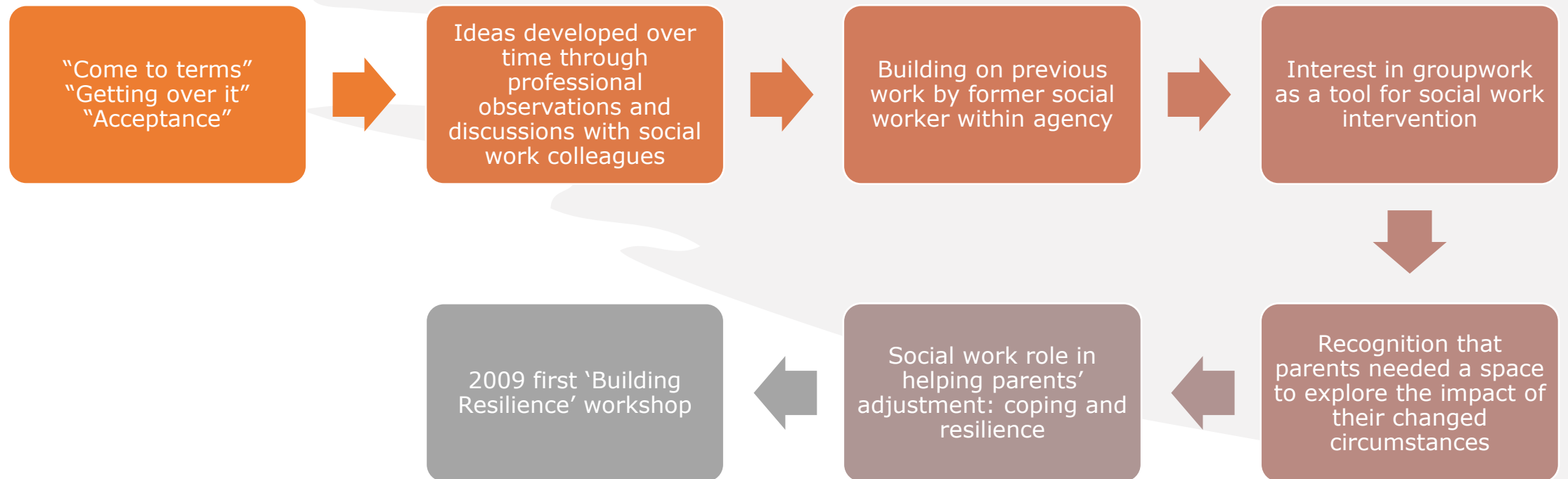


Hidden Loss in Parent Carer's: Enhancing Social Workers' Knowledge and Skills through an Online Experiential Workshop

Completed as part of
Masters Dissertation

Practice to Research



Background to research

- Parents experience a range of emotional responses to the birth of a child with a disability (shock, concern, uncertainty)
- Life is changed and parents may experience the loss of future expectations, dreams and assumptions
- Loss may be disenfranchised
- Loss and Change recognised as significant themes

Exploring Loss

- **Loss:** Losing something that is significant to us. Loss is a constant companion in life
- **Circumstantial Losses:** (Parkes, 1971/1988)
 - Not common to everyone
 - Loss or change which takes place over a relatively short period of time with little time or opportunity for preparation
 - The implication of the loss or change are lasting rather than transient
 - There is a need to revise one's assumptions about the world in a major way
- **Grief:**
 - It is the natural process of reaction and adjustment to loss and change
 - Intense sorrow-mental, physical, emotional and spiritual suffering resulting from loss
 - Is a transforming experience, can lead to personal growth

Background to Project

- Action Research (AR) project as part of an MSc Loss and Bereavement
- Aim of the study was to establish if social workers identified loss in parents and saw it as important to address
- These losses are referred to as non-finite loss and include;
 - The loss of hopes, dreams, wishes and expectations
 - The loss of a 'normal' parenting experience
 - The loss of future opportunities for their child
- Study is focused on enhancing the emotional support provided by social workers to support parents to adjust to their changed circumstances
- AR allows that knowledge accrued by the 'insider' researcher can be used to investigate issues or concerns in order to bring about change (i.e. use of practice wisdom is allowed!!)

Taking Actions



Research Findings

Survey: establish baseline of SW's knowledge and Skills

11 participants had provided emotional support specific to the loss of the "anticipated" child to ten or more families

Responses to questions on training indicated that 12 respondents strongly agreed and a further 2 agreed that they would like further training

Ten participants addressed issues of loss at the initial assessment stage.



Thematic Analysis: 4 semi-structured interviews

The Story of the Loss: using the narrative process to affect change

Navigating Alone: individual practitioner responses

Opportunities for Support: mapping Interventions

Semi-Structured Interviews

- **Theme1: Telling of their story: Using the narrative process to affect change**
- Conceptualised as an activity, event and/or process
- Social Workers recognised their role as empathic listeners
- Facilitating parents to express emotion was seen as important for both validating and normalising feelings.
- Supported parents to recognise, understand and deal with their changed circumstances.
 - "I think normalising that for parents can be very healthy because they feel that there's something wrong with them...society tells us those feelings are to be pathologised or fixed."

Semi-Structured Interviews

- Helped parents to explore the impact of these changes, integrate these changes into their lives and make sense of their experience
- Involved revising future expectations which might not be fulfilled
 - *"I would say that they're scared...their dreams have been shattered, there's something going on they may or may not know what that is so their life really has been turned upside down and inside out."*
 - *"I suppose what you're really trying to get to is parents being as comfortable as they can with their child's needs so that parents can enjoy their child."*

Semi-Structured Interviews

- Social workers spoke about “starting where the client is at”
- Timing and readiness were important considerations
 - “I remember one Dad that I spent an hour talking about making silage...he was so wary he didn't want a child coming into service and he didn't want to know about services, here was a social worker sitting in his house wanting to talk. I think that was all about loss and grief.”
- Social Workers saw when information was not shared sensitively it counted for large part of the story and had a long-lasting impact
- Times of transition and developmental stages were part of the story
 - “The loss of expectation that you have for your child’s life or your family life can be heightened at different developmental stages or different family stages you know whether it’s birthdays or all those kinds of rituals and transitions going to school or that expectation you had for your life heightened because of those times it’s like a bereavement you can be caught off guard.”

Semi-Structured Interviews

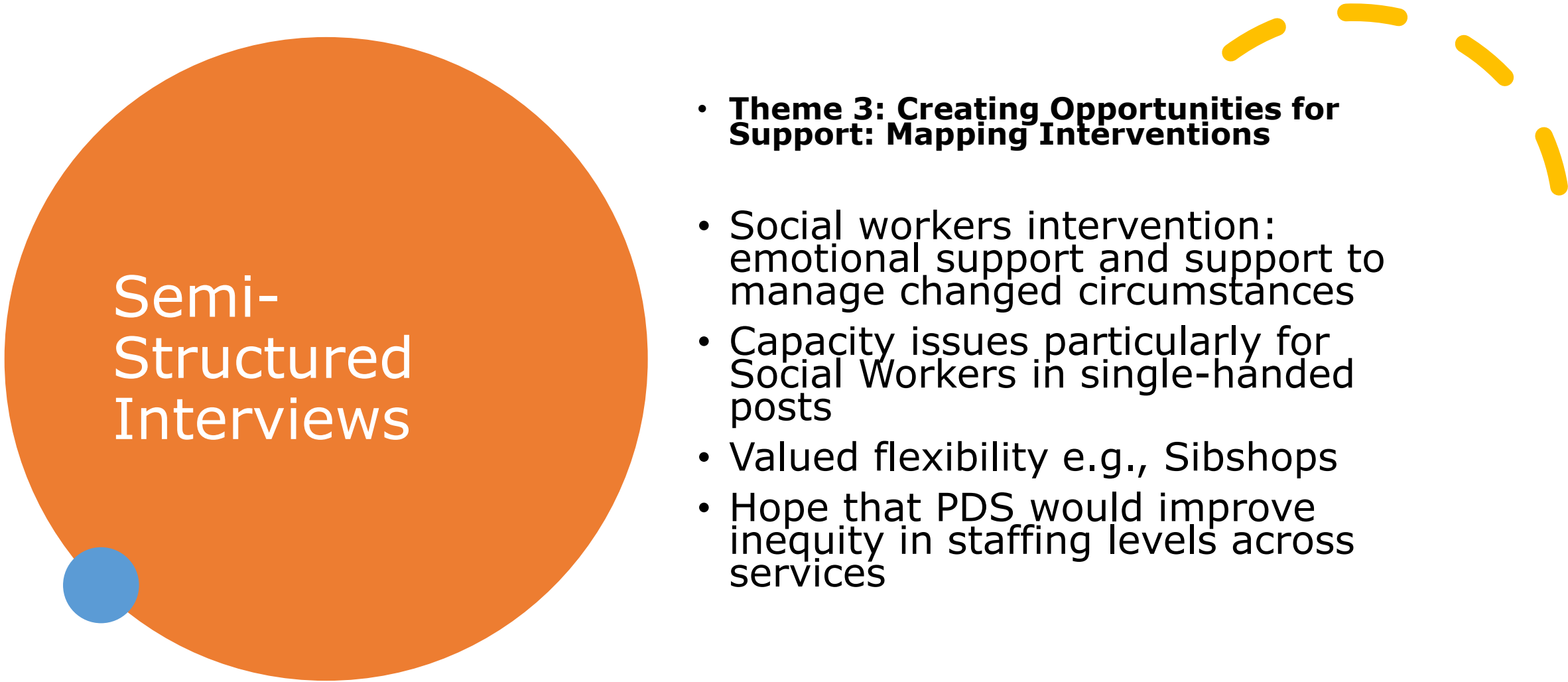
- **Theme 2: Navigating Alone: Exploring grief and loss**
- All social workers recognized the presence of grief and loss
 - “I think it does run through every family I think that has a child with a disability and it rears its head at various different times throughout their life.”
- Social workers working autonomously without practice guidance from agency, the profession or academia
- All using psychosocial assessment but not standardised
- “rollercoaster of emotions”; traumatic experience
 - “...an awful lot of trauma...still holding onto that hope but then there’s that awful niggle at the back of their mind that uncertainty.”

Semi-Structured Interviews

- Sense of being different from others and led to lifestyle changes
- Meaning of the loss was different for everyone
 - “If somebody’s had to give up work that’s a huge issue...”
- Casework relationship was vital to revisiting these issues over time
- Different views on therapeutic value of naming grief and loss
 - “I would name it, because I think that’s kind of helpful... and say look it, you had all these hopes and dreams for your little baby and you look to me like your world has been turned upside-down and that’s okay, you have to name it and acknowledge it I think... it’s setting the scene for them to think about it further.”
 - “You can get the essence of the emotion in some ways without putting the name on it”.

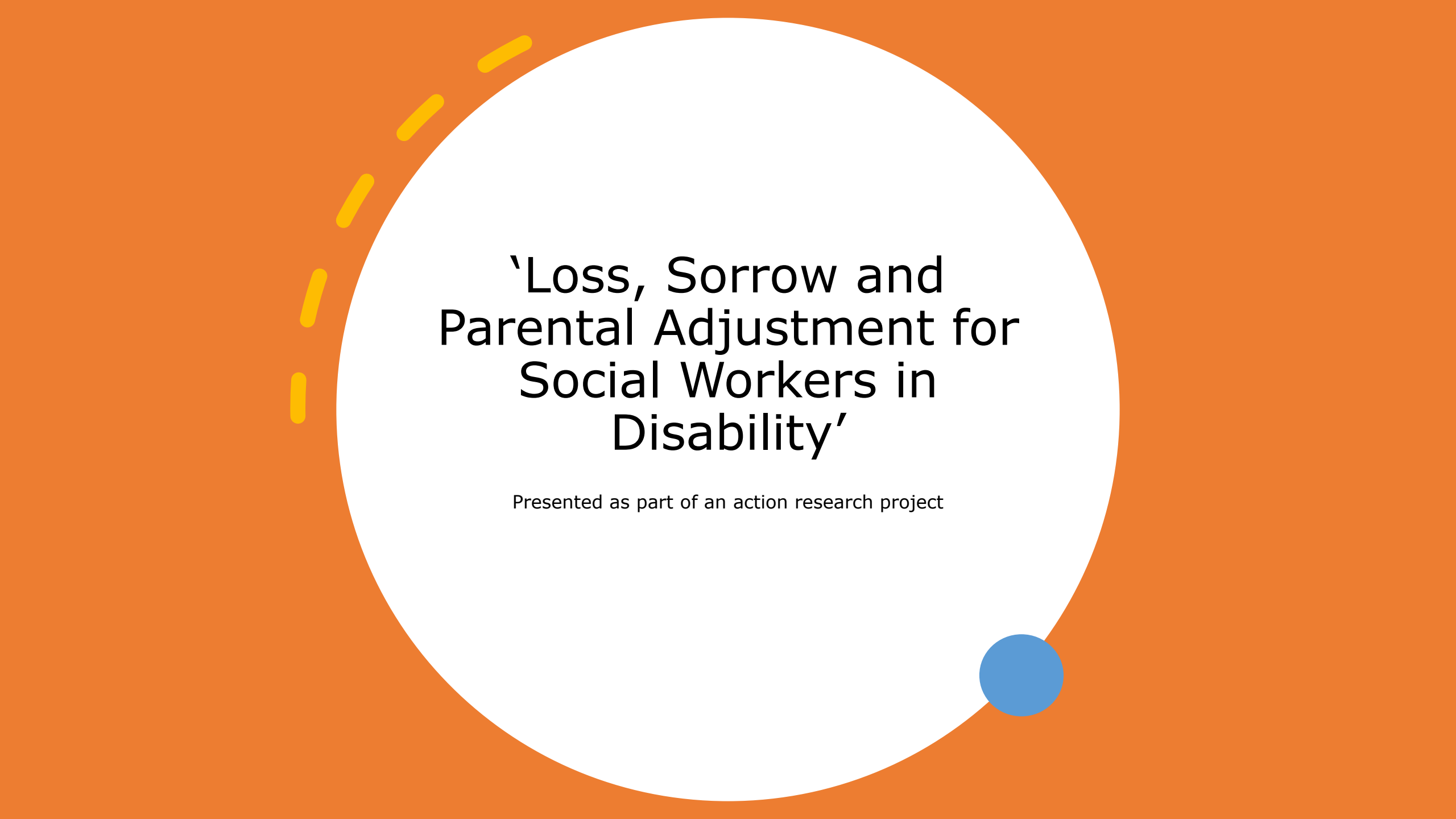
Semi- Structured Interviews

- Professional judgement and had a high level of skill to navigate emotions
 - “That Mum I met yesterday and toilet training, she knows her child is not going to toilet train in the near future...and then you end up in that conversation you know how do you feel about this”
 - “You can often pick up on that if someone is giving you a hint to ask something or if they don’t want to talk about it they won’t get into any kind of emotional talk and they just want to talk about the practicalities of getting more support.”
- Social workers used the MDT for support and the importance of knowledge and awareness of grief and loss across the team



Semi-Structured Interviews

- **Theme 3: Creating Opportunities for Support: Mapping Interventions**
- Social workers intervention: emotional support and support to manage changed circumstances
- Capacity issues particularly for Social Workers in single-handed posts
- Valued flexibility e.g., Sibshops
- Hope that PDS would improve inequity in staffing levels across services



'Loss, Sorrow and Parental Adjustment for Social Workers in Disability'

Presented as part of an action research project

Key Learning Outcomes



Confidence in considering loss as part of the parental experience



Explore the significance of the story of the loss experience



Enhance knowledge and skills in working with loss and grief in the parents we work with to support their adjustment and build resilience



Exploring your own life losses to date:

- Using the handout for guidance complete the reflective piece on your own
 - Decide how much you want to share
Think of this as a parallel process for parents (what would you / they struggle with)
 - Take a few minutes to reflect and become aware if there are any things coming into your awareness that need a few minutes to think about
- 

Personal Loss reflection

Personal Loss Experience:

Please draw a ring around any of the following losses you have experienced. There is space at the end to write in other experiences you may have experienced.

Draw a square around a *significant loss* you experienced.

Cat died	home broken into	purse stolen	car accident
Lost job	dog died	children left home	loss of health
Grandmother died	friendship ended	partner died	failed exams
Loss of home	miscarriage	friend died	broke arm or leg
Father died	Mother died	loss of faith	parents separated
Marriage breakdown	moved away from place where you grew up	moved country	
Loss of financial security	changed school	fell out with best friend	
End of relationship with first love	good neighbour or friend moved away		
Moved to the other end of the country	failed exams	didn't get specific job	
Birth of sibling caused upset	death of sibling	adoption	abortion
Suicide	Mental health issues	Other.....	

Current Models

- Chronic Sorrow (Olshansky, 1962)
- Psychosocial Transitions (Parkes, 1971)
- Dual Process Model (Stroebe and Schut, 1999)
- Ambiguous Loss (Boss, 1999)/Disenfranchised Grief (Doka, 2004)
- Concept of Nonfinite Loss (Bruce and Schultz, 2001)
- Resilience (Bonanno, 2004)
- Range of Response to Loss (Machin, 2001)
- Meaning Reconstruction (Neimeyer, 2002)

Reflective Practice – Mirroring the AR Process

- Does the theory presented resonate with you?
- Is it applicable to your practice?
- Can you share an example with participants today?

Ambiguous Loss/ Disenfranchised Grief

Loss that is uncertain, incomplete or unresolved – a major stressor which can defy resolution

Losses associated with the Assumptive World are frequently ambivalent

Permission to grieve not always present/lack of rituals for the person, the family and the wider community

People are not mal-adapted but their circumstances are complicated or “ambiguous”.



Reflection

- Do these theories resonate with you?
- Can you relate it to your practice?
- Can you give an example?

Meaning Reconstruction

- Grieving is the act of affirming or reconstructing a personal world of meaning that has been challenged by the loss.
- Reconstructing a world that restores a semblance of meaning, direction and predictability to a life transformed.
- The task of the counsellor is to help the griever build a bridge between the past and a changing and uncertain future.



Reflection



- Does this theory resonate with you?
- Can you relate it to your practice?
- Can you give an example?



Range of Response to Loss Model

Model and Scale to identify positive adaptation to loss

Key word is resilience which is defined as:

- personal resourcefulness
- positive life perspective
- social embeddedness

Resilience

- Is the source of stress greater than the resourcefulness of the individual
- Coping capacity is not predictable but has to be looked at in the context of the interplay between the individual and the events which occur

Narrative Process-Making Sense of the Loss

- External- the story of what happened helps confirm the reality of the loss “ tell me about ...”
- Internal- telling the story of the impact of the loss helps address the emotional consequences of it “ tell me what you are feeling and thinking...”
- Reflexive- the story is a way of integrating the loss into changed life circumstances and making sense of the loss experience “ tell me how you are making sense of what happened..”

PhD Research

- Qualitative research exploring how HCP's discuss anticipatory grief and loss with parents of children with life-limiting neurodevelopmental disabilities
- Year 1 Scoping Review of the literature
- Year 2 Qualitative research