Chapter 12

Challenging Behaviour And Change In Intellectual Disabilities: Family Therapy, Families, And The Wider System

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Clinical intervention for challenging behaviour in intellectual disability has come a long way since institutionalisation and a reliance on psychopharmacology and restrictive behavioural practices. Positive programming provides an ethical and contextual approach to community integration, forming a critical set of skills for any clinician working with this population. One of the limitations of this approach, however, is that systemic constraints to intervention are not sufficiently explained. They are often relegated to mediation analysis without a sophisticated account of how to negotiate complex interactional and relational obstacles to effective behavioural work. This chapter aims to provide a detailed a account of family therapy's approach to developmental disability, with the aim of identifying a variety of potential directions for intervention when behavioural approaches fail to be effective.

Positive Behaviour Support: An Introduction

For the past twenty years applied behaviour analysis, or positive programming (LaVigna, Willis & Donnellan, 1989; Horner & Carr, 1997) has played a critical role in the process of deinstitutionalisation of people with intellectual disabilities. Positive programming provides a means for understanding challenging behaviour, as a form of communication, and a signal of limited life opportunities. It provides the clinical tools to examine behaviour in these terms and provide appropriate interventions, rather than relying solely on restrictive practices and psychopharmacological intervention. From this perspective, problematic behaviours are seen as functional. That is, behaviours can be a means by which an individual has his/her specific needs met (when there are no communicative alternatives) or an indication of when there is a poor match between an individual and his/her current environment.

In practical terms the outcomes of an effective behavioural intervention are varied and may include,

- Development of opportunities and routines that match the age-appropriate needs and capacities of an individual;
- Design of augmentative communication systems to allow the individual to better understand his/her environment and exercise come control;
- Introduction of coping strategies and carefully designed reactive strategies to improve the safety of care-givers; and
- Acquisition of a wider range of adaptive skills for daily life.

The Limitations Of Positive Programming

One of the limitations of this approach is that it offers no comprehensive answer to the problems that are caused by complex relationship problems in the family and wider service system (Rhodes, 2003). While the Behaviour Assessment Guide (Willis, LaVigna & Donellan, 1993) offers a sophisticated tool for the conceptualisation of challenging behaviour, it fails to adequately conceptualise problems requiring mediation. Parents, caregivers, and service providers are seen as the implementers of behavioural and ecological programs, despite the potential for a range of significant personal, professional, and relational issues to interfere with their capacity to carry out this role. Issues of grief, insecure attachment, marital conflict, chronic stress or neglect may not be adequately considered when working in the family context. In addition, issues of post-traumatic stress, burn-out, team dysfunction, and poor management may not be adequately considered when working in the service context.

The conceptualisation of challenging behaviour will be further discussed from a variety of lenses that are primarily from the field of family therapy. These lenses can provide a theoretical backdrop to allow for a more sophisticated understanding of mediation analysis in developmental disabilities.

Challenging Behaviour From A Systemic Perspective

Systemic family therapy, also known as 'Milan Systemic Family Therapy', was pioneered by Selvini-Palazzoli, Boscolo, Cecchin, and Prata (1978) in response to the predominance of individual psychoanalytic therapy for children. They postulated that problems experienced by children could be understood as intra-personal, rather than intra-psychic problems. They considered the child's behaviour as one step in a family's dance of interactions, rather than the problem itself. In particular, they emphasised the concept of homeostasis, that is, the idea that families become stuck in rigid patterns of interaction in response to stressful life events and life-cycle transitions. These patterns are predictable, escalate over time, and help to mediate against the conflict, stress or intimacy that might arise during the process of adaptive change.

One of the most eloquent applications of the principle of homeostasis in developmental disability is presented by Birch (1986). He proposed the concept of 'timelessness' as an alternative to homeostasis. He suggested that members of the family unit can become lost travellers in the family life-cycle, becoming enchanted by certain beliefs that restrain change for prolonged periods of time, even as the person with intellectual disability approaches adulthood. Beliefs such as 'a mother is the only person who can care for a child with developmental disability' can have a significant and traumatic effect on the independence of the whole family, not just the person with

the disability. This is similar to Todd and Shearn's (1996) notion of 'perpetual' or 'captive' parents who can lose touch with what was once a 'normal' life.

Goldberg, Magrill, Hale, Damaskinidou, and Tham (1995) provided an additional lens to understand the potential of an extended duration of homeostasis in developmental disability. They described how interactions, in some cases, could be governed by complex grief reactions concerning the loss of the perfect child, the loss of one's own independence, and the interconnectedness of these losses with those from the parental family of origin. Family therapy becomes highly emotive in these cases, aiming to facilitate a grieving process that allows for a more normative family life-cycle to proceed.

These concepts provide some clear hypotheses that can be useful when considering possible constraints to effective behavioural intervention. From a behavioural perspective, parents are considered to be potential mediators of behavioural change, employing alternative communication techniques, redesigning routines, and teaching new skills, all of which may enhance the self-determination of the person with an intellectual disability. However, an exclusive reliance on a behavioural approach will not apply to families who are stuck in rigid patterns of interactions with one another. In this situation a great deal of systemic intervention will need to be employed first.

Another way to articulate this point is to raise the distinction between a communicative and homeostatic function of challenging behaviour (Rhodes, 2003). Positive programming postulates a communicative function of challenging behaviour, arguing that an analysis of the meaning of a challenging behaviour leads to a clearer understanding of the communicative intent behind the behaviour (e.g., a request for escape from aversive stimuli, boredom in the face of poor productivity or seeking

personal interaction). Alternatively, systemic therapy postulates that a challenging behaviour serves a homeostatic function for the person with an intellectual disability. That is, the challenging behaviour serves as a symbol of the need for significant changes in the person's relationships, and the rules and affect that govern them.

In a clinical example, the meaning of a person's challenging behaviour can be hypothesised from two angles. From a positive programming point of view, a challenging behaviour might mean *'I'm bored, I want to do something that is interesting, makes me feel valued and helps me feel like my 20-year old peers'*. However from a systemic therapy interpretation, the behaviour may have a different meaning such as, *'If I became more independent my mother and father might separate because they have drifted apart so much over the past 20 years'*. In the first case, the assumption is that the person actually thinks or feels this particular statement but in the second, it is a symbolic meaning or a way for the clinician to reframe and understand the direction of treatment.

Challenging Behaviour From A Structural Perspective

Structural family therapy was developed by Minuchin (1974), and like systemic therapy, was a direct reaction to the predominance of individual therapy for children. While Selvini-Palazzoli et al. (1978) focussed on patterns of interaction, Minuchin was interested in hierarchy. In particular, he believed that a strong but flexible parenting team was critical to the health of the family, providing the boundaries and emotional security to facilitate emotional growth in children. Problems were seen to arise when parents entered into coalitions with their children, triangulating the child between them as a means of managing marital conflict or fears of intimacy. Harris (1982) is one of the

few clinicians to apply this model to intellectual disability. She postulated four types of structural deficits for behaviourists to consider when planning interventions. In one category, for example, a mother and child with a disability may be over-involved, with a father who appears distant and an older sibling. In another, a sibling might be parentified in support of the mother, while the father remains distant and uninvolved in family life. In both cases, Harris advised behaviourists to invite the father to serve as an expert consultant, valued for his objectivity, with the aim of supporting his wife to manage the behaviour, and in the second case, relieve the sibling of the parentified role.

Challenging Behaviour From Solution-Focussed And Narrative Perspectives

In the 1980s, de Shazer (1982) made a significant break from the systemic and structural models by proposing a solution-focussed approach to family therapy. In particular he was concerned that therapists were inadvertently pathologising clients, looking for dysfunction and deficits at the expense of solutions based on the amplification of pre-existing strengths. de Shazer believed that families needed support to recognise times when they had been successful in overcoming problems, both in the present and the past, experiences that could be garnered for the development of improved family life in the future. His model was revolutionary in that it rejected notions of aetiology, seeing the cause of a problem as less critical. This view was an even more significant break with the tradition of psychoanalysis. Coles (2001) further argued that this was a crucial position if clinicians were to avoid seeing families as disabled themselves. Stainton and Besser (1998) conducted a qualitative study that seemed to support this notion. They asked families the question, ‘What could the positive impact of intellectual disability be on your family?’, and found that parents

reported an increase in closeness, enhanced spirituality, and an increased involvement with the community. These findings suggested that one of the restrictions to effective behavioural intervention can sometimes be the clinician's own perspective of family functioning. Families have many strengths that need to be recognised and actively mobilised for successful outcomes.

Narrative therapy was developed by White and Epston (White, 1989; White & Epston, 1990). It has many conceptual similarities with solution-focussed therapy, particularly when it comes to the rejection of the functionality of presenting problems. It differs, however, in that it is heavily influenced by social contructionism. As such, narrative therapy pays particular attention to the effect that dominant and oppressive societal stories can have in the development of problems in families. Goddard, Lehr and Lapadat (2000) and Gray (2001) argued that professionals can be complicit in the promulgation of these stories, with the emphasis on maternal enmeshment or chronic grief serving more as a means of control than an accurate account of the family's lived experience. This can be particularly relevant when working with clients with intellectual disability who are violent to their parents and siblings. Fiddell (2000) raised the idea that there were parallels between the effects of this behaviour and domestic violence. Therapeutic practices that propose that family dysfunction is responsible for a client's challenging behaviour may have an abusive effect, amplifying parental guilt and self-blame and increasing the cycle of violence and disempowerment that can often prevail. Narrative therapy, like solution-focussed therapy, suggests that the position of the clinician needs to be evaluated when it comes to identifying impediments to the effective amelioration of challenging behaviour. From this perspective, clinicians need to be reflective about their own inadvertent participation in the subjugation of families,

developing wariness about how the expert role may serve to obscure subtle abuses of power.

Integration Of Behavioural And Family Therapy Approaches

The application of family therapy to understanding challenging behaviour in developmental disabilities demonstrates that the field has the potential to redress the balance between the comprehensive behavioural and ecological technologies available, and the limited consideration of mediation analysis. The aim of this chapter, of course, is not to argue for family therapy as an alternative to applied behaviour analysis, as no amount of systemic intervention could teach a client to communicate in a more adaptive manner or learn valued skills for independent living. Rather, the aim is to propose integration of approaches, where family therapy deals with constraints to change that improve the efficacy of the positive programming approach. A more comprehensive description of an integrative model for systemic and behavioural assessment, and intervention can be found in Rhodes (2003) who described four stages of intervention,

1. Behavioural assessment following the Behaviour Assessment Guide (Willis, LaVigna & Donellan, 1993);
2. Milan systemic family assessment and intervention with the aim of isolating the homeostatic function of the behaviour (Selvini-Palazzoli et al., 1978);
3. Amplification of small deviations in interactions using solution-focussed and narrative questions; facilitating morphogenesis, and further change from stuck patterns (Rhodes, 2008); and
4. Behavioural intervention, including the development of a multi-element treatment plan underpinned by the principles of positive behaviour support.

What About The Wider System?

One of the limitations of a pure family therapy approach to mediation analysis is its failure to consider the wider system. The sometimes overwhelming demands of caring for a child or adult with developmental disabilities mean that families are dependent on interactions and relationships with professional staff in schools, respite services, group homes, recreational facilities, case workers, and the wider governmental bureaucracies. Relationships within these services, and between them and the family can sometimes become fraught, adding to the complexity of the clinician's role when considering interpersonal restraints to effective behavioural intervention. Problems are likely to arise during family life-cycle stages, when changes in one setting are at odds with those in another (Baum, 2006) leading to conflicting needs, beliefs, and expectations.

Imber-Black (1987) provided a rich set of systemic hypotheses to explore when considering patterns in the interactions between families and professional organisations. She suggested, for example, that problematic interactions could escalate in both complementary and symmetrical ways. In the first case, a family's helplessness can be matched with the professional's tendency to offer more and more help, until a myriad of unmanageable and sometimes unnecessary services become involved. This cycle needs to be broken by taking a proper account of the natural resources within the family, encouraging the use of these resources, and employing them in a collaborative planning process with professionals to ensure specific outcomes are achieved. A solution-focussed perspective may be useful in these situations, as described earlier. In symmetrical patterns, values held by the family concerning the care of the client may be at odds with the service, leading to fierce struggles, blaming, and the eventual isolation

of the family. Intervention needs to take conflicting values into account, focus on mediation, and where necessary to challenge certain beliefs. Problems can, of course, be a great deal more complicated than those between two parties. Individuals within families and organisations can develop coalitions with one another, leading to triangulation, and a host of complex and restrictive interactions.

One of the most important tools that can be employed in these situations is a sociogram (Moreno, 1934) that can be used to carefully map all of the stakeholders involved. This allows clinicians to develop multiple hypotheses regarding potential to shift the presenting issue using systemic, structural, solution-focussed, and narrative lenses. The sociogram should include a genogram of the family as well as pictorial representations of other services. These services can be represented in a similar way to family genograms where managers can be placed at the top, with staff and clients below. Relational markers, including close, conflictual, distant, enmeshed, and breached can also be used to identify potential relationships (McGoldrick & Gerson, 1986). Hypothesising is best done with peers in a group situation as it allows for the brainstorming of possible interpersonal restraints based on current information. It can also promote neutrality on the part of the clinician, reveal gaps in the system to guide further assessment, and eventually support the development of strategic plans to respond directly to the relational needs of the system.

Potential Issues In Group Homes

In many situations the clinician may encounter obstacles to behavioural intervention in the group home setting alone. Clients may no longer be living in the home setting, necessitating a specific focus on this unique professional system. Group homes can

sometimes be problematic due to the blurred boundaries between the professional and personal roles of staff. Some may have been employed for many years, developing attachments with the client, who has few external sources of support. The high level of stress involved in responding to severe challenging behaviour may also affect interactions, causing breaches in attachment, the development of coalitions amongst staff, the erosion of authoritative leadership, or escalating symmetrical patterns of interaction between staff and behavioural consultants who present as if they know best.

Smyly (2006) provided an important overview of her work with group homes in her application of the systemic organisational approach of Campbell, Coldicott and Kinsella (1994). Smyly was critical of the expert consultant role and suggested that clinicians needed to engage group home staff in reflective conversations that allowed them to develop new ways of making sense of a client's challenging behaviour. Staff within a group home may be more likely to implement new strategies if they feel there has been a respectful collaboration, one that contextualises behaviour in terms of the life-cycle of the house itself and one that assists them to find their own solutions, rather than the strategies being imposed from above. This principle is highly consistent with the solution-focussed and narrative approaches described earlier. Rhodes (2000) suggested a variety of strategies that could be used by clinicians to assist in the process of group home consultation. These included,

1. Meeting with all staff at the same time for consultations rather than joining shifts where multiple perspectives are not possible;
2. Spending time engaging with each staff member, including a review of his/her philosophy for working with intellectual disability and understanding of challenging behaviour;

3. Assessing the onset of challenging behaviour with the staff using a detailed timeline of significant events in the house, including changes to staffing, to residents, difficulties with other clients etc.;
4. Using a sociogram to help staff review patterns of the effects of these events and on interactions that include the challenging behaviour;
5. Gradually assisting staff to develop a new understanding of the meaning of the behaviour (e.g., the homeostatic function); and
6. Conducting a behavioural assessment following the principles of the Behaviour Assessment Guide (Willis, LaVigna & Donellan, 1993). Many clinicians use this guide to develop a comprehensive written report that is then given to staff. It can be more useful to co-construct the intervention, based on the facilitated insights and ideas of the team with the written record representing this collaboration.

Conclusion

Family therapy has reached a degree of maturity in the field of generic child and adolescent mental health. There is growing evidence for the efficacy of family therapy (Carr, 2004) and an acceptance that it offers a rich set of skills that are fundamental to clinical practice in family settings. The field of intellectual disability has been relatively slow to respond to these developments (Rhodes, 2002), relying to a large degree on the behavioural approach and to a lesser degree on person-centred (Coyle, 2007) and cognitive behavioural approaches (Dagnan, Jahoda & Kroese, 2007). The aim of this chapter has been to advocate for the integration of family therapy with traditional behaviour modification approaches, not as an alternative to positive behaviour support, but as an augmentation that allows clinicians to more effectively respond to

interactional and systemic constraints. Milan systemic, structural, solution-focussed, and narrative models all provide a host of principles and strategies suited to this purpose.