to communicate effectively is not enough if there is no time or system for communication. The most successful working partnerships are underpinned by a combination of ‘time to talk’ and a system of both spoken and written communication. Staff working with people with challenging behaviour will be acutely conscious of how essential this is in order to provide consistency.

There are many ways of setting up communication systems but common methods include hand over time, and joint planning sessions or workshops where specific issues are addressed. I recently was involved in workshops for staff teams who had had to cope with a whole series of major organisational changes and the death of a greatly loved service user. The workshops enabled to staff to explore the impact of all these changes on themselves and the service users and to explore ways of increasing support and decreasing stress.
Where opportunities to talk and plan are built in it is essential that all staff have the opportunity to contribute and in many services this includes day and night staff. It is good practice to pay staff if they need to do extra hours to attend training or extra handover sessions. If a member of staff cannot attend for any reason then someone should take responsibility for going over information generated by the session. Where workshops are used some record of the content and what emerges should be left behind. It is an unfortunate fact that many services cope with high staff turnover so sessions may need to be repeated in some format.

Alongside the efforts to communicate over planning and recording, it is also important to exchange information about each other. When a new member joins a team it can be extremely useful to make an informal list of all the skills and expertise that you have between you. Then you can discuss how best to use these in meeting needs. This can be seen as important investment of time as it can help the team work together effectively more quickly. There are some other activities and discussions that are very useful for the investment period. For example doing a ‘strengths-needs analysis’ on individual adults and sharing any interventions for challenging behaviour can quickly pool knowledge and can enable a consistent service to be maintained. Agreeing on where everyone is headed with individual service users is vital and will come up again when we are talking about the multidisciplinary team and again with partnership with families.

_Talking with a Colleague_
In the half hour for discussion, it would be good if you could talk with someone who you work with closely in your service. You could form a trio with your mentor or more experienced colleague and discuss the strengths of the way you work now and how you might develop your teamwork. You could use the form below to guide your discussion.
<table>
<thead>
<tr>
<th><strong>This is about the partnership between....</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>The principles of the way we work together</strong></td>
</tr>
<tr>
<td>------------------------------------------------</td>
</tr>
<tr>
<td><strong>The strengths of the way in which we work together</strong></td>
</tr>
<tr>
<td>------------------------------------------------</td>
</tr>
<tr>
<td><strong>Any problems and what we need to develop or change</strong></td>
</tr>
<tr>
<td>------------------------------------------------</td>
</tr>
<tr>
<td><strong>How we are going to develop or change</strong></td>
</tr>
<tr>
<td>------------------------------------------------</td>
</tr>
<tr>
<td><strong>How we will know that we’ve been successful?</strong></td>
</tr>
</tbody>
</table>
**Gathering Evidence**

There are several kinds of evidence that you could collect to help your practice to develop, depending on what you have identified as important in the previous activity. For example if you wanted to focus on the way you work together in planning interventions then you may want to collect evidence related to how you exchange information, share records or provide just the right amount of support for individual adults. The following form may or may not be helpful for you.

<table>
<thead>
<tr>
<th>The development we are focusing on</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>The evidence we are collecting</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Our evaluation of the success of the development</th>
</tr>
</thead>
</table>
SESSION 18: WORKING WITH OTHER AGENCIES

In the previous session, we focused on two people working together on a daily basis in the same service. In this session, we will move on to thinking about staff working together when they come from different services.

Below is a list of professionals who work with a particular group of adults with multiple disabilities who attend a special needs resource base in the community and have a range of activities like college, swimming etc

<table>
<thead>
<tr>
<th>College lecturer</th>
<th>College Teaching assistant</th>
<th>Physiotherapist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech and language therapist</td>
<td>Occupational therapist</td>
<td></td>
</tr>
<tr>
<td>Mobility instructor</td>
<td>Orthoptist</td>
<td>Music therapist</td>
</tr>
<tr>
<td>Advocate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>Consultant ophthalmologist</td>
<td>Psychiatrist</td>
</tr>
<tr>
<td>Orthopaedic consultant</td>
<td>General practitioner</td>
<td>Dentist</td>
</tr>
<tr>
<td>Residential staff</td>
<td>Clinical psychologist</td>
<td></td>
</tr>
<tr>
<td>Day care staff/support workers</td>
<td>Massage therapist/aromatherapist</td>
<td>Dietician</td>
</tr>
<tr>
<td>Chiropodist</td>
<td>ICT specialist</td>
<td>Geneticist</td>
</tr>
<tr>
<td>Community nurse</td>
<td>Respite care staff</td>
<td></td>
</tr>
</tbody>
</table>

All those people share knowledge and understanding of the same group of adults and it is important that they communicate with each other in the most effective way. Getting to know all these different people is impossible for everyone to achieve and so there needs to be a system by which contact can be manageable. It is often best to begin by working closely with the few people who are in the most frequent contact.

**Sabina**

Sabina has a small team of people who work with her regularly. (We are not including families at the moment as our focus is on professionals working together.) They are:

- Residential staff
- Day service staff
- A physiotherapist
- An occupational therapist
- A speech and language therapist
- Community nurse

Sabrina has complex health needs which involve tube feeding and daily medication as well as both passive and active physiotherapy. Once a week the physiotherapist herself works with Sabina but for the rest of the week, the residential and day service
support workers do her exercises. She needs behavioural interventions to manage self injury.

Communication between these team members is both formal and informal. They meet formally but they exchange notes, quick conversations and planning documents to help them work together. Each of these team members also has a job liaising with and gathering information from other members of the wider network of people who provide services for Sabrina. For example, the physiotherapist attends Sabrina’s appointments with the orthopaedic consultant and also liaises with the aroma therapist. She makes sure that everyone else in the team knows the results of appointments and sessions. In this way the network is rather like a spider’s web with each person passing on what they know or do to those in the centre. The residential and day care staff are the most constant people in Sabina’s life (apart from her family) and thus act as the hub for the information. When communication and behavioural interventions are devised they include the people in Sabrina’s life and one programme is written for daycare and residential care so everyone is clear what they need to do.

Sabrina is an example of multi-agency teamwork working well but unfortunately there are many examples of not such good teamwork. There are various reasons why things might go wrong and identifying some of these can help you, at least, to understand why the teamwork is not so good but it can also help you to set about trying to change the situation for the better.
<table>
<thead>
<tr>
<th>Different service structures, conditions and working practices</th>
<th>Different attitudes to confidentiality</th>
<th>Different aims for the same adult</th>
</tr>
</thead>
<tbody>
<tr>
<td>Large caseloads and not enough time for each service user. Redundancies may be on the cards.</td>
<td>No time to talk with other team members</td>
<td>Feeling threatened if you give away too many of your skills to other people</td>
</tr>
<tr>
<td>Team member’s own service is threatened, is not working well or is being reorganised.</td>
<td>Team members don’t know enough about each other</td>
<td>Team members don’t know what they are expected to do</td>
</tr>
<tr>
<td>No or limited joint training</td>
<td>No or poor communication systems in place</td>
<td>Mismatch in personal characteristics</td>
</tr>
<tr>
<td>Not enough resources</td>
<td>Nowhere to meet</td>
<td>Separate assessments &amp; records</td>
</tr>
</tbody>
</table>

When you talk with your colleague at the end of this session, you may be able to identify these and other things that are sabotaging your efforts at multi-agency teamwork.

*Talking with a Colleague*

| My questions |
You might like to ask a member of a different service to come and join your discussion so you can talk together about how you work in a multi-agency team. The form below might help your discussion.

<table>
<thead>
<tr>
<th>Our multi-agency team members</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Ways we work together effectively</td>
<td></td>
</tr>
<tr>
<td>Ways in which we could improve</td>
<td></td>
</tr>
</tbody>
</table>

*Collecting Evidence*

You might like to try out one of the ways in which you think you could improve and monitor how well you both/all do.

<table>
<thead>
<tr>
<th>The new way of working</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive examples</td>
<td></td>
</tr>
<tr>
<td>Evaluation</td>
<td></td>
</tr>
</tbody>
</table>
SESSION 19: PARTNERSHIP WITH FAMILIES

Valuing People 2001, is very clear in its expectations that families need respect, support and for their unique understanding and perspective to be taken into account through the opportunity to work in partnership with professionals. Throughout their lives, people with learning disabilities may be supported by a changing array of professionals, but their family should be a more stable and continuous influence, especially if they are helped to form relationships across the different generations.

Today families come in many shapes and forms and it is important for carers to know who constitute the key members of the service user’s family. For people living in community homes or care situations this is important for liaison purposes but also so that the service user can be supported to remember birthdays and Christmas or other religious celebrations.

In a multi-cultural country like the UK, it is also important for carers to take active steps to understand and respect the culture of the families they will be working with. There is growing evidence that many minority ethnic groups are not accessing services because they do not understand what services are available or how to get referred to them. Also families need to have confidence that services will respect their culture. Even very everyday activities like skin and hair care may be carried out very differently by different ethnic groups.


Adult services frequently find themselves working with older carers and will find Good Practice Guidelines In supporting carers of Older People with Learning disabilities (2003) very useful. It can be found at www.learningdisabilities.org.uk/publications/?EntryId=15149&char=G

Sometimes staff teams in adult services feel a dilemma about how far they should be sharing information with families when the people in their care are legally adult. Every family circumstance will be different but it is important to remember that the majority of family members do want continuing involvement, and that they all need to trust the services that provide care and support to their family members.

Families are vital sources of information, especially at times of transition when staff may be getting to know a new service user. If you are having meetings with families, do be sensitive to planning meetings at a time and place where everyone in the family who wants to attend is able to do so. It is very easy to just assume that it is only the person’s mother who will be involved. Towards the end of this section there are resources for supporting and involving fathers and siblings. If parents are
attending a meeting, make sure that the language and pace of the meeting are such that families can participate and make their views known.

If you are setting up communication or behaviour programmes, it is useful to consider whether this is an approach that will work across all settings that the person accesses and this includes the family home. If something new is being introduced, like some new signs or symbols, families need training and information as well as carers.

There are some times in a person’s life when very careful and sensitive work involving families may be necessary. Families who are handing over the care of a relative for the first time will need support in their own right. They are bound to be anxious and need re-assurance. There should be a clear plan in place to ensure regular communication and quick action if problems arise. It is also good practice to have information about local support groups and to have this available for families.

Another area that requires careful work is when a person with severe learning difficulties wishes to have a sexual relationship. Dilemmas may arise as to whether family members need to be informed and what to do if they are unhappy. Under the Sexual Offences Act 2003 it is illegal for anyone to have sex with someone who does not have the capacity to consent and that consent must not be given under duress. A person would therefore need to show that despite their disability they freely communicated that they wanted to have sex with their partner. People with learning disabilities will need help with sexual health and with contraception. They have a right to this being provided confidentially. They also have a right to protection from abuse so if a member of staff believes that a person with learning disabilities is being sexually abused they must report this in line with No Secrets: guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse (DOH 2000). This can be found at www.dh.gov.uk/en/Publicationsandstatistics

It’s important that families know you have a duty to protect their relative from harm.

Sometimes families and carers find themselves working together because of terminal illness or death of a family member or in a service user. They will need to agree what information or approach needs to be taken. In the past people with learning disabilities did not attend funerals and sometimes were not even told that someone had died. Today, whenever, possible it is believed that people with learning disabilities will cope better if they are involved in the rituals of grieving. Sometimes they may need additional resources and support, for example, in the creation of memory boxes or photo albums to commemorate the life of the person who has died.
Below are some ideas for what good partnerships should look like.

Partnership between families and services means:

<table>
<thead>
<tr>
<th>Each listens to the other</th>
<th>Neither judges the other but tries to understand the situation</th>
<th>Each shares information with the other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Both have expertise to share with the other</td>
<td>Decisions are made together</td>
<td>Aims are shared</td>
</tr>
</tbody>
</table>

Sometimes the relationship is not about sharing equally but about services supporting families to achieve the best outcome for their relatives, so in this case, partnership means services:

<table>
<thead>
<tr>
<th>Provide support for the whole family and not just relative with learning disabilities</th>
<th>Give pertinent information families so they can make decision themselves</th>
<th>Arrange services to suit the family (not the services)</th>
</tr>
</thead>
</table>

You might like to add to these lists, remembering that the ultimate aim is to act in the best interests of the services user and their family.

No doubt this section will have raised a number of questions for you to discuss with your colleagues.

My questions are:
Some things you might wish to discuss with your colleague include:

Do we have a policy and good practice guidelines for working with families?

What policies do we have for people who wish to have a sexual relationship?

What support and advice is available for supporting families and service users when there is a bereavement or terminal illness?

**Task**
Choose one of the following areas to explore a little further by searching for information starting with the sites suggested below.

Bereavement
www.askmencap.info

Sexuality
www.fpa.org.uk and

Working with elderly carers
www.learningdisabilities.org.uk/publications/?EntryId=15149&char=G

Supporting families including fathers and siblings
www.mencap.org

It would be useful to note down the main points from your area of study and add it to the resources of your service.
SESSION 20: THE VOICE OF THE SERVICE USER

Right at the beginning of this induction course, we began by looking at what was meant by 'severe or profound learning difficulties or disabilities'. We explored what kind of difficulties and disabilities were involved and we considered some different syndromes and conditions. Here, at the end of the course, we want to return to the people with severe and profound disabilities and think about how we can enable them to speak for themselves, however disabled they may be. This sixth section has been all about working together and we have focused on everyone in the team, except the central member, the person with the disabilities... So this very final session is about the way in which staff in services can work together with the adults that they serve: to help develop their services to meet individual’s needs. It is about the ‘voice of the service user’.

For many years, people with learning disabilities were considered to be unable to make important life decisions. Now we have clear legislation in the form of the Mental Capacity Act (2007) which instructs us to assume people have capacity unless it can be proven otherwise. It also instructs us that capacity can vary across different situations. This means that someone might not have the capacity to consent to major surgery but might be capable if communicating that they are very unhappy in their current living environment and wish to move.

In order to make choices, people do need to understand the choice and have a means of communicating that choice. This is often very dependant on the skills of the carers to set up situations that allow choice to be expressed, so for example, if someone is always given a choice of two drinks and can sample each before deciding which to drink, that person is encouraged to exercise control. If they were only offered one drink and rushed into finishing it quickly, their choice would have been taken away. If they are at an even earlier stage of communication they may not communicate like or dislike until they have sipped the drink and they may need a very vigilant carer to note their responses.

A skilled carer will assess each situation to see how much choice can be offered, and how the person can be enabled to express that choice. This is why skills in communication are so essential for carers. In order for their voice to be heard, people with severe and profound learning disabilities will need access to relevant forms of communication, like clear routines with pauses to encourage choice,
gestures, signs, pictures, photos and symbols. Even with all this in place staff may need to help to interpret the meaning of the person’s responses.

BILD have published some guidelines to help interpretations called ‘See What I Mean’. You can find it on their website.

http://www.bild.org.uk/03books_communication.htm

See what I mean systematically collects information about particular choices that a person needs to make to help carers interpret behaviour on the basis of evidence rather than guess work.

Talking Mats

There are other tools to help find out people’s preferences, choices and opinions and one that has been developed by researchers at Stirling University is called ‘Talking Mats’. This is a low-tech framework to help people with severe communication difficulties express their views and involves moving pictures about on a piece of carpet to capture what the person likes and dislikes. You can find out a little about it from the website:

http://www.talkingmats.com/index.htm
The next website that might be useful for you is the Call Centre at Edinburgh University where they publish several books and resource packs to help practitioners and families to listen to what children and young people are trying to ‘say’. For example, the book ‘Listening to Children 2004’ is a mine of information.

http://callcentre.education.ed.ac.uk/About_CALL/Publications_CAA/Books_CAB/LtC2004_CAC//ltc2004_cac.html

Although this is designed for children with a little adaptation it is a useful resource for people working with adults. It is designed to be useful in different settings including social care.

Advocacy and people with learning disabilities
In response to the years when many people with disabilities were not given choices, there is an independent advocacy movement in the UK and in many other countries.

The following explanation of citizen advocacy is taken from the BILD fact sheet on advocacy (www.bild.org.uk) accessed 09/07/07.

British Institute of Learning Disabilities
Campion House
Green Street
Kidderminster DY10 1JL
Telephone 01562 723010
enquiries@bild.org.uk
www.bild.org.uk

Factsheet – advocacy
Summary

- The Government's White Paper "Valuing People" says that advocacy is an important way for people with a learning disability to have more choice and control in their lives.
- Advocacy can take a number of forms, this factsheet talks about citizen advocacy, peer advocacy and self and group advocacy.
- The Government has made money available over a three year period to help develop advocacy schemes, as it hopes that everybody with a learning disability who wants to have access to an advocacy scheme can do so.

Citizen Advocacy

A citizen advocate is an ordinary person who is prepared to commit to a long-term and one-to-one advocacy relationship, and speak up for and represent an advocacy partner's interests.
An advocacy partner is someone at risk of having choices, wishes and decisions ignored or not listened to, and who needs support in making these known and put into effect.

Citizen advocacy is not exclusively for people with learning disabilities, but it can be a powerful tool for giving them increased control over their own lives.

Basic principles of citizen advocacy include:

- the citizen advocate is an unpaid volunteer, who is independent of services;
- the citizen advocate’s loyalty is to the advocacy partner, and the two always work together in partnership;
- the advocacy relationship is based on trust and confidentiality;
- the citizen advocate identifies the advocacy partner’s choices and decisions, but does not make them.

Citizen advocate attributes include:

- a sense of right and wrong, and of fair play;
- understanding what it is like to be in someone else’s shoes;
- patience, and a willingness to communicate;
- confidence to speak up for another in all circumstances.

There is another form of advocacy called self-advocacy. This is speaking up for yourself. This is very difficult for people with severe and profound learning disabilities, so they may be invited to belong to a group where the whole group are supported to take action over particular issues. For example, in one area people with learning disabilities were supported to do gardening work which they enjoyed. However, they were only paid £1 for the whole day and a self-advocacy group supported them to make a complaint. Sometimes when services are re-organised, individuals loose out in services that they really need. A self-advocacy group may complain, ask to be consulted, give alternative ideas.
It is good practice for organisations to have good links with their local advocacy and self-advocacy service. You might wish to use them to help with difficult decisions, make sure that a person’s voice is heard during behavioural assessments and interventions etc. If you would like to visit an advocacy website Central England People First is a good example.

**Central England People First**  

*Conversation with your colleague*

**My questions are:**

You might like to ask about times your organisation has worked with an independent advocate. What happened? What are the good things? Were there any problems?

Ask if any of the service users belong to a self advocacy group. If possible, ask that person what they do at the group.

**Task**  
Contact your local Citizen or Self Advocacy Group. Ask them to send you information leaflets about their service. See if they have other resources like DVDs or videos that they will lend you.

Also talk about what you and your service do now and how you might develop the way you listen to service users voices.
<table>
<thead>
<tr>
<th>Collecting information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ways I listen to service users voices at the moment</td>
</tr>
<tr>
<td>Other ways I could develop</td>
</tr>
<tr>
<td>This is where I could start</td>
</tr>
<tr>
<td>How well I did</td>
</tr>
</tbody>
</table>