

'Counselling in complexity': The use of social constructionist ideas within a community-based approach to working with families affected by disability

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This paper describes the development of a service delivery model for families within a disability context. The design approach makes use of action research methodology (Carson & Sumara, 1997) and is a collaborative exercise and a work in progress.

Since the Clinical Psychology Service at Serennu Children's Centre in Newport, South Wales opened its doors 18 months ago, over 100 parents and 14 siblings have been seen on an individual basis or in a group setting. The service forms part of a Big Lottery Project and the four broad aims of the project, as set out in the Sparkle Appeal: People and Places project are:

- (i) Utilising an holistic approach by taking care of the whole family's mental health needs.
- (ii) Considering the family unit – providing more leisure opportunities for the whole family unit.
- (iii) Providing young people and their parents with better access to information, professionals and the voluntary sector organisations.
- (iv) Engaging children with disabilities and their siblings in a wide range of appropriate play activities.

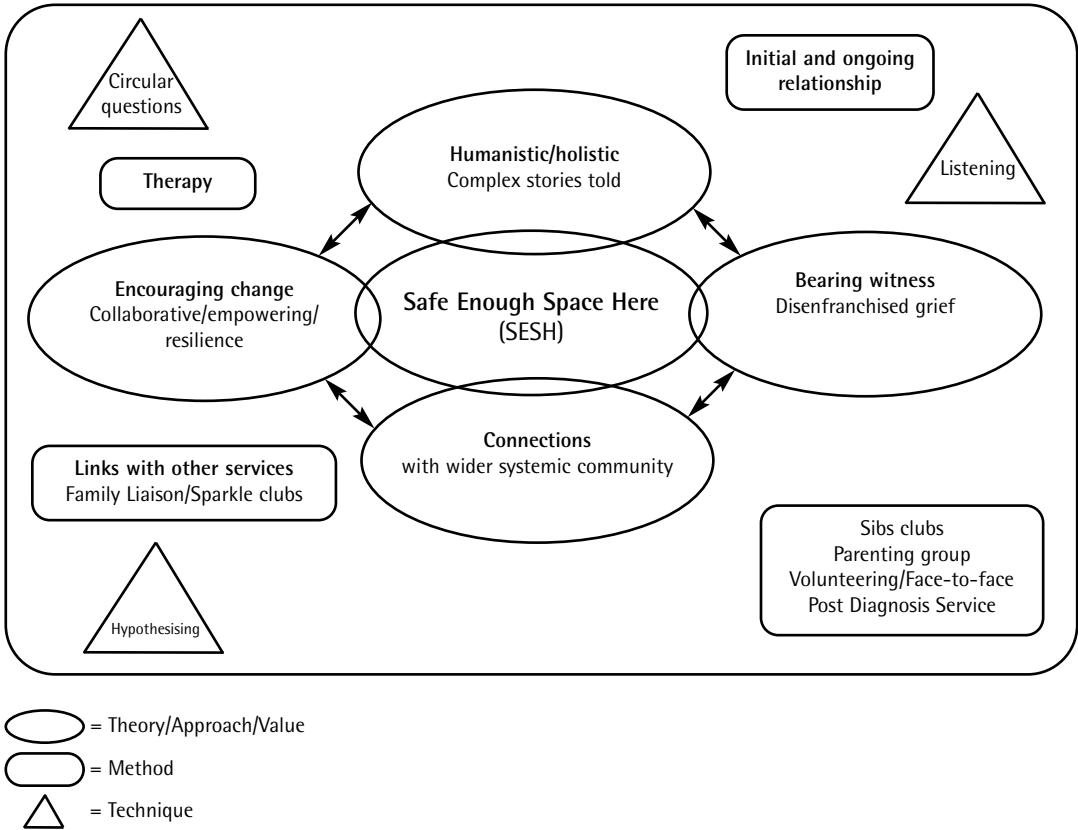
The model that is being developed is very much based on the needs of the client group receiving the care and can be described as a model of 'prudent healthcare' (Bradley & Willson, 2014). It has been shared and reflected upon with my colleagues in my systemic consultation group, my supervisor and my manager. Feedback was received and it has been further developed. These cycles of reflection form part of reflexive feedback loops and at the time of writing the next steps

are to share it with the various staff groups at Serennu Children's Centre by presenting this paper and inviting feedback, to facilitate the ongoing development of the model.

How my helping hands were constrained

Through a process of consultation with a focus group of parents using the Serennu centre, the service aims were to increase the well-being of families whose emotional needs were not being met within the current NHS system. Part of the premise that also set the service apart from statutory services, and contributed to it meeting the criteria for lottery funding, was that parents could self refer to a clinical psychologist for consultation/counselling, as and when they felt that they needed it. However, this idea is suggestive of empowered parents able to articulate their needs and to know that what they needed to cope better is psychological support. Society and cultural rules do not make it easy for parents of children with disabilities to feel that way because cultural beliefs tend to be: 'It is selfish to put your own needs as a parent first', 'There are answers and solutions to all problems you just need to find them', 'Crying and struggling to cope make you weak and you need to just man up' (Weingarten, 1994). In Lalvani's (2011) study, mothers of children with disability recount being recipients of admiration: people calling them brave, blessed, courageous or chosen-by-god to have a 'spe-

Figure 1: Different levels of approach, method and technique



cial baby’. The mothers felt that although the comments were probably well intentioned, they nevertheless convey negative messages about their children not being ‘normal’ and of themselves needing to be ‘heroic’. The very meaning of motherhood is being shaped by the technologies of prenatal testing and an increasing cultural expectation of birthing a ‘perfect child’. It is therefore really not easy to admit you might need help and certainly not from a psychologist, who in many parents’ eyes is indistinguishable from a psychiatrist, and parents are fearful of being seen as pathological themselves. The parents do not have any experience of what a clinical psychologist might do, aren’t aware of their own thinking and feeling processes or emotional needs, and often hide behind their own coping mechanisms, which may or may not be functional or helpful. My experience to date is

that very few parents have truly self-referred for help.

How I developed more helpful hands to reach out to parents

To address these difficulties and to offer something different to a clinic-based model, I sought to develop various arms of the service to embrace an approach that puts connection, resilience, normalising and psychoeducation at the forefront. I wanted to pay particular attention to the referral process, which might help the family enter into contact with the service with more open minds. The six arms of the service are:

1. post diagnosis clinic;
2. siblings club and groups;
3. parents support group;
4. individual/family sessions;
5. consultation and liaison; and
6. staff training.

The model I have been developing employs the very helpful distinctions made by Burnham (1992), by distinguishing between levels of approach, method and technique, and is shown in Figure 1.

The practice culture I have been trying to create encompasses four different theories and epistemological approaches. At any time one or more of these will be given a privileged position in leading the methods and techniques I use.

1. Humanistic/holistic approach to hearing complex stories

Using Pearce and Cronen's (1980) co-ordinated management of meaning model, which suggests that human communication is a complex interactive process in which meanings are generated, maintained and changed, and coming from the stance that people's lives are too complex to try to fully understand, I allow space for family to tell their stories. I experience them emphatically, so the families feel supported. Normalising is an important part of my work. Ideas about family functioning tend to be developed on the basis of people whose lives are not dominated by illness, but what are the norms to help people make sense of what is exceptional circumstances? I draw on the family systems-illness model (Rolland, 1994) that has many useful ideas about adjustment when living with a child with a disability/chronic illness.

Many parents try to deny or avoid their negative reactions to their child's condition. They may feel pressure to 'get over it' and a lack of empathy from others. Efforts to avoid, minimise or hurry negative feelings interferes with the adaptation process (Barnett, Clements, Kaplan-Estrin & Fialka, 2003). Adaptation is a lifelong process, and accompanied by building new dreams for their child. When people experience the unbearable anguish of a loss, they do often emerge transformed, reviewing life, themselves and their relationships. Devastating experiences can therefore help people reshuffle their lives and imbue them with new meaning (Papadopoulos, 2007):

I was heard, supported and was able to share things I wasn't able to say before. I believe in myself more now.'

'I was able to think, discuss and reflect on issues without feeling I shouldn't be upset. Emma has a sensitive and sympathetic style. She was patient, understanding; listened and advised without being patronising. I am very grateful for Emma's support, help and guidance during a very difficult time.'

*The unbearable
anguish
of loss...*

Family life cycle is also a useful non-pathologising model (Carter & McGoldrick, 2006). It recognises that a family is a developing dynamic unit and that children and families change over time. Their needs and resources change and service provision must provide both a continuity and a flexible adaptation process to help families through changing periods. At each new developmental phase the parent is likely to experience new emotions related to their child's condition. This can be very stressful, as parents think they have mastered their own thoughts and feelings only to have them reawakened over and over. For example, a parent may understand that a child has serious motor impairments and will not walk but it may be years before they actually experience the emotions. They may not fully realise their grief until they see their child not walking when their peers are or not running when others are.

2. Bearing witness to

When a child dies the loss is openly acknowledged, publically mourned and socially supported. However, having a child with a disability is often experienced as the loss of an anticipated child, which tends to spark a disenfranchised grief, which it is not socially acceptable to mourn. Roos (2002) talks about this in terms of chronic sorrow, which is a set of pervasive, profound, continuing and reoccurring grief responses resulting from a significant loss, or the absence of crucial aspects of self or another to whom there is a deep attachment. I aim to acknowledge, recognise and witness the pain, not eliminate it – which validates the

Vignette

In the post diagnosis clinic, the husband of a couple who had just received a diagnosis for their baby was struggling to come to terms with some lost dreams he had for his child. He was convinced that the diagnosis meant she would never be sporty and he was spending his time feeling very sad inside and watching YouTube videos of children with the same diagnosis with severe behavioural problems. Curious about this, I wanted to understand what he usually did when he got bad news or something upset him. The couple were able to say that he would always look at the worst case scenario and then he would talk it through with his wife, who would be very understanding but also help him see the reality of the situation. Using circular questioning techniques to focus on the relationship between them, I enquired further about what was different in this case, and together we were able to work out that it was usually work situations that upset her husband (which did not connect for her emotionally in any way), but in this case the wife could not be empathetic towards her husband as she was so emotionally connected to her daughter and thought he was being too negative towards the daughter. So their usual pattern of mutual support and care had been broken, and the husband was very much left struggling with feelings and emotions he did not know how to contain. By seeing the process in this way the couple were able to normalise and contextualise their struggle, and the husband teased us that he felt he was undergoing therapy because he needed more help than his daughter! The turnaround and change in the atmosphere in the room could be felt by all; the husband verbalised this by telling us that he felt like a gust of fresh air had been blown over him. His view of himself, his daughter and his relationship with his wife had changed. The couple were then more able to keep open their channels of communication with each other.

experience and begins the healing process (Graziano, 1997). I see pain as the potential to be understood as having a function that can lead to change. For example, grieving the loss of an imagined child does not mean parents do not love their actual child but helps them learn to live with ambivalent feelings. If this does not happen, discrimination and stigma will erode resilience and narrow the possibilities for coping and adaption.

Boukydis (1994) found that parents of children with disabilities feel that other parents with similar circumstances would be best able to provide them with emotional support. This has been paramount in the development of the face-to-face service. In addition, the parent group I facilitate has a psychoeducational element as well as time for open discussion, and uses this idea in the frame of definitional ceremonies and outsider-witnesses, and allows parents to discuss dilemmas with people who have an insider experience of the challenges they face (Broome & Stuart, 2006). In groups, members can help to validate the feelings and emotions of other members, establishing the validity of grief. Group members can also share information with one another. By sharing their experiences parents become more aware of their thoughts and feelings and realise that not all their thoughts are realistic or accurate, and/or that more of their ideas are useful than they originally thought.

3. Connection

I believe that engagement is key to developing a relationship with someone, so I work really hard to develop a relationship initially and join with the families rather than helping them to solve the mystery/fix the problem (Minuchin, 1978). I am not looking for the 'truth' of people's difficulties and I do not always need to devise solutions/problem solve/teach/or advise. I need to attend to the discussion and acknowledge people's experiences, dilemmas they face, struggles they have, and the efforts to change they are making:

'I liked the way I was related to. I have gained so much knowledge from the sessions. Thank you.'

'I felt comfortable and at ease.'

My work is non-compartmentalised as people and families do not exist in isolation. I'm always thinking: 'How does my work with this family link with others? Does it need to? And if so with who?'

Most of the families I see are connected with various agents of change: paediatrician, speech therapists, physiotherapists, social workers and the various people in education – and each of these has a theory of change to implement.

In addition, therapists now define resilience as a complex relational process that must include community (Boss, 2006). A sense of community helps families heal. Reiss and Oliveiri (1980) highlight that the community context is a major influence on how families respond to stress. Parents need to connect to someone familiar in their community, as such relationships are more likely to be ongoing. The relationship with a therapist can only offer a temporary connection. Serennu is an ideal environment in which to foster and grow a supportive community. This is an important part of the Serennu service and recognises that there may be other resources which are useful; for example, after school activities, siblings clubs, youth clubs, stay and play club, face-to-face/peer support model and parent groups. Siblings have fed back that they use to see Serennu as somewhere where just their brother went but since coming to the sibling club they now see it as somewhere where the whole family belongs. Ultimately, the communal sharing of narratives helps people to find meaning by developing flexibility and resilience as others encourage new ideas and change. White and Epston (1990) called it re-authoring lives.

'The Serennu Centre has been a lifeline for me over the past 18 months. Without the "Sparkle clubs", the Sparkle Family Liaison Service and Emma's Helping Hands Service I think I may have given into the depression and despair instead of picking myself up and fighting for my son and my family.'

4. Encouraging change

I am developing and exploring with families ideas about change almost as soon as we meet by being curious about what has brought them to me, what their expectations are, and what sort of help they are looking for. I typically engage in a mutual exploration of the families' understanding and experience, and maintain a collaborative position towards the process of change in therapy. New concepts and meanings emerge from the conversations I have, and are co-created (Anderson & Goolishian, 1988). I do not produce change during therapy itself;

rather, I ask questions that open up spaces for new conversations and not yet said stories, with change in the story and the self-narrative being a consequence of the conversation. In the absence of facts, the multiple perceptions of family and community members are essential for the social construction of meaning. However, I do recognise that some families do want practical help

from me, and in these circumstances it is no good adhering to a non-directive approach. Instead, I try to explore advice giving with families, and frame suggestions as ideas to explore/experiment with rather than fixed solutions.

'I was understood. Overall objectives were looked at and discussed at all our meetings. A very good service.'

'I was understood and taken seriously and given clear advice that helped my family life.'

More recently, some of my work has developed into using the acceptance and commitment (Harris, 2009) model of therapy in parental workshops. This approach is effective in helping parents develop meaning and cope more effectively with the day-to-day stresses that having a child with disabilities incurs. Change comes from learning to be more mindful and living in the present moment rather than getting hooked into their own thoughts and feelings.

*The relationship
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'Now I am better able to cope with daily life stress and able to communicate the difficulties with others in my family. I was listened to and guided to develop coping mechanisms to help me accept things as they are.'

Conclusion

Using an action research approach has allowed the various strands of the model to develop as required. I find myself spending most time in the connection and bearing witness circles, and I wonder whether they are perhaps the areas which families do not usually experience within professional circles, due in part to other constraining factors for professionals, and worries and concerns about how to 'be' with families. In summary, I think social, emotional, cognitive and behavioural processes are all needed to promote positive

adaptation. Social support comes from parent groups, peer support and the parental relationship. Emotional support comes from being able to express negative emotions and finding ways to cope with these feelings. Cognitive and behavioural approaches enhance knowledge about child development and coping mechanisms. Each of these ingredients makes a unique contribution towards healthy adaptation. However, central to developing satisfying attachments in families living with disability and building realistic dreams is having the stories of resilience heard, witnessed, validated and thickened.

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References

- Anderson, H. & Goolishian, H.A. (1988). Human systems as linguistic systems: Preliminary and evolving concepts about the implications for clinical theory. *Family Process*, 27(4), 371–392.
- Barnett, D., Clements, M., Kaplan-Estrin, M. & Fialka, J. (2003). Building new dreams: Supporting parents' adaptation to their child with special needs. *Infants and Young Children*, 16(3), 184–200.
- Boss, P. (2006). *Loss, Trauma and Resilience: Therapeutic work with ambiguous loss*. London: W.W. Norton & Co.
- Boukydis C.F. (1994). Cited in Barnett, D., Clements, M., Kaplan-Estrin, M. & Fialka, J. (2003). Building new dreams: Supporting parents' adaptation to their child with special needs. *Infants and Young Children*, 16(3), 184–200.
- Bradley, P. & Willson, A. (2014). Achieving Prudent Healthcare in NHS Wales. *Cardiff: 1000 Lives Plus*.
- Broome, M.E. & Stuart, P. (2006). Interventions with families of an acutely or chronically ill child. In D.R. Crane & E.S. Marshall (Eds.) *Handbook of Families and Health: Interdisciplinary perspectives*. London: Sage.
- Burnham, J. (1992). Approach, method, technique: making distinctions and creating connections. *Human Systems: Journal of Systemic Consultation and Management*, 3, 3–26.
- Carson, T.R. & Sumara, D.J. (1997). *Action Research as a Living Practice*. New York: Peter Lang.
- Carter, B. & McGoldrick, M. (2006). *The Expanded Family Life Cycle: Individual, family and social perspectives*. Boston, MA: Allyn & Bacon.
- Graziano R. (1997). The challenge of clinical work with survivors of trauma. In J.R. Brandell (Ed.) *Theory and Practice in Clinical Social Work*. New York: Free Press.
- Harris, R. (2009). *ACT Made Simple: An easy-to-read primer on acceptance and commitment therapy*. Oakland, CA: New Harbinger Publications.
- Lalvani, P. (2011). Constructing the (m)other: Dominant and contested narratives on mothering a child with Down syndrome. *Narrative Inquiry*, 21(2), 276–293.
- Minuchin, S. (1974). *Families and Family Therapy*. Cambridge, MA: Harvard University Press.
- Pearce, W.B. & Cronen, V.E. (1980). *Communication, Action and Meaning: The creation of social realities*. New York: Praeger.
- Papadopoulous, R. (2007). Refugees, trauma and adversity-activated development. *European Journal of Psychotherapy and Counselling*, 9(3), 301–312.
- Reiss, D. & Oliveira, M.E. (1980). Family paradigm and family coping: A proposal for linking the family's intrinsic adaptation capacities to its responses to stress. *Family Relations*, 29, 431–444.
- Rolland, J. (1994). *Families, Illness and Disability: An integrative treatment model* (1st edn.) New York: John Basic Books.
- Roos, S. (2002). *Chronic Sorrow: A living loss*. Oxford: Psychology Press.
- Weingarten, K. (1994). *The Mother's Voice: Strengthening intimacy in families*. New York: Harcourt Brace.
- White, M. & Epston, D. (1990). *Narrative Means to Therapeutic Ends*. New York: W.W. Norton.