Utilising behavioural family therapy (BFT) to help support the system around a person with intellectual disability and complex mental health needs: A case study

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Abstract
There is a higher incidence of mental health problems amongst people with intellectual disabilities. Family members and support staff who provide support to people with intellectual disabilities with mental health difficulties are more likely to experience increased stress. In the mainstream mental health literature it has been demonstrated that psycho-educational family interventions have a positive impact on the person with mental health difficulties and on the family members who support them. This article uses a case study to illustrate the implementation of a family intervention with the support system around someone with intellectual disabilities, autism and chronic mental health difficulties. Following intervention the family member reported a marked decrease in levels of strain. Both the family and team members reported improvement in functioning within the support system.

Keywords
behavioural family therapy, family stress, psycho-education, staff stress, support system

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Introduction

People with intellectual disability are at increased risk of developing a broad range of mental health problems compared to the general population (Dosen and Day, 2001; Elliot et al., 2003). It is recognised that the diagnosis of mental health problems with people with an intellectual disability can be more difficult compared to those in the general adult population. It is also recognised that a label of challenging behaviour can be used when people with an intellectual disability are experiencing emotional distress (Cooper et al., 2007). It is considered that this is often unhelpful since it is essential that appropriate psychological models are used to inform the interventions that people with intellectual disabilities receive (Hatton and Taylor, 2005).

Many psychosocial interventions used within intellectual disability services typically focus on the individual (e.g. cognitive behaviour therapy and art therapy). There has been some attempt within these modalities to involve those who provide support to the person (Willner, 2005; Haddock and Jones, 2006; Brown and Marshall, 2006). Whilst it is considered that supporting others can assist with the delivery of therapeutic work and help with therapeutic gain, there is little guidance as to how we engage others in the therapeutic process. There is also uncertainty as to how effective relevant others are in supporting the person. Despite these difficulties it is asserted that there will be some benefit to including others around the person with an intellectual disability, those being family members, friends or paid carers. Many people with an intellectual disability will have some form of support with living skills. It is considered that the nature and style of support can have an impact on the mental health of the person with intellectual disability. A number of factors are likely to impact on the nature and style of support that others provide. One significant factor identified within the literature is stress within the supporting system.

Stress within the system

Parents of children with an intellectual disability report higher levels of stress and mental health problems than parents without a child with an intellectual disability (Beckman, 1991; Dumas et al., 1991; Dyson, 1991; Emerson, 2003; Friedrich and Friedrich, 1981). The factors associated with stress in families where intellectual disability is present may be different in comparison to stress factors in other populations (e.g. families with a relative with psychosis). For families who have someone with an intellectual disability the stress is likely to be persistent and chronic over longer periods of time (Dyson, 1993; Glidden and Schoolcraft, 2003). It has been identified that families will experience a number of life cycle transitions which impact on stress. These include: the acceptance of a diagnosis of intellectual disability; the loss associated with parental aspirations for their child (e.g. education and employment); and the loss for the person with an intellectual disability in achieving developmental milestones and subsequent comparison to non-intellectually disabled people (Hastings and Beck, 2004). Further, Fidell (2000) identified other factors that may have an impact on stress for the family including: perceived or actual vulnerability of the person with an intellectual disability; transition between child and adult services; and concerns about what support will be in place when the parents reach old age. Equally, there is a wealth of research highlighting that staff who support people with an intellectual disability with complex presentations experience increased levels of stress (Hastings, 2002; Jenkins et al., 1997). It is asserted that, for both the person with intellectual disability and for those who support them, it is important to work on reducing stress within the supporting system. Thus, we turn towards literature from other clinical populations who have demonstrated efficacy within this area.
Family interventions

Over the past 30 years a robust body of research has developed demonstrating the efficacy of psycho-educational family interventions in working with families where a member experiences severe mental health problems, particularly psychosis (Pilling et al., 2002; Pfammatter et al., 2006). Numerous studies have demonstrated that family interventions decrease the frequency of relapse and hospitalisation (Pharoah et al., 2006). These findings are culturally robust and maintain over time (Fadden, 1998). Family interventions improve general social impairment and encourage compliance with medication (Pharoah et al., 2006). Over the past 15 years various policies and guidelines have highlighted that to provide effective treatment to those with serious mental health problems, services must include working with families (NICE, 2010; SIGN, 1998). Few studies have investigated the impact of family intervention on family members. Whilst the extent of research is limited and focuses on diverse outcomes, the results are promising, suggesting that family interventions may improve knowledge about illness and medication (Pfammatter et al., 2006), improve family member mental health (Brooker et al., 1992; 1994), enhance global satisfaction with service (Brooker et al., 1992; 1994) and significantly reduce expressed emotion (Pharoah et al., 2006).

What is a psycho-educational family intervention?

Whilst there is some variation in the content of psycho-educational family interventions, it is considered that these refer to interventions where the patient and family members are seen together and where there is both information provision and skills development components (Fadden, 1998). The components of a psycho-educational family intervention aim to address issues surrounding family stress. The principles are clear in acknowledging that:

- Family care is the greatest resource for the clinical management of all health problems.
- Chronic high levels of stress place the individuals who are vulnerable to stress-related mental health problems at increased risk of experiencing those mental health problems.
- Families and systems with the resources to effectively manage high levels of stress are considered to support the reduction of acute episodes and to contribute to a full and sustained recovery from many disabling conditions (Falloon et al., 1993).

A social system that enhances effective communication and robust strategies to help deal with difficulties will minimise the likelihood of stress overwhelming that system (see Figure 1).

The ethos behind family interventions would suggest this should be a viable approach in working with systems around people with an intellectual disability. We follow the broad definition of what defines a family (Falloon et al., 1993):

- either those people who live in the same household living unit, sharing the everyday responsibility for the organisation and maintenance of the unit
- or those people who are key providers of emotional support for an individual on an everyday basis, regardless of the location of their residence.

Thus, given that both traditional family members and support staff are key providers of emotional support, it is argued that this could be a valuable approach in targeting stress within the whole system.
What is behaviour family therapy (BFT)?

BFT is a family intervention that comes under the umbrella term of psycho-educational cognitive-behavioural approaches. The component parts of BFT were developed across a number of different clinical settings and with different patient groups (Falloon et al., 1993). This approach was initially evaluated by Falloon et al. (1982). Since then similar approaches have been developed with different variants and names. The BFT approach is manualized with a structure, but remains flexible in its application to different family needs.

BFT aims to enhance understanding through sharing information about mental health issues, encouraging the service user to take the lead in the discussions about how their illness affects them. Family members are encouraged to set personal goals, and to seek help from other family members to help make these goals achievable. The approach also builds on skills the family already demonstrate, helping to enhance problem solving and positive communication skills. Table 1 illustrates the typical BFT process.

Method: case study

This article illustrates the implementation of behaviour family therapy within a system that supports a person with intellectual disabilities who experiences complex mental health issues using a single case design.

George is a 45-year-old man with a mild intellectual disability and diagnoses of schizophrenia and autism. George had a long history of unsuccessful supported living placements. There was a familiar pattern to his previous placement breakdowns where his mental health would deteriorate and he would present with paranoid ideas about being poisoned. During these times he would also become verbally and physically abusive towards staff. This would often be the immediate precipitant to placement breakdown. In addition to community placements George had previously spent time in hospital, in an out of area specialist placement and in prison as a result of his difficulties. Over the years there have been multiple attempts to treat his paranoid symptoms and his presenting challenging behaviours with pharmacological intervention. These have been unsuccessful.
At the time of referral George had recently moved into his own tenancy with visiting support. Prior to this move he had been living at home with his parents. Consistent with his previous experiences, the move to his own tenancy was precipitated by an increasingly difficult situation at home where he presented with paranoid ideas and verbal abuse. This had a significant effect on his mother (who was his main carer) who experienced chronic high levels of stress. George’s transition to his new placement initially went smoothly but difficulties arose when he again presented with paranoid ideas and was verbally abusive towards staff. During this time George’s mother was taking on more of a supporting role in an attempt to maintain her son in his own flat. There was little effective communication between mum and the support team in relation to dealing with the ongoing difficulties that George was presenting with.

It was during this period George was referred to the local community learning disabilities team. Individual or group work with George was not an option as he was disparaging of the intellectual disability service and people with an intellectual disability in general. George was considered for out of area assessment and treatment from a private care hospital, which would have been a costly alternative. Given the complex history and presenting circumstances it was considered that it would be helpful to work with the system around George to help support him more effectively. An agreement was reached with his mother and support team to try a BFT approach. It was agreed that this would include George’s mother and two support team members who provided direct, daily support to George. The sessions were facilitated by two therapists, a cognitive behaviour therapist and a clinical psychologist.

**Assessment**

Assessment within the context of behaviour family therapy includes an individual assessment with each family and team member as well as an assessment of their problem solving skills. The BFT individual assessment is a structured interview schedule. In this case it provided information on:

- family and team members’ knowledge of George’s current experiences and difficulties
- the effect of George’s difficulties on family and team members’ coping strategies
- family and team members’ personal goals
- exploration of the family member’s daily life pattern and how this is affected by stress.

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**Table 1. Typical BFT Process**

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<tr>
<th>Engagement of the family</th>
<th>Individual family member assessments and setting personal goals</th>
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<tr>
<td>Formulation and setting up family meetings between sessions</td>
<td>Information sharing around mental health</td>
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**Developing communication skills:**
- expressing pleasant feelings
- making positive requests
- active listening
- expressing unpleasant feelings

**Problem solving: the six step approach**

**Maintenance plan**
A structured assessment of problem solving examined how the family and team members solved problems as a collaborative team.

**Outcome measures**

*The Caregiver Strain Questionnaire (CGSQ) (Brannan et al., 1997).* The Caregiver Strain Questionnaire is a 21-item self-completed questionnaire that assesses three different dimensions of caregiver strain: (1) objective strain, (2) internalized subjective strain, and (3) externalized subjective strain. The three subscales have good internal reliability and alpha coefficients ranging from 0.73 to 0.91. The items are rated on a five-point scale (0–4) with lower scores reflecting lower levels of strain. The range of scores is 0–84 with higher scores reflecting higher levels of strain.

*The Family Functioning Questionnaire (FFQ) (Roncone et al., 2007).* The Family Functioning Questionnaire is a 24-item self-completed questionnaire that helps the assessment of families before and during psycho-educational interventions. The questionnaire comprises three core dimensions: problem solving, communication skills and personal goals. It has good psychometric properties. The items are rated on a four-point scale (0–3). The range of scores is 0–72 with higher scores reflecting better functioning.

*The Family Functioning Questionnaire (FFQ) (adapted for use with support workers).* In this study the Family Functioning Questionnaire was adapted to enable its use with support workers. In the adapted version the eight questions pertaining to ‘personal goals’ were excluded since it was deemed they would not be a suitable focus for intervention for paid support staff. Thus, the adapted questionnaire was a 16-item self-completed questionnaire which incorporating the problem solving and communication dimensions. Further, the term ‘family’ was replaced with ‘team’ throughout the questionnaire. Staff members were asked to consider the questions in relation to George’s team (including his mother and the paid support staff). Again, the items are rated on a four-point scale (0–3). The range of scores is 0–48 with higher scores reflecting better functioning.

Outcome measures were completed by the family member and two support workers immediately pre and post intervention.

*Formulation summary.* Formulation in BFT focuses on highlighting the strengths of the family/team and on identifying areas for development within the BFT framework. George’s formulation highlighted that family/team members had some knowledge about the difficulties George faced but there were significant gaps in their understanding of intellectual disability, schizophrenia and autism and how these diagnoses specifically affected him. It was identified that family/team members communicated effectively when their stress levels were reduced but developed ineffective strategies (i.e. criticism and/or avoidance) when stress levels were increased. Finally, each individual family/team member had strengths in some of the components of effective problem solving but they did not have a coherent method which they consistently implemented as a combined team. This formulation was shared with family/team members and an intervention plan was agreed.
Behaviour family therapy intervention

Following on from the formulation work, we carried out 11 sessions with the family and support team members. The composition of the sessions followed the typical BFT process. This incorporated the following:

- In the early sessions family and support team members established ground rules (e.g. to be respectful of each other’s views) giving some boundaries to the sessions.
- Meetings between the family and support team were set up to take place between the sessions without the facilitators. This encouraged the group to take ownership of the process and gave them the opportunity to practise the components of the work together.
- The facilitators provided information regarding George’s diagnoses of intellectual disability, autism and schizophrenia and the likely impact of these diagnoses on his presentation. This was complemented by information provided by George’s mother who gave a detailed historical perspective to his difficulties.
- Problem solving was introduced into the early sessions as there were difficult issues arising between George, his support team and his family at the outset. Initially, the facilitators needed to take a more instructional approach to guide the group through this process. Over the course of the sessions the family and support team members took ownership of the process and independently utilised the approach to address difficulties they were facing during their meetings where the facilitators were not present.
- Family and team members developed their communication skills. The skills covered were: expressing pleasant feelings, making positive requests and expressing unpleasant feelings. Family and team members initially practised these in and between sessions but quickly implemented them in their regular meeting where any problems or issues were constructively communicated and addressed using problem solving approaches.
- Towards the end of the block of sessions the facilitators encouraged the group to construct a crisis prevention and maintenance plan. This incorporated early warning signs relating to George’s difficulties. They were then encouraged to explore ways of responding to difficulties when they arose, and how they could utilise the skills from the sessions to help with this.
- During the intervention no other new psychological or pharmacological interventions were implemented.

Results

Outcome measures were obtained pre and post intervention. As seen in Figure 2, George’s mother reported decreased strain after the sessions and an improvement in her level of functioning.

As can see in Figure 3, the support team members reported an improvement in levels of functioning. The adjusted scale reflected communication and problem solving issues.

It is also noteworthy that George has successfully maintained his community placement for 30 months. This is significant since historically George’s community placements would break down after 2–3 months.

Discussion

This case study provides a first account of the clinical value in delivering behavioural family therapy to the system of support around someone with intellectual disability and complex mental
health issues. Despite George’s lack of interest in engaging with the BFT process the family and support team have worked together effectively to respond to difficulties as a collaborative group. It was difficult in this case to pinpoint particular aspects of the BFT approach that appeared to make the greatest difference to the group members’ functioning and stress. The support team reported that they found the problem solving process the most effective and subsequently used the same process effectively with other clients whom they support. George’s mother commented on the usefulness of the positive communication skills.

In this case there were only minor adjustments to the typical BFT individual assessment interview to ensure that it was relevant to both staff and family members. Other than this the typical BFT assessment, formulation and intervention process was implemented. This was perhaps more straightforward in this case since the person with intellectual disabilities chose not to engage in the

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**Figure 2. Mother’s Caregiver Strain and Family Functioning Questionnaire scores**

**Figure 3. Team members’ Family Functioning Questionnaire (adapted) scores**
process. However, it is strongly advocated that, with some amendments, BFT can be implemented with people with intellectual disabilities who wish to participate with their families and/or support teams.

This study is limited by its lack of follow-up data. It is not known whether the improved functioning in family/team members and the reduced strain reported by George’s mother were maintained beyond the intervention. Since this article illustrates the usefulness of BFT in one particular case it is not possible to generalize its findings. However, it is advocated that the BFT process shows real potential for reducing stress in family members and support team members, whilst increasing the resilience and skills to continue to support someone with an intellectual disability with complex needs. Further research is required on the effectiveness of the process with different types of participants (i.e. possibly incorporating the person with intellectual disabilities, their families and/or support teams) working together to develop ways to effectively support people with intellectual disabilities who experience a range of complex presenting problems.

It is considered that family/team interventions are particularly pertinent since, in times of austerity in social and health services, we need to be creative in our use of resources. There is no greater resource available to services than family members and support teams. We need to look at better ways of reducing stress and building resilience within these resources to help give people like George a better quality of life.

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**References**


