Community based services for children and adults with learning disabilities
Bereavement and People with Intellectual Disabilities

Dr Noelle Blackman
CEO
Historical perspective

Belief that people with LD:

- not affected by bereavement
- could not make emotional attachments.
- Institutions separated people from their families, the emotional impact of this loss went unnoticed
- Psychotherapy and counselling have traditionally been considered inappropriate for this client group
PhD research

- The study aimed to build an understanding of the internal and external factors that affect the bereavement process in people with intellectual disabilities.
Designing the study

• Based on findings from 15 years clinical work as a dramatherapist with bereaved people with Intellectual disabilities

• Included 3 critical literature reviews and drew on my previously published work
Why this research topic?

• Rise in the longevity of UK population means people with intellectual disabilities also living longer
• Therefore more likely to experience at least one death of someone of significance
• Loss of a significant other through death is psychologically traumatic
• Little significant research on clarifying the grief experience of people with intellectual disabilities
• Current research indicates that there is an increased vulnerability to atypical or complicated grief in this client group
Three fold literature review included:

1. Bereavement and people with ID
2. Generic bereavement
3. Psychotherapy with people with ID
1st critical review - bereavement and people with ID

- On examining over three decades of literature on bereavement and PWID, it became apparent at the start of this study there was a lack of clarity about how best to support bereaved PWID
1\textsuperscript{st} critical review - bereavement and people with ID

- Small amount of rigorous research on this subject
- Evaluative work, individual case studies and recommendations drawn from practice were included
- Much of the work was practitioner led
- Large amount of what existed had flawed or limited methodology
Key themes from 1st review

• Environmental factors often disable the natural bereavement process

• Little that contextualises the bereavement experience within a relational or societal perspective

• Significant emphasis on educating PWID and paid carers to understand more about bereavement and death

• PWID experience a high percentage of complicated grief (Conboy-Hill 1992, Blackman 2003, Brickel & Munir 2008; Dodd & Guerin 2009)
2nd critical review - Generic bereavement literature

• This review shed some light on the many reasons that may contribute to why PWID may experience such a high proportion of complicated grief (CG)
Key themes from 2\textsuperscript{nd} review

- Increasing evidence to suggest at least 10\% of general population will develop complicated grief (Maccallum & Bryant 2010)

- Characteristics that can be seen = bereaved person appears to be stuck in chronic state of mourning, with intense yearning and longing for the deceased continuing unabated (Prigerson et al 2008)
Relevance of key themes to PWID

• Many of the key vulnerability factors attributed to complicated grief occur when someone with ID is bereaved

• Such as isolation, lack of recognition, concurrent losses, attachment difficulties, low self esteem, identity issues
This part of the review focused on the use of counselling and psychotherapy with this client group.
Key themes from 3rd review

• Historically PWID have not been considered suitable candidates for psychotherapy

• It is well documented that PWID are significantly vulnerable to psychological disturbance

• Barriers to PWID accessing psychotherapy

• PWID can benefit from psychotherapy

• There are newly developing models of ‘disability psychotherapy’
Three domains contributing to complicating factors in PWID

(Blackman 2012 in press)

- The learning disability
- Environmental factors
- The impact of disability on attachment
Difficulties connected to learning disability that can complicate bereavement

- Cognition
- Delayed processing of information
- Communication
- Difficulty in identifying and expressing emotions
- Handicapped smile (Sinason 1992)
- Multiple losses
Environmental factors that can complicate bereavement of PWLD

• Lack of recognition of emotional life
• Lack of recognition of relationships
• Not giving accessible information
• Not including PWID in rituals etc
• Expression of grief not recognised
• Lack of knowledge and confidence of carers in supporting bereavement
Environmental factors continued

• The literature points to an over-emphasis on teaching direct care staff about bereavement rather than addressing staff confidence in applying knowledge (Kitching 1987 & Reynolds et al 2008)

• This indicates that different models of training and support for staff are needed and has implications for future training of the work force
The impact of disability on attachment

• The significance of early experiences of a baby born with a disability
• How early attachments affect relational experiences throughout life
• The significance of this to the bereavement experience
The impact of disability on attachment

- Trauma of birth
- Difficulties re feeding
- Emotional robustness of the parents
- Separation due to birth complications
- Continuous separations in early childhood due to hospital stays
- Child may lack behaviours which attract attention of parent
- Parents may abuse the child
- Parents may ‘over protect’ the child
Why is attachment theory important?

- Grief is the emotional response to the loss of a significant relationship
- Important to understand something about relationships in order to gain some understanding of the impact of grief.
Attachment theory

• In order to promote survival, all mammals have developed a motivational system

• Bowlby’s interest and further study of this system led to the development of Attachment theory (1960)
Attachment theory

• Focuses on the formation of the significant early relationships of human infants with their primary carer

• How these patterns of relating build the ‘internal working models’ of the world within the child

• These internalised models then become the blueprint for relationships for each person throughout their lifetime
Attachment patterns

- Ainsworth (1978) and Main (1984) developed the theory further
- Making the important distinction between strength of attachment and security of attachment
- Ainsworth found one secure pattern of attachment and two patterns of insecure attachment; anxious/ambivalent and avoidant
- Main added a third insecure pattern - disorganised attachment
Neuro-elasticity

• Earlier belief that attachment patterns were set for life

• However, it is possible to make some changes to insecure patterns of attachment (therapeutic foster care, adoption, psychotherapy etc)
The development of coping mechanisms

- We form our identity in relation to others.
- Negative attachment patterns contribute to a number of difficulties - low self esteem, being too self reliant, or not trusting one’s own judgement
Grief is a time of stress

• At times of stress our attachment behaviours are triggered more strongly

• Coping methods we have learnt in connection to our early attachment are activated
anxious/ambivalent attachment

- Commonly exhibit clingy and dependent behavior, but will be rejecting of the attachment figure when they engage in interaction.
- The child will have failed to develop any feelings of security from the attachment figure.
- They exhibit difficulty moving away from the attachment figure to explore novel surroundings.
- When distressed they are difficult to soothe and are not comforted by interaction with the attachment figure.
- This behavior results from an inconsistent care giving.
Case study 1

- Woman, in 40’s
- Witnessed Mother dying unexpectedly on family holiday 12 years previously
- Born with serious intestinal complications. Spent much of early life in and out of hospital
- Lived until mother’s death in parental home
Case study 1

- Anxious ambivalent attachment
- Many separations in early childhood
- Parent who gave message that she would not survive without them
- Difficult to please or placate
- Grow up with low self trust
- Prone to severe protracted grief (Parkes)
Case study 1

• At first sat silently crying, no eye contact
• Showed commitment
• After a few weeks less crying, clearly listening to others. Still said little
• Ethos of group – empathic curiosity. Similarities and differences explored. Support staff also to listen.
• Gradually began to see that the group and others could tolerate her overwhelming feelings, she began to share
• Outcome access more balanced memories, less overwhelmed by intolerable feelings. able to engage more in life.
Disorganised attachment

- The people who are meant to keep the infant safe cause them harm.
- Sets up tension within the child of seeking comfort from the parent who is also neglectful or abusive.
- Leads to the child having little sense of their own identity, low self-esteem and feeling that they are to blame for everything that happens to them.
- Someone who has grown up with this attachment pattern can becoming self-punishing and they are likely to turn away from others when in distress as they cannot trust that others will help them (Parkes 2006).
Case study 2

- long term bereavement psychotherapy with a woman with ID and disorganised attachment
- Neglected and abused in early childhood
- Self harm and regular attempts on life
- powerful transference felt the during the often silent sessions
Case study 2

• The silence can be understood as mirroring early experience with a neglectful mother

• Sinason (1992) has described how one way that infants learn to survive the experience of feeling frightened daily due to the absence of an emotionally available mother, is to “give up all hope of communication and become quiet, sleep a lot, and become deeply depressed” (p189).
Case study 2

• An infant who has developed a secure attachment will learn to regulate their emotions through the careful containment of the mother (Gerhardt 2004). This is done in a mainly non-verbal way.

• “Caregivers who can’t feel with their baby, because of their own difficulties in noticing and regulating their own feelings, tend to perpetuate this regulatory problem, passing it on to their own baby” (Gerhardt 2004 pp23-24).
Case study 2

• Supported the client to recognise when she was becoming stressed or feeling angry or sad and to learn ways to regulate her feelings

• Developed strategies using music and relaxation that she could also use outside of the sessions

• Through the therapeutic relationship she experienced different sort of attachment which she could carry into future relationship experiences
Case study 2

- After eight years of bereavement psychotherapy with this very disturbed client, she was able to move from having lived for most of her adult life in secure settings due to regular acts of self-injury and attempts on her own life to moving into a flat of her own (with a few hours of weekly support), and now several years later has been able to remain stable and independent.