

Preventing residential care for young people with intellectual disabilities and challenging behaviours: the development of the Ealing Intensive Therapeutic and Short Breaks Service

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Abstract We describe the development of a service providing intensive intervention for young people with intellectual disabilities and complex challenging behaviours that is aimed at preventing family placement breakdown and a move to residential care. The therapeutic interventions are provided by a clinical psychologist and utilise a short break package that is tailor-made to meet the needs of the young person and their family. This model has been effective for 15 out of the 16 children referred to the service over a 40 month period. In these 15 cases, residential placement has been prevented in the short to medium term, challenging behaviours have reduced, and families have reported increased ability to cope. Case material is used to illustrate how this approach can reduce challenging behaviours and secure home placement stability for a small but significant number of children and young people whose behaviour would otherwise most likely result in a move to residential placements.

Keywords Short breaks; challenging behaviours; intensive intervention; positive behaviour support; family placement breakdown prevention; learning disability

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Key points

Clinical practice:

- Intensive intervention using positive behaviour support is effective in enabling children with severe challenging behaviours to remain with their family and community settings.
- Short breaks can be a helpful adjunct to positive behaviour support for preventing home placement breakdown.

Further research and practice development:

- Develop more robust quantitative and qualitative outcome measures and analysis for the service, including longer term follow-up of families.
- Further research into cost analysis of services such as the Ealing Intensive Therapeutic and Short Breaks Service in contrast to residential care.

Social, economic and policy background

Research suggests that between 5% and 15% of people with intellectual disabilities display behaviours which pose a significant challenge to carers, place the individual at risk of physical harm, and/or impact on their access to ordinary community resources (Borthwick-Duffy, 1994; Qureshi & Alborz, 1992). Historically, people with

intellectual disabilities and challenging behaviour were placed in long-stay institutions, away from their families and communities. Today, this may continue to be the case for a group of children with severely challenging behaviours, who may be placed in specialist residential schools. These placements are associated with high costs

(ranging from £130,291 to £266,968 per year for 52 week residential placements funded by Ealing in 2012), and usually require young people to be moved a long distance from their family and local community.

There is little evidence about the positive impact of residential care on people with intellectual disabilities. On the contrary, the risks of residential placement were illustrated by the recent case of Winterbourne View (Mencap and Challenging Behaviour Foundation, 2012). This report highlighted that far too often people with intellectual disabilities are sent away to institutional settings that tend to be too large and too far from their home. Once there, it is often difficult for them to return home again. The report demonstrated that often this pathway begins in childhood because of difficulties at school and lack of good support for the family, which can mean that the only option is a residential school.

The White Paper *Valuing People: A New Strategy for Learning Disability for the 21st Century* (Department of Health, 2001) aims to ensure that people with intellectual disabilities have rights and choices, and are included as part of the community. This document prompted local agencies to work together to find ways to support, understand and reduce challenging behaviour, and provide help to families in ways that enable young people to remain within their community setting (as opposed to home breakdown and residential placement). In the report *Aiming High for Disabled Children* (HM Treasury and Department for Education and Skills, 2007), the Government set out plans for improving outcomes for children with disabilities and their families. Central to these plans was a transformation of short break provision and delivery of local services. This included better planned and integrated services and early intervention for children and young people with disabilities. This report was crucial in informing the development of the Intensive Therapeutic and Short Breaks Service in Ealing, in that it emphasised the need to further develop the traditional short break model and integrate this with intervention services.

The Ealing Intensive Therapeutic and Short Breaks Service model

The Intensive Therapeutic and Short Breaks Service is an initiative based within the Ealing Service for Children with Additional Needs (ESCAN), a multi-agency service consisting of education, social care, health and mental health services for children with disabilities. The intensive service was developed to support young people with intellectual disabilities who display severe challenging behaviours and are at imminent risk of residential placement. Families are provided with short-term intensive psychological interventions and additional short breaks in order to reduce challenging behaviours, provide a break for the family/young person and increase carer coping. The ultimate aim is to enable the young

person to remain long term within their family home and community settings.

Selection criteria

The service was successfully piloted with one case between October 2008 and March 2009. This was in response to increasing numbers of young people with intellectual disabilities and challenging behaviour going into residential placements. A survey of this group of young people in Ealing in July 2008 indicated that those most likely to experience a family breakdown and a move to residential placement were males, aged at least 11 years, with moderate/severe intellectual disabilities and challenging behaviour. This tended to be because the family and school found it harder to manage challenging behaviour as the person grew older and larger. This resulted in the following criteria being developed for the selection of young people/families to be offered the Intensive Therapeutic and Short Breaks Service:

- diagnosis of moderate/severe intellectual disability;
- 10–18 years old (though the service has been offered to a younger child owing to exceptional circumstances);
- family and other carers are reporting severe challenging behaviour, high levels of distress and lack of ability to support the young person;
- already receiving short breaks (or eligible/about to start receiving);
- has an allocated social worker, though the young person must not currently be subject to a child protection plan;
- no acute mental health difficulties currently requiring inpatient admission or intensive psychiatric input;
- home/family situation is at risk of breaking down in the near future;
- family, school and carers are actively engaged in wanting to address the young person's difficult behaviour;
- family and school are both committed and able to consistently implement a positive behaviour support (PBS) programme at home and school with support from the service.

Consideration of potential referrals is undertaken jointly by the clinical psychologist, the manager of the local residential Short Breaks Service and the head of the Children with Disabilities Social Care Team, using the above criteria. Referrals have so far been received from social workers, the Short Breaks Funding Panel, the Joint Funding Panel (where requests for residential placement or change of school are received), community paediatrics, the child and adolescent mental health service and special schools. Referrers are usually invited to meet with the clinical psychologist from the service before deciding whether to refer a case, and then may attend the service's referral meeting to present the potential new case.

Preparing families and the network

Once selected, families are invited to meet with a clinical psychologist to discuss the programme and consider whether they are able and willing to commit to working with the service. Following their agreement, the family are invited to a network meeting with all involved professionals so that they can meet the team, and the network can plan goals, address any immediate risk issues, think about a useful way forward together and discuss individuals' roles. Although the service comprises clinical psychology and short breaks, its location within the multi-agency Ealing Service for Children with Additional Needs means that other disciplines and agencies can be accessed when needed. Other key disciplines that are usually involved in the network of these families include social workers, paediatricians, psychiatrists, specialist nurses, occupational therapists, speech and language therapists, special school staff, educational psychologists and transport assistants, as well as short breaks staff.

Assessment

All young people and families who are identified as suitable for the service then receive a comprehensive clinical psychology assessment which takes place intensively over 6–8 weeks and includes:

- observations of the young person and carers at home, school and in their short break settings to identify the range of challenging behaviours, their severity, possible triggers/functions of the behaviours, and caregivers'/young person's responses;
- a number of meetings to collect information from family, school and short breaks staff to gain a full history and understanding of the young person, their family, development and strengths/interests as well as information regarding their needs, difficulties and challenging behaviours;
- functional analysis – using observation and interview and recording data to analyse the challenging behaviour, antecedents and consequences to develop an understanding of the functions of challenging behaviour; this is guided by Willis, Lavigna & Donnellan's (2011) *Behaviour Assessment Guide*.

Formulation

Pulling together the above information, the clinical psychologist develops a psychological formulation to help staff and family understand some of the possible reasons that were leading to the challenging behaviour and home placement breakdown. The formulation incorporates predisposing, precipitating (triggers), perpetuating (maintaining) and protective factors (referred to as PPPP factors) associated with challenging behaviours (Carr, 1999; Weerasekera, 1996). The formulation is

shared through training sessions and network meetings with the family, carers and school with the aim of supporting them to better understand the young person, the challenging behaviours and the impact of their own responses on the behaviour. It is hoped that that they will then feel more motivated and able to support the child and family and engage in the intervention phase.

Intervention

The intervention is developed in line with the formulation and includes:

- 1 **Development of a positive behaviour support (PBS) plan** led by the clinical psychologist in collaboration with the family and the entire network. PBS combines behavioural, cognitive, biophysical and environmental factors to develop environments that promote desired behaviours and minimise the development and maintenance of problem behaviours. Within a PBS model, all behaviour is viewed as happening for a reason; that is, as being 'functional' for a person (Sailor et al., 2009). PBS therefore involves assessing the functions of challenging behaviour and finding new alternatives to support an individual's needs. Following the functional assessment, the PBS plan details the behaviours to be addressed, functions of the behaviours, and proactive and reactive strategies for the family and staff to use to reduce challenging behaviours. This is informed by the Institute for Applied Behavior Analysis approach (Donnellan et al., 1988) and the work of Sailor et al., 2009.
- 2 **Provision of additional short breaks.** Initially this consisted of the young person going for an extended short break (lasting 2–3 weeks) at the local residential short breaks service, while intensive psychological therapy and other work was carried out with the young person, their family and support network. In order to meet a wider range of needs, the service has now started to access a broader menu of short break models in conjunction with the intensive psychological intervention, including working with agency carers who go into the family home and out into the community, Family Link foster carers who take a young person into their own home, sitters who work within the family's home, and family/friend carers paid through direct payments. Short breaks staff involved in the project are provided with ongoing training and consultation from the clinical psychologist as part of the service. The extended short break is used to give the family and young person a break to reflect on and consider change, and to allow the opportunity for the PBS plan to be implemented with additional staff support, to be rehearsed and modelled with the family (by carers and the clinical psychologist) and to be adapted as needed. The short break package of

each family accessing the service is reviewed after the intensive intervention phase to decide on what type of package is needed to ensure maintenance of the progress made and to allow the family to manage in the longer term.

- 3 **Psychological interventions.** The clinical psychologist and assistant psychologist meet weekly with the family and also offer regular support to other professionals and short breaks staff. Drawing upon a systemic framework is vital here in considering all young people within their family, social, cultural and developmental contexts. This involves acknowledging and using the multiple perspectives of people/agencies within the system, considering the family life cycle and issues of loss and transition, and focusing on identifying resources and strengths within the young person, family and network and building upon these in our work (Baum & Lynggaard, 2006). Solution-focused approaches have also been useful in drawing out ideas and strategies from the network and in helping carers/staff feel motivated and empowered again (de Shazer, 1985). In addition, this model is useful in helping the network notice and celebrate even very small or gradual changes, which is vital when working with this client group. Ideas from narrative therapy have also been helpful (White, 1989; White & Epston, 1990). Often the young people seen have 'problem saturated' stories surrounding them, for example of being 'violent', 'unmanageable', 'damaged' or 'unable to live in the community'. Their families and support staff may also have negative stories about themselves as being 'bad parents', 'failing the young person' or feeling 'rejected by' the young person. It has been useful here to help staff and families develop alternative more helpful stories about themselves as carers and about the young person. Useful tools here have included writing therapeutic letters to parents/families after sessions (White, 1989; White and Epston, 1990) as well as using creative and playful approaches when involving the young people and their siblings in therapy (Freeman, Epston, & Lobovits, 1997). Some of the young people accessing the service

also have difficulties with anxiety, phobias or low self-esteem. Here an adapted cognitive behavioural therapy approach has been useful (Stenfert Kroese, Dagnan, & Loumidis, 1997). Finally, in all of these cases, use of attachment theory (e.g. Bowlby, 1969, 1988; Crittenden, Landini, & Claussen, 2001) to make sense of the attachment needs and patterns of the young person and their parents is vital. Considering the attachment needs of the young person is also important when deciding on the model of short break to offer. Staff from the residential short breaks service have also reported finding training about attachment and intellectual disabilities useful in understanding the young people they support, their parents, and their own responses to them.

Staffing and caseload

The service has been running since October 2008, with funding attached since March 2009. The number of families seen per year has varied in line with funding. For the first year, the service employed a 0.5 whole time equivalent (WTE) clinical psychologist to work with four new families per year. In year 2 this was increased to include a 1 WTE assistant psychologist so the service could work with six to seven new families per year. Since year 3 and currently, the service funds a 0.8 WTE clinical psychologist and a 1 WTE assistant psychologist to work with seven to eight new families per year.

Sixteen cases in total were offered the service between October 2008 and March 2012. Of the 16 young people seen, 14 were male and two female. The ages of young people referred ranged from 7 years 11 months to 17 years 9 months, with a mean age of 13 years 5 months. Nine of the young people were living in single parent families, and seven lived with both their parents. Thirteen of the young people had between one and six siblings and, of those, three had a sibling also with a diagnosis of autism spectrum disorder (ASD). The ethnicity and type of special school attended for children/young people seen is presented in Table 1. All the young people had a diagnosis of intellectual disability (though no IQ data are available), and 14 of them also had a diagnosis of ASD and five also had a diagnosis of epilepsy.

Table 1 Ethnicity and type of special school attended for children/young people seen by the Ealing Intensive Therapeutic and Short Breaks Service, October 2008 to March 2012 (N= 16)

Ethnicity	No. of children/young people	Type of special school	No. of children/young people
Asian British	5	Autism spectrum disorders	8
Mixed Race British	6	Severe and profound learning difficulties	7
Black African	3	Mild and moderate learning difficulties	1
White Irish/British	1		
White British	1		

A typical referral to the service includes most of the following:

- significant reports of physical aggression;
- destructive behaviours;
- absconding and risky behaviour in public;
- self-injurious behaviours;
- obsessions and compulsions;
- sleep difficulties;
- soiling and smearing;
- high anxiety and low mood.

In addition, for many of the families seen in the intensive service, there was a previous history of domestic violence, disrupted relationships, multiple losses or other traumas. Some of the work of the service is illustrated below through two case examples.

Case 1: Joseph

At the time of referral to the Intensive Therapeutic and Short Breaks Service, Joseph was 11 years old. He is a British Mixed Race boy with a diagnosis of autism and intellectual disability. He is able to speak using short phrases, and also uses Makaton and visual supports. Joseph lives with his mother and older brother who has a diagnosis of Asperger's syndrome. He attends a local special school for children with autism spectrum disorder, the short breaks service and after-school club. Joseph's father also lives locally and offers support when needed (e.g. taking Joseph out for a couple of hours). Joseph was referred to the intensive service by his consultant community paediatrician, his social worker and the short breaks service because he was displaying a number of challenging behaviours that appeared to be escalating. In addition, his mother had heard about the service via another parent and felt that their family would benefit from this approach.

Assessment

Observations of Joseph and interviews with Joseph's mother and staff team across various settings highlighted a number of concerns that were resulting in carers and professionals thinking that he required a residential placement. These included:

- physical aggression towards staff and family, including smacking, kicking, punching, scratching, pulling hair, and breaking objects and stabbing (with broken plastic, glass, etc);
- shouting, swearing, threatening ('I'll stab you') and needing constant attention – for example, clinging to his mother and becoming physically aggressive if she spoke to anyone else;
- destructive behaviours such as breaking windows, toys and other objects around the family home and short breaks settings; previously Joseph had tried to light fires but this stopped after he burned himself;
- scratching and injuring himself with sharp objects;
- other risky behaviours such as jumping around in the car or grabbing his mother while she's driving, absconding when out in public places, playing with plug sockets or ripping them from the wall, and pouring liquid or urine into electrical sockets;
- sleep difficulties;
- high anxiety levels.

These behaviours were exhibited across all settings Joseph attended, and it was noted that staff and family responses to prevent and manage behaviour were different across all the settings.

The assessment also highlighted a complex family history including Joseph's mother experiencing domestic violence by previous partners and physical and sexual abuse as a child. At the time of referral she was presenting with physical health problems and low mood. Joseph's father also reported experiences of abuse and neglect as a child. Until the age of 3, when Joseph's parents separated, he had witnessed high levels of conflict between his parents, as well as controlling behaviour and emotional abuse from his father to his mother. The parents continue to have a complex relationship despite living separately, and reducing the risks to Joseph in relation to this and contact with his father had to be worked on and considered closely with social care throughout the work.

Intervention

A comprehensive PPPP formulation (as described earlier in this article) was developed to support Joseph's family and staff team in understanding the above behaviours in the context of Joseph's disability, patterns of learned behaviour, and family experiences of trauma. Initial work involved liaising with social care and occupational therapy to ensure Joseph's safety. This included gaining funding for physical adaptations to be made to the family home (e.g. to prevent smashing glass, playing with electricity, etc.) and having joint meetings with social care and Joseph's father. A PBS plan was developed and the family and network supporting Joseph were trained in its use. An extended short break was then provided for two weeks at the residential short breaks service (which he already knew and accessed). During his stay there, the PBS plan was implemented and amended as needed in consultation with the clinical psychologist, and Joseph's mother spent time visiting him so she could see staff following the plan and practise it herself in a safe setting. During this extended period that he was at the short breaks service, adaptations were made to the family home.

When he returned home, the clinical psychologist had daily telephone contact and carried out weekly clinical psychology sessions in the family home and community with Joseph and his mother (and occasionally his brother). These sessions focused on improving family relationships through positive play and interaction, as well as modelling to and supporting Joseph's mother in

implementing positive behavioural strategies. Psychological support was also offered weekly at the clinic for Joseph's mother to help her reflect on and manage her role in caring for Joseph. Work was undertaken to help her reduce and manage stress and exhaustion in relation to supporting a child with complex needs while also dealing with her own medical needs, to help her understand and come to terms with Joseph's disability, and to help her reflect on and adjust her parenting styles in the context of her own traumatic history. Attempts were also made to engage Joseph's father in individual therapy sessions. These were less successful; however, he did engage in learning about the PBS plan and learning more about autism and how to support Joseph. Video recordings in different settings were used to support the family and short break carers in reflecting on how they were interacting with and supporting Joseph, and to identify examples of improvement. These were explored in whole-network training sessions, which the family, short breaks staff, school staff, after-school club staff, occupational therapist and social worker attended. In addition to whole-network training, smaller staff consultation sessions were offered regularly to the short breaks staff.

Key outcomes

Joseph continues to live with his family and to attend his local special school and short breaks settings. He is no longer at risk of requiring a residential placement and planning is now in place to find a suitable local post-16 school placement for him. A number of positive developments have been noted, including:

- Joseph's mother and care staff report that they have observed a significant decrease in challenging behaviours, particularly physical aggression and destructive behaviours.
- Joseph appears to be calmer and less anxious, and his sleep, communication skills and independent living skills have improved.
- Both his parents have reported feelings more confident and skilled in managing his challenging behaviours, and both parents and his brother report that their relationship with Joseph has improved and they now enjoy spending time with him.
- The above positive changes are also evident on outcome measures including questionnaires, some of which are reported later in this article.

Case 2: Mark

Mark was 17 years old at the time of referral to the Intensive Therapeutic and Short Breaks Service. He is a White British boy who lives alone with his mother. His father lived locally until just before the referral, when he moved away with his partner and her children. Mark also has two adult brothers who live locally outside of the family home and with whom he has a close relationship. Mark has a diagnosis of intellectual disability and epilepsy. At

the time of referral, he attended the post-16 department of a special school for people with severe and profound learning difficulties. Mark was referred to the service by a consultant community paediatrician following a number of incidents where he had threatened to harm himself or others. This included him holding a carving knife to his mother for 2 hours and attempting to strangle himself with a telephone cord at school. This escalation in behaviour was placing Mark at risk of needing to be accommodated in a residential placement.

Assessment

During assessment, observations and interviews with Mark and his mother, his school and his social worker highlighted the following concerns:

- self-harm attempts by Mark including attempts to cut himself with sharp objects and to strangle himself;
- absconding from school/class and barricading himself into areas or wandering around the school;
- threats of physical aggression towards others, such as threatening with a carving knife, brick or sharp object (although he never actually followed through on these threats);
- low mood and high anxiety levels.

The assessment also highlighted that over the preceding three years Mark and his mother had experienced bereavements of two close family members and a friend. These had been people who Mark and his mother tended to confide in and turn to for support, but, in addition, they had both helped care for these relatives/friend up until their death, and it was felt this had given Mark a sense of purpose and responsibility that he had valued. Mark had also experienced other losses – his father moving away, and him moving up into the sixth form department of school, which was away from the staff he trusted and confided in.

Intervention

A formulation was shared with Mark, his family and staff team, which considered the above behaviours in the context of Mark and his family struggling to cope with numerous family bereavements at the same time as Mark transitioning into post-16 at school and adult life. Liaison was carried out with social care and direct payments were put into place as well as a buddy system, to allow Mark to increase his activities and independence (and to give him and his mother a break from one another). Consultation was offered to these carers and they attended network meetings to ensure they were confident in supporting Mark. Therapy sessions were offered weekly by the clinical psychologist to Mark and his mother together to focus on exploring their feelings and coping with bereavements, losses and transitions, and to draw out positives in their relationship with one another. Initially, pictures of emotions and situations

relevant to Mark's life were used in these sessions, but he needed these less as time went on and he began to be more able to communicate verbally about things that angered or worried him. Alternative coping strategies were explored and practised with Mark to support him when he felt upset and to prevent the need for threats or self-harm. In addition, after Mark disclosed that he had been exposed to drugs in his local neighbourhood, joint sessions were held with a drug worker to offer psycho-education about use of drugs and alcohol. In order to support the wider network, manage difficulties at school and plan for Mark's transition to adult services, the clinical psychologist held network meetings every 4–6 weeks with school staff, the educational psychologist, the social worker, Mark and his mother. Extensive liaison and planning was carried out with adult services to ensure a smooth and positive transition into adult services for Mark when he reached 18, including joint sessions with the adult clinical psychology service.

Outcomes

At the end of the work, Mark continued to live with his family and had chosen to leave school and to work part time for his brother's delivery company instead. Mark was no longer at risk of needing a residential school or inpatient placement. Mark has now moved over to the adult service, where he continues to be supported, and they are looking into local supported living options for Mark in the future so that he can become more independent but still live near his family. When our intervention ended, Mark and his mother reported the following positive changes:

- There had been a huge reduction in self-harm and physical aggression. (There had been no incidents of self-harm or physical aggression since the intensive clinical psychology work had begun.)
- Mark continued to show some destructive behaviours and absconding but he no longer put himself or others at risk when displaying these behaviours. He increased his independence and safety in the community by working on this when out with his buddy and direct payment carer.
- Mark and his mother both felt much happier, calmer and more confident, and Mark's behaviour was more settled at home. Mark and his mother also reported him being more able to communicate his feelings to others and to make use of strategies that he knows help him calm down when stressed.
- Mark was in a position to seek paid employment with a relative (in contrast to residential care).

Service outcomes and cost comparisons

Number of children in residential placements

For 15 of the 16 young people seen by the Intensive Therapeutic and Short Breaks Service between October 2008 and March 2012, residential placement was prevented

and quality of life was reported to have improved. For one young person, residential placement was not prevented and, at the end of the assessment carried out by the intensive service, a recommendation was made that a residential placement was most appropriate at that time. Factors involved in this decision included the young person already being in a part-time residential placement, imminent risk to the parent of housing eviction and homelessness, and parental mental health difficulties. The young person did spend some time in a residential placement outside of London but following an improvement in the home situation and in his parent's mental health he has since returned to live back at home part time (and lives part time in a local residential facility).

Outcome measures

The current article has focused on the early development of the Intensive Therapeutic and Short Breaks Service. A follow-up study conducted by Reid, Sholl and Gore (2013) reports quantitative outcome data for the service, which showed a statistically significant reduction in challenging behaviour as reported on standardised measures.

In addition to this quantitative data, the service has routinely collected data on outcomes for carers and carers' experiences of the service using the Carer Outcome Measure (a mixed quantitative and qualitative questionnaire that was developed within the service to tap into changes in the carers' coping) and the Commission for Health Improvement Experience of Service Questionnaire (CHI-ESQ), a questionnaire about the carer's opinion of the service. The Carer Outcome Measure has been collected for eight of the 16 families seen so far, and the ESQ for nine of them. The demographics of these cases are presented in Table 2. Of the remaining families seen by the service, data have not yet been collected in five cases as they are still being actively seen by the service (and these questionnaires are given when cases are closed), two have not yet completed the questionnaires, and one of these is the case that went to residential placement and the carer felt it was appropriate to complete the CHI-ESQ but not the Carer Outcome Measure.

Table 3 shows the responses of the parents of young people seen by the Intensive Therapeutic and Short Breaks Service on the Carer Outcome Measure. This indicates that at referral all parents seen felt that the problems they were experiencing were either fairly or very severe, and all respondents felt that the problems improved as a result of intervention (with five parents noting a 'great' improvement). All parents seen reported that meeting with the clinical psychologist was helpful, and all parents reported an improvement in their ability to cope with the problems as a result of the intensive intervention.

Table 4 shows the responses of the parents of young people seen by the Intensive Therapeutic and Short Breaks Service on the CHI-ESQ. Feedback about the service was positive, with parents reporting that they felt

Table 2 Demographics of young people seen by the Ealing Intensive Therapeutic and Short Breaks Service whose families completed the Carer Outcome Measure and CHI-ESQ at the end of their work with the service (N=9)

	Age at referral (years)	Gender	Ethnicity	Length of time in service (months)	Residential placement prevented	No. of months post intensive intervention
1	13	Male	White Irish/British	26	Yes	45
2	14	Male	Asian British	7	Yes	36
3	11	Male	Mixed Race British	36	Yes	22
4	11	Male	Mixed Race British	6	Yes	29
5	17	Female	Asian British	5	Yes	25
6	14	Male	Asian British	4	Yes	24
7	17	Male	White British	10	Yes	17
8	10	Male	Asian British	19	Yes	4
9	15	Male	Asian British	2	No	24

Table 3 Responses on the Carer Outcome Measure (N=8)

Item	Responses	No. of responses
Severity of problem	<i>No problem</i>	0
	<i>Slight problem</i>	0
	<i>Fairly severe problem</i>	2
	<i>Very severe problem</i>	6
Change in problem during intervention	<i>Improved greatly</i>	5
	<i>Improved moderately</i>	2
	<i>Improved slightly</i>	1
	<i>No change</i>	0
	<i>Worse</i>	0
Meeting with clinical psychologist helpful?	<i>Yes, very helpful</i>	7
	<i>Yes, quite helpful</i>	1
	<i>Not really helpful</i>	0
Change in ability to cope with problems	<i>Greatly improved</i>	6
	<i>Moderately improved</i>	1
	<i>Slightly improved</i>	1
	<i>No change</i>	0
	<i>Slightly worsened</i>	0
	<i>Much worsened</i>	0

listened to, felt treated well, felt the service knew how to help, and that they would recommend the service to others.

In addition, families who have accessed the service gave qualitative feedback in both of the above measures about their experience of the service. Examples of the feedback included:

- Improved ability to manage and improved understanding of the behaviour:

It has helped me to find positive solutions to my child's problems... and made me look at my son's

problems in a different way. I no longer feel at the mercy of his temper and he doesn't feel the need to lash out because he knows I'm on his side and I'm trying my best to understand him.

- Feeling more confident:

Thank you for your kindness and help over the last year. You both helped [child] and myself [mother] enormously by giving us so much more confidence in the things we do and believe in. Carry on the great work with others...

Table 4 Responses on the CHI-ESQ (N=9)

Item	No. of responses			
	Certainly true	Partly true	Not true	Don't know
Felt listened to	8	1	0	0
Easy to talk to	8	1	0	0
I was treated well	9	0	0	0
My views and worries were taken seriously	7	2	0	0
They know how to help	7	2	0	0
I was given enough explanation	9	0	0	0
The staff were working together	7	2	0	0
Comfortable facilities	8	1	0	0
Appointments convenient	8	1	0	0
Easy to get to	8	1	0	0
Would recommend to a friend	9	0	0	0
Overall the help received was good	9	0	0	0

- Improved relationship/attitude towards child:

I used to cry every day and dread [child] coming home, but now I cry less and sometimes even miss [child] when he is out, and look forward to him coming home.

Cost comparisons

Table 5 displays the typical annual costs of the Intensive Therapeutic and Short Breaks Service for one young person compared with the typical cost of a residential placement for this client group. As can be seen, offering an intensive local community service is considerably cheaper than the cost of both 38 week and 52 week residential placements. In addition, residential placement costs recur year on year.

Discussion and conclusions

Since it was first piloted in 2008, the Ealing Intensive Therapeutic and Short Breaks Service has succeeded in preventing a move to residential placement in the short to medium term for a small but significant number of young people who were at immediate risk of home placement breakdown at the point of referral to the service. The evidence obtained thus far indicates that this

model should be considered as a viable and cost-effective option for young people presenting with severe challenging behaviours whose home placements are at risk of breaking down.

There are several aspects of the service that are likely to be contributing to its success, though this requires further research. These aspects include:

- the intensive/extended short break gives the young person and family a break from the norm, allowing them space to develop new patterns of behaviour and more helpful responses;
- the intensive/extended break also gives the family time to sleep and recover, time to think about their child and their wishes for his future, time to attend clinical psychology appointments and consider new management strategies to address challenging behaviours, and time to reorganise the home and make changes so the environment becomes more supportive to their child's needs;
- intensive clinical psychology input means that it is possible to gain a thorough understanding of one young person, their family and the challenging behaviour presenting, across a variety of settings, and develop and implement an individualised PBS plan to promote consistent responses and strategies across settings;

Table 5 Cost comparisons of the Intensive Therapeutic and Short Breaks Service versus a 38 week or 52 week residential placement for a typical case for 1 year in 2012

Cost of Intensive Therapeutic and Short Breaks Service for one child for 1 year (2012)	Range of costs for a 38 week residential placement for one child for 1 year (2012)	Range of costs for a 52 week residential placement for one child for 1 year (2012)
£8,857* (CP) + £4,028 (SB) = £12,885	£57,492 to £210,000	£130,291 to £266,968

CP=clinical psychology; SB=additional short breaks.

*This cost was derived by dividing the total cost of the clinical psychology posts for the service by the number of clients offered the service in that year (in 2012 this was eight). This cost may be slightly higher or lower depending on the needs of the young person and family.

- clinical psychology input also gives the family an opportunity to explore and find ways to improve their relationships with one another and reflect upon their experiences of having a child in the family with a disability and how they cope with this physically and emotionally.

There are also a number of challenges involved in this work, including managing the timing of getting the multiple agencies and professionals involved to provide a coordinated intensive intervention, and the challenge of engaging the network in working cohesively together and sharing responsibility for managing risk and supporting the young person and family. Often in this service we are faced with having to manage and tolerate high levels of risk, while helping the network remain motivated and optimistic that the risk will reduce and behaviour will become more manageable. We are often working with limited physical resources such as overcrowded family homes and inner-city special schools with limited space, and with families living in deprivation with very little social support or money. The families and networks we work with are often feeling disempowered, burnt-out and unable to meet the needs of a young person, and staff may have the belief that a residential placement is the only option and any other intervention will fail. Our experience of the success of this model has now made this aspect of the work easier to manage over time, and we have also noticed a cultural shift within the agencies we work with. Offering regular staff and network support has been really important here, and this has highlighted to us the key role of the clinical psychologists in providing training and consultation to the network as well as direct support to the young person and family (and the importance of the clinical psychologists receiving their own weekly supervision when working with these cases). Therapeutic boundaries can also be difficult to negotiate in work such as this where the clinical psychologist may be spending very large amounts of

time with a family, taking a hands-on modelling role, and offering psychological therapy and support in the home, park, supermarket and other community settings as opposed to in a clinic room. However, this flexibility in where therapy and support are offered is also an aspect of the service that families frequently comment positively on and that they feel contributes to the effectiveness of the model.

The Intensive Therapeutic and Short Breaks Service is still in the early stages of being thoroughly evaluated, and it continues to develop and expand as a model. Our aims from here are to continue to develop the service's research base by developing more robust quantitative and qualitative evaluation measures (including longer term follow-up of families post-discharge), building further research links, and seeking further support in cost analysis.

Owing to the effectiveness of this approach, our funding has been continued and extended to include an assistant psychologist to support the work of the clinical psychologist. The costings displayed above indicate that, although this service does require additional staff resources and financial support, this is considerably less than the cost of a residential placement. In addition, children with intellectual disabilities and their families have a right to receive the support that they need to help their child continue to live and participate in their community settings, while also experiencing a good quality of life.

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Edited by Mark Lovell and Orlee Udwin

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Introduction: Intellectual disabilities and challenging behaviour

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Learning disability child and adolescent mental health services (LD CAMHS) within the UK and Ireland are highly variable, with some areas providing minimal or no service and other areas having received substantial investment. Invariably, they are less resourced than generic child and adolescent mental health services and the staff involved have had to receive additional or alternative training and are highly committed to working within this challenging field. It is illegal to discriminate against this disadvantaged group of young people; however, it is rare that there is a truly equal or equitable service on offer. Not only have LD CAMHS developed more slowly than other mental health services, but the current global financial situation is resulting in shrinkage of many services, including these. And if services are smaller and more limited to begin with then any reduction is inevitably more significant. This has resulted in new challenges which this Occasional Paper hopes to address.

The idea for this Occasional Paper was conceived following a joint conference organised by the Yorkshire and Northeast branches of the Association for Child and Adolescent Mental Health (ACAMH) which was held in Leeds, UK, on 28 January 2011. The event was titled *Child and adolescent learning disabilities: perspectives, innovations and developments* and was in collaboration with the ACAMH Child and Adolescent Learning Disabilities special interest group, the British Psychological Society (Child LD and Developmental Disability Network) and the Child and Adolescent Learning Disability Psychiatry Network (CALDPN). This allowed representation from the main psychiatric, psychological and multidisciplinary special interest groups from within the UK and Ireland.

This Occasional Paper includes contributors from the original programme: Ann Alcorn writes about UK-based perspectives on legislation and gives an overview of the historical and recent advances in the area of child and adolescent intellectual disabilities and the focus by governments on addressing the issues. Catherine Sholl and Brian Cranna and colleagues gave talks describing two innovative service approaches from the UK, including a successful alternative to psychiatric admission and the

use of car production models within mental health care to produce high-quality, lean pathways of care. These are both described here in greater detail. An ACAMH conference would not be complete without a focus on research and how to put this into practice (a core aim of ACAMH). Jeremy Turk gives an overview based upon his original talk on translational research, with a focus on psychotropic medications for psychological problems and challenging behaviours in children and young people with developmental disabilities – a growing field of research and clinical practice.

A selection of the original presenters has contributed to this Occasional Paper and additional contributors were sourced to cover some other specific topics. These were suggested by the original collaborative groups and from other ACAMH branch events. With austerity measures and outcome measures featuring highly as priorities for all services, we have included commentaries covering inpatient and outpatient services and management perspectives on the current pressures on services (Lisa Rippon, Clare Dover and Martin Barkley), and also an article on outcome measures and their use with children with intellectual disabilities by Heather Armstrong and colleagues to complement the other papers. An ACAMH Masterclass titled *Learning disabilities in the context of child and adolescent mental health with special focus on complex mental health and behavioural issues* by Eileen Vizard and Oliver Sindall fitted well with the subject matter and has therefore been summarised for the Occasional Paper.

The additional contributions have allowed an increased focus on the issues around challenging behaviour and intellectual disabilities. We are also pleased to include an international contribution from Gary LaVigna and colleagues on their evidence-based applied behaviour analysis approach, which is used with young people with intellectual disabilities and complex challenging behaviours.

We hope that this collection of ten articles stimulates readers' interests and helps provide a useful overview of the current issues facing providers and commissioners, and in addition contributes to improvements in the delivery of care for this vulnerable group of young people.