
Foundation for People
with Learning Disabilities

Learning with Families: A Training Resource



Learning with Families:

A Training Resource

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Disclaimer:

It is important to recognise that we are not speaking for all families who have a relative with a learning disability. Families may share some similar feelings and reactions, but we need to recognise their individuality and respect their differences. The views of the families expressed in this training resource do not necessarily represent those of the Foundation for People with Learning Disabilities.

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Introduction to the Training Resource

INTRODUCTION TO THE TRAINING RESOURCE

Aim

This training resource aims to enable staff to have a greater understanding of what it means for families to have a relative with a learning disability, and how this can affect their relationships with professionals.

It should allow family carers and staff to work together more effectively and this, in turn, will improve the quality of life for people with learning disabilities.

Background

The Government's White Paper, *Valuing People* (Department of Health, 2001) calls for a new relationship between families and staff in learning disability services.

Valuing People proposed the involvement of family carers in staff training and development. Using family carers to design and deliver training in learning disability services can help staff to understand the experiences of families.

Information about the training resource

This training resource consists of a video presenting the experiences and views of four families to be used in conjunction with the written training materials. Groups will explore issues together, through exercises and discussion points. There are eight sections which include handouts and overheads. There is an evaluation form in Appendix 2.

Developing the training resource

This training resource has been designed by family carers to be delivered to staff working in learning disability services. It was piloted in eight sites and a small number of family carers were invited to attend to give feedback on the accuracy of the contents of the course.

How to use the training resource

The training can be delivered by a family carer in partnership with a professional or two family carers together.

There are two core components: Introduction to Learning with Families (Section A) and Life in the Family Home (Section B). They provide the underpinning knowledge for other sections of the training.

The training resource has been designed to be used flexibly. For example, the entire course can be used over two whole days or over a number of shorter sessions.

If training is held at intervals then it may be helpful to see the first part of the video, 'Meet the Families', again at the beginning of the session.

It should be noted that not all of the sessions will be appropriate to all organisations.

How many participants?

- Ideally groups should consist of between 10 and 16 people.
- Larger groups will need more time for discussion so this will affect how you decide to structure the session.
- With fewer participants you may not always divide them into small groups.
- Services may want to think about inviting a small number of family carers when organising training sessions. Then they in the future may be able to deliver training.

Preparation for training

- Familiarise yourself with both the video and the written materials before planning your training.
- Plan a timetable for the available time. An example can be found in Appendix 1.
- Prepare for activities involving the use of questions and flipcharts.
- Assemble the following: TV/video player and the video; flipchart stand with paper and pens; overhead projector and overheads and/or photocopies of handouts; labels for participants' names and blu-tack.
- Familiarise yourself with the area in which you will be doing the training? Is it urban or rural? The mix of the local population will have an impact on the experiences of the families you will be discussing.

Delivering the training

- If training is to be spread over more than one day remind the participants about the ground rules developed from the first session.
- This training resource has suggestions for different activities (discussions, watching video clips, exercises, role play). You may choose to ask participants to work on their own, in pairs, in small groups, or with the group as a whole. You will want to vary this throughout the training.
- Following most of the exercises are trainers' notes that can be used to ensure a full coverage of the issues. You may also want to add your own experiences if appropriate.
- The overheads and handouts are placed at the end of each section.
- We have given estimated timings for individual exercises as well as approximate timings for the overall sessions, which allow for 5-10 minutes for introductions and/or further discussions.
- Decide in advance how you will end the session and it is a good idea to ask everyone in the group to say something at this point. You could do this by asking participants one or more of the following questions: 'What have I learned today? What have I enjoyed today? What have I found difficult today? What do I want to go away and learn more about?'

Please see Appendix 1 for further suggestions on delivering training.

Mapping to Learning Disability Awards Framework (LDAF)

The following table maps the content of **Learning with Families** to the learning outcomes of LDAF Unit 016: *Contribute to supporting relationships – families, carers and friends*. This unit is located in Option Group B in the *Level 2 Certificate: Working with People who have Learning Disabilities*.

Learning with Families covers all the units in the learning outcome 'Work positively with carers/family'. However there is not enough information to cover the learning outcome 'Encourage and support friendships'.

LDAF Unit 016 Learning outcome	Learning with Families
Work Positively with Carers/Family	
1. Understand the range of different patterns/structures of family life.	Section A. Exercise 1.
2. Understand the possible effects of having a person with a learning disability in the family.	Section A. Exercise 2. Section A. Exercise 3. Section B. Exercise 4.
3. Identify ways to involve parents/carers in decisions about the support offered to them and to the service user.	Section B. Exercise 5. Section B. Exercise 6. Section C. Exercise 7. Section C. Exercise 8. Section D. Exercise 9. Section D. Exercise 10. Section E. Exercise 11. Section E. Exercise 12. Section F. Exercise 15. Section F. Exercise 18. Section G. Exercise 20. Section H. Exercise 21. Section H. Exercise 23.
4. Identify ways to encourage positive contact between service users and their families/carers.	Section E. Exercise 14.

5. Understand the boundaries of confidentiality in relation to families/carers.	Section E. Exercise 12.
6. Recognise the carer's right to assessment of their own needs under the Carers Recognition Act 1995.	Section B. Introduction. (with follow up reading required).
7. Understand how to enable families/carers to access and use complaints procedures.	Section H. Exercise 21 and summary on complaints following it.

SECTION A

***Introduction to
Learning with Families***

SECTION A

INTRODUCTION TO LEARNING WITH FAMILIES



Section A will take approximately 40 minutes to complete.

Aim

For participants to be introduced to the Learning with Families training programme; to enable them to discuss positive and negative aspects of family networks and consider the particular characteristics of families with a relative with a learning disability.

Welcome and introductions



15 minutes.

- Welcome the participants.
- Trainers will introduce themselves.
- Family carers will also introduce their relative with a learning disability. It is a good idea to describe briefly some of their relative's different roles in life e.g. daughter, niece, aunt, friend, and employee, and they may also wish to bring a photograph to show the participants.
- Introductions by participants by giving their name, and saying where they work and how long they have worked there.
- Be aware that there might be participants in the group with a family member with a learning disability and everyone needs to be sensitive to this.
- Introduce the four families featured in the video.



Watch Video
Section A: Meet the Families

Plan of the session(s)

Describe the plan for the two hours, half or full day, to include times of breaks.

Housekeeping

These should cover the following:

- Location of toilets.
- Health and safety issues such as fire exits.
- Arrangements for refreshments.

Ground rules

Below is a list of ground rules trainers may find useful due to the sensitive issues that will be discussed during the training.

- Treat as confidential everything that is said in the room and avoid discussing specific families known to the participants.
- Listen to one another and do not interrupt each other.
- Accept that other people may express views that differ from your own and respect those differences.
- Avoid using professional jargon.

Introduction to Learning with Families: Exercise 1



10 minutes.

Aim

For participants to understand the differing positive and negative experiences in family networks by looking at their own family structures.

Guidance notes

Before we think about the families of people with learning disabilities we need to think about our own experiences and perceptions of families in general and the interactions of the various members and friends.

Instructions

- Show Overhead 1 Section A.
- Ask participants to work in pairs for two minutes and think of some positive and negative experiences they have had interacting with their family.
- Ask participants to think of words that describe the feelings associated with those experiences: e.g. love, anger, stress, sadness, loyalty, confidence, trust and support.

Feedback

- Ask participants what words they came up with. Record these on a flipchart.
- At the end of the activity reinforce the fact that all families will be different because of their varied family structures, ethnic backgrounds, beliefs and values.

Stress Experienced by Family Carers: Exercise 2



10 minutes.

Aim

For participants to understand that bringing up a child with a learning disability has plenty of rewards but there are particular stresses experienced by such families.

Instructions

- Do this exercise with the whole group.
- Ask participants to identify the particular stresses that might occur in families with a member with a learning disability.

Feedback

- Write down all their suggestions on the flipchart.
- Show Overhead 2 Section A.

Welcome To Holland: Exercise 3



5 minutes.

Aim

For participants to discuss a personal account of how one family adapted their way of life after the birth of their disabled child.

Instructions

- Trainer to read out Handout 1 Section A
- Handout to be distributed to the group.

Section A Outcomes



At the end of the session, participants will have an understanding of:

- the complexity of human emotions in the family context
- the rewards that families experience living with a person with a learning disability
- the particular stresses that families with a relative with a learning disability can experience.

Overhead 1 Section A

Introduction

- Family carers and professionals working in the field of learning disabilities want to work together to form strong partnerships rather than in isolation from each other.
- Many organisations such as the government, health and social services are trying to encourage this.
- Family carers know professionals work hard to support them but the strong feelings and emotions family carers experience can create barriers to good communication.
- This training pack has been developed by the Foundation for People with Learning Disabilities and family carers as a tool to help professionals have a greater understanding of the family's perspective.

Overhead 2 Section A

Stress experienced by family carers

Compared to families without a disabled relative, families with a disabled child may experience:

- higher levels of stress
- financial hardship (loss of earnings; high costs of caring)
- health problems (of carers)
- isolation
- problems with finding suitable housing
- increased risk of marital breakdown.

Source: Department of Health, 2001; Beresford, 1995.

For families from black and minority ethnic communities, the situation is often worse.

The difficulties may include:

- poverty
- poor housing
- social isolation
- lack of information
- culturally inappropriate services.

Source: Baxter, 1998; Mir et al., 2001.

Handout 1 Section A

Welcome to Holland

I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this....

When you're going to have a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting. After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place. So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts. But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned." And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.



SECTION B

***Life in the
Family Home***

SECTION B

LIFE IN THE FAMILY HOME



Section B will take approximately 90 minutes to complete.

Aim

To enable participants to gain an understanding of life in the family home by looking at the impact of having a family member with a learning disability, the difficulties which family carers can have in acknowledging their need for services and the needs of older family carers.

Introduction

Show Overhead 3 Section B.

Impact on the Family: Exercise 4



40 minutes.

Aim

For participants to be aware of the range of feelings that families experience when they have a relative with a learning disability.

Instructions

- Before watching the video ask participants, as they watch it to look at *each* family and to think about how they would describe the impact on that particular family. (This is a more comprehensive version of the clip shown in Section A: Meet the Families.)
- Tell the participants that there will be time for discussion after they have watched each clip. Pause the video at the end of each clip.



Watch Video
Section B: Life in the Family Home

Feedback

- Allow a maximum of five minutes discussion after each video clip.
- Read out the trainers' notes, if any of the points have not been mentioned by the participants.

TRAINERS' NOTES

- Feelings which commonly occur include: love, wanting to protect, wanting the best possible help and support, disappointment, fear, disbelief, sadness, loss, anxiety.
- These feelings will affect other family members such as siblings and the extended family.
- Families are often sensitive to reactions from the general public.
- Intense feelings can arise when the person with a learning disability reaches significant ages (e.g. their 18th or 21st birthdays) or there are other family events (siblings marrying, or having children).
- There can be a loss of spontaneity in day-to-day life. Family carers may need to plan for activities which other families take for granted, (e.g. going out for a meal with friends, going to a wedding).
- Some families feel reluctant to ask professionals for help.
- Financial hardship can arise if family members, especially mothers, want to work but are unable to do so.
- Family carers may feel torn if they have several caring responsibilities: for an elderly relative, teenage children, and a relative with a learning disability.

Acknowledging the Need for Services: Exercise 5



20 minutes.

Aim

For participants to be aware of family carers' difficulties with asking for help, and how this may affect the way they communicate with professionals.

Instructions

- Divide participants into small groups.
- Write up this question for the groups to discuss:
'Why may professionals experience difficulties in understanding the feelings of family carers when they are talking with them?'
- Record the main points of their discussion on the flipchart.

Feedback

- Ask one person from each group to feedback the main points of their discussion.
- Read out the trainers' notes if any of the points have not been mentioned by the participants.

TRAINERS' NOTES

- The strain and pressure of caring is sometimes hidden from other people (e.g. family members, friends, professionals) if carers want to protect their dignity and not appear vulnerable.
- Family carers can find it difficult to ask for help.
- People may differ in their reactions e.g. anger, denial, frustration, and confusion.
- Family members (e.g. spouses, partners) may have different reactions and expectations; this can be confusing for professionals.
- Family carers may experience contradictory and conflicting feelings about asking for help and using services: feeling a failure for not being able to cope, but needing to feel positive about getting support for the relative with a learning disability.

The Needs of Older Family Carers: Exercise 6



25 minutes.

Aim

For participants to be aware of the specific difficulties facing older family carers.

Instructions

- Ask the group to suggest answers to the following question: 'What do you think are some of the difficulties facing older family carers?'
- Facilitate the discussion and record any key points on the flipchart.

Feedback

- Read out the trainers' notes if any of the points have not been mentioned by the participants.

TRAINERS' NOTES

- Most older family carers identify two main concerns that become overwhelming worries as they grow older. Firstly, 'what will happen to the person I care for in an emergency?' and secondly, 'how do we plan for the future?'
- Many older family carers have been supporting their relative for more than 40 years and in their lifetime experience of caring, there have been many changes in the provision of services and support that have not always been communicated effectively to them. As a result, older family carers may feel isolated and insecure with little idea of realistic options for the future.
- Many older family carers may be experiencing increasing difficulties with their health and mobility related to ageing. It is important to recognise these additional factors and provide practical help such as written information in larger font sizes or on audiocassette.

- Sometimes services have to respond to a crisis (e.g. the carer's admission to hospital) and then older families may have very little choice about a placement in a crisis. Many older family carers worry about who will speak up and advocate for their relatives if they are no longer able to fulfil that role.
- Older family carers may feel a sense of relief and/or loss when the relative with a learning disability makes a planned move to live elsewhere. For many older family carers, supporting their relative has become a way of life and has made up an enormous part of their identity for most of their lives
- Some older family carers may find it difficult to accept changes (e.g. clothes, hairstyle), when the person with a learning disability is living away from home.

Section B Outcomes



By the end of the session, participants will understand that:

- family carers do not always disclose their feelings to others, including professionals
- family carers can have conflicting feelings about acknowledging their need for help
- family carers can find it difficult to communicate with professionals
- older family carers may have differing needs from younger family carers.

Overhead 3 Section B

Life in the Family Home

- This section will be covering three main areas:
 - impact on the family
 - acknowledging the need for services
 - specific needs of older family carers.
- Approximately 60% of adults with learning disabilities are still living with their families.
- One third of these adults living with their families are living with a family carer aged 70 years and over (Department of Health, 2001).
- It is only recently that carers have the right to an assessment of their own needs under the Carers (Recognition and Services) Act 1995 and the Carers and Disabled Children Act 2000.
- Families are often the only people to have a continuous relationship with their relative from birth but they will have met many different professionals from many services during that time.

SECTION C

Planning for the Future

SECTION C

PLANNING FOR THE FUTURE



Section C will take approximately 55 minutes to complete.

Aim

For participants to understand some of the feelings family carers experience when it is time to plan ahead and how to promote better planning, support and decision-making.

Introduction

Show Overhead 4 Section C.

The Need to Plan for the Future: Exercise 7

 **Watch Video**
Section C: The Harvey family



15 minutes.

Aim

For participants to understand how difficult it can be for family carers to plan for the future.

Instructions

- This exercise is to be done in pairs.
- Ask participants to think of something they have been involved in planning (e.g. moving house, change of job). What steps did they need to take, how did they feel and what helped in the process?
- Allow five minutes for discussion.
- Record the points on the flipchart.

Feedback

- Read out the trainers' notes if any of the points have not been mentioned by the participants.

TRAINERS' NOTES

- It is important to start preparing well in advance for any big changes.
- Finding out information about what options are available helps with making an informed decision when planning for the future.

Decisions about Moving from Home: Exercise 8

 **Watch Video**
Section C: The Crawforth family



30 minutes.

Aim

For participants to understand the importance of informed and realistic decision-making when the person with learning disabilities is moving from home.

Instructions

- Ask participants to think what aids good decision-making.
- Divide participants into small groups and ask them to record their ideas.

Feedback

- Ask each small group to display their list so that other groups can share their ideas.
- Read out the trainers' notes if any of the points have not been mentioned by the participants.

TRAINERS' NOTES

- The person with a learning disability should be central to and involved in the decision making process.
- Having clear and accurate information on which to base decisions gives confidence and encourages openness, reduces fear and creates open and effective partnerships.
- Goals need to be realistic.
- It is vital to be certain about the safety and quality of life of their new home e.g. staff ratios, risk assessments.
- It is important to feel comfortable and at ease and to be able to communicate openly with those involved in planning the move.
- The cultural and religious needs of the person with learning disabilities should be taken into account.

Section C Outcomes



By the end of the session, participants will understand that:

- family members experience anxiety when it comes to planning for the future
- family members need time to feel part of the planning process
- cultural and individual family backgrounds will influence decision-making.

Overhead 4 Section C

Planning for the Future

- This session will cover the following topics:
 - the need to plan for the future
 - decisions about moving from home.
- Planning for the future is something that many of us do automatically – it is natural and we want to look forward with confidence.
- For families who have a member with a learning disability the reality is that they have many fears about the future for the person with a learning disability. These uncertainties create anxieties.

SECTION D

***Working
in Partnership***

SECTION D

WORKING IN PARTNERSHIP



Section D will take approximately 45 minutes to complete.

Aim

For participants to understand how family carers and professionals can develop effective partnerships.

Introduction

Show Overhead 5 Section D.

Effective Partnerships: Exercise 9



30 minutes.

Aim

For participants to develop more effective ways of working together with families.

Instructions

 **Watch Video**
Section D: The Doll family

- Ask participants to break into small groups.
- Ask the groups to discuss: 'How can family members and professionals achieve effective partnerships?'
- Ask them to record the main points of their discussion.

Feedback

- Ask each small group to feedback the main points of their discussion.
- Read out the trainers' notes if any of the points have not been mentioned by the participants.

TRAINERS' NOTES

- Creating opportunities for family carers and professionals to learn and work together enables them to gain a better understanding of their individual and complementary roles and maximise available resources and experience.
- Family carers and staff should be encouraged to have realistic expectations of each other.
- It is important to be open about procedures such as complaints, risk assessment, adult protection.

Mutual Respect: Exercise 10



10 minutes.

Aim

For participants to explore the different possible meanings of the term mutual respect.

Instructions

 **Watch Video**
Section D: The Khan family

- Ask participants to suggest as many different definitions of the term mutual respect. Write these on the flipchart.

Feedback

- Read out the trainers' notes if any of the points have not been mentioned by the participants.

TRAINERS' NOTES

Mutual respect includes:

- treating others as we would like to be treated ourselves
- listening and being listened to
- accepting that difference is okay
- valuing each other's roles in equal partnerships
- giving – and being given – honest answers (and if there's no answer, work towards one)
- wanting to make time for each other.

Section D Outcomes



At the end of the session, participants will understand that:

- effective partnerships can be formed through understanding and respecting the different roles
- mutual trust can create clear, realistic expectations from one another.

Overhead 5 Section D

Working in partnership

- This session will cover the following topics:
 - effective partnerships
 - mutual respect.
- *It is important not to lose sight of the fact that the impact on families of children with disabilities, and their need for support, is lifelong. The reality for them is that they face recurrent and unpredictable challenges. (Carpenter, 2000)*
- Family members are usually the only people who will have a continuous relationship with the person with a learning disability. Their contribution needs to be recognised, valued, listened to and acted upon.
- In some services a culture has developed that sees families as a problem and suggests that families can be difficult to work with (Department of Health 2001).
- Most family carers want to work in partnership with professionals and service providers to achieve the best results for their relatives.

SECTION E

A Place to Live

SECTION E

A PLACE TO LIVE



Section E will take approximately 90 minutes to complete.

Aim

For participants to gain a greater understanding of the feelings and emotions that family carers experience when their relative with a learning disability leaves home, the preparations which need to take place and adjustments which family carers need to make, following a move.

Introduction

Show Overhead 6 Section E.

Preparation for the Move: Exercise 11



25 minutes.

Aim

For participants to consider what arrangements and information need to be discussed, before the person with a learning disability moves to their new home.



Watch Video
Section E: The Crawforth family

Instructions

- Divide the participants into small groups and ask the group to suggest answers to the following question: 'What preparation is necessary for the family and professionals before the person with a learning disability leaves the family home?'
- If two flipcharts are available, use one to write participants' suggestions relating to families and the other for their ideas relating to professionals.

Feedback

- Ask a representative of each group to feedback their responses.
- Read out the trainers' notes if any of the points have not been mentioned by the participants.

TRAINERS' NOTES**Families may want to discuss:**

- how the wishes of the person with learning disabilities will be central
- how families will get information about different options
- how choices will be made
- how they will find out what life will be like in the new home, whether it is a group home, or supported living for example
- what preparations will be made for the move
- how they can be involved in the life of the person with learning disabilities after they leave the family home
- whether they can develop with their relative a life history to give a more holistic view.

Professionals may want to discuss:

- the family's background and values
- what the person's level of independence is in relation to daily living skills
- who are the other important people in the life of the person with a learning disability (e.g. extended family, friends)
- the different aspects of the person's life (e.g. likes, dislikes, activities, communication, medical history)
- ways in which the family will continue to be involved in the life of their relative.

The Move: Exercise 12



25 minutes.

Aim

For participants to understand that family carers and professionals experience different feelings when a person with a learning disability is leaving the family home. Although staff and family carers may see this as progress and moving forward, family carers, particularly parents, are likely to experience sadness and loneliness and may find life difficult at this time.

Instructions

- Ask the participants to divide into two groups and each group to suggest answers to either part (a) or (b) of the following question: 'When a person with a learning disability is moving from the family home, what do you think this means to:
(a) to the family
(b) to professionals?'
- If two flipcharts are available, use one to write up suggestions relating to the family, and the other for the professionals.

Feedback

- Ask a representative from each group to discuss their ideas.
- Read out the trainers' notes if any of the points have not been mentioned by the participants.
- It is important to mention the last point from the notes about confidentiality.
- Show Overhead 7 Section E.

TRAINERS' NOTES

When the person with a learning disability is leaving home, their family carers may:

- feel they are no longer 'in control'
- experience a sense a loss
- feel relieved (but some can feel a sense of loss and relief)
- feel guilty that they have relinquished their central caring role
- be confused about their role when they visit their relative (e.g. Can I make a cup of tea? Where am I supposed to sit?)
- need to accept that they and the person with a learning disability now have new and different lives
- want staff to be aware of the person's network of friends from home and day and leisure activities to ensure that they are maintained.

When a person with a learning disability is leaving the family home, professionals should:

- see the family carers as an important thread of continuity in the life of the person with a learning disability
- be aware of their shared responsibility with family carers and understand each others' roles in the person's life
- be aware of the tensions that may exist – between family carers and professionals. For example, family carers may show their anxiety by complaining about something relatively minor such as a missing button on an item of clothing
- be aware that there may be a conflict between the wishes of the person with a learning disability and their family carers
- be aware that the person with a learning disability is also likely to be experiencing a period of loss and adjustment
- ensure they do not lose links with older friends and encourage the development of new networks of friends
- explain to carers that there are boundaries of confidentiality, for example when the person with a learning disability asks that information is not shared with the family.

Risk and Trust: Exercise 13

Please note that this is an optional exercise.

Introduction

The following optional exercise focuses on the issue of risk taking and how it can create concern for family carers. Risk and trust are words that can evoke very different reactions, yet in services for people with learning disabilities they often have to exist in parallel with each other. Perceptions of risk and trust can vary greatly between family carers and professionals.



15 minutes.

Aim

For participants to look at the meanings of risk and trust from the perspectives of family carers and professionals.

Instructions

- Depending on the time available, this exercise can be done with the whole group or as two groups.
- Ask participants to suggest how they would define risk and trust and write their ideas in two columns on the flipchart.
- Ask participants to suggest how they think family carers would define risk and trust and write their ideas in two columns on the flipchart.
- Ask participants to provide examples of situations in which family carers and professionals may have different perceptions of risk and trust.

Feedback

- Discuss the differing perceptions of family carers and professionals.
- You could share the dictionary definitions of risk and trust.
- Describe situations where risk and trust are involved e.g. an adventure holiday.
- Show Overhead 8 Section E.

Caring for the Person After They Leave Home: Exercise 14



20 minutes.

Aim

For participants to understand what adjustment means to family carers after the relative with a learning disability leaves home.

Instructions

- Ask participants to get into small groups.
- Ask them to discuss the following question: 'What do you think adjustment means for family carers and how will they feel after their relative has left the family home?'
- Ask them to record the main points of their discussion.

Feedback

- Feedback to the whole group by asking each group to share what they have written.
- Read out the trainers' notes if any of the points have not been mentioned by the participants.

TRAINERS' NOTES

Family carers may:

- continue to feel responsible for the person with a learning disability
- still wish to be involved with their family member
- be concerned for the safety and well-being of their family member
- be anxious about staffing levels and staff changes
- miss the support systems that have helped them throughout the years
- need to talk over with their relative and staff about when to visit e.g. how long and how often
- need time for adjustment to the loss of feeling needed and valued
- want to strike a balance between encouraging the person to become more independent and maintaining normal family contact (which will vary between families)
- encourage and support opportunities for the person with a learning disability to make new friendships and maintain old ones
- feel cut off from their family member's life if previous communication (e.g. about their day activities) has stopped.



Watch Video
Section E: The Doll family

Section E Outcomes



At the end of the session, participants will understand that:

- preparation for leaving the family home requires families and professionals to have sufficient time, good communication and exchange of relevant information
- when the person with a learning disability moves out of the family home, there are losses for family carers, including loss of their caring role
- adjustment following a move means family carers accepting change, developing a shared role with support staff and respecting the greater independence of their family member.

Overhead 6 Section E

A place to live

- This session will focus on three important issues:
 - preparation for the move
 - the move
 - caring for the person after they leave home.
- Most family carers feel ultimately responsible for their relative with a learning disability. This often creates worry and anxiety when needing to share their care with others.
- Most families want to remain involved in the lives of their relative with a learning disability working in partnership with providers and support staff but sometimes their feelings and emotions can cause defensive behaviour, which may create barriers.

Overhead 7 Section E

Confidentiality

One of the most difficult areas is the issue of confidentiality between the person with a learning disability, family carers and professionals.

Practical steps:

- We should acknowledge that situations can arise concerning confidentiality and may create conflict.
- It is important to address the principles and boundaries of confidentiality early in the partnership. This gives families the opportunity to think about the implications and come to terms with what this may involve before a conflict or crisis arises.
- Trust and good communication are essential for the issue of confidentiality to be addressed in a sensitive way.

Overhead 8 Section E

Risk and Trust

- Family carers' and professionals' definitions of trust are often similar e.g. confidence, reliability, honesty and dependability.
- Trust needs to be built and family carers may take longer to build trust and confidence – especially if they have had a negative past experience.
- However, family carers and professionals perceptions of risk vary greatly.
- Family carers tend to think of risk in the context of the dictionary definition i.e. possibility of meeting danger or suffering harm and this can create barriers to change and moving forward.
- Professionals tend to see risk as a way of eliminating unacceptable risks – e.g. through using risk assessments, and can lead to the person becoming more independent.

SECTION F

Daily Activities

SECTION F

DAILY ACTIVITIES



Section F will take approximately 90 minutes to complete.

Aim

To understand the changes that affect family members when their relative with a learning disability moves from full-time education to different daytime activities and the importance of a satisfying way of life.

Introduction

Show Overhead 9 Section F.

Smooth Transition: Exercise 15



15 minutes.

Aim

For participants to consider the stresses experienced by families when the young person with learning disabilities is preparing to leave full-time education.

Instructions

 **Watch Video**
Section F: The Harvey family

- Facilitate a discussion about why there are anxieties about the transition from full-time education to adult life and how these can be reduced.
- Write up the points on a flipchart.

Feedback

- Read out the trainers' notes if any of the points have not been mentioned by the participants.

TRAINERS' NOTES

- Early information and awareness of the alternatives to adult services is invaluable. This should happen from the age of 14.
- School has usually provided stability. There is greater uncertainty after full-time education.
- Transition is the fear of the unknown for family carers.
- For the young person with limited speech, the use of photographs, a diary or a communication passport is valuable in explaining to new staff their ways of communicating.
- A series of visits to the new college, work placement or day service is helpful in alleviating anxieties in helping to plan for the future.

The Impact of Transition: Exercise 16



30 minutes.

Aim

To understand the impact of the major change from school to different daytime activities.

Instructions

- In groups ask 'what preparation do you think families need before their relative with a learning disability moves into adult daily activities/services?'

Feedback

- Read out the trainers' notes if any of the points have not been mentioned by the participants.
- Distribute Handouts 2 and 3 Section F to participants.

TRAINERS' NOTES

Families need to know about:

- differences in staff and procedures from school/college/other day activities
- the ways day services are changing. If this does not happen lack of information causes family carers to be overprotective/over-anxious
- different services, for example, college, work experience
- the possibility of direct payments, which should bring more choice and inclusion to the person's life. Family carers need to be well informed of all that this involves
- the ways they can communicate with staff supporting people with learning disabilities in their daytime activities. This helps reduce the family's sense of isolation.

The Importance of Daily Activities: Exercise 17



15 minutes.

Aim

To consider the importance of rewarding daytime activities for the person with a learning disability and the implications of the modernisation of day services for people with learning disabilities and their families.

Instructions



Watch Video

Section F: The Doll family

- Facilitate a discussion following the video to focus on
 - the range of day time activities available
 - the implications of modernising day services, whereby people with learning disabilities are more likely to engage in community based activities than to attend a large day centre.
- Read out the trainers' notes if any of the points have not been mentioned by the participants.

TRAINERS' NOTES

- People with learning disabilities may appreciate the break from family and/or carers as much as their families.
- Organising different activities creates a time to form or maintain friendships.
- The development of person centred planning allows for a more imaginative approach to develop a person's potential.
- The move away from large day centres can be a cause for concern for people with learning disabilities, staff and families.
- There is a range of activities that people with learning disabilities may engage in, e.g. work, college, volunteering, social activities, sport etc.

Working Together: Exercise 18



20 minutes.

Aim

For participants to develop more effective ways of joint working between family carers and professionals.

Instructions

- Divide the participants into small groups and ask ‘what suggestions do you have for improving working relationships with families as their relative engages in daily activities?’

Feedback

- Ask a representative of each group to feedback their responses.
- Read out the trainers’ notes if any of the points have not been mentioned by the participants.

TRAINERS’ NOTES

- People with learning disabilities and their families value informed choices of what options are available to them.
- Family carers need to be reassured that their relative with a learning disability will be safe, valued, and reach their potential.
- Families value regular honest communication.
- Families need information regarding staffing and other changes.
- Families need to be aware of policies and guidelines of the service, for example, risk taking, complaints.

Section F Outcomes



By the end of the session, participants will understand that:

- family members experience fears/anxiety when full-time education comes to an end
- families may feel they carry a heavier responsibility if their relative is not supported and engaging in activities five days a week
- uncertainty about and changes in day services creates concern for the future needs of the person with a learning disability
- good communication between all agencies involved with the person with a learning disability limits the isolation of the family.

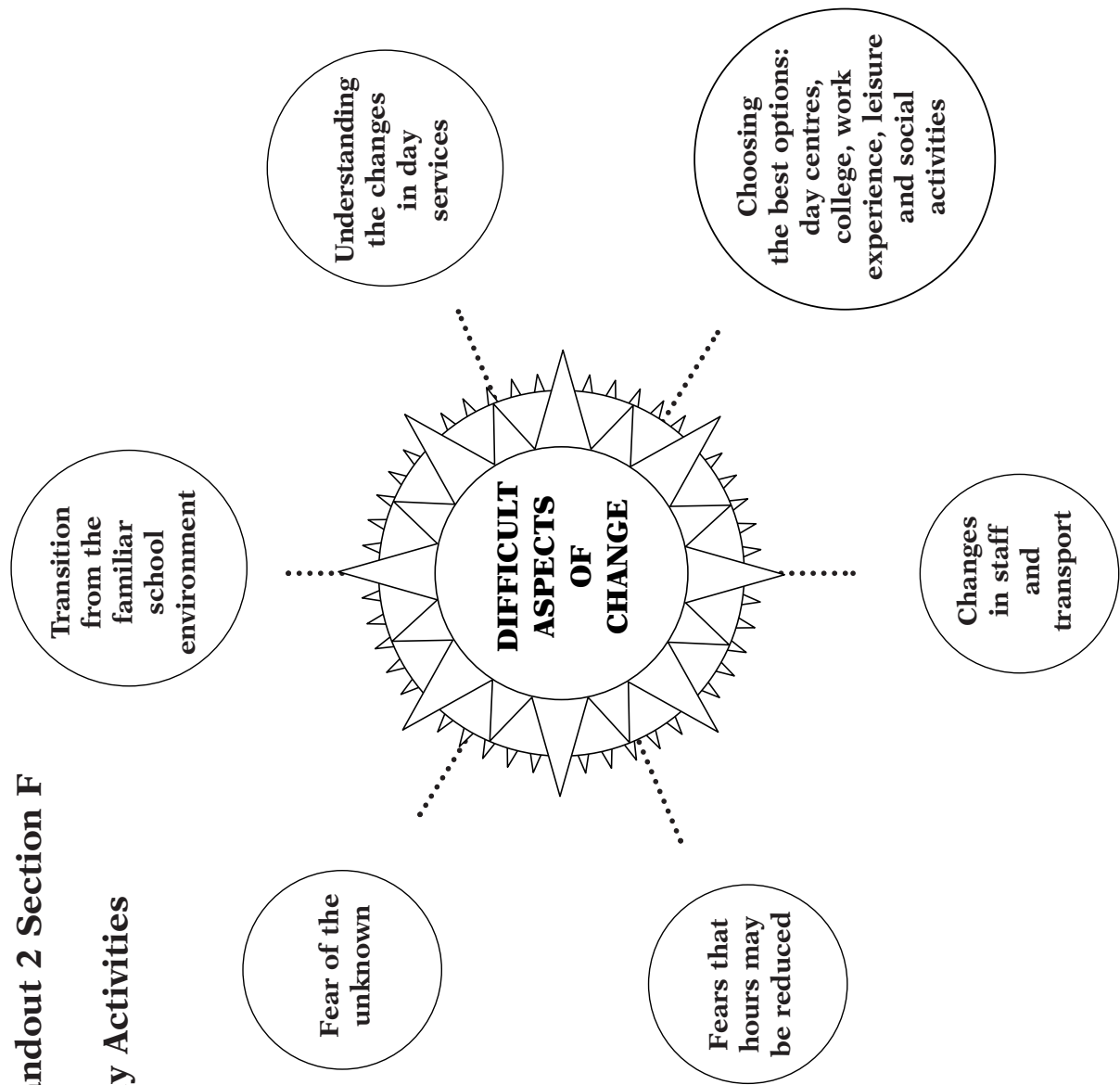
Overhead 9 Section F

Daily Activities

- This session covers three main areas:
 - smooth transition
 - the importance of daily activities
 - working together.
- The transition from school to varied daytime activities can be very challenging but at the same time, very exciting for the family and for the person with a learning disability.
- There are uncertainties about the changing role of day services which creates concern for the future needs of the person with a learning disability.
- Given the right information, thought and care, it can provide real opportunities for development, education and reaching full potential.

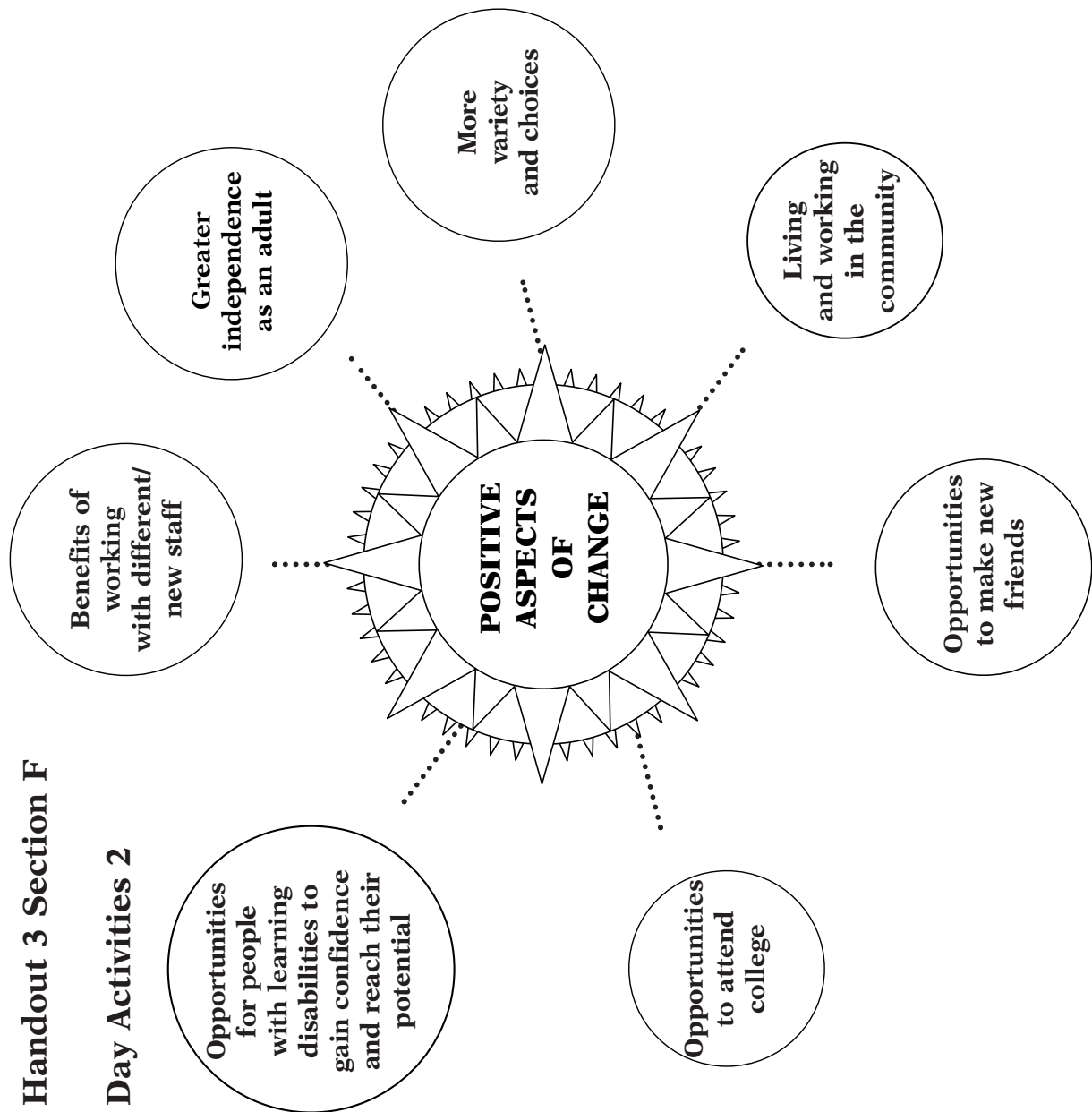
Handout 2 Section F

Day Activities



Handout 3 Section F

Day Activities 2



SECTION G

Short-Term Breaks

SECTION G

SHORT-TERM BREAKS



Section G will take approximately 90 minutes to complete.

Aim

For participants to understand the difficulties family carers may have in acknowledging their need for breaks from caring; the benefits of short-term breaks for the person with a learning disability and their family carers and that short-term breaks may serve as a preparation for the future.

Introduction

Show Overhead 10 Section G .

Conflicting Feelings About Using Short-Term Breaks: Exercise 19



25 minutes.

Aim

For participants to explore the conflicting feelings experienced by family carers when needing to take a break from their caring role.

Instructions

- Before watching the video ask participants, as they watch it, to identify the conflicting feelings which family carers may have.



Watch Video
Section G: The Crawforth family

Feedback

- Ask participants for their feedback and record the main points on a flipchart.
- Read out the trainers' notes if any of the points have not been mentioned by the participants.

TRAINERS' NOTES

Family carers may:

- need short-term breaks but not want to use them
- have concerns about the person with a learning disability being away from the family home
- find it difficult to come to terms with their need for a break from caring
- initially feel a failure because they are asking for help
- enjoy spending time with others, but feel guilty about having the break from caring
- worry that they won't be considered needy enough to be eligible for short-term breaks
- experience fear and concerns that unless they are given a break, the family may breakdown.

Benefits of Short-Term Breaks for the Whole Family: Exercise 20



30 minutes.

Aim

For participants to understand the benefits of short-term breaks for family carers and the family member with a learning disability.

Instructions



Watch Video
Section G: The Harvey and Khan families

- You can then divide participants into two groups.
- Give each group flipchart paper and pen.
- Ask one group to list the benefits of short-term breaks for **family carers**.
- Ask the other group to list benefits of short-term breaks for **people with learning disabilities**.

Feedback

- Ask each group to display their lists on the flipchart.
- Read out the trainers' notes if any of the points have not been mentioned by the participants.

TRAINERS' NOTES

Benefits for the family carer may include:

- having time and energy for other activities (e.g. swimming, seeing friends and going to the pub or the cinema)
- having time to relax and do nothing
- spending more time with other family members
- having a flexible service available for varying lengths of time e.g. three hours, overnight, a week at weekends and in the evenings. This will depend on local services
- time to adjust to being separated from the person with a learning disability in preparation for a future move.

Benefits for the person with a learning disability may include:

- spending time with other people often of their own age
- trying out new activities
- doing things they might not have the opportunity to do at home e.g. going out for a meal or a coffee with peers
- trying out what it feels like to spend some time away from home and the family
- becoming more independent
- learning new skills.

Preparing to Use a Short-Term Breaks Service: Exercise 21



30 minutes.

Aim

For participants to understand the issues which family carers may need to consider when thinking about using short-term breaks whether their family member goes to a residential unit, a link family or carers come to the home.

Instructions

- You can do this exercise with the group as a whole.
- Ask participants to draw up a list of issues that family carers may think about when starting to use a short-term breaks.

Feedback

- Write up their suggestions on a flipchart.
- Read out the trainers' notes if any of the points have not been mentioned by the participants.

TRAINERS' NOTES

Issues that family carers may think about will include:

- building trusting relationships
- establishing good communication
- ensuring the likes and dislikes of the relative with a learning disability are fully known
- everyone respecting each other's roles and views
- ensuring consistency for the relative with a learning disability
- finding out about the service's procedures for safety and adult protection, if it is a residential unit
- treating short-term breaks as a positive step for the future if it is an overnight service.

Section G Outcomes



By the end of the session, participants will have understood that:

- family carers can have conflicting feelings about acknowledging their need to use short-term breaks
- short-term breaks can have benefits for both the person with a learning disability and the family
- short-term breaks can be a good preparation for when the person with a learning disability moves out of the family home.

Overhead 10 Section G

Short-Term Breaks

- This session will focus on three issues for family carers
 - conflicting feelings
 - the benefits for the whole family
 - preparation.
- Caring for a relative with a learning disability can be very rewarding, but it can also be very demanding, particularly if the person has additional physical/health needs or behavioural needs.
- Short-term breaks are an excellent preparation for the whole family for a future move to more independent living arrangements or into residential care.
- Short-term breaks are a very valuable service and families' requirements for these vary considerably, for example, weekly, monthly, with another family, someone coming to the home or a residential unit.
- Families need to be given plenty of information to help them understand how to access short-term breaks and what the service provides.

SECTION H

Communication

SECTION H

COMMUNICATION



Section H will take approximately 2 hours to complete.

Aim

For participants to understand how family carers and professionals can communicate more effectively with one another to maximise available resources and experience.

Introduction

Show Overhead 11 Section H.

Difficulties in Communicating: Exercise 22



Watch Video Section H: Harvey and Crawforth families



25 minutes.

Aim

For participants to be aware of the reasons why family carers and professionals may have difficulty communicating with one another.

Instructions

- Divide the participants into two groups.
- Ask one group to discuss this question: 'What do you think are the reasons why **family carers** sometimes find it difficult to communicate with professionals?'
- Ask the other group to discuss this question: 'What do you think are the reasons why **professionals** sometimes find it difficult to communicate with family carers?'
- Ask them to record their answers.

Feedback

- Ask one person from each group to feedback their ideas to the others.
- Read out the trainers' notes if any of the points have not been mentioned by the participants.

TRAINERS' NOTES**Family carers may find it difficult to communicate because they:**

- had previous negative experiences of trying to communicate with professionals
- are afraid of losing their dignity if they reveal deep-seated feelings
- do not want to 'go public' with information about their family
- need to build trust before sharing delicate information
- feel inadequate if they don't understand jargon or how services operate
- feel too isolated to be able to communicate
- attend meetings where they find themselves outnumbered by professionals
- feel they are a failure for needing services because they should be able to cope
- don't know the best person to talk to
- feel guilty about asking for help
- do not feel very confident if they are meeting on professionals' 'territory'.

Professionals may find it difficult to communicate because they:

- worry that family members might get upset
- are ruled by policies/procedures/frameworks
- worry that a 'them and us' attitude may exist
- may feel inadequate if they are less experienced – some parents can have a great deal of knowledge and can appear daunting
- don't want to burden families too much
- may be aware that some families are known to be difficult and this can lead to barriers
- are afraid that family carers will be angry with them
- know there are limited resources
- fear that, if they get things wrong, a formal complaint might be made.

Complaints: Exercise 23

Please note that this is an optional exercise.



10 minutes.

Aim

For participants to accept the possibility that family members may make a complaint.

Instructions

- Ask participants to read Handout 4 Section H.
- Ask the group to give ideas on what specific help might families need if they make a complaint.
- How can communication be maintained in this situation?

Asking for Help: Exercise 24



10 minutes.

Aim

For participants to experience how family carers feel when asking for help through role-play.

Instructions

- Ask the participants to work in pairs and decide who will play the family carer and the professional.
- Read out the following scenario: *'Patricia has been receiving short-term breaks on a regular basis at the same service for many years. Her father recently died and her mother is finding it more difficult to care for her. The other respite facility in the area closed last year and as a result breaks are being strictly rationed due to the increase in demand for the service Patricia is using.'*

How will Patricia's mother and her care manager or respite manager work towards a solution?

- Allow five minutes for the participants to role-play.

Feedback

- Ask the participants for feedback on how they felt from both the family carer and professional's perspective
- Ask the participants if they reached a positive or negative solution

The Effects of Poor Communication on Family Carers and Professionals: Exercise 25



30 minutes.

Aim

For participants to understand the effects of poor communication on family carers and professionals.

Instructions

- Ask the group to think about the following question: 'What do you think the effects of poor communication and lack of information might be on family carers?'

Feedback

- Record the answers on the flipchart.
- Read out the trainers' notes if any of the points have not been mentioned by the participants.

TRAINERS' NOTES

Poor communication may result in:

- family carers and the person with a learning disability not accessing support or not using appropriate services
- misunderstandings by either or both parties
- family carers and professionals feeling discouraged about their partnership
- one party or both making incorrect assumptions based on what they thought was said.

Improving Communication: Exercise 26



10 minutes.

Aim

For participants to experience how family carers and professionals can improve communication through role-play.

Instructions

- Ask the participants to work in pairs and decide who will play the family carer and the professional.
- Read out the following scenario: *'Jim recently moved into a residential home with three other people. His parents are very interested in his welfare and it has been noted that they telephone the home at inconvenient times, usually around mealtimes.'*
How would you approach this?
- Allow five minutes for the participants to role-play.

Feedback

- Ask the participants how they felt when doing the role-play from both the family carer's and professional's perspective.
- Ask the participants if they reached an amicable solution.

How to build effective communication: Exercise 27



25 minutes.

Aim

To enable participants to develop more effective methods of communication.

Instructions

- Ask the group to work in pairs.
- Each pair to explore ideas around the question 'What suggestions do you have for developing good communication?'

Feedback

- Ask participants to bring their ideas back to the whole group.
- List their ideas on the flipchart.
- Read out the trainers' notes if any of the points have not been mentioned by the participants.

TRAINERS' NOTES

Developing good communication requires:

- listening to each other
- clarifying what the other person is saying by reflecting back 'I think what you are telling me is...'
- having a sense of humour
- accepting and valuing differences, e.g. cultural differences
- adopting a flexible approach
- being open and honest
- celebrating good things together
- offering encouragement to each other
- having realistic expectations
- choosing to work and learn together
- being willing to give time to discuss concerns.

**Watch Video**

Section H: The Crawforth, Doll and Khan families

Section H Outcomes



By the end of the session, participants will understand that:

- the differing perceptions and experiences of family carers and professionals, and poor communication, often lead to inaccurate assumptions, isolation and misunderstandings
- choosing to work and learn together encourages understanding of each other's roles and an acknowledgement that everyone has valuable parts to play
- good communication leads to effective partnerships which enhance the life of the person with a learning disability.

Overhead 11 Section H

Communication

- This session will focus on three main aspects of communication:
 - difficulties in communicating
 - the effects of poor communication on family carers and professionals
 - ways of building effective communication.
- We should never underestimate the value of good communication.
- Effective communication is the foundation and basis for successful partnerships.
- Most families want to communicate and work together with professionals but their feelings and emotions can create barriers.

Handout 4 Section H

If things break down...

- Ongoing good communication is the most effective way of preventing a situation where a formal complaint might be made.
- An open approach to working together must include accepting the possibility that family members might make a complaint if they feel things cannot be resolved in any other way.
- Professionals should make sure that family members are aware of how they can complain, as a last resort. The best way is to make sure that the complaints procedure is made available, in an open and accessible form, as part of the general information given to a family when they first have contact with a service.

If participants are using 'Learning with Families' to gain assessment on LDAF, they will need to:

- Check that they understand how to use their own organisation's complaints procedure and where to find guidance about it.
- Spend some time finding out, and reflecting on, how it might feel for a family member faced with using a complaints procedure. What would help them really understand what it says? What would help them feel confident enough to use the system if they had to? What specific help might they need? How can communication be maintained even in this situation?

References and Appendices

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APPENDIX 1

Guidelines for those new to training

If you are new to training you may find these tips useful.

- What is the training room like? You may want to check it out before the day of the training. Sometimes you may have to make the best of using a room that is not ideal, but it should preferably be large enough, comfortable and free from interruptions. If participants are going to work in pairs or small groups, you will need enough space for this.
- If the sessions will cover a number of exercises it's best to change the size and composition of the groups to encourage participants to work with different members.
- A session may cover one or more of the sections in the pack, but whichever is the case, you will need to plan a timetable for the available time, for example:

Sample plan for half-day training session

9.15	Introduction to Learning with Families
9.55	Life in the Family Home
11.25	Tea/coffee
11.45	Planning for the future
12.40	Close

- There are advantages to training in pairs, particularly if you are doing more than a short session. This allows you each to have a breather because training uses plenty of energy. The participants will benefit from working with trainers from different families and with different styles of working.
- Training sessions usually generate a great deal of discussion; exercises can take longer when it's a larger group, so you need to keep an eye on the time and judge when it is time to move on to the next activity.
- We recommend that family carers should be recompensed, taking into account the maximum allowance if on benefits.

APPENDIX 2

Evaluation Form for Participants

Date:.....

Location:

Please comment on the sessions you participated in

	Very useful	Useful	Not very useful	Poor
Did you think this training session was:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Further comments

.....

.....

	Very useful	Useful	Not very useful	Poor
Did you think the time given to this was:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Further comments

.....

.....

What was the most valuable part of the session?

.....

.....

.....

What was the least valuable part of the session?

.....

.....

.....

Was there anything important that was missing?

.....

.....

.....

What did you learn from the session that would be useful to you in your work?

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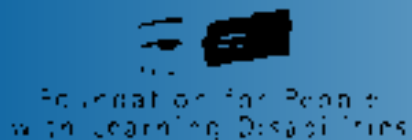
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The Foundation for People with Learning Disabilities works to improve the lives of people with learning disabilities through:

- Funding innovative research and service development projects and disseminating the findings.
- Listing to people with learning disabilities and involving them and their families in its work.
- Seeking to influence policy.
- Providing information to people with learning disabilities, family carers and professionals.

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