It’s difficult but it’s not rocket science: Discussing death, loss and bereavement with people with learning disabilities and autistic people

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Dedication

This study was done in the year following a bereavement in the community of people with learning disabilities and autistic people in the Derry City and Strabane District Council area. On 27th October 2021 the community lost Bronagh McLaughlin. The loss of Bronagh has been felt throughout the entire community. We would like to dedicate this report to Bronagh and to everyone else who has died and those who miss them.

“Each person’s grief is as unique as their fingerprint but what everyone has in common is that no matter how they grieve, they share a need for their grief to be witnessed.”

David Kessler, 2019

“I found in our service, when we had lost a young person or when anyone has died within, I suppose the circle of disability, because a lot of the young people are connected through all the groups, it's nearly like a tsunami coming towards you as a staff team and as an organisation”

Support worker

Statement of contribution

This project was conceived and implemented by Informing Choices NI in collaboration with Ulster University using funding allocated by the Ideas Fund. Informing Choices NI is a sexuality and reproductive health charity in Northern Ireland who have worked with people with learning disabilities and autistic people for over 20 years.

We want to acknowledge and thank the Ideas Fund for their funding and support throughout the process. Their commitment to community-based research is invaluable. We also want to thank Roisin McLaughlin and The North West Community Network as the local mentor who provided support on the ground.

Planning of part 1 of the project was done by Deborah McGinn, Mark Breslin and Grainne McAnee. The ethics process was completed by Grainne McAnee and Deborah McGinn. Facilitating focus groups and other data collection was done by Deborah McGinn and Mark Breslin. Analysis of the data was done by Grainne McAnee. Write up of the report was done by Grainne McAnee. The report was reviewed by Deborah McGinn and Mark Breslin. Planning of part 2 of the project was done by Deborah McGinn, Mark Breslin and Grainne McAnee. Training was delivered by Deborah and Mark and feedback collected by them. Feedback was analysed by Grainne who then completed part 2 of the report.
I would like as a researcher to note my admiration at the skill of Deborah and Mark at facilitating these sessions and at delivering training on such an important and sombre subject. It was a humbling experience to be part of.

The most important contribution was from the community of people with learning disabilities and autistic people in Derry. We would like to thank the whole circle of people in this community, people with learning disabilities and autistic people, their parents, carers, and their support workers. Thank you for being so generous with your time and your stories.

A Note on Language

Informing Choices NI work closely with the community of people with learning disabilities and autistic people. The terms “people with learning disabilities” and “autistic people” are currently how they would like to be referred to and as such will be the language used in this report.

This report will use the term people with learning disabilities to incorporate all of these, this is for brevity in typing and to facilitate flow of the document. No abbreviation of the term will be used as it feels dehumanising to shorten people to an acronym.

Summary

The Ideas Fund provided the opportunity for Informing Choices NI to realise a piece of research which was of interest for many years. This was to investigate what happens for people with learning disabilities and autistic people when they experience a loss. This study focuses on loss through bereavement but loss of course comes in many forms and impacts people with learning disabilities.

The reason this question was of interest to Informing Choices NI was, through working in this community, there were many occasions when they were asked to work with people who were exhibiting "challenging behaviour." It became apparent that for a number of these cases the challenge was related to a person experiencing grief which could be characterised in psychological terms as disenfranchised. Disenfranchised grief is a grief that has not been given the room to be expressed. It is a grief that is not acknowledged as legitimate and does not receive the same attention and support.

Part 1 of the research project asked people with learning disabilities, their parents/carers and support workers, what their experiences were around loss and bereavement. The project saw high engagement from people with learning disabilities but much lower numbers of parents/carers and support workers engaging with the topic. It was also necessary to adapt the way in which these groups were taking part. Rather than participating in focus groups, they preferred anonymous questionnaires or one to one interviews.

Part 1 of the project concluded that there is a need to change the way in which grief and loss is responded to in the community of people with learning disabilities and autistic people. This report outlines the process followed, the results and the findings in full for part 1 of the project.

Part 2 of the project was completed with further funding by The Ideas Fund. The training was delivered to professionals. Part 2 of the report describes the training, the process for evaluating the training, findings, and further recommendations.

Final Recommendations

This work has highlighted the strong need for a co-ordinated, consistent response to loss and bereavement within the community of people with learning disabilities/difficulties and autistic people.

This response should be delivered at a regional level. Responses in all trust areas should be the same and should be contained within documented procedures and guidelines. These should be reinforced by a repository of resources that are available to affected individuals, families and professionals.

Professionals want to help but many feel they do not have the confidence. A co-ordinated consistent approach will help achieve this. The fundamental core of that approach is this training. It has been well received and effective and should form the primary element of a regional approach. Furthermore, the approach that Informing Choices NI have used has proven to be novel and thought provoking and they should remain central to that delivery. The product needed already exists.

Alongside training, professionals also would benefit from the establishment of a network of peers alongside training who they have protected time to meet in order to raise any concerns and keep their confidence high.

It is imperative that work is facilitated with families to achieve buy-in to an honest and factual approach when a person with learning disabilities/difficulties or autistic person experiences loss or is bereaved. All three points of the triangle of support – the individual, their families and the professionals who support them – must be joined together to provide the consistency needed to properly meet the needs of the individual affected. It complicates and confuses, rather than protects when a person is not told the truth and adequately supported through grief.

Part 1 Identifying the need and coproducing the programme

Part 1 Recommendations

1. This study is the starting point for the conversation which is needed in relation to supporting people with learning disabilities and autistic people when they experience a loss or bereavement. This conversation should bring together people with learning disabilities or autistic people, their families and carers and the people who provide support and work in the community.

2. People with learning disabilities and autistic people feel like we all do when we lose someone. We all need support when death and loss happen. The taboo around death is part of a wider societal taboo. There is great understanding and compassion for the fears that families have and their need to protect their children. However, it must be understood that despite those fears, people in this community will experience death and they will experience loss. This report reflects that they are more than able to articulate what their experiences are and how they would like to be supported. The fears of those who love and support them cannot be prioritised over the needs they themselves have.

3. Each individual needs support when they lose someone, for example a family member. Beyond this there are losses within the community and these losses affect everyone. These have been described by both individuals and by support workers as being like a wave or tsunami approaching the support organisations. When these losses occur, as well as supporting people with learning disabilities and autistic people, provision must also be made for those who work closely with and support them.

4. A regional, coordinated approach to supporting people when someone dies is needed and it should be funded. The support which was provided as outlined in this report by support workers was excellent and appropriate. It was however completely dependent on the support workers having their own connections and being able to call on them as well as having funding available. A number of models can be considered which may provide training for those who are already working

within the community and also people from outside of the community who have expertise and who are removed from the death such as support workers, social workers.

5. Support should be provided by professionals, including counsellors and therapists who have been trained in working with this community. People with learning disabilities have particular needs which exist on a wide spectrum and require an adaptive approach to communication. Their services should be provided by people with the appropriate experience.

6. Support may be needed on an ongoing basis. It will be needed when the loss first occurs and as time goes on if required. This support should include access to consistently updated resources and material.

7. Informing Choices NI work within this community delivering relationships and sexuality education programmes. They use a very successful adaptive format using flexible approaches that incorporate appropriate tools and techniques. This is a format that can be adapted in terms of the content of the programme and can be used to deliver a programme based on the needs of people with learning disabilities and autistic people when they experience a loss or bereavement. It is recommended that the first programme to be developed and piloted is a training programme for the professionals who support this community.

Ethical Approval

Ethical approval for this study was given by the Ulster University School of Psychology Ethics Filter Committee. The research protocol and all documents related to the project are not listed here but are available on request and include but are not limited to consent forms, participant information sheets, distress protocol, adults at risk policy, GDPR policies, focus group guides, ethical approval and Covid policies.

Background

A review of the research base

Barber (2011) asserts that there are two areas of learning disability care that tend to be forgotten by healthcare professionals. The first of these is sexuality and the second is death, dying and bereavement. A scoping review of the literature from 2000 till the present day supports this. Dealing with bereavement is consistently reported as an area of life from which people with a learning disability and autistic people tend to be excluded (Barber, 2012a; Barber, 2012b; Graham, 2014; Gray & Abendroth, 2016; Handley & Hutchinson, 2013; McEvoy & Smith, 2005; Read & Papakosta-Harvey, 2004; Tuffrey-Wijne et al., 2017). This phenomenon has been described in the literature as 'the elephant in the room' (Barber, 2012a) with people with learning disabilities being perceived as 'forgotten people' in respect to loss, death and bereavement (Read & Papakosta-Harvey, 2004). This same elephant in the room can exist for autistic people however for autistic people, this is something much less frequently researched (Graham, 2014).

Studies show that people with learning disabilities are often excluded from the grieving process (Dodd et al., 2008; Gray & Abendroth, 2016; McEvoy & Smith, 2005). The ways in which this manifests are in the withholding of information, in lack of time or privacy to grieve and being physically excluded from mourning rituals (McEvoy & Smith, 2005; Raji et al., 2003). There are a number of reasons this exclusion happens. Historically there was a belief that people with learning disabilities or autistic people do not experience loss, a belief which was held until the 1970s (Dodd et al., 2005; Handley & Hutchinson, 2013). While that belief is no longer held, families and carers may lack knowledge of the bereavement and grief processes of people with learning disabilities (Murray et al. 2000) and may think they are protecting the person from distress that they might not be able to cope with or they can lack the confidence to support people through bereavement (Handley & Hutchinson, 2013).

People with learning disabilities experience loss and grief just like we all do (Barber, 2012a; Barber 2012b; Graham, 2014; Gray & Abendroth, 2016; Handley & Hutchinson, 2013; McEvoy & Smith, 2005; Raji & Hollins, 2003; Read & Papakosta-Harvey, 2004; Tuffrey-Wijne et al., 2017). Not allowing people access to the tools to understand and process grief can lead to experiences of increased emotional discomfort, disenfranchised grief or traumatic grief (Gray & Abendroth, 2016; Handley & Hutchinson, 2013; McEvoy & smith, 2005). Dodd and colleagues (2005) assert that as autistic people can often have a very limited number of close relationships, the loss of one of these can be catastrophic. This may then manifest as emotional and behavioural difficulties (Gray & Abendroth, 2016) with professional help being sought for these outward displays of distress as opposed to the core issue, which is the experience of loss and grief (Raji et al., 2003). Although research shows that repeated explanations, supported involvement in rituals such as funerals and activities such as visiting the grave can all help people to cope with death research also shows that this does not appear to be happening (Raji et al., 2003).

Why the project was created

Informing Choices NI found that their work with people with learning disabilities supported the review findings above. They observed that as a community, people with learning disabilities were often left out of discussions and rituals when someone died. This could then manifest as behaviours which were termed as ‘challenging’. At this point Informing Choices NI would be contacted to work with the person who had experienced the loss. They realised that what was actually happening was that the behaviours were related to unresolved grief and the confusion and pain which goes with that. Informing Choices NI decided to apply for funding to the Ideas Fund to begin the process of finding out what was needed to support the community.

The aim of the project

This project was seen as the first stage in developing services and resources which would allow a coordinated and effective approach for this community to be properly supported when they experience death and loss. Specific aims are shown in Figure 1 Project aims.

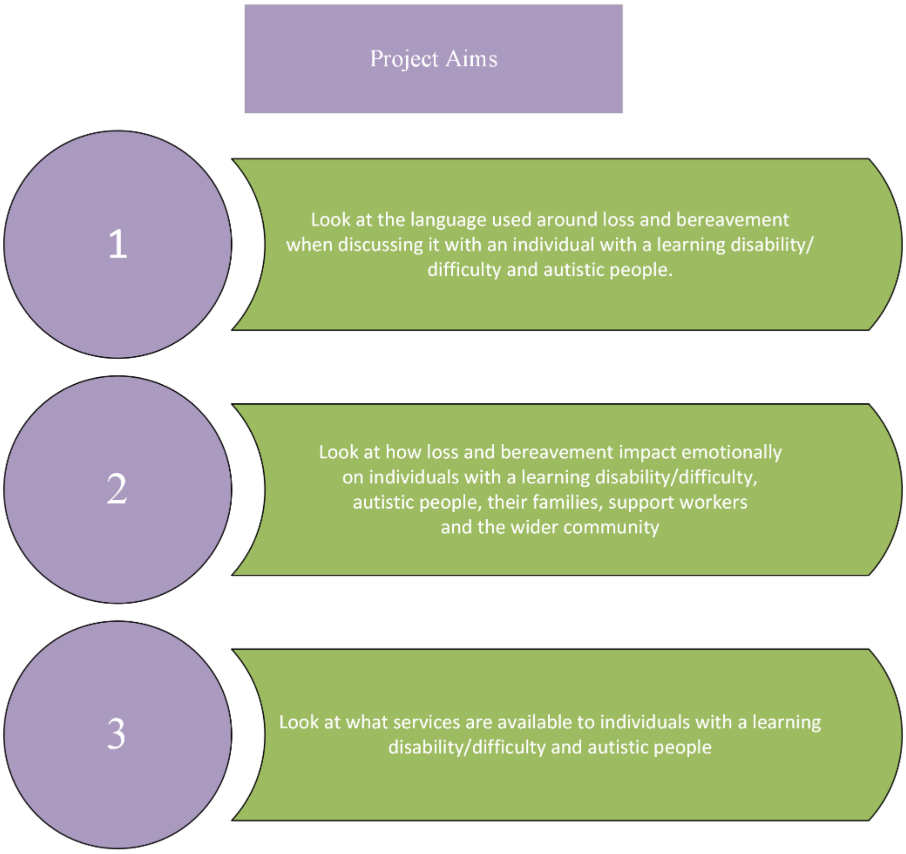


Figure 1 Project aims

What we did

The study was designed as a collaboration between Informing Choices NI and the community of people with learning disabilities or autistic people in the Derry City and Strabane District Council area in partnership with researchers from Ulster University. Informing Choices NI conducted all parts of the study that involved working with the participants.

Recruitment

The study recruited from three groups shown in Figure 2.

- Group 1: People with learning disabilities or autistic people.
- Group 2: Family members.
- Group 3: Support workers/ SEN staff.

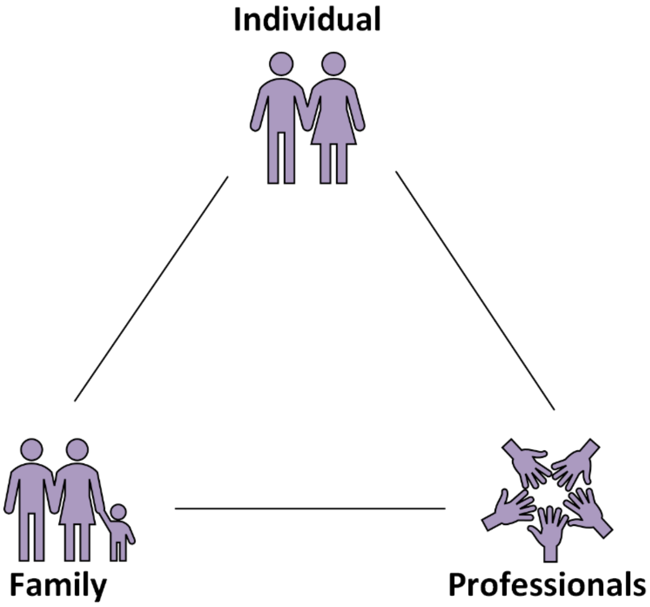


Figure 2 Groups recruited for project

Informing Choices NI recruited adults over 18 years old for groups 1, 2 and 3 through a number of partners with whom they work on a regular basis:

- Destined. Destined are a voluntary charitable organisation based in Derry who seeks to address the needs of people with learning disabilities in a whole life context. They work to empower people with learning disabilities and promote social inclusion. http://destined.ie

- The Liberty Consortium @ The Playtrail is a unique play and educational facility based in the grounds of Ardnashee School and College in Derry. The facility hosts a range of programmes and activities which include the BUD club which provides social opportunities for people with learning disabilities. http://libertyconsortium.org.uk/bud

Destined were a central body in the recruitment process. All of the participants of group 1 recruited use the services of Destined. The study also recruited for groups 2 and 3 through these core organisations.

Issues with recruitment

Whilst recruitment was very successful for the group of people with learning disabilities and/or autistic people, the other groups proved harder to recruit. To accommodate this, methods of data collection were widened to include one to one interviews with parents and the distribution of questionnaires to support staff. Seventeen people were recruited for the group 1 focus group, two were recruited for the group 3 focus group with an additional nine people returning questionnaires. One parent was interviewed on a one-to-one basis.

The work itself

All work was planned to be done in the form of group work. Research supports working with groups as an effective way of engaging with people with a variety of learning disabilities (Read & Papakosta-Harvey, 2004). For group 1 this was the case and focus groups were held. In the case of groups 2 and 3 data collection was adjusted as above in response to recruitment issues.

Focus groups were run by Informing Choices NI. Topics covered in the focus groups are shown in Figure 3. Sessions were run using the techniques which Informing Choices NI regularly use when working with people with learning disabilities and/or autistic people. They were based on visual rather than written communication techniques. Sessions began with social chats and ended with an uplifting exercise such as asking for one good thing that had happened this week for people, and with some food! Check-ins were conducted through the session to be sure everyone was ok as the session went along.

For group 2 which was family members, data collection was widened to the use of one-to-one interviews as family members were reluctant to take part in focus groups. For support workers, group 3, a focus group with two participants was held. In addition, questionnaires were distributed to other staff.

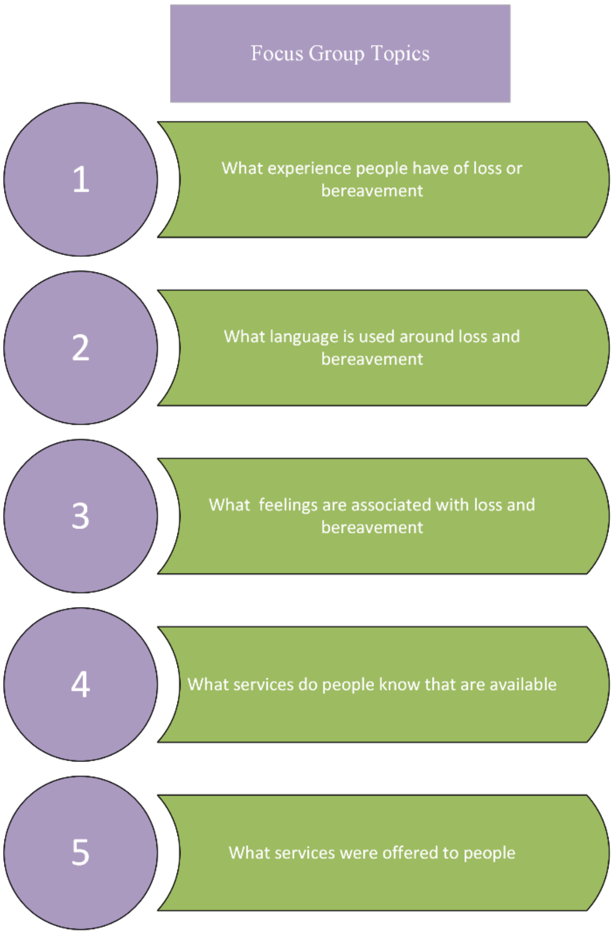


Figure 3 Focus group topics

Data analysis

Qualitative analysis was done on all data collected. Focus groups were audio recorded and transcribed. Data transcripts, questionnaires and feedback sheets were thematically analysed using reflexive thematic analysis to identify themes (Braun & Clarke, 2006; Braun & Clarke, 2109; Braun & Clarke, 2020). Themes were organised into overarching and sub-themes as appropriate. A broad and descriptive coding framework was employed, with coding conducted on both semantic and latent levels.

Reflexivity

A qualitative analyst must make sense of the themes that emerge therefore it is important to acknowledge that perspectives may be influenced by personal beliefs and opinions as shown in Figure 4 . Recognising this allows the researcher to be mindful that they should remain open to data being contradictory to their own preconceptions (Larkin et al., 2006). Reflective practice is therefore recommended (Smith et al., 2009).

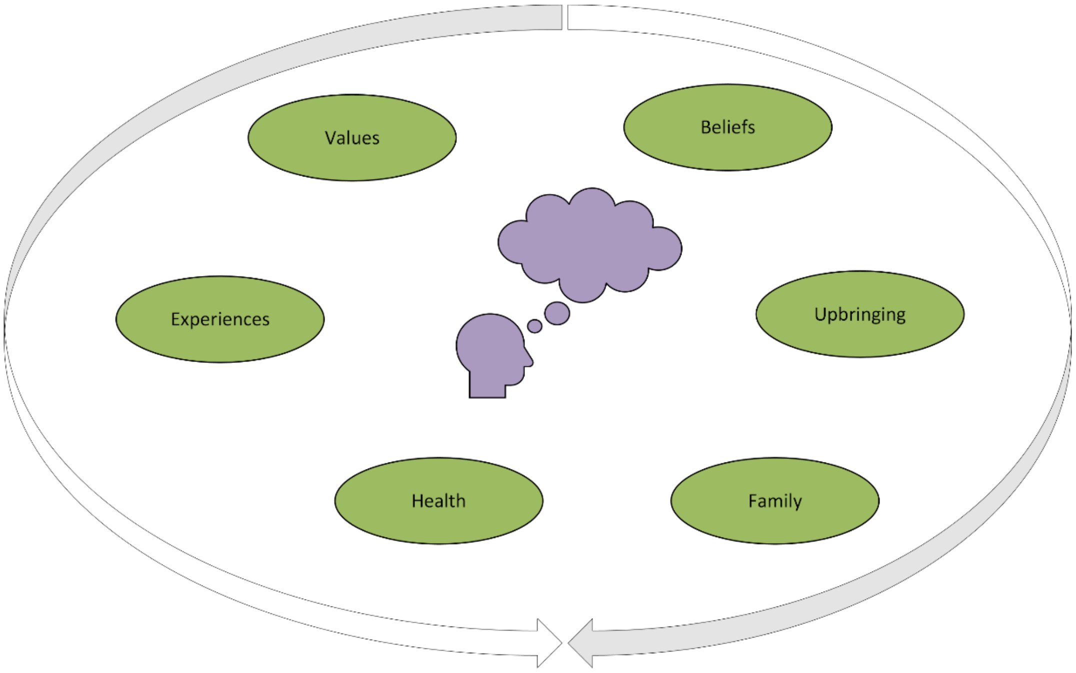


Figure 4 Researcher Circle of Influence

This process allowed me as the analyst to be aware of my own previous life history and experiences. For me this included very limited interaction with people with learning disabilities as well as some interaction with autistic people. I had some trepidation about the work as being with a community with whom I had no previous interaction. I realised also as the work progressed that I had some preconceptions about people with learning disabilities, their understanding and what they can do. I really hope that if this report is being read by others who share that preconception and it changes their views in the way that mine have been changed. I did find it reassuring that one of the support workers expressed that before they did their job for a few years they would have been "*as green around the ears as everyone else*". They offered an insight that I related to in that,

> **"there's just a big fear of doing the wrong thing, that stops you from doing anything."**

I also had to acknowledge that my personal belief is that everyone should be allowed to grieve and have full access to all the help and support they need to do that. I had to be vigilant that all views even those different to mine were included. It seemed though, as the project progressed, that those interested in becoming involved were those who also felt like this. That in itself is a finding.

Research also changes the researcher and I am grateful for my own learning through the work I have done on this project.

What we found

The sections below describe what the various groups told us. This section is followed by a review of the themes. Although the work was done with the groups separately one of the most striking things about this work was how close the community of people with learning disabilities, their families and carers and their support organisations and workers are. This is a fundamental feature of this community.

What people with learning disabilities and autistic people told us

Are we treated differently?

When the participants were directly asked if, as people with learning disabilities, they were treated differently when it comes to death the group became quite silent as they considered it and the mood was more sombre than it had been previously in the session. Although one person did not think they were treated differently, the consensus from the group in answer to the question was that sometimes they were treated differently and when it comes to death,

> **"I think we are."**

What we think about death

This group were forthcoming and confident in talking about how they felt around the subject of death and loss. The word cloud (Figure 5) summarises the feedback they gave us in response to the question of what words and phrases they think about when they hear the word death.

This group had no reluctance or inhibitions when discussing the experiences they have had with death and bereavement. One participant told us how they could not eat or sleep following the death of their loved one. Another told us how they saw a person in the street and thought it was 'their' person. Other thoughts expressed were if a person was suffering, there was an element of relief to know that they were no longer in pain. Another participant described a "*wave of feelings and emotions*" being experienced when a person dies

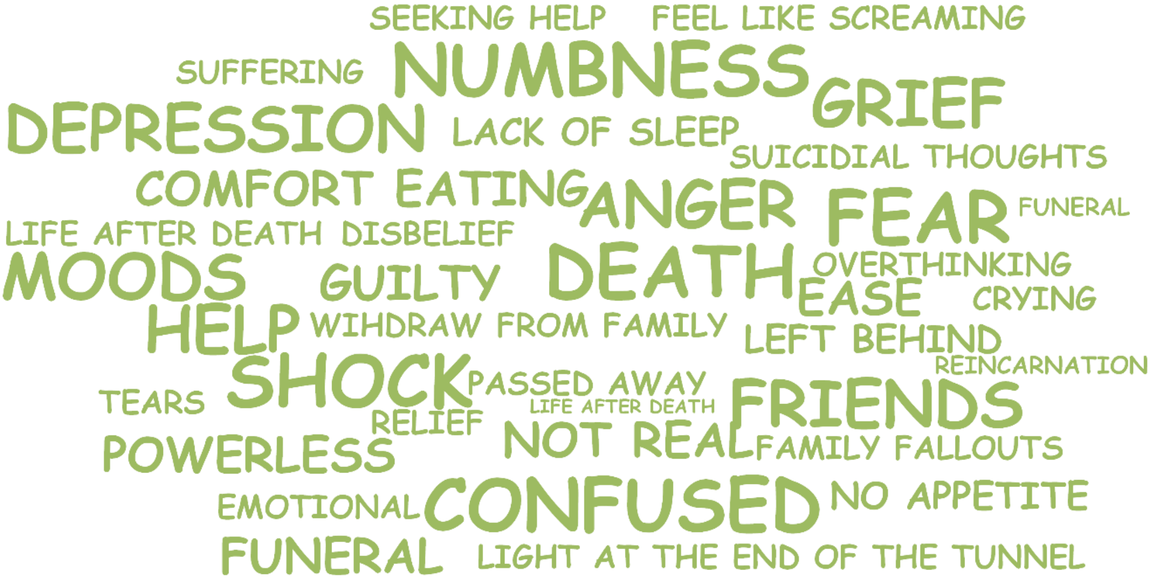


Figure 5 Word cloud showing words and phrases people think of when they hear the word death

This was echoed in the focus groups with support workers when they also described the impact of a death within the community as a "*tsunami coming towards you as a staff team.*" A range of feelings were described by the group. These included, sadness, powerlessness, moods being up and down, guilt, anger, relief that the person was no longer suffering, shock, depression, confusion, disbelief, overwhelm, fear, hate, loneliness, comfort and feeling ease for the person being released from pain. Physical manifestations of loss and grief were also discussed as something people experienced. These included crying, being unable to eat, being unable to sleep, feeling stressed and anxious, wanting to scream, shouting, shaking, feeling floaty in their body and feeling numb.

Patterns of thought were another way in which grief and loss affected people. These included overthinking or ruminating, having suicidal thoughts and putting emotions away.

Are our feelings ok?

The group were asked in the second session if they felt like all the feelings, thoughts, and emotions they had discussed in the first session were ok. A conversation followed where most of them were allocated to the group of being ok. There was some more in-depth discussion around some areas.

The first of these areas was around experiencing suicidal thoughts when someone has died which was an experience reported by the group. The conclusion was reached that "*a lot of people go through that*" and given the emotions discussed such as feeling sad, feeling lonely, missing the person, feeling numb, feeling confused, you could see why a person would feel they wanted to die as well but that it would be important "*if it didn't go away, to talk to someone about it*." That in this case you are "*going to need help*". One participant poignantly described how

> **"Sometimes although you have all your family and friends, sometimes you still feel lonely even though you have everyone around you."**

Another area that generated more detailed discussion was around putting your feelings away i.e., compartmentalising them. It was decided that it might be ok to do that when "*feelings were overwhelming*" and that it can help people to "*deal with their feelings*" but it was agreed that it is important to "*put your feelings back together again*". One participant told us what happened for his father when his grandmother (his dad's mum) died,

"My father didn't cry when his mother passed. Six months down the line, that was when he let it go. I felt sad for him then too."

Feelings that might be perceived as more negative provided scope for further discussion. These included anger and hate. Links between feelings, thoughts and how these can show up in the body were talked through and these links were used to help understand these more "negative" feelings. Feelings of guilt, for example, might lead to you overthinking that maybe there was something more you could have done for the person. To change what happened. That you may feel powerless because you think you could have done more and also because you can't change it. And that given all these range of feelings and thoughts, it's not surprising that a person may feel suicidal. That some people might cry when they have all these feelings, some people might want to shout instead. Ultimately the group decided that all feelings are ok because *"they are all temporary, you don't have to hold onto them"*. The group agreed that *"there is no right way and no wrong way"* to deal with the feelings that come from losing a person you love.

"I think it's ok to have any type of feelings because they are your feelings, it's what you do with them."

Who we go to for help

When asked where they would go for help most of the participants said that they would talk to someone. This was a very strong response from the group. Figure 6 represents the people who were discussed as potential people who they might speak to. Over twenty different sources of support were listed. The people they would talk to might be a family member either immediate or extended, a friend, a neighbour, a boyfriend or girlfriend or a pet because *"animals know and they give you cuddles."* They said they might speak to a fiancé(e), a husband or a wife.

Figure 6 Who helps us

In terms of professionals that person might be a doctor, a worker in one of the groups they attend, a teacher, a psychologist, a psychiatrist, a social worker, a key support worker or, in one case, a personal trainer because *"exercise is good for your mind too and I can talk to my PT."* In this case however the PT had lost their daughter so it was more about talking to someone who had also experienced a loss. In another case their hairdresser was someone who a participant felt they could talk to.

Participants told us that attending their regular clubs, support groups and talking therapy were all ways in which they might get help. One participant said they would talk to work colleagues. Another way of moving through the grieving process was using a diary to talk to yourself about how you were feeling and to help process the feelings.

Several participants had been prescribed medication. Sometimes medication was prescribed in order to help them sleep as they felt like "*a walking zombie*". It could be used short term or longer term. The participants discussed in depth how people react differently, with their own responses to the loss. One participant attended a psychologist because,

> **"I was very sad when my father passed away. I didn't get saying cheerio to him and it really did annoy me."**

This participant spoke to a psychologist, with their friends, with staff at Destined and is working through the feelings. Another participant spoke of their sadness when his uncle died. They also spoke to family members, with siblings being as important as parents. They spoke in addition to people in the services they use,

> **"it's a good job we have Destined because we would be lost without talking to somebody"**

In spite of the group in general being jolly as they talked through the topics, the real sense of sadness could be felt in the room when they talked in depth about losing those they loved.

Who we would like to go to for help

A mix of support was discussed as being needed from a range of people. One participant shared that her mother and sister knew about bereavement counselling and had helped her talk about her emotions and her feelings using emotion sheets and cards. This approach to helping someone with a death was discussed at length and one participant felt that,

> **"If there was more help available, I think people would go for it."**

The group felt that as well as talking to family and friends they would like to receive support of this kind, support specifically targeted at how they felt around the death from a professional,

"The support we would be looking for is to talk about grief, how it affects you and all that."

Other approaches were discussed as not everyone felt one to one support was what they liked. Other forms of help discussed could be journalling, art therapy, music therapy, dancing or it might be group-based support. A range of support would be ideal so that people could find something that they are comfortable with. The group discussed how the sessions with Deborah and Mark had allowed them to talk freely about how they felt around death and the experiences they have had. They discussed how they themselves might help other people in a group setting to talk about how they feel.

The language of loss

The direct question was asked and discussed by the group about how they would like to be told someone had died. The question was very clear,

"Would you like to be told directly that [person] is dead, or would you like it to be broken to you gently?"

"I would like to just be told."

There was quite a bit of discussion about it being ok for the "teller" and if they were ok with their grief. But the conclusion was that they were going to find out about the death as they move through their day and their life and the shock and pain is made worse if the loss is not directly communicated to them.

A particular question was directed at men in the room to address any gender issue that might be present. The discussion did uncover that maybe men are more reluctant to show their feelings and might try to be braver for other people in their life.

A discussion took place about if younger family members asked the participants questions around a death, how they would respond. They felt that would be careful about the words they used to make sure they didn't scare younger people or use words they didn't understand.

Brave faces

A few of the thoughts from the initial session when people were asked to write down their thoughts when they hear the word death were teased out using further discussion. One of these was 'putting on a brave face'. This was discussed in more detail from the perspective of themselves putting on a brave face. One participant told us about losing a friend and being in "*shock and disbelief*" but also being unable to get away from the loss because it was being reported in the papers so when they went to work, they "*put on that brave face*" which helped them to get through the day at work.

Another perspective was from the other people in their life, people they maybe turn to for help with managing and validating their feelings also putting on a brave face. On participant described that they felt their parents,

> **"didn't want to be sad, they wanted to be all brave for me…trying to hide their emotions"**

Another described how their dad asked him to leave the room when his granda died because he was crying and didn't want to cry in front of him. The young person left the room, but he knew his dad was crying and he knew why. People may put on a brave face thinking they are hiding their emotions from their loved one with a learning disability but they are not.

Being Involved

Being involved in last rituals around the person that is dying or has died was expressed as being both important and comforting. They spoke of the importance of touching and kissing someone for the last time to say their own goodbye.

> **"I went into the room he was lying in and I kissed him for the last time. Cos if I hadn't done that, I would be worse."**

Most participants told us they were included in the rituals around death, they were included in the funeral for example. One participant told us about how they wrote a speech when their spouse died that celebrated their life and how important that was. Discussions took place about how younger people are moving away from the more traditional approach to funerals, like not necessarily wearing the more traditional black to funerals, wearing something that reflects who the person was and what they loved when they were alive. The support worker in the focus group described how when someone she knew died, the local shops ran out of a particular football jersey and all his friends wore that to the funeral in tribute to him. Traditions change with time and maybe funerals can be celebratory of the person's life and what they loved as well as sad.

What Covid taught us about death and loss

There were a number of discussions with the influence of Covid on the bereavement process. Covid meant that people had each other in terms of their family when someone died, it also meant they did not have the support they usually had outside the home in terms of being able to go to Destined, a place they describe often as being somewhere they can talk and be free in saying how they feel.

One participant spoke of the pain their daddy felt when he could not say goodbye to his own dad because of visitor restrictions during Covid. Covid highlighted, for a lot of us first-hand, the pain that is experienced when we do not get to say goodbye, when we cannot have our comforting rituals that help us. For anyone excluded from saying goodbye, from the grieving process, that pain would be no different. It might be because of Covid, it might be because people that love us think they are protecting us.

Life goes on

Participants told us about 'difficult first times' without their loved ones. One participant described how they attended a wedding without their spouse and it was the first time they had attended a wedding without them. In addition, the wedding was of one of their best friends. They talked to their mum about their feelings and agreed that if they felt like they were "*getting too overwhelmed or emotional*" they would ring their mum however they described how they,

"…got through it because everyone was looking after me. And that was a big step."

The loss was described as being felt keenly when it happened and also as time went on. One participant shared that as time went on, it was more difficult to talk about their person. One participant said that their dad was dead for 12 years and it was only in the last few years that they felt they were coming to terms with the loss.

What support workers told us

This group did prove more difficult to engage than predicted. Because of this as well as running a focus group, questionnaires were sent out. This section includes feedback from the focus group which was attended by two support workers and a summation of feedback from the questionnaires.

Focus Group Feedback

Commitment and respect

The commitment of the support workers who talked to us was clear. Support workers become a large part of the lives of the people who use their services.

"I've been to our young people's family weddings, I've been to 21st Birthdays [parties], I've been to 18ths [birthday parties], I've lay on the floor with young people when they went through loss and cried with them"

Support workers were also very aware of the fact that they can "*can only give the viewpoint of people who work with people with learning disabilities*" as only the individual themselves can tell anyone how they feel or what they need.

Returning to being treated differently

Support workers feel that people with learning disabilities are treated differently when it comes to bereavement, grief and loss. This was discussed from a number of perspectives. There is the balancing act which is described in the section above which means that people who are directly involved such as family or services may all hold different beliefs about what is right for the individual.

From another perspective, support workers also discussed that they believe that there is still very much a wider societal stigma around learning disability which also means that they are treated differently. One support worker told us the story of when a group went fundraising at a local supermarket,

> **“If there's a young person at the bagging area and somebody comes along and they spot, [that the person has a learning disability] the person turns to them and in their head they’re going, what do I say. And then our young person talks to them. And you know, it's them that makes the first move rather than that person. So, I get that, you know.”**

Support workers report that they feel that people are afraid to do the wrong thing and so they do nothing.

> **“there's stigma around learning disability and people don't want to talk about it and then there's just a big fear of doing the wrong thing that stops you doing anything.”**

Learning through sad experience

The support workers told us about the day in which they learned that a core member of their community had died and the young people were out with the service at the time. They told us of their own distress and then how they had to manage the distress they knew the young people would feel.

> **“…they passed in October and immediately we panicked. Because I remember, we got the phone call and I was in [location]. We work across six age groups. And that age group that they were in, were in a cafe and getting the phone call off [support workers name] and he could barely hold it together. I could barely receive the news. I had to walk away and just sort of like try to figure out immediately how do we support them, this group of young people.”**

They went through a number of steps which involved telling the group together in a safe space with parents also being invited in to be told. They used their own contacts and knowledge to bring in a range of services over time to respond to the needs of the group both as a group as and individuals. And through all of this, the service had to keep going.

> **“The service has to keep going. We've got to a stage now where we feel confident enough that we're doing the right thing. And if we needed, we could reach out to somebody again and say we need help again to come in. So, it's a balancing act.”**

Loss of course does not only occur in this way. Loss can also be of a parent, of a spouse, of a sibling, of a pet or any other person close to the individual. This loss although felt greatest by the individual affected is also important within the context of the community as the bonds are so strong and emotions and behaviours often impact the whole group or community.

Ripples, waves and domino effects

The way in which any loss impacts this community was described several times as creating a *“ripple”* or *“domino”* effect. The loss manifests in the individual experience but also within the group and those manifestations will influence the group dynamic. Support workers told us about how “*one person becoming upset can lead to another three or four*” also becoming upset. And sometimes in this group becoming upset can mean “*squaring up to a staff* *member*” or “*hitting another young person*”. Showing an understanding that this behaviour is related to the loss or death must be balanced with an understanding that it isn’t ok to hurt other people when you are hurt. They described that you are trying to focus on supporting the young person rather than the behaviour whilst keeping the environment safe for everyone. What is very beneficial also however is that the ripple effect is also seen with positive emotions. This was seen very strikingly in the way the focus group was run. When the facilitators felt that the mood had become sombre, they were very skilled at lifting the mood and once the focus was changed to something fun, everyone in the room became infected with that sense of fun. It is easy to see how this group dynamic could lead to challenging manifestations but also how it could be harnessed as part of a healing process for the whole group.

> **“I found in our service, when we had lost a young person or when anyone has died within, I suppose, the circle of disability, because a lot of the young people are connected through all the groups, it's nearly like a tsunami coming towards you as a staff team and as an organisation”**

The complexity of different needs

The support workers who took part in the focus group have the expertise of helping people to deal with death and loss and have a knowledge of what resources are out there in part because of going through the experience of loss within their service. They used their contacts and resources to identify sources of support.

Within their service they also *“encourage young people to talk to staff if they are ever feeling upset or sad.”* They ensure communication is clear, for example, they use direct and clear language to explain death.

"…in the learning disability field, there's various resources that we already use… like visual timetables, pecs boards, Makaton sign, various ways of like, getting information out. A lot of that will be visual and there are a lot of resources around death that have been produced already, which you can print out and bring into a session. But there's also therapeutic services which are much more recognised. So, we find art therapy fantastic. Play therapy, fantastic. We have a music therapist employed again, just other ways of communicating. Because a lot of learning disability is not necessarily verbal. So just different ways of processing and expressing themselves and then the relief that comes from expressing yourself is really beneficial and we have found a way for dealing with grief so there are services out there already that are brilliant."

They also need to be aware however if a person is not able to talk about a loss and be cognisant of all information from parents around what they feel the young person is able to handle. They informed us they use counselling services and named Youth Life in the local area as well as tools such as emotion charts, art therapy, music therapy and Winston's Wish. Expertise with this community exists within statutory services however accessing these proved difficult as the issue of waiting lists came up several times.

"We were told things like language has to be very direct, so the person has died. It's not you know, there's a new angel in the sky, or there's someone shining down on us"

"Probably most people won't have the best opinion of statutory services because of waiting lists…if you want to see a speech and language therapists, you're waiting nearly two years. You want to see a grief counsellor. Again, there's quite a long waiting list there."

Given these barriers to accessing statutory services in a timely manner, a concern existed that the *"right people with the right training"* are called upon to provide support. Support workers talked of the difficulty of trying to support each person individually but also trying to ensure the work of the service is still focused on.

"You're juggling loads of different needs and trying to work it out"

When needs aren't met

This group shared that they felt when the process of grief is not supported there will be a long-term effect on the person who has lost their loved one. They report that a young person may repeat things they have been told by others about how they feel but unless they have been allowed to express their own feelings, this is not helpful. Over time this unexpressed grief can lead to becoming agitated and one young person started hurting themselves. This is when the person might be characterised as showing challenging behaviour which may be unexpressed grief.

The balancing act

There is a balancing act that is evident in the relationship between support services, the needs of those they support and the wishes and beliefs of families and carers, and even between different services that may each have a different ethos and approach. Everyone feels strongly and they all have the best interests of their loved ones or service users at the centre but it is easy to see how these competing approaches could be confusing for the person with learning disability.

Support workers reported a difference in beliefs and attitudes which can depend on a number of factors. Learning disability and autism brings together people who may only have one thing in common and that is that their family member is affected. There exists a wide range in terms of demographics. One such factor is the age of the parents as a result of changing attitudes with the progression of time.

"Parents' experience of being told their child had Down's Syndrome is completely different to now … so much negativity and doom and gloom … I've seen that in our 13 to 19 or even 8 to 12 group. The younger age group are nearly more able than that older age group because society and the education system has just been better suited for them. It wasn't until, I think it was mid 70s that you had a right to go to mainstream education. Before you didn't even have a choice."

Some parents and carers take a direct approach and feel that death is a subject their child needs to be able to talk about and express their emotions around. Support workers told us about parents who were being trained in how to talk to their child about the topic of loss and death so they can support them. Other parents feel they are protecting their children by not addressing the issue. Support workers however expressed that they need to be "proactive rather than reactive" as this was something their service will need to know how to deal with and they want to be,

"Resourced and able to go, 'right we know how to approach this.'"

Capacity building and future planning

Getting this balance right and bringing the community supporting a person with a learning disability together will allow grief to be processed. This is of importance for the individuals mental and emotional health and is also an important aspect of capacity building. For a person with learning disability to be able to be part of the grieving process and to understand their own journey through grief and loss, they need to understand what death is and how to get help when they experience it. Related to that is the importance of death and loss being a topic from an early age, using the appropriate tools and language for that age group and the persons learning disability. This allows a safe and continuous build up to a level of understanding that grief is acceptable when it does happen. It is not a matter of if but when.

Who helps the helpers?

Because of the close bonds formed in this community, staff also need support as they provide support “because they're also going through the same loss”,

> **“Not only did I have to worry about the young people, I also had staff that were experiencing the loss because we do become such a massive part of young people's lives”**

Support workers told us of how they are with the people in their service through so much of their lives. Long term support workers have been part of people’s lives for up to 10 years or more and have been there for weddings, and 18th birthday parties and 21st birthday parties. They often know families really well through their involvement in the service. This means they are impacted as an individual by the loss as well as watching people they care about struggling with this loss. They need supported as they provide support.

A coordinated approach

There was a very strong message that a coordinated approach that allows staff to respond to death either for an individual or within the community is needed. An approach that also ensures that the needs of support workers are also met. This approach needs to be able to be adapted across age groups and abilities. It is important that it is present for everyone to access when they need it. The services that the support workers were able to provide were down to relationships and good will rather than a concrete and secure response service. Money is also an important factor.

“…not every organisation has the resources and I am sure because we are well known in the city, we're very lucky in the support that we get and the following and people go out of their way to do it and people are really good. But across Northern Ireland I don't know.”

Discussions took place around what the approach should be. An awareness of the complexities was evident. Issues like

- the range of age groups,
- the range of levels of disability within the age group itself,
- the level of difference between people in the same range of disability,
- that things can be different on different days for each person,
- the range of people who work in learning disability services and that some of these are volunteers and
- differences in different services and at home which may cause confusion.

It was also discussed that as well as people within the service being trained, it was important to have experts in both grief and working with the people with learning disabilities.

“We were lucky in the sense that by chance or whatever, we did the right thing instead of trying to deal with it ourselves because I think a big thing is that is you can give all the training to the staff that you want, but still there are people with expertise… no matter how trained you are, as an individual it's always good to have other people come in as well.”

A consensus in the focus group for support workers was that there are resources out there already, these resources do help. It is a complicated matter but it isn't an impossible matter to provide help with.

> **"…in one sense it's really complex, but in the other sense, it's not rocket science, right? It's difficult but it's not rocket science."**

Discussions took place about the similarity between the taboo topic of death and the taboo topic of relationships and how Informing Choices NI deal with this with their existing Relationships and Sexuality Education (RSE) training package. The tools used to accommodate communities needs are the same, in this case the content would be loss and bereavement.

Questionnaire Feedback

This section lists the questions that were asked and summarises the responses.

Have you ever supported someone with a learning disability/difficulty or autistic person through loss and bereavement?

Nine support workers responded to the questionnaire. Of those six told us they had supported someone with a learning disability through a bereavement.

What support services/resources were available to that person and how easy was it to access these?

Of those who said they had supported someone, one said the sources of support they used were Cruise bereavement Counselling, who had a long waiting list while three said they used professionals available within their services that helped with social stories, advice and guidance. One said that they did not know of any resources, and another said they could not find any that were suitable. One support worker said that the support they provided was within a context of the family having different views as to how the bereavement should be handled.

Was there support and conversations around loss and bereavement from the individual’s family?

Five support workers responded to the question. One said that there was, two said it depended on the family. One of these expanded their answer to say that they felt the conversations were avoided in some families because they believed the individual would not understand and would become upset. One said that it only rarely happened that these conversations took place, and the final response was that for most families, there were no conversations.

Was the individual involved in the wake/funeral process?

Six participants responded to the question asking if the individual was involved in the wake and funeral process. Five people said yes that they were and typically that was attending the wake and/or the funeral. One said that it depended on the family, and it was the family who decided depending on what the individual wanted or what they thought was best.

Were there support services available to you?

Six respondents answered this question. One said that nothing was offered to them as a support worker or to the wider family and one said they did not seek support. The third said that they discussed it with their line manager in supervision and was signposted to counselling if they needed it. The fourth respondent said they were supported and added that,

> **“The impact of this work should not be underestimated on the worker also and support should be offered by managers, quite often this is lacking. I am not an expert on grief/loss/death and working through this with someone with an LD can have an impact on me as a professional and personally. During covid I lost a family member and supported LD service users with loss. This is often left unpacked and no-one queries how we are. For a caring profession, it is often too consumed with caring for others and self-care becomes less of a priority.” [support worker]**

The fifth respondent said that they had attended a workshop on death and bereavement run by the Western Health and Social Care Trust and had asked to be directed to specific services but that it was never developed any further. The final support worker who replied to this question said that some training is provided.

What support do you know is out there, currently, for people with a learning disability/difficulty or autistic people around loss and bereavement?

All nine respondents answered this question. Five said they didn't know of any support. One said that family and floating support services could provide talking and listening support, that referrals could be made to psychologists and that Cruise bereavement could offer counselling. Another said that Mencap have some resources. Another said that service users could be referred to a speech and language therapist or behavioural support if their behaviour changed following a bereavement. The final respondent said that some training was provided.

How confident would you feel supporting someone with a learning disability/difficulty or autistic person around loss and bereavement and please explain why you feel like this?

Again, everyone answered this question and the answers ranged from very confident to not at all confident. Of those who were confident or very confident they pointed to their many years' experience while others said that in spite of having many years' experience, they still did not feel confident in this area,

> **"I have good experience supporting service users and getting to know them, but I am not confident to support them around loss and bereavement."**

Some respondents pointed to how individual the experience can be and how many variables were involved. It depended on the level of understanding a person with learning disabilities had, for example. Four respondents felt that they would like training or more training so they could be more confident.

"I would like more training in this respect as I feel everyone has their own value base on what is the right thing to do at a time of huge loss. Some people want to protect, which in some cases excludes the adult with LD from grieving how everyone else does. I feel that culturally in Ireland/N Ireland we have a clear process when someone passes away and there are certain things which happen to allow us to process and get support from those we love. It is very fast for someone with an LD to process and understand what is happening and it is a very difficult time for the family already to start to have discussions with."

Do you think death and dying is properly discussed with people with a learning disability/difficulty or autistic people?

Again, everyone answered this question. Three people said no they didn't believe it was. One said they were not sure. The remaining five said it depended on the family and sometimes it was and sometimes it wasn't.

"It depends on the individual family and what they want to discuss. Some families have a healthy understanding of death and others prefer not to talk about death."

The general feeling of the responses was that people with learning disabilities are the same as everyone else, but support is lacking.

“I feel there is little difference in people with a learning disability/difficulty or autism and people without, we all grieve differently, it is a very individual process therefore everyone’s understanding of death can be different. I think they would prefer to be seen like everyone else that having a disability, doesn’t make their loss any different than anybody else’s. Support in general is lacking for bereavement so offering a service that listens, validates, and holds space for any individual as they navigate through grief would be beneficial for all”

People talked of several ways this impacts on people with learning disability. One of these was that after a person they supported was excluded from the wake and the funeral they were then taken to visit the grave of a close family member. The person then started to develop challenging behaviours. The second impact was to do with future planning,

“There is a huge number of elderly carers who will have to give up their caring role at some point but are unable to look at this which then leaves a crisis for that loved one left behind. They not only lose their parent/carer but they have to adjust to living somewhere new and being cared for by different people. Work needs completed with parents about future planning to include loss and bereavement alongside moving into a different care setting”

What parents told us

The spectrum of losses

“So, there’s loads of loss. It isn’t just about bereavement.”

Parents told us of the nature of the losses their children had experienced. This involved a range of people from parents, other family members, close friends and acquaintances. They have lost people they were close to and people they were not especially close to. They have lost people over the span of their life to date. Again, the same as everyone else.

Parents told us of the many different types of losses their children have encountered alongside loss through death. One parent told us how their other children had all grown up, went to university and moved away which meant that their child with a learning disability was the only child left at home,

> **"…their sisters left, their brother who they were very close to, left."**

Another of these types of losses falls into the spectrum of ambiguous loss. Ambiguous loss can be of two types, when a person is physically here but is not here psychologically, for example if a person has Dementia or has an addiction. The second type is if they are not here physically but are very much present psychologically and the person experiencing the loss is unsure of the status of the relationship. This could be for example if a parent is no longer in the child's life and there is a lack of clarity around their relationship which was the experience of one of the people in the study. The young person reacted to this loss in a similar way as they have to bereavements.

> **"'I'm just heartbroken, mummy.' ... And I just think it's almost a bit like a bereavement where… they are not here anymore… I think as with any other loss, she just gets on with it and doesn't dwell on it. And it doesn't seem to change her behaviour or anything ..."**

A further loss described by parents was the loss that happens as their children get older and the differences with their peers become more pronounced,

> **"You did start to notice it more as they got older. Obviously, friends are maturing more than she is and they're starting to go out and there is that loss."**

Reactions to death

Parents report different reactions to death. Some children appeared "matter of fact" when they experienced someone dying,

> **"…very matter of fact, would have been very comforting to me but didn't cry, didn't show that kind of emotion that you would maybe expect."**

One parent observed that when the group experienced the loss of a member, that the young people who are autistic or with autistic tendencies, were less emotive although they were sad.

> **"They were sad, they knew exactly what had happened, they understood that but they were comforting the ones that were crying."**

Interestingly one parent told us that although their child was matter of fact about real deaths they had experienced, they got really upset and would cry about sad songs or television programmes depicting sadness or death.

Parents told us about how their children were very aware of the feelings of others, that could be their friends as described above, or their parents.

> **"I would get a text, 'are you ok mummy?'"**

The influence of our own experiences

Parents told us how their own experiences were very influential in their thoughts about how death and bereavement should be dealt with. One parent told us about an experience when they were young in which they were excluded from the funeral of a sibling and the negative impact this had on them. They feel this definitely shaped their belief that their child needs to be aware of death and be fully included in the grieving process.

"… I had a sister who died when she was twenty-one and I was seventeen, and I never saw her dead. I never saw her. And that has stayed with me, because I knew that that isn't the way it should be"

Parents discussed how their children learn how to react to events from them and how this is true in all families with all children and is no different in this community.

"So, I do think it applies to so many aspects of life. Is there anything at all that our parents don't influence us?"

How we supported our child

Parents were completely sure that their child should be involved in the grieving process and rituals. Their child attended wakes and funerals and were fully permitted to openly express their feelings in whatever way works for them. One parent told us that when their child talks about a close friend that died,

"If you mention [friend] they will maybe relate some story about [friend] but doesn't really talk about them being dead."

One parent told us that their child had always been included in the rituals around death and when their close friend died it meant that "there was no fear" in attending the wake and funeral. The parent discussed how parents within the community were unsure of what the right thing to do was and were checking with each other. This parent had no doubt that their child was going because it was their close friend who had died.

Being visible and also invisible

Having a learning disability particularly for people with Down's Syndrome which is a syndrome that can be seen by looking at a person makes them both visible and invisible. Because people can see that they have Down's Syndrome they tend to not directly talk to them. This was reported without judgement by parents but one parent told us how much it meant when they took their child to a service in hospital and the practitioner spoke only to their child,

> **"He didn't speak to me once, he completely directed it to [name] and I had to say to him at the end, 'that was brilliant, you don't realise how much that means…it means so much to me that you saw [name] as the patient, as the person who was here, not me, I was just sitting in the background.'"**

Capacity building and future planning

Capacity building and future planning was a theme that came out of the parent interviews as well. One parent told us that although their child was not overtly emotional when faced with an actual loss through death, they would get upset if they were encouraged to do things because their parent was preparing them for when they would not be alive.

> **"I don't know if that is because it would actually upset them, or do they just not want to think about it, I don't know."**

This highlights that this parent is aware that building towards this day is an important process for the future welfare of their child. Part of this is the difficulty that manifests when parents act from a place of protecting their child by not exposing them to experiences and making all decisions for them. One parent told us of conversations around not projecting your own ideas onto people with learning disabilities,

> **"So, we have to be also very careful that we are not trying to put our wishes and our values or whatever, onto them, when they have decided"**

That same parent shared the concern expressed to us by the support workers who took part in the focus group that the future must be prepared for. This parent and others are being proactive in working towards the future. They are engaged with support organisations to arrange supported housing,

> **"Because there's a small group of us who are obviously getting on and we know that, at some stage, it's going to have to happen, and we don't want it to be a crisis situation."**

They discussed an issue which may give insight into one reason parents might be reluctant to both take part in this study and to help their children live more independently,

> **"During that programme I kept saying to her, wouldn't it be lovely to have your own house? I hate the idea of Jill not being in the house. So, part of that will be my loss."**

The challenges and conflicts and need for radical self-awareness and reflection were evident from the parents who spoke to us. The needs of people with learning disabilities must however come first while acknowledging how difficult it can be for parents.

> **"That preparation must be done. And it has to involve them [people with learning disabilities]."**

Themes

Using all the feedback provided, thematic analysis was conducted which aimed to generate themes from across the groups that talked to us. Those themes are shown in Figure 7. Main themes are represented in oval shapes and sub-themes are represented in rectangles. Main themes are based on who took part, the current picture they painted, what they said was needed and how they think that can be delivered.

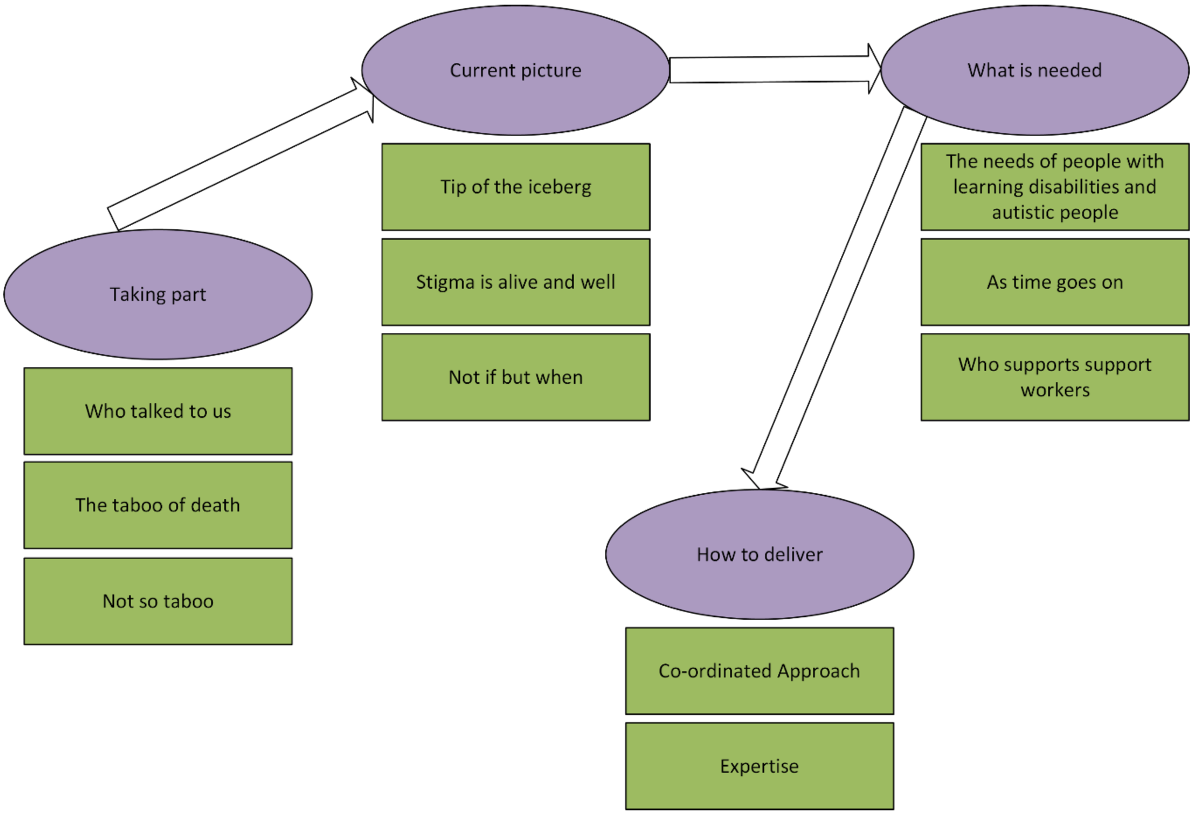


Figure 7 Thematic map showing themes from analysis

Taking Part

Some groups where easy to recruit to the study and others were not. This theme explores who took part in the study. It also explores reasons why people did take part as well as potential reasons they did not take part.

The story in who talked to us

It was expected that the community of people with learning disabilities would be enthusiastic and prepared to engage with this topic. What was not expected was the difficulty in recruiting for the other groups. In spite of indications that many people were happy to be involved, this was not reflected in the numbers of people who agreed to come to focus groups. This may be reflective of the trepidation that people surrounding those with learning disabilities feel around this topic. We have to strongly note that this is a trepidation not shared by the community themselves. They engaged fully and provided openly their feelings, thoughts, and experiences around the issue of death, loss and bereavement.

Those who did engage with the study from the pool of support workers and parents, gave open and honest accounts and were firmly of the belief that this is an area which must be met head on. The numbers were small and we cannot know why more did not engage but no answer is also an answer so perhaps they do feel fear about discussing the subject of death. Perhaps there is a lack of confidence in broaching the topic. Perhaps there is reluctance tied to worry of reawakening old wounds around death and loss for themselves. Perhaps there is conflict in what the right thing to do is.

More support workers were happy to be involved using the questionnaire for data collection. Some questionnaires were sparse in their responses while others gave important insights into how support workers feel. There may of course be issues in being able to find the time to attend focus groups but it is unusual in a study for whole groups of target participants to be unable to find the time to participate when they have indicated they would. The indication of willingness to take part and then not taking part suggests a conflict within this group.

The taboo of death

Part of the reason that people from the group of support workers and the group of parents did not engage may be that we know there is a taboo around death, bereavement and loss. There is a fear of talking about death and that fear is often with the parent/carer or the support worker as opposed to the person with learning disabilities. This taboo around death exists in the local culture and indeed in many cultures. Whilst we have many comforting and established rituals once a person has died, we do not like to talk about death either before or after it happens. When this is combined with the need to protect people with learning disabilities, the result often is that they can be excluded from fully participating in the grieving process and are therefore at risk of not processing and understanding their feelings and thoughts.

Not so taboo for people with learning disabilities and autistic people

This group had no problem within the focus groups discussing how they felt when they lost people, who they turned to, what helped and what did not. Discussions were open and frank and both simple and quite complex issues were described and talked about. If anyone reading this report thinks otherwise, I recommend they come along and talk to our group. It is important to note the skill and experience of the Informing Choices NI staff in safely facilitating these discussions.

The current picture

This theme contains the main components of what participants feel happens now with the community of people with learning disabilities and autistic people when that community experiences a death.

The tip of the iceberg

From what we are told by those who engaged and the pattern of those who did not, it is clear from that these discussions are the tip of the iceberg in terms of engaging the whole community of people with learning disabilities, their families and carers and those who support them. There was a clear sense of overwhelm when support workers spoke of a death that affected their whole community, a community they are firmly embedded in themselves and there was also a clear desire to do what is right for the individual while balancing the concerns and beliefs of parents and carers around what is appropriate for the individual, which can sometimes create a conflict.

Stigma is alive and well

Stigma around people with learning disabilities still exists. This was evident in the stories support workers talked about when their groups are out and about doing activities. People are afraid of doing or saying the wrong thing. As long as this exists, people with learning disabilities will be treated differently. The reasons for this are beyond the scope of this report as this is a complex matter in itself, we want to note that the stigma is there and it creates a barrier. People with learning disabilities need to have that learning disability taken into account but when it comes to grief and loss, we are all human and all experience the same feelings.

This is not an issue of 'if' but 'when'

The importance of responding to the needs of people within this community is driven by the fact that they will definitely be affected by death and loss. In spite of the need, families and loved ones might have to protect them, this is not possible. And as they get older, the certainty of experiencing death and loss increases. As well as allowing people with learning disabilities the chance to feel and process their loss, there is also a clear need for forward planning and for decisions to be made about what will happen when an older carer or parent dies.

What is needed

This theme was generated from what participants told us around what their needs actually are when someone dies or they experience a loss in the community.

The needs of people with learning disabilities and autistic people

As the results from the discussions show strongly, people with learning disabilities and/or autistic people have the same needs as everyone else when it comes to processing a loss or bereavement. And they are as individual as the needs of the wider community. The narrative in the previous sections illustrates that people with learning disabilities go through the same range of reactions to a death or loss, that those reactions are many and varied, they move through different stages in their grief and they sometimes need help and support to do that. Support that they have a right to access.

As time goes on

Support is not just needed when the loss happens. It may be needed on an ongoing basis as grief can change and develop over time. Just like the rest of us, when we lose someone, there are needs which are immediate and needs which are longer term.

Who supports the support workers

In addition, the response to a death, in particular one which affects the entire community, must include support for those who support people with learning disabilities. The impact of supporting someone through grief is something we all need supported with and, in particular, when this death happens in a close-knit community there are multiple people who need to be supported. As well as the effect of this, the support worker themselves is dealing with the loss of someone they knew and cared about. Or staff may be supporting other staff. And within all of this they are making sure the service itself, with its day-to-day schedule, keeps running.

How to deliver what is needed

This theme contains the main elements offered by participants as being important to meet the needs of people with learning difficulties and autistic people when a bereavement occurs.

A co-ordinated approach

The people with a learning disability who took part in the study, the two support workers in the focus group, and the parent all advocate for proper support for this community in the face of a death or a loss. They spoke of appropriate and helpful responses, such as bringing in counsellors and family members doing grief work. These are without doubt the right responses and the group was lucky to have the conditions in which that happened, support workers had contacts and there was funding available. What is needed however is a planned, well laid out set of guidelines and protocols which is available to everyone in Northern Ireland who works with people with learning disabilities. It cannot depend on luck.

The need for expertise

People with learning disabilities react in the same way as everyone else to loss and bereavement, with a range of reactions and emotions. They do however have different needs in how those reactions and emotions are communicated and responded to. As with this study, there is a distinct requirement for people who take care of those needs in a professional capacity to be people who have expertise in the communication needs of this community and working with them.

Conclusions

This study was conceived and pursued because of a need identified by Informing Choices NI. The observation was that people with learning disabilities were being potentially excluded from the grieving process and this observation is one which is prevalent in the grief literature (Barber, 2012a; Barber, 2012b; Graham, 2014; Gray & Abendroth, 2016; Handley & Hutchinson, 2013; McEvoy & Smith, 2005; Read & Papakosta-Harvey, 2004; Tuffrey-Wijne et al., 2017). Informing Choices NI observed that one outcome from this exclusion was that people with learning disabilities were being referred to services as they were displaying what is commonly and unhelpfully termed as 'challenging behaviours'. This is also supported by findings in the research which suggest that these are in fact manifestations of distress as a result of being excluded which then leads to disenfranchised grief (Gray & Abendroth, 2016; Handley & Hutchinson, 2013; McEvoy & Smith, 2005).

There are reasons suggested by research as to why this exclusion may take place. These reasons include a belief that people with learning disabilities do not experience loss or cannot understand loss (Dodd et al., 2005; Handley & Hutchinson, 2013). This is an outdated belief which is unlikely to be the reason in modern times. More likely is that parents or carers are unsure or confused about what to do and so err on the side of protecting their child, even when that child is an adult and would be helped in their journey through grief by being included in the rituals that many of us find comforting and that help us understand and resolve the loss (Handley & Hutchinson, 2013; Murray et al. 2000).

The issue in the study was that as only one parent took part, we cannot know for certain what the experience of parents has been. A number of different formats were offered to parents, as well as complete flexibility in terms of time and location of interviews. However, it proved extremely difficult to involve parents. The parent who did take part told us after a recent bereavement in the community, parents were asking each other if they were going to take their children to the wake or the funeral. This indicates uncertainty around the question of involving people with learning disabilities in the grieving process. This along with the lack of engagement with the study does suggest a degree of stigma around the topic. There is great understanding and compassion for the fears that families have and their need to protect their children. The taboo around death is part of a wider societal taboo. However, people in this community will experience death and they will experience loss. The fears of those who love and support them cannot be prioritised over the needs they themselves have.

The group who were most ready and willing to talk to Informing Choices NI, were the people with learning disabilities. What they told us is that they feel the same as everyone else when they experience a loss or bereavement, a finding reported overwhelmingly in research

(Barber, 2012a; Barber 2012b; Graham, 2014; Gray & Abendroth, 2016; Handley & Hutchinson, 2013; McEvoy & Smith, 2005; Raji & Hollins, 2003; Read & Papakosta-Harvey, 2004; Tuffrey-Wijne et al., 2017). They told us about a variety of grief reactions which were as individual as each person. Some participants told us about feeling very emotional while others report feeling very stoic in the face of losing someone. The length of time a person was affected by the loss also varied. We can conclude then like just like everyone else, there is a need for grief to be witnessed and there is a need for people to be supported.

The engagement of support workers was more than parents but less than people with learning disabilities. Again, a number of formats and flexible arrangements were offered. There was a lot of initial enthusiasm about the study but then a definite reluctance to take part. We cannot know the reasons for this. The support workers who engaged with the study through the focus groups were of the belief that people with learning disabilities need to be supported in the same way as everyone else through loss and grief. They reported experiences they had and how they responded to loss when it happened. The support which was provided as outlined in this report was excellent and appropriate. It was also completely dependent on the support workers having their own connections and being able to call on them as well as having funding available. The support which was provided also came through mainstream services, which were excellent but also are not specialised in supporting this community who have very wide-ranging needs in terms of communication. Although the grief is the same as everyone else, their spectrum of needs and the way in which they communicate is different and this must be respected.

This study showed that there is a clear need for coordinated and funded protocols, guidelines, and services within the community of people with learning disabilities and/or autistic people when responding to loss and bereavement. Further, that those who are in supporting roles also need support. This support should be of twofold. They need support and training to look after people with learning disabilities and they also need support for themselves as when a death occurs in the community, they experience a loss alongside those they work with. There is a clear need for a conversation in which everyone is engaged. The study suggests that the most important group, people with learning disabilities and autistic people, know what they need and are ready to have the conversation. This report presents a series of recommendations and it is truly hoped that they will be implemented. This topic is difficult, but it’s not rocket science.

Part 2 Evaluating the training

Part 2 Recommendations

1. This training or some form of training is needed for parents. There is a triangle of support which works to support people with learning disabilities and autistic people. The three points of that triangle are represented by the three groups included in this research: people with learning disabilities and autistic people, professionals who support them and their parents. It is of central importance that these three groups provide a clear and consistent message and clearly understand the need for honest and open communication with this sensitive topic. For that to open, a full understanding of everyone's needs is vital. Part 1 of this work provided this for people with learning disabilities and autistic people. Part 2 provided this for professionals. A strong recommendation is that as parents are not as strongly represented, they should be engaged.

2. This training should be rolled out further to all support workers who work with people with learning disabilities and autistic people. That includes rolling the training out beyond the area covered by the remit of The Ideas Fund so beyond the Derry City and Strabane District Council area. This training has been impactful in a positive way, it is however step 1 in a process of providing the training and support needed to people with learning disabilities and autistic people and to those who support them.

3. The training becomes part of a full package of support which includes providing specific bereavement support which is tailored for people with learning disabilities and autistic people. This should be in the form of group work but should also include an option for one-to-one counselling specific to the needs of this group.

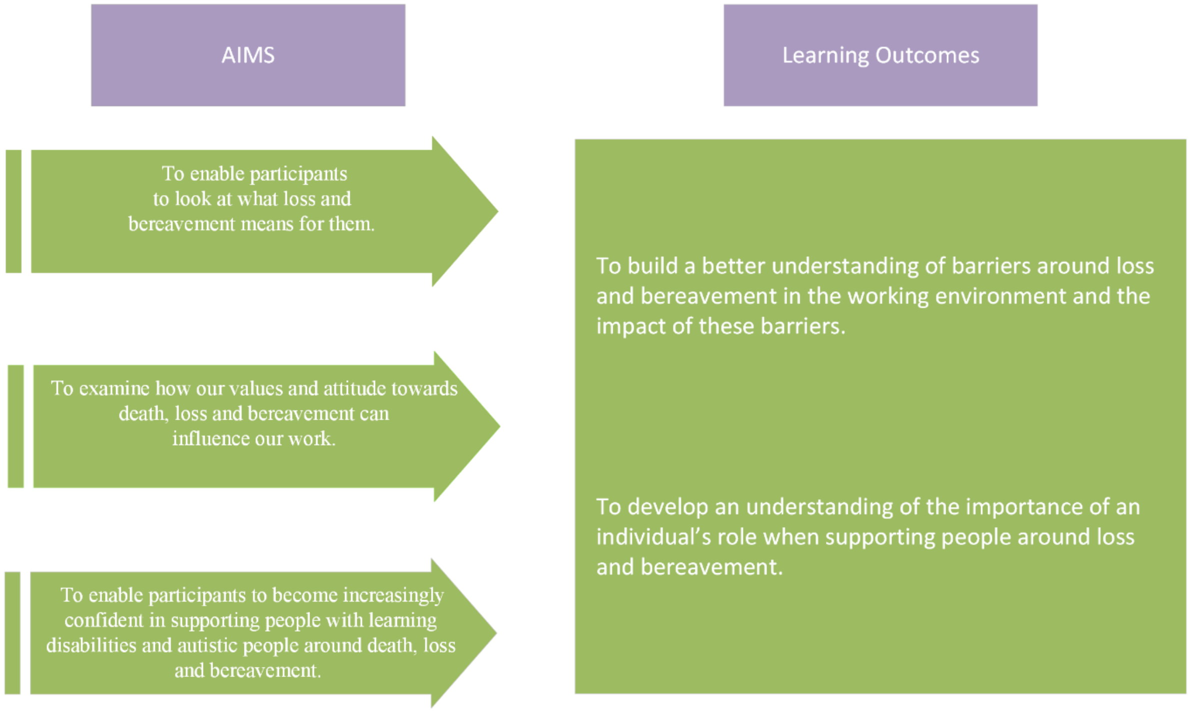
4. A network is set up for professionals with regular meetings to allow swapping of experiences and ideas. This would help to ensure that professionals can share resources and ideas and can feel confident in the support they are providing.

What we did

For this part of the project pilot training was delivered to group 3 – support workers and professionals who work with people with learning disabilities and autistic people.

The training

Training was delivered using the model which Informing Choices NI deliver their RSE training. This model involves flexibility to adapt to the group needs while focusing on the core topic. Delivery is in an informal setting centred on group discussions with thought provoking activities built in. The training carried the central messages of part 1 of the project. It lasted for 3 hours and numbers in a group ranged from 6 to 17 people. The aims and learning outcomes are described in Figure 8.



AIMS

To enable participants to look at what loss and bereavement means for them.

To examine how our values and attitude towards death, loss and bereavement can influence our work.

To enable participants to become increasingly confident in supporting people with learning disabilities and autistic people around death, loss and bereavement.

Learning Outcomes

To build a better understanding of barriers around loss and bereavement in the working environment and the impact of these barriers.

To develop an understanding of the importance of an individual's role when supporting people around loss and bereavement.

Figure 8 Learning aims and outcomes

Training schedule

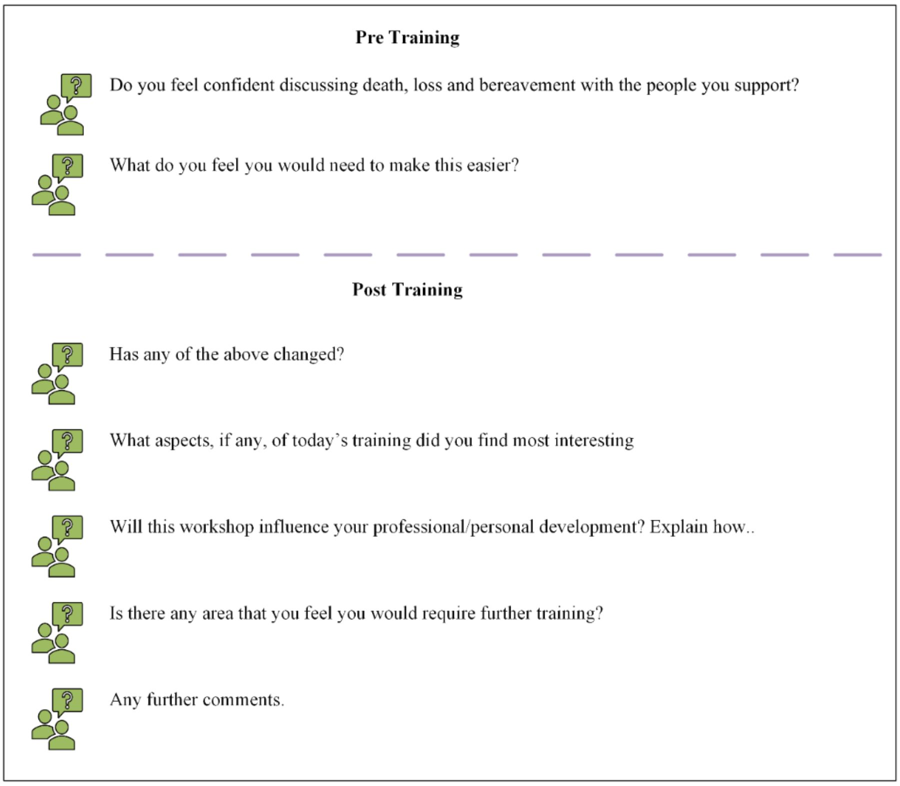
The schedule for a training session is not included as a large element of the effectiveness is contained in the novelty around the training. Informing Choices NI use a range of thought-provoking training exercises and provide an informal setting to create conditions in which serious topics can be discussed in a way that simultaneously provides relief from the intensity that comes with such topics as well as providing the topic the respect it requires.

Data analysis

Qualitative analysis was done on all data collected. Questions that were asked are shown in Figure 9. Questionnaires and feedback sheets were thematically analysed using reflexive thematic analysis to identify themes (Braun & Clarke, 2006; Braun & Clarke, 2109; Braun & Clarke, 2020). Themes were organised into overarching and sub-themes as appropriate. A broad and descriptive coding framework was employed, with coding conducted on both semantic and latent levels.

Who took part

In total 61 professionals took part in the training with 55 of those completing evaluations. Participants were from a range of contexts in the statutory and voluntary sectors. The range of roles they perform is shown in Figure 10



Pre Training

Do you feel confident discussing death, loss and bereavement with the people you support?

What do you feel you would need to make this easier?

Post Training

Has any of the above changed?

What aspects, if any, of today's training did you find most interesting

Will this workshop influence your professional/personal development? Explain how..

Is there any area that you feel you would require further training?

Any further comments.

Figure 9 Feedback questions

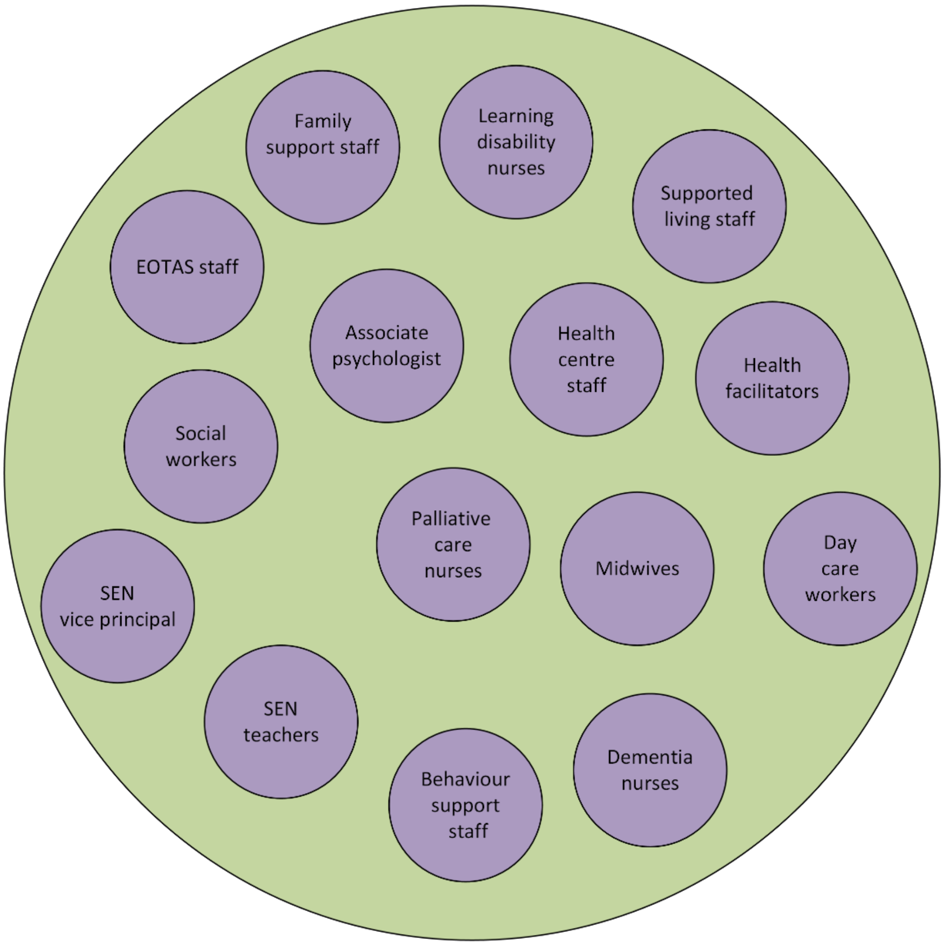


Figure 10 Who took part in the training

What we found

The themes identified in the analysis of responses from professionals who took part in training and the relationship between them are illustrated in Figure 11. Overarching themes are indicated in purple and in oval shape while sub-themes are in green and rectangle shaped. Overarching themes describe a significant area repeated within the responses given and are made up of sub-themes which are also repeated within that area. The main themes found were that there were barriers to the ability of professionals to respond to people with learning disabilities and autistic people within their work roles. The main barrier is centred around the relationship triangle and is one of the sources of fear and lack of confidence that professionals expressed.

The second overarching theme is centred on how the training offered by Informing Choices

NI made an impact on those barriers. It is of note that in presenting professionals with a training opportunity as opposed to attendance of a focus group, we were able to uncover a lot more about how professionals feel and indeed add to our knowledge of what is needed to provide appropriate and relevant support to people with learning disabilities and autistic people when they experience a loss or bereavement. The sub-themes are the training techniques which were all referenced repeatedly in the feedback as being able to provide a sense of freedom to express and explore this topic.

The final over-arching theme is what we found as a result of employing the Informing Choices NI method and is at the heart of this study – what do professionals need to meaningfully support people with learning disabilities and autistic people as they navigate loss and bereavement.

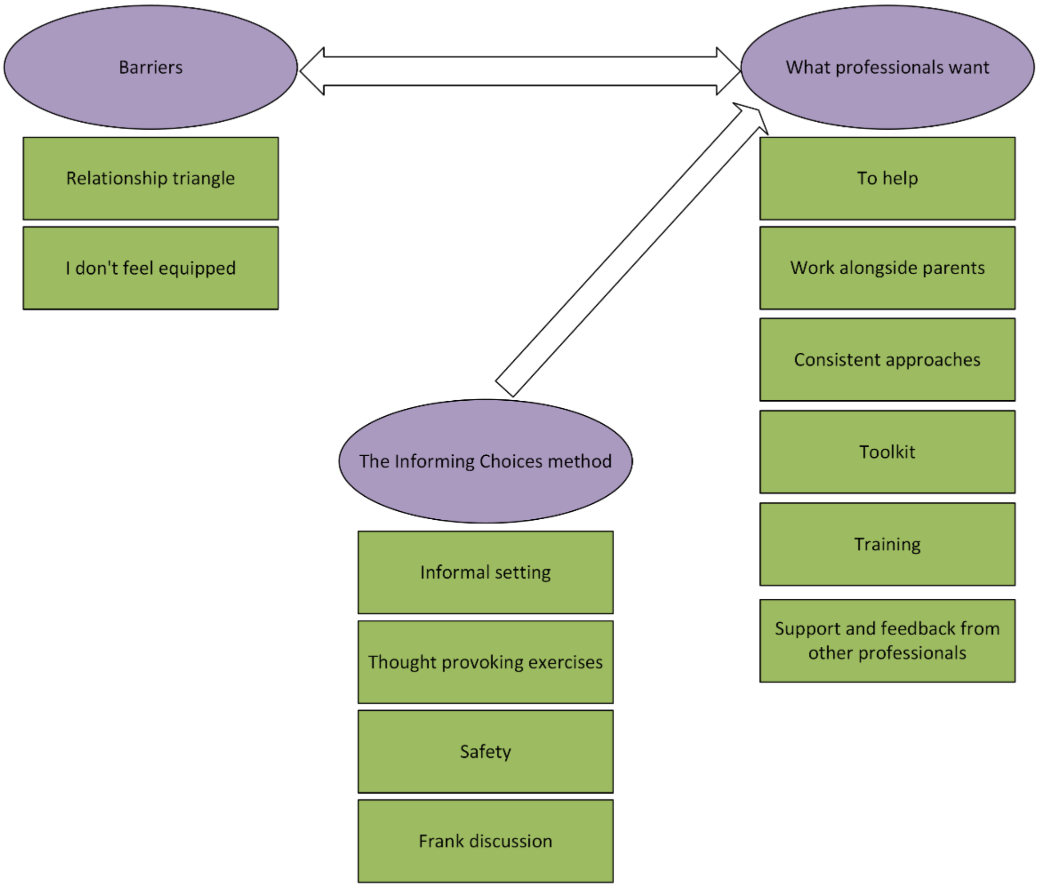


Figure 11 Thematic map

Part 1 of this study gave a comprehensive understanding of what the individual needs in the relationship triangle – the most important person in the triangle. This part provided the same comprehensive picture of what professionals need. So, as well as providing a sound endorsement of the training provided from the co-production element of part 1 of the study, part 2 adds to that exploration of what is required beyond even this initial training.

Barriers

There were a number of recurring themes in terms of what professionals felt stood in the way of them being able to give proper support to people they work with who have been bereaved or experienced loss. At the heart of these is the relationship triangle which comes into play very often in all relationships.

The relationship triangle

The relationship triangle is spoken of often in the Informing Choices NI training and represents all the people involved in providing support to people with learning disabilities and autistic people, called the 'individual' in the relationship triangle. The individual is the

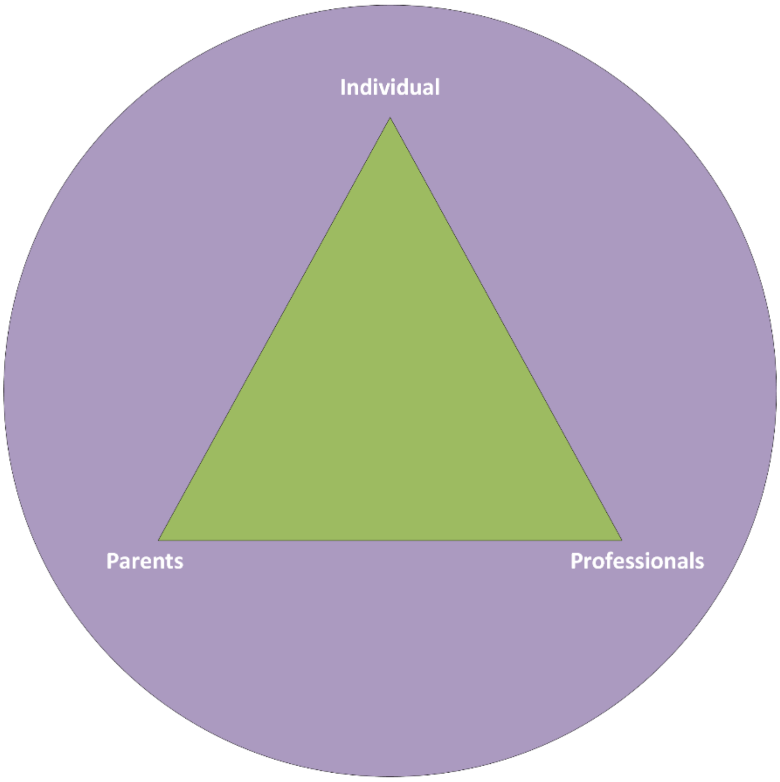


Figure 12 The relationship triangle

most important person in the triangle, and their needs must always be at the forefront. The other points of the triangle are the parents of the individual who usually play a core part in a person's life, providing care and looking after them. Parents in the relationship diagram includes parents and anyone else who fulfils this role. Finally, the professionals who support the individual are the final point in the triangle.

For all the points to successfully join up, a clear and consistent message needs to be coming from parents and from all professionals in the triangle. Anything else leads to lack of clarity and confusion for the individual.

I don't feel equipped

Before the training session, an overwhelming majority of people responded that they did not feel confident to support someone who is autistic or has a learning difficulty or disability through a loss or bereavement. Only 15% of professionals replied with a direct yes, while 85% replied that they did not feel confident.

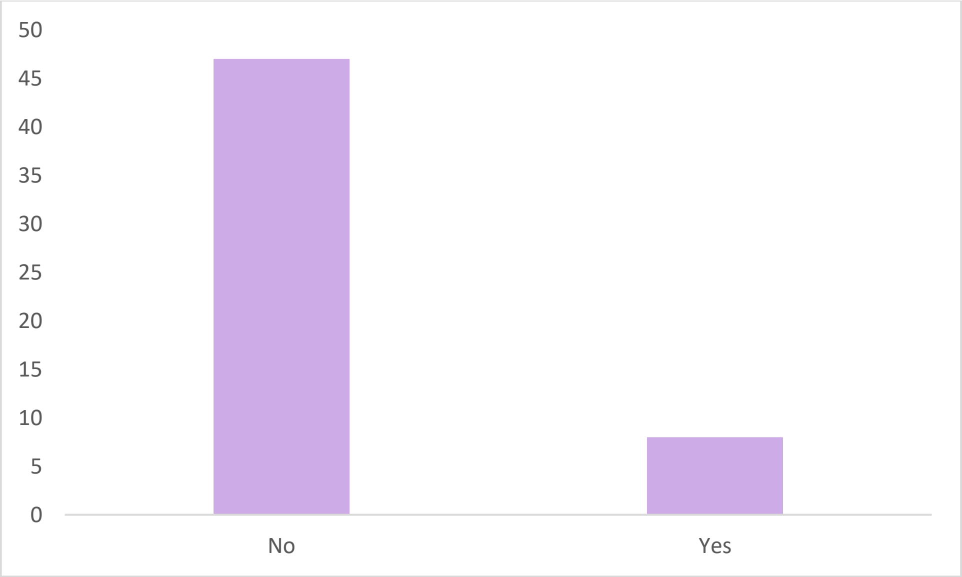


Figure 13 Numbers of people who were confident they could support someone

"No, I don't feel equipped to explain death, loss and bereavement in a way suited to someone with a learning disability/autism to ensure they can understand and process."

> **"Happy to discuss but not equipped to advise or support effectively."**

Professionals reported a number of suggestions of things that would help them feel more equipped. The suggestions that were given are outlined in Figure 14. Professionals were able to give as many suggestions as they wished.

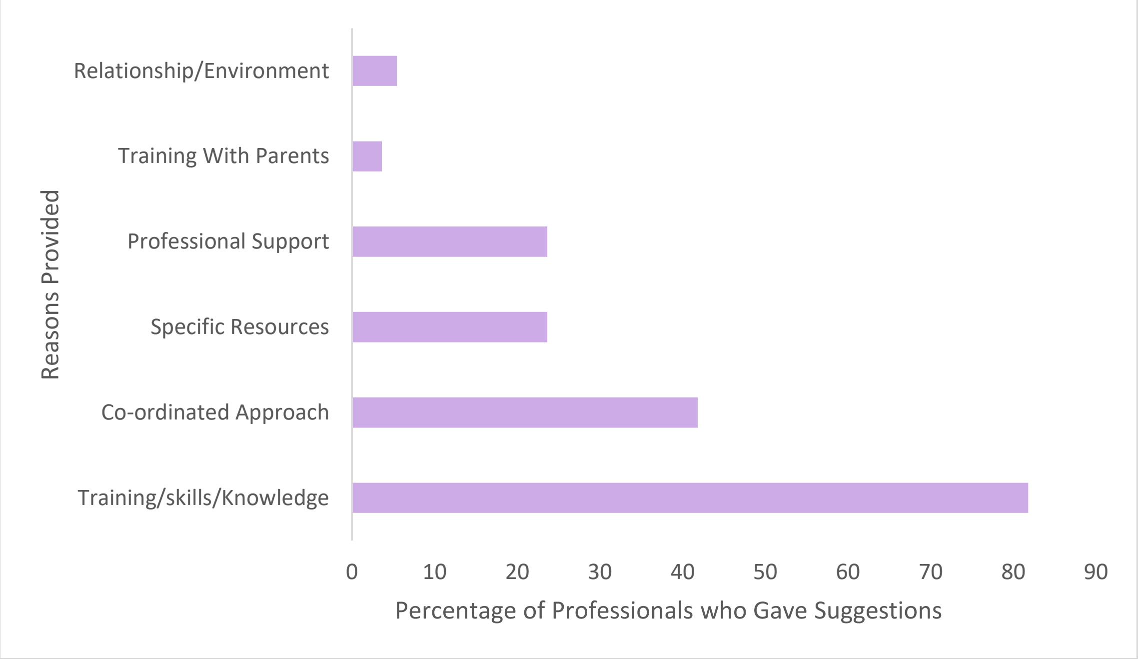


Figure 14 Reasons that professionals gave for not feeling equipped

More training which encapsulated training, knowledge and skills was the most commonly recurring answer provided, 82% of professionals felt that training would help them to feel equipped to provide this support. The next most common suggestion was a co-ordinated approach which 42% of participants felt would help. This encapsulated suggestions including a toolkit of resources, best practice examples and guidelines to follow. Specific resources were suggested by 24% of resources, this meant specific resources for people with learning disabilities and autistic people. The same number of professionals felt that professional support would help them. This was in a number of forms: support from line management; support from peers; and specifically, a network of professionals who would meet regularly to support each other. The last two categories were training which included parents and providing the conditions to allow a solid relationship to be built with the people being supported. A lack of confidence was reported by most professionals.

"I have been through death, loss and bereavement, most people have, but I feel specific training that goes into detail would be of benefit to me and the people/children I support, to help them."

As well as the lack of feeling prepared through training and resources, for some, the lack of confidence stems from them feeling they do not have the relationship or connection needed to support someone with an experience which is so serious.

"I feel confident if I am supporting someone with whom I can connect. But if I cannot connect for various reasons – person's emotional state/ability to communicate etc, I feel at a loss sometimes."

Sometimes this lack of confidence leads to doing nothing, which was a theme which was also generated from Part 1,

"I feel some could struggle while supporting them – is it better not to discuss?"

Professionals again pointed to conflict within the relationship triangle, a lack of consistency in the messages being given between all points in the triangle and getting into trouble for overstepping the perceived boundaries.

"…there's often opinions on what clients 'need to know' from family/staff and communication difficulties."

"I feel I may open a can of worms."

"Worried about saying wrong thing."

Professionals also revealed they struggled with the impact on them and that hindering their ability to do the right thing and for them to be ok as, "**these conversations are extremely emotive and stressful**" and it "**can be difficult to monitor composure.**"

What professionals want

The first main theme talked about barriers. For every barrier there is an opportunity as illustrated in Figure 15. Simply put, professionals want to help in a meaningful way that they can have confidence in. The findings here very much echo the findings from part 1 of this report. Given the small numbers of professionals who took part in the research element of the project, the similarities provide validation for the initial findings.

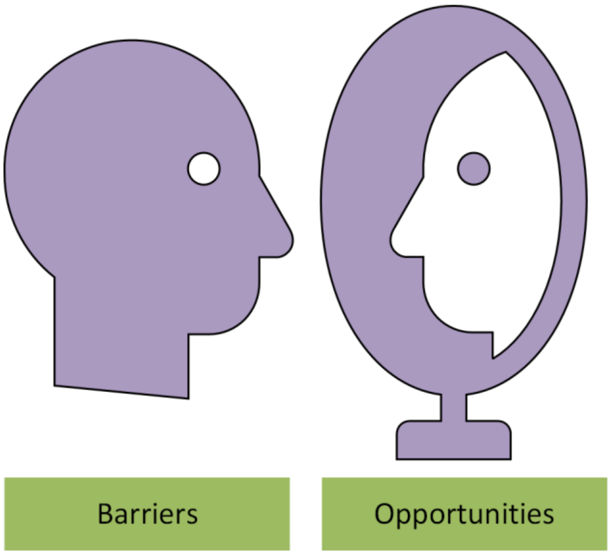


Figure 15 Barriers and opportunities

To help

It was very clear from the feedback from professionals that they want to do the best job that they can of supporting the people they work with. It is important that the needs of professionals are met to allow them to feel confident and supported.

"…I just need to believe I can do this."

Consistent approaches

Professionals want a consistent co-ordinated approach which allows them to feel confident that they are properly and correctly supporting the individuals they work with. Key ways in which they feel consistency can be facilitated are by having guidelines for everyone to follow, training in those guidelines, best practise examples of how to handle this most sensitive of human experiences and a bank of resources that everyone uses.

> **"That we all have the language and that we all have to be consistent in all services"**

Training

Professionals want training which again is co-ordinated and consistent and ensures they are all approaching the questions asked and the support needed from the same viewpoint. They would like the time for that training to be protected and they would like that training to be repeated at regular time interval so they can refresh and update their skills and knowledge.

Support and feedback from other professionals

It is very important to professionals that they can check in regularly and discuss with other professionals how they approach this situation and other situations that come up and are unique in working within this community. It allowed them to get ideas when they feel they are struggling and to have confidence that what they are doing is correct.

There were several specific forms of professional support that participants outlined. They want to talk to other professionals and they also want support from their line management. Again, this is in the form of practical ideas and reassurance but also in the form of emotional support. This work takes an emotional toll. It is a difficult area. It is an area that all human beings struggle with. It goes beyond 'work.' It's at the core of the difficulties we all face as humans. Loss, particularly to death is the ultimate pain most of us fear.

Work alongside parents

Professionals want to work with parents and join up the points of the relationship triangle. They recognise the important of **"consideration of the need to engage fully with carers or the person's support network"** while being aware of the implications for the individual if their needs are not made the main priority.

> **"Looking at the consequences of talking and not talking about death. Can use this with parents who do not want to talk to their children about death"**

People with learning disabilities and autistic people deserve transparency, honesty and to have their needs met above all else. What several professionals specifically mentioned in their feedback was something they might not have considered before – what are the implications when people are not fully informed about death or not told that a person has died – has the person just disappeared? Do they no longer love them? A person (usually) has no choice in death, it is much more painful to think a person has just left. As humans we fill in the narrative ourselves in order to make sense of the world, without accurate information, people can construct narratives in which they feel rejected and unloved.

> **"Taking the lead from the individual, challenging family members and others who think it is best not to discuss death and dying with service user."**

One professional specifically mentioned how hard it is to deal with more complicated deaths. If a person has died through suicide, it adds a further dimension of difficulty. It is important that this is something that is accounted for in resources that are produced, as a result of this work.

The Informing Choices NI method

This theme was firmly centred on the training itself and what participants felt about it. The response to the training was overwhelmingly positive with only one person from the 55 who completed responses reporting that it had not helped. This was because they felt the only thing that could help was having a strong relationship in place with the bereaved person. For the remaining 54 who provided feedback, it was overwhelmingly positive.

> **"…this session has helped me to think about the reasons why I feel/felt unequipped to support others through grief/loss. It challenged my personal thoughts/values around grief and how these may interfere with my interventions with the families I support. The exercises gave me food for thought in terms of how we talk to people about illness and dying."**

> **"I have different thinking on this topic now. Much more confident"**

The subthemes are centred on the recurring features of the training that participants reported on.

Informal setting

Participants enjoyed the informal nature of the training and felt that this meant they could relax. It acted as an antidote to the very serious and sombre nature of the topic being addressed. This helped to lighten the atmosphere and helped people to relax while providing professionals with information and knowledge which made them feel more confident.

> **"Information being given was useful and in a relaxed manner."**

“…improved confidence and knowledge of how to approach and discuss death and grief. New contacts and knowledge of resources.”

Thought provoking exercises

The participants reported that they found the exercises provided to be challenging and thought provoking. They allowed them to explore their own feelings and their own beliefs about both death and about the people they work with and support. Each of the exercises was highlighted by a range of participants as being something that stimulated them into considering their own approach. Specific examples are not included as the novelty of the training exercises is a large part of their effectiveness.

Safety

Due to the relaxed nature of the environment created by the methods Informing Choices NI use and fuelled by the creative and thought-provoking exercises, participants felt that they could ask questions. They felt that the space created was a safe one in which they were not expected to know all the answers and they would not be criticised for what they felt were their shortcomings. In reality, when it comes to the topic of loss and bereavement no one can be expected to know all the answers for another person and that vulnerability is as important as knowledge when supporting people through a loss or bereavement. Participants described what they had gained,

“Knowing to take a breath before answering. Knowing it’s ok not to know the right answer.”

“It will allow me to prepare and have the conversations. Shown me to breathe and take a step back before answering the questions.”

Frank Discussions

Participants reported overwhelmingly that they were often afraid to say and do the wrong thing. Having this forum where they are able to work through approaches allowed them to be totally honest in what they think and what their fears were. This gave them a safe space to organise and consider how to approach the situations discussed in real life and counteracted the uncertainty they often feel.

Conclusions

Uptake of the training was very successful which was somewhat surprising given how difficult it had been to engage professionals to attend focus groups. It is possible of course that professionals attach more value to training than to research, they feel that in a busy working life, training has a value for them that research does not and more likely to allocate time to this. It is also reasonable to assume that they are more likely to be released to attend training events. The training however also doubled as a forum to allow additional insights to be gained, insights which are valuable and important as this work continues. It was important that the findings validated and reinforced the work of part 1 lending further support to the need for this training.

The response to the training was extremely and overwhelmingly positive with only one participant reporting that it had not made any difference to their practice. The remaining professionals who filled in feedback sheets (55 of 61 attendees) expressed passion and enthusiasm for the training in terms of the way it was delivered, the content, the facilitation, and the potential for it to influence their personal and professional development. The way that this challenging topic is approached is important. A relaxed environment where safety is quickly established means that participants can be candid in sharing what issues they are facing.

There is much work still to be done and the professionals who engaged in the training have pointed the way in what they need. A consistent, co-ordinated approach, a bank of appropriate resources which they can avail of and regular contact with their peers in order to facilitate shared learning and support in what is a very important but very challenging area to work in.

A re-occurring theme in this work is related to how tight-knit the communities of people with learning disabilities and autistic people are. They are a strong community. The community is made up of the relationship triangle which is often mentioned and referenced. There is a strong message that professionals remain concerned that families may not be happy if they address an individual's needs around the topic of death and loss. This is something which must be addressed while keeping at the forefront of all decisions that the professionals first priority must always be the individual they work with.

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