Tizard Learning Disability Review The Ealing Intensive Therapeutic and Short Break Service: An Update Five Years On

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Abstract

Purpose – *This paper presents an update on the Ealing Intensive Therapeutic and Short Breaks Service (ITSBS).*

Design/methodology/approach - *The challenges the service has faced are reviewed, including the service's response to those challenges. Also provided is a more detailed analysis of the outcomes of the service.*

Findings - *The ITSBS continues to succeed in supporting young people with intellectual disabilities (ID) and challenging behaviour to stay at home with their families.*

Originality/value – *Despite considerable challenges and adaptations to the model, the ITSBS is still achieving successful outcomes for vulnerable young people and is considered nationally to be a best-practice model. Few prior articles have provided an account of how innovative service models are maintained and evolve over time.*

Keywords *intellectual disability, Autistic Spectrum Disorder, challenging behaviour, positive behaviour support*

Paper type *General review*

Introduction

The Ealing Intensive Therapeutic and Short Breaks Service (ITSBS) was set up in 2008, following an initial pilot, and aims to prevent young people with intellectual disabilities (ID)

and challenging behaviour going into residential care. In 2013 the ITSBS published a paper describing the characteristics and early findings from the service (Reid *et al.,* 2013), with further details published in Sholl *et al.* (2014). The key components of the service were its multi-agency working and its psychological approach. The results reported in Reid *et al.* (2013) showed that between 2008 and 2012, 15 out of 16 young people supported by the service had avoided residential placements.

Since then, preventing the placement of people with ID in residential care settings has increasingly come to the forefront of national policy with the publication of "Transforming Care: A National Response to Winterbourne View Hospital" (Department of Health, 2012). This specified that children and young people with ID and challenging behaviour should have access to community-based care and support near their family and friends. "Transforming Care for People with Learning Disabilities – Next Steps" (Transforming Care Delivery Board, 2015) also emphasised the importance of joint commissioning between health and social care.

Consequently there has been a growing interest in the way services support people with ID and challenging behaviour, leading to an increased evidence base for interventions. In 2015, new guidelines were published for the prevention and intervention of challenging behaviour for people with ID (NICE, 2015), which specified the importance of functional analysis and Positive Behaviour Support (PBS).

Despite this, a recent review of residential special schools found that there are 6,146 children with education, health and care plans residing in 334 residential special schools and colleges in the UK (Lenehan and Geraghty, 2017), with 70% having Autism Spectrum Disorder (ASD)/severe ID, or social/emotional/mental health concerns, in addition to challenging behaviour. Experience of these placements can be mixed for young people and their families (Gore et al. 2015) and return to their local community is unlikely, with young people often transitioning to adult residential placements or hospital settings (McGill, 2008;

Gore et al. 2015). This highlights an ongoing need for services like the ITSBS, which are in line with current policy and evidence base.

This paper provides an update on the ITSBS five years on. The authors first describe the current format of the service. They then look at how resource changes in the current economic climate have created challenges for the service and how the service has dealt with those challenges, before providing an overview of the outcomes. This includes a follow up of the cases reported in Reid *et al.* (2013) and the outcomes of new cases supported since. Finally, there is a brief discussion considering the future of the ITSBS. We hope that providing details on how the values and mission of a service can be maintained over time, whilst continuing to evolve and meet new demands will provide a useful resource for colleagues in the field.

Ealing ITSBS

Multi-agency working

Ealing ITSBS is a collaborative approach between the local Child and Adolescent Mental Health Service for Learning Disabilities (CAMHS-LD) and Ealing's Children with Disabilities Social Care Team (CWDT). It continues to be funded by Ealing Local Authority and is situated within the multiagency Ealing Service for Children with Additional Needs (ESCAN). This means that young people within the ITSBS are also able to access support from other professionals within ESCAN, such as Educational Psychology; Speech and Language Therapy; Occupational Therapy; Community Paediatrics; Special Educational Needs (SEN) department; psychiatry; and nursing.

The clinical work is led by two Band 8a clinical psychologists (1.0 whole time equivalent (wte)) supported by a 1.0wte Band 5 Assistant Psychologist. Each young person has an allocated social worker from CWDT who arranges an individually tailored short breaks package. Monthly team meetings are chaired by the CWDT Service Manager.

Psycho-social approach

The ITSBS approach is detailed in the previous two papers (Reid *et al*. (2013) and Sholl *et al*. (2014)). They describe the use of a Positive Behaviour Support (PBS) framework, taking a person-centred approach to functional assessment and multi-element support planning, in partnership with stakeholders (Gore et al., 2013). The ITSBS' use of PBS places particular emphasis on systems wide change; the inclusion of additional therapeutic interventions; and provision of short-break services.

ITSBS has continued to work within this framework except that families are no longer offered extended overnight short breaks that were sometimes used previously. For many young people it was either not wanted by the family; not deemed appropriate; or was not available, as the local respite service was only registered to care for children from age 10. Instead the short break packages usually comprise a combination of agency carers supporting the young person at home and in the community, as well as some weekly/fortnightly overnight stays in local respite units. In addition, those that are under 16 usually attend a specialist after school club and holiday play scheme.

Referral criteria

Referral criteria for the ITSBS continue to be young people (under 18 years old) with an ID (most of whom also have ASD). There needs to be an imminent risk of home/family situation breakdown due to severe challenging behaviour, high levels of distress and family/carers

feeling unable to support the young person. The placement breakdown must not be primarily due to child protection concerns. The family need to have an allocated social worker in the CWDT. The family of the young person need to be committed to maintaining the home placement and be prepared to actively engage with the ITSBS to make changes. Previously, acute mental health difficulties were an exclusion criterion. However, this is no longer the case and since 2012 three young people have been supported to return home following admission to an Assessment and Treatment Unit (ATU). The ITSBS also now accepts referrals for young people for whom the home placement has already broken down, resulting in emergency foster care, where parents are committed to the young person returning home again.

Resource changes

Funding

Since 2010, the government has made significant spending cuts to the NHS and Social Care in an effort to reduce the financial deficit. The organisation 'Young Minds' found that 67% of CCGs and 65% of local authorities had frozen or cut their CAMHS budgets every year since 2013 (Knapp *et al.* 2016). In Ealing, the council expects that by 2020 it will have less than half what it had to spend on services in 2010 (Ealing council website, 2015).

Whilst the ITSBS has not experienced any direct cuts in funding, the impact of reduced funding in other areas affects the client group and the services provided. Some examples include: a lack of locum cover provision for staff on maternity leave; thresholds for the CAMHS-LD rising and cuts to early intervention services such as portage, meaning a greater risk of families presenting to the ITSBS in crisis; significant housing shortages in Ealing mean families are often living in inappropriate or temporary accommodation; and greater limitations on the short break services social care can offer, for example fortnightly (rather than weekly) overnight stays.

Staff changes and vacant posts

Since April 2012, there have been a number of staff changes within the ITSBS. In early 2013 it was agreed that the level of skills and experience in working with and managing systems required was more appropriate for a more experienced Band 8a clinical psychologist, rather than a newly qualified Band 7, so the post was upgraded. Temporarily reducing 0.4wte to a Band 7 again in 2014, reinforced that the role was too challenging for a psychologist with less clinical experience and leadership skills. Furthermore, over the past four years there have been a number of periods with reduced clinical psychology provision due to staff leaving or going on maternity leave, resulting in a lack of cover (see above) or delayed recruitment.

The ITSBS is strongly supported by the CAMHS-LD team, through supervision and joint working, and this service has also experienced significant staff changes and vacant posts. Reduced CAMHS-LD provision and increased need has resulted in fewer early interventions, leading to increased need for ITSBS support at a later stage, as well as reduced capacity to step cases back down to CAMHS-LD once a less intensive intervention is required.

Closure of local respite services

Ealing's overnight short break service began reducing its capacity in early 2015 and closed in May 2016. Overnight short breaks are now spot purchased as needed by the CWDT from three out of borough providers. Previously, clinical psychology worked closely with one provider, offering regular training for staff and regular visits to support the implementation of PBS plans. This is no longer possible, due to the number of providers involved and the distance from Ealing. However, staff from these services are still included in the network trainings for the young people they support.

Lack of support workers

Whilst the CWDT recognise the need to fund large packages of support to ensure young people remain in their family placement, there is a shortage of domiciliary care staff in Ealing, trained to work with young people with ID and challenging behaviour. CWDT commission carers through a small number of agencies, who are often unable to provide carers as experienced/trained as is required for this group of young people or enough carers for the hours requested. There is also high staff turnover and agencies find it a challenge to provide consistent care, meaning young people may have unpredictable care packages, which can exacerbate family stress and challenging behaviour. In addition, whilst the ITSBS provides consultation to carers, it has proven difficult establishing this in a meaningful way due to changes to care staff and the large numbers of carers involved.

Overcoming the challenges

Embedding the ITSBS approach within Ealing

The ITSBS continues to follow the original psycho-social approach, maintaining the key components of a detailed and regularly updated PBS plan; regular short breaks to provide the family with respite and to help develop skills and independence; and therapeutic interventions offered to the young person, their parents/carers and sometimes their siblings (Rye *et al.,* 2018) to ensure that the whole family feels supported. However, a key strength of the service is the format of network trainings for providing system support and enabling systems wide change; something recognised in PBS, but an area that has received less focus in research. A network training focuses on an individual young person and brings together everyone supporting that young person, encouraging them to contribute to and own the PBS plan, rather than it being imposed by psychology. Strategies can be discussed and re-developed as necessary and the plan updated. When possible, video observations of the young person with people in their network are used in training sessions to bring strategies to

life. Trainings also help to improve consistency and relationships across the network and provide a space for parents and carers to feel validated in their successes and challenges. As network trainings have been offered by the ITSBS for nine years, they are now well understood and valued by professionals across ESCAN, care agencies and local schools. They have helped to establish relationships between these settings that can be built on, when taking on new referrals. Trainings are well attended and the feedback from them is overwhelmingly positive.

Close working relationships with other agencies

As aforementioned, the ITSBS receives significant support from CAMHS-LD, as well as the other agencies situated within ESCAN. Being in the same building as all the other agencies supporting a young person with ID enables staff from all services to have good working relationships and makes joint working, through both planned and unplanned meetings, much easier to facilitate. ITSBS cases are recognised by everyone as high priority and information is shared effectively between services, meaning fewer gaps in provision. For example, the clinical psychologist can provide psychiatry with regular, up to date information regarding the psychological interventions being offered, the impact of medication and any additional context, helping to reduce over-medication of young people with challenging behaviour.

Physical intervention training to parents

Despite intensive support by the ITSBS, high risk of harm to the young person and those supporting them can still remain. One response to the challenge in providing skilled and consistent domiciliary carers, has been to provide parents with physical intervention training for use as part of a reactive management plan. To date this has only been commissioned for

two cases where extreme levels of behaviour are displayed and parents are already physically restraining young people in ways that are not deemed safe. Enhancing parents' skills to use the safest physical techniques, as a last resort, has been necessary to reduce the level of risk. The training involved a specialist provider visiting the young person at home, to develop bespoke and individualised training suited to the young person and their home environment.

Outcomes of the service

Cases seen by the ITSBS before April 2012

Reid *et al.* (2013) reported on 16 cases, seen in the service between September 2008 and March 2012. Three cases remained on the caseload for ongoing long-term support and are included in the current paper. Another six cases were re-referred to ITSBS after April 2012 for further input and are therefore also included in the current paper. Seven cases were discharged from ITSBS prior to April 2012 and not seen again, all of whom are now adults and remain at home with their families, with ongoing support from adult social care and the adult learning disability team.

Cases Seen by Ealing ITSBS since 2012

Between April 2012 and April 2017 Ealing ITSBS provided assessment and intervention to 19 new referrals and the nine cases from the previous paper referred prior to April 2012. This means the ITSBS supported 28 young people (26 families) in total. The length of the assessment/intervention varied considerably from case to case, from a few months to a number of years.

Table 1 displays the demographic information of the 28 young people seen in the ITSBS 2012-2017.

(Insert Table 1 here)

Successful Outcomes

Of the 28 children seen by Ealing ITSBS since 2012, six young people (including two siblings) transferred to residential school placements. However, the two siblings have since returned home. One of the families moved abroad before the intervention was complete and therefore the outcome of the young person is unknown. Therefore, 23 currently remain at home living with their family or in their community. Seven of these are currently still accessing the ITSBS, with 16 discharged.

Three young people received ITSBS until they were transitioned to adult services; six were stepped down to a less intensive CAMHS-LD service and seven were discharged completely as no further input was required at that time.

Admissions to ATU

Since 2012, three of the young people supported were admitted to an ATU. Two of these were planned admissions following a significant deterioration in their mental health and after a six month stay, both young people returned back to their family home/local area with support from the ITSBS. The third young person was referred to the ITSBS whilst he was in an ATU and was supported by the ITSBS to return home to his family.

Residential Outcomes

Of the six young people that transferred to residential schools, one was influenced by maternal mental health and a difficult attachment relationship, which meant that a residential

placement was ultimately seen as the safest option for the young person. Two had very complex and multiple medical needs, in addition to an ID. One was a young person whose family experienced a significant life event that impacted upon their ability to continue caring for their child. Another case was a young person who experienced a traumatic life event that led to increased challenging behaviour to the degree it was no longer safe for them to be at home. However, this was six years after they were initially referred to the ITSBS, so the move to residential care had been successfully postponed until they were much older. The sixth young person to transfer to a residential placement experienced a breakdown in school placement and their residential placement was a combination of the family finding it extremely hard to support them and the local authority being unable to find an appropriate day school placement for them in the area. They are therefore in a 38-week residential placement, returning home at weekends and holidays.

The six children who transferred to residential placements were supported by ITSBS for at least a year prior to this move. In the instances when a move to residential placements could not be prevented, it was delayed by between one and six years. Three of the young people were referred twice to ITSBS, indicating that parents/services managed for some time between referrals without intensive input. One young person was re-referred after just three months, but another family were re-referred after three years and seven months.

Overall Outcomes

In total, the ITSBS has seen 36 young people since it was setup in 2008 and only four of these are currently in residential school placements, with one unknown and the rest all living at home or in the local community. Sixteen of these are now adults, supported by adult services where necessary. As all young people with ID considered at risk of residential placement are now referred to the ITSBS first, it is believed this has resulted in an overall reduction in the total number of children from Ealing in residential placements.

Discussion

The Ealing ITSBS remains a successful service, continuing to achieve its main aim of preventing unnecessary residential placements for young people who present with high levels of challenging behaviours. An independent review into the experiences and outcomes of children in residential school, (Lenehan and Geraghty, 2017) concluded that the results achieved by the ITSBS are “exceptional, with research showing improved outcomes for children and their families, as well as substantial savings for the local authority, by avoiding the need for residential placements”. A collaborative project with the London School of Economics demonstrated that the ITSBS is cost-effective when compared with the cost of residential placements for children with ID and challenging behaviour (Iemmi *et al.,* 2016)

Whilst the model of short breaks has adapted slightly and the team has seen many staff and resource changes, the core principles and therapeutic approach have remained the same. The interventions are still based on PBS and the young people still receive short breaks. The combination of detailed PBS plans, therapeutic support for the family and network trainings, continues to work effectively. The NHS England Transforming Care programme recognises the ITSBS as a best practice example (Transforming Care Model Service Specifications 2017).

Adapting to the current climate

It has been crucial for the ITSBS to adapt the way it works with more complex networks, changing resources and staff team. The logistics of supporting young people is becoming more complex; working with multiple care providers and overnight short breaks services, as well as, where needed, now supporting young people who are in ATU’s– communicating with the hospital and family whilst the young person is an inpatient, ensuring they have a well-supported transition back to their home and spend as little time as possible in hospital.

Lenehan and Geraghty (2017) highlighted that one of the difficulties for supporting children with complex needs to remain in the community is often the mistrust that has built up between services within the sector; causing families to get 'caught in the middle'. They recommend that services be respectful of the significant financial pressure authorities are under and focus on finding solutions rather than dwelling on the problems faced. The ITSBS' strong working relationships between agencies, particularly with CAMHS-LD and social care enable it to do this.

The ITSBS has not prevented 100% of cases from transferring to residential schools. However, it is worth noting that the residential placements were always delayed, often by a number of years, meaning the young person spent more of their childhood with their family and moving away when they were much older.

Development of Ealing ITSBS

Ealing ITSBS would like to develop a new narrative around residential schools; for families and professionals to perceive them as a temporary placement, to maintain a strong possibility of the young person returning to live with their family or an alternative placement in their local community. Currently, young people who move to a residential placement are discharged from the ITSBS, although they remain open to CWDT, but the ability to continue to provide ongoing input, with a view to facilitating a transition home, is a future service development target.

Another area of service development would be to address the challenges of fulfilling domiciliary care packages. This could be done through employing support workers within the ITSBS that were appropriately trained/supervised by clinical psychology and social care to implement PBS plans at home and in the community. This could provide more consistent care packages for young people and enable greater joint working between psychology and carers.

In addition, there is a need for skilled foster carers trained to manage young people with ID and challenging behaviour who could work alongside the ITSBS. Currently overnight respite is provided in a residential short break setting and residential schools often become the inevitable option if the family are no longer able to care for their child at home, even if their day school is still a suitable educational placement. Skilled foster carers may provide a better and more local alternative to this. After all, the ITSBS believe that all young people, regardless of disability, have the right to be loved and cared for in a safe family home.

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Table 1	Characteristics of young people accessing the ITSBS from April 2012 – April 2017.			
Number of Participants	*Average age at referral*	*Gender*	*Ethnicity*	*Average length of time seen by ITSBS during period April 2012 – April 2017*
Cases opened pre-April 2012 and continued to be seen*				
3	11.5	2 Male 1 Female	2 Black British 1 Mixed Race British	2 years 7 months
Cases that were discharged and then re-referred post-April 2012				
4	13	4 Male	2 Asian British 1 Mixed-Race British 1 White British/Irish	2 years 6 months
Cases opened post April 2012				
19	11	15 Male 4 Female	3 Mixed Race British 3 White British 2 British Bangladeshi 2 Mixed White Asian 1 African British 1 Asian British 1 Bangladeshi 1 Black African 1 Black British 1 Caribbean British 1 Irish Traveller 1 Sri Lankan 1 Unknown	1 year 3 months

Note: * Cases had already been in the service a number of months/years before April 2012 and were reported on in Reid *et al.* (2013).