

"The Keys to the Door" - Guidance

The following information brings together various elements of the on-line resource for your use as a facilitator. Please acknowledge EDG as the source even if you choose to adapt it in anyway.

Supporting emotional responses

Given the nature of the topics included in the film, some people might become upset. This is a natural response to the issues being discussed. As the facilitator it is important that you think through the possibility of this before beginning the session and discuss with your group how they would like you to behave.

It would be useful to 'flag up' the emotional content of the film and clips, "some of you might find the experiences that the parents share in these clips quite emotional" and link it to developing and agreeing some ground rules at the start that can include –

- "how we will behave towards each other if we become upset"
- agreed behaviours e.g. acknowledge what is happening, focus or not focus on the person who is expressing their emotion, take a break etc

Keeping the discussion going

Use of non verbal clues -

- eye contact
- head nodding
- sounds to let the other person know they are listening

It is essential that your body language matches up to the words you are using and how you go onto respond after someone has shared something with you.

'Active listening'

Being listened to and heard is something that we all need to experience. Parents tell us that they don't always feel that this is happening when they are talking to professionals (or parents of non-disabled children and adults). It is important that we learn to give people the attention they need.

If you find yourself with a parent repeating themselves to you, it might be worth considering the following -

"Is this happening because they don't feel heard by me?"

"Do they feel they need to say this again because I have not acknowledged what they have said?"

"Am I too quick to come up with a 'solution' i.e. tell them what I do in their situation (which I'm not in actually), rather than listening to what they are saying and the feelings behind the words?"

"Am I 'checking out' what I am hearing by saying 'this is what I heard, Have I got it right?' If I do this and share my understanding we can catch any misinterpretations early"

Film - reflective questions

There are no right or wrong answers; this is an opportunity to respond to what is shared and for you to think about your own situation.

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1. What did you feel when you heard these parents talking about their adult children and young people?
2. The parents are being interviewed and so of course the situation has been created for the camera, however, what do you see in the faces of the parents as they talk about their children and their plans for them?
3. What are the main concerns for all the parents whatever the age of their children?
4. How does Frances feel about being more independent?
5. Is there a key message that the older parents are giving as they think back on the journey they have been on?
6. .What causes a shift in the thinking of Nadine and Shona after listening to the older carers?

Facilitator

You may wish to work your way through all these questions or invite the group members to look at some questions in pairs or smaller groups and then feedback.

You might wish to capture their responses under the four headings of – Feel, See, Hear and Learn

Writing up some of what is fed back within the wider group under these headings is a useful way to validate the feedback and helps to embed the learning by showing the comments visually.

Video clips - reflective questions

Clip 1: Claire and Joe

- What does Claire identify as 'shared experience' with the older carers?
- Claire refer to a 'natural separation' that occurs with typically developing young people – what do you understand by this term and what do you think are the issues for parents of children with Learning Disability?

Thoughts and comments

Some thoughts and comments shared with EDG by parents/carers in individual sessions, focus groups and within the Older Carer's Group

'Shared experience'

Feelings of concern and anxiety about the future

"Who will care for him/her?"

"Will they care for him/her as well as I do?"

"What will happen when I am gone?"

'Natural separation'

Typically developing young people begin to want to separate emotionally and physically from their parents. This is a natural process that generally begins in adolescence as the child tends to identify more with other young people rather than their parents and family. It can be challenging for all involved but as most parents will have experienced it for themselves when they were younger it is generally understood that this is what is happening and that independence is a natural goal as children move into adulthood within Western society.

Separation of parent and a disabled child doesn't happen naturally. Most young people with learning disability are operating at a younger age and continue to need the reassurance and support of their parent(s).and in some cases family members who have a caring role. Some young

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people may indeed want some form of independence but need a great deal of support to develop the skills and confidence to be away from their parent(s) because of their learning disability.

I find it difficult to have to talk about people with Learning Disability in terms of deficits (what they lack) but the concern and anxiety that parents experience is rooted in our understanding of the impact of our child's cognitive impairment on their –

- decision-making
- assessment of risk
- capacity to focus
- awareness of surroundings etc

"Typical young people start to move away from you, they get their own friends and want a life outside of the home. Our young people may want some of that too but they can't always imagine it or articulate it"

"For my son, it doesn't seem to be a concept he can grasp – too abstract – what he knows is being with us. In fact he becomes quite agitated when this is discussed at all"

"Sometimes we are called 'over protective', but can people not see how frightening it is to imagine her out in the world, trying to cope and possibly being taken advantage of?"

"It often feels 'one step forward, two back', we practice a task, a routine and he seems to have got it but then we'll go out and it is as if he never did any of it before"

Facilitator

Support parents to -

- identify the strengths and abilities of their child (whatever their age) to be built on
- acknowledge the challenges the child faces and how this makes the parents feel
- spend time on addressing their fears and anxieties
- take small steps to reduce the risk of becoming overwhelmed

Clip 2: Linda and Kim

1. What is that Linda wants for all her children?
2. How does she go about ensuring that Kim has an independent life 'in her mind'?
3. How did Linda's experience as a social worker influence her parenting?

Some parents have told us that they have faced particular challenges when their own child has a disability because of their professional background, with other people assuming that they will 'cope better' and 'know what to do'..

"My own mother said 'why are you getting so upset? You're a nurse, you should be able to deal with this'. Looking after a patient is totally different from dealing with my son's disability, my emotions are involved. He's my baby!"

"You've worked with people with Down's for years, you'll be a natural at this"

Some parents have put themselves under that pressure too, believing that they **should** 'find it easier' when in reality of course, being a parent and being a professional are different things. Living 24/7 with a disabled child and being emotionally involved as you are when you are the parent is a very different experience from being professionally involved, however compassionate and empathetic.

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Clip 3: Iris and Andrew

Facilitator

The stark reality of Iris situation may be very hard for your participants to hear. You can best assess whether to address what is said after viewing the clip or move gently onto the next clip and include some reference to in the later discussions.

Clip 4: Nadine and Jessie

Discussion point

What are the ways that parents and professionals can gauge the views and feelings of a person with complex disability and health needs?

Facilitator

Asking this question provides an opportunity for parents and family members to share how they 'read' and understand their child's gestures and noises. Listening to each other can validate a parent's knowledge of their child and give ideas for similar things to look out for their in child.

This 'expertise' needs to be recognised and valued by professionals working with the families - asking about this knowledge can be a useful way to begin a new relationship with a parent and develop trust between you both.

Clip 4: Linda and Kim

Discussion point

What do you think about the issue of choice?

What do you understand by the term 'informed' choice?

Facilitator

You can explore -

- This 'bone of contention' for some parents
- Role of support workers in interpreting 'choice'
- How can we address the consequences of the choices that are made e.g. diet, dress etc.

Clip 5: Shona and Gregor

Discussion points

What are your experiences of being in groups?

Do you relate to what Shona says?

Facilitator

It can be helpful to acknowledge that -

- Parent to parent contact is viewed by many parents as extremely helpful
- However, being in a group is not for everyone
- An on line resource provides another way for parents to hear about other people's experiences, at their own pace and at a time that works best for them

Clip 6: Iris and Andrew

Facilitators

This last clip can be used to summarise and conclude your session. It echoes the theme of this project for your participants -

- begin the conversations as early as you can
- before you need to be making decisions.