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Lizzy: Understanding attachment and loss in young people with complex needs

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Introducing Lizzy

Lizzy is now a twenty year-old young woman with brown hair, lovely blue eyes and the most amazing smile. She has a great sense of humour and is a very sociable person. She enjoys going out and about, be it to the cinema, shopping trips, ten-pin bowling or for something to eat. When on form, she sparkles. She is an avid Dunfermline supporter attending all their home games with Richard, her foster father. One of the highlights of the year is Lizzy's summer holiday which she really enjoys. She is absolutely passionate about desserts, especially anything chocolate flavoured. Lizzy enjoys being in company but also enjoys her own space. She knows her own mind.

Lizzy lives in a long-term residential house located in the local community. The house offers residential care to five young people with complex physical and intellectual disabilities. The house is spacious and was designed for the young people who are currently living there. All of these young people have been living in the unit for between four and thirteen years. Lizzy has her own bedroom with en-suite toilet and bathing facilities. Her bedroom reflects her personality and is adorned with Dunfermline football team posters and flags as well as photos of her family and lots of soft toys.

Lizzy spends most of her life in a wheelchair and her only form of communication is by eye pointing. When you get to know her, she can use this quite effectively.

She requires total assistance to eat and drink, as she has problems with food and its consistency and everything has to be liquidised. Indeed Lizzy requires total assistance to stay alive.

A story of attachment, loss, inclusion and recovery

Lizzy was born by caesarean section in 1987 and had a very traumatic birth. By six months old she had been diagnosed as having cerebral palsy with dyskinesia which affects muscle tone and limits the use of trunk and limbs. It became apparent to her parents that her development across the board was delayed. By the time Lizzy was a year old, her mum was becoming depressed about her lack of progress and beginning to wonder about their future as a family. The pain experienced by the family at this time is palpable in the following extracts taken from a diary kept by Lizzy's mum (with her permission).

Her mum writes:

In late 1988 Lizzy started to attend the Early Education Unit at Westerlea. I was full of hope that they would help her to develop physically. It never occurred to me that she would have any learning disabilities.

In 1989 Lizzy and I had our first trip to the Peto Institute in Budapest and we had been told that with a lot of work we might teach Lizzy to walk and that she would almost certainly talk. By the time Lizzy was eighteen months I started to carry out gruelling exercise programmes twice daily with Lizzy. Both Lizzy and I found this very distressing. I worked hard to make this work for Lizzy.

In May 1990 Lizzy's brother was born. We went to the Spastic Society in Edinburgh with Lizzy and were told she would never talk and that we should try alternative communication. They also said children like Lizzy always end up in an institution in their adult lives due to the demands they put on their carers.

With much heartache and soul-searching, the family decided to proceed with fostering for Lizzy in the summer of 1991. Whilst they made this decision, they have continued to be an important part of Lizzy's life and involved in any major decisions regarding her future and other aspects of her life.

When Lizzy was four and a half years old, she was placed in short-term foster care where she lived for the following year before being placed with Linda, Richard and their two sons in a long-term placement. She appeared settled and happy for the next three and a half years keeping some contact with her birth family.

When Lizzy was nine years-old, Linda developed cancer. At this point, Lizzy began to receive shared care from the unit in which she currently resides, to support Richard and Linda during Linda's illness. When Linda died, Lizzy moved into the unit on a permanent basis. During this very sad time Richard remained and still remains a constant feature in Lizzy's life.

When she first moved in with us, she screamed constantly and there was no eye contact. She was a sad and distressed little girl. After Lizzy's initial settling-in period, however, she appeared to enjoy all the experiences and opportunities that had opened up to her. When Lizzy was 15 years-old, however, staff noticed deterioration in Lizzy's general well-being. She lost her sparkle, she lost her laughter, and she did not want to connect with anyone anymore. Lizzy started self-harming, biting and gouging her hands and arms. She would also bite staff, and she was in a constant state of agitation. She was not eating or sleeping well. As time went on, staff had to protect her by putting cotton gloves on her hands, as this helped prevent her from biting and gouging her hands. She also had to wear special walking socks to prevent her feet blistering from her constant agitation and movement. Although Lizzy had always bitten her upper arms, this increased and staff had to introduce elastic upper arm supports as she had been prescribed antibiotics for the severe bites she had given herself on several occasions.

Staff became more seriously concerned about Lizzy's physical and mental health as time went on. They were convinced that Lizzy's behaviour was not connected to her complex physical needs. Advice was sought from a number of health professionals with very little success. Looking back now and stepping into Lizzy's shoes, she had faced many major challenges in her life from a difficult birth to separation from her birth family to the loss of her foster mother. Her world must have been turned upside down – how could she understand what had happened and why she was taken away from people she loved and who loved her. Where did Linda go? Why did she not live with Richard any more? Why was she living with all these people she did not really know? Only one stable part of her life, the school, remained the same.

When the staff team discussed Lizzy's life, the amount of loss, trauma and change she had experienced became apparent to them. She would have poor understanding of what had happened, no meaningful explanation, and little opportunity to grieve. Staff realised that she must have felt abandoned and frightened. Staff wanted to help Lizzy to understand what had happened, to reassure her that she was not to blame and to help her to rebuild her trust in people and relationships. Were theoretical understandings of attachment and loss a key to understanding Lizzy's present self-destructive behaviours?

When looking for therapeutic approaches to help Lizzy, the service manager discovered an intervention called Dyadic Developmental Psychotherapy. This therapy, developed by Hughes (2006), an American clinical psychologist, is based on attachment theory. He evolved this approach specifically to assist children who have experienced trauma and loss to start on the road to recovery. Research on attachment theory for children with complex difficulties is sparse. What little there is suggests that 'professional carers need to take on board

that facilitating secure attachment relationships for distressed clients may be difficult for professionals, but partial assuagement of their attachment needs is a realistic clinical goal' (Clegg and Lansdall, 1995, p. 296). It was decided to contact a therapist or psychologist who could offer this Dyadic Developmental approach to see if a way could be found to create an intervention which would halt Lizzy's downward spiral.

The therapist suggested that a training day for the team was organised to ensure all the staff received a basic understanding of attachment theory and its importance with respect to child and human development. This was an excellent day. The staff spent some of the time reflecting on Lizzy's past and ways of supporting her to move forward. Out of this training day came a therapeutic plan for Lizzy's emotional recovery.

Theoretical perspectives

Inclusion and attachment theory (Bowlby, 1979) tells us that warm, close, trusting relationships that grow with us, making choices, developing skills and abilities, and having a respected and valued role are important for our well-being. Everyone needs to be included, everyone needs relationships, everyone can communicate, everyone can learn, everyone has their own gifts and strengths and everyone needs support – some more than others.

Attachment theory informs us that our experiences of care from our parents in our early years shape our view of relationships, potentially for the rest of our lives. Secure relationships are built on the foundations of secure parenting. Our resilience to meet life's challenges develops as we build positive relationships and have success in our skills and talents (Daniel, Wassell and Gilligan, 1999).

As Dan Hughes (2006) states:

In healthy families, a baby forms a secure attachment with her parents as naturally as she breathes, eats, smiles and cries. This occurs easily because of her parents' attuned interactions with her. Her parents notice her physiological affective states and they respond to her sensitively and fully. Beyond simply meeting her unique needs, however, her parents 'dance' with her. Hundreds of times a day, day after day, they dance with her. There are other families where the baby neither dances nor even hears the sound of any music (Hughes, 2006, p. ix).

This 'dance of attunement' that forms secure attachment can be disrupted by different factors – parental, environmental or child. For example, parents who have mental health problems or difficulties in their own attachment histories may not be able to attune to the needs of their infants. Poor housing,

unemployment and other forms of social exclusion can all make attunement more challenging for a parent. Some children, for example premature babies, babies with chronic illness, children with autism or learning disabilities or sensory impairments, may struggle to signal their needs and this can make it difficult for parents to attune.

Loss, change (particularly enforced change) and trauma affect us all and are often accompanied by strong feelings such as despair, depression, anger, anxiety, shame, loneliness, hopelessness and helplessness (Herman, 1992; Mallon, 1998; Wayment and Vierthaler, 2002). There is evidence that such issues are exaggerated in children who are looked after (Meltzer et al., 2003). How feelings are expressed in behaviours will depend on the individual's personality, resilience, past experience of relationships and support network. Extreme behaviours such as self-harming, hitting out and even suicide attempts are not unusual responses to such overwhelming feelings, particularly when the person cannot make sense of what has happened and there is no-one to share their emotional pain. Children in particular often blame themselves for the loss of, or separation from, parents and carers. They need much reassurance that it was not their fault. Such evidence was used to inform the therapeutic plan for Lizzy.

Developing a therapeutic plan

The therapist met Lizzy, her foster father and her staff team and talked about her personality, her likes and dislikes, her strengths and talents, her successes, her struggles and her life story. Work was done to help the staff to understand that much of Lizzy's distressed and challenging behaviour (self-harming, biting staff, and not eating or sleeping well) was an ordinary human reaction to separation and loss. Lizzy's self-harming could be construed as deliberate as she seemed numb to hurting herself, with no discernable pain reaction, whereas if she was hurt accidentally she reacted to the pain. Lizzy seemed to be experiencing powerful feelings with poor understanding of events and limited opportunity and means to share her feelings. Overall, it was no surprise she had lost her 'sparkle'. The therapist facilitated a training day on attachment and loss for the whole staff team and then worked with all concerned to formulate a therapeutic plan aimed toward Lizzy's emotional recovery. The needs identified by the staff and her foster father were as follows:

- To be and feel safe;
- To feel special – loved and cherished;
- To be accepted;
- To belong and to feel included;
- To have fun;

- To be heard and to communicate;
- To have success.

These needs had to be met within the context of a secure attachment relationship. All but one of Lizzy's actual and potential close relationships were with paid professionals. This situation (although often the norm for children and adults with complex support needs) did not assist her to have an ordinary life and be included in society. The one consistent, close relationship in her life was with her foster father. To meet Lizzy's needs the following elements were included in the therapeutic plan:

- Work on maintaining eye contact with Lizzy, allowing her access to a communication channel which is intense yet non-verbal;
- Maximising touch;
- Empathising with Lizzy;
- Getting warm and cosy;
- Sharing experiences;
- Just having fun.

The plan unfolded gradually, initially starting in February 2007. This was made into a reality using the following strategies:

- Enlisting the permission and support of Lizzy's birth family to undertake this work;
- Her foster father continuing his weekly visits to spend time with Lizzy, extending this from going to see Dunfermline play football to spending time with her in the residential unit;
- Four members of the staff team becoming Lizzy's anchors committing to spending individual time with her every day helping her to feel special and doing things that she used to enjoy. This included reading to her, holding hands, watching TV, cuddling her, telling her about their day and encouraging her to tell them the stories of her day (Lizzy cannot speak but she can most definitely communicate not only with eye pointing but with sounds that clearly indicate her mood from grouching to giggling!) A vital part of the work was to engage Lizzy in eye contact, responding to Lizzy's reactions and allowing her to lead the conversation. The team thought a good time and place would be in Lizzy's bedroom between her return home from day-care and tea-time. Lizzy had the choice not to participate. She has only decided not to participate on a few occasions;
- The service manager put together a photographic Life Story Book for Lizzy

starting from when she was a baby, explaining the events in her life including the separation from her family and the death of Linda, her foster mother. It also celebrated her past and present successes. One member of the team would read this with Lizzy, acknowledging the privacy of such a story;

- Using relaxing pleasurable sensory experiences to give Lizzy an opportunity to enjoy and trust touch. These included Reiki, hand massage, foot massage, and nail painting. The staff started to remove Lizzy's gloves a few minutes at a time, to give her back as much freedom as possible;
- Creating opportunities to have fun and laugh with Lizzy;
- Staff acknowledged and stayed (safely) with Lizzy's anger and emotional pain. They assisted her to open up her strong feelings by showing empathy ('This is hard for you', 'you look upset', 'I am here to help you stay safe', 'I want to stay with you just now') rather than deny these feelings or try to joke or talk her out of it ('don't be angry', 'no need to be upset', 'let's cheer you up' 'you'll be OK')
- The staff talked to Lizzy appropriately about her feelings and how staff were feeling, taking care to show emotions in their faces as well as with words;
- After reading Dan Hughes' book, the service manager realised that Lizzy's problems with sleeping could be as simple as not feeling secure in her bed. This was rectified by buying a larger duvet and tucking it tightly round Lizzy and under the mattress. Lizzy now sleeps soundly;
- Good communication and recording in the team to be clear what is working and what is difficult and/or challenging;
- Continued consultation between the team and the therapist concerning understanding Lizzy's feelings and behaviour, the pace of unfolding the plan, monitoring success and tackling challenges.

As a result of the implementation of the therapeutic plan, the change in Lizzy has been amazing and all this has been achieved without having to increase her medication. Lizzy has her 'sparkle' back and she is much more communicative and vocal, smiling and laughing. Her eye contact is much better and she is now interested in what is happening around her. People who know her have commented on how happy, healthy and well she is looking. Lizzy's anchors have mentioned they have noticed how responsive she is, especially during her special time with them. The agitation has lessened and she has only bitten herself once in the last six months. Staff are still working on preventing Lizzy from hurting herself. The permanent removal of her gloves is a long way off but continues to be pursued at every opportunity. Lizzy loves skin-on-skin contact and is now able to enjoy the experience of both massage and Reiki massage. It is lovely to see her lying still, calm and totally relaxed.

Conclusion

A therapeutic approach based on attachment theory has been beneficial in Lizzy's case. Staff are able to see through the label of 'complex needs'. They understand that there was an isolated, frightened young person who was having extreme difficulties in dealing with feelings of separation and loss. This empowered staff to work in a pro-active way with Lizzy and to help her on her road to having an ordinary life.

Every child, every human being, is quite unique. We are all a mix of genetics, early years' experiences of being looked after by our parents or carers and events in our life. Every child needs to feel special. It is clear that the quality of the affectionate bonds a child has in their early years affects how they feel about themselves, how they feel about and relate to other people, and their world view. Secure attachments build resilience to deal with life's challenges and the child grows up knowing that if something happens with which they cannot cope, there will always be someone there to help sort it out. As practitioners, we should not forget the truth of this for our children and young people with severe and complex needs.

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Practitioner review

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This well-constructed paper describes a situation which is fairly common in the care of young people with disabilities; namely that even in a caring environment, there can be a tendency for these young people to be viewed as a homogeneous group with shared characteristics, rather than as individuals in their own right. As was the case with Lizzy, this can result in important issues being overlooked.

An interesting feature of the paper, and one which I imagine most residential workers would recognise as common, was the initial description of Lizzy. It was imbued with warmth and affection, but I was a little worried that she came across as a somewhat two-dimensional character. I could not help but wonder, for example, how she really felt about Dunfermline football team. Was she an avid supporter or had this myth been perpetuated to the point where it came to define her, regardless of other aspects of her identity? My worries were soon put to rest as I read through the rest of the paper.

For me, a real momentum and turning point in the paper was the description of the realisation by the staff of Lizzy's pain, and their subsequent change of approach. Lizzy became a unique complex being, and understanding her was going to take time and effort. This sends an important message to residential workers. We are better placed to observe, pick up and tune in than many other professionals because of the significant relationships we develop, through spending so much time in the intense milieu of the lifespace. This practice wisdom would not be so easily acquired in another setting, and this paper encourages us to use this professional expertise, as advocates for the vulnerable people in our care.

It was sobering to realise that Lizzy's salvation depended on the intense concern and initiative of a particular service manager, and her motivated caring staff group. Fortunately for Lizzy this was available, but there will be many young people for whom this will not be the case. In my workplace, understanding attachment and loss is of central importance, and Dan Hughes' work is particularly significant in informing and supporting this understanding. What this paper demonstrates is that theory only becomes truly potent and effective when we make the effort to internalise it, and then use it creatively in the best interests of the young people in our care.